

**The 2014 International Conference on Stillbirth, SIDS and Baby Survival**  
**Amsterdam, 18-21 September 2014**

**Program and Abstracts**

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## WELCOME

From the Dutch organizing committee

With great pleasure the Dutch organizing committee welcomes you to *The 2014 International Conference on Stillbirth, SIDS and Baby Survival (ISA/ISPID Congress)* in Amsterdam. This conference is a call for global action to reduce perinatal and infant mortality. Worldwide, there are enormous differences in infant mortality. Perinatal mortality may be below 10 per 1,000 births for certain developed countries and more than 10 times higher in developing countries. In 2012, according to WHO data, nearly 3 million deaths occurred during the first month of life and almost 5 million within the first year of life. Stillbirth is a major, global health problem, and around the world many professionals are involved in research in order to reduce its incidence. Targets of this conference are to reach agreement about universal classification systems which are under development and to reduce antepartum, intrapartum, maternal and neonatal deaths and to learn from international interventions, also in the psychosocial field. The death of a baby, either during pregnancy, labor or in the first years of life is a devastating experience for parents, family and the caregivers involved. New ways of culturally sensitive support, use of social media and internet fora may help young, modern parents everywhere around the world. These new developments and technologies will be presented during this conference.

In western countries, Cot Death or Sudden Infant Death Syndrome (SIDS) is the leading cause of death among infants aged 1–12 months. This used to be the case in the Netherlands as well. Until in 1986 Professor Dr. Guus de Jonge, pediatrician, observed five infants in the neighborhood of Amsterdam, that had died in the prone position. He was puzzled: is this a coincidence or not? Almost at the same time, at the other site of the world, Professor Dr. Davies made a similar observation in Hong Kong. This observation was also made earlier, in 1944 and in 1965. Meanwhile, parents were distraught; they could not believe cot death was a “mysterious killer”. Parents got organized and asked for research or....rather forced more research. This was an effective strategy. Step by step the world learnt which risks were involved, and more importantly, how these risks could be reduced. SIDS rates vary significantly by population from 0.05 per 1000 in Hong Kong to 6.7 per 1000 in American Indians. Due to excellent prevention and careful examination and analysis of cases by general practitioners, pediatricians, forensic doctors and pathologists, the cot death incidence in the Netherlands is low. In surrounding countries the incidence rates are 3 to 4 times higher.

Child death is the only medical subject, as far as we know, where parents have such an enormous impact on the reduction of the incidence of these unnecessary infant deaths. Lucebert wrote in 1974; *Everything of value is defenseless*. But parents, physicians, nurses, and other professionals jointly can become a powerful lobby for better prevention programs. Prevention is possible, not only in the Netherlands, but everywhere.

We hope during this conference you will share ideas, bring them home, and make a change.

On behalf of all conference committee members, including professionals and parents, we wish you a fruitful, constructive conference,

Monique L'Hoir  
Dutch organizing committee, ISPID

Jan Jaap Erwich  
Dutch organizing committee, ISA



## **WELCOME**

From the International Stillbirth Alliance (ISA, [www.stillbirthalliance.org](http://www.stillbirthalliance.org))

On behalf of the Board of the ISA, I welcome you to our 2014 conference on babysurvival. This unique get-together of care-givers, bereaved parents and involved people from many other backgrounds makes these conferences such a great experience. Our common goal is to exchange experiences and knowledge in order to lower the global burden of the loss of our children. That this is still very much needed is painfully clear from the present evaluation of the Lancet series 2011. The pace of improvements in the position of women in general and specifically in obstetric care remains too slow. We know to a great extent what needs to be changed. How can we implement best practices world-wide? This should be a common felt urge.

I would like to thank all ISA participants both present or not able to come from our member organisations for their continuing role to give stillbirth the attention it needs. Both research into the causes and prevention of stillbirth and modern insights into the bereavement and grief processes for parents is progressing because of your efforts. I expect this conference again to be a forum to stimulate further progress. Over the last two years the collaboration with ISPID, the conference committee and the organizational bureau has been great and has now accumulated in today's start of the conference. Many other people have helped as well, I thank them and last but not least our sponsors without whom this conference would not have been possible.

I wish you a great time in Amsterdam and The Netherlands, and an inspiring conference.

Jan Jaap Erwich  
Chair, International Stillbirth Alliance



## **WELCOME**

From the International Society for the study and Prevention of perinatal and Infant Death (ISPID, [www.ispid.org](http://www.ispid.org))

Welcome to the 2014 Baby Survival Conference on behalf of The International Society for the study and Prevention of perinatal and Infant Death (ISPID). The sharing of information, the new ideas and the determination by all to tackle baby mortality from every facet during pregnancy, birth and infancy is what makes this conference remarkably successful.

Since we left Baltimore in 2012 our colleagues from the Netherlands have put incredible energy into organising this event in Amsterdam and we are very grateful for their tremendous efforts. I urge you to study the program closely and plot a path that will support you in our collective international journey to prevent the sudden and unexpected death of our most vulnerable human beings- our babies. It is only through working together that we can we find answers for parents who have experienced the death of a baby or child.

There is so much more to do in expanding our knowledge of how to prevent the tragedy of Stillbirth or Sudden Unexpected Death in Infancy (SUDI) or Sudden Unexpected Death in Childhood. We have made many leaps in what we know and this has had a huge impact on the number of lives saved, however we still do not know the cause of many deaths. In addition we can always know more about the best ways to support those impacted by the death of a baby or child.

Kind regards

A handwritten signature in black ink that reads "L. K. Raven". The signature is written in a cursive style.

Adjunct Associate Professor Leanne Raven  
Chair  
ISPID

## GREETINGS FROM THE MAYOR OF AMSTERDAM



The Amsterdam municipality is pleased to offer a sincere and warm welcome to all national and international attendees of the 2014 International Conference on stillbirth, SIDS and baby survival.

Amsterdam is fortunate to be the host city for this conference and the Royal Tropical Institute is well chosen for a meeting that is as international as this one. In 1985 interested parents and scientists came together in Brussels for a first meeting and since 1985 biannual congresses have been organized on Sudden Infant Death Syndrome (SIDS) all over the world. In 2010 and 2012, the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) joined with the International Stillbirth Alliance (ISA) in organizing these meetings together in Sydney and Baltimore. We are proud that Amsterdam has been chosen as venue for the 2014 joint conference.

Based on my information this is the only conference where parents, physicians, nurses and other scientists and professionals work together, side by side, to reduce risks and prevalence of infant deaths and to support and assist parents.

The Dutch government has recognized the problem of infant mortality and actively supports this conference. Amsterdam is honored to facilitate the international conference and I am sure that your gathering over the next few days, here in our capital city will be stimulating and enjoyable for all delegates.

I hope you achieve, more insight in the medical issues of perinatal and infant death, and also ensure that support for bereaved parents is optimal and effective. The wide range of disciplines that is attending makes me confident that this will be the case. I am sure that your gathering here in Amsterdam over the next few days will be memorable. We are proud to have you in Amsterdam.



Mr. E.E. van der Laan  
Mayor of Amsterdam

## **ORGANISATION**

### *Organising committee*

#### **Chair**

Prof. Jan Jaap Erwich, MD, PhD, gynecologist/obstetrician (the Netherlands)

#### **Members**

Mr. Rien de Krom, registered accountant (the Netherlands)

Mr. Maarten Witlox, L.L.M. parent, lawyer (the Netherlands)

Dr. Magda Boere-Boonekamp, MD, PhD, youth healthcare physician, epidemiologist (the Netherlands)

Drs. Fenneke van Swigchum, consultant in care and former managing director of the Dutch Perinatal Audit (the Netherlands)

Dr. Adèle Engelberts, MD, PhD, pediatrician (the Netherlands)

Dr. Monique L'Hoir, PhD, clinical pedagogue, psychotherapist (the Netherlands)

### *Scientific subcommittee*

#### **Chair**

Dr. Adèle Engelberts, MD, PhD, pediatrician (the Netherlands)

#### **Members**

Dr. Sanne Gordijn, MD, PhD, gynecologist/obstetrician (the Netherlands)

Ass. Prof. Vicky Flenady, PhD, MMedSc, midwife (Australia)

Dr. Alexander Heazell, MBChB (Hons), PhD, MRCOG, gynecologist/obstetrician (UK)

Prof. Dr. Mechtild Vennemann MD, MPH, epidemiologist (Germany)

Prof. Dr. Rachel Moon, MD, PhD, pediatrician (USA)

Dr. Ferry Cornelissen, parent, MSc, biologist/immunologist (the Netherlands)

Prof. Jan Jaap Erwich, MD, PhD, gynecologist/obstetrician (the Netherlands)

Dr. Magda Boere-Boonekamp, MD, PhD, youth healthcare physician, epidemiologist (the Netherlands)

Prof. Dr. Sicco Scherjon, MD, PhD, gynecologist/obstetrician (the Netherlands)

#### **Extra members, for the review of the abstracts:**

Dr. Peter Blair, BSc (Hons), MSc, Reader in Medical Statistics (UK)

Siri Hauge Opdal, PhD, Norwegian Institute of Public Health (Norway)

### *Parent subcommittee*

#### **Chair**

Dr. Monique L'Hoir, PhD, clinical pedagogue, psychotherapist (the Netherlands)

#### **Members**

Ms. Mariëtte de Groot-Noordenbos, social worker (the Netherlands)

Drs. Jeannette Rietberg, parent/author and speaker on perinatal loss & bereavement (the Netherlands)

Drs. Marga Vintges, parent/former member of the scientific committee of the Dutch Cot Death Foundation (the Netherlands)

Ms. Leonie Troost, parent/author of a children's book and speaker on loss & bereavement (the Netherlands)

Mr. Mirjam Spagnoletti, parent and lawyer (the Netherlands)

Ir. Léonie Berkouwer, parent & sociologist (the Netherlands)

### *Social evening program committee*

#### **Chair**

Mr. Maarten Witlox, LL.M. parent, lawyer (the Netherlands)

#### **Members**

Dr. Nicoline van Voorst Vader-Boon, MD, PhD, pediatrician (the Netherlands)

Ms. Machteld Vleugel, parent (the Netherlands)

Ir. Léonie Berkouwer, parent & sociologist (the Netherlands)

**WELCOME**

The Social Evening Committee is pleased to invite you for the gala dinner and the memorial service. The meeting for the memorial service will take place on Friday evening, at 6.30 pm, in the attractive atmosphere of the former church “de Duif” (The Pigeon) on one of the beautiful canals, namely the “Prinsengracht”. Parents and professionals are welcome to attend this Memorial Service, where music will be performed by a father who memorizes his child, and also by a beautiful choir of one of the organizing parents. Stories about our precious children will be shared that evening and together we will remember all those babies who have died unnecessarily. The social evening committee wishes you a valuable and unforgettable evening.



On behalf of our committee,  
Maarten Witlox



On behalf of the The Scientific Committee I wish you 4 educational and inspiring days. There are a multitude of lectures and key-notes: it might even be difficult to make a choice to whom you are going to listen. Stillbirth and SIDS both have a multifactorial etiology. At this meeting there is an unique opportunity to meet with colleagues and scientists from many different fields. This will be beneficial in broadening our scope of research. We also hope that through this meeting networks are formed and strengthened. The aim of this conference for physicians, nurses, scientists and other professionals is to share knowledge in order to further reduce the infant mortality rates to save parents the great pain of losing a child. However, we also want to support as best as we can, those who have already suffered a loss. To further this, our program also encompasses speakers on bereavement and grief. The scientific committee values the close collaboration with parents and parent's organizations, without whom we would not be where we are today, and without whom this conference could not be held.

On behalf of our committee,  
Adèle Engelberts



The Parent Committee wishes you a conference where you get inspired and you feel supported. We hope you will get to know other people, recognize parent's feelings, behaviors and thoughts. Our committee hopes that the conference will offer you a stimulating stay, while sharing ideas and full and open discussions and more understanding.

On behalf of our committee,  
Mariette de Groot





## **THANK YOU TO OUR SPONSORS**

We would like to thank all of our generous sponsors without whose support the 2014 International Conference on stillbirth, SIDS and Baby Survival would not have been possible.

### **GOLD Sponsors**

American SIDS Institute

DANONE

Ouders van Wiegedoodkinderen (Association for Parents of Cot Death children; Ministry of Health, Welfare and Sports)

SANDS Stillbirth and neonatal death charity

### **SILVER Sponsors**

First Candle and CJ Foundation for SIDS

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Menzis Health Insurance Company

Maternal and Fetal Health Research Centre, University of Manchester

### **Friends of Baby Survival 2014**

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Nemo Healthcare

Netherlands Organisation for Scientific Research (NWO-WOTRO)

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Rabobank

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SIDS and Kids Australia

SIDS Bel Air

SIDS Calgary Society

Soroptimistclub Helmond-Peelland

Stichting Lieve Engeltjes (Sweet Angel Foundation)

Stichting Veiligheid.nl (Consumer Safety Institute)

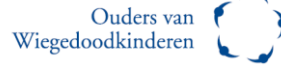
Stichting Wiegendood (Dutch Cot Death Foundation)

TNO

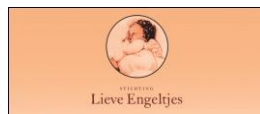
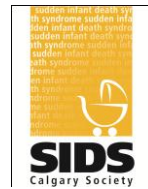
Vereniging Ouders van een Overleden Kind (Association for Parents of a Deceased Child)

The Lullaby Trust UK

Furthermore we would like to thank all the persons who shared our goals for this conference, and therefore contributed so much, both materially and immaterially, helping us with ideas, their time and generous assistance in many ways because they are well disposed to the aims of the congress.



LC Hamaland Germany



## SUDDEN INFANT DEATH RESEARCH

At this conference we hope to build towards more prevention, more support, more knowledge. We would never be where we are now if not for some remarkable people that can not join us at this meeting. This is a small tribute to them.



**Kareene Fitzgerald**

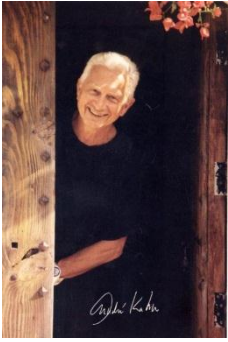
The day following the death of her son Glenn on July 10, 1977, Kaarene commenced the formation of the Sudden Infant Death Research Foundation Inc in Victoria, Australia. As a result of this personal tragedy, Kaarene worked constantly and tirelessly to develop the SIDS Foundation into a vital and vibrant organisation, she was responsible for the great deal of planning that has resulted in the perception of SIDS changing from one of suspicion to one of the understanding of the phenomenon as an unsolved medical problem. The Foundation has funded millions of dollars for research, has changed policy and practice by educating health professionals, has saved the lives of thousands of babies with the Reducing The Risks of SIDS health care program, and all of this is the monumental outcome from the death of one very small, very loved baby.

During a 25-year period, Kaarene co-founded both the National SIDS Council of Australia and SIDS International, holding Executive positions with both groups. As a result of work during her term as chairman of SIDS International, the World Health Organisation (WHO) accepted SIDS as a cause of death. With her strong interest in research, it was a natural progression to establish, in 1992, the Global Strategy Task Force (GSTF) on SIDS. Kaarene was the inaugural chair of the GSTF a body liaising with international researchers developing strategies for solving the problem of SIDS. In 2003 it was decided to merge the GSTF with the European Society for the Study and Prevention of Infant Death (ESPID) to form the International Society of the Study and Prevention of Infant Death (ISPID).

In 1999, Kaarene was awarded the highest honour in Australia with a Companion in the Order of Australia (AC) Australia Day Honours List. "For service to the community through commitment and support for Australian medical research into Sudden Infant Death Syndrome (SIDS) and in coordination of world wide efforts to develop research and educational strategies to reduce sudden death in infancy."

Kaarene had a unique breadth of understanding and knowledge about all aspects of work related to SIDS and infant death. Her commitment and passion in over 25 years was to try and find the causes of SIDS and to eliminate them, so that people would not continue to experience the devastation and grief that follows each death. Kaarene actively demonstrated that commitment, energy, vision, and listening to people, enabled the Sudden Infant Death Research Foundation to achieve an outstanding success on state, national and international levels and she achieved all this without any formal professional qualifications.

Kaarene died after a formidable battle with cancer on Saturday May 24, 2003 with her loving family around her.



**André Kahn**

André Kahn was Professor of Pediatrics at the Free University of Brussels (ULB), Head of the Department of Pediatrics at the Hôpital Universitaire des Enfants Reine Fabiola, Doctor Honoris Causa of the Tokyo Women's Medical University, co-founder of the European Society for the Study and Prevention of Infant Death, the Pediatric Sleep Study Group of the American Sleep Research Society and the Task Force of Pediatric Arousals of the Japan SIDS Research Society.

In 1985, Professor Kahn organized an international meeting in Brussels where both scientists and SIDS parents met and exchanged ideas and experiences. This was one of the meetings where the idea of a SIDS International community took place. He always encouraged dialogue between parents and researchers. His research focus has always been centered on mechanisms for SIDS, with particular emphasis on obstructive sleep apnea and arousal mechanisms. He reported on the largest accumulation of polygraphic recordings in subsequent SIDS victims ever collected; these data were instrumental in giving us insights into respiration during sleep and the component of upper airway obstruction in these infants.

Professor Kahn was an exceptional teacher, a dedicated physician, a rigorous scientist and an inspiring, visionary leader. He has influenced a generation of young scientist that are now very successful in various fields. He was also a wonderful speaker and had participated in most international conferences on SIDS. His last participation was at the SIDS International conference held in Edmonton Canada in 2004 where he was on the International Advisory Committee and had led a few workshops and activities.



**Jonne Huber**

When I was young, more years ago than I care to remember, I often attended these joint meetings of doctors, parents and researchers all concerned about and actively engaged in efforts to reduce infant mortality and more specifically SIDS. John Emery from Sheffield and me were trusty companions during almost all these conferences.

Gradually the perception gained ground that we ought to widen our view to include stillbirths, prenatal development and the whole of postnatal care in all its aspects.

It is therefore a good thing that at the present conference all the above subjects are dealt with, not the least of which are reliable, readily available and practical information for parents and doctors alike.

Parents, doctors and researchers have to learn to talk to each other in a meaningful way. Mutual respect is of the essence.

Listening to each other, each from his own background and expertise, emotional or scientific, joined to reach our common goal to reduce the number of lost babies but perhaps more important: to soften human suffering.

Wishing you all well,  
Salve Jonne Huber



**Guus de Jonge**

Guus de Jonge was the pediatrician who first noticed that many of the Dutch cot death infants died when lying prone. He collaborated with the organization of well-baby clinics and advised against a prone sleeping position at the end of 1987. The incidence of cot death/ SIDS was more than 30% lower in the next year. However, it caused much commotion amongst Dutch pediatricians, who initially could not believe that such a simple measure could make such a big difference. It was not until later that he was rehabilitated and honored for his work by the Dutch Pediatric Society.

When Guus retired he felt this enabled him to spend even more time doing things he thought important: cot death prevention was certainly one of these. He worked tirelessly for many years.

Guus de Jonge founded the Dutch cot death committee, a subgroup of the Dutch Pediatric Society which collects data on children that die a cot death for research purposes. But the committee not only collects data, it also offers support to families that have suffered a loss. Guus, together with his wife Baukje, who was a physician at well baby clinics, visited numerous families and helped them cope. Their empathy and warmth helped many.

Now the Netherlands has the lowest cot death incidence in the Western world: we owe a lot to Guus.

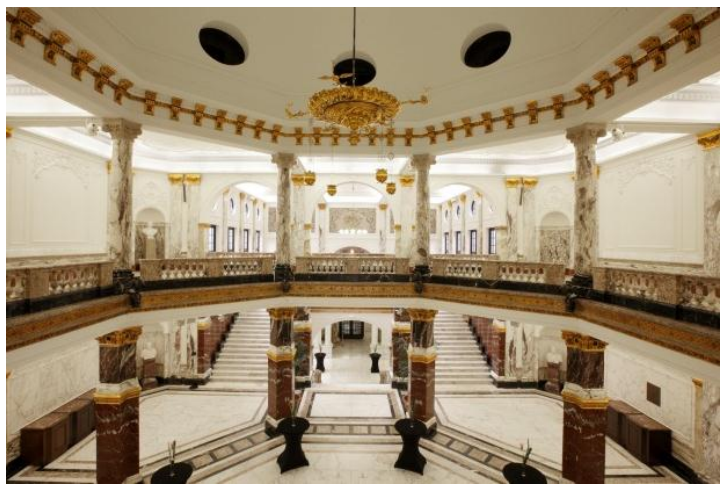
**OPENING RECEPTION, THURSDAY 18 SEPTEMBER, 18.00 PM, ROYAL TROPICAL INSTITUTE, MARMEREN HAL (MARBLE HALL)**

The conference will be opened Thursday evening by the deputy major of Amsterdam, Udo Cock, and Monique L'Hoir, member of the organizing committee and chair of the parent committee.

This opening will be a great opportunity to get to know each other in an informal way, with drinks and snacks. We want to welcome you as our guests and hope you will feel the warmth, understanding and inspiration of all the people present.

Harpist Sterre Koopman, a rising star, will play the musical accompaniment to the opening.

We are looking forward to meeting you there.



## PROGRAM AT A GLANCE

Sessions which will be interesting for parents and health care workers who interact with and support parents are marked with\*\*\*

### FRIDAY 19 SEPTEMBER 2014

<b>Time</b>	<b>Grote Zaal</b>					
<b>08.30</b>	08.30 Opening, <i>Erwich, J.J. (chair ISA), Raven, L. (chair ISPID)</i> 08.45 How parents make a difference, <i>Vintges, M., Plandsoen, B</i> 09.00 What still needs to be implemented of the Lancet Stillbirth series?, <i>Ellwood, D., Flenady, V.</i> 09.30 Successful implementation of safe sleeping messages, <i>Moon, R.</i> 10.00 Implementation in health care, <i>Grol, R.</i>					
<b>10.30</b>	Break					
	<b>Grote Zaal</b>			<b>Raadzaal</b>	<b>Clauszaal</b>	<b>Bestuurskamer</b>
<b>11.00</b>	11.00 The future of infectious causes for stillbirth <i>Silver, B.</i> 11.30 From physiology to epidemiology in SIDS <i>Horne, R.</i>			1A: Death reviews***	1B: Children & grief***	1C: Return to zero, movie about stillbirth***
<b>12.00</b>	Lunch					
	<b>Grote Zaal</b>	<b>Mauritszaal</b>	<b>Muiderpoortzaal</b>	<b>Raadzaal</b>	<b>Clauszaal</b>	<b>Bestuurskamer</b>
<b>13.30</b>	2C: Safe sleep devices	2A: Predictions of pregnancy complications	2D: Pathology and clinical model	2E: Sands UK - New program for bereavement care***	2F: New ways of parent support***	2B: Classification workshop
<b>15.00</b>	Break					
	<b>Grote Zaal</b>	<b>Mauritszaal</b>	<b>Muiderpoortzaal</b>	<b>Raadzaal</b>	<b>Clauszaal</b>	
<b>15.30</b>	3B: Epidemiology ISPID	3A: Perinatal care issues	3C: Workshop SIDS and suppressed hearing?	3D: Fathers & grief***	3E: Care for parents and children***	
<b>16.30</b>	Drinks & Posters					
<b>18.30</b>	Remembrance Service location "De Duif"					

### SATURDAY 20 SEPTEMBER 2014

<b>Time</b>		<b>Mauritszaal</b>	<b>Bibliotheek</b>		<b>Clauszaal</b>
<b>08.00</b>		4C: Workshop Potential animal models relevant to SIDS	4A: ISA Workshop How to get people to change their care (-behavior) into best practices		4B: Workshop Safe to breathe
<b>09.00</b>	<b>Grote zaal</b>				
	09.00 Grieving in the digital age, how we deal with death and social media, <i>Westerink, D.</i> 09.30 Religious aspects of terminal care and post mortem investigations, <i>Schilderman, H.</i> 10.00 Coping with traumatic grief by means of EMDR, <i>Spierings, J.</i> 10.30 One child too few: the struggles of a subsequent pregnancy, <i>Rietberg, J.</i>				

<b>11.00</b>	Break				
	<b>Grote Zaal</b>			<b>Raadzaal</b>	<b>Clauszaal</b>
<b>11.30</b>	11.30 Cardiogenetics and arrhythmias in SIDS and Stillbirth, <i>Clur, S.</i> 11.50 Reduction in stillbirth rates in England through improved antenatal recognition of fetal growth restriction, <i>Gardosi, J.</i> 12.10 Perinatal death in a developing country, <i>Kidanto, H.</i> 12.30 Care of low birth weight infants in rural Zambia: formative research and a feasibility trial of community-based kangaroo care after discharge, <i>Sacks, E.</i>			5A: Parents & health care professionals***	5B: Return to zero (movie about stillbirth)***
<b>12.50</b>	Lunch				
	<b>Grote Zaal</b>	<b>Mauritszaal</b>	<b>Bibliotheek</b>	<b>Raadzaal</b>	<b>Clauszaal</b>
<b>14.00</b>	6B: Pathology symposium <b>-This session ends at 16.45-</b>	6A: Placenta	6C: Implementation ISPID	6D: Workshop Healing through writing and visual art***	6E: Innovative ways of care***
<b>15.00</b>	Break				
		<b>Mauritszaal</b>	<b>Bibliotheek</b>	<b>Raadzaal</b>	<b>Clauszaal</b>
<b>15.30</b>	Continuation 6B (until 16.45)	7A: Decreased fetal movements	7B: Implementation ISPID continued	7C: Innovative bereavement care***	7D: Innovative ways of bereavement support***
<b>16.30</b>	Drinks & posters				
<b>18.00</b>	Departure boat to gala dinner venue				
<b>19.30</b>	Start gala dinner & dance				

#### SUNDAY 21 SEPTEMBER 2014

<b>Time</b>	<b>Grote Zaal</b>	<b>Mauritszaal</b>	<b>Bibliotheek</b>	<b>Raadzaal</b>	<b>Clauszaal</b>
<b>08.30</b>	8A: Perinatal audit	8B: ISPID: Epidemiology and call to global action	Parallel 8D***	8C: ISPID Science	Parallel 8E***
<b>10.30</b>	Break				
<b>11.00</b>	<b>Grote Zaal</b> 11.00 Every Newborn Action Plan: changing the future for the world's newborns and stillbirths, <i>Lawn, J.</i> 11.30 What has caused the recent reduction in mortality in New Zealand?, <i>Mitchell, E.</i> 12.00 New insights on SIDS and future role epidemiology, <i>Hauck, F.</i> 12.30 New insights on stillbirth and decreasing perinatal mortality, <i>Fretts, R.</i> 13.00 Awards & closing remarks/Presentation 2016 conference, <i>Erwich, J.J. &amp; L'Hoir, M.</i>				
<b>14.00</b>	End				



## **PRECONFERENCE PROGRAM THURSDAY 18 SEPTEMBER**

Delegates will be welcome to the official registration from 12.00 pm on Thursday 18 September. The conference program will commence at 13.00 pm with a small meeting for the ISA/ISPID delegates.

### *Preconference workshops and board meetings ISA*

ISA pre-conference half-day workshops (separate registration and payment)

1. On placental pathology (organizer Dr. S. Gordijn, NL). An international group of opinion leaders in placental pathology, will discuss current controversies and the aim is to reach consensus. These results will be presented during the conference on Saturday. Target audience: pathologists, persons involved in classification of causes for perinatal death. Many pathologists have been invited to attend. We have only some places for the workshop left.

2. IMPROVE- workshop (organizer Dr. F.J. Korteweg, NL). This Australian developed workshop (Prof. Vicki Flenady, Australia) consists of 6 stations of each 30 min. In these stations the everyday practice of the care around perinatal mortality will be presented and discussed. From diagnosis, causes, and medical issues, such as bereavement care, classification and follow up. Target audience: nurses, midwives and registrars/consultants in O&G, and all involved in the care of couples confronted with perinatal death.

17.00-18.00 Board meeting ISA

### *Preconference activities ISPID*

09.00-12.00 ISPID Grantholders meeting Lullaby trust

13.00-14.30 ISPID working group meetings

14.30-15.00 ISPID General membership meeting

15.00-16.00 ISPID Board meeting

18.00 Opening reception for all participants

## AGENDA

Sessions which will be interesting for parents and health care workers who interact with and support parents are marked with\*\*\*

### Thursday 18 September

Timeslot	Program	Speaker	Room
18.00	Opening reception - <b>Sponsored by ABN AMRO</b> -		Marmeren Hal

### Friday 19 September

Timeslot/no.	Program	Speaker	Room
07.00	ISA scientific advisory committee		
08.30	Opening	Erwich, J.J. (chair ISA) Raven, L. (chair ISPID)	Grote zaal
08.45 O1	How parents make a difference	Vintges, M. Plandsoen, B.	Grote zaal
09.00 O2	What still needs to be implemented of the Lancet Stillbirth series?	Ellwood, D. Flenady, V.	Grote zaal
09.30 O3	Successful implementation of safe sleeping messages	Moon, R.	Grote zaal
10.00 O4	Implementation in health care	Grol, R.	Grote zaal
10.30	Drinks & Posters		
11.00 O5	The future of infectious causes for stillbirth	Silver, B.	Grote zaal
11.00	Parallel sessions parents 1A/1B/1C		
11.30 O6	From physiology to epidemiology in SIDS	Horne, R.	Grote zaal
12.00	Lunch & Posters		
13.30	Parallel sessions 2A/2B/2C/2D/2E/2F		
15.00	Break		
15.30	Parallel sessions 3A/3B/3C/3D/3E		
16.30	Drinks & Posters		
18.30	Remembrance Service, location "De Duif" - <b>Sponsored by River's Gift</b> -		

#### Fri Parallel 1A Death reviews\*\*\*, chairs: Vintges, M. / Boere-Boonekamp, M.

Timeslot/no.	Program	Speaker	Room
11.00 O7	Improving professional practice after unexpected infant death	Garstang, J.	Raadzaal
11.15 O8	Parents' experiences with support after their child's death	Gijzen, S.	Raadzaal
11.30 O9	When something goes wrong: being open and honest with patients	Cochrane, R. Broderick, S.	Raadzaal
11.45 O10	Death scene investigations. Experiences of bereaved parents after sudden, unexpected death of an infant	Kristensen, P.	Raadzaal

#### Fri Parallel 1B Children & grief\*\*\*, chairs: Troost, L. / Plandsoen, B

Timeslot/no.	Program	Speaker	Room
11.00 O11	It's not just the parents: personal perspectives on the loss of a sibling to sudden death in infancy	Mitchell, I.	Clauszaal
11.15 O12	When small children grieve. Grief and support to children under six years	Schrader, L.	Clauszaal

#### Fri Parallel 1C Film\*\*\*, chairs: Rietberg, J. / Groot, M. de

Timeslot	Program	Speaker	Room
11.00	Return to zero, movie about stillbirth		Bestuurskamer

**Fri Parallel 2A Predictions of pregnancy complications, chair: Scherjon, S.**

Timeslot/no.	Program	Speaker	Room
13.30 O13	Identifying the placental phenotype of adverse pregnancy outcome: potential novel biomarkers of the at-risk pregnancy	Higgins, L.	Mauritszaal
13.45 O14	Placental arterial Doppler surveillance in pregnancy can distinguish normal from abnormal placental vascular structure	Higgins, L.	Mauritszaal
14.00 O15	Prospective audit of antenatal patients in a tertiary obstetric unit to determine detection rate of Small for Gestation Age (SGA) babies	Hunter, A.	Mauritszaal
14.15 O16	Placental specific mRNA in the maternal blood identifies pregnancies at risk of stillbirth due to preterm and term fetal growth restriction	Whitehead, C.	Mauritszaal
14.30 O17	VoorZorg, nursing support in high-risk young pregnant women	Heijkant, S. van den	Mauritszaal
14.45 O18	Anxiety and satisfaction related to case/control participation in stillbirth research	Bond, D.	Mauritszaal

**Fri Parallel 2B Classification workshop, chair: Neilson, J.**

Timeslot/no.	Program	Speaker	Room
13.30-15.00 O19	Classification workshop	Presenters: Flenady, V. Erwich, J.J. Leisher, S. Reinebrant, H.	Bestuurskamer

**Fri Parallel 2C Safe sleep devices, chair: Taylor, B.**

Timeslot/no.	Program	Speaker	Room
13.30 O20	A randomised controlled study of an innovative sleep intervention for the prevention of sudden unexpected death in Infancy, in high risk Maori and pacific infants, in South Auckland New Zealand	McIntosh, C. Trenholme, A.	Grote zaal
13.40 O21	Beyond innovation - what happens after the good idea?	Cowan, S.	Grote zaal
13.50 O22	Safe sleep advice to safe sleep action: a model for creating change in Aboriginal and Torres Strait Islander communities	Young, J. Craigie, L. Watson, K.	Grote zaal
14.20 O23	Panel Taylor	Taylor, B. Baddock, S. Tipene-Leach, D.	Grote zaal
14.50	Joint panel discussion		Grote zaal

**Fri Parallel 2D Pathology and clinical model, chair: Krous, H.**

Timeslot/no.	Program	Speaker	Room
13.30 <b>O24</b>	Neurochemical abnormalities in the SIDS brainstem and piglet models- where to from here?	Machaalani, R.	Muiderpoortzaal
13.40 <b>O25</b>	Decreased orexin immunoreactive expression in the hypothalamus of Sudden Infant Death Syndrome (SIDS) infants	Hunt, N.	Muiderpoortzaal
13.50 <b>O26</b>	Feasibility of autopsy brain analysis in the safe passage study	Folkerth, R.	Muiderpoortzaal
14.00 <b>O27</b>	A deletion in LRP1B is associated with somatic overgrowth in a subset of Sudden Infant Death Syndrome cases	Paterson, D.	Muiderpoortzaal
14.10 <b>O28</b>	Alterations in metabolic proteins in SIDS as determined by mass spectrometry-based proteomics	Haynes, R.	Muiderpoortzaal
14.20 <b>O29</b>	Panel: Towards a clinical model for SIDS <b>- Sponsored by First Candle/CJ Foundation for SIDS -</b>		Muiderpoortzaal
	1. Biological precursors in SIDS in the back to sleep era	Goldstein, R.	Muiderpoortzaal
	2. A case series of infants and toddlers evaluated by the program on sudden unexpected death in pediatrics	Kinney, H.	Muiderpoortzaal
	3. A collaborative model for examining children who have died suddenly an unexpectedly	Nields, H.	Muiderpoortzaal

**Fri Parallel 2E Sands UK - New program for bereavement care\*\*\*, chairs: Long, N. / Groot, M. de / Rietberg, J.**

Timeslot/no.	Program	Speaker	Room
13.30-15.00 <b>O30</b>	Bringing about change in the UK - a collaboration of parents and professionals	Tuner, R. Bevan, C. Calderwood, C. Johnson, G.	Raadzaal

**Fri Parallel 2F New ways of parent support\*\*\*, chairs: Witlox, M. / L'Hoir, M.**

Timeslot/no.	Program	Speaker	Room
13.30 <b>O31</b>	Film fragments on the website; an innovative way to support parents	Linge, B. van	Clauszaal
13.45 <b>O32</b>	Evaluating the changing picture of bereavement support	Ward, J.	Clauszaal
14.00 <b>O33</b>	Alternative ways of supporting bereaved parents	Hartog, P. den Harrison, L.	Clauszaal
14.15 <b>O34</b>	How to help bereaved parents and reinforce prevention against sudden infant death?	Tran Quang, C.	Clauszaal
14.30 <b>O35</b>	"The medium is the message"- Rebranding Foundation for the Study of Infant Deaths; step change to reduce SIDS	Bates, F.	Clauszaal

**Fri Parallel 3A Perinatal care issues, chair: Hephzibah, N. / Scherjon, S.**

Timeslot/no.	Program	Speaker	Room
15.30 O36	Exploring Quality of Care (QOC) from patients' and providers' perspectives in accessing Emergency Obstetric and Newborn Care (EmONC) services in hard-to-reach areas in Bangladesh - <i>Sponsored by NWO/WOTRO</i> -	Khan, R.	Mauritszaal
15.45 O37	Perinatal Interventions in Suriname: the Perisur project	Mohangoo, A.	Mauritszaal
16.00 O38	Supine sleep position in late pregnancy is associated with increased risk of late stillbirth	McCowan, L. Thompson, J.	Mauritszaal
16.15 O39	Service user coinvestigators should attend ethics committee meetings for sensitive research: lessons from the insight study of stillbirth & bereavement care	Siassakos, D.	Mauritszaal

**Fri Parallel 3B Epidemiology ISPID, chair: Himes, B.**

Timeslot/no.	Program	Speaker	Room
15.30 O40	A pooled analysis of breastfeeding and Sudden Infant Death Syndrome: How much is enough to reduce the risk?	Thompson, J.	Grote zaal
15.45 O41	Evaluation of bedtime basics for babies: A U.S. Crib Distribution program to reduce the risk of sleep-related sudden infant deaths	Hauck, F.	Grote zaal
16.00 O42	Infant deaths occurring on sofas	Moon, R.	Grote zaal
16.15 O43	Swaddling and SIDS: Do we need to provide risk reduction advice?	Blair, P.	Grote zaal

**Fri Parallel 3C Workshop SIDS and suppressed hearing? chair: Krous, H.**

Timeslot/no.	Program	Speaker	Room
15.30 O44	SIDS and suppressed hearing? Mystery or a new perspective on SIDS?	Rubens, D. Ramirez, N. Paterson, D.	Muiderpoortzaal

**Fri Parallel 3D Fathers & grief\*\*\*, chairs: Plandsoen, B. / Heuker, J.**

Timeslot/no.	Program	Speaker	Room
15.30 O45	An integrative review of men's experiences of subsequent pregnancy after stillbirth	Murphy, M.	Raadzaal
15.50 O46	Fathers & Grief	Borman, D.	Raadzaal

**Fri Parallel 3E Care for parents and children\*\*\*, chairs: Groot, M. de / Swigchum, F. van**

Timeslot/no.	Program	Speaker	Room
15.30 O47	Patient-centered care in the next pregnancy	Cochrane, R. Broderick, S.	Clauszaal
15.45 O48	Supporting families with subsequent children - experience over 25 years	Waite, A.	Clauszaal
16.00 O49	Centering Pregnancy	Rijnders, M.	Clauszaal

## Saturday 20 September

Timeslot/no.	Program	Speaker	Room
08.00	Parallel sessions 4A/4B/4C		
09.00 <b>O50</b>	Grieving in the digital age, how we deal with death and social media	Westerink, D.	Grote zaal
09.30 <b>O51</b>	Religious aspects of terminal care and post mortem investigations	Schilderman, H.	Grote zaal
10.00 <b>O52</b>	Coping with traumatic grief by means of EMDR	Spierings, J.	Grote zaal
10.30 <b>O53</b>	One child too few: the struggles of a subsequent pregnancy	Rietberg, J.	Grote zaal
11.00	Break		
11.30 <b>O54</b>	Cardiogenetics and arrhythmias in SIDS and Stillbirth	Clur, S.	Grote zaal
11.30	Parallel session 5A/5B parents		
11.50 <b>O55</b>	Reduction in stillbirth rates in England through improved antenatal recognition of fetal growth restriction	Gardosi, J.	Grote zaal
12.10 <b>O56</b>	Perinatal death in a developing country <b>- Sponsored by ISA -</b>	Kidanto, H.	Grote zaal
12.30 <b>O57</b>	Care of low birth weight infants in rural Zambia: formative research and a feasibility trial of community-based kangaroo care after discharge	Sacks, E.	Grote zaal
12.50	Lunch		
13.15-14.00	General Assembly Meeting ISA		Bibliotheek
14.00	Parallel sessions 6A/6B/6C/6D/6E		
15.00	Break		
15.30	Parallel sessions 7A/7B/7C/7D		
16.30	Drinks & posters		
19.30	Gala dinner & Dance		

### Sat Parallel 4A ISA Workshop: How to get people to change their care (-behavior) into best practices, chair: Ellwood, D.

Timeslot/no.	Program	Speaker	Room
08.00 <b>O58</b>	Understanding the providers' perspective as barriers for retention in remote public facilities to ensure 24/7 Emergency Obstetric and Newborn Care (EmONC) services: a qualitative investigation - <b>Sponsored by NWO/WOTRO -</b>	Sultana, M.	Bibliotheek
08.10 <b>O59</b>	Implementing antenatal magnesium sulphate for improving outcomes of preterm survivors: the WISH project	Middleton, P.	Bibliotheek
08.20 <b>O60</b>	Implementation of changes in perinatal care in the north of the Netherlands, the ACTION Project	Drost, A.	Bibliotheek
08.30	Discussion		Bibliotheek

### Sat Parallel 4B Workshop Safe to breathe

Timeslot/no.	Program	Speaker	Room
08.00 <b>O61</b>	Safe to breathe: the art of translating evidence into understanding for protecting infant life	Young, J. Cowan, S.	Raadzaal

**Sat Parallel 4C Workshop Potential animal models relevant to SIDS, chair: Leiter, J.**

Timeslot/no.	Program	Speaker	Room
08.00 O62	Modeling the yin and yang of cardiorespiratory control in SIDS using neonatal animals	Leiter, J.	Mauritszaal
O63	Impaired responses to hypoxia and failed autoresuscitation in neonatal rodent models of 5-HT dysfunction	Corcoran, A.	Mauritszaal
O64	Brainstem Serotonergic and GABAergic Mechanisms, Arousal and SIDS	Darnall, R.	Mauritszaal
O65	The pre-Bötzinger Complex and the physiological determinants of SIDS	Ramirez, N.	Mauritszaal

**Sat Parallel 5A Parents & health care professionals\*\*\*, chairs: Swigchum, F. van / Troost, L.**

Timeslot/no.	Program	Speaker	Room
11.30 O66	Groningen experience of close cooperation	Groot, M. de Spagnoletti, M.	Raadzaal
11.50 O67	Parenting after perinatal loss: parenting with intention	Warland, J.	Raadzaal
12.10 O68	Psychosocial implications of stillbirth for the mother and her family: a crisis-support approach	Human, M.	Raadzaal

**Sat Parallel 5B Film\*\*\*, chair: Rietberg, J.**

Timeslot	Program	Speaker	Room
11.50-12.50	Return to zero (movie about stillbirth)		Clauszaal

**Sat Parallel 6A Placenta, chair: Gordijn, S.**

Timeslot/no.	Program	Speaker	Room
14.00 O69	Placenta workshop results	Khong, Y.	Mauritszaal
14.15 O70	Markers and risk factors for antepartum stillbirth: emerging evidence from the International Fetal and Newborn Growth Consortium for the 21st Century (INTERGROWTH-21st)	Hirst, J.	Mauritszaal
14.30 O71	Increased birthweight:placental weight ratios and reduced placental weight centiles in stillbirths of 'unknown' and 'non-placental' causes suggests an under-estimation of the placental contribution to stillbirth	Worton, S.	Mauritszaal
14.45 O72	Characterising villitis of unknown etiology in stillbirth	Derricott, H.	Mauritszaal

**Sat Parallel 6B Pathology symposium - Sponsored by American SIDS Institute -**

Timeslot/no.	Program	Speaker	Room
14.00	Introduction	Co-chairs McEntire, B. Byard, R.	Grote zaal
14.10 O73	Sleep-related deaths: classification dilemma	Discussant: Hunt, C. Presenters: Byard, R. Shapiro-Mendoza, C.	Grote zaal
14.50 O73	SUID Tissue for research: international perspectives	Discussant: McEntire, B. Presenters: Bell, M. Rognum, T. Cohen, M.	Grote zaal
15.30 O73	Brain & Genetics	Presenters: Kinney, H. Paterson, D.	Grote zaal
16.15 O73	New scientist presentation	Bright, F.	Grote zaal
16.35-16.45	Final discussion		Grote zaal

**Sat Parallel 6C Implementation ISPID, chair: Blair, P.**

Timeslot/no.	Program	Speaker	Room
14.00 <b>O74</b>	Reports of infant sleep behaviors from a national sample of mothers: the Study of Attitudes and Factors Affecting Infant Care (SAFE)	Colson, E.	Bibliotheek
14.10 <b>O75</b>	Today'sBaby: helping mothers make safe sleep choices using social marketing strategies via mobile technology	Hauck, F.	Bibliotheek
14.20 <b>O76</b>	What mothers know about SIDS risk factors in the UK: results from a cross sectional survey	Pease, A.	Bibliotheek
14.30 <b>O77</b>	Infant sleep environments depicted in stock photographs and magazines targeted to women of childbearing age	Joyner, B.	Bibliotheek
14.40 <b>O78</b>	Randomized messaging trial to reduce African-American infant mortality	Mathews, A.	Bibliotheek
14.50 <b>O79</b>	One community's collaborations to reduce infant mortality through the promotion of consistent safe sleep messages	Ahlers-Schmidt, C.	Bibliotheek

**Sat Parallel 6D Workshop\*\*\*, chairs: Vintges, M. / Troost, L.**

Timeslot/no.	Program	Speaker	Room
14.00 <b>O80</b>	Healing through writing and visual art	Chute, A.	Raadzaal

**Sat Parallel 6E Innovatives\*\*\*, chairs: Groot, M. de / Heuker, J.**

Timeslot	Program	Speaker	Room
14.00 <b>O81</b>	Social media and grief	Westerink, D.	Clauszaal
14.20 <b>O82</b>	Nurses can have great impact on parents they encounter	Shatz, A.	Clauszaal
14.40 <b>O83</b>	Why did my baby die? A guide for parents deciding on post-mortem examination/Perinatal post-mortem facilitating a diff. conversation	Verling, A.	Clauszaal

**Sat Parallel 7A Decreased fetal movements, chair: Ellwood, D.**

Timeslot/no.	Program	Speaker	Room
15.30 <b>O84</b>	DFM: Risk factors and implication	Gardosi, J.	Mauritszaal
15.45 <b>O85</b>	The 'My baby's movements' study: using mobile phone technology to reduce third-trimester stillbirths	Gardener, G.	Mauritszaal
16.00 <b>O86</b>	Impact of a decreased fetal movement policy on induction of labour and pregnancy outcomes	Gordon, A.	Mauritszaal
16.15 <b>O87</b>	My baby might die, but I have to wait?!? - the 39-week rule, recent trends in USA term stillbirth rates and the ethics of "non-indicated" term labor induction	Nicholson, J.	Mauritszaal



**Sat Parallel 7B Implementation ISPID continued, chair: Schlaud, M.**

Timeslot/no.	Program	Speaker	Room
15.30 <b>O88</b>	A French non-governmental prevention program of Sudden infant Death Syndrome	Harrewijn, I.	Bibliotheek
15.40 <b>O89</b>	Moving on: engaging teen parent networks in education to protect the older, more mobile baby	Clarke, J.	Bibliotheek
15.50 <b>O90</b>	1,000 grandmothers-promoting safe infant sleep for American Indian babies	Covington, T.	Bibliotheek
16.00 <b>O91</b>	Safe sleep saves lives. Best practices in the hospital setting	Himes, B.	Bibliotheek
16.10 <b>O92</b>	A qualitative analysis of a hospital-based program on achieving institutional culture change regarding Infant Sleep Safety (ISS)	Goodstein, M.	Bibliotheek
16.20 <b>O93</b>	Building sustainable infrastructure: reducing SIDS in African American communities	Scott, S.	Bibliotheek

**Sat Parallel 7C Innovative bereavement care\*\*\*, chairs: Groot, M. de / Rietberg, J.**

Timeslot/no.	Program	Speaker	Room
15.30 <b>O94</b>	Systematic review & meta analysis/training in bereavement care - the present & future	Siassakos, D. Hills, A. Chebsey, C. Turner, R. Storey, C. Hezell, A. Lewis, J.	Raadzaal

**Sat Parallel 7D Innovative ways of bereavement support\*\*\*, chairs: Witlox, M. / Heuker, J.**

Timeslot/no.	Program	Speaker	Room
15.30 <b>O95</b>	Make a memory: providing the gift of a memory of photography for parents suffering the loss of a baby	Eefting, W.	Clauszaal
15.45 <b>O96</b>	Providing last memories in funeral services (working title)	Reijerink, A.	Clauszaal
16.00 <b>O97</b>	Personal Enrichment Program (PEP) for bereaved parents	Hartog, P. den	Clauszaal

**Sunday 21 September**

Timeslot/no.	Program	Speaker	Room
08.30	Parallel sessions 8A/8B/8C/8D		
10.30	Break		
11.00 <b>O98</b>	Every Newborn Action Plan: changing the future for the world's newborns and stillbirths	Lawn, J.	Grote zaal
11.30 <b>O99</b>	What has caused the recent reduction in mortality in New Zealand?	Mitchell, E.	Grote zaal
12.00 <b>O100</b>	New insights on SIDS and future role epidemiology	Hauck, F.	Grote zaal
12.30 <b>O101</b>	New insights on stillbirth and decreasing perinatal mortality	Fretts, R.	Grote zaal
13.00	Awards & closing remarks/Presentation 2016 conference	Erwich, J.J. / L'Hoir, M.	Grote zaal
14.00	End		

**Sun Parallel 8A Perinatal audit, chair: Erwich, J.J.**

Timeslot/no.	Program	Speaker	Room
08.30 O102	International registries for perinatal mortality	Frøen, F.	Grote zaal
09.00 O103	Utilization of partograph is one of the effective measures for reducing still birth rate in the health facilities of Bangladesh	Begum, A ara	Grote zaal
09.15 O104	Evaluation of the Standardised Clinical Outcome Review (SCOR) pilot project	Gardosi. J.	Grote zaal
09.30 O105	MBRRACE-UK - enhancing the surveillance and quality of care provision for perinatal and neonatal deaths in the United Kingdom	Draper, E.	Grote zaal
09.45 O106	Perinatal mortality in Ireland: A national clinical audit	Corcoran, P.	Grote zaal
10.00 O107	Stillbirths in Scotland: four decades of improvement	Lennox, C.	Grote zaal
10.15 O108	Progress on a global classificationsystem for perinatal mortality	Flenady, V.	Grote zaal

**Sun Parallel 8B ISPID: Epidemiology and call to global action, chair: Cote, A.**

Timeslot/no.	Program	Speaker	Room
08.30 O109	Theme: The power of working together: from a SUID case review to a national safe sleep promotion program and a national coalition	Covington, T.	Mauritszaal
08.40 O110	Implementation of child death review in the Netherlands: results of a pilot	Gijzen, S.	Mauritszaal
08.50 O111	Child death review - helping to understand and prevent SUDI	Garstang, J.	Mauritszaal
09.00 O112	Three years of death scene investigation in cases of sudden death in infants and small children in Norway	Bøylestad, L.	Mauritszaal
09.10 O113	Modifiable Risk Factors for Sudden Infant Death Syndrome (SIDS) in Germany: Current Prevalence and Trends	Schlaud, M.	Mauritszaal
09.20 O114	Do pre-birth demographic characteristics of the family identify post-natal SIDS risk factors for the infant?	Pease, A.	Mauritszaal
09.30 O115	The poorest infants are at increased risk of SIDS: Experience in Bogota, Colombia	Latorre, M.	Mauritszaal
09.40 O116	workshop Darnall et al; A call to global action: proposal for multidisciplinary consensus; conference to standardize the classification of unexplained sleep related deaths	Hunt, C. Fleming, P. Darnall, D.	Mauritszaal

**Sun Parallel 8C ISPID Science, chair: Rognum, T.**

Timeslot/no.	Program	Speaker	Room
08.30 O117	Dummy use increases blood pressure in preterm infants	Horne, R.	Raadzaal
08.45 O118	Dummy use improves control of heart rate in preterm infants	Horne, R.	Raadzaal
09.00 O119	The stress peptide, PACAP, regulates the autonomic response to hyperthermic stress in neonatal mice: relevance to SIDS	Barrett, K.	Raadzaal
09.15 O120	Altered gene expression and possible immunodeficiency in cases of sudden infant death syndrome	Ferrante, L.	Raadzaal
09.30 O121	Is genetic variation in AQP1 involved in SIDS?	Opdal, S	Raadzaal
09.45 O122	Serotonergic brainstem analysis in SIDS infants born prematurely	Haynes, R.	Raadzaal
10.00 O123	The diagnosis of anaphylaxis in unexpected infant death. A blinded study	Carpenter, B.	Raadzaal
10.15 O124	Hippocampal pathology in sudden unexplained death in young children: an extended series	Kinney, H.	Raadzaal

**Sun Parallel 8D\*\*\*, chairs: Vintges, M. / Heuker, J.**

Timeslot/no.	Program	Speaker	Room
09.00 O125	Multicultural views on stillbirth and maternity bereavement care	Chebsey, C.	Bibliotheek
09.20 O126	Who tells a mother her baby has died? Racial differences in death disclosure	Gold, K.	Bibliotheek
09.35 O127	Narratives about having a stillborn child and the support from the church	Itkonen, J.	Bibliotheek
09.55 O129	The spiritual impact of stillbirth on bereaved parents and consultant obstetricians	Nuzum, D.	Bibliotheek
10.15 O130	Historial perspective of stillbirth	Bleyen, J.	Bibliotheek

**Sun Parallel 8E\*\*\*, chairs: Witlox, M. / Swigchum, F. van**

Timeslot/no.	Program	Speaker	Room
09.00 O131	Distance and closeness; About the effects on therapists and professionals & self management	Groot, P. de	Clauszaal

## CONFERENCE INFORMATION

### Access

Royal Tropical Institute, Mauritskade 63, 1092 AD Amsterdam, +31 (0)20 - 5688711.

### Accreditation

Accreditation (20 hours in total) has been requested from:

- ABAN (artsen/specialisten) (a total of 15 points has been awarded)
- KNOV (a total of 17 points has been awarded)
- Kwaliteitsregister V&V (a total of 20 points has been awarded)
- Kenniscentrum Kraamzorg (KCKZ)

Dutch professionals will get 15 CME points for following the total program; participants from other countries can receive a certificate if they wish.

### Admission to conference sessions

Admission to conference sessions is strictly by badge only. Please ensure that you are in your seat at least five minutes prior to the start time of each session and ensure that all phones and electronic devices are switched to silent.

### Badges

In the interest of security please make sure that your badge is clearly visible at all times during the conference. If you lose your badge, please report it to the Registration desk where you will be issued with a replacement. You are also kindly asked to recycle your badge and the badge holder at the end of the conference.

### Emergencies

In the event of an emergency please contact the Registration desk or the reception desk of the Royal Tropical Institute. Alternatively dial 112 or raise the nearest fire alarm should the need arise.

### Evaluation

In our bid to support sustainable events an email will be sent to you with a direct link to an online conference evaluation. All your comments are greatly valued and feedback plays an important part of congress planning for future years.

### Internet access

The Royal Tropical Institute is offering delegates access to a free Wi-Fi service. You should be able to log on easily via your browser. Login: KIT congres, WW: 5432154321.

### Lunch and refreshments

Lunch and refreshments are included in the price of your congress place on the days for which you are registered and will be served from the catering points in the Marmeren Hal (marble hall).

### Parallel sessions

Concurrent streams will take place in various breakout rooms located throughout the venue. Staff will be at hand to direct you to your chosen session.

### Poster presentations

Posters will be on display on the first floor 'Onder de bogen' (beneath the arcades) for the duration of the event. Authors and presenters will be present to answer any questions on Friday (mostly ISPID related) or Saturday (mostly ISA related) from 16.30 to 18.00 pm.

### Prayer room

The Royal Tropical Institute does not have a dedicated prayer room but, if you need to use a quiet place during the conference to pray, please speak to the registration staff who will direct you.

### Registration desk

If you have any queries please make your way to the Registration desk located in the Marmeren Hal. Organisation staff from will be at hand to answer any questions you may have. The registration desk will be open during the conference hours.

### Twitter

Feel free to inform as many people as possible about the Babysurvival Conference! If you use Twitter please mention #babysurvival2014.

West tube IJtunnel and part Amsterdam-Centre closed due to Dam to Dam Run

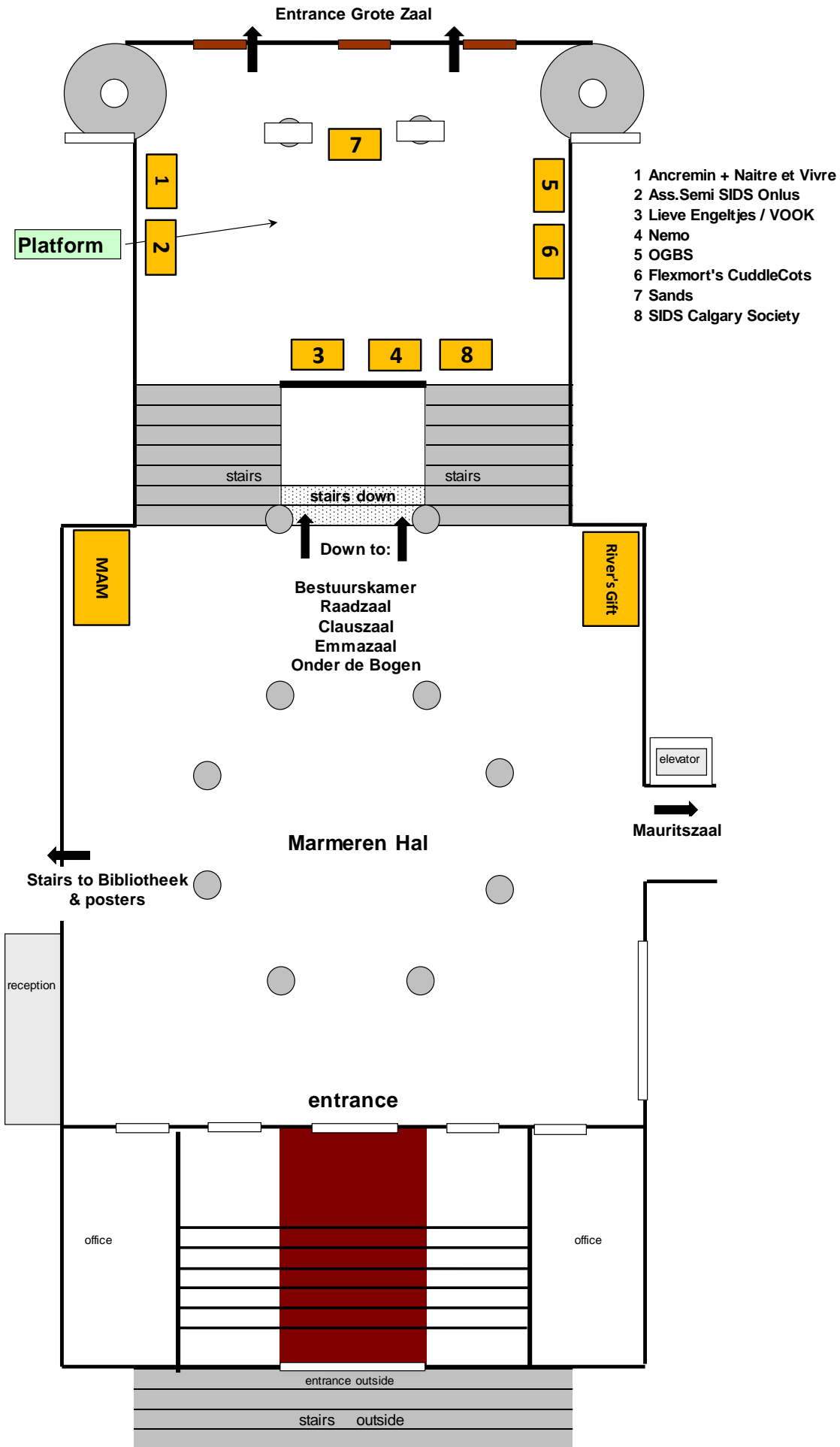
The west tube of the IJtunnel (from Amsterdam-North to Amsterdam-Centre) will be closed on Sunday the 21 September from 7.00 to 17.00 o' clock due to the Dam to Dam Run.

The streets Prins Hendrikkade, Oosterdokskade, Oosterdoksdam and Stationsplein in Amsterdam-Center will also be closed on Sunday from 7.00 to 17.00 am.

Our conference venue is not situated in the running area. But please inform yourself Sunday if you are leaving Amsterdam to prevent delay. Our hosts at the KIT will be able to give you up to date information.

For more information: <http://www.damloop.nl/bewoners/>.

**FLOORPLAN**



Please attend the  
**Memorial Service**

**Friday 18th of September 2014, 18.30**

The congress organization invites all to attend the memorial service which will be filled with music and rituals.

Together we will remember the children we have lost. These children are in our hearts and are the heart of our congress program.



**Registration**

The service is free for all participants of the congress. If you didn't register to participate in this service, you can still do so at the Registration Desk in the central hall of the KIT.

Registration is preferred, but not required.

**Route**

Tram 10 from Alexanderplein to Frederiksplein (3min.)  
It's a 5 minute walk to and from the tramstations. There's a bus available for people who have difficulty walking

**Location**

De Duif  
Prinsengracht 756  
1017 LD Amsterdam

**For more information go to the Information & Registration Desk in the central hall.**

## ARTISTIC EXPRESSIONS

### FILM RETURN TO ZERO

RETURN TO ZERO is based on the true story of a successful couple, Maggie (Minnie Driver) and Aaron (Paul Adelstein) who are preparing for the arrival of their first child. Just weeks before their due date they are devastated to discover that their baby son has died in the womb and will be stillborn. Maggie and Aaron attempt to go on with their lives but cannot escape their postpartum grief. Their lives and relationship have been forever altered by this loss. And no one seems to understand the hell they are going through. Aaron's dad, Robert encourages his son to bury himself in work, while Maggie's Mom, Kathleen always says the wrong thing. Maggie and Aaron try to cope in a myriad of ways - through denial, escape, and alcohol - but when Maggie ultimately discovers that Aaron is having an affair with Dana a co-worker, she decides to end the marriage. Just when Maggie believes she has started a new life, she discovers that she is pregnant by Aaron (from a last ditch 'save the marriage' getaway to Vegas.) With the help of Claire an empathetic doctor who experienced a similar loss years ago, Maggie finally grieves for the loss of her son. Then she and Aaron must reunite to face a turbulent and terrifying pregnancy.

### FILM STILL LOVED

Polly Perkins is the creative/line producer of "Still loved". Having graduated in Film Theory and Production, she started out working for Channel 4's TFI Friday as a production assistant/celebrity wrangler until the show's finale. Polly developed further production and aesthetic understanding on independent short films as an art director, props master and as a production office manager. She works for an independent film producer: Big Buddha.

Still Loved, a feature documentary, breaking the silence around stillbirth and baby loss. Filmed in the UK, which has one of the worst rates of stillbirth in the developed world, coming 33rd, below Poland and the Republic of Korea. Seventeen babies die within the first 24 hours of life, every single day in the UK.

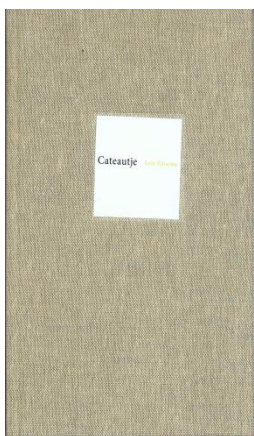
The death of these babies is still a taboo subject, many people are unwilling to acknowledge it, to discuss or to recognize the reality of it. However, this loss devastates thousands of people each year, not only parents, but also their families, friends and colleagues. It has a profound impact, too, on those working in the areas of pregnancy, childbirth and mental health.

Still Loved tells three unique stories, each focusing on a different aspect of baby loss and all connected by a common thread. Supported by an interactive website, complete with a regularly updated blog, gallery and user generated content - a space for the audience to share experiences- this documentary has already gained a strong social media following across the international baby loss community. With intimate access, we follow our families' compelling struggle to find a way forward, uncovering their pain, fears and dreams for the future as they find ways of expressing their love and loss. These families tenaciously turn their grief into generosity, creativity and friendship, becoming powerful advocates for the baby loss community. Transforming their lives, they commemorate their babies and show how people can come through the darkest sorrow to find the light of hope.

You can preview the seven minute trailer here: <https://vimeo.com/93524106>.

Password: SL7minteaserDeb

### KRIN RINSEMA



[www.krinrinsema.nl](http://www.krinrinsema.nl)

Krin Rinsema (1947) Sids Mother of Cateautje, Dutch artist with expositions in the Netherlands, Paris, France. The loss of a child is a theme in her work.

The work she exposes during the conference is specially made for the occasion. Her little book Cateautje will be for sale, during the conference.



## **GALA DINNER IN KRASNAPOLSKY - SATURDAY 20 SEPTEMBER 19.30 PM**

Traditionally there will be a gala dinner. The gala dinner will take place in Hotel Krasnapolsky (Dam 9, Amsterdam) and starts at 19.30 (7.30 pm). This will be a special dinner. Of course there will be music; music is the connection between ratio and emotions. And one can, of course, dance. We hope you will register for this unique and special evening.

There is a unique opportunity to travel from the Royal Tropical Institute to the dinner venue, Hotel Krasnapolsky in the centre of Amsterdam, by canal boat. This will be an extraordinary experience for our foreign guests: where else can you be transported by boat through the canals? This can only be in Amsterdam. To participate in this canal boat trip be sure to assemble in the foyer on time; departure of the first boat will be at 6.00 pm from KIT.

Those who leave on the first and second boat will have a more extensive tour of the canals and have the opportunity to visit an unique local distillery in the time before the dinner starts. For those traveling on the later boat there might be not enough time to make use of this extra activity.

## ABSTRACTS - ORALS

### O1 HOW PARENTS MAKE A DIFFERENCE

Marga Vintges, Ben Plandsoen

Our life as parents with a deceased child in their heart,



Judith Willemijn  
\* 18-03-1989 19-09-1989

The year 1989 was the year that made/has transformed us (in) who we are because we had a lovely daughter who we were not able to keep for more than six months. She has lived. She was a half year our life. She has become our inspiration.



Simon, Yael, Emma

Don't forget: we have four children now.



Joris-Jan Plandsoen



Hannah, Lara, Julia

### O2 THE LANCET'S STILLBIRTH SERIES; THE 'CALL TO ACTION' AND WHAT STILL NEEDS TO BE DONE

David, Ellwood<sup>1</sup>, Vicki Flenady<sup>2</sup>

<sup>1</sup>Griffith University School of Medicine and Gold Coast University Hospital, Queensland, <sup>2</sup>Mater Research Institute, University of Queensland, Australia

The first Lancet's Stillbirth Series (LSS) was published in April 2011, and situated the importance of stillbirth in the context of reproductive, maternal, newborn and child (RMNCH) survival with the goal of bringing together epidemiology, evidence for interventions, costing estimates and policy analysis. The international team for the series included 69 authors, from more than 50 organizations and 18 countries. The LSS contains the six series papers, two research articles, and eight linked commentaries, which included parent's stories to highlight the tragedy of the loss of a child when a baby is stillborn. It is a comprehensive and state-of-the-art account of what was known about stillbirth at that time, written by an expert global team. The series presented the first comprehensive, global set of stillbirth estimates by country data for advocacy and decision-making related to stillbirths and RMNCH, and new data on costs of priority interventions to reduce stillbirth to more effectively assist countries with implementing priority interventions.

It also covered the major causes of stillbirth, research gaps and priorities globally, risk factors and interventions relating to high-income countries (HIC). The final paper in the series was a 'call to action' to address stillbirth by improving data collection to ensure accuracy of numbers and causes of stillbirth, implementing known effective interventions, addressing the specific needs of disadvantaged women, and ensuring that the loss of a child to stillbirth is acknowledged and women and families receive appropriate bereavement care. The dissemination of the LSS commenced with simultaneous events in London, New York, Hobart, Geneva, Pakistan, Florence, and Cape Town, followed by wide dissemination. The launch of the series was met with unprecedented media coverage with around 1000 individual media hits that were estimated to have reached almost a billion people worldwide. The active dissemination phase culminated with a panel discussion at FIGO 2012 with LSS authors and other key stakeholders making a commitment to address the 'call to action'.

Over three years on and it is important to ask if the LSS has made a significant impact? Has it raised awareness of the scale of the burden of stillbirth, and more importantly, has it changed practice? The next series is being planned for publication in 2015 and will look at a range of issues including an update on the global estimates, and specifically a paper on the way in which health care providers in HIC have responded to the 'call to action'. An international survey is being planned to provide data from health care providers and consumers on how clinical practice has changed, and to identify research and education gaps. This presentation will look back at the first LSS, examine the success of the 'call to action' and look forward to the next series.

### **O3**

#### **SUCCESSFUL IMPLEMENTATION OF SAFE SLEEPING MESSAGES**

Rachel Moon

*Children's National Medical Center, Bethesda, USA*

Although many interventions to promote infant sleep safety and to reduce the risk of sudden and unexpected infant death exist, few have been evaluated in a rigorous manner. Dr. Moon will describe many interventions and provide the data, when available, for each intervention. A handout with resources (websites, contact information) for the interventions will be provided to attendees.

### **O4**

#### **REDUCING STILLBIRTH, A SYSTEMATIC APPROACH TO IMPLEMENTING EVIDENCE**

Richard Grol

*Radboudumc, IQ healthcare, Nijmegen, the Netherlands*

1,2 million stillbirths occur every year, many could be saved by good quality care. It is estimated that by optimal implementation of evidence based interventions 45% of stillbirths could be prevented. Implementation of these interventions is not very effective currently, in line with the implementation of other evidence based interventions in healthcare. Improvements, even after well designed programs is usually slow and small.

Research and experiments with the implementation of research evidence and clinical guidelines in the last decades show that a systematic approach over a longer period of time, with a variety of actions at different levels of care provision (patient, professional, team, management and executives, local and national policy making) is required to be successful. Elements of such an approach may be:

- continuous monitoring of a small set of very concrete targets for change, feedback
- involving patients in the process of improvement
- use of standardisation and checklists
- improving coordination and team training, particularly at handovers
- teaching professionals the skills and attitude for improving quality
- investing in better leadership for change

A Program to reduce stillbirth and implement evidence based interventions need to integrate such actions to be ultimately successful.

### **O5**

#### **INFECTION AND STILLBIRTH**

Bob Silver

*University of Utah MFM, Obstetrics and Gynecology, USA*

Stillbirth is one of the most common obstetric complications, affecting over 3 million births per year. It is emotionally difficult for families and clinicians since many cases are potentially preventable. Infection is a major cause of stillbirth, accounting for 10 - 25% of cases in developed countries. An even higher proportion of stillbirths are due to infection in developing countries. Indeed, up to 50% of stillbirths in low resource settings are associated with infection. Many organisms including viruses, bacteria, and other microbes have been implicated in stillbirths. Nonetheless, it can be difficult to ascribe a stillbirth to infection. Women may have evidence of an infection that may have nothing to do with a stillbirth. For example, most women with positive vaginal cultures for group B streptococcus (GBS) or positive serology for parvovirus have uncomplicated live births. Also, there are numerous pathways whereby infection may potentially cause stillbirth. These include direct fetal infection leading to sepsis, hypoxia or deformation, placental infection leading to placental insufficiency, systemic maternal infection leading to placental hypoperfusion / insufficiency, and intrauterine infection leading to preterm birth or preterm premature rupture of membranes, especially at pre-viable gestational ages. The optimal evaluation for potential causes of infectious stillbirth is controversial. The most useful tests appear to be clinical evaluation, placental histopathology and perinatal autopsy, with directed cultures or nucleic acid based tests as appropriate.

The benefit of routine serology or cultures is uncertain. Few studies have systematically assessed microorganisms associated with stillbirth using modern nucleic acid based technology. Recently, the Stillbirth Collaborative Research Network in the US used such an approach, including quantitative molecular methods and 16S rRNA gene sequencing to evaluate 93 stillbirths (placenta and liver). Total bacterial load was highest in stillbirth early in gestation and in non-Hispanic Black women. Group B streptococcus (GBS), Ureaplasma species and Prevotella bivia were the top three organisms found in stillbirths. Ureaplasmas were associated with early stillbirths while GBS was associated with extremes of gestational age. The organisms associated with bacterial vaginosis were associated with stillbirths in non-Hispanic black women. These data implicate a wide variety of bacterial species in stillbirth and show that specific bacterial species are associated with race and gestational age of stillbirth.

## O6

### FROM PHYSIOLOGY TO EPIDEMIOLOGY IN SIDS

Rosemary Horne

*The Ritchie Centre, Monash Institute of Medical Research and Prince Henry's Institute and Monash University, Melbourne, Australia*

**Background:** Despite the dramatic reduction in the Sudden Infant Death Syndrome (SIDS) in by over 80% since the introduction of these safe sleeping campaigns, SIDS still remains the leading cause of postnatal death in western countries. SIDS has a unique age distribution with over 90% of infants dying in the first 6 months of life, with a distinct peak at 2-3 months of age. Currently it is believed that SIDS occurs during sleep, and that impairment of cardiorespiratory control, together with a failure to arouse from sleep, are both involved in the final pathway. Over the last 20 years our group has been investigating how the identified epidemiological risk factors for SIDS such as prone sleep and preterm birth alter infant physiology to try to better understand the mechanisms of SIDS.

**Methods:** Studies in infants have been carried out longitudinally at 2-4 weeks, 2-3 months and 5-6 months of age across the age of greatest SIDS risk using daytime polysomnography to investigate the effects of prone sleeping and prematurity on cardiovascular control and arousability.

**Results:** When infants sleep prone arousability from sleep is depressed 3 fold. Furthermore, there is a fall in blood pressure despite an increase in heart rate, and cardiovascular control is impaired. We have shown that prone sleeping is also associated with reduced cerebral oxygenation. These impairments are most marked at 2-3 months of age. In preterm infants we have shown that blood pressure, blood pressure and heart rate control and cerebral oxygenation are lower compared to age matched term infants despite similar heart rates. These effects are more marked when preterm infants sleep prone.

**Conclusions:** In normal healthy infants cerebral oxygenation decreased with postnatal age and this was most marked between 2-4 weeks and 2-3 months of age. This reduction may underpin the decreased arousability from sleep exhibited by normal infants in the prone position. Preterm infants have impairments in cardiovascular and cerebrovascular control compared to age matched term infants which may underpin their increased vulnerability to SIDS. Physiological studies in infants can provide important insights into the likely mechanisms for SIDS and provide important evidence for SIDS prevention campaigns.

## O7

### IMPROVING PROFESSIONAL PRACTICE AFTER UNEXPECTED INFANT DEATH

Joanna Garstang, Peter Sidebotham, Frances Griffiths

*University of Warwick, UK*

**Aims:** Since 2008, in England, all unexpected infant deaths must be investigated jointly by police, health and child welfare services; with the intention of establishing the causes of death and supporting the family. This study aims to learn of bereaved parents' and professionals' experiences of this joint agency approach (JAA) and use this knowledge to improve professional practice.

**Methods:** Bereaved parents, whose unexpected infants' deaths were investigated by a JAA were eligible to participate in the study. Case records from all services were analysed and parents could complete questionnaires or have in-depth interviews. Professionals working with families were interviewed about their experiences of the JAA. Data were analysed using a Framework Approach.

**Results:** There were 111 eligible families, of whom 23 were recruited giving theoretical saturation. 16 families had in-depth interviews, 5 completed questionnaires and 2 allowed case note access only. The median time between infants' deaths and study participation was 33 weeks; data collection took place between 2011-3. 12 police officers, 11 paediatricians, 3 specialist nurses and 2 social workers were interviewed. There is an inherent conflict between the need to investigate the cause of death and support the family; most families therefore had mixed experiences of the JAA.

Non-specialist police often arrived at the parents' home along with the ambulance. Lacking experience of infant deaths they commenced a crime investigation distressing parents further. Families were required by the police to leave their homes immediately without collecting possessions.

In the Emergency Department, nurses cared for the families while other professionals focused on investigating the death. The joint home visit (death scene examination) by police and paediatrician is a key investigative process and most parents found this helpful. However, for a few mothers it was too distressing to return home so soon after the death or talk with professionals.

After completion of all investigations parents should have paediatric follow-up. Parents' experiences of this varied; most welcomed the explanations as to why their baby died but complained of months waiting with no information or support. Some parents wanted help accessing emotional support, feeling unable to do this themselves. Specialist police were concerned about the initial police actions and are addressing these issues. Professionals who carried out joint home visits found these helpful as it offered different perspectives on the situation and allowed the police to be seen in a more supportive than investigative role. Police and paediatricians commented on the lack of engagement by child welfare services in the JAA even when there were child protection issues.

**Conclusion:** Overall most parents feel supported by professionals during the JAA; however there is scope for improvement. Professionals can be compassionate whilst carrying out a thorough investigation. Non-specialist police should not routinely attend infant deaths. Paediatricians should ensure that parents are kept updated with the progress of the investigations. Some parents require more emotional support and professionals should assist them in accessing this.

## O8

### PARENTS' EXPERIENCES WITH SUPPORT AFTER THEIR CHILD'S DEATH

Sandra Gijzen<sup>1</sup>, Monique L'Hoir<sup>2</sup>, Magda Boere-Boonekamp<sup>1</sup>, Ariana Need<sup>3</sup>

<sup>1</sup>Department HTSR, IGS Institute for Innovation and Governance Studies, University of Twente, <sup>2</sup>TNO Child Health, Leiden,

<sup>3</sup>Department Public Administration, IGS, University of Twente, the Netherlands

**Background:** A child's death is an enormous tragedy for both the parents and other family members. Parents experience intense feelings after the child's death and the family system is disrupted internally. Support to the family is important to cope with the loss of the child. In the Netherlands, professionals from different organizations often are involved when children die. The support these professionals give to the family hardly receives any attention in Dutch protocols, guidelines or other working agreements.

**Objective:** To determine which emotional, instrumental and informational support Dutch parents receive before, around or after the death of their child and what type of care meets or does not meet the needs of the parents.

**Methods:** Parents who have lost their child during pregnancy, labor or after birth, until the age of 2 years, were eligible for participation. Members of three parents' associations, namely the Association of Parents of Cot death Children, the Association of Parents of a Deceased Child and the Sweet Angel Foundation, were approached by post or email to participate in the study. Respectively 33, 39 and 1 parents signed-up for participation.

Data on background characteristics of the parents were gathered through an online questionnaire. Four online focus group discussions provided data on the type of bereavement care parents received before, around and after the death of their child. SPSS was used to analyze the questionnaires and Atlas ti. for the focus group discussions.

**Results:** Twenty-nine members of the Association of Cot death ('cot death group'), 34 of the Sweet Angel Foundation and 1 of the Association of Parents of a Deceased child ('other deaths group') participated in the online focus group discussions. In total 57 questionnaires were completed by the 64 participants. All respondents were Dutch. Most of them were mothers (93%). The children died between 1970 and 2012. Nearly half of the deaths were due to Sudden Infant Death Syndrome (SIDS); other causes of death were pregnancy and childbirth related conditions and congenital malformations, deformations and chromosomal abnormalities.

Sixteen of the 35 parents (46%) in the 'other deaths group' reported that they received support before their child died (i.e. anticipatory support), 34 (97%) in the period around the time of death until burial or cremation, 28 (80%) in the period until 1 year after death, and 17 (49%) in the period after 1 year.

Twenty-three of the 29 parents in the 'cot death group' (79%) reported that they received support in the period around the time of death until burial or cremation, 24 (83%) in the period until 1 year after death, and 22 (76%) in the period after 1 year. Detailed figures on different forms of support for both groups are presented in Table 1.

With respect to the emotional support parents in the 'cot death group' received this especially from primary care (general practitioner, social worker, home care professional) and pastoral and mental health care. Parents in the 'other deaths group' received this especially from secondary care (pediatrician, gynaecologist, other medical specialist, nurse) and pastoral and mental health care.

Twenty-five of the 35 parents in the 'other deaths group' (71%) and 25 of the 29 parents in the 'cot death group' (86%) mentioned to have missed support mainly in the period around the time of death until 1 year after their child's death.

**Discussion:** The results of this study can be used to help professionals to optimize their response to a child's death. Parents in both groups made several recommendations focusing on offering emotional, instrumental and informational support. Based on the results of this study we recommend that the general practitioner or another professional contacts the parents six to twelve months after a child's death to check whether the family needs any support. Another recommendation is that professionals provide support and (more) information about the grieving process and the possibilities in support shortly after the death of a child.

Table 1. The number of parents who reported that they received bereavement care after the death of their child.

	Period before the time of death	Period before and around the time of death until burial or cremation		Period after burial or cremation until 1 year		Period after 1 year		Period not specified	
	other death (n=35)	cot death (n=29)	other death (n=35)	cot death (n=29)	other death (n=35)	cot death (n=29)	other death (n=35)	cot death (n=29)	other death (n=35)
<b>Support</b>									
Emotional	10 (29%)	23 (79%)	32 (91%)	23 (79%)	19 (54%)	20 (69%)	12 (34%)	19 (66%)	26 (74%)
Instrumental	11 (31%)	14 (48%)	29 (83%)	10 (34%)	17 (49%)	12 (41%)	2 (6%)	3 (10%)	14 (40%)
Informational	8 (23%)	3 (10%)	19 (54%)	6 (21%)	16 (46%)	4 (14%)	2 (6%)	4 (14%)	7 (20%)
Unspecified	8 (23%)	8 (28%)	25 (71%)	4 (14%)	9 (26%)	3 (10%)	3 (9%)	6 (21%)	11 (31%)

## O9

### **WHEN SOMETHING GOES WRONG: BEING OPEN AND HONEST WITH PATIENTS**

Ruth Cochrane, Sheila Broderick

*Co-authors of 'Perinatal Loss: a handbook for working with women and their families', University Hospital Lewisham, UK*

In the UK there is a nationwide policy of being open and honest with patients about 'poor outcomes'. Despite this, hospital staff still find it difficult to be open, often for fear of being blamed or sued.

When things go wrong this will sometimes be because of a mistake or an omission by a member of staff, but terrible things happen without anyone being to blame. Both of these versions present challenges for the person who talks to the patient and her family. Delegates will work in small groups with a list of scenarios in which the outcome has been poor. They will have the opportunity to describe how they would discuss these various scenarios with the patients and their relatives, and explore their feelings with regard to how honest they are able to be.

## O10

### **DEATH SCENE INVESTIGATIONS. EXPERIENCES OF BEREAVED PARENTS AFTER SUDDEN, UNEXPECTED DEATH OF AN INFANT**

Pål Kristensen

*Norwegian Centre for Violence and Traumatic Stress Studies (NKVTS), Oslo, Norway*

Since 2010 a certain practice has existed in Norway where bereaved parents are voluntarily offered a death scene investigation when a child aged 0-3 dies suddenly and unexpectedly in the home. The death scene investigation is only conducted when there is no criminal suspicion. The aims of the investigation are to be better able to determine the cause of death, and to learn more about potential risk factors for sudden, unexpected infant death. The death scene investigation is conducted in the parents' home within 48 hours after the death by a forensic pathologist (who did the autopsy) and a police officer. The investigation consists of a conversation with the parents, informing the parents of preliminary results from the autopsy, and a reconstruction in the room where the child was found dead.

In this presentation I will report results from a project that evaluates bereaved parent's experiences of participating in a death scene investigation after losing a child to sudden, unexpected death. In the project bereaved parents are in-depth interviewed and a set of questionnaires are self-reported approximately 5 weeks after the investigation. A qualitative content analysis of 16 interviews show that the majority of parents view participation as a demanding, but generally positive experience. Few adverse reactions are reported. Parents rate the availability of crucial information related to what may have/may not have caused the death received shortly after the child's death from caring and competent persons as the most valuable parts of the investigation. For many this also meant a reduction in specific grief/trauma reactions such as subjective feelings of guilt related to the death. Evaluating the investigation negatively was mainly related to parents experiencing it as mandatory, and expecting to get concluding answers on the cause of death. Results from the self-report measures are consistent with what was found in the interviews. The study shows that bereaved parents primarily view death scene investigations as a positive experience, and while not intended to be an intervention it also has the potential to alleviate certain grief/trauma reactions commonly reported by bereaved parents after sudden, unexpected infant death.

## O11

### **IT'S NOT JUST THE PARENTS: PERSONAL PERSPECTIVES ON THE LOSS OF A SIBLING TO SUDDEN DEATH IN INFANCY**

Linda Fountain<sup>1</sup>, Ian Mitchell<sup>2</sup>

<sup>1</sup>Alberta Health Services, <sup>2</sup>University of Calgary, Canada

**Background and rationale:** The concerns and issues of siblings whose parents have lost a baby to sudden, unexplained death have rarely been examined. Most studies on bereaved siblings have been based on other types of losses. Those focusing on SIDS relied on parental report. This qualitative study probes the reflections of adolescents and young adults on how their lives have been impacted by the loss. We explore their beliefs about the death, their perception of its impact on family members and themselves, and what was helpful.

**Methods:** Seven young people between the ages of 12 - 26 were interviewed, using a semi-structured, open interview format. A qualitative description design explored the loss from the participants' perspective, and probed the meanings they ascribe to the experience. Interviews were audio taped and transcribed. Transcriptions were analyzed and coded to identify patterns, themes, commonalities and differences.

All study participants had other living siblings at the time of the interview. Three were living at the time of the death and four were born following the loss.

**Results:** Those born before the death of their sibling had vivid, though fragmented memories of the event, and recalled feeling a great deal of confusion at the time. All born after the SIDS recalled becoming aware of the loss of a sibling early on in life, primarily through asking questions about the baby in photographs. Similar themes emerged for all the participants. These included: an increasing awareness over time of the magnitude of the loss for their parents; a description of parents as being highly anxious and overprotective, particularly of subsequent children; and a heightened awareness of death. Participants identified challenges and strengths resulting from the experience. All participants were primarily impacted by the parental response to the loss; a sense of personal loss only emerged over time. Consistent patterns of what was helpful and what was not were identified, as well as advice they would give parents facing a similar loss.

**Interpretation:** The sudden, unexpected death of a baby impacts very young children and those born subsequently. Young children are primarily impacted by parental response and reaction, but gradually begin to feel a sense of personal loss as they get older. Siblings are keenly aware of the loss and need to process the experience as they reach new levels of maturity. Participants found the interview helpful and were able to gain insights about their experience through the discussion. Most were surprised by the grief that surfaced while talking about their experience as a bereaved sibling. The findings provide insight for parents, medical professionals, counselors, and others who support the family. Further study is needed to gain a deeper understanding of the perspectives of bereaved siblings, and how they can best be supported at the time of the loss and throughout their childhood.

## O12

### **WHEN SMALL CHILDREN GRIEVE - GRIEF AND SUPPORT TO CHILDREN UNDER SIX YEARS**

Line Schrader, Eline Røkholt, Kari Elisabeth Bugge, Trine Kalstad

*Norwegian SIDS and Stillbirth Society, Norway*

The Norwegian SIDS and Stillbirth Society has developed an information booklet about preschool children (0-6 years old) and grief. The booklet provides information about how young children express grief when someone close dies, and how close adults can support them. It is developed in cooperation with a reference group representing various disciplines related to young children. This booklet is part of a series of booklets about children and grief made by the Society.

**Background:** Grief can have serious consequences for children's lives and development. The youngest ones are especially vulnerable as they are completely dependent on their close caregivers. Grief experienced by children under the age of six is often misunderstood or overlooked. The adults are often uncertain how to approach the youngest children, they do not know how to talk with them or show compassion. Neither do they know how to involve the smallest children in the events around a death. How can we help the smallest children to express grief when they do not have any words?

Because children quickly switch from expressing sadness to happiness, many adults are afraid to bring them into the grief by asking questions or giving attention to the loss. The grief lives within the body, it isn't gone even though it isn't expressed all the time. Both children and adults need to go close to the grief *and* to focus on everyday matters. Because children lack a language for grief they need help to express their sadness and thoughts by i.e. looking at pictures and books, drawing and playing. What we do or do not do as close adults is what children learn is accepted and normal ways of coping with grief.

**Goal:** Develop and publish an information booklet about grief and support to bereaved children between the age of zero and six.

**Target group:** The social network around preschool children; family, kindergarten staff, health professionals etc.

**Result:** The booklet's main chapters:

- Small children's grief reactions and grief actions
- Family interaction and parents' grief
- How to support small children in grief
- Grandparents, other family and network: How to help
- Small children's participation in rituals around death
- The kindergarten as an arena for supporting the child
- How can the support system contribute to help

The booklet gives answers to questions like: How to tell young children about serious illness and death? How to differentiate between a child's normal development and expressions of grief? What do we do when the toddler does not have language or does not speak about the loss?

The content is based on professional experience, literature, observations, interviews and conversations with bereaved children and parents. It has quotes from bereaved children and parents, and illustrated with photographs of and drawings from small children. The booklet is free of charge and is also published on the Society's website. Financed by the ExtraFoundation Health and Rehabilitation.

## O13

### **IDENTIFYING THE PLACENTAL PHENOTYPE OF ADVERSE PREGNANCY OUTCOME: POTENTIAL NOVEL BIOMARKERS OF THE AT-RISK PREGNANCY**

Lucy Higgins, E. Johnstone, M. Wareing, C. Sibley, Alexander Heazell

*Maternal and Fetal Health Research Centre, Manchester, UK*

**Background:** "Timely evaluation of women reporting decreased fetal movements" (DFM) is an ISA recommendation to reduce stillbirth rates. Yet evidence guiding how to evaluate these pregnancies is lacking. DFM pregnancies are at two- to three-fold increased stillbirth risk and preliminary evidence links DFM with placental dysfunction.

**Objectives:** We hypothesised that DFM pregnancies with adverse pregnancy outcome (APO) display a placental phenotype distinct from that of DFM pregnancies with normal pregnancy outcome (NPO) and aimed to identify differences in *ex vivo* structure and function between NPO and APO placentas.

**Methods:** 257 singleton pregnancies complicated by DFM after 28 weeks of gestation were studied. APO was defined as: stillbirth, individualised birth weight centile <10, five minute APGAR score <7, umbilical artery pH <7.1 or base excess <-10.0 or neonatal intensive care admission. 68 Placentas were examined for length, width, depth, volume, weight and area, and then assessed for either villous vascularity (CD31 immunostaining), wire myographic chorionic plate arterial (CPA) function (thromboxane sensitivity, U46619 EC<sub>50</sub>; nitric oxide sensitivity, SNP EC<sub>50</sub>; vessel compliance, Tau; peak active tension generation, PAT) or villous tissue hormone content (ELISA of tissue lysate). Statistical analysis was performed by Mann-Whitney U test followed by ROC curve analysis for features with statistical significance (p < 0.05).

**Results:** 50/257 (19.5%) of DFM pregnancies resulted in APO. Table 1 summarises the placental findings in NPO and APO placentas. Data are displayed as median (IQR). Compared with NPO placentas, APO placentas are smaller, less vascular, with altered vascular and endocrine function.

Feature	Categorical analysis			ROC analysis	
	NPO	APO	p	Area	p
Size: NPO N=53, APO N=15					
Length (cm)	21.9 (19.9 – 23.5)	19.7 (17.2 – 20.3)	0.0005	0.78	0.00081
Width (cm)	18.9 (17.5 – 20.8)	15.9 (15.0 – 17.1)	< 0.0001	0.82	0.00019
Depth (cm)	2.2 (1.9 – 2.4)	2.1 (1.9 – 2.4)	0.50		
Volume (cm <sup>3</sup> )	502 (445 – 581)	364 (312 – 416)	<0.0001	0.84	<0.0001
Weight (grams)	544 (456 – 604)	377 (351 – 474)	<0.0001	0.83	0.00011
Area (cm <sup>2</sup> )	296 (277 – 356)	238 (215 – 261)	< 0.0001	0.86	<0.0001
Vascular structure: NPO N=15, APO N=9					
Villous (vessels/mm <sup>2</sup> )	1315 (1204 – 1472)	1042 (974 – 1184)	0.0020	0.85	0.0030
Vascular Function: NPO N=20, APO N=9					
U46619 EC <sub>50</sub> (nM)	46.3 (31.8 – 65.6)	49.3 (32.7 – 90.0)	0.43		
SNP EC <sub>50</sub> (nM)	12.0 (5.9 – 23.5)	30.4 (18.9 – 50.0)	0.020	0.82	0.021
Tau (1/k)	432 (281 – 581)	510 (341 – 616)	0.48		
PAT (mN/mm <sup>2</sup> )	1.3 (1.0 – 2.0)	1.7 (0.7 – 3.2)	0.19		
Endocrine Function: NPO N=13, APO N=9					
HCG content (mIU/mg)	60.2 (21.5 – 116.9)	17.7 (11.2 – 60.5)	0.019	0.75	0.020
HPL content (mg/mg)	36.0 (5.4 – 64.5)	2.8 (1.5 – 7.9)	0.0031	0.81	0.0040
Progesterone content (ng/mg)	532.4 (292.0 0 841.3)	389.2 (156.4 – 649.4)	0.37		

**Conclusions:** A placental phenotype of APO can be identified in DFM pregnancies. If these placental biomarkers can be measured accurately *in vivo*, they may aid prediction of APO in DFM pregnancies.

## O14

### PLACENTAL ARTERIAL DOPPLER SURVEILLANCE IN PREGNANCY CAN DISTINGUISH NORMAL FROM ABNORMAL PLACENTAL VASCULAR STRUCTURE

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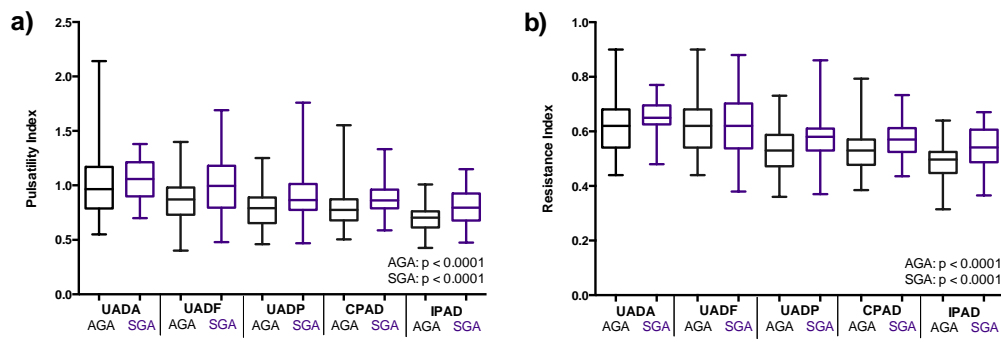
**Background:** “Doppler for high risk pregnancy” is an ISA recommendation to reduce stillbirth rates. Whilst an abnormal umbilical artery Doppler (UAD) is highly predictive of compromise, it is rarely abnormal in late pregnancy and has not been shown to be of benefit in “low risk” pregnancy.

**Objectives:** We hypothesised that Doppler waveforms from placental circulation arteries can distinguish normal from abnormal placental vascular structure and function. We therefore examined the relationship between placental arterial Doppler waveforms at different sampling sites and *ex vivo* measures of placental vascular structure and function.

**Methods:** Pulsatility index (PI) and resistance index (RI) values were calculated from Doppler traces (N = 255) of the umbilical artery abdominal insertion (UADA), free loop (UADF), placental insertion (UADP), chorionic plate arteries (CPAD) and intraplacental arteries (IPAD). PI and RI were compared between sites (Kruskal-Wallis test) and between pregnancies resulting in births above (AGA) and below (SGA) the 10<sup>th</sup> individualised birth weight centile (Mann-Whitney U Test). If delivery occurred within seven days, placental vascular structure (N = 34) and/or function (N = 30) was assessed *ex vivo* and correlated with PI and RI. Structure was quantified by CD31 immunostaining of villous tissue (raw number and density of villous CD31 positive structures). Function was quantified by wire myography as follows; thromboxane sensitivity (U46619 EC<sub>50</sub>), nitric oxide sensitivity (SNP EC<sub>50</sub>), vessel compliance (Tau) and peak active tension (PAT). Statistical significance was set at p < 0.05.



**Results:** PI and RI decreased with proximity to the placental microvasculature; pregnancies resulting in SGA birth demonstrated higher resistance (Fig 1). CPAD PI ( $R_s = -0.42$ ,  $p = 0.0076$ ) and RI ( $R_s = -0.39$ ,  $p = 0.014$ ) and IPAD PI ( $R_s = -0.40$ ,  $p = 0.011$ ) and RI ( $R_s = -0.36$ ,  $p = 0.023$ ) each inversely correlated with the number of vessels per field of view. When correlating against vessel density only CPAD PI remained significantly related ( $R_s = -0.34$ ,  $p = 0.031$ ). No other relationships were detected between vascular structure or function and PI or RI at any Doppler site ( $p > 0.05$ ).



**Figure 1: Trend in PI (a) and RI (b) by sampling site and birthweight category.**

**Conclusions:** Arterial Doppler resistance declines with proximity to the purported site of abnormal resistance. Whilst CPAD and IPAD PI and RI correlate significantly with villous vessel number, only CPAD PI remained significantly related to villous vessel density suggesting that placental size may be related to PI and RI. UADF PI and RI were not related to any studied aspect of placental vascular structure or function; this may explain why the UADF is often normal in compromised pregnancies at term. The CPAD may offer improved detection of placental disease and assist prediction and prevention of adverse pregnancy outcome in late pregnancy.

## O15

### PROSPECTIVE AUDIT OF ANTENATAL PATIENTS IN A TERTIARY OBSTETRIC UNIT TO DETERMINE DETECTION RATE OF SMALL FOR GESTATION AGE (SGA) BABIES

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**Background:** Using ReCoDe, 43% of stillbirths in UK studies are attributed to intrauterine growth restriction (IUGR). Identification of IUGR remains challenging antenatally. Gardosi et al. found that with *customised* growth charts, a Small for Gestational Age (SGA) fetus, defined as <10<sup>th</sup> centile, is associated with poor neonatal outcomes including death and is synonymous with IUGR. RCOG have produced guidelines to help identify and stratify antenatal care in those at risk of SGA.

**Objectives:** Using RCOG Guideline 31, our objectives were:

- To ascertain whether patients have accurate assessment and management for SGA risks at booking appointment.
- To determine percentage of women who delivered SGA babies and in how many SGA was diagnosed antenatally.
- To identify if the intrapartum outcomes differed in the SGA group compared to matched controls.

**Methods:** A 50 day, prospective data collection of all deliveries in a tertiary hospital. 846 charts included, 25 could not be located. Postnatal discharge lists were crossed checked with the delivery book to ensure no births were missed.

- Notes were reviewed for evidence that fetal surveillance was undertaken where risk factors for SGA existed.
- Using customised growth charts, we ascertained whether babies were SGA and whether this was detected antenatally.
- We reviewed the intrapartum care for evidence of pathological CTGs, expedited delivery due to fetal distress and neonatal unit admission in 155 SGA cases and 155 control cases matched for maternal age, parity, smoking status and overall risk of SGA.

**Results:** 821 charts reviewed.

	Managed appropriately?	SGA at birth?	SGA diagnosed antenatally?	% of SGA diagnosed antenatally
High risk patients for SGA (n=278)	Yes-86	Yes-27	Yes-15	56%
	No-192	No-59	No-12	
Low risk patients for SGA (n=543)		Yes-63	Yes-15	24%
		No-129	No-48	
		Yes-73	Yes-29	37%
		No-448	No-44	

Overall SGA detection rate was 36%.

The SGA group had increased number of pathological CTG's (42 vs 27) and delivery due to presumed fetal distress. (35 vs 27) 31% of SGA babies (13/42) with a pathological CTG were admitted to the neonatal unit compared to 11% of control cases (3/27) who had a pathological CTG.

**Conclusions:** SGA is often missed antenatally. Correct risk management increases detection of SGA babies. Even in correctly managed high risk women, detection rate was only 56%. Fundal heights and Estimated Fetal Weights on ultrasound are not reliably detecting SGA. Education, skills training and re-configuration of our service is advised including antenatal booking proforma and display of the RCOG flowcharts in clinic rooms. Implementation of this guideline has shown to be beneficial in detection of SGA infants

The SGA babies had a more problematic intrapartum course and increased rates of neonatal admission, however, longterm outcomes of these babies could not be determined by this study. Further work is required to establish if implementation of this guideline will reduce the number of undiagnosed SGA infants with poor neonatal outcomes.

## O16

### PLACENTAL SPECIFIC MRNA IN THE MATERNAL BLOOD IDENTIFIES PREGNANCIES AT RISK OF STILLBIRTH DUE TO PRETERM AND TERM FETAL GROWTH RESTRICTION

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**Background:** Fetal growth restriction (FGR) is a major cause of stillbirth. If identified, half of stillbirths due to FGR may be preventable. Unfortunately, current methods of detection fail to identify the majority of FGR before stillbirth occurs. A biomarker to identify pregnancies complicated by FGR could significantly improve perinatal mortality. FGR occurs throughout pregnancy but management differs depending on whether it is identified at preterm or term gestations. Therefore it is essential to include both cohorts in new strategies to identify FGR. Nucleic acids from the placenta circulate in the maternal blood during pregnancy and provide a unique insight into placental function not otherwise available without invasive sampling.

**Objectives:** To determine if placental specific RNA in the maternal blood may be a novel biomarker to identify pregnancies at risk of stillbirth due to preterm and term FGR.

**Methods:** Using in silico analysis and microarray, placental specific genes (PSGs) in the maternal blood were identified and their expression in pregnancies complicated by FGR investigated. The expression and localization of these PSGs in the placenta in FGR was assessed using RT-PCR and ISH. Putative PSGs were measured in maternal blood at 28 weeks gestation in women with preterm FGR (n=20, birthweight <5<sup>th</sup> centile, delivery <34 weeks) and in a prospective longitudinal study of women who developed term FGR (n=650, birthweight <5<sup>th</sup> centile, delivery >37 weeks) using microarray, PCR array and digital PCR. Term FGR was studied in 2 stages:

1) 100 low risk women were recruited at 28 weeks gestation and underwent serial ultrasound and maternal blood sampling. The expression of PSGs in those who developed term FGR (n=12) was studied across gestation compared to healthy controls.

2) A large prospective study of 550 low risk women recruited at 28 weeks gestation compared PSG expression in maternal blood in women who developed term FGR (n=40) compared to controls (n=80).

**Results:** We identified 137 PSGs in the maternal blood in FGR, of which 75 were significantly dysregulated. At 28 weeks gestation ADM, CRH, CSH1, KISS1, PAPP2, ERVWE1 and TAC3 were dysregulated (p<0.05) in pregnancies affected by both preterm and term FGR. The expression of each PSG was higher in pregnancies complicated by preterm FGR than term FGR. A combined gene score had a positive likelihood ratio for term FGR of 2.7 (95% CI 1.8-4.2). Further testing at 36 weeks improved the sensitivity of predicting term FGR. Ultrasound confirmed the expression of the PSGs was elevated 10 weeks prior to any clinical evidence of term FGR but ultrasound did not identify those pregnancies destined to develop term FGR.

**Conclusion:** PSGs are dysregulated in the maternal blood at 28 weeks gestation in pregnancies complicated by preterm FGR and at risk of term FGR. PSGs in maternal blood outperform current serum analytes and ultrasound for identifying term FGR. A maternal blood test for placental specific mRNA performed at 28 weeks identifies pregnancies that may benefit from increased surveillance and early delivery to prevent stillbirth.

## O17

### VOORZORG, NURSING SUPPORT IN HIGH-RISK YOUNG PREGNANT WOMEN

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**Introduction:** VoorZorg is the first program in the Netherlands for primary prevention of child abuse. VoorZorg is a translation and cultural adaptation of NFP (Nurse Family Partnership), an effective program in the US.

**Methods:** The target group consists of young women who are pregnant with their first child, with low education, low income and several other adverse risk factors such as domestic violence in the past or present relationship, little social support, an unhealthy lifestyle with smoking, drugs or alcohol abuse.

We offer VoorZorg as an intervention from pregnancy until the children are 2 years of age for this difficult target group. The specially trained nurses do 40-60 structured home visits during 2,5 years.

**Results:** For the Randomised Controlled Trial 460 women have been enrolled by means of a two -step selection procedure. This effect study shows:

(1) the right women are reached: young pregnant women with many risk factors (76% single, 74% poverty, 68% violence in the past and/or present, 19% depression and 25% substance abuse).

(2) 98% have four or more risk factors.

(3) during pregnancy smoking is reduced (number of women and number of cigarettes). After pregnancy, the women in the VoorZorg group smoke half as much compared with the usual care group.

- (4) women in the VoorZorg group don't smoke near the baby, unlike the women in the group who received usual care.
- (5) when the babies are 6 months of age, the VoorZorg group (14%) is significantly more breastfeeding in comparison with the usual care group (6%).
- (6) domestic violence has declined in the VoorZorg group compared with the usual care group, both during pregnancy and two years later, particularly with regard to the psychological and physical violence.
- (7) there are nearly two times as many reports of child abuse in the usual care group (31/164, 19%) as in the VoorZorg group (18/168, 11%). This is a significant difference.

Discussion: A strong point is that the intervention is initiated during pregnancy, causing reduction of prenatal damage. Risk factors are addressed before these have led to a downward spiral in (future) parenting. Also, women learn to exploit their social network and enhancing social services such as child care, debt restructuring, appropriate work, tackling addiction or seeking psychiatric help. To achieve good results in these women who are often damaged in confidence and frustrated in care, it is required to build a longer lasting relationship between a well- trained VoorZorg nurse and the participant.

Conclusions:

1. VoorZorg appears to be able to positively influence the lifestyle of the target population.
  2. VoorZorg appears to be able to actually improve the lives and security situation of mothers and their children. The program offers opportunities to improve the perspective of participants and their children in many areas.
- Given the proven cost effectiveness early intervention for high-risk pregnant women through the VoorZorg program is a good investment in the municipal preventive youth health care policy

## O18

### ANXIETY AND SATISFACTION RELATED TO CASE/CONTROL PARTICIPATION IN STILLBIRTH RESEARCH

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<sup>4</sup>University of Sydney, Australia

Background: Stillbirth research is often hampered by the need to 'protect' both bereaved families as well as healthy pregnant women from distress resulting from recruitment by research staff. No studies have investigated anxiety levels of recently bereaved or healthy pregnant women participating in stillbirth research. The aim of this study was to assess anxiety levels and acceptability of women participating in a stillbirth case-control study.

Method: A mixed methods questionnaire was posted to all participants of the Sydney Stillbirth Study in 2012. The questionnaire assessed the anxiety level and satisfaction experienced as a result of their participation in the study. Questions related to the level of anxiety at time of consent and after the interview, and satisfaction of the initial approach by the research staff, explanation of the study and overall satisfaction with participation. A 5-point Likert scale, the Spielberger (STAI-6) anxiety scale and open-field responses were included.

Results: 36/103 case participants and 65/192 control participants returned the questionnaire. The majority participated for altruistic reasons. 20/36 (cases) and 58/65 (controls) stated they disagreed/strongly disagreed that participation in the study increased their anxiety. There was a significant decrease in anxiety among control participants as a result of their participation ( $P < 0.001$ ). Timing of interview did not affect anxiety scale responses ( $F = 1.2$ ;  $P = 0.37$ ). 30/36 (cases) and 63/65 (controls) stated they agreed/strongly agreed that they were satisfied participating in the study.

Conclusions: These findings suggest high levels of satisfaction amongst both cases and controls and no significant increase in anxiety with involvement in stillbirth research. 'Protecting' families may require further justification.

## O19

### WHO GLOBAL CLASSIFICATION SYSTEMS FOR STILLBIRTH AND NEONATAL DEATH

Objectives of the session

To raise awareness of the WHO initiative to develop a global classification system and to obtain feedback from experts gathered at the conference.

Characteristics of a global system

Introduction and expert panel consensus on characteristics of a good system - Vicki Flenady

- Systems and categories currently in use. A description of systems in use globally - Susannah Leisher
- Frequently reported categories of stillbirth and neonatal deaths globally - Hanna Reinebrant

Progress toward a global system - Jan Jaap Erwich

## O20

### A RANDOMISED CONTROLLED STUDY OF AN INNOVATIVE SLEEP INTERVENTION FOR THE PREVENTION OF SUDDEN UNEXPECTED DEATH IN INFANCY, IN HIGH RISK MAORI AND PACIFIC INFANTS, IN SOUTH AUCKLAND NEW ZEALAND

Christine McIntosh<sup>1,4</sup>, Adrian Trenholme<sup>2</sup>, Joanna Stewart<sup>3</sup>, Shirley Tonkin<sup>4</sup>

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**Background:** Tragically 100 babies died in the CMDHB region from sudden unexpected death in infancy (SUDI) in the years 2002-2009. Sixty-eight of these babies were Maori, 26 were Pacific and six were European or other ethnicities. In 2007 there were 8998 live births in this region including 30% Maori and 31% Pacific. There is an obvious ethnic disparity in SUDI rates in this region, and in New Zealand (NZ), with a rate ratio of 4.46 in Maori and 2.49 in Pacific, compared with NZ European. David Tipene-Leach et al 2010, concluded that the knowledge of SUDI risk reduction is low in the Maori population, as evidenced by the poor recollection of SUDI risk factors, and the prevalence of high risk behaviour such as smoking in pregnancy and bed-sharing.

Recently Pepi-pods have been developed in New Zealand by Change for Our Children. They are thought to be safer option when parents choose to sleep in a bed with their baby.

**Objective:** To test the hypothesis that a programme of safe sleep education, delivered with the Pepi-pod infant sleep device, is acceptable and improves knowledge and safe sleep behaviour in high risk Maori and Pacific families.

**Methods:** Between October 2012 and February 2014, 240 babies under two weeks of age, of Maori or Pacific ethnicity with smoke exposure, and resident in CMDHB region were studied. Community health workers (CHW) obtained a baseline standardised safe sleep knowledge and sleep practice questionnaire. Families were then randomised to intervention or control groups. The intervention group were delivered the safe sleep programme and a Pepi-pod. The control group had no further education other than that provided by their usual maternity care provider. A portable cot, that had met safety standard, was provided to any family who had no suitable safe bed for their baby. Safe sleep knowledge and sleep practice questionnaires were completed at two months and four months after birth for both groups. Frequency tables and logistic regression analysis will be performed for safe sleep knowledge and practice comparing intervention and control group.

**Results:** Recruitment is complete and final data will be obtained in early June 2014. We will describe the usefulness of engaging families at higher risk in the Pepi-pod safe sleep device programme and determine if it improved safe sleep knowledge and behaviours, and if these were sustained until infants were four months old.

## O21

### BEYOND INNOVATION - WHAT HAPPENS AFTER THE GOOD IDEA?

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<sup>1</sup>Change for our Children Ltd, <sup>2</sup>Waikato District Health Board, <sup>3</sup>Health Share Ltd, New Zealand

**Introduction:** The supply of portable sleep spaces (PSS) for protecting more vulnerable infants when sleeping in high-risk environments, is now an integrated part of health care in eight regions of New Zealand. The innovation is not the sleep space itself, but the three-pronged strategy on which it is based : align with evidence, build networks of influence within priority populations, and develop approaches of value to the intended audience. From 'new idea' to its widespread adoption, our presentation reports on the process and impact of implementing this strategy, using the example of the portable sleep space programme.

**Implementation:** The PSS is a simple plastic box fitted with an attractive cover, mattress and bedding, for use as a place of sleep for young babies when not in cots or bassinets. After concept testing with families, a programme was designed around PSSs, based on the strategy above. In every detail the intervention aimed to achieve power (from strong scientific evidence), scale (from broad community participation) and uptake (from an option that solved problems for people). Core components of implementation were: the standard safety briefing, the sleep space itself, and the role of spreading safe sleep awareness to others. A lead agency coordinated all aspects of the programme and engaged with participating health boards and families through signed agreements.

**Impact:** Eight of twenty health boards, being those with higher Maori birth rates (39% vs 21%), have adopted the PSS programme and embedded it into their standard health care for vulnerable infants. For 1822 infants whose families received the programme during 2012 and 2013, 99% had identified SUDI risks (74% were exposed to smoking in pregnancy, 26% were born before 37 weeks, and 75% were Maori). For 1483 (81%) of their families who could be contacted after a period of initial use, 89% wanted to keep their PSS and 84% had spoken to others about safe sleep for babies. A collective 7397 people from within priority networks were drawn into these conversations. Survey feedback from a sample of 444 users, showed that most (95%) rated highly (7-9/9) the overall idea, as well as its support of them with safety (88%), convenience (87%) and settling their babies for sleep (71%). While no causal association can be claimed, it is promising that total infant mortality in New Zealand fell to an all-time low during 2012 (from 4.72 to 4.18 deaths/1000 live births ). This was effectively maintained during 2013. The fall in both years was most evident for Maori, and in regions distributing the PSS programme.

**Conclusion:** The PSS programme solved problems for health boards, infants and families. It fostered easy engagement with more vulnerable groups and tapped into a powerful influence for change that every country has - the peer-to-peer conversation.

## O22

### **FIRST STEPS IN THE SYSTEM FIRST MODEL FOR CREATING CHANGE TO REDUCE RISK FOR ABORIGINAL AND TORRES STRAIT ISLANDER BABIES: STRONG COMMITMENT, CLEAR SYSTEMS AND CULTURALLY APPROPRIATE EDUCATION TO SUPPORT HEALTH WORKERS**

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**Background:** Australia does not compare well to other Organisation for Economic Co-operation and Development (OECD) countries of the same level of industrialisation, ranking in the lower third due to comparatively high rates of Indigenous infant mortality. The issue of infant care practices is multifaceted and requires a holistic interpretation of relevant data to guide quality advice and practice by health care workers and services.

The System First Model for Creating Change focuses on development of organisational capability as a foundation for creating supported and sustainable evidence-based change in health care. This approach builds healthy public policy, creates supportive environments, strengthens community action, develops personal skills and re-orientates health services, which are essential strategies for successful health promotion identified within the WHO Ottawa Charter for Health Promotion.

**Objectives:** The objectives of this presentation are to

1. Share an approach based on the Systems First Model for Creating Change in the context of effective safe infant sleep health promotion and action in Aboriginal and Torres Strait Islander communities;
2. Outline how to achieve strong commitment from organisations and clear systems to embed evidence-based education into practice;
3. Share sustainable modes of culturally appropriate staff education for safe infant sleeping and reducing the presence of risk factors for SUDI.

**Methods:** This presentation will outline a collaborative Queensland program which has contributed to the first four key elements identified in the System First Model for Creating Change:

**Evidence and Strong Commitment:** incorporation of the revised 2012 Australian Safe Sleep, My Baby campaign and risk minimisation approach to co-sleeping into policy and guidelines for several influential government and peak professional bodies to promote consistency of parent advice about safe sleeping will be discussed;

**Clear Systems:** commitment to a) provide Safe Sleep education for health workers has been embedded into current state Safe Sleeping guidelines; b) identify family safe sleep practices has been integrated into clinical pathways, parent discharge information and community health follow-up.

**Staff Education:** a free, culturally appropriate safe sleeping eLearning program targeted to support health workers in Indigenous communities has been developed, tested, and integrated into resource support by government and nongovernment agencies in response to an identified need.

**Results:** Multidisciplinary policy and guideline development and culturally appropriate educational interventions, emerging from a search for evidence to support best practice, demonstrate how this model can support Health Workers to lead the way as child advocates for better services, education and family support, and how the results of such programs may positively impact government and public health agendas.

**Conclusion:** Health promotion and preventive actions need to be targeted and culturally appropriate if we are to influence infant mortality attributed to Sudden Unexpected Deaths in Infancy, of which over 95% is associated with preventable risk factors. Strong commitment, clear systems and effective education programs will lead to positive and sustained changes in health professional practice and ultimately contribute to a reduced incidence of SUDI for Aboriginal and Torres Strait Islander communities.

## O22

### **NEXT STEPS IN THE SYSTEM FIRST MODEL FOR CREATING CHANGE TO REDUCE RISK FOR ABORIGINAL AND TORRES STRAIT ISLANDER BABIES: EMPOWERING HEALTH PROFESSIONALS AND FAMILIES WITH TARGETED AND INNOVATIVE HEALTH SERVICE DELIVERY**

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**Background:** Queensland has one of the highest rates of SUDI compared to other regions in Australia, while Aboriginal and Torres Strait Islander are almost three times more likely to die than non-Indigenous infants. Many infant deaths amongst this population have been associated with co-sleeping environments, a common practice in Australia that has cultural significance for Aboriginal and Torres Strait Islander families.

The Pēpi-pod program is a health promotion initiative originating in New Zealand<sup>3</sup> that draws attention away from problems for vulnerable babies in unsafe sleeping situations and focuses on a solution: support for parents and protection for the baby. The program encompasses a portable safe infant sleep space paired with a Safe Sleep educational program that has been adapted for Aboriginal and Torres Strait Islander communities. Support for health professionals through evidence-based safe sleep education and allocation of leadership roles within service teams aims to empower communities.

**Objectives:**

1. How to identify safe sleep practices of families through empowering and providing staff with clear roles as Safe Sleep Champions in the communities they serve;
2. Share a novel approach, the Pēpi-pod Program, a safe sleep space combined within a targeted safe sleeping health promotion initiative for Queensland families with known risk factors for SUDI.

**Methods:** This project aims to determine the acceptability, effectiveness, feasibility and sustainability of the Pēpi-pod Program in Aboriginal and Torres Strait Islander communities in Queensland (target n=350 families). An exploratory descriptive design is used to evaluate and report parent and health worker experiences of the Pēpi-pod Program. Measures include family risk assessment, acceptability, safe sleeping awareness (effectiveness), and extent of social networking in communities using longitudinal data collection through timed repeated participant survey. Health worker capacity is measured through completion of key training components. Feasibility, sustainability, and community awareness will be measured through feedback from participating services and community representatives.

**Results:** To date six sites providing maternity care to Aboriginal and Torres Strait Islander families across Queensland have undergone competency training and are implementing the Pēpi-pod Program in their respective communities. This presentation will review the success of the consultation and development undertaken for the Pēpi-pod Program and competency training and development of Safe Sleep Champions at participating sites. The three interlinked components of the Pēpi-pod program: Safe Space; Safe Care and Role of the Family will be discussed in relation to the process of empowering families and carers to provide for safe sleep, every sleep for their babies. The findings to date will also be presented.

**Conclusion:** Positive outcomes have been reported for two consecutive years to date in the parent study and pilot results for the current study identified that the Pēpi-pod was acceptable as a portable sleep space for infants with positive responses relating to utilisation, acceptability, safety and convenience. The results from this larger cohort will determine if the Pēpi-pod Program influences health outcomes for Aboriginal and Torres Strait Islander families in Queensland and will inform future implementation of the program within this population.

## O22

### **THE BEGINNING IN THE SYSTEM FIRST MODEL FOR CREATING CHANGE TO REDUCE RISK FOR ABORIGINAL AND TORRES STRAIT ISLANDER BABIES: COMMUNITY CONSULTATION, ENGAGEMENT AND OWNERSHIP**

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**Background:** The definition of health for Aboriginal and Torres Strait Peoples goes beyond the physical health of an individual, adopting a whole-of-community view. Community well-being and individual well-being are intertwined. It is a whole-of-life view including "the cyclical concept of life-death-life". Previous research has demonstrated that conventional safe infant sleeping messages and campaigns have had little impact in Aboriginal and Torres Strait Islander communities. Health promotion programs successful in engaging Aboriginal and Torres Strait Islander people are ones which use a collaborative approach, involving Communities in all aspects of program development, implementation and evaluation; respecting the diversity in local knowledge and culture by tailoring the approach to reflect the needs of the community.

**Objectives:**

1. Demonstrate the clear need to break through traditional boundaries within government sectors, between government and non-government organisations, and between the public and private sector.
2. Demonstrate how an integrated, community owned capacity building approach is essential to unlock the potential for health promotion inherent in many sectors of society, among local communities and within families.
3. Demonstrate how this approach has created new partnerships for health on equal ground between the different sectors at all levels of governance.

**Methods:** Communities taking part in the study expressed interest in participating after viewing the Pēpi-pod Program at community events and workshops. All sites have a strong maternal child health workforce. Resource development for promotion and education was informed through a search for best practice examples of safe infant sleeping health promotion and education in Indigenous populations elsewhere in the world. The SUDI star and new safe sleeping illustrations were commissioned to provide a focus for the health issue and for use in community settings.

**Results:** Government (Queensland Health) and non-Government services (Aboriginal Community Controlled Health Services, Medicare Locals, Royal Flying Doctor Service) have joined the project. Pēpi-pods are now a core element of the Apunimpia Baby Basket Program which will be highlighted in the presentation. The Pēpi-pod Program and safe infant sleeping displays have been delivered in partnership with each community. Safe infant sleeping has been embraced as both Men's and Women's Business leading to the delivery of novel ways to engage whole-of-community. This presentation will provide examples of resources and initiatives developed specifically for health education and health promotion. With permission, stories and images from families and Communities will be shared with the audience.

**Conclusion:** The Pēpi-pod Program will only work in areas where there is a strong, committed maternal child health workforce, supported by their organisation and trusted by their Community. Processes are in place to ensure all program activities are relevant to the needs of each individual community and can be sustained and owned by Community during the years to come. Sustainable, community owned programs which translate safe infant sleep health promotion into safe infant sleep action will achieve continued reductions in infant mortality for Australian Aboriginal and Torres Strait Islander peoples.

## O23

### A RANDOMIZED CONTROLLED TRIAL TO INVESTIGATE INFANT SLEEP RISKS AND BENEFITS WHEN USING A CULTURALLY-APPROPRIATE SLEEP DEVICE COMPARED TO A STANDARD BASSINET

Barry Taylor<sup>1</sup>, David Tipene-Leach<sup>1</sup>, Sally Baddock<sup>2</sup>, E. Macleod<sup>1</sup>, Sheila Williams<sup>3</sup>, Angeline Tangioray<sup>1</sup>, Raymond Jones<sup>1</sup>

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**Introduction:** Sudden Unexpected Death in Infancy [SUDI] (including Sudden Infant Death Syndrome [SIDS]), is the biggest single component of post neonatal death in the developed world. One recognised risk factor for SIDS is bed-sharing, which is a common and valued childcare practice in many cultural groups, including Māori families in New Zealand. Unfortunately, like many indigenous groups, Maori have an elevated risk for SIDS. To address these risk factors, the Māori community developed a culturally-appropriate sleep device (wahakura). There is currently no research, however, showing what happens when a significant number of babies use this device.

**Aim:** To compare the wahakura with a standard recommended bassinet on currently recognised dangers in sleep environments (bedsharing, infant sleep position, hypoxia and hyperthermia), other possible consequences (maternal sleep quality and quantity, maternal fatigue) and to investigate the potential benefits of a culturally-sensitive sleep device for promoting breastfeeding.

**Methods:** 200 mainly Māori participants were recruited through midwifery practices in deprived areas, and were randomized to receive a wahakura (W) or a bassinet (B) during pregnancy. At 1, 3 and 6 months after giving birth, mothers completed questionnaires regarding their use of the allocated or other sleep devices, bedsharing, infant sleep position, maternal sleep quality and quantity, maternal fatigue, and breastfeeding. Infrared video, infant HbO<sub>2</sub> saturation, heart rate and peripheral temperature were recorded overnight at 1 month of age.

**Results:** Participants were relatively high risk with 29% of mothers being of single marital status, 59% living in the most deprived quintile. Seventy-five percent were of Māori ethnicity and 43.6% had some smoking in pregnancy.

Intention to treat analysis was used. Use of device and other sleep surfaces is reported separately. Infant sleep position was not different between groups (80.9 vs 82.8% supine,  $p = .636$ ). Maternal sleep quantity ( $p = .835$ ) and quality ( $p = .25$ ) was also not different between groups with 59% of each group describing enough sleep at 1 month with good or very good quality of sleep in 95%. The numbers of mothers fully breastfeeding were also equivalent across groups ( $p = .374$ ) with 48, 39 and 15% fully breast feeding at 1, 3 and 6 months. The results of the video and physiological recordings at 1 month of age are reported separately.

**Conclusion:** Preliminary analyses show that the safety and benefits of the wahakura are at least equivalent to the currently recommended bassinet. As such, the wahakura appears to represent a safe, culturally-appropriate sleep device to offer to new and expectant parents. Further analysis of the video data, including a pragmatic analysis will provide greater understanding of the risks and benefits to mothers and infants when using the wahakura.

## O23

### COMPLIANCE TO ASSIGNED SLEEPING DEVICES IN A RANDOMISED CONTROLLED TRIAL OF WAHAKURA VERSUS BASSINET

David Tipene Leach<sup>1</sup>, Sally Baddock<sup>2</sup>, Angeline Tangiora<sup>1</sup>, Sheila Williams<sup>1</sup>, Raymond Jones<sup>1</sup>, Barry Taylor<sup>1</sup>

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**Aim:** Māori New Zealanders have reclaimed a traditional sleeping device called the wahakura (a woven item capable of use in a shared bed) as a response to the risk associated with bedsharing where there was smoking in pregnancy. This study aimed to evaluate the safety of this sleeping device compared with the standard bassinet. How assigned devices get used in these real life community intervention trials has important implications for effective public health improvements.

**Methods:** 200 mainly Māori families from a socio-economically deprived area were randomised to receive a wahakura or bassinet at the antenatal visit. Usage of sleeping devices and place of sleep was collected at 1, 3 and 6 months postpartum by face to face or telephone interview. Overnight video and physiological monitoring was carried out in the home at 1 month of age.

**Results:** Use of assigned sleep device for more than 5 hours per night was 73% for the bassinet group and 50% for the wahakura group at 1 month of age. At this age 27% of the wahakura group were using a bassinet. The fall in use over time of each device was similar with approximately 20% still using the assigned sleeping device (wahakura 18%, bassinet 23%) at 6 months. The use of a cot, not assigned at all in the study, rose consistently across both groups from approximately 25% at 1 month (wahakura 27%, bassinet 20%) to 65% at 6 months (wahakura 67%, bassinet 63%). Between 15-20% of both groups slept in an adult bed at each of the 1, 3 and 6 time periods.

**Discussion:** Despite signed informed consent, adherence to allocated sleep devices was not as high as expected, with even lower use of the wahakura likely to be because of its relative unfamiliarity to a naïve recipient. If wahakura are shown to be safe then this sleeping device will need socialisation and wider public acceptance for their use to increase. Despite provision of a free infant sleeping device, there was a consistent 15-20% of both groups who seemed to default immediately to an adult bed as a usual sleeping space for the baby suggesting this group may be committed to this sleep arrangement leading to the need and possibility of identifying this group in the perinatal period. Further research would be needed to identify what would be successful strategies for making sure these babies sleep safely, especially if the mother smoked in pregnancy.

## O23

### A RANDOMISED CONTROLLED TRIAL USING OVERNIGHT VIDEO IN THE HOME TO EVALUATE SLEEP OPTIONS IN AN INDIGENOUS COMMUNITY

Sally Baddock<sup>1</sup>, Sheila Williams<sup>2</sup>, David Tipene-Leach<sup>3</sup>, Angeline Tangiora<sup>3</sup>, Raymond Jones<sup>3</sup>, Barry Taylor<sup>3</sup>

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**Introduction:** In New Zealand, the Māori SUDI rate is 5 times that of non Māori, non Pacific (2.34 deaths per 1000 live births vs 0.52). Many deaths are associated with bedsharing and maternal smoking. These behaviours have proved resistant to change. The wahakura (flax bassinet) is designed from a cultural perspective as a potentially safer sleep place. To date there has been no assessment of the safety of this traditional sleeping device.

**Aim:** to compare wahakura with bassinets as sleep options acceptable to Māori families.

**Methods:** 200 participants were recruited, through midwifery practices supporting mainly Māori families in deprived areas, and were randomized to receive a wahakura (W) or a bassinet (B) during pregnancy. At 1 month, overnight videosomnography, oximetry and temperature recordings of 80 bassinet and 79 wahakura babies were completed.

**Results:** Intention to treat analysis was used. Mean study time (B:9.9 vs 10.1h), mean asleep time (B:6.7 vs W:6.7), head covered time (B:0.45 vs 0.43h), and breastfeeding (B:0.38 vs W:0.44) were not significantly different. Similarly, the number of head coverings (mean, B:2.1 vs W:1.5, p=0.4) and breastfeeding events (B:3.2 vs W:3.9, p=0.3) were not different between groups. On the study night babies slept in a bassinet (mean time B:6.7h vs W:1.9hr, p<0.0001), wahakura under adult bed-covers (B:0 vs W:0.4h), wahakura on bed-covers (B:0 vs W:1.8h), and wahakura off the bed (B:0 vs 2h), in mother's bed (B:1.7h vs 2.1h, p=.48) and in a cot (B:0.4 vs W:0.5, p=.74).

**Conclusion:** This study suggests it is as reasonable to provide a wahakura as it is to provide a bassinet as a safe sleep intervention in this population. The findings show no difference between the behaviours for the two options. Further analysis will provide greater understanding of behaviour while sleeping in the wahakura.

## O24

### NEUROCHEMICAL ABNORMALITIES IN THE SIDS BRAINSTEM AND PIGLET MODELS- WHERE TO FROM HERE?

Rita Machaalani, Karen Waters

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**Introduction and Aim:** The brainstem has been a main focus in Sudden Infant Death Syndrome (SIDS) research for the past 30 years. This stemmed from physiological and animal model data showing that cardiorespiratory, sleep and arousal mechanisms are abnormal and since the brainstem houses these regulatory centres, it is the site most likely to also show abnormalities. In this study, we will review the work that has been undertaken in our laboratory over the past 15years, examining neurotransmitters, receptors, and markers of apoptosis in the brainstem of SIDS infants and in our 2 piglet models of: 1) Intermittent hypercapnic hypoxia (IHH) which is associated with the risk factors of prone sleeping and bedsharing, & 2) nicotine, associated with the risk factor of cigarette smoke exposure.

**Method:** Our two brain tissue datasets are from infants who died suddenly and unexpectedly, and the piglet models of IHH and nicotine. Findings in SIDS cases (n=67) were compared to non-SIDS cases (n=25). Findings in brain tissue from IHH (n=14) and nicotine (n=14) exposed piglets were compared to controls (n=14). Tissue from all groups was immunohistochemically stained for apoptotic markers (caspase-3 & TUNEL), NMDA receptor 1, Brain Derived Neurotrophic Factor (BDNF), its receptor TrkB, and serotonin receptor 1A (5HT1A). Neurons were quantified in eight nuclei of the caudal and rostral medulla.

**Results and Conclusion:** Across a number of studies, amongst SIDS infants and in piglets exposed to IHH & nicotine, neurotransmitter and apoptotic markers were consistently altered in the dorsal motor nucleus of the vagus (DMNV). Markers of 5HT1A & apoptosis were altered in the nucleus of the solitary tract (NTS) & the arcuate nucleus (AN). These data will be discussed, along with the physiological implications of the abnormalities identified, and where current research of the SIDS brain is now heading.

## O25

### DECREASED OREXIN IMMUNOREACTIVE EXPRESSION IN THE HYPOTHALAMUS OF SUDDEN INFANT DEATH SYNDROME (SIDS) INFANTS

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Loss of orexin (Ox) immunoreactive (-ir) expression in neurons has been shown to occur in response to repetitive exposure to hypercapnic hypoxia. Impaired Ox signalling reduces sleep quality, impairs arousal thresholds and increases the occurrence of sleep apnoeas. Infants at risk of, or who later succumb to, Sudden Infant Death Syndrome (SIDS) have been shown to have poor arousal thresholds. The role of Ox in the pathogenesis of SIDS is yet to be determined. This pilot study examined the expression of OxA and OxB in the hypothalamus of control (n=11) and SIDS (n=14) infants using immunohistochemistry on formalin fixed and paraffin embedded brain tissue. Ox is expressed in only three regions of the hypothalamus (dorsal medial, perifornical and lateral; DMH, PeF and LH). Data was quantified to determine the change in the percentage of Ox-ir neurons compared to non-Ox-ir neurons in these 3 regions, and the sum total. Both OxA and OxB are co-localised in the same neurons in control and SIDS infants.



Results showed a decrease in the % positive Ox-ir expression (10%(Control % Ox-ir:28%; SIDS % Ox-ir:25%) for the combined regions (entire hypothalamus) of SIDS infants compared to controls ( $p \leq 0.005$ ). Separated by region, this was not attributed to any one of the 3 regions (LH, DMN or PeF), although a greater trend towards a decrease was evident for the LH ( $p=0.09$ ). These findings provide initial evidence of defective Ox expression in the hypothalamus of SIDS infants, and justify further exploration of relationships between sleep regulation and sleep apnoeas in these infants.

## O26

### FEASIBILITY OF AUTOPSY BRAIN ANALYSIS IN THE SAFE PASSAGE STUDY

Rebecca Folkerth

*Boston Children's Hospital, Harvard Medical School, Boston, USA, for the PASS Network*

**Background:** The Safe Passage Study is an international, prospective study of 12,000 pregnancies to determine the effects of prenatal alcohol exposure upon fetal and infant mortality and morbidity in populations at high risk for maternal drinking during gestation.

**Objectives:** A key objective is to elucidate the role of prenatal alcohol exposure on human neurotransmitter development in cerebral cortical and hippocampal nodes of diverse cognitive networks clinically abnormal in fetal alcohol spectrum disorders. Here we analyzed 5-HT<sub>1A</sub> receptor and 5-HT transporter (5-HTT) binding using autoradiography because of 5-HT's influence upon various cognitive functions, as well as reports of 5-HT abnormalities in prenatal alcohol exposure animal models. Our goal was to outline the baseline development of the 5-HT markers in Brodmann Areas (BAs) 11, 17, 24, 37, 39, and 46 and hippocampus, as a guide for the 7-year study accrual, as little is known about human 5-HT trajectories in these nodes.

**Methods:** We analyzed 8 brains of fetuses and infants dying of heterogeneous causes (age: 23 weeks-6 postnatal months) (postmortem interval: 24-48 hours without obvious effect). We analyzed brains without developmental or other major abnormalities, and were blinded to alcohol exposure data.

**Results:** In all 6 BAs at midgestation ( $n=2$ ), 5-HT<sub>1A</sub> receptor binding preceded 5-HTT binding, with negligible 5-HTT binding, suggesting cortical expression of 5-HT<sub>1A</sub> receptor expression precedes 5-HT fiber ingrowth. Intracortical patterns changed across late gestation ( $n=2$ ), but "stabilized" at term ( $n=1$ ) into the postnatal period studied ( $n=3$ ), with high 5-HT<sub>1A</sub> binding in superficial laminae compared to high 5-HTT binding in deep laminae in all 6 BAs. These patterns were similar to those in 5 age-related, laboratory reference brains. Hippocampal 5-HT<sub>1A</sub> and 5-HTT binding (in different subdivisions) were greater than cortical levels at all ages studied, suggesting the hippocampus is a major developmental 5-HT target relative to cortex.

**Conclusions:** This study provides an initial framework for future study of prenatal alcohol exposure upon 5-HT development in human cortex/hippocampus.

**Funding:** The Prenatal Alcohol in SIDS and Stillbirth (PASS) Research Network, funded by the National Institute on Alcohol Abuse and Alcoholism, Eunice Kennedy Shriver National Institute of Child Health and Human Development, and National Institute on Deafness and Other Communication Disorders: U01 HD055154, U01 HD045935, U01 HD055155, U01 HD045991, and U01 AA016501.

Presented in part at American Association of Neuropathologists Annual Meeting, 2013.

## O27

### A DELETION IN LRP1B IS ASSOCIATED WITH SOMATIC OVERGROWTH IN A SUBSET OF SUDDEN INFANT DEATH SYNDROME CASES

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**Background:** The sudden infant death syndrome (SIDS) is defined as the sudden death of an infant less than 12 months of age that is associated with a sleep period and remains unexplained after a complete autopsy and death scene investigation. It is the leading cause of postneonatal death in the United States with an overall incidence of 0.57/1,000 live births. The cause of SIDS remains unknown, but it is thought to have complex etiology involving multiple environmental and genetic risk factors. To date however, genetic studies in SIDS have failed to identify any variant that is necessary or sufficient for a SIDS death to occur.

**Objectives:** In other sporadic diseases with complex etiology, including autism and schizophrenia, high penetrance cytogenetic abnormalities such as copy number variations (CNVs) play a role in disease pathogenesis. In this study, we performed genome wide analysis of SIDS cases in the San Diego SIDS Dataset in order to identify CNVs that potentially cause or contribute to the pathogenesis of SIDS.

**Methods:** Genome wide CNV analysis of DNA from 50 SIDS cases (14 females, 36 males) was performed using comparative genomic hybridization with a SurePrint G3 Human 4x180K CGH array (Agilent Technologies). Variants of potential functional significance were identified using an automated analysis pipeline that eliminated common, thus likely innocuous, variants from consideration. qPCR was subsequently used to confirm the presence of variants of interest in the affected cases.

**Results:** CGH analysis identified a total of 384 CNVs, including a novel 113kb deletion in chromosome 2q22.1 affecting the low-density lipoprotein receptor-related protein 1b (LRP1B) gene. The deletion introduces an early stop codon into the gene suggesting that it results in haploinsufficiency. Using qPCR we confirmed the deletion in 2/50 original SIDS cases and in an additional 6/91 (total 8/141) SIDS cases from the San Diego SIDS Dataset. The deletion was not detected by genome wide array based CNV scans over 9,000 non-SIDS samples ( $p < 10^{-11}$ ) that were collected for other phenotypes.

Moreover, male cases with the deletion display evidence of somatic overgrowth that appears to result from accelerated growth after birth suggesting an epiphenomenon associated with the deletion. LRP1B is highly expressed in the human brain, including brainstem regions responsible for regulating respiratory function, suggesting that the deletion may contribute to the homeostatic dysfunction proposed to cause SIDS.

**Conclusions:** These observations identify a recurrent genetic cause for a previously un-identified subset of SIDS cases, and provide new mechanistic insight into SIDS causation.

## O28

### ALTERATIONS IN METABOLIC PROTEINS IN SIDS AS DETERMINED BY MASS SPECTROMETRY-BASED PROTEOMICS

Robin Haynes<sup>1</sup>, K. Broadbelt<sup>1</sup>, C. Maggioletto<sup>1</sup>, Elisabeth Haas<sup>2</sup>, O. Mena<sup>3</sup>, G. Berry<sup>1</sup>, Hannah Kinney<sup>1</sup>, H. Steen<sup>1</sup>  
<sup>1</sup>*Boston Children's Hospital and Harvard Medical School*, <sup>2</sup>*Rady Children's Hospital*, <sup>3</sup>*San Diego County Medical Examiner's Office, USA*

**Background:** The sudden infant death syndrome (SIDS) is defined as the sudden and unexpected death of an infant that remains unexplained after a complete autopsy and death scene investigation. In studies over the last two decades, our laboratory has reported abnormalities in SIDS infants within the brainstem in regions involved in cardiovascular, respiratory, and sleep/waking regulation. The abnormalities we have found in SIDS brainstems relate mainly to the neurotransmitter serotonin (5-HT), and to a specific family of proteins called 14-3-3 that is involved in the stabilization and regulation of a large variety of cellular molecules, including 5-HT.

**Objectives:** In an effort to define additional factors related to 5-HT and/or 14-3-3 abnormalities, we undertook a broad-based proteomic pilot study of a major brainstem region with 5-HT binding deficits and that contains 5-HT source neurons, i.e., the raphe obscurus (RO) in the rostral medulla. Proteomics applied to a tissue sample at autopsy can detect abnormal levels of proteins that directly or indirectly interact with one another in a biochemical network, and may be increased or decreased at the same time in a particular disease process, thereby reflecting a biochemical "signature" of that disease.

**Results:** In this pilot analysis of the RO, we generated a profile of proteins abnormal in SIDS cases (n=4) relative to controls dying of known acute causes (acute controls) (n=4) using spectral counting analysis. Within the cohort, 1539 proteins were identified. Functional Gene Ontology (GO) analysis revealed that 48% (745/1539) of the proteins were metabolic-related, including proteins associated with anabolic and catabolic pathways as well as macromolecular processes such as DNA repair and replication, protein synthesis and degradation. 14% (314/1539) of the identified proteins showed significant (p<0.05) differential expression in the SIDS cases compared to acute controls with 25% (79/314) of the altered proteins being elevated in SIDS cases and 75% (235/314) being decreased in SIDS cases compared to acute controls. Alterations were identified in SIDS cases in multiple proteins involved in cellular energetics and metabolism, including in glucose and fatty acid metabolism as well as mitochondrial electron transport and ATP synthesis.

**Conclusions:** It has long been recognized that abnormal levels of these proteins lead to changes in the energy state of the cell and in altered function, including in the function of serotonin and other neurotransmitters in nerve cells involved in breathing and blood pressure control during sleep. This altered profile of metabolic proteins has never before been shown in SIDS and potentially represents a global alteration in the intermediary metabolism in the medullary system, and potentially in serotonergic neurons. These alterations likely stem, not from a single inborn error of metabolism, but rather related to deficiencies in 14-3-3 and/or 5-HT, or in response to an underlying trigger such as hypoxia. In summary our data suggest the possibility that metabolic changes within the medulla contribute to the underlying vulnerability of SIDS infants. A large-scale study of metabolic proteins in SIDS is currently underway.

## O29

### BIOLOGICAL PRECURSORS IN SIDS IN THE BACK TO SLEEP ERA

Richard Goldstein<sup>1</sup>, Hannah Kinney<sup>1</sup>, Henry Nields<sup>2</sup>  
<sup>1</sup>*Boston Children's Hospital, Harvard Medical School*, <sup>2</sup>*Commonwealth of Massachusetts, USA*

**Objective:** To present evidence that SIDS/SUID in the Back to Sleep era likely involves a collection of clinical entities and precursor conditions affected not only by trends in sleep environment but overall mortality trends.

**Description:** presenting epidemiologic evidence demonstrating that SIDS in the Back to Sleep era is significantly associated with factors involved in infant mortality reduction and prevention beyond the sleep environment. Using US National Center for Health Statistics (NCHS) linked mortality data (1984-2009), he will review infant mortality trends and the changing prevalence of risk factors to argue that there is evidence for intrinsic infant vulnerabilities reflected in these epidemiologic trends. As the argument for underlying vulnerabilities and biological precursors becomes clearer, so too does the need for a more consistent diagnostic nomenclature and consensus on nosology. This becomes the basis for a new clinical approach to understanding SIDS and SUDC from the perspective of precursor conditions and clinical phenotypes

**O29**

## **A CASE SERIES OF INFANTS AND TODDLERS EVALUATED BY THE PROGRAM ON SUDDEN UNEXPECTED DEATH IN PEDIATRICS**

Richard Goldstein<sup>1</sup> Hannah Kinney<sup>1</sup>, Henry Niels<sup>2</sup>

<sup>1</sup>*Boston Children's Hospital, Harvard Medical School,* <sup>2</sup>*Commonwealth of Massachusetts, USA*

Objective: To describe cases reviewed in a pilot program at Boston Children's Hospital Program on Sudden Death in Pediatrics (SUDP) and implications for program design.

Description: The Program on Sudden Unexpected Death in Pediatrics is a newly opened program at Boston Children's Hospital. The program offers the comprehensive, multidisciplinary evaluation of children who have died suddenly and unexpectedly. These evaluations include clinicians and researchers from the fields of general pediatrics, cardiology, neurology, genetics, metabolism, endocrinology, emergency medicine, critical care, psychiatry, pediatric and forensic pathology, and neuropathology. During a preliminary pilot period, 41 patients were evaluated in order to better understand the spectrum of presenting clinical phenotypes and to develop a systematic approach to their evaluation. Dr. Kinney will present the results of these evaluations and their implications for the development of a clinical model.

**O29**

## **A COLLABORATIVE MODEL FOR EXAMINING CHILDREN WHO HAVE DIED SUDDENLY AN UNEXPECTEDLY**

Richard Goldstein<sup>1</sup> Hannah Kinney<sup>1</sup>, Henry Niels<sup>2</sup>

<sup>1</sup>*Boston Children's Hospital, Harvard Medical School,* <sup>2</sup>*Commonwealth of Massachusetts, USA*

Objective: To introduce a newly implemented clinical model for the evaluation of all children dying suddenly and unexpectedly under the age of 3 years, involving collaboration between the SUDP program and the Massachusetts Office of the Chief Medical Examiner, using advanced molecular diagnostics and academic pediatric specialists.

Description: Dr. Niels will describe the motivation and planning of the collaboration between the Massachusetts Office of the Chief Medical Examiner and the Boston Children's Hospital Program on Sudden Unexpected Death in Pediatrics. He will review the responsibilities of a medical examiner in the evaluation of infant and child deaths. He will then present a model developed for children in Massachusetts, with SUDP acting as a family advocate and scientific resource, explaining the emergent approach and its constraints. Dr. Niels will review the standardized approach to autopsy, tissue preparation, and family support and disclosure of findings developed for this collaboration. The approach to the use of advanced molecular diagnostics will also be presented.

**O30**

## **BRINGING ABOUT CHANGE IN THE UK - A COLLABORATION OF PARENTS AND PROFESSIONALS - SANDS UK**

The session will look at: the work in the UK to reduce stillbirths and to improve bereavement care; the role Sands has played as a parent group bringing about change; and the benefits of our collaborative approach with health care professionals.

**O31**

## **THE NEED OF SHARING EXPERIENCES**

Bertram van Linge

*Ratio Design BV, Haarlem, the Netherlands*

After the loss of our nine months old daughter, my wife and I expressed our grief in different ways. We both experienced great mourning, but we differed in the ways we tried to process our pain, share our emotions and our need for information. Everybody has their own approach in dealing with and searching for information. This distinction was something I noticed among other couples as well. Therefore we welcomed the initiative of Monique l'Hoir and I teamed up to create a new website. With this new web based tool we achieve to connect people, and make sharing different experiences as easy as possible. By doing so we hope to bring people support of fellow sufferers and advice of professionals in an approachable way, and share an insight of the awful experience of losing your child. In my presentation I would like to share our methods, approach and results.

**O32**

## **EVALUATING THE CHANGING PICTURE OF BEREAVEMENT SUPPORT**

Jenny Ward, Felicity Sullivan

*The Lullaby Trust, London, UK*

Introduction: The Lullaby Trust's bereavement support services have been running for over 40 years. With the charity's rebrand in April 2013, a more proactive stance was taken to encourage bereavement contacts, most notably through online promotion and support. This study compares contacts pre and post rebrand taking into consideration the changing nature of support to bereaved families in the UK.

Methods: The study used data collected on each 'first time contact'; the initial contact regarding the death of a baby. By calendar year, the analysis considered who made the initial contact (parents, professionals or friend/relative) and by which method (phone, email or written).

Post rebrand, online contacts were also added; this data was not recorded previously nor were online forums utilised fully. The time between the death and the first contact was analysed, and compared with who made the contact and by which method. Data was then compared across each variable. All data was analysed anonymously.

**Results:** An overall 27% increase in new bereaved contacts since the rebrand has been achieved we can also report a number of key trends. Contacts by email increased by 180%, as expected, whilst phone contacts decreased by 18% over the same period. 4% of new contacts since the rebrand are marked as originating 'online', meaning via facebook or the online discussion forum.

A shift has also taken place in who makes the initial contact; with fewer contacts coming from professionals. However, this has led to over 84% being from parents or friends and relatives; an increase of 17%, which may reflect the rebrand of the charity with a softer, family-friendly image.

The rebrand and its associated promotions also appear to have greatly increased contacts from families 5 years or more since their bereavement, with a 300% increase in long-term bereaved families making a first time contact.

**Discussion:** Whilst the bereavement services have remained largely the same, this analysis highlights that services need to continue to adapt their promotion and methods of support to continue to reach bereaved families. Whilst this must include newer forums for support such as online services, we need to continue to cater for families who were bereaved many years ago and may not have sought specialist support since their bereavement. Many contact in response to for example an article in the press or promotion of an event and then use bereavement support. As the health and social care sector in the UK continues to change, new ways of promoting services to professionals needs to be considered. We need to also remember that friends and families are also affected by the grief of their loved ones and their own grief, and support must also be available to the wider community.

### **O33**

#### **ALTERNATIVE WAYS OF HELPING BEREAVED PARENTS**

Petra den Hartog, Lorraine Harrison

*SIDSandKids, Eastcoast, Australia*

**Objective:** To describe the different ways we support bereaved parents, both on line and face to face by peers and grief counsellors.

SIDSandKidseastcoast is a self- help organisation which supports parents whose baby or child, from the age of twenty weeks gestation to six years of age, has died from SIDS, stillbirth, neo-natal death, accident, illness, homicide or after a medical termination following a diagnosis of abnormality.

Parents have a choice of support options. They can just receive resources, our newsletter and invitations to memorial activities such as the Red Nose Day service, fathers' fishing trips and the annual Walk to Remember as well as receive a Treasured Babies pack - items of clothing of specific gestation sizes which can be used to bury/cremate the baby in and be a memento as well.

On- line bereavement support has been provided for eight years and compliments the other services provided: it does not replace face to face support. Many of our families come from rural and remote areas of Australia and on- line support reduces some of the isolation many experience.

Parents can also select one or more of the following options including counselling, either one on one or as a couple. This option is also available to others in the family or network such as grandparents, aunts/uncles and bereaved children. A network meeting helps family and friends understand the norms of parental grief and the 'do's and don'ts' of support.

A variety of support groups are available, most of which are led by a counsellor and co-facilitated with a trained parent supporter. These focus on the needs of parents of stillborn babies or babies who died soon after birth, parents of older children, parents having a subsequent pregnancy and the needs of other family members such as grandparents and children. There are specialised workshops such as arts therapy and an intensive weekend personal enrichment program.

It is also possible for a parent to be paired with a trained Parent Supporter who has had a similar loss and who can support and communicate with them as needed. These Supporters help to normalise grief responses, provide strategies for coping and give hope that they too will survive, heal and grow.

There is an extensive range of resource material written by counsellors in collaboration with bereaved parents, incorporating their wisdom and experience. These include self- help booklets on children's grief, the needs of grandparents, subsequent pregnancy and peri-natal grief. There are also booklets written by bereaved children, and a collection of stories by bereaved fathers called 'Men Grieve Too'.

Our latest booklet, "When Relationships Hurt, Too" deals with the impact that grief has on relationships and the fear that many parents have that their relationship will break down. Drawing on the experience of over 50 families, the booklet details practical strategies for helping people through the worst experience of their life and includes five comprehensive case studies. The experience both of these parents and that of the counsellors is that the relationships of bereaved parents who receive comprehensive support are no more likely to break down than those of non-bereaved parents.

### O34

#### HOW TO HELP BEREAVED PARENTS AND REINFORCE PREVENTION AGAINST SUDDEN INFANT DEATH?

Christine Tran Quang, E. Briand-Huchet, Emmanuelle Gauthier, Corinne Giroux, Anna Goychman, Myriam Morinay

*Association Naître et Vivre, Paris, France*

Sudden Infant death syndrome (SIDS) is impacting 250 babies in France per year, yet recent studies suggest that the number of cases of Sudden unexpected death in infant (SUDI) is rather approaching 500 babies per year. Studies from the INVS (Institut National de veille sanitaire) realized between 2007 and 2009 have shown that 40% of the death were associated with the prone position and that a large number of these death could have been avoided if the sleeping environment had been better done (no prone position, no pillow for instances). Although the conclusions were clear, no broad campaign for “safe sleep” has been undertaken by public health institutions in France, the last one performed being now 16 years old! Naître et Vivre (Born and Living), an association created 30 years ago and at the origin of the “safe sleep” campaign of 1994, is composed both of medical staff and of bereaved parents. The goals of the association are to (i) welcome and accompany parents that lost a baby up to the age of three years old; (ii) provide information about infant sudden death and broaden the information for a secure sleep environment; (iii) support research dealing with sudden infant death.

Bereaved parents: because the experience of losing suddenly a baby is traumatic and inducing acute feelings (sadness, culpability, loneliness), it is essential for parents to meet people that have experienced a similar situation. To this end, Naître et Vivre organizes regular meeting either in collaboration with psychologist on specific topics (“the next pregnancy”, “how to deal with the previous children” etc....) or reuniting parents for open discussions on their experience of mourning. We will also depict one of our tool, a book written by Marie-Hélène Delval in collaboration with Naître et Vivre, designed to explain the death of a baby to its brother and its consequences on the life of the family.

Prevention of sudden death: since many years, the association is providing flyers to broaden the secure sleep conditions and works on improving its message for it to be better understood. For instance, we recently renewed our website for any people to be able to download these flyers. Another achievement of the association is the realization of a poster for “safe sleep” translated in more than 10 different languages. Both of these works will be presented.

### O35

#### “THE MEDIUM IS THE MESSAGE”- REBRANDING FOUNDATION FOR THE STUDY OF INFANT DEATHS; STEP CHANGE TO REDUCE SIDS

Francine Bates, Jenny Ward, Felicity Sullivan

*The Lullaby Trust, London, UK*

Introduction: The Foundation for the Study of Infant Deaths (FSID) was established in 1971 primarily to carry out research into sudden infant deaths. In 2013 the charity re-branded as The Lullaby Trust with the main aim of halving the numbers of SIDS deaths by 2020. The rebrand also sought increase support offered to bereaved families and those with young babies. This presentation will explore the driving factors and strategy for the re-brand, and evaluate the outcomes across several domains.

Methods: The presentation will focus on three main areas of the rebranding process: initial consultation on the need to rebrand, in-depth consultation on how the rebrand would look and evaluation of its impact post-launch.

In early 2012, a communications audit was conducted, using an independent consultancy to consider how FSID presented itself as an organisation.

This audit was used to inform the next stage of the process; designing the charity’s rebrand. This examined the opinions of a wide range of internal and external stakeholders and included both quantitative and qualitative analyses. Key stakeholders were involved in the rebrand throughout the process.

Post-relaunch an evaluation took place which considered impact in feedback but also those using the services of the charity compared to the period before the relaunch.

Results: The initial audit highlighted that the charity’s name was ‘confused’, ‘wordy’, ‘outdated’ and ‘irrelevant’. Further market research with key stakeholders and professional branding advice informed the next stage of the process. These results showed only 28% of respondents preferred FSID to the alternatives, particularly amongst the key group of young parents. Crucially, 80% found Lullaby Trust easy to remember and 68% found it distinctive.

Following relaunch the quantitative results are extremely positive. Uninitiated comments from supporters and stakeholders were 61% positive, 8% neutral and 31% negative. Comparing the 12 months pre and post launch showed: new bereavement contacts up 27%, all bereavement support up 17% and general advice contacts up 26%. Huge increases were shown in the rebranded information materials, with orders for a generic parent information leaflets up by 360%, easy read cards up 235% and bereavement support leaflets up 456%.

Discussion: The initial finding about the name being ‘irrelevant’ and ‘outdated’ seems to have been addressed by the relaunch and had a huge impact on the charity’s reach to both bereaved families and parents with young babies. The purpose of the rebrand was to give the charity a new platform on which to reach its strategic aim of reducing SIDS deaths. The results show a significant step towards achieving this goal. A discussion for all those working with families should now focus on how best to communicate messages to families. The rebrand cost less than £40,000 and this has increased our reach. We now await the publication of official statistics in August 2014 to see whether this has translated into fewer deaths.

### O36

#### **EXPLORING QUALITY OF CARE (QOC) FROM PATIENTS' AND PROVIDERS' PERSPECTIVES IN ACCESSING EMERGENCY OBSTETRIC AND NEWBORN CARE (EMONC) SERVICES IN HARD-TO-REACH AREAS IN BANGLADESH**

Rasheda Khan, Ruksana Gazi, Marzia Sultana, Tamanna Sharmin, Nazib Zaman, Afroza Khanom Roza, Mahbub Elahi Chowdhury

*International Centre for Diarrhoeal Disease Research, Dhaka, Bangladesh*

**Background:** Although Bangladesh has made progress in achieving MDG 4&5 targets, neonatal and maternal mortalities are still high. For further reduction of these deaths, Govt. of Bangladesh is implementing a Maternal and Neonatal Health Initiative (MNHI) Program in certain hard-to-reach areas. This study was carried out to understand program experiences and gaps for EmONC services.

As part of this, we examined QOC for EmONC services in health facilities. By "QOC", we meant timely and appropriate care through apposite interpersonal communication and appropriate privacy along with adequate and clean infrastructures and logistics support, which accelerate care-seeking, referral and follow-up visits.

**Methods:** We conducted Key Informant Interviews with providers (132), observation of patients (41) and interviewed their family members (68) who sought care in these facilities.

**Results:** Though human resource (HR) was one of the major interventions, the problem is still dire, especially in sub-district level. Providers' shortage put extreme workload on the existing manpower. This often deters them from providing timely care and/or using unskilled support-staff for skilled activities. Extreme providers' shortage results into poor safeguarding of privacy and poor interpersonal communication with patients/their family-members. All these dissuade continuation of treatments, follow-up visits and enrollment of further treatments. Certain logistics supplies and infrastructures were improved, however, providers and management bodies still face problems offering timely and appropriate care due to poor supplies of consumables and poor maintenance system.

**Discussion and conclusion:** While improved supplies of consumables and proper infrastructure addressed many underlying problems, HR gap was the core of many concerns for providing QOC services. We recommend an urgent initiative to fill-up HR gaps, especially with a 24/7 staff team trained in counseling which will guarantee proper interpersonal communication with clients. A package of such will ensure timely and appropriate care-seeking for EmONC services and strengthen people-centered health systems to promote greater responsiveness, better health, human rights and social justice.

### O37

#### **PERINATAL INTERVENTIONS IN SURINAME: THE PERISUR PROJECT**

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**Background:** Perinatal mortality in Suriname (40 per 1000 births) is approximately five times higher than the Netherlands. Suriname will not be able to achieve the millennium goals in 2015. This finding calls for further investigation of underlying causes of perinatal deaths and specific preventive strategies in the field of perinatal health and health care.

**Objectives:** The Perisur project aims to develop and implement preventive interventions in Suriname in order to reduce mortality and morbidity during the perinatal period. Interventions include preconception counseling, improving knowledge and adequate use of folic acid, centering pregnancy and perinatal audits.

**Methods:** Existing perinatal interventions from the Netherlands will be adapted for Suriname by perinatal health care workers from Suriname and the Netherlands. Interventions will be implemented by perinatal health care workers from three hospitals in Paramaribo. These hospitals account for 60% of all births in Suriname. An expert meeting and pilot projects were done.

**Results:** Preterm birth, low birth weight, breech presentation, low and high maternal age were associated with an increased risk of perinatal mortality in Suriname. A pilot project estimated that three-quarter of women visiting for routine antenatal care had some knowledge of folic acid. However, only 12.5% used it adequately. Lower educated women and non-Dutch speaking women were at higher risk of having insufficient knowledge. In another pilot project health care workers ranked hypertension, pre-existing diabetes and teenage pregnancies as highest risk pregnancies. Lack of pregnancy planning was the most alarming risk behavior while unawareness of preconception risks and lack of adequate health care services were important personal and environmental determinants, respectively.

**Conclusions:** Perinatal interventions in Suriname should focus on different approaches, such as a high-risk group approach (e.g. teenage women as target group), a health professional approach (e.g. more training), a health care services approach (e.g. use of evidence based protocols) and a public health approach (e.g. improve awareness).

The Perisur project is funded by TNO Innovation for Development and the Twinning Facility Suriname Netherlands (UTSN)

### O38

#### **SUPINE SLEEP POSITION IN LATE PREGNANCY IS ASSOCIATED WITH INCREASED RISK OF LATE STILLBIRTH**

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**Background:** The Auckland Stillbirth Study reported that women who slept supine or on their right side, the last night before the baby was presumed to have died, had an increased risk of late (> 28weeks') stillbirth. Since this publication two additional reports have noted an increased rate of stillbirth associated with supine sleep position in late pregnancy.

**Objectives:** To determine whether self-reported supine and/or non-left sided sleep position are associated with increased risk of late stillbirth.

**Methods:** We are undertaking a case control study of risk factors for late stillbirth in large New Zealand centres. The cases are women with singleton pregnancies and late stillbirth (not due to congenital abnormality) and controls women with singleton ongoing pregnancies, recruited to match the expected gestation and District Health Board of the stillbirths. A multi-faceted history is obtained by research midwives which incorporates detailed information about sleep practices including maternal self-reported sleep position.

**Results:** At the time of interim analysis data were available on 85 women with late stillbirths and 310 controls. With this number of cases and controls we have power to detect a fourfold increase in risk of late stillbirth with supine sleep position and twofold increase with non-left sleep position (80% power, alpha 0.05). Maternal age, ethnicity and parity did not differ between groups but women with late stillbirths had significantly higher BMI in early pregnancy [29.7 (7.5) vs 25.9 (5.8)  $p < 0.0001$ ]. Gestation of late stillbirth 36.6 (3.7) weeks' and at interview in controls 36.0 (3.5) weeks' did not differ  $p = 0.15$ .

<b>Sleep position last night</b>	Late stillbirths N=85	Controls N=310	Univariable* Odds ratio (95%CI)
Left	38 (46.3%)	179 (57.7%)	1.00
Non-left	44 (53.7%)	131 (42.3%)	1.53 (0.93, 2.52)
Supine	11 (13.4%)	9 (2.9%)	5.63 (2.18, 14.57)
Non-supine	71 (86.6%)	301 (97.1%)	1.00
<b>Sleep position last week</b>			
Left	43 (50.6%)	163 (52.8)	1.00
Non-left	42 (49.4)	146 (47.2)	1.08 (0.66, 1.77)
Supine	10 (11.8%)	7 (2.3%)	6.31 (2.23, 17.81)
Non-supine	75 (88.2%)	302 (97.7%)	1.00

\*Controlled for gestational age of interview and hospital of birth

The population attributable risk of supine sleep position for late stillbirth was 8.8%.

**Conclusions:** Our interim analysis has demonstrated a significantly increased risk of late stillbirth for women who sleep in the supine position in late pregnancy. This relationship was apparent for the last week and the last night before the presumed stillbirth and is consistent with previous reports. Non-left sleep position was not associated with increased risk of late stillbirth in this interim analysis. It may be timely to develop public health messages advocating that women should not sleep supine in late pregnancy.

### O39

#### **SERVICE USER COINVESTIGATORS SHOULD ATTEND ETHICS COMMITTEE MEETINGS FOR SENSITIVE RESEARCH: LESSONS FROM THE INSIGHT STUDY OF STILLBIRTH & BEREAVEMENT CARE**

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**Background:** Service user collaboration in research has been encouraged. Sensitive research topics, like stillbirth and bereavement, pose specific challenges to such collaboration; including the potential for harm not just to the study participants but also to the service user collaborators.

**Objectives:** We describe our experience of a service user expert being involved in the design of a multicenter study of bereavement care funded by Sands.

**Method:** The involvement included preparation for and attendance at the research ethics committee interview that resulted in approval of the project.

**Results:** The service user expert co-designed key aspects of the study, supported by a representative of a maternity service user panel for research. Specific contributions included study questions, recruitment processes and documents, and strategies to reduce risk and prevent harm to participants. It was therefore only natural that the service user expert attended the ethics committee interview with two clinical investigators, to discuss the plan of investigation and help obtain approval. The effort was successful.

**Discussion & Conclusion:** Researchers have a duty of care to identify risk and reduce harm to study participants, but more work may be required on the part of research teams to identify risk and reduce harm to service user collaborators at earlier stages in the research process. In the UK, INVOLVE has produced general guidance for the ethics of service user input to research. Nevertheless, a literature review reveals no published report of active involvement of service users in obtaining ethical approval, and the impact of such involvement on both the approval success and on the collaborators. We discuss our lessons from Insight and implications for policy, practice, and research.

## O40

### A POOLED ANALYSIS OF BREASTFEEDING AND SUDDEN INFANT DEATH SYNDROME: HOW MUCH IS ENOUGH TO REDUCE THE RISK?

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<sup>4</sup>Institute of Legal Medicine, University of Muenster, Muenster, Germany

**Background:** Breastfeeding has regularly been associated with a protective effect in relation to the occurrence of Sudden Infant Death Syndrome (SIDS). A previous meta-analysis found that breastfeeding was protective against SIDS, and the effect was stronger when breastfeeding was exclusive. The effect size and the duration of breastfeeding required to incur this protective effect have not previously been established.

**Objectives:** To establish the protective effect of breastfeeding at various time points and to assess the length of breastfeeding required to incur a protective effect. We also aimed to establish the protective effects of both any breastfeeding and exclusive breastfeeding.

**Methods:** We carried out a pooled analysis of duration of breastfeeding using data from the New Zealand Cot Death Study, German SIDS Study and the Chicago Infant Mortality Study. Data were analysed at an individual level with a total of 986 cases and 2850 controls available, with analyses taking account of centre effects. Multivariable analyses were carried out controlling for a wide range of potential confounders available in all the studies, including other known risk factors for SIDS.

**Results:** In univariable analyses any length of any breastfeeding was associated with a decreased risk of SIDS. After controlling for potential confounders those with breastfeeding durations of less than 2 months were found to no longer have a protective effect. The protective effect of breastfeeding improved with longer durations up to 4 months; adjusted odds ratio (aOR) (95% CI) = 0.37 (0.24, 0.58); however, periods of breastfeeding beyond this did not appear to convey any additional protection. Likewise, for exclusive breastfeeding any length of time was associated with a decreased risk in univariable analysis. Similar to the effect seen with any breastfeeding, after controlling for potential confounders no significant protective effect was seen with length of breastfeeding below 2 months of duration. Beyond this duration, exclusive breastfeeding appeared to increase the level of protection: 2 to 4 months aOR (95% CI) = 0.56 (0.40, 0.80) and greater than 4 months aOR (95% CI) = 0.44 (0.28, 0.71). The protective effect of exclusive breastfeeding was not of any greater magnitude than any breastfeeding.

**Conclusions:** Breastfeeding of 2 months or longer is associated with protection against SIDS, and the protective effect appears to be of greater magnitude with increased length of breastfeeding until a plateau at approximately 4 months. Exclusive breastfeeding does not provide a protective effect above that of any breastfeeding.

## O41

### EVALUATION OF BEDTIME BASICS FOR BABIES: A U.S. CRIB DISTRIBUTION PROGRAM TO REDUCE THE RISK OF SLEEP-RELATED SUDDEN INFANT DEATHS

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**Background:** There is growing evidence that roomsharing without bedsharing is associated with a reduced risk of SIDS. Several countries, including the US, recommend that infants sleep in a crib or bassinet next to the parents' bed. However, many parents continue to bedshare for a number of reasons, including lack of access to a safe crib. A number of free crib distribution programs have been implemented throughout the U.S. However, no large-scale evaluation of the impact of crib distribution programs has been conducted.

**Objectives:** To evaluate the effectiveness of Bedtime Basics for Babies (BBB), a national crib donation program, that included distribution of a crib, pacifier, wearable blanket and safe sleep/SIDS and SUID risk reduction education to high-risk families. The specific objectives were to:

1. Compare parental knowledge and practice regarding infant sleep position and location before and after receipt of the BBB materials.
2. Compare bedsharing rates before and after receipt of the crib.
3. Compare use of pacifiers before and after receipt of the BBB materials.

**Methods:** A total of 17,243 cribs, pacifiers and wearable blankets were distributed in Washington State, Indiana, and Washington, DC. During the first 2 years of the project, data were collected using a standardized survey before and 1-3 months after crib distribution. Surveys asked about parental beliefs, attitudes and practices with regard to infant sleep and about the impact of receiving a free crib. Bivariate analyses were conducted.

**Results:** 3,303 mothers responded to the prenatal survey (conducted prenatally, before distribution of materials); 1,483 responded to the postnatal survey (conducted before distribution of materials in the early postnatal period); and 1,729 responded to the follow-up survey. Knowledge of the recommended sleep position was 76% in the prenatal survey, 77% in the postnatal survey, and 94% in the follow-up survey. The proportion of infants placed supine for sleep "last night" was 80% and 87% in the postnatal and follow-up surveys, respectively (P <0.001). In the prenatal survey, 8% of mothers responded that they would sleep with their baby, compared with 38% in the postnatal survey who reported that they were bedsharing (pre-intervention). However, post-intervention, 16% reported bedsharing compared with 38% in the postnatal survey (P < 0.001). Among mothers who reported smoking postnatally, 33% were bedsharing before the intervention and 22% after the intervention (P <0.01). Sleep location in crib/bassinet increased from 51% in the postnatal survey to 90% in the follow-up survey (P <0.001). Pacifier usage was not affected by the intervention, with 71% and 74% of infants reported as using a pacifier in the postnatal survey and the follow-up survey, respectively (P = 0.17, NS).

**Conclusions:** Receiving free cribs and education about safe sleep recommendations influenced mothers' behavior and thus has the potential to reduce the incidence of sudden sleep related infant deaths in high-risk families. We recommend that all families who would otherwise not be able to afford a crib be provided one and be given consistent safe sleep advice.



## O42

### INFANT DEATHS OCCURRING ON SOFAS

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**Objective:** Epidemiologic studies suggest that sofa sleeping increases the risk of sudden and unexpected infant death as much as 67-fold. The purpose of this study is to describe the demographic and situational risk factors for sofa-related infant deaths and compare them with other sleep-related infant deaths.

**Methods:** This is a secondary data analysis of sofa-related infant deaths from 24 states during 2004-2012 contained in the National Center for the Review and Prevention of Child Deaths Case Reporting System (CDR-CRS) database. De-identified data were extracted for infant ( $\leq 365$  days of age) deaths that occurred on sofas and similar cushioned products (armchairs, beanbags, futons). Variables analyzed included caretaker characteristics (e.g., alcohol and/or drug use), surface-sharing, objects in sleep environment, pregnancy history, sleep environment changes (e.g., new location), and position (e.g., prone). The data were compared to data on other sleep-related infant deaths in the CDR-CRS database. Missing data were imputed. Univariate and logistic regression analysis was completed, using SPSS Statistics Data Editor 20.0 (IBM Corporation).

**Results:** 1,024 sofa-related infant deaths were analyzed. They comprised 12.9% of deaths in the CDR-CRS database. The majority of infants were 0-3 months of age (72.1%) and male (59.5%). 49% were non-Hispanic white. 32.7% non-Hispanic black, 13.8% Hispanic, and 4.5% other race/ethnicity. 86.9% of infants were sleeping with another person at the time of the incident, compared to 66.2% of other sleep-related infant deaths within the database ( $p < 0.001$ ). 81.1% of infants were in a new/different sleeping environment, compared to 41.4% of other sleep-related infant deaths ( $p < 0.001$ ). 29.9% of infants were placed for sleep in the prone position and 37.9% were found in the prone position. During pregnancy, 30% of mothers smoked tobacco, 8.6% used illicit drugs, and 1.9% had heavy alcohol use, compared to 24.2% ( $p < 0.001$ ), 7.6% ( $p = NS$ ), and 1.6% ( $p = NS$ ) in other sleep-related deaths.

**Conclusions:** Sofa-related infant deaths exhibit the same risk factors as other known sleep-related infant deaths, such as position, co-sleeping, young age, tobacco smoke exposure, and sleep environment. There was a higher incidence of sleeping with another person and new/different sleeping environment in sofa-related infant deaths compared to other sleep-related infant deaths within the CDR-CRS database. Additionally, mothers of sofa-related infant deaths had a higher incidence of tobacco use during pregnancy. These results further support the evidence that parents should be advised against placing their infants to sleep on sofas and other similar furniture (e.g. futons).

## O43

### SWADDLING AND SIDS: DO WE NEED TO PROVIDE RISK REDUCTION ADVICE?

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**Objective:** The risk of sudden infant death syndrome (SIDS) among infants swaddled for sleep is unclear and needs to be quantified in relation to sleeping position.

**Methods:** A systematic review of the literature was carried out using the search term "SIDS or SUDI or SUID" and "SWADDLING or WRAPPING" across 9 databases to identify SIDS case-control or cohort studies suitable for meta-analysis. A search was also made of the ISPID archive of observational SIDS studies.

**Results:** Four studies conducted in the last 20 years were found, two conducted in the UK, one in Tasmania and one in the United States involving 712 SIDS infants and 1767 age-matched controls. Two studies reported a significant unadjusted risk associated with swaddling and two were non-significant but in the same direction. Just two of the studies reported adjusted risks and only one of these was significant. Pooled results of the four studies shows that 16% of the SIDS infants were swaddled compared to 11% of the controls. This difference was significant (pooled OR=1.64 [95% CI: 1.28-2.10]) although the proportion swaddled varied considerably between studies. Three of the studies have so far provided data on sleeping position suggesting the risk of swaddling was raised when infants were put down on their side (pooled OR=3.33 [95% CI: 2.20-5.05]) or prone (pooled OR=13.86 [95% CI: 4.43-43.39]) but there was still a significant risk associated with being swaddled and placed supine (pooled OR=1.78 [95% CI: 1.34-2.26]).

**Conclusion:** These findings suggest further scrutiny of these data is required and potential benefits of swaddling need to be assessed to determine if and in what ways our risk reduction campaigns should advise about swaddling.

## O44

### SIDS AND SUPPRESSED HEARING? MYSTERY OR A NEW PERSPECTIVE ON SIDS?

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Sudden Infant Death Syndrome (SIDS) remains the leading cause of infant mortality in Western societies. SIDS infants are for the majority of cases, ostensibly healthy infants prior to a sudden fatal event during sleep. For this reason, the majority of research to date has focused on post mortem autopsy findings. Thus, a major goal for SIDS researchers has been to find ways to identify high-risk infants before they succumb to SIDS. In 2008 Rubens et al. reported an association between right-sided hearing suppression on the newborn hearing test and subsequent death from SIDS. This provocative finding opened up the possibility that an abnormality in SIDS cases could be identified prior to death by a universally available screening tool.

However, not surprisingly, this unexpected finding triggered a controversy: The data were based on a relatively small number of SIDS cases in Rhode Island, and secondly, it was not obvious how an altered hearing test could be causally associated with SIDS.

Dr. Henry Krous, a leading forensic pathologist will chair this workshop. Dr. Peter Fleming will describe ongoing efforts to conduct a larger prospective study of the relationship between SIDS and newborn hearing tests in England. Dr. Daniel Rubens will report new experimental data indicating that inner ear dysfunction precipitates a marked suppression of the hypercapnic ventilatory response (HCVR), as well as suppression of the body movement arousal response to hypercapnic/hypoxic stimuli during sleep. Dr. Jan-Marino Ramirez will describe ongoing research that demonstrates the role of the vestibular nucleus in CO<sub>2</sub> sensing; the connectivity of the vestibular nucleus to the pre-Boetzing Complex, an area within the ventrolateral medulla which is essential for breathing, as well as the role of the pre-Boetzing complex in generating the hypoxic and hypercapnic response. Dr. Bill Yates will summarize his years of research on the role of the vestibular system in respiratory control and Dr. David Paterson will discuss the neuro-anatomical association between serotonin and the vestibular nucleus, as well as the disturbances of serotonin in SIDS. Finally, Dr. Marta Cohen will discuss the planned study to analyze pathological inner ear disturbances in SIDS cases and ongoing efforts to use forensic and imaging tools to further investigate a possible association of SIDS with inner ear dysfunction. Clearly, it is too early to conclude that hearing dysfunction in babies is a predictor of SIDS, but this symposium will provide an overview of the current state of research in this fascinating, yet still provocative association with SIDS. Aside from learning about the association between hearing dysfunction and SIDS, the audience will obtain an up-to-date overview of the mechanisms that underlie arousal and the hypoxic, hypercapnic response and the audience will learn how a failure to arouse may lead to SIDS. To our knowledge, the finding of hearing suppression with the newborn hearing screen is the first early sign of any abnormality in SIDS cases prior to a fatal event. We propose that there is great potential value in investigating this finding and its origins in greater detail.

## O45

### **AN INTEGRATIVE REVIEW OF MEN'S EXPERIENCES OF SUBSEQUENT PREGNANCY AND BIRTH AFTER STILLBIRTH**

Margaret Murphy

*University College Cork, Ireland*

**Background:** Notwithstanding advances in maternity care, babies die around the time of their birth and the reasons can be varied. It is estimated that 98% of the 3 million annual stillbirths globally occur in low resource countries. Stillbirth remains an issue too for high resource countries and is of concern to parents, practitioners and policy makers alike. It is estimated that in high resource countries 1 in 200 births will end in stillbirth. The worldwide stillbirth trend is declining, though at a much slower rate than maternal or infant mortality.

The majority of couples who experience a stillbirth will go on to have a successful pregnancy, many within a short timeframe. Couples are often pregnant again while still grieving the lost baby. Men's experience of pregnancy after stillbirth has been under-explored to date, within the research and greater focus has been given to women's experiences. Where men have been considered, it is usually as a part of a bereaved couple or wider family. Men may have unique support requirements for pregnancy and birth following stillbirth that are independent from their partner's needs. By exploring men's experiences of pregnancy following stillbirth, care can be tailored to best suit men's distinct needs.

**Objective:** To review the literature on men's experiences of subsequent pregnancy and birth following stillbirth utilising Whittemore and Knafel's integrative review framework.

**Methods:** A systematic search strategy of several key databases (CINHAL, MEDLINE, and EBSCO including PsycARTICLES, Psychology and Behavioral Sciences Collection, PsycINFO, SocINDEX with Full Text) was conducted on 14<sup>th</sup> April 2014 to include relevant studies. Search terms including m\*n OR father\* OR male AND stillbirth OR perinatal loss OR perinatal death OR intrauterine death OR miscarriage OR infant death OR peripartum death AND subsequent pregnancy OR next pregnancy OR pregnancy after loss.

**Main Results:** A total of 24 studies met the inclusion criteria. The themes that emerged from the review included the significant impact that stillbirth has on men; misunderstandings of the impact of this loss on men; the expectation on men to fulfil certain roles and the consequence that these and other factors have on men's experiences of subsequent pregnancy and birth after stillbirth.

**Conclusion:** Men are aware that their perceptions of pregnancy and birth are forever altered by their experiences of stillbirth and this may result in hyper-vigilance and emotional distancing or conversely intentional parenting of their unborn child. There is a need for further research into men's unique experiences of subsequent pregnancy and birth following stillbirth.

**Implications for Practice:** Healthcare professionals need to be aware of the importance of empathetic, supportive, continuous care at the time of a stillbirth, in subsequent pregnancies and after the birth of a healthy baby for women and men. Men's support needs should be considered as well as the women's when caring for couples who are pregnant again following stillbirth.

## O46

### **FATHERS' PERSPECTIVE**

David Borman

*Midwife and trainer, trainer @ Monkberry Trainingen, the Netherlands*

The loss of a child has an enormous impact on both parents. In this lecture the focus will be on differences between men and women, and to what extent attention and quality is offered to fathers in the support and guidance after the loss of their child.

Both the perspective of the fathers as well as advices and tips for professionals will be discussed.

David Borman is as Regional President of the middle part of the Netherlands affiliated with the PAN (Perinatal Audit Netherlands), provides education on perinatal bereavement to medical students in Utrecht and developed and gives courses for expectant fathers.

## O47

### PATIENT-CENTRED CARE IN THE NEXT PREGNANCY

Ruth Cochrane, Sheila Broderick

*Lewisham Hospital, London, co-authors of 'Perinatal Loss: a handbook for working with women and their families, UK*

Having experienced a pregnancy loss, it is highly likely that women and their families will be scared at the thought of the next pregnancy. In this workshop we will discuss how women may find it hard to trust their own bodies and even harder sometimes to trust healthcare professionals to enable them hopefully to have a baby.

Women bring their history with them, of the loss itself and how well (or otherwise) they were treated during that pregnancy and its aftermath. It is vital that caregivers understand and acknowledge this history and that they are able to put a plan together with the woman that takes her previous experiences into account.

The plan for the management of a future pregnancy will often begin before conception. The workshop will take delegates through the various stages of the next pregnancy, each of which will produce its own anxieties. We will discuss the nature of these anxieties with the delegates, and put forward suggestions as to how these anxieties may be alleviated.

## O48

### SUPPORTING FAMILIES WITH SUBSEQUENT CHILDREN - EXPERIENCE OVER 25 YEARS

Alison Waite<sup>1</sup>, Angela MacKenzie<sup>2</sup>

*<sup>1</sup>Sheffield Children's Hospital, <sup>2</sup>London School of Hygiene and Tropical Medicine, UK*

The Care of Next Infant (CONI) programme was set up in the UK in 1988 to provide support to parents with children born following a sudden unexpected death in infancy. 25 years on we can advise on reducing risk for SIDS but do not know how to eliminate it. Today's parents face the same fears as those of 25 years ago – anxiety that another child may die and how to cope with their ongoing bereavement which impacts on their relationship with their new child as well as affecting relationships with partners, family and friends. Over 12000 babies have been enrolled on CONI and offered regular health visitor visits at home, access to a paediatrician, apnoea monitoring, symptom diary, Sheffield weight chart and room thermometer. Feedback questionnaires and mortality reviews identify some key issues for helping parents.

All parents are sent questionnaires on completion of the programme (mean 48% returned). The questionnaires have varied over the 25 years. From 2002, 80% parents responding have rated CONI as very helpful and a further 13% as helpful. Data from 2 cohorts of babies have been reviewed to identify which aspects of the programme have been most valued by the parents.

The first cohort enrolled 1988 – 1998 (questionnaires returned = 3170) were asked to rank the elements of support offered by their perceived helpfulness. The second cohort enrolled 2002 -2012 (questionnaires returned = 1991) rated each element using a Lickert scale 1 -5, 5 = very helpful. In the first cohort, the health visitor visits were ranked 1 – 3 by 70% parents responding and the apnoea monitor by 89% parents. In the second cohort, the health visitor was rated 4 or 5 on Lickert scale by 89% parents responding and the monitor 4 or 5 by 92% parents. The 2 questions are different but the inference we take is that both cohorts found health visitor support and the use of a monitor to be very important elements of the care they receive from CONI. Written comments show the health visitor especially helps by listening and the monitor aids parents' sleep.

Current CONI parents show high risk behaviours. For babies born in 2010 - 2011, 49% of mothers and 56% of their partners were smokers. Only 37% of babies were breastfed at one week. Of 10 sudden infant deaths occurring since 2004, 2 died while sofa-sharing and 4 while bed-sharing with parents who smoked and or had consumed alcohol.

CONI continues to meet the emotional needs of parents, and consistently health visitor visits and the apnoea monitor have been ranked high. Smoking and bottle feeding remains high in this population. The incidence of SIDS is 4-6 times higher than the UK rate since 2002. The CONI families most at risk need to be identified and targeted: to enable breastfeeding, reduce smoking and unsafe sleep practices.

## O49

### CENTERING PREGNANCY

Marlies Rijnders

*TNO Child Health, Leiden, the Netherlands*

To improve the prevention of perinatal morbidity and mortality, care providers and parents need to understand each other better and work together. However the involvement of parents-to-be in perinatal care is difficult to achieve. Our model of care does not allow much time for in depth discussions, sharing knowledge or the provision of client centered information. By redesigning care time can be gained to tackle this problem. CenteringHealthcare is a model of care in which most of the individual care is replaced by group care. In the group sessions active client participation in medical care is combined with sharing knowledge and experiences, self-assessment and building support systems. This allows parents-to-be to prepare themselves better for pregnancy, birth, healthy living and raising a child. By understanding more and being aware of potential risks and how to prevent them, parents can play an important role in the reduction of perinatal mortality. In the Netherlands, CenteringPregnancy (in the prenatal period) and CenteringParenting (in youth health care) are now successfully implemented in over 30 organizations.

In the presentation CenteringHealthcare care model will be further explained and discussed.

## O50

### **GRIEVING IN THE DIGITAL AGE: BEREAVED PARENTS ARE ONLINE (AND THERAPISTS SHOULD BE TOO)**

Daan Westerink, Research journalist, loss and bereavement trainer, the Netherlands

"I didn't see that I had anything in common with younger parents who had lost a baby. But when I heard these parents talking in a group I recognize the same pain. I feel so sorry for those parents. At least we had our son for 19 years", says Dave, a bereaved father in 'On the Death of a child', written by Celia Hindmarch. The author shows – through interviews, case studies, and mentioning new understandings of grief, how challenging the death of a child is. She states that those who have lost a parent, a spouse and a child, will invariably describe their grief for the child as the most painful, enduring, and difficult to survive. No matter how old the child is, or whether it died during birth, through illness, an accident, or suicide. Not only is it heartbreaking for the bereaved parents; Hindmarch emphasizes that friends, health and social care professionals who support them sometimes can hardly cope either, with the confrontation of their loss. As other books on bereavement, it supplies background information about the influence of losing a child on parents, and provides guidelines to professionals in what to say, what to do, how to behave and when it is time to be quiet and listen to the real experts: the bereaved parents themselves. In the last chapter, some of them tell their admirable stories of loss, hope, meaning and resilience. But what this book, and others, lack, is the way bereaved parents grief online, and how it comforts and supports them.

Facebook can provide family, friends, co-workers and therapists with a better understanding of the world from a bereave parent's perspective according to O'Farrell (2012'. She suggests therapists should invite clients to show them their Facebook profile, how they present themselves to others, how they choose to define themselves, who they associate with and groups they choose to affiliate with. 'This can be a helpful way to understand your client from their worldview as well as get a better understanding of their context as an individual in relation to others', as long as it is used in a safe and ethical way

## O51

### **RELIGIOUS ASPECTS OF TERMINAL CARE AND POST MORTEM INVESTIGATIONS**

Hans Schilderman

*Chair 'Religion and Care'/ Faculty of Philosophy, Theology en Religious Studies Radboud University Nijmegen, the Netherlands*

Stillbirth is an event that remains shocking and disturbs one's life, leaving significant scars in the biographies of those that stay behind. I will define events of stillbirth in terms of the concept of tragedy and will subsequently clarify that religions fulfil functions of explaining, enduring and transcending pain in the suffering that is implied in these tragic circumstances. Subsequently, I will raise three issues that illustrate how various religious traditions model these functions in beliefs and practices. These issues - foetus definition, medical decision making, and death-attitude – tend to be reflected in rather divergent beliefs and practices in the world religions, and probably require a phenomenological study of their own. Finally, I will make the case that spiritual care is an upcoming discipline that combines the expertise necessary to deal with suffering from the perspective of religious traditions and life philosophies, in order to contribute to the quality of life of those affected by tragedies of stillbirth.

## O52

### **...AND WHAT IF THE WOUND DOES NOT HEAL? EMDR FOR TRAUMATIC LOSS**

Joany Spierings

*Short-term care of de Department of Mental Health*

Our human body has the amazing capacity of healing it's own wounds; even though you can't explain how this self-healing process works, your body knows exactly what to do.

The same holds true for traumatic events. 'Trauma' is an ancient Greek word, meaning 'wound of the soul'. The human mind, like the body, has an innate capacity for self-healing.

Human beings can recover from devastating experiences, sometimes to their own surprise, sometimes contrary to their own expectations.

For the vast majority, no psychotherapeutic intervention is needed after a traumatic loss, but for some people the wound does not heal and professional help is necessary.

This is where EMDR can help.

Eye Movement Desensitization and Reprocessing (EMDR) is a psychotherapeutic technique, proven effective for the treatment of trauma. It is both a structured, protocolled approach and a unique, deeply personal and meaningful experience at the same time.

EMDR started in 1989 as a highly controversial therapy, too good to be true, but by now its effectiveness has been scientifically proven over and over. Experimental research has uncovered the working mechanisms. Yet still there is something magical about it: EMDR touches the heart, and brings unexpected gifts of meaning.

In this presentation both sides of EMDR will be discussed:

-the structured approach, with its cognitive, emotional and physical aspects

-the meaningful, personal healing process

An illustrative case story will be presented of the EMDR treatment of a young mother.

A couple of years ago she lost her baby daughter, shortly after giving birth, and now she is pregnant again. Somehow she does not connect to the little one inside, she does not feel any attachment, there is no tenderness. No baby room, no hopeful anticipation, no nothing.

Within a few treatment sessions EMDR helped her to develop a new relationship to her deceased daughter, and opening her heart to her soon to be born baby.

## O53

### **ONE CHILD TOO FEW: THE STRUGGLES OF A SUBSEQUENT PREGNANCY**

Jeannette Rietberg

*Parent speaker and author/trainer on perinatal loss and bereavement, the Netherlands*

Jeannette Rietberg holds a Master's Degree in English linguistics and literature (University of Leiden) and worked in marketing and communications. In co-operation with high risk pregnancy specialized OB/GYN dr. Maria Pel (Academic Medical Center Amsterdam), she wrote the first handbook on pregnancy after perinatal loss in The Netherlands (published april 2013) entitled 'Altijd een kind te kort' (One child too few). This book covers Rietberg's own trial of losing her firstborn child and the physical and emotional challenges of her three subsequent pregnancies. Experiences of nine other bereaved mothers are also included. The book aims to educate and inform bereaved mothers in regaining trust in herself, her body and in medical care. Rietberg has been an advocate for good doctor-patient communication for many years, sharing her personal story with medical students at the Academic Medical Centre in Amsterdam. Being a proud mother of three children to care for and one in her heart, she writes articles and gives lectures and workshops on the subjects of perinatal loss and bereavement. Rietberg has a particular interest to help improve care of bereaved parents and to support and train care providers who interact with bereaved families. Her research interest is on psychological effects of stillbirth and neonatal death and its long-term impact.

## O54

### **CARDIOGENETICS AND ARRHYTHMIAS IN SIDS AND STILLBIRTH**

Sally-Ann Clur

*Amsterdam Medical Centre, Paediatric Cardiology, the Netherlands*

There is increasing evidence for the role of undiagnosed inherited cardiac conditions in SIDS and SUDI. The triple risk model for the pathogenesis of SIDS proposes a host with an underlying genetic predisposition, a critical developmental period and an exogenous stressor. Primary electrical disease resulting in lethal arrhythmias cannot be detected by standard post mortem examinations, however molecular autopsies and genetic analyses of cohorts have revealed mutations in ion channel-related genes ("channelopathies") linked to inheritable arrhythmia syndromes. Based on population-based cohort studies it can be concluded that every fifth SIDS case may be a cardiac ion channel-related gene mutation carrier. In this talk the clinical features of the long QT syndrome, catecholaminergic polymorphic ventricular tachycardia and Brugada Syndrome and their relationship to SIDS and SUDI will be highlighted. Other channelopathy-associated targets and polymorphisms and triggers will be dealt with in the context of the triple risk model. The role of family screening and the molecular autopsy in the clinic will be discussed using a case study."

## O55

### **REDUCTION IN STILLBIRTH RATES IN ENGLAND THROUGH IMPROVED ANTENATAL RECOGNITION OF FETAL GROWTH RESTRICTION**

Jason Gardosi

*Perinatal Institute, Birmingham, UK*

Most stillbirths used to be categorized as 'unexplained' and were considered, by implication, unavoidable. However independent case reviews have found that many deaths are associated with a failure to recognize risk factors and to afford them the appropriate standard of care. The majority of normally formed fetal deaths had preceding, unrecognized intrauterine growth failure.

Improved multidisciplinary training and adoption of standardized protocols have led to improved antenatal detection of fetal growth restriction in low and high risk pregnancies, and this in turn has led to significant reductions in stillbirths in the national health service regions with high uptake of the training programme. This has resulted in a significant downward trend in stillbirth rates in England to their lowest ever levels in 2013, with an estimated 500 fewer stillbirths per year compared to the previous 10 year average. Currently, this initiative is being rolled out as the comprehensive, evidence-based growth assessment protocol (GAP) and has already been implemented in the majority of hospitals in the UK.

## O56

### **STILLBIRTH IN DEVELOPING COUNTRIES**

Hussein Lesio Kidanto

*OBGY, Department of Obstetrics and Gynecology, Dar es Salaam, Tanzania*

Worldwide, the stillbirth rate has declined by 14% from 1995 to 2009, representing an annual decline of 1.1% per year. However, this decline is less in developing countries. There are over 2.6 million stillbirths globally, with more than 8 200 deaths a day. The majority of these deaths occur in developing countries. Ninety-eight percent occurred in low- and middle-income countries. The majority of stillbirths are preventable, evidenced by the regional variation across the world. The rates correlate with access to maternal healthcare. At least half of all stillbirths occur in the intrapartum period, representing the greatest time of risk. Intrapartum deaths account for 45% of third-trimester stillbirths globally but only 14% of third-trimester deaths in developed countries.

Two-thirds of stillbirths occur in south-east Asia and Africa and 55% occur in rural families from these areas. This reflects a similar distribution of maternal deaths and correlates with areas of low-skilled health professional attendants at birth. The causes of stillbirth have remained the same for decades (childbirth complications, maternal infections in pregnancy, maternal disorders (especially hypertension and diabetes), fetal growth restriction and congenital abnormalities). Almost half of stillbirths happen when the woman is in labour reflecting inadequate monitoring during labour. Despite similar disparities for maternal and neonatal deaths, which are currently being addressed under the Millennium Development Goals, stillbirths remain an invisible public health priority. It is high time now stillbirth problem is addressed adequately.

## O57

### **CARE OF LOW BIRTH WEIGHT INFANTS IN RURAL ZAMBIA: FORMATIVE RESEARCH AND A FEASIBILITY TRIAL OF COMMUNITY-BASED KANGAROO CARE AFTER DISCHARGE**

Emma Sacks, J. Hamwaba, P. Thuma  
*Medical Institute at Macha, Choma, Zambia*

**Background:** In Choma District, southern Zambia, the neonatal mortality rate is approximately 40 per 1000 live births and, as in many rural parts of sub-Saharan Africa, more than half of deliveries take place outside of formal facilities. Hospitals provide skilled care, but no neonatal intensive care or Kangaroo Care. Infants born at home are almost never weighed; understanding how well local practices identify and care for small or preterm infants is essential for optimizing newborn care programs and reducing neonatal deaths. Newborns are discharged from the Macha Mission Hospital at 2000g, thus there is an opportunity to teach kangaroo care in the facility and carry it forward to the community.

**Objectives:** 1) To understand local practices for identifying and caring for small or preterm infants; 2) To test the feasibility of community-based kangaroo care for low birth weight infants (<1500g) born in a facility and discharged back to their homes in rural Zambia.

**Methods:** We conducted 45 in-depth interviews, five focus groups and four observation sessions with recently-delivered women and traditional birth attendants, focusing on skin, thermal and cord care practices in the home for term and preterm newborns. We specifically aimed to determine if there were different practices for term and preterm infants, and which were protective, harmful or neutral to the health of the infant. We conducted a "Trial of Improved Practice" with eight mothers of low birth weight infants who had delivered at the Macha Mission Hospital. Women received a kangaroo training session from a nurse supervisor prior to discharge and were followed up at home for observation sessions within 48 hours and one week.

**Results:** In addition to size and gestational age, small and preterm infants were identified in the home by poor skin turgor and weak movement. Newborns were generally kept warm, however nighttime bathing was common, often in cold water. The vernix was considered important for the preterm newborn, but immediate bathing was common for term infants. Mothers applied various substances to the skin and umbilical cord, with special practices for preterm infants, who were massaged often with Vaseline or cooking oil. Mothers with low birth weight infants were generally eager to try kangaroo care at home and were able to wrap themselves and their babies easily. Women who had cesarean sections were reluctant, believing that their bodies were not "ready." Women generally believed that hats and blankets would keep their infants warmer than kangaroo care and were most comfortable with a combination of both. Women reported that the easiest time to implement KMC was directly before, during or after breastfeeding. In interviews, many women said they understood that this could help low birth weight infants as a medical practice, but would not see the necessity for full term infants.

**Conclusions:** Thermal care for newborns is generally practiced in rural Zambia, with extra protection given to small and preterm infants. It is highly feasible that mothers of small and preterm infants would be open to special practices to care for their newborns, including kangaroo care, which is feasible for home-based care of low birth weight infants after discharge from a facility with proper training. Messaging should be tailored to explain that this is a useful practice for all newborns, is as warm as blankets and that women's bodies are ready to warm their infants despite any medical procedures. In addition, using breastfeeding as a facilitator could be a useful strategy. Further research is needed on implementing this practice for all infants and for those born at home globally, especially in regions with higher risk of hypothermia.

## O58

### **UNDERSTANDING THE PROVIDERS' PERSPECTIVE AS BARRIERS FOR RETENTION IN REMOTE PUBLIC FACILITIES TO ENSURE 24/7 EMERGENCY OBSTETRIC AND NEWBORN CARE (EMONC) SERVICES: A QUALITATIVE INVESTIGATION**

Marzia Sultana, Rasheda Khan, Rukhsana Gazi, Tamanna Sharmin, Nazib Zaman, Mahbub Elahi Chowdhury  
*International Centre for Diarrhoeal Disease Research, Dhaka, Bangladesh*

**Background:** Currently, Bangladesh faces major challenge in retaining health professionals, particularly medical doctors in sub-district and rural health facilities. There is a lack of documentations on providers' perspectives understand the related barriers for policy advocacy.

**Methods:** This study was conducted between April-September 2012 in 4 districts of Bangladesh having maternal and neonatal health interventions being implemented by the Government and the UN agencies. Key Informant Interviews (103) were carried out with providers involved with EmONC services in different types of health facilities.

**Results:** Providers explained myriad of reasons for not being interested to serve in health facilities on outside of the cities. Providers who served at sub-district level facilities said that they end up staying in remote areas longer than they were supposed to. Staying in such areas meant remaining detached or forgotten by the upper level administration and being deprived of on-going opportunities which results into lagging behind in career. Overburdened duties due to high absenteeism, often challenging in providing quality service. Other issues like social security, lack of opportunity for private practice, poor housing condition, lack of incentives to serve in remote areas, poor children's schooling facilities, were also mentioned as barriers. Female providers mostly mentioned insecurity and husband's job in a different region. Providers suggested that appointments in remote areas should be supported by attractive remuneration package along with opportunities for higher education and training in abroad after completion of the tenure.

**Conclusion:** To retain skilled providers in public facilities to ensure round the clock EmONC services, programmers and policy makers should consider that providers should obtain a good package of incentive for staying and serving the facilities in remote areas. Initiatives also should be taken for improved residential facilities, opportunities for higher education and systematic transfer provision after a certain period of serving in remote areas.

## O59

### **IMPLEMENTING ANTENATAL MAGNESIUM SULPHATE FOR IMPROVING OUTCOMES OF PRETERM SURVIVORS: THE WISH PROJECT**

Philippa Middleton<sup>1</sup>, E. Bain<sup>1</sup>, C. Crowther<sup>1,2</sup>, Vicki Flenady<sup>3</sup>, James Morris<sup>4</sup>, M. Beckmann<sup>3</sup>, K. Groom<sup>5</sup>, S. McIntyre<sup>6</sup>

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**Background:** Well-designed and conducted randomised trials and systematic reviews provide reliable evidence of the effectiveness of treatments; however they form only part of a 'research cycle'. While in 2009 a Cochrane review 'Magnesium sulphate for women at risk of preterm birth for neuroprotection of the fetus,' showed that magnesium sulphate given to women at risk of preterm birth could substantially reduce the combined risk of death (including stillbirth, neonatal and infant death) and cerebral palsy for the children (RR 0.85, 95% CI 0.74-0.98; four trials, 4446 infants), real-life health impacts rely on the translation of this evidence into clinical practice.

**Objectives:** To assess the impact of evidence, from Cochrane review, to clinical guidelines, translational research, implementation projects and further studies.

**Methods:** Description of and comment on knowledge translation processes and efforts to address research gaps post-publication of the 2009 Cochrane review.

**Results:** Following publication of the 2009 Cochrane review, guidelines (including bi-national guidelines for Australia and New Zealand) were developed recommending administration of magnesium sulphate to women prior to preterm birth at 30 weeks gestation to prevent unnecessary deaths or children with cerebral palsy. An ongoing project, 'WISH' (Working to Improve Survival and Health for babies born very preterm) has been supporting 25 tertiary maternity centres for implementation, providing educational materials, assisting audit and feedback, and assessing local individual and system level barriers, including attitudes and motivation, supports, resources and processes. Addressing identified research gaps, the MAGENTA and IRIS randomised trials have been designed and initiated, exploring benefits at later gestational ages, and strategies to improve the comfort of women receiving this therapy. Audit results have shown appropriate magnesium sulphate administration for fetal neuroprotection has increased in many tertiary settings; from almost zero to over 80% in two years at lead hospitals. The WISH Project Follow Up Study now aims to optimise bi-national uptake, and assess the effects of this therapy on health outcomes for children at two to five years of age, including on the rates of death (stillbirth, neonatal and infant death) and cerebral palsy.

**Conclusions:** High-quality research alone does not ensure the translation of evidence into practice. The WISH Project has facilitated increased uptake of antenatal magnesium sulphate, however it is imperative that the use of this therapy is optimised through sustained implementation support, to continue to prevent unnecessary deaths and children with cerebral palsy. To enable the continued surveillance of this treatment across Australia and New Zealand, bi-national clinical indicators of use and impact are required. The WISH Project Follow Up Study will ensure that health outcomes, particularly survival free of cerebral palsy, are fully assessed.

## O60

### **IMPLEMENTATION OF CHANGES IN PERINATAL CARE IN THE NORTH OF THE NETHERLANDS, THE ACTION PROJECT**

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**Background:** Perinatal Audits are used to discuss the causes of stillbirth and neonatal deaths. These audit-meetings are organized in every hospital and attended by midwives, gynecologists, nurses, pediatricians, and managers from hospital and maternity care organizations at least twice a year. Every audit group formulates its own local improvements. Unfortunately it appears that not all improvements are implemented properly.

Therefore, to foster implementation skills of involved professionals, the project 'Audit generated Changes in perinatal care using 'Tailored' implementation strategies' (ACTion) started in 2013 (-2017).

**Objective:** To improve implementation skills of professionals who work in perinatal care to enhance changes that were identified during audits.

**Methods:** The project covers the three provinces in the northern region of the Netherlands. In this region there are 11 groups who execute perinatal audits. With a stepped-wedge design approach, we offer implementation training to these professionals in 3 consecutive time periods. During the training we introduce the implementation methodology according to GroL and Wensing as well as the basics of change knowledge, which is subsequently applied to improve on local problems. All groups are offered 3 guided follow-up meetings over 1 year to support further implementation of their changing skills. The training is evaluated through standardized evaluation forms. The progress of the groups as well as their motivation is monitored by questionnaires. During the follow-up phase progress is monitored by observation, process journals, questionnaires and interviews.

**Results:** Since the start of the project, 11 groups have been trained. The size of the groups varies between 4 and 10 people, for a total of 78 professionals with 7 different backgrounds. The 11 groups have applied the newly learned implementation method to 22 improvement items in the first year of the project.

The training was evaluated with a mean score of  $2.8 \pm 0.4$  (range 2.1-3.2) out of 4. The pre- and post self-assessment showed a mean increase from  $2.6 \pm 1.1$  to  $3.9 \pm 0.7$  ( $P < 0.001$ ) on a scale from 1 to 5. Results and implementation grade of the improvements differed from group to group as a result of various determinants. The follow-up sessions were considered necessary for grounding the learned implementation method.

**Conclusions:** After the 3-sessions training all involved professionals were more knowledgeable on the implementation method and all were positive on their increased ability to incorporate improvements derived from perinatal audits. However, guided follow-up meetings are considered necessary for sustainment and to build more experience.

## O61

### **SAFE TO BREATHE: THE ART OF TRANSLATING EVIDENCE INTO UNDERSTANDING FOR PROTECTING INFANT LIFE**

Stephanie Cowan<sup>1</sup>, Jeanine Young<sup>2</sup>

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**Background:** Research has revealed many sleep environments for infants that carry an increased risk of infant injury and mortality. Sudden, unexpected infant deaths and sudden neonatal collapses have been associated with infant car seats, slings, baby hammocks, while breastfeeding, during mobile phone use, in cots, on sofas, in shared sleeping situations, and in delivery suite during kangaroo-care. No environment is risk free for a baby. Babies are obligatory nose breathers and any position which occludes a baby's nose or promotes chin-to-chest positioning may cause positional asphyxia and slow suffocation. Babies who have impaired arousal mechanisms through exposure to tobacco smoke, alcohol, illicit or prescription drugs, or those who are born premature or of low birth weight, are particularly vulnerable. Health professionals are bombarded with many guidelines that they are expected to impart as part of parent education. This workshop will present a novel approach using the baby's perspective and share a simple set of principles applicable to all environments for a baby placed to sleep.

**Using different kinds of evidence:** Scientific evidence comes from group data. While it is an important part of the communication and prevention story, it is by no means all of it. It lacks the specificity that other types of information can add. Jeanine will lead a discussion about current communication challenges that participants' experience in their prevention work. This will be followed by a short presentation of the different kinds of evidence needed for effective translation of science into understanding and action, using coroners' reports and case reviews, as examples. This will be followed by the opportunity to review coroners' reports for communication clues that can enhance programme development and the translation of evidence.

**Using translation tools:** Effective translation requires that we know the language we are translating from and the language into which we are translating. Stephanie will present briefly on the four domains of learning (cognitive, emotional, spiritual and physical) and the power of analogies in designing effective communication experiences for rippling into communities. Participants will practise using a simple plastic tube to simulate an infant's airway, and use it to explain how babies can suffocate and how safe sleep recommendations can protect them.

**Putting these together in a real communication situation:** The session will end with a short demonstration of the standard safety briefing that goes with the issue of portable sleep spaces to vulnerable infants in some regions of New Zealand and Australia. It combines the art of translation with the science of prevention to enable understanding of infant vulnerability to accidental suffocation, and practical ways to set a baby up to be 'safe to breathe' when sleeping, wherever that may be.

## O62

### **MODELING THE YIN AND YANG OF CARDIORESPIRATORY CONTROL IN SIDS USING NEONATAL ANIMALS**

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Apnea and bradycardia seem to be at the center of the pathogenesis of SIDS. Both apnea and bradycardia are generated by inhibitory responses to cardiorespiratory stimuli, yet the characteristics of most mature, adult responses to respiratory stimuli are excitatory. Thus, SIDS can be seen as a conflict between inhibitory and excitatory reflex control of breathing and cardiac function in which inhibitory responses are inappropriately elicited or inappropriately enhanced. We have been studying the laryngeal chemoreflex (LCR) in neonatal piglets and in rat pups between post-natal day 4 (P4) and P21. The laryngeal chemoreflex is a complex set of inhibitory responses to fluid in the larynx – responses that include apnea and bradycardia. The reflex pathway mediating the LCR has its first central synapse in the nucleus of the solitary tract (NTS), and the reflex seems to function as a labeled line. Stimuli arrive from the larynx, and there is some integration of information at the first order neuron in the NTS, but once the first order neuron is stimulated, the reflex seems to unfold without further modification. Modulation of the LCR response seems to occur at this first synapse in the NTS where a variety of pre-synaptic receptors modify the intensity of the LCR. Activation of TRPV1, adenosine 2a receptors, and GABAA receptors within the NTS prolongs the LCR, and activation of 5-HT3 receptors and possibly cannabinoid 1 receptors shortens the LCR. The role of 5-HT3 receptors is particularly interesting given the apparent deficiency of serotonin in certain brainstem nuclei, including the NTS, in infants who died of SIDS. Thus, the conflict between inhibitory and excitatory control of respiration is played out in the neurotransmitter receptor diversity within the very first synapse in the reflex arc controlling the LCR in neonatal animals. Moreover, the receptors involved appear to be modulated by risk factors for SIDS. For example, elevated temperature and inflammation related to recent infections, both well-recognized risk factors for SIDS, sensitize TRPV1 receptors and may enhance the duration and potency of the LCR. Maternal smoking (and nicotine exposure) during pregnancy, a significant risk factor for SIDS, also increases the strength of the LCR, apparently by increasing the sensitivity of TRPV1 receptors since nicotine increases the thermal prolongation of the LCR. In summary, studying the LCR in neonatal animals provides a model in which to understand the interactions among risk factors for SIDS, neurotransmitter deficiencies in SIDS and the inappropriate dominance of inhibitory cardiorespiratory reflex control in the pathogenesis of SIDS. Perhaps more importantly, some of the receptors identified may be suitable targets for therapies to prevent SIDS. (Supported by NICHD 036379).



## O63

### IMPAIRED RESPONSES TO HYPOXIA AND FAILED AUTORESUSCITATION IN NEONATAL RODENT MODELS OF 5-HT DYSFUNCTION

Andrea Corcoran

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Sudden Infant Death Syndrome (SIDS) is a devastating occurrence of early developmental premature death. Neurochemical and anatomical findings indicate that a significant proportion of SIDS cases are associated with abnormalities in the medullary serotonin (5-HT) system. This has led to the working hypothesis that such a deficit in neonates creates an underlying vulnerability sufficient to alter physiological responses to exogenous homeostatic stressors (such as low oxygen) and produce mortality. Sleeping in the prone position, a risk factor for SIDS, can give rise to exposure to hypoxia (asphyxia) from re-breathing exhaled gases. Failure to arouse from and/or adequately respond to this type of environmental stressor may have lethal consequences. Asphyxia initiates a series of events that in a normal infant will lead to a reflex known as autoresuscitation: an increase in ventilation occurs in response to the low oxygen, followed by hypoxia-induced respiratory arrest (or apnea) and coincident bradycardia. In a final effort to obtain oxygen, hypoxic gasps are generated. If air is available, these large breaths provide oxygen to the tissues and restore regular breathing and heart rate. The goals of our studies were, in neonatal rodent models: 1) to examine the effect of several types of 5-HT deficiency on the ability to autoresuscitate from severe hypoxia, and 2) to evaluate the effectiveness of caffeine administration in promoting respiratory responses to hypoxia. Our distinct and innovative experimental models of serotonin dysfunction include: a transgenic Pet1 null mouse (missing ~70% of medullary 5-HT neurons from birth), a chemicogenetic approach allowing for acute and reversible inhibition of 5-HT neurons in transgenic mice, and a tryptophan deficient diet model resulting in rat pups with ~50% less medullary 5-HT. We looked at the success of autoresuscitation from hypoxic-apnea (induced by repeated episodes of anoxia). All three 5-HT deficient models showed a deficit in the ability to autoresuscitate (to varying degrees), with an age-specific phenotype observed in Pet1 null pups. Administration of caffeine (a known respiratory stimulant and commonly used to reverse or prevent apnea of the premature newborn infant) rescued Pet1 null mice from autoresuscitation failure. These results demonstrate the importance of 5-HT in several key steps in autoresuscitation and provide evidence for a potential therapy that might reduce autoresuscitation failure in response to hypoxic exposure. (Supported by NICHD 036379 and Parker B. Francis Foundation).

## O64

### BRAINSTEM SEROTONERGIC AND GABAERGIC MECHANISMS, AROUSAL AND SIDS

Robert Darnall

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Arousal is an important protective response to hypoxia. Many SIDS infants have clusters of apnea, bradycardia and hypoxia in the days and weeks prior to death and arousal deficits have been observed in infants who subsequently died of SIDS. We hypothesized that: 1) exposure to repeated episodes of hypoxia (asphyxia) results in a progressive blunting of the arousal response or "arousal habituation", and 2) dysfunction of brainstem serotonergic (5-HT) and/or GABAergic mechanisms, analogous to those reported in SIDS infants, contribute to blunted arousal responses and enhanced arousal habituation.

In newborn and infant rodents, arousal during hypoxia has easily identifiable stereotypical characteristics. We determine the time to arousal (latency) from the onset of repeated exposures to hypoxia and continuously record body temperature (TB), heart rate (fH), respiratory rate (fR) and oxygen consumption (VO<sub>2</sub>). Our early experiments confirmed that arousal latency progressively increases over the course of 4-8 hypoxia exposures and showed that this phenomenon is dependent on the length of the hypoxia exposure and/or the length of the "recovery period" between hypoxia exposures.

Based on studies showing that hypoxia increases medullary concentrations of GABA, we postulated that a progressive accumulation of GABA contributes to arousal habituation. We micro-injected a GABAA agonist, and antagonists of both GABAA receptors and GABA re-uptake mechanisms, into the medullary raphe and determined the time to arousal during repeated episodes of hypoxia. Stimulation of GABAA receptors (muscimol) significantly prolonged arousal latency indicating that this region of brainstem contributes to arousal during hypoxia. Blockade of GABA re-uptake mechanisms (nipecotic acid) also prolonged arousal latency, highlighting the role of endogenous GABA in hypoxic arousal. Finally, blockade of GABAA receptors (bicuculline) reduced or abolished arousal habituation indicating that activation of medullary GABAA receptors is important for hypoxic arousal.

We used two strategies to explore the role of 5-HT mechanisms in arousal during hypoxia. We studied 1) mouse pups lacking 70% of 5-HT neurons (Pet1<sup>-/-</sup>), and 2) rat pups with selective destruction of medullary 5-HT neurons via intra-cisternal injections of 5, 7-DHT, a specific 5-HT neuronal toxin. Pet1<sup>-/-</sup> pups (P6-P10) had prolonged arousal latency and enhanced habituation compared to WT/Pet1<sup>+/-</sup> controls. They were also smaller and had lower fH, fR, VO<sub>2</sub> and TB. Rat pups injected with DHT at P2 had an ~80% reduction in 5-HT neurons at P25 isolated to the raphe obscurus/magnus and portions of the PGCL. DHT treated pups had longer arousal latencies and a reduced respiratory frequency response to hypoxia compared to controls. These data not only confirm that serotonin plays a role in arousal, but also that 5-HT neurons specifically located in the caudal medullary raphe are important for arousal in response to hypoxia.

Our current experiments are exploring the interactions between medullary 5-HT and GABAergic mechanisms and intrauterine exposures to nicotine, alcohol and intermittent hypoxia and their role in the ontogeny of sleep and arousal. (Supported by NICHD 036379).

## O65

### THE PRE-BÖTZINGER COMPLEX AND THE PHYSIOLOGICAL DETERMINANTS OF SIDS

Jan-Marino Ramirez

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There is growing consensus that environmental and biological risk factors result in the failure of an infant to overcome cardio-respiratory challenges. Thus, it is critical to unravel the physiological determinants that actually cause the sudden death, to synthesize how these determinants are affected by the known risk factors, and to develop novel ideas for SIDS prevention. In this talk I will review the role of the preBötzinger complex (preBötC) as a multi-functional network that is critically involved in the failure to adequately respond to hypoxic and hypercapnic challenges, and that may play a role in the gender and age distributions that are characteristic for SIDS. The preBötC is essential for the generation of breathing and intrinsically sensitive to hypoxia. Its function is tightly linked to serotonergic modulation which controls neurons essential for gasping and which has been implicated in SIDS. I will also discuss the link between SIDS and prematurity; and how the preBötC may process central chemosensitivity arriving via the vestibular nucleus.

## O66

### THE IMPORTANCE OF PSYCHOSOCIAL AFTERCARE FOLLOWING PERINATAL DEATHS: THE UMCG MULTIDISCIPLINARY APPROACH

Mariëtte de Groot-Noordenbos, Jan Jaap Erwich

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The main aim in the care of perinatal death, is offering a strategy for coping with loss (or coping with impending loss), which facilitates the final goodbye. A range of intense care and support is offered by the Obstetrics centre at the UMCG by doctors and nurses. Parents are encouraged to spend all available time with their baby. These actions of cuddling, holding, caressing, stroking and taking photographs are very important steps of making the (impending) loss tangible. Also hand and footprints are made. Virtually without fail parents reflect on this period as being incredibly powerful, allowing them to create a lasting memory. All parents who have had to cope with intrauterine deaths are invited to choose a quilt of love. These quilts have been hand stitched by volunteers as a lasting keepsake (and physical recognition) of their unviable but much loved and desired child. Again, the tangibility of this keepsake has a positive impact on the coping with loss skills of the bereaved parents.

Parents are invited to meet the gynaecologist 3 to 6 weeks after their child's death. Should parents not cope as expected under the circumstances they will be invited to contact the Obstetrics social worker and a referral will be made by the gynaecologist. Although individual/parental aftercare is a possibility, the UMCG prefers to offer aftercare in a group context. An information evening on the subject of neonatal death is held twice a year, and has been available for the last 17 years. This has evolved to a second yearly information evening for parents who have lost their child prior to birth. Doctors and nurses are available during these evenings of information sharing, in order for medical questions to be asked and to be adequately answered. A couple tells their story.

Interested parties can put their names forward for the group counselling sessions (minimal 3 couples, maximum 6 couples). The meetings are held every fortnight for the duration of 6 sessions. A follow-up is organised 6 months after the last session.

The essence of group counselling is for parents to receive recognition and support for their loss and to freely speak about their child in a safe and respectful environment. Legitimacy for the existence of their child is a second important factor. The fact there is no physical child to show for many months of pregnancy does not equal not being a parent. It is this important issue of being a parent without a child which gets facilitated in the group. The loss of a baby needs not be 'let go of' but indeed to be integrated into the parent's lives and to become part of their present and their future.

The group has themed sessions to encourage integration of the experience:

- How did you say goodbye, which memories do you have, how do you keep them, how do you share them?
- Were you happy about the care you received at the UMCG. How could it have been improved?
- How do you cope with other people's reactions to your loss.
- What impact does the loss have on your relationship and on the relationship you have your other children
- The future, a following pregnancy

It can be concluded that the aftercare group counselling sessions have met a strong patient need. Sometimes networks do not have this flexibility or do not offer the safety to explore the depths of grief. It is often in sharing with people who have had a similar experience that true loss is being worked through. Mothers have empty arms and empty laps. Fathers feel their expectations have been killed and buried.

These parents deserve our support not only during the immediate aftermath of the loss, but also for the year that follows. Indeed, possibly in particular for the duration of their next pregnancy since good psychosocial aftercare following bereavement can greatly reduce the chance of postnatal depression and overprotective parenting in years to come.

## O67

### PARENTING AFTER PERINATAL LOSS: PARENTING WITH INTENTION

Jane Warland<sup>1</sup>, Joann O'Leary<sup>2</sup>

<sup>1</sup> *University of South Australia, Adelaide, Australia,* <sup>2</sup> *University of Minnesota, USA*

**Background:** When parents become pregnant, even when unplanned, most intentionally want to raise an emotionally healthy child. Whilst intentional parenting is a recognized parenting style in the non-bereaved parent the idea of intentional parenting is strikingly different when parents suffer the loss of a baby during pregnancy or in the newborn period.

In the context of this paper, intentionality signifies a course of action where parents adopt a parenting style where spontaneity is avoided and deliberation, intent and planning valued.

**Objective:** This presentation addresses the experiences of parenting after perinatal loss using the voices of bereaved parents.  
**Methods:** Information is drawn from a secondary analysis of both authors' qualitative research. Participants had experienced the loss of a baby and were raising children alive at the time of the loss and/or children born into the family following the loss.  
**Results:** Our combined studies from two different continents with similar participant groups have found a previously unreported common behavior in regards to bereaved parents. Bereaved parents raising their children use words like "deliberate" and "conscious" choice and "intention" in describing their parenting behaviors. After completing a secondary thematic analysis we found that bereaved parents described this intentionality beginning during their subsequent pregnancy and continuing well into parenting of their subsequent child. This presentation will focus on the five sub- themes identified during parenting; 1) changed view of self as parent 2) intentionally different from others, 3) finding a balance, 4) judging others 5) wanting others to understand. This presentation will describe each of these sub-themes using the voices of the participants to show what we mean by intentional parenting, and why parents say they became intentional.  
**Conclusions:** Parenting is something many take for granted however, bereaved parents have a uniquely different perspective of intentionality; that of valuing their children's life as gifts and not taking their parenting responsibility lightly. They no longer assume they will "always have tomorrow" with their children. Without intervention to help parents address their fears and anxieties, attachment to the child that follows may be difficult. The fact that these parents consider their children precious and cherish them is certainly an admirable approach to parenting and one which those who work with the bereaved should highlight and encourage.

## O68

### **PSYCHOSOCIAL IMPLICATIONS OF STILLBIRTH FOR THE MOTHER AND HER FAMILY: A CRISIS-SUPPORT APPROACH**

Melanie Human<sup>1</sup>, Coen Groenewald<sup>1</sup>, Sulina Green<sup>2</sup>, Richard Goldstein<sup>3</sup>, Hannah Kinney<sup>4</sup>, Hein Odendaal<sup>1</sup>

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*(In collaboration with the PASS Network)*

**Introduction:** Stillbirth is a major problem in South Africa. During 2010 - 2011; 32,178 stillbirths were reported by the Perinatal Problem Identification Programme. The National Department of Health and several organizations are addressing various issues to reduce stillbirths and support bereaved mothers. An event that should have been a joyous birth ends in a tragic death, forcing the mother to deal with the emotions of birth and death simultaneously. The bereaved mother needs to receive specialised support as soon as possible. The crisis intervention approach, as a social work method, is helpful to regain a sense of equilibrium in her, and the family's life.

**Objectives:** To explore and describe the experiences of 25 mothers who experienced a stillbirth within the Safe Passage Study ([www.safepassagestudy.org](http://www.safepassagestudy.org)) in South Africa.

**Methods:** The mothers' feelings about the stillbirth were examined, between 6 and 18 months after the event, as well as its impact on relationships with partners and children. All participants received crisis intervention within a week of the loss, and a follow-up visit 6-18 months later to evaluate the effectiveness of this crisis intervention. A combination of quantitative and qualitative research approaches were used during individual interviews to provide detailed demographic and other data of stillbirth. Different types of coping mechanisms were explored with focus on seeing, holding and taking photographs of the baby. Attention was given to feelings regarding medical care, autopsy and support from the community.

**Results:** Mothers still longed for their stillborn babies after six months and the father or partner and other children were also affected by the stillbirth. Eighteen (72%) mothers saw the loss of their baby as a crisis and needed support. Only 1 mother did not perceive the loss as a crisis. Mothers felt crisis-intervention was beneficial, but preferred on-going therapy for at least 4 months. The stillbirth also resulted in feelings of alienation from community, friends and family. Only seven (28%) mothers received community support and 3 (12%) were teased. Five (20%) mentioned that most people avoided them. Eight (32%) mothers did not give consent for autopsy but 17 (68%) did. Of these 13 (76.5%) perceived autopsy as helpful as it indicated the cause of death. It contributed to the lessening of guilt and made dealing with grief easier. Four (23.5%) mothers specified that the autopsy wasn't helpful due to equivocal findings, prolonged feedback or lack thereof. Four of the 8 mothers who did not give consent, regretted it 6 months later and wished they could have had more closure on why their babies died.

**Conclusions:** This study indicates that crisis intervention directly after the stillbirth is effective when rendering service for bereaved mothers and families. The majority of mothers, who experienced their loss as a crisis, will benefit from professional help in regaining a sense of equilibrium. Receiving support from a social worker is essential, and encouraged them to openly grieve for their stillborn babies - much needed in an environment where a stillbirth is seen as a silent birth.

## O69

### **PLACENTAL PATHOLOGY AND STILLBIRTH CLASSIFICATION**

Yee Khong, E. Mooney, Sanne Gordijn

*On behalf of the Amsterdam Placental Workshop Group*

There are over 60 classification systems of stillbirths with many created in the last decade. Placental, cord and membrane pathology is permitted in some but not in other classification systems. Attribution of placental, cord and membrane pathology as causative of stillbirth varies from 0-65% in four classifications (TULIP, modified Aberdeen, extended Wigglesworth and ReCoDe). Placental lesions are more often described in qualitative terms and the sampling protocols are varied between institutions. Many of the placental pathology lesions that are seen in stillbirths are also seen in liveborn pregnancies, suggesting that they may be of uncertain significance or that they should be interpreted in context of other placental, maternal and fetal parameters.

Most cogently, agreed definitions of placental lesions, preferably incorporating quantitative or semi-quantitative criteria, and studies of reproducibility of these definitions by anatomical pathologists who are not pediatric pathologists, are needed. The workshop will attempt to define several of lesions or pathophysiological manifestations in the placenta and discuss agreed pathways to achieving international consensus on terminology.

## O70

### **RISK FACTORS FOR ANTEPARTUM STILLBIRTH IN THE INTERGROWTH-21ST PROJECT POPULATION**

Jane Hirst, D. Finkton, E. Ohuma, F. Barros, A. Lambert, A. Papageorghiou, S. Ash, M. Carvalho, Y. Jaffer, E. Bertino, M. Gravett, D. Altman, M. Purwar, I. Frederick, J. Noble, R. Pang, L. Cheikh Ismail, S. Kennedy, J. Villar, Z. Bhutta

*For the International Fetal and Newborn Growth Consortium for the 21st Century (INTERGROWTH-21st)*

**Background:** Approximately 1.46 million babies die every year before the onset of labor (ante-partum stillbirth, ASB).

**Objective:** To explore risk factors for ASB in a large, multi-ethnic, multi-country, population-based project in settings where most pregnant women had access to reliable pregnancy dating by ultrasound.

**Design, Setting and participants:** The INTERGROWTH-21st Project assessed fetal growth and newborn size in eight geographically defined urban populations, selected because the health and nutrition needs of mothers were met and adequate antenatal care was provided. All babies delivered over one year (approximately 7,000 births per site) were included. Maternal demographic, medical and pregnancy and birth outcomes were obtained. All babies were classified as low or medium-to-high risk of fetal growth disturbance based on a subset of 40 questions from the maternal history. Analysis was performed using Cox Proportion Hazard models applying a hierarchical model building strategy.

**Results:** Of 60 147 babies, 20 866 babies were classified as low-risk of growth problems based on maternal history factors and 39 173 at medium-high risk. Within the entire study population 554 babies were stillborn ( $\geq 16$  weeks of gestation): 446 ASB and 108 intrapartum deaths. ASB rates were 4.8 per 1000 births in the low-risk group and 8.8 per 1000 births in the medium-high risk group.

Considering the entire group, compared to live-born babies, significant risk factors for ASB (after adjustment) were socioeconomic deprivation HR: 1.55 (95% CI 1.16-2.09), single marital status, HR 2.00 (1.41-2.84), maternal age over 40 years, HR 2.23, (1.35-3.68), essential hypertension HR: 3.98 (2.69-5.89), HIV/AIDS HR: 4.26 (2.00-9.10). During pregnancy (after adjustment) independent predictors were preeclampsia HR: 2.32 (1.46-3.71) severe preeclampsia HR: 5.00 (2.99-8.36) bleeding after 15 weeks HR: 3.86 (2.85-5.22), antenatal detection of fetal distress HR: 1.98 (1.16-3.36), suspicion of IUGR HR: 1.84 (1.28-2.65) and multi-fetal pregnancy HR: 2.38 (1.61-3.51) Likelihood ratios indicated that HIV/AIDS and severe preeclampsia only moderately increased the risk of ASB (positive LR  $> 5$ ). Of the 40 screening questions used to identify the low-risk group, the strongest associations with ASB were with hypertension, failure to have an early ultrasound dating scan and multiple pregnancy.

**Conclusion:** This large, multinational study has confirmed that factors in the maternal history can identify a sub population at twice the risk of ASB.

## O71

### **INCREASED BIRTHWEIGHT:PLACENTAL WEIGHT RATIOS AND REDUCED PLACENTAL WEIGHT CENTILES IN STILLBIRTHS OF 'UNKNOWN' AND 'NON-PLACENTAL' CAUSES SUGGESTS AN UNDER-ESTIMATION OF THE PLACENTAL CONTRIBUTION TO STILLBIRTH**

Stephanie Wornton, Alexander Heazell

*Maternal and Fetal Health Research Centre, Institute of Human Development, Faculty of Medical and Human Sciences, University of Manchester & St. Mary's Hospital, Central Manchester University Hospital NHS Foundation Trust, Manchester Academic Health Science Centre, Manchester, UK*

**Introduction:** Placental abnormalities, structural or functional, contribute significantly to stillbirth. Modern stillbirth classification systems, such as the Relevant Condition at time of Death (ReCoDe) System, which incorporate evidence of placental contribution to stillbirth, have significantly reduced the incidence of recording of 'unexplained stillbirth'. Despite using a modern classification system 15-20% of stillbirths remain "unexplained"; the role of the placenta in these cases is uncertain.

**Methods:** All cases of singleton stillbirth in a tertiary UK obstetric unit from 2010-2013 were reviewed retrospectively. Where placental weight was recorded ( $n=126$ ), centiles for placental weight and birthweight:placental weight ratio (BW:PW) were determined using population-based, gender and gestational-age-specific centile curves defined by Thompson et al. Stillbirth cases were allocated to 3 groups according to hierarchical ReCoDe classifications previously assigned at multidisciplinary perinatal mortality meetings; (1) 'placental causes' comprising fetal growth restriction, placental insufficiency, hypertension or placental abruption ( $n=75$ ), (2) 'unexplained causes' where no relevant condition was identified ( $n=23$ ), (3) 'non-placental causes' comprising all other ReCoDe allocations ( $n=26$ ).

**Results:** In all stillbirths, placental weight was  $<10$ th centile in 61% of cases (77/126); the BW:PW centile was  $>90$ th centile in 54% of cases (69/126 cases). The incidence of placental weight  $<10$ th centile and BW:PW  $>90$ th centile was highest in stillbirths attributable to placental causes; 73% and 59%, respectively. A high incidence of reduced placental weight or increased BW:PW centile was also present in stillbirths of non-placental cause (42%, 46%) and 'unexplained' stillbirths (43%, 57%). An extreme placental weight or BW:PW was detected in 76% (57/76) of stillbirths due to recognised placental causes. Amongst stillbirths without any recorded placental contribution, abnormal placental weight or BW:PW was detected in 59% of cases (29/49).

**Conclusion:** Amongst stillbirth cases, the incidence of placental weight and BW:PW ratio at the extremes of population-based centiles considerably exceeded those anticipated. Reduced placental weight may indicate a placenta which is inadequate, or insufficient, to meet fetal demands. Increased BW:PW indicates the growth of more grams of fetus per gram of placenta compared with cases with a lower BW:PW ratio. This phenomenon is observed in FGR, where it is interpreted as increased placental efficiency in response to meet fetal demand. This observation in stillbirths may indicate a period of increased placental efficiency preceding subsequent placental insufficiency. In this cohort, increased incidence of reduced placental weight and increased BW:PW were present in stillbirths without a diagnosis of placental abnormality. This provides further evidence of the high prevalence of placental dysfunction in stillbirth; modern classification of stillbirth may continue to underestimate the contribution of placental causes of stillbirth. In future, routine assessment of placental size and BW:PW may improve recognition of role of the placenta in cases of stillbirth.

## O72

### **CHARACTERISING VILLITIS OF UNKNOWN ETIOLOGY IN STILLBIRTH**

Hayley Derricott<sup>1</sup>, Rebecca Jones<sup>1</sup>, Susan Greenwood<sup>1</sup>, Gauri Batra<sup>2</sup>, Alexander Heazell<sup>1</sup>

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Placental pathology has been implicated as a causative factor in up to 77% of fetal deaths, particularly in the latter stages of pregnancy. Villitis of unknown etiology (VUE) is an inflammatory condition reported to occur in 5-15% of term placentas. It is associated with poor pregnancy outcome; occurring in 28.6% of pregnancies where the infant is growth restricted. There is also suggestion of an association with recurrent miscarriage and stillbirth. VUE has been characterised in live births, but not in stillbirths. The literature reports that macrophages and T-lymphocytes predominate, with few B-lymphocytes or neutrophils present and that the origin of the inflammation is not infectious. We hypothesized that the immune cells involved in VUE would be comparable between stillbirths and live births, but that the number of cells and the extent of infiltration would be more severe. We aimed to phenotype the immune cells present in VUE lesions in placentas from stillbirth and to ascertain whether altered infiltration occurred in the placenta in stillbirths.

Placental tissue blocks were obtained from pregnancies ending in stillbirth (n=5) whose cause of death after post-mortem was recorded as VUE. Immunohistochemistry for immune cell markers: CD45, CD68, CD4, CD8 and neutrophil elastase was performed on serial tissue sections from multiple regions of each placenta. Inflammatory foci were identified, serial images taken and image analysis software used to quantify the number of immunostained cells in the samples. To assess pan-placental leukocyte infiltration, the number of CD45+ and CD163+ cells were counted in 10 random images of tissue sections from stillbirths with VUE (n=5), stillbirths with FGR (n=12), live births with FGR (n=12) and healthy controls (n=12).

Inflammatory lesions were present in all placentas from stillborn infants with VUE (22/26 sections). The number of CD45+ cells in the lesions contributed 32% to the total number of nuclei. This proportion of leukocytes was comprised: 12% CD163+ macrophages, 12% CD4+ T lymphocytes, 7% CD8+ T lymphocytes and 1% neutrophils. Analysis of random images demonstrated significantly greater numbers of CD45+ leukocytes in FGR and stillbirths compared to healthy controls and significantly more CD163+ macrophages in placentas from stillborn infants (P<0.0001).

The inflammatory infiltrate of VUE in stillbirths is similar to that in live births and is suggestive of a 'host-versus-graft' immune rejection. Previous reports typically describe VUE as being focal in nature. We, however, also observed a pan-placental increase in the number of leukocytes, more specifically macrophages, suggesting a wider inflammatory response. This merits further investigation and may prove significant in predicting poor outcome.

## O73

### **SIDS/SUID PATHOLOGY SYMPOSIUM - Sponsored by the American SIDS Institute -**

Betty McEntire, Roger Byard, Carl Hunt, Carrie Shapiro-Mendoza, Michael Bell, Torleiv Rognum, Marta Cohen, Hannah Kinney, David Paterson, Fiona Bright

### **THE SIDS/SUID PATHOLOGY SYMPOSIUM**

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We are proud to host the SUID/SIDS Pathology Symposium at the 2014 International Congress on stillbirth, SIDS and baby survival in Amsterdam. We're honored to have scientists and experts from around the globe to share their work. The first topic will involve the dilemma of classifying sleep-related deaths in infancy. The term SIDS has fallen from favor with medical examiners, however, there is no agreement as to what term(s) should be used. Most agree that suffocation plays a larger role than had previously been thought in these types of deaths, but diagnostic issues are still found in individual cases.

The next topic examines the international shortage of SUID research tissue. One presentation will highlight the US SUID Tissue Consortium which is an effort to bank tissue nationally. Next a hospital-based project in England will be discussed, and then issues facing Norway regarding the collection and use of tissues will be presented.

The next three presentations will explore exciting research into the brain and genetics, including the role of serotonin and other neurotransmitters, such as substance P, in the control of autonomic function and in the participation in terminal autonomic failure.

**O73**

## **SUDDEN UNEXPECTED INFANT DEATH (SUID): A DIAGNOSTIC DILEMMA: INTRODUCTION TO THE PROBLEM**

Carl Hunt

*Uniformed Services University of Health Sciences, Bethesda, Maryland/George Washington University, USA*

Unsafe sleep environment is a major risk factor for sudden unexpected infant death (SUID). We therefore need to continue to strengthen our public health education efforts to more effectively overcome persisting cultural, historical and other behavioral and socio-demographic barriers to safe sleeping for all infants. Concurrently, however, there is a diagnostic dilemma in assigning cause and manner of death that is due to discordant perspectives and approaches.

This dilemma affects pediatricians and other health care professionals, scientific investigators, medical examiners and coroners, law enforcement agencies, families, and support or advocacy groups.

We need an interdisciplinary strategy to develop a comprehensive classification for SUID that will account for intrinsic risk factors or vulnerability in addition to the well-established environmental risk factors including unsafe sleep environments. We need an approach to classification that is consistent not only with our current understanding of environmental risks contributing to an unsafe sleeping environment but also interactions with maturational and biologic vulnerability including genetic risk factors. Rapidly evolving advances in genetic technologies including next-generation sequencing and other systems biologic approaches including metabolomics will lead to progressive expansion of our knowledge of relevant genetic risk factors and gene-environment interactions. We thus need an approach that not only addresses our current dilemma but that is sufficiently flexible to accommodate progressive future expansion of our knowledge of the complex interactions resulting in sudden unexpected infant death.

**O73**

## **SHARED SLEEPING DEATHS ARE DIFFERENT TO SIDS DEATHS**

Roger Byard

*University of Adelaide, Adelaide, Australia*

The role of shared sleeping in causing infant deaths has been vigorously debated. It has been asserted that bed sharing is only hazardous for infants of parents who smoke, and recent large meta-analyses have grouped all infant deaths in shared sleeping situations under the umbrella of "SIDS" without acknowledging the possibility of accidental suffocation.

Recent studies have shown however that the male to female ratio in shared sleeping deaths approaches unity and that the amount of  $\beta$ -amyloid precursor protein (APP) staining in the brain is significantly higher in infants who sleep alone compared to those who bed-share. The lack of a male predominance typical of SIDS cases in infants who were sleeping with others and the lower levels of  $\beta$ -APP indicates that these groups are different.

This suggests that different lethal mechanisms may be involved in some shared sleeping situations. In previous years any infant who died in a cot was labelled a "cot death"; it now appears that the death of any infant in a parental bed is being attributed to SIDS. How does this approach help us to i) recognize the possibility that some of these deaths may be due to accidental asphyxia, and ii) take steps to understand and prevent such deaths?

**O73**

## **CDC SUID CASE REGISTRY AND CLASSIFICATION SYSTEM**

Carrie Shapiro-Mendoza

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Nearly 4000 US infants die suddenly and unexpectedly each year. These deaths account for about 1 in 7 of all infant deaths and 1 in 3 postneonatal deaths. Although the causes of many of these deaths remain unexplained after an investigation, most occur while an infant is in an unsafe sleeping environment. The extent to which these deaths result from accidental suffocation due to soft bedding or overlay is not clearly understood because these deaths are often unwitnessed. Furthermore, definitive biomarkers to distinguish SIDS from suffocation are not available. To complicate matters, reporting practices for cause of death in these types of cases vary and information about the circumstance of the event obtained from the death scene investigation is often incomplete.

To monitor sudden unexpected infant deaths (SUID), the US has historically used vital statistics data. However, vital statistics data do not contain comprehensive information about the circumstances and events leading to these deaths. To better capture this information, the US Centers for Disease Control and Prevention developed the SUID Case Registry, a multistate surveillance system. The Registry, which builds upon existing child death review programs, attempts to identify all SUID cases in participating states to learn about the extent to which cases are thoroughly investigated and how factors like unsafe sleep may contribute to deaths.

A major aim of the SUID Case Registry is to use standardized categories of SUID to monitor the magnitude and characteristics associated with different types of SUID. To do this, we created a classification system with standardized definitions and a decision-making algorithm that groups cases in distinct SUID categories. The system builds upon previously developed (peer-reviewed and published) SUID classification systems and incorporates the contributions of other experts in the field. Notably, the classification system emphasizes the uncertainty about how suffocation or asphyxiation may have contributed to death, accounts for unknown and incomplete information about the death scene and autopsy, and has an algorithm that guides the assignment of cases. SUID categories in our classification system include the explained category which is referred to as suffocation with unsafe sleep factors, as well as five unexplained categories, including no autopsy or death scene investigation, incomplete case information, no unsafe sleep factors, unsafe sleep factors, and possible suffocation with unsafe sleep factors. For the suffocation and possible suffocation categories, the system also allows for designation of the mechanism (i.e., overlay, soft bedding, wedging or entrapment, and other). Multiple mechanisms could be designated.

A pilot test of the SUID Case Registry classification system involved applying the system to 436 cases reported in 2011 from seven states. Most cases were classified as unexplained SUID (n = 382; 88%) and most occurred in an unsafe sleep environment (n = 320; 73%). In the five states with 35 or more reported deaths, the proportion of cases without a documented complete investigation varied from 5% to 55%. Of the 95 possible suffocation with unsafe sleep factors deaths and 54 explained suffocation with unsafe sleep factors deaths, the mechanism most frequently reported was soft bedding (n=63), followed by overlay (n=29), wedging/entrapment (n=18), and other (n=10).

The SUID Case Registry's classification system allows programs to quantify the number of cases that: (1) have incomplete investigations, (2) occur in an unsafe sleep environment such as one containing soft bedding or a shared sleep surface, and (3) are possible or explained suffocation cases by mechanism. By identifying and quantifying incomplete case information, local and state jurisdictions can identify strategies and target appropriate resources to improve scene and forensic investigations, as well as child death review programs. Using these standardized categories may help programs better understand the circumstances that potentially contribute to or actually cause suffocation or asphyxiation, which could lead to more targeted interventions.

## O73

### SUDDEN UNEXPECTED INFANT AND CHILD DEATH TISSUE CONSORTIUM FOR RESEARCH

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<sup>1</sup>Palm Beach County, West Palm Beach, Florida USA, <sup>2</sup>Miami-Dade Medical Examiner Department, <sup>3</sup>American SIDS Institute, Naples, Florida USA

**Problem:** The sudden unexpected death of an infant or toddler challenges the forensic science community while bringing emotional trauma to families. Research is needed to understand the interplay between the medically vulnerable child and unsafe sleep conditions. To determine what genetic and physiological abnormalities may contribute and in what circumstances, researchers require data from large numbers of infant/toddler cases, including autopsy results, scene investigation findings and infant/family medical information.

A national infrastructure is needed which facilitates parental consent, encourages uniform tissue collection paired with appropriate data, and allows for safe tissue banking. To that end, the Sudden Unexpected Infant Death (SUID) Tissue Consortium was created, following the San Diego (SUID) program model.

**Participants:** The pilot project began in three Medical Examiner (ME) districts in Florida, (Miami, Naples and West Palm Beach) the University of Miami Tissue Donor Services, National Institute for Child Health and Development Brain and Tissue Bank in Maryland (NICHD BTB) and the American SIDS Institute. Only infants were included (0-12mo). After about a year of refining the system, toddlers were added and other ME Offices and other tissue donor services organizations joined the consortium (Tampa and Lakeland, FL and Atlanta, GA).

Lab equipment and dry ice are provided by American SIDS Institute, and tissue kits and overnight shipping are provided by NICHD BTB. Monthly consortium virtual meetings allow for monitoring the progress of consented cases, exchange investigative information and address system deficiencies.

**Process:** The participating Tissue Donor Services organization is notified of an unexpected infant/toddler death by the hospital or the ME office. They approach the family for tissue/organs for live recipients, and then they introduce the family to Research Consortium. If the family is interested the case is referred to NICHD BTB to obtain formal consent.

When consent is obtained, body fluids, tissue samples and the brain of infants and toddlers ( $\leq 4$  years regardless of cause of death) are collected during the autopsy process. Organ and tissue transplantation as well as the evidentiary needs of the ME take precedence over research tissue, so not all samples may be collected in every case. Samples are either frozen at minus 80°F or fixed in 10% buffered formalin and are shipped for banking at the NICHD BTB. Additionally, they provide the ME a neuropathology report on each brain received. ME autopsy and investigative data is collected by the American SIDS Institute and is de-identified and made available by NICHD BTB with the tissue for researchers.

**Consent:** Our biggest challenge is obtaining consent in time for the autopsy. Currently consent is at only 18% for infants and 4% for toddlers. A recent review of the consent process showed that 20% of the cases were ruled as inappropriate for donation, either by the ME or NICHD BTB. In another 22%, there were referral errors by the donor services and others. In 23% of the cases the families could not be reached. Of the remaining who were reached 30% gave consent.

**Summary:** Because all unexpected infant/toddler deaths are ME or coroner cases, a US SUID tissue project must be layered within the death investigation system. We have demonstrated that it is possible to establish and fund an infrastructure that allows banking of infant/toddler tissue linked with necessary data to enable the next generation of SUID-related research. Our current objectives are to add ME offices and to increase consents among current participants.

## O73

### SIDS BIOBANKING IN NORWAY

Torleiv Ole Rognum, Siri Hauge Opdal, Marianne Arnestad, Arne Stray-Pedersen, Linda Ferrante, Åshild Vege  
*University of Oslo, Division for Forensic Sciences, The Norwegian Institute of Public Health, Norway*

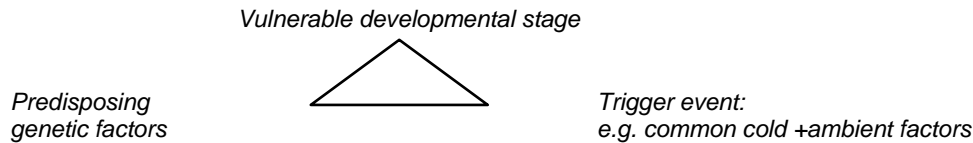
**Objectives:** All over the world there is controversy concerning obtaining samples for research from medico-legal autopsies. The purpose of the present presentation is to discuss current challenges concerning biobanking of samples from cases of sudden unexpected deaths in infants and small children.

**Background:** Since 1984, samples from 700 cases of sudden death in infants and small children have been collected and kept for diagnostics, development of new methods and for research in the SIDS biobank in Oslo. International diagnostic criteria have been followed (Bajanowski et al 2007).

The biobank as well as all the research projects were approved by The Regional Committee for Medical and Health Research Ethics. The research projects have also been approved by the Prosecutor General in Norway and the Ministry of Justice's Committee for Professional Secrecy.

The biobank have provided basis for a large number of scientific papers and 8 doctoral theses. Keywords: High hypoxanthine levels in vitreous humor as indication of hypoxia prior to death, exaggerated mucosal immune responses and increased IL 6 levels in the cerebrospinal fluid in SIDS cases, studies of mtDNA, genes coding for interleukins and genes predisposing for long QT syndrome as well as genes of importance for immune response to bacteria, genes of the serotonergic network and genes regulating the aquaporins of the brain.

Our SIDS research has been performed according to the hypothesis of a fatal triangle proposed by Rognum and Saugstad in 1993:



Challenges due to Unclear Legislation: Norwegian laws regulating autopsy practice describe hospital autopsies and it is unclear whether forensic autopsy is covered by these regulations. It is also unclear whether the laws regulating health research cover our research on tissues sampled during forensic autopsies.

Since forensic autopsies are ordered by the police, the forensic pathologists will not have opportunity to inform the families before the autopsy. The Regional Committee for Medical and Health Research Ethics was aware of this challenge and the biobank and the research projects have been approved in spite of the lack of any option for reservation against research. There are certain challenges that must be clarified to help bring research in SIDS into the open without risk to investigators to be accused of unethical practice. We want to adjust routines, preparing information for families, focusing the option of reservation against research, and we will have to establish a routine to handle these reservations.

The SIDS research in our institute has been supported by The Norwegian SIDS and Stillbirth Society for almost 30 years. A large number of parents have expressed their hope that the research will continue nationally and internationally, in order to prevent SIDS in the future.

In many autopsy rooms the following inscription is found on the wall:

*HIC LOCUS EST UBI MORS GAUDET SUCCURERE VITAE*

*(In this place the death is delighted to serve the living)*

Hopefully, the research on autopsy samples may be continued for the sake of future babies and their families! (**Ref:** Bajanowski T, Vege Å, Byard RW, Kous HF et al. Sudden infant death syndrome (SIDS)- standardised investigations and classification. *Forens Sci Int* 2007; 165: 129-143 Rognum TO & Saugstad OD. *Biochemical and immunological studies in SIDS Victims. Clues to understanding of the death mechanism. Acta Paediatr Suppl* 1993; 389S: 82-85

## O73

### AVAILABILITY OF TISSUE IN THE UK

Marta Cohen

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In the United Kingdom, cases of sudden unexpected infant death (SUID)/sudden infant death syndrome (SIDS) are under the jurisdiction of Her Majesty's Coroner and consent for post mortem is not required from the next of kin. During the post mortem, and as per the Kennedy Report Guidelines (2004), usually 1 sample of liver, heart, kidney and muscle are kept frozen at -80°C for potential use in further genetic tests or in ethically approved research. Informed consent is required after the Coroner's purposes have been fulfilled with regard to disposal, storage or use of material taken during a Coroner's post-mortem. This includes blocks, slides, organs and the frozen tissue. The Human Tissue Act (HTA, 2004) and the Human Tissue Authority (HTA, 2006) are -respectively- the law and the regulatory body governing the tissues taken at post mortem.

A Coroner who orders a post mortem examination is to be notified about the material being preserved for examination and has a duty to inform the relatives or personal representative of the deceased person about the following: 1) that the material (organs or tissue) is being preserved; 2) the period or periods for which it needs to be preserved and 3) the options for dealing with the material once it is no longer required for the Coroner's purposes. These options are: 1) lawful disposal of the material by burial, cremation or other lawful means by the pathologist; 2) return of the material to relatives to make their own arrangements; 3) retention of the material with appropriate consent for medical research or other purposes. It therefore constitutes an offence to retain or dispose of this material without parental consent under the HTA licence (HTA, 2006).

When the HTA was established in 2006, there was a blanket agreement that all tissues taken at post mortem examinations prior to 2006 would be available to use anonymised. This included the frozen tissues taken during SIDS/SUID post-mortems.

Each institution in the UK keeps its own tissue bank. There is no a centralized tissue bank available to any researcher provided there is ethical approval (as is currently the case with paediatric tumours banking used in research).

The Lullaby Trust (formerly Foundation of Sudden Infant Death) supports the view that it is a parent's right to have the opportunity to donate tissue for research and urges that all parents are given that option. Sharing this view, Sheffield Children's Hospital have developed a procedure to ensure that all parents are approached to ascertain their wishes regarding retention or disposal of tissue. Consent is a process that needs time and sensitivity. We actively encourage all families to visit our bereavement suite and, with the permission of the Coroner, our trained mortuary staff actively seeks consent directly from relatives. This results in a high percentage of parents providing consent for use of the tissue for research. Our tissue frozen bank currently stores 1153 samples at -80°C pre-HTA from the 90's and further 1240 samples stored after 2006 with consent for research. A percentage of these tissues belong to SIDS/SUID cases.

A centralized tissue bank should be the next step that would allow researchers to access a large number of samples without difficulty. Unless we join efforts to maximize the number of samples available for research, SIDS/SUID will continue to be the 1<sup>st</sup> cause of death in infancy: today's research is tomorrow's cure.



**O73**

## **BRAIN AND GENETICS: THE BRAIN**

Hannah Kinney

*Harvard Medical School, Boston, Massachusetts USA*

**Background:** Hypotheses about the basic mechanism underlying sudden and unexplained death in vulnerable infants must account for at least four key factors: 1) the unexpected nature of the death, with no obvious clinical warning; 2) an unrevealing anatomic autopsy and negative ancillary testing; 3) the critical developmental period in which death occurs, i.e., the first postnatal year; and 4) the relationship of the death to a sleep period. The brain, heart, lung, and metabolism are the major targets of SIDS/SUID research because of their role in vital functions (e.g., breathing, heart rate and rhythm, blood pressure, temperature, cellular energy balance), and in homeostasis (e.g., corrective adjustments to potentially dangerous changes in vital function such as hypoxia, asphyxia, or pressor or thermal fluctuations) during sleep itself, and/or the many transitions between sleep and arousal throughout sleep periods. Recognizing that SIDS is likely due to heterogeneous causes/mechanisms, research needs to concentrate upon exploring the possibility that subsets are present, affecting one or some combination of these targets.

**Objective:** The objective of our laboratory is to determine the role of the brain in SIDS, or SIDS subsets. Brain pathology is well-recognized in other disease entities to result in sudden death by multiple pathways, including by: 1) direct involvement of vital brainstem sites, and/or involvement of rostral regions, particularly in the limbic system, that project to and normally modulate brainstem vital functions; and 2) seizures originating within limbic or other forebrain/brainstem regions that propagate to and disrupt brainstem vital functions. In our laboratory, we have sought to determine if these brain pathways are involved in SIDS or subsets of SIDS by cellular and molecular analysis directly in SIDS brains at autopsy. We are testing the hypothesis that SIDS, or a subset of SIDS, is associated with abnormalities in brainstem or limbic (forebrain) regions inter-related to the brainstem that are critical for autonomic and respiratory control, and/or for the mediation of protective responses to homeostatic challenges, during sleep, and/or play a role of seizure genesis and propagation.

**Results:** In this presentation, I will highlight findings from our laboratory that are observed within the brainstem and limbic system in SIDS infants compared to infants dying of known causes. Over the last two decades, a variety of approaches have been applied to postmortem brain tissues in SIDS and control samples by us, including cellular morphology, immunocytochemistry, tissue receptor autoradiography, western blotting, proteomics, genomics, metabolomics (in progress), and transcriptomics (in process). Findings include neurotransmitter defects, including in serotonin, and signal transduction defects in the medulla oblongata (caudal brainstem), as well as, more recently, hippocampal (limbic) abnormalities. Of note, the hippocampus projects to brainstem sites critical to cardiorespiratory control, and abnormalities within it increase seizure susceptibility. The relationship of the brain findings to epidemiologic risk factors for SIDS, e.g., prone sleep position, will be discussed. We also found neuroanatomic connections between cardiorespiratory regions in the brainstem, including related to serotonin function, and the hippocampus in humans using state-of-the-art brain neuroimaging and tractography.

**Conclusion:** Brain studies in SIDS infants provide evidence that certain SIDS infants are vulnerable to sudden death due to underlying pathology in brain circuits that control autonomic and respiratory function, mediate protective responses to homeostatic challenges, and/or are prone to generating seizures.

**O73**

## **BRAIN & GENETICS: GENETIC STUDIES IN SUDDEN UNEXPLAINED INFANT DEATH (SUID)**

David Paterson

*Children's Hospital Boston and Harvard Medical School, Boston, Massachusetts USA*

Significant research effort has been expended in trying to identify gene variants responsible for SIDS/SUID because they could form the basis of genetic screening to identify living infants at risk at or soon after birth thereby providing the potential of therapeutic intervention.

Evidence suggests that SIDS/SUID is comprised of multiple disease subsets with distinct phenotypes characterized by different risk factors and pathological features rather than a single disease entity. This complexity argues against a single gene mutation that is responsible for all or a large number of SIDS/SUID cases. Rather, SIDS/SUID is likely to occur from the simultaneous presence of multiple relatively common "susceptibility variants" that in isolation cause only minor biological dysfunction but that in combination with other genetic factors and environmental exposures act synergistically to precipitate the death of the infant. In addition, rare causative gene variants may be responsible for small subsets of SIDS/SUID cases.

This presentation will review genetic studies in SIDS/SUID to date before discussing the utility of "next generation" sequencing technologies and new approaches to identifying gene variants responsible for SIDS/SUID.

**O73**

## **CHARACTERISING THE ROLE OF SEROTONIN AND SUBSTANCE P IN THE CONTROL OF RESPIRATORY DRIVE IN THE SUDDEN INFANT DEATH SYNDROME**

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SIDS is one of the most significant causes of post neonatal mortality in developed countries. The precise cause of death in SIDS has not been identified, however the leading hypothesis postulates that SIDS cases have an underlying abnormality in homeostatic brainstem systems that results in a failure of protective responses to life-threatening stressors during sleep. A neural network employing multiple neurotransmitter systems mediates homeostatic function in the brainstem and several different laboratories have reported abnormalities in this network in SIDS cases. The most consistent and widespread of these abnormalities concern the neurotransmitter serotonin (5-HT) but it is likely that other neurotransmitters are also affected. The current project aims to determine the potential role of one of these neurotransmitters, the neuropeptide substance P (SP), in the failure of homeostatic function in SIDS.

Substance P is a modulatory neurotransmitter that plays a critical role in the neural control of respiration, the ventilatory response to hypoxia and gasping (autoresuscitation). SP is released by 5-HT neurons and colocalises with 5-HT in multiple brainstem nuclei that modulate homeostatic function including the Prebotzinger complex (PBC). The PBC is a region of the ventrolateral medulla identified as an essential part of the medullary respiratory and rhythm-generating network, centrally involved in the neural rhythm generation of eupnea, sighs and gasps. Both 5-HT and SP modulate PBC activity and interneurons of the PBC express high levels of neurokinin-1 receptor (NK1R) the primary receptor mediating the effects of SP. These observations suggest that abnormalities in SP, in conjunction with medullary 5-HT deficiencies, may contribute to respiratory dysfunction, e.g., failure of gasping, proposed to precipitate the death of the infant in SIDS.

This study will evaluate the expression of SP and NK1R in the medullary 5-HT system in SIDS infants compared to controls. The study also aims to assist in localising the PBC, to further understand its role in respiratory drive and potential implication for abnormalities in modulatory neurotransmitters such as SP and 5HT in this region in SIDS. It is hypothesised that SP and NK1R expression will be significantly decreased in the brainstem medullary 5-HT system in SIDS cases compared to controls. SP, NK1 and TPH2 (rate limiting enzyme of 5HT) immunoreactivity will be assessed in formalin fixed human infant brainstem tissue from South Australia, using Avidin Biotin immunohistochemistry. SP/NK1R binding density will be assessed in fresh frozen brainstem tissue from the San Diego SIDS database, using Bolton Hunter <sup>125</sup>I SP autoradiography.

Preliminary data from these studies indicate a significant reduction in SP and NK1R immunoreactivity in the arcuate nucleus (putative chemosensitive region at the ventral medullary surface) and a trend for decreased NK1R binding density in multiple medullary nuclei in SIDS infants compared to controls. The New scientist presentation will discuss the complete data from SP autoradiography determining NK1 binding density across multiple medullary nuclei in SIDS compared to controls.

## O74

### REPORTS OF INFANT SLEEP BEHAVIORS FROM A NATIONAL SAMPLE OF MOTHERS: THE STUDY OF ATTITUDES AND FACTORS AFFECTING INFANT CARE (SAFE)

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<sup>1</sup>Yale School of Medicine, <sup>2</sup>Eunice Kennedy Shriver National Institute of Child Health and Human Development, <sup>3</sup>Slone Epidemiology Center, Boston University, <sup>4</sup>Boston University School of Public Health, <sup>5</sup>Boston University Schools of Medicine and Public Health, USA

**Background:** To decrease SIDS and SUID, the American Academy of Pediatrics (AAP) recommends that infants sleep on their backs and share a room but not a bed. Studies about infant care practices to date have not been representative samples of the US.

**Objective:** To determine percentages of mothers following AAP recommendations in a US representative sample of mothers of young infants.

**Methods:** Using probability sampling techniques and the American Hospital Association list of birth hospitals for frame building, we recruited a sample of mothers from 32 U.S. maternity hospitals. Targeted enrollment during the postpartum hospital stay at each hospital had a goal of recruiting a total sample of 1250 mothers, including 25% Black mothers, 25% Hispanic mothers and 50% all other mothers. When the infant was 2-6 months of age, mothers completed an in-depth survey either online or over the telephone about infant care practices, including bedsharing and infant sleeping position. SUDAAN statistical software was used to perform weighting and adjust for cluster sampling. Weighted results were of demographic characteristics were obtained for comparison with national vital statistics data. National prevalence estimates and 95% CI were calculated for each infant care practice, for the total population and within race/ethnicity strata.

**Results:** Of the 1,276 mothers enrolled between January 26, 2011 to February 1 2013, 1,030 (81%) completed the follow-up survey. The targeted unweighted percentages of approximately 25% Black and 25% Hispanic mothers were achieved, and after statistical weighting was performed demographic characteristics closely matched US National Vital Statistics Reports birth data for 2011. For example weighted maternal characteristics were: 61% White, 13% Black and 25% Hispanic; 57% married, and maternal age 8% 14-19 yrs., 24% 20-24 yrs., 29% 25-29 yrs., and 36% 30+ yrs. Table 1 shows the weighted estimated national prevalence and 95% CI of mothers reporting usual bedsharing, usual supine sleep and usual prone sleep overall and by race.

**Conclusion:** Overall, the estimated national prevalence of prone infant sleeping is close to the Back to Sleep Campaign goal of <10%, however, prone infant sleeping is reported by over 20% of Black mothers. The estimated national prevalence of bedsharing is quite high at 18.5%, and is reported by 28.0% of Hispanic mothers.

Table. Weighted Percent of Mothers Reporting Infant Care Practices Related to Sleep by Race (95%CI)

Behavior	Overall	White	Black	Hispanic
Usual Bedsharing	18.5 (13.5, 23.4)	13.7 (10.3, 17.0)	18.4 (11.6, 25.3)	28.0 (14.5, 41.6)
Usual Supine Sleeping	72.3 (66.1, 78.5)	75.4 (69.7, 81.0)	58.0 (44.3, 71.8)	69.9 (62.4, 77.4)
Usual Prone Sleeping	10.3 (7.2,13.4)	10.4 (6.4,14.4)	21.6 (14.1, 29.1)	7.1 (1.6,12.6)

## O75

### TODAYS BABY: HELPING MOTHERS MAKE SAFE SLEEP CHOICES USING SOCIAL MARKETING STRATEGIES VIA MOBILE TECHNOLOGY

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**Background:** Research shows that safe sleep recommendations for infants may not resonate with many people, often because of misconceptions or perceived barriers. It has been shown that some of these barriers explain, at least in part, disparities in adherence to safe sleep practices by race-ethnicity or socioeconomic status (SES). Therefore, addressing these barriers would be expected to improve adherence and reduce disparities. Social marketing is the use of commercial marketing concepts to design and implement programs to effect social change. Most Americans now have Internet access on their cellular telephones and smartphones. The highest usage rates for cell phones are among Blacks, adolescents, younger adults, and adults with lower SES and educational levels. Research has shown that the use of mobile health (mHealth) technologies (those that use mobile communication) to provide health services and information, have resulted in increased behavior change. Thus, mHealth strategies are likely to be well-accepted and effective, particularly among minority and low-income populations.

**Objectives:** Our goal is to develop safe sleep educational messages for mothers that utilize social marketing strategies via mobile health technology to maximize impact on behavioral outcomes.

**Description:** We partnered with a design company to develop a parent organization name, tagline and logo for the program: "TodaysBaby: Helping you make the best choices for your baby." We also retained the services of a video production company for shooting, editing and additional conceptual design of 19 videos; the video content and approach were based on mother focus group feedback, and revised based on additional mother and family member feedback. These videos contain safe sleep messages and provide testimonials from parents who have lost babies to sleep related sudden death, and directly address common barriers to following the recommendations. The TodaysBaby intervention will deliver messages and videos to mothers by text or email starting at enrollment in the birth hospital and at frequent intervals until the baby is 2 months old. Our platforms will enable us to monitor usage by mothers, and those who do not open their messages will be sent reminders and inquiries to encourage participation. Mothers will also be asked to answer short questions about infant care every few days as a way to evaluate immediate response to the messages, and will receive individualized feedback based on their responses. An evaluation will be done, after the infants turn 2 months old, to assess the effectiveness of the messaging.

**Expected Outcomes:** This mHealth strategy has the potential to be highly effective, because of its accessibility and appeal to the target population (i.e., new mothers). Our innovative strategy will use mHealth to build upon the success of video education by 1) providing short, targeted videos via personalized text or email messages that can be accessed at the mother's convenience, and 2) using social marketing techniques to create interactive, tailored messages. If shown to be effective in improving adherence to safe sleep recommendations, this technology could also be readily applied to multiple other health care messages.

## O76

### WHAT MOTHERS KNOW ABOUT SIDS RISK FACTORS IN THE UK: RESULTS FROM A CROSS SECTIONAL SURVEY

Anna Pease, Peter Fleming, J. Ingram, Peter Blair  
University of Bristol, UK

**Objectives:** A survey investigating mothers' knowledge of SIDS risk factors was carried out in deprived areas of Bristol, UK, as part of an ongoing mixed methods study examining decision making for the infant sleep environment.

**Methods:** Recruitment is currently taking place (Jan-Dec 2014). This is an interim analysis of the first 120 participants. The survey asked participants to recall 3 SIDS risk reduction strategies, and scored responses to 14 SIDS risk-related infant sleep scenarios. This analysis compares participants with infants at higher risk of SIDS to the rest, and those with little or no health professional advice regarding SIDS prevention with the rest. The 'high risk' group was identified by the presence of three or more of the following factors; young maternal age, smoking, higher parity and high deprivation score.

**Results:** In the current sample, 21/120 (18%) mothers were classified as high risk and 22/120 (18%) received little or no SIDS advice when the baby was born. Mothers who had little or no SIDS advice were equally likely to have infants at high or normal risk for SIDS. Mothers in the high risk group were less likely to mention supine sleeping, 19% vs 50%, (OR=4.17 [95%CI: 1.31-13.26] p=0.02) as a safe sleep strategy. Mentioning supine sleeping was also less common among mothers who had received little or no advice (36%) vs those who received advice lasting 5 minutes or more (42%) although this difference was not significant (p=0.58). A score of 12/14 or more correct answers, was used as a cut off to represent adequate knowledge of safe infant sleep strategies. The amount of SIDS advice given made no difference to adequate knowledge (p=0.64), however only 29% of high risk mothers scored above 12 compared to over half mothers in the normal risk group (55%), a statistically significant difference (OR=3.0 [1.08-8.37] p=0.03). Notable, only 53/120 mothers overall in this survey (44%), identified supine sleeping as a risk reduction strategy for SIDS, despite public health campaigns over the last 20 years.

**Conclusions:** The results of this interim analysis indicate that mothers belonging to a high risk group are disadvantaged. It is of concern that less than half of this sample mentioned supine sleeping as a SIDS risk reduction strategy.

## O77

### INFANT SLEEP ENVIRONMENTS DEPICTED IN STOCK PHOTOGRAPHS AND MAGAZINES TARGETED TO WOMEN OF CHILDBEARING AGE

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**Background:** Advertisements and photographs can affect individual behavior by influencing beliefs and attitudes and by communicating that it is normal and desirable to purchase a product or behave in a particular manner. Magazine advertisements are most effective in influencing the intent to purchase a particular product. Stock photographs are readily available on internet sites and are often used in advertisements and promotions.

**OBJECTIVES:** To evaluate pictures in magazines widely read by women of childbearing age and in popular stock photo websites, for adherence to American Academy of Pediatrics (AAP) guidelines for safe infant sleep practices.

**Methods:** Magazines were included in this study if they had an average female readership of >5 million, circulation of >900 000, and median age of female readers of 20-45 years. 23 magazines met these criteria. An additional 3 magazines targeted toward expectant parents and parents of young children were included, for a total of 26 magazines. In addition, the top 3 stock photo websites appearing on a Google search for "stock photo" were searched for photos using phrases, such as "safe infant sleep" or "baby sleep in crib." The first 100 photos for each key phrase were selected. All pictures and photos were analyzed for adherence to AAP guidelines for a safe infant sleep environment.

**Preliminary results:** A total of 36 unique pictures from 13 magazine issues, and 612 unique photos from 3 stock photo websites, have been included in the interim analysis. In the magazines, Of 12 pictures portraying sleeping infants not being held by an adult, 4 (33%) infants were in the nonsupine position (all prone), and 2 (17%) of sleeping infants were portrayed as sleeping with another person. Only 7 of 24 magazine pictures (29%) of infant sleep environments portrayed a safe sleep environment. Among the stock photos, 291 (50.3%) portraying sleeping infants not being held by an adult portrayed the infants in the supine position, and 96 (15.7%) of infant sleep environments portrayed a safe sleep environment.

**Conclusions:** 33% of pictures of sleeping infants in magazines geared toward childbearing women demonstrated infants in an inappropriate sleep position, and 71% of pictures of infant sleep environments were not consistent with AAP recommendations. This is similar to our 2009 survey of magazines, in which 36% of sleeping infants were in a nonsupine position, and 63.6% of infant sleep environment pictures portrayed unsafe sleep environments. In contrast, 50.3% of stock photos of sleeping infants demonstrated infants in an inappropriate sleep position, and 84.3% of stock photos of infant sleep environments were inconsistent with AAP recommendations. Messages in the media that are inconsistent with health care messages create confusion and misinformation about infant sleep safety and may lead inadvertently to unsafe practices

## O78

### RANDOMIZED MESSAGING TRIAL TO REDUCE AFRICAN-AMERICAN INFANT MORTALITY

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**Background:** Racial disparities in SIDS and other sleep-related deaths, including suffocation, have increased in the US over the past decade, with African-American infants twice as likely to die as other infants. Given that African-American parents have a high degree of self-efficacy with regard to preventing infant suffocation and many of the behavioral risk factors for SIDS and preventable sleep-related deaths are the same, providing these parents with an enhanced message that emphasizes risk reduction for both SIDS and suffocation may be the key to promoting safe sleep habits and healthy development among high-risk families with infants.

**Objective:** To compare African-American parental behaviors with regard to infant sleep when given the standard "SIDS risk reduction" message or an enhanced "SIDS and suffocation risk reduction" message.

**Methods:** We conducted a prospective, randomized, controlled trial of African-American mothers of both lower and higher socioeconomic status. Mothers were randomized to receive either a standard message to avoid bed sharing, eliminate use of soft bedding and soft sleep surfaces and to place infants in the supine position for sleep to reduce the risk of SIDS, or an enhanced message to avoid these behaviors to both reduce the risk of SIDS and to prevent infant suffocation. We conducted a baseline survey during enrollment, followed by three follow-up phone surveys at 1-2 weeks, 2-3 months and 5-6 months after the infant's birth to obtain information on parental knowledge of and attitudes towards safe sleep recommendations, degree of self-efficacy with regards to preventing sleep-related death, and practice with regards to infant sleep position, sleep location, and use of soft bedding and soft sleep surfaces.

**Results:** We recruited 1201 mothers. Preliminary data analysis on 444 mothers is presented here. Data at the first follow-up suggest that mothers in the enhanced messaging group are more likely than mothers in the standard messaging group to believe that infants who sleep prone are at higher risk for SIDS deaths (84% vs. 81%), are more likely to believe that bedsharing can increase the risk for SIDS (82% vs. 76%) or suffocation (93% vs. 89%), and that soft items in the sleep area can increase the risk of death from SIDS (88% vs. 77%) or suffocation (97% vs. 95%). The degree of self-efficacy for suffocation was very high, as more than 90% of mothers at baseline believed that having soft items in the baby's sleep area could increase the risk of suffocation.

**Conclusion:** If the enhanced "SIDS and suffocation risk reduction" message increases adherence to safe sleeping habits over the 6-month follow-up period, this intervention could be disseminated to other high-risk populations and may ultimately result in a reduction in sleep-related infant mortality rates.

## O79

### COMMUNITY BABY SHOWERS TO PROMOTE SAFE SLEEP

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**Objectives:** To describe a community-based, grass-roots project to promote safe sleep to families who might not receive the education from traditional sources.

**Description:** In recent years, Kansas has ranked 40th among the 50 states for worst infant mortality rates. For African American infant mortality, Kansas had the highest rate in the nation. The rate for Hispanic infants is rising. Because of these statistics, initiatives have been implemented by the KIDS Network, in partnership with the Wichita Black Nurses Association and the National Association of Hispanic Nurses.

The initial Community Baby Shower was targeted to African American women via black churches, physician offices, clinics, black sororities, word of mouth, radio, and print. Along with education, parents were provided resources to create a safe sleep environment, including a portable crib, wearable blanket, and pacifier. The anticipated results were that parents would know: (1) the ABCs of infant safe sleep (Alone, on their Back, in a Crib), (2) to place their infant supine for every sleep, and (3) to place infants in a safe sleep environment (i.e., crib) when they otherwise would not have. All participants (N=180) were asked to complete a brief survey following the Community Baby Showers.

The majority were African American (61%) with a high school diploma or less schooling (63%). Nearly all (97%) planned to place their baby supine for sleep. However, less than half (47%) planned to have the baby sleep in the parents' room in a separate crib, as recommended. Attendees exhibited high levels of safe sleep knowledge, stated intentions to utilize most safe sleep recommendations, and reported babies would have slept in unsafe environments without the portable crib.

Following the initial success, baby showers were expanded to target Spanish-speaking parents. Surveys collected at these Community Baby Showers showed similar results in terms of knowledge and intentions.

Recently, Baby Showers were held at local Obstetrical and Pediatric resident clinics which serve high need populations. Data collection was modified to include separate pre and post-test measures. Participants (N=43) were less likely to be high-risk, than those attending the community-based showers (e.g. 16% African American vs 61%). However, results suggest significant increases in percent of participants identifying the ABC's of safe sleep (14% vs 91%), knowledge that pacifier use reduces SIDS risk (54% vs 67%), and comfort sharing safe sleep information with other caregivers (56% vs 88%). Non-significant increases were observed for all other variables.

For example, of the 9% who identified unsafe position and the 9% who identified unsafe locations at pre-test, all (100%) identified safe location and position at post-test.

In conclusion, Baby Showers were attended by the target audience, although community showers reached more high risk participants. Following the Baby Showers, participants exhibited high levels of safe sleep knowledge, and stated intentions to utilize most safe sleep recommendations following the Baby Showers. However, some participants remained resistant to following at least some of the recommendations.

## O80

### HEALING THROUGH WRITING & VISUAL ART

Alexis Marie Chute

Edmonton, Canada

It is often challenging to put words to the feelings of grief yet creative writing and art are powerful tools to unlock the path to healing. A bereaved person can find release for their pain by being creative, thereby clearing their hearts and minds and becoming open, forgiving and joyful as they embrace and move forward with their loss.

**Content for each Objective:**

1. **WRITING:** Due to the narrative nature of the written word it is exceptionally effective in expressing the stories around pain and loss. Literary art forms employ the use of stylistic voice, symbolism, point of view, past and present tense, rich description, plot, stream of consciousness, child-like word play and associations which can form a new vocabulary and method in the pursuit of healing. **ART:** Due to the abstract nature of art it is extremely effective in expressing the often intangible emotions and the grief process of bereaved parents. Art employs symbolism, meaning through color, and child-like creative play which form a new vocabulary and method to find healing.

2. **WRITING:** Writing approaches to be presented: poetry, words to accompany images, blogging, memoir, and fiction. Project examples: (1) Write your story from a different perspective of someone who was involved. (2) Write with a stream of consciousness on a painful topic by first not addressing the topic at all, then approaching the topic gradually writing down every detail and thought that comes to mind. (3) Write a letter to your past self, without revealing what was coming, but giving advice to help you get through the painful time. (Three examples of many). **ART:** Artistic materials to be presented: painting, sculpture, drawing, mixed media art, collage, photography, word and image. Projects: (1) Create a piece of art of three stages of your life reflecting who you were, who you are now and who you want to become. (2) Create a collage from photographs, magazines and newspapers. Then deconstruct parts of the collage and incorporate these sections into a larger painting, making something new of the original artwork. (Two examples of many).

3. **WRITING & ART:** Strategies for creating a safe environment include: removing the perception or actual external judgment through privacy and isolation, removing self-judgment, mindfulness and meditative surroundings and mental state, replacing fear of failure with freedom of exploration, eradicating expectations and time constraints in exchange for freedom and play.

## O81

### SOCIAL MEDIA AND GRIEF

Daan Westerink

*Research journalist, loss and bereavement trainer, the Netherlands*

Many misconceptions exist on grief: "it should be resolved after a year, there are different stages, the pain will go away". Westerink will explain that there are no laws in grief: so many people, so many ways to come to terms with grief and loss. She will discuss the pros and cons of social media in matters of grief and loss.

## O82

### NURSES CAN HAVE GREAT IMPACT ON PARENTS THEY ENCOUNTER

Anat Shatz, Gale Adina Dorembus, Tzippi Sivan

*Atid and Shaaree Zedek Medical Center, Ganey Tikva, Israel*

The compliance in reducing the risk practices among parents in Israel is quite low. Two surveys conducted in 2006 and in 2012 found a low percentage of parents (33% and 40%, respectively) placing babies on their backs when laying them down to sleep.

Our study of infant care practices found 53% of mothers followed the advice of the community health care center's nurse, 29% followed the advice received from the neonatal department. Only 4.5% followed their grandmothers' advice.

In contrast, nurses' advice was followed by 82% of mothers.

The National Infant Sleep Position Study, conducted from 1993 to 2000, found that recommendations from health care providers can greatly influence parents' choice of infant sleep position.

Among health care providers, nurses exert a powerful influence and are uniquely positioned to help correct misconceptions and counter myths about SIDS and a safe sleep environment.

Nurses can help ensure caregivers know the best available practices for reducing the risks associated with SIDS.

It is important that nurses be aware of the strong influence they have on how parents care for their infants. Nurses should use this influence to help reduce the risk of SIDS, especially in the 24 to 48 hours following delivery. This is the best window of opportunity in terms of a nurse's ability to influence parents' behaviors.

People learn best through observation. Research shows that parents are more likely to follow safe sleep practices -particularly placing infants in the back sleep position- when they see nursery staff consistently apply these practices in the hospital.

Safe sleep position behaviors can also be demonstrated during the postpartum period both within and out of the hospital setting. Community health centers focused on the well-being of babies (Tipat Chalav) are an example of the latter.

In order to find out whether nurses in Israel set the right example and deliver the correct messages, we conducted a study among nurses in 6 wards at SZMC and surveyed NICU nurses all around the country.

We will present the results of these studies and surveys and discuss recommended strategies to further educate nurses and in turn, help them to educate parents.

## O83

### WHY DID MY BABY DIE; A GUIDE FOR PARENTS DECIDING ON POST-MORTEM EXAMINATION

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**Introduction/ Background:** Investigating the cause of stillbirth can provide closure for parents, as well as giving clinicians valuable information in managing a subsequent pregnancy, and helping to identify recurrence risks. Post-mortem examination (or autopsy) is acknowledged as the gold standard of informative investigation in the post natal period. Perinatal post-mortem uptake rates are low in Ireland. A key factor for this low rate is lack of parental consent through poor communication and consenting procedures.

**Aim / Objectives:** Our aim was to develop a consistent accurate standardised approach to the information bereaved parents receive around post-mortem procedure and consent, as well as to help remove the fears and uncertainties they may have. It is hoped this approach will bring a human face to the post-mortem procedure and will address some of the fears, myths and perceptions associated with post-mortem examination. Our goal is to aid parents in their understanding and decision-making around post-mortem examination for their baby. We aimed to develop a multimedia information DVD to help parents in their decision making process.

**Method:** We sought production quotations from professional media companies and created a content and topic list to be included in the DVD. Filming of the DVD took place over one day on the hospital site, with all members of the pregnancy loss team including the Perinatal Pathologist involved.

**Results:** We produced a 20 minute DVD to sensitively provide key information about the post mortem process and to answer some of the questions frequently asked by parents. This includes questions about the process, the timing of post-mortem and arranging memorial services after examination. The DVD introduces parents to some of the staff involved in their care and their babies' care at Cork University Maternity Hospital. Parents receive an explanatory leaflet and sign written consent prior to watching the DVD. As this is a new initiative we also created a questionnaire to be used in the evaluation process. Initial feedback from parents, focus groups and medical staff prior to introduction of the DVD was positive and some changes were made as a result of recommendations received.

The DVD was introduced in April 2014 and evaluation is now taking place. Parents will be surveyed 6 months and 1 year from introduction on their experience of the DVD and whether it was helpful or not in their decision making process to have a post-mortem examination on their stillborn infant.

**Conclusion:** Given the extensive impact of stillbirth physically, psychologically, spiritually and emotionally on parent's wellbeing it is imperative that we try to understand the underlying causes and to potentially identify the underlying factors that result in stillbirth. Innovative use of multi-media appears to be useful for parents and staff when explaining perinatal post-mortem. Parents can watch this DVD in their own time and allows them the privacy and space to make what is a very important decision in the care of their baby.

The DVD contributes to informed decision making for parents: stillbirth deserves the same systematic processing and evaluation as adult death. It is planned that this DVD will be a useful education tool for healthcare professionals and will eventually lead to an increase in uptake of perinatal post-mortem.

## O84

### **DECREASED FETAL MOVEMENTS: RISK OF FETAL GROWTH RESTRICTION AND STILLBIRTH**

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*Perinatal Institute, Birmingham, UK*

**Objective:** We wanted to quantify the association between decreased fetal movements (DFM), fetal growth restriction (FGR) and stillbirth in a maternity population which routinely receives reminders throughout pregnancy about the significance of DFM.

**Method:** The database was collected between 2009 and 2012 from the English national hand held maternity record, which contains auditable prompts for midwives to provide standard information along RCOG guidelines, including the need to present immediately with any change in perceived quality or frequency of fetal movements. FGR was defined as <10<sup>th</sup> customised birthweight centile. Multifetal pregnancies and congenital anomalies were excluded.

**Results:** Maternal presentation with one or more episodes of DFM was recorded in 23,621 of 108,102 pregnancies (21.9%). The FGR rate was 14.1% in pregnancies with DFM and 13.1% without (OR 1.09, CI 1.04-1.13). In stillbirths following DFM, the presentation with DFM was the first during the index pregnancy in 86%. The modal interval between presentation and delivery of a stillborn fetus was 2 days, with 56% occurring within 3 days or less. The stillbirth rate (/1000) was 4.1 overall, 9.4 in pregnancies with DFM, and 5.0 if stillbirths delivered within 3 days of DFM were excluded.

**Conclusions:** Pregnancies with DFM have only a slightly increased risk of FGR, which suggests this symptom is not a good screening method for abnormal fetal growth. In pregnancies ending in stillbirth, DFM appears to be a late manifestation, and its reported association with high stillbirth rates may in part be explained by in-utero deaths presenting with an absence of fetal movements.

## O85

### **THE 'MY BABY'S MOVEMENTS' STUDY: USING MOBILE PHONE TECHNOLOGY TO REDUCE THIRD-TRIMESTER STILLBIRTHS**

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**Introduction:** Stillbirth is a devastating event for women and their families. Many stillbirths occur in the third trimester in apparently healthy pregnancies and are precipitated by decreased fetal movements (DFM). A woman's perception DFM of may be a simple and inexpensive screening tool to reduce these deaths.

**Methods:** My Baby's Movements (MBM) is a mobile phone software program designed to increase pregnant women's awareness of fetal movement and to support their decision-making about when to seek care for DFM. Using a stepped-wedge cluster randomised controlled design, we will implement MBM across over 30 hospitals in Australia and New Zealand as part of a large-scale multicentre clinical trial assessing the impact of MBM on stillbirth >28 weeks, neonatal morbidity, maternal psychosocial outcomes and health service utilisation and costs.

**Results:** MBM is currently being developed and pilot tested among pregnant women attending the Mater Mothers' Hospital antenatal clinics. Through preliminary focus groups and interviews with women and clinicians, we have identified the kinds of information most useful to pregnant women about fetal movements, and how MBM should function in order to best meet their needs and preferences. This information is critical to maximise the utility and appeal of MBM prior to the multicentre clinical trial commencing in 2015.

**Conclusions:** Mobile phone technology is increasingly being utilised in innovative healthcare information interventions. We aim to determine whether this technology can be effectively used to raise pregnant women's awareness of fetal movements in the third trimester, and reduce avoidable stillbirths precipitated by DFM.

## O86

### **IMPACT OF A DECREASED FETAL MOVEMENT POLICY ON INDUCTION OF LABOUR AND PREGNANCY OUTCOMES**

Adrienne Gordon<sup>12</sup>, Jyoti Chaku<sup>1</sup>, Ariane Anicq<sup>13</sup>, Lucy McCudden<sup>1</sup>, Harmonie Wong-See<sup>1</sup>, Jon Hyett<sup>12</sup>

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**Background:** Decreased fetal movements (DFM) affect 8 – 15% of pregnancies and are associated with adverse pregnancy outcomes. Recent UK and Australian guidelines assist with management of women presenting with decreased fetal movements. Their implementation has not been evaluated.

**Method:** Retrospective hospital cohort study from 24/03/2011 to 30/04/2013. This comprises one year before and one year after local implementation of the NSW DFM policy.

The cohort included all women who contacted the hospital with a perception of decreased fetal movements. Phone triage records were linked to the electronic medical record, NICU record and fetal medicine database. Outcomes were compared pre and post policy implementation.

**Results:** 1168 calls were received by labour ward with delivery and infant data available for 1107 calls (95%). 80% (888 women) contacted the hospital once with 20% (100 women) calling 2 or more times representing a total cohort of 988 births. There were no significant changes pre and post policy in the % of pregnant women presenting with a concern, gestation at call or delivery, maternal BMI, smoking or maternal age. There was an increase in the number of ultrasounds performed (20% to 46%;  $p = 0.001$ ). There was a significant increase in induction of labour for term pregnancies from 32.9% to 39.6% ( $p = 0.038$ ) and a reduction in term caesarean sections (33.1% - 22.1%;  $p = 0.001$ ).

There were less nursery admissions for term infants (9.3 – 5.1%;  $p = 0.013$ ) and a non-significant reduction in perinatal deaths from 10.6/1000 to 5.8/1000. No perinatal deaths in term infants whose mothers had presented with DFM occurred in the post policy year. The overall hospital perinatal death rate for the same time period remained unchanged (12.6/1000 pre and 13.3/1000 post).

**Conclusions:** Implementation of a policy on management of DFM has in our centre increased service utilisation, increased inductions of labour and reduced caesarean section deliveries. It has led to a non-significant but clinically important reduction in perinatal deaths.

## O87

### MY BABY MIGHT DIE BUT I HAVE TO WAIT?!? - THE 39-WEEK RULE, RECENT TRENDS IN USA TERM STILLBIRTH RATES AND THE ETHICS OF "NON-INDICATED" TERM LABOR INDUCTION

James Nicholson

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The risk of term stillbirth increases as a function of increasing gestational age starting at 37 weeks of gestation. In addition, certain risk factors - such as chronic maternal hypertension, borderline intrauterine growth restriction, maternal obesity and advanced maternal age – also increase the risk of term stillbirth. Considering the concept of additive risk, it might seem reasonable to encourage women with risk factors for stillbirth to deliver relatively early in the term period of pregnancy. However, none of these risk factors for term stillbirth are on the accepted list of “indications” for either early-term or full-term labor induction, and most countries in the developed world now follow “the 39-week rule.” According to the 39-week rule, the use of non-indicated labor induction prior to 39 weeks 0 days of gestation must be strictly restricted. Unfortunately, recent reports suggest that the incidence of term stillbirth has increased following the imposition of the 39-week rule.

This presentation will begin by examining the two sets of observational studies that collectively form the basis of the 39-week rule: first, that delivery after labor induction, as compared to delivery after the spontaneous onset of labor, is associated with a higher risk of both cesarean delivery and neonatal intensive care unit admission; and second, that delivery in the 37th or 38th week of gestation, as compared to delivery in the 39th or 40th week, is associated with less favorable rates of both short-term and long-term infant outcomes. The examination of these two sets of studies will reveal that the “dangers” associated with pre-39 week “non-indicated” term labor induction may be the result of serious methodological flaws, and that neither set of studies should be used to justify the strict imposition of the 39-week rule. Next, this presentation will examine the incidence of term stillbirth in the USA between 2007 and 2012, and it will identify an association between the imposition of the 39-week rule and a significant increase in the rate of term stillbirth.

Finally, this presentation will contain a discussion of how basic ethical principles might be applied to the setting of “non-indicated” term labor induction. Two often conflicting principles of medical ethics are autonomy (where a patient has the right to choose her medical treatment) and beneficence (where providers have an obligation to protect their patients from harm). Generally speaking, if high-quality evidence is not available to guide medical care, then it is unethical to restrict patient autonomy. If the risk of term stillbirth increases with both increasing gestational age and the presence of identifiable risk factors, and if the impact of “non-indicated” term labor induction on childbirth outcomes is really not known, then patient choice with regards to the use and the timing of labor induction should be not only allowed but encouraged.

## O88

### A FRENCH NON-GOVERNMENTAL PREVENTION PROGRAM OF SUDDEN INFANT DEATH SYNDROME

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**Background:** The major role of the sleeping conditions in the prevention of sudden infant death syndrome (SIDS) is world widely known. In France, it can be estimated that about by 150 SIDS per year still can be avoided if sleep safety prevention tips are properly applied. But without a national campaign for more than 15 years, experts note that the collective mobilization decreases and deaths tend to increase again.

**Objectives:** Jointly with the creation of a reliable epidemiological basis via a national observatory, our program aims to assess 1) the knowledge of parents / professionals about SIDS 2) the impact of a prevention cartoon on their own perception of prevention, and 3) to intensify their information on different protective SIDS factors.

**Methods:** With the support of the french ANCRéMIN, the “Naître et vivre” parents association, the Loire Departmental Council and the Mustela Foundation, 2 main actions were acted:

- 1) Creation of a one minute cartoon free diffused on the Web, with a public evaluation report: <http://www.youtube.com/watch?v=jbBUQ-uvIRU>
- 2) Starting a non-governmental national prevention campaign with posters and flyers.



**Results:** Between February 1 and March 31-2014, the prevention cartoon “back-to-sleep” had about 8000 views on the Web. 251 answers to the questionnaire evaluation were collected: 163 perinatal or early childhood clinicians, 87 non-professionals, 1 unspecified replied. 77% of respondents felt apply all the tips for safe sleeping before viewing the cartoon, yet only 24 % of clinicians and 10 % of non- professionals did know all the SIDS risk factors concerning sleep conditions. Only 30 % of professionals and 20 % of non-professionals showed good knowledge of all the SIDS protective factors about the baby’s bed. Although 52% of persons were “shocked” by this spot, 75% say they’ll discuss it with their friends or parents of an infant. Finally, viewing the spot has changed the attitude of 63% of respondents who did not initially apply best practices.

**Conclusions:** This program allows us to recall the security for infant sleep. Currently, we see a decrease in the formation of health professional and a negative influence of certain commercial products. These and the results of our survey confirm us the urgency to national prevention to secure the sleeping babies.

## O89

### **MOVING ON: ENGAGING TEEN PARENT NETWORKS IN EDUCATION TO PROTECT THE OLDER, MORE MOBILE BABY**

Judith Clarke, Stephanie Cowan, Sharon Bennett  
*Change for our Children, Christchurch, New Zealand*

**Introduction:** This programme responds to increased risk of sudden unexpected infant death (SUID) for infants of teenage mothers, and the numbers of older, more mobile infants dying in New Zealand. It sits within a strategy of end game SUID prevention<sup>3</sup> and mirrors the best practice approach of the portable sleep space work of targeted education, enabling ‘technology’ and a promotion role for recipients. The programme was designed to use a sleep bag as a ‘leaflet’ to enable discussions with young mothers about safer sleep for the older baby.

**Implementation:** In New Zealand, Teen Parent Units (TPU) with attached child care facilities exist for young mothers to continue their high school education. A targeted approach to education was developed using recycled infant sleep bags as a mechanism to discuss safe sleep for the older baby. In addition, staff were supported with a facilitation guide and a picture card modelling safe sleep. These materials were used in discussions about potential hazards for babies who roam about the sleep space. Staff used the infant sleep bag to demonstrate how to reduce the chance of head covering, and a recycled bag was offered to mothers to keep. To measure the impact of using a sleep bag as a tool to enable discussions, data was collected on mothers’ rating of their safe sleep confidence and the spread of awareness to others. Staff were interviewed to determine their perceptions from participating in the programme.

**Impact:** Of 76 bags distributed to TPU, 45 were given out to families between October and December 2013, and data was received from 40 mothers. Of these, 85% of mothers rated highly (7-9/9) their increased confidence in sleeping their older baby safely. Spread of awareness to others within their networks was high, with over 100 ‘others’ spoken to about safe sleep within the first two weeks. Feedback from staff suggest the sleep bag ‘leaflet’ facilitated a non-judgemental discussion that may otherwise not have taken place. This is meaningful in a group of parents who may be resistant to current approaches to safe sleep promotion. This suggests we have found a mechanism to engage and reach this teen parent group and support them to sleep their infants safely, especially as they develop mobility.

**Conclusion:** This work is about more than just ‘distributing sleep bags’ to a high risk population. It is an approach that focuses less on messages and more on enabling. Using a sleep bag as a leaflet, engaged staff and parents in a topic that may otherwise not have been discussed. Parents have been enabled to sleep their baby safely, and empowered in their role as promoters of safe sleep. By creating an approach of value to teen parents, and to TPUs, we have strengthened the alignment of safe sleep practices with developing mobility.

## O90

### **1,000 GRANDMOTHERS-PROMOTING SAFE INFANT SLEEP FOR AMERICAN INDIAN BABIES**

William Benson<sup>1</sup>, David Baldrige<sup>1</sup>, Theresa Covington<sup>2</sup>

<sup>1</sup>*International Association of Indigenous Aging, Silver Spring,* <sup>2</sup>*National Center for the Review and Prevention of Child Deaths, Washington*

American Indian babies have the highest rates of Sudden Unexpected Infant Deaths (SUID) and SIDS among all racial and ethnic groups in the United States. They are 2-3 times more likely to die of SUID than white babies. In the Northern Plains communities, the rates are even higher. Although the risks factors are not completely understood, it is known that American Indian parents tend to bed-share more often than whites and have higher rates of smoking. A number of efforts have been attempted to reach young Indian parents about safe sleep with limited success. In 2013, the US Center for Disease Control and Prevention provided funds to the International Association for Indigenous Aging (IA2) to design and implement a project that would capitalize on the status elder Indians have in native communities. IA2 has worked with elder communities around Indian aging needs for a number of years. IA2 hypothesized that grandmothers and other elders may be seen by young Indian mothers as trustworthy and a respected source of knowledge and wisdom about how best to protect their babies from SUID. Young mothers might listen more to elders about safe sleeping practices, especially if the messages are consistent with traditional tribal values.

IA2 partnered with the National Center for Child Death Review at the Michigan Public Health institute in identifying three tribal communities willing to pilot this concept. Three tribes agreed to participate in the project: the Turtle Mountain Band of Chippewa (North Dakota), the Snow Bird Band of the Eastern Cherokee (N. Carolina) and the Sault Band of Chippewa (Michigan). The project first engaged tribal leaders through the Tribal Councils to obtain their support. The Tribal council then brought together traditional elders with maternal and child health staff. Following a number of meetings with each tribe, the elders agreed to participate. At each Tribe, the elders participate in a learning session about current infant safe sleep practices and then discuss how their own traditional practices align with the current messages. The elders then work with IA2 to design their own program to engage with young mothers.

Each tribe has designed a different approach, including the use of talking circles, traditional games, and traditional craft-making as their venues to meet with and educate young mothers. Each has also partnered with tribal maternal and child health programs to encourage follow-up with the young mothers for other pregnancy and well-baby care.

This presentation will describe the project, present video that includes the voices of participants, present the results from each tribal community, and discuss the successes and challenges in working with traditional communities. These challenges include engaging with isolated tribal communities and promoting safe sleep messaging that is not consistent with traditional tribal beliefs. The presentation will offer recommendations to support the importance of including elders and the aging services community in safe infant sleep promotion, especially for indigenous populations.

## O91

### **SAFE SLEEP SAVES LIVES - BEST PRACTICES IN THE HOSPITAL SETTING**

Barbara Himes

*First Candle, Indianapolis, USA*

Overview: Far too many babies die each year of Accidental Suffocation and Strangulation in Bed (ASSB). This is significant because the injury-related nature of ASSB is an opportunity for prevention unlike Sudden Infant Death Syndrome (SIDS), which is clinically determined after a complete autopsy, thorough death scene investigation, and all other causes have been ruled out. Nurses, are in a unique position to educate parents and caregivers about the importance of safe sleep in preventing ASSB. Nurses have opportunities to educate parents during pre-natal visits, at the hospital when the baby is born, and well-baby check after the baby goes home. Nurses have the ability to correct misconceptions and counter myths about SIDS and safe sleep practices, as well as model appropriate risk reduction techniques. One example of a misconception is parents who see NICU infants placed on their stomach (prone) to sleep may use this practice with their infant after discharge.

Methodology: Seven hospitals conducted a safe sleep consultation program in 2012. Some areas of focus included staff and patient education, audits, and staff surveys. The objectives were to assess current infant sleep policy and practices for hospitals, to evaluate these results, and to provide technical assistance and identify resources. A key component of the hospital consultation program was a hospital safe sleep policy template. This evidence-based sample policy includes teaching points for staff and families and citations based on 2011 recommendations from the American Academy of Pediatrics (AAP) and current research.

The consultation program begins with a comprehensive hospital assessment. The implementation process includes the use of a Plan-Do-Study-Act (PDSA) model. Recommendations may include training and developing support for successful implementation.

Findings: The consultation program produced both positive outcomes and difficult challenges to overcome. One positive outcome was the engagement of participating hospital; particularly their enthusiasm toward their involvement in the assessment process. Some found room for positive growth and others were able to appreciate their efforts as reflecting current standards. Nearly all felt the opportunity for positive growth. Routine audits were established in one hospital. Another organization instituted practices at six additional hospitals within their system. A challenge was the availability of staff to address current shortcomings. Some staff showed resistance to completing audits because of concerns about where the information would go and how it would be used externally. This hospital initiative made it possible for two hospitals to examine the subject of infant falls during the hospital stay. It appeared that infant falls are often not reported or reviewed due to lack of knowledge regarding these events. An important part of the consultation process is to provide the hospitals assistance where they are in need and continue to support their growth efforts. Within the framework of the study, Safe-To-Sleep Champions were identified as hospital staff who exuded pride and commitment toward the efforts needed to make a difference. Staff behavior change from a concept to a practice require routine reviews and continuing education opportunities. Culturally appropriate materials are significant to the success of this approach. The safe sleep messages should be congruent with breastfeeding messages in order to support both practices and achieve a common goal of "A Breastfed Baby who sleeps safely".

## O92

### **A QUALITATIVE ANALYSIS OF A HOSPITAL-BASED PROGRAM ON ACHIEVING INSTITUTIONAL CULTURE CHANGE REGARDING INFANT SLEEP SAFETY (ISS)**

Michael Goodstein

*Department of Pediatrics, York Hospital, York, USA*

Background: Despite the success of the Back to Sleep Campaign, infant sleep-related deaths are still the leading cause of post-neonatal mortality in the US. Multiple studies have demonstrated increased parental compliance with safe sleep recommendations when healthcare providers reinforcement the messages. Yet providers have knowledge gaps regarding ISS and often fail to model a safe sleep environment.

To address the lack of consistent messaging and promote a culture of ISS, a comprehensive education program was implemented at York Hospital in 2008. Based on research suggesting a positive program impact, other hospitals in PA and the Eastern US began to replicate the program.

Objective: To determine whether other institutions could maintain a culture of ISS through replication of a hospital-based ISS program.

Design/Methods: The entire program was made available with detailed instructions at:

<http://cribsforkids.org/hospital-initiative-tools/>. The author and a small group of colleagues provided guidance and in some cases, direct educational services, to help develop the program at other institutions. The hospital-based program was modeled after a family education program by Dias that decreased abusive head trauma cases. Family education consists of: viewing an educational DVD; modeling and education by staff; and signing an acknowledgement statement of receipt and understanding of ISS behaviors.

After at least 1 year from our interaction with outside sites, we sent an open-ended questionnaire to determine progress made and challenges ahead regarding the development of an ISS culture. Responses were analyzed for common themes regarding program implementation, sustainability, challenges, and lessons learned.

**Results:** Of the 24 health systems, there were 17 respondent organizations which included small and large delivery service hospitals, Children's Trusts, Health Departments, and regional organizations. The hospitals ranged from 600 to 10,000 deliveries per year. 94% of respondents felt they were making good progress with their ISS programs and 71% felt they were doing "very well."

5 themes were developed from discussions about achieving a culture of ISS:

- 1) Leadership: champions to promote and sustain the program.
- 2) Education: promotes "buy-in" and then on-going education for staff, patients, and the community.
- 3) Persistence: it takes more than one education event to maintain competency.
- 4) Personalize: knowing that deaths occur locally creates a "moral imperative" to do something about it.
- 5) Institutionalize: Developing an ISS standard of care creates ownership of the program, behavioral expectations, and repercussions if standards are not maintained.

Roadblocks to overcome included nurses fear of infants choking in supine position, parental desire for bed sharing, cultural barriers, and time constraints. But institutions built upon the blue print and experience of the original program and also made use of creative collaboration with other childhood injury prevention programs.

**Conclusions:** A hospital-based ISS program is a practical, cost-effective and reproducible model. Successful implementation follows a model predicted by diffusion of innovation theory, requiring leadership, education and reinforcement, and time and effort. Although the experience of each hospital may vary, the common process can be used. Use of a hospital-based ISS program can lead to sustained, long-term cultural change.

## O93

### **BUILDING SUSTAINABLE INFRASTRUCTURE: REDUCING SIDS IN AFRICAN AMERICAN COMMUNITIES**

Stacy Scott

*In Black Print, Inc., Contractor for the Eunice Kennedy Shriver National Institute of Child Health and Human Development, USA*

A disproportionate gap remains in the incidence rate of SIDS among African American infants, who are more than twice as likely as white infants to die of SIDS. The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) formed the Partnerships for Reducing the Risk of SIDS in African American Communities. This national effort established a collaborative that included government partners, key stakeholders, infant health organizations, and diverse communities. The partnerships between the NICHD, the Alpha Kappa Alpha Sorority, 100 Black Women, and Women in the NAACP were prime examples of how a national organization with broad-based trust and respect within the community is well positioned to promote SIDS risk reduction messages to African American communities. These partnerships allowed the NICHD to benefit from the resources and experiences of organizations already working in the community to educate parents, caregivers, and community members about ways to reduce the risk of SIDS among African American infants. The partnership emphasized the importance of responding to a community's diversity, infusing cultural competence, and engaging community leaders. Following the success of the national initiative, the NICHD implemented community-based risk reduction activities on the state level. Mississippi had the highest SIDS rate in the United States and, as a result, became a major focus for NICHD's outreach efforts to contribute to the reduction of SIDS rates in African American communities. A total of 108 mini-grants, up to \$2,000 each, were awarded to community- and faith-based organizations from 2006 to 2012 within each of Mississippi's nine health districts. Mini-grantees conducted outreach activities—including health fairs, community baby showers, community walks, mother and daughter teas, and luncheons—to disseminate information on SIDS risk reduction. In the fall of 2012, the NICHD moved its efforts to Arkansas, another state with a high rate of SIDS. As of 2014, the NICHD has awarded 65 mini-grants, up to \$2,000 each, throughout Arkansas to organizations such as sororities, community health centers, health coalitions, childcare and youth development agencies, hospitals, and universities. Local organizations used the mini-grants to support community educational initiatives to increase public awareness about techniques to reduce the risk of SIDS and other sleep-related causes of death. The NICHD's public health outreach strategy emphasizes educating community leaders about safe infant sleep, providing materials, offering training on the use of campaign resources, and providing ongoing technical assistance for community leaders to educate their communities.

## O94

### **SYSTEMATIC REVIEW & META-ANALYSIS (META-SUMMARIES) OF BEREAVEMENT CARE RESEARCH**

Alison Hills<sup>1</sup>, Caroline Chebsey<sup>1</sup>, S. Bradley<sup>1</sup>, Sue Jackson<sup>2</sup>, Claire Storey<sup>3</sup>, Alexander Heazell<sup>34</sup>, Vicky Flenady<sup>35</sup>, Dimitrios Siassakos<sup>13</sup>

<sup>1</sup>University of Bristol & North Bristol NHS Trust, UK, <sup>2</sup>University of Surrey, UK, <sup>3</sup>International Stillbirth Alliance, UK, <sup>4</sup>Manchester Stillbirth Research Centre, UK, <sup>5</sup>Mater Medical Research Institute, Australia

**Background:** The Lancet series identified intrauterine death and stillbirth as one of the "most shamefully neglected" areas of public health, recommended improving interaction between families and frontline caregivers, and made a plea for increased investment in relevant research. The sensitive nature of stillbirth and small sample sizes make it difficult to develop clinical trials. Hence, Cochrane reviews have recommended other research designs to collect evidence to improve care. There is qualitative and mixed-methods evidence on parent's views on their experience of stillbirth and the maternity bereavement care received; and on key healthcare workers' experiences of caring for these parents. However, such studies alone might provide useful information, yet seldom influence care worldwide unless systematically integrated to produce concise lessons for improvement.

**Objective:** A systematic review was designed by an expert interdisciplinary team to inform research, training, and improve care for bereaved parents. The objective was to meta-analyse qualitative and mixed-methods studies of parents' and staff's experience of maternity bereavement care for stillbirth, in Western (Europe, North America, Australasia) High-Income-Country hospital settings. The focus was: What is done well? What could be improved and how?

**Methods:** We applied the SPIDER framework to search with HDAS software the AMED, EMBASE, MEDLINE, Psych INFO, BNI and CINAHL databases up to March 2014 (Appendix 1). We also hand-searched ISA conference abstracts. Studies were excluded if they exclusively addressed miscarriage in the first and early second trimester, lethal fetal diagnosis, neonatal death, non-western health systems, and views of indirect family members. Meta-analysis and quantitative aggregation (meta-summary) (Sandelowski,2003) was used to extract findings, reduce them to thematic sentences, and calculate effect sizes for each theme (*frequency* effect; how many studies described each theme) and each study (*intensity* effect; how many themes described in each study).

**Results:** The search strategy identified 7906 abstracts; 4479 after deduplication. 111 were selected by team consensus for full text extraction, further assessment for eligibility, extraction of findings, and meta-analysis.

Initially, two investigators completed the data extraction form for the same three papers. Inter-rater reliability was concluded by consensus, in view of the qualitative nature of the data. The two investigators extracted data independently with a revised form thereafter.

The *findings* were reduced to *abstracted thematic sentences* which were grouped under care areas considered to be important in international (RCOG) guidelines:

1. Diagnosis of fetal death
2. Mode of birth decision
3. Post mortem consent process
4. Hospital follow-up consultation

We calculated *frequency* and *intensity* effect sizes for each theme and study, and compiled *inter-study* and *intra-study* matrices respectively.

The matrices allow for aggregation of the themes, assessment of the importance of each theme for optimising bereavement care, and sensitivity analyses depending on whether only high-intensity studies are included.

**Conclusion:** This is the first systematic review of qualitative and mixed-methods research on bereavement care; using the meta-summaries method to enabled advanced meta-analysis, including sensitivity analysis to test the robustness of conclusions. We will present the findings and discuss implications for bereavement training, care, and further research, including for non-western settings.

#### Appendix 1 - SPIDER Search Framework

Sample	Mother, father, mum, dad, parent, couple, family, patient, woman, women, men, male, female, midwife, midwifery, nurse, doctor, medical, obstetrician, staff, healthcare worker
Phenomenon of Interest	Stillbirth, intrauterine death, intra-uterine death, in-utero death, IUD, IUFD, fetal loss, foetal loss, fetal death, foetal death, fetal demise, foetal demise, perinatal death
Design	All types of study in Western high-income countries will be included
Evaluation	Attitude, experience, perspective, opinion, view, theme, interview, focus group, questionnaire, survey
Research type	Qualitative studies, including surveys, and mixed method studies

## O95

### MAKE A MEMORY FOUNDATION: PROVIDING A GIFT OF A MEMORY OF PHOTOGRAPHY FOR PARENTS SUFFERING THE LOSS OF A CHILD

Wieke Eefting

*Wieke Eefting Fotografie, Utrecht, the Netherlands*

As a professional photographer, dr. Wieke Eefting volunteers for the Make a Memory Foundation. This foundation offers parents who suffer the loss of a child (from 23 weeks up to age 16), a photo series of their terminally ill, dying or deceased child. These series are made by a professional photographer and are free of charge. The foundation exists almost 6 years. At this moment, more than 150 photographers are affiliated with the foundation. They make over 800 series per year, (85% are series of babies up to 6 months, 15% are series of children aged 6 months-16 year). Wieke Eefting will elaborate on the motivation of the founders and coordinators of Make a Memory, Rian and Ed van Schaik, to start with this valuable work and how Make a Memory works. She will explain her motives to work for the foundation and how she deals with the emotional aspects of this work. Further, she will give insight in the new challenges and developments Make a Memory is facing in the future and she will explore the possibilities for international collaboration.

## O96

### PROVIDING LAST MEMORIES IN FUNERAL SERVICES

Anita Reijerink

*Entrepreneur in specialized perinatal death funeral articles*

Until a couple of years ago parents were not able to choose special, very small clothes or suitable coffins or baskets for very young, tiny babies who had passed away. Nowadays almost everything is possible, also with a funeral. Thanks to the internet, parents can inform themselves about a lot of this. Every child is unique and deserves a unique funeral and Reijerink will show some pictures and products. Some baskets, clothes for children of 24 weeks of pregnancy etc.

Reijerink's goal is to give parents the possibility of a respectful and warm way to say goodbye under these tragic circumstances. She will tell about her experiences in farewell rituals in The Netherlands. She will also tell something about World Wide Candle lighting, how important it is for parents, brothers and sisters, grandparents to keep remembering the lost children.

## O97

### PERSONAL ENRICHMENT PROGRAM (PEP) FOR BEREAVED PARENTS

Petra den Hartog

*SIDSandKids eastcoast Australia*

**Objectives:** To describe this program and present feedback from participants.

PEP is a weekend residential and experiential program for bereaved parents whose baby or young child died at least one year prior to attending. It is held in a coastal camp site surrounded by the Australian bush. Kangaroos are present at dusk and walks are encouraged during the weekend for exercise and reflection. Nourishing food is provided throughout the weekend. It is open to any parent registered with SIDSandKids and is mandatory for anyone wishing to be trained as a Parent Supporter in future. It is run by two counsellors who are themselves bereaved parents. Knowing that the counsellors themselves have also had a baby or child die and have also experienced a bereavement program such as this, enhances the trust participants have in the program and that they will be well supported during and after the weekend.

During the weekend the parents share their stories, memories, memorabilia and the strategies they have used to help themselves through the worst period of their lives. This sharing is intense and beneficial in normalising experiences, reducing feelings of isolation and enhancing self esteem and confidence.

The program begins with an evening meal with participants introducing themselves. After this the outline of the program is given and parents are asked to share any concerns for the weekend. Self help strategies are given so parents can cope with stresses generated by going over the events of their child's death the next day. The Saturday focuses on these events, the happy and sad memories. Parents write a letter to their child and share these with the other participants. The Sunday is more about the future, parents' strengths, achievements, goals and hopes for the future. Rituals are performed at the end of each day.

We have held about 12 of these weekends. Feedback from parents has been overwhelmingly positive. Parents become more aware of their achievements and feel more confident in facing the future. At the same time parents feel more able to keep alive the positive memory of their child. The weekend provides them with an opportunity to revisit experiences from the past and to honour their child, despite the pressures and complexity of day to day life. It helps to "shift the grief" to a more manageable level and to lesson extreme feelings such as guilt, and anger.

After completion of the program participants are able to apply for training to be a Parent Supporter as they are now more able to assess whether they are ready to do this in and to positively support others in their grief journey.

## O98

**No abstract available**

## O99

### WHAT HAS CAUSED THE RECENT REDUCTION IN SUDI MORTALITY IN NEW ZEALAND?

Edwin Mitchell<sup>1</sup>, Stephanie Cowan<sup>2</sup>, Keith Gell<sup>3</sup>

<sup>1</sup>Department of Paediatrics, University of Auckland, <sup>2</sup>Change for Our Children, Christchurch, <sup>3</sup>Whakawhetu, University of Auckland, New Zealand

In the late 1980s/early 1990s SIDS and total postneonatal mortality dropped considerably and this has been attributed to the advice not to place babies to sleep on their fronts. Mortality continued to fall, probably due to a change from side to back sleeping, but several countries have reported that SIDS and postneonatal mortality rates have plateaued in the last decade.

In 2012 and 2013 all cause postneonatal mortality declined in New Zealand to 1.65/1000 live births from 2.17/1000 (for 2001-2011). The reduction has been predominantly in Maori (Maori: 2001-2011=3.71/1000, 2012-2013=2.35/1000; Non-Maori: 2001-2011=1.55/1000, 2012-2013=1.38/1000).

What has caused this reduction? In New Zealand in the last few years there has been a focus on safe sleeping, particularly with the recognition that more than 50% of sudden unexpected death in infants (SUDI) is associated with bed sharing. Indeed mortality rate for deaths categorised as accidental suffocation in bed are now higher than that from SIDS.

Possibly the most innovative strategy in New Zealand to reduce mortality has been the wahakura and pepi-pod. These are bassinet like structures; the wahakura is woven from flax and the pepi-pod is plastic. They provide a safe sleeping space for an infant from birth to 6 months of age and can be taken into the parental bed. Some district health boards (DHBs) have supplied pepi-pods to at risk families. From the original pilot studies, these are now available in more than half the country for high risk families (provided to approximately 5% of all births in these DHBs). The engagement of the families in using the pepi-pods has been encouraging. The families that receive them are invited to spread the safe sleeping message to other families/whanau. Frequently the pepi-pods are given or loaned to other families, although we are not able to quantify this.

In addition there has been a renewed focus on education of both health professionals and families. This has been largely through safe sleep champions to health and community service providers. Whakawhetu, the Maori SIDS Prevention Team, has played a crucial role in educating Maori community health workers.

Has this made a difference? Surveys of mothers of infants aged 2-4 months in Auckland in 2005 and 2013 show an increase knowledge of SUDI risk factors. Knowledge of avoiding bed sharing during sleep increased from 46% to 63%. This was also accompanied by a reduction in infants reportedly bed sharing during sleep from 15% to 8%.

In the DHBs supplying the pepi-pods there has been a 28% reduction in number of postneonatal deaths in 2012-2013 from the 2001-2011 period compared with 7% reduction in DHBs without pepi-pod programmes.

The major challenge is continued funding of the established wahakura and pepi-pod programmes. These programmes need to be introduced in all DHBs. The education programme must continue. Although there have been great strides in SUDI prevention, SUDI continues to be the major cause of death in this age group.

## **O100**

### **NEW INSIGHTS ON SIDS AND FUTURE ROLE EPIDEMIOLOGY**

Fern Hauck

*Department of Family Medicine, University of Virginia, Charlottesville, Virginia, USA*

In this session, highlights from the conference will be presented, focusing on new insights into SIDS and other sudden unexpected infant death: epidemiology, education, pathology and physiology. Thoughts about future directions in research and education will be presented.

## **O101**

### **THE STILLBIRTH SCANDAL AN UPDATE ON PROGRESS ON THE STUDY OF STILLBIRTH**

Ruth Fretts

*Harvard Medical School, Harvard Vanguard Medical Associates, USA*

The scope stillbirth has been overlooked by many, rarely is the risk of late stillbirth discussed, and until recently there were few references to stillbirth in the lay press. The progress and barriers to the study of stillbirth will be reviewed.

Research has led to some important observations. The first step includes not only a thorough evaluation of stillbirths, the "saves" are worth high-lighting too. Perinatal reviews often reveal missed opportunities as well as the optimal management of the fetal and maternal condition. Education of providers has been slow but parent advocacy groups have raised awareness and "raised the bar". This unique combined effort will hopefully reduce the number of families of that join "the stillbirth club".

## **O102**

**No abstract available**

## **O103**

### **UTILIZATION OF PARTOGRAPH IS ONE OF THE EFFECTIVE MEASURES FOR REDUCING STILL BIRTH RATE IN THE HEALTH FACILITIES OF BANGLADESH**

Anjuman ara Begum, Lumbini Roy, Taposh Kumar Biswas, Maksudur Rahman, Mahbub Elahi Chowdhury  
*ICDDR, Bangladesh*

**Background:** The partograph is an effective tool to monitor progress in labour to take decision for intervention and referral if needed. The partograph is a tool that graphically represents key events during labor. This tools guide birth attendant to identify women whose labor is delayed and therefore decide appropriate action and monitor the fetal condition. Despite more than 50 years of efforts, still the partograph use rate is low in resource poor settings. In Bangladesh, there is a dearth of data on factors related to low use of partograph which is important to know to promote its use for preventing still berth as well as nearly neonatal death.

**Method:** A facility assessment was conducted in all the health facilities providing obstetric and newborn care services in 24 districts in Bangladesh during May-September 2012. The study was conducted about 2275 different health facilities in Bangladesh. The relevant data for this study were extracted from those collected by the 'review of partograph' module of the Averting Maternal Deaths and Disability (AMDD) tools. The questions were asked about use of partograph in the last one year from the date of interview.

**Result:** In all the health facilities partograph was used only 2.9% cases of deliveries for monitoring progress of labour in the last three month. Among the causes of unavailability for partograph use, the most common cause was identified that 89.3% facilities had lack of supply of partograph form. The second major causes was identified that 56.4% facilities had untrained provider or providers didn't have sufficient training to provide the services and 33.3% facilities mentioned that their providers didn't have enough time to fill up the partograph form. Overall the proportion of still births among the district categories varied between 3% and 3.3% in the last 12 months. Intrapartum death rate, which stands for the proportion of births that result in an intrapartum death (stillbirth) in EmONC facilities. The highest proportion of still births (3.3%) in the last 12 months in the district level facilities. Among the 24 districts, the highest proportion of still birth in EmONC facilities was seen in Sunamgonj (7.2%) followed by Sylhet (7%). On the contrary, the lowest still birth rate was seen in Panchagarh and Satkhira (1.4% in both districts).

**Conclusion:** The partograph can enhance communication and increase interaction between providers and the laboring women. For preventing still birth, partograph used should be promoted. In Bangladesh, where population-based cesarean section rate have risen to 17% (about 60% of all facility deliveries are conducted by cesarean section); the use of partograph needs to be promoted. Necessary measures needs to be taken to ensure supply and training. Policies should be taken to introduce mandatory use of partograph in all the facilities providing delivery care services in the public and private sectors in Bangladesh.

## O104

### EVALUATION OF STANDARDISED CLINICAL OUTCOME REVIEW (SCOR) PILOT PROJECT

Fiona Cross-Sudworth<sup>1</sup>, Jason Gardosi<sup>2</sup>

<sup>1</sup>Birmingham Women's NHS Foundation Trust, <sup>2</sup>Perinatal Institute, Birmingham, UK

**Background:** A series of regional perinatal confidential enquiries and comparisons with local reviews showed wide variation of how maternity units review and learn from such deaths. In response the Perinatal Institute developed a secure web based tool for comprehensive and standardised case review and action planning. The Standardised Clinical Outcome Review (SCOR) pilot was launched in 2011 across 17 UK units to support in-house perinatal death reviews.

**Method:** Analysis was conducted on anonymised cases in the SCOR application (n=529) while a semi-structured survey was also sent out to all SCOR users (n=68) across the pilot sites in order to evaluate the user experience.

**Results:** 302 of the 529 deaths entered were stillbirths (57%). Of these, 144 (48%) had a low customised birthweight centile suggesting intra-uterine growth restriction (IUGR). 105 (35%) of mothers with stillbirths had reported reduced fetal movements (RFM) during pregnancy, compared to 13% in pregnancies resulting in live births. Of the normally formed term pregnancies, 15/84 (18%) were given CESDI grades 2 or 3 after unit review on SCOR, suggesting the death was potentially preventable. The survey found that most SCOR users considered that SCOR helped to improve safe practice 25/28 (89%) and provided a comprehensive and effective strategy to review cases (24/28 - 86%).

**Conclusion:** Through its structured approach, the SCOR application increases the information available about perinatal deaths and allows clinicians to improve their review of the standard of care. It enhances learning from adverse outcome and has been a catalyst for improving the in-house review process.

## O105

### MBRRACE-UK - ENHANCING THE SURVEILLANCE AND QUALITY OF CARE PROVISION FOR PERINATAL AND NEONATAL DEATHS IN THE UNITED KINGDOM

Elizabeth Draper, Lucy Smith, Bradley Manktelow, Jennifer Kurinczuk, David Field (on behalf of MBRRACE-UK)  
*Department of Health Sciences, University of Leicester, UK*

MBRRACE-UK (Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries across the UK) is a collaboration of researchers, clinicians and patient/parent representatives newly appointed to continue the UK's national Clinical Outcome Review Programme investigating stillbirths, neonatal deaths and maternal deaths.

The perinatal arm of MBRRACE-UK has two main elements:

(i) annual perinatal surveillance for all late fetal losses, stillbirths and neonatal deaths (~7,000 deaths/year) using a new secure, bespoke, web-based data collection/validation system, coding cause of death using the CODAC classification system. Ascertainment of case notification is validated against civil death registration. Inclusion of fetal losses from 22 weeks will facilitate improved standardisation of perinatal/neonatal mortality rate calculations and more robust comparisons at hospital, national and international level. Access to individual-level clinical and socio-demographic data on all births will enable the calculation of appropriately case-mix adjusted mortality rates. This will allow the identification of care providers with potentially outlying rates of stillbirth and neonatal death. Individual-level clinical and socio-demographic data on all births will enable the calculation of appropriately case-mix adjusted mortality rates.

(ii) a rolling programme of confidential enquiries assessing the quality of care provision to mothers and babies for all aspects of the care pathway for a random sample of births with congenital diaphragmatic hernia (2013/14) and term normally formed antepartum stillbirths (2014/15).

MBRRACE-UK will provide robust information to support the delivery of safe, equitable, high quality, patient-centred maternal, newborn and infant health services, with service improvement for mothers, babies and their families at its heart.

## O106

### PERINATAL MORTALITY IN IRELAND: A NATIONAL CLINICAL AUDIT

Paul Corcoran, E. Manning, Sarah Meaney, R. Greene, on behalf of the Perinatal Mortality Group

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**Background:** Perinatal mortality has decreased in high-resource countries but cause of death, especially for stillbirths, is often unexplained. The Irish National Perinatal Epidemiology Centre (NPEC) established a national clinical audit on perinatal deaths to better identify causes of death and associated risk factors.

**Methods:** After piloting the NPEC Perinatal Death Notification Form and Classification System in three maternity units in 2010, the national audit was initiated and all 20 Irish maternity units have provided anonymised data on perinatal deaths since 2011.

**Results:** For 2011, 491 perinatal deaths were reported - 318 (65%) stillbirths, 138 (28%) early neonatal deaths and 35 (7%) late neonatal deaths - giving a perinatal mortality rate of 6.1/1,000 births, stillbirth rate of 4.3/1,000 births and early neonatal death rate of 1.9/1,000 live births. Fourfold variation in the perinatal mortality rate was observed across the 20 maternity units. The common causes of death in stillbirth were congenital anomaly (26%), placental conditions (17%) and ante/intrapartum haemorrhage (11%), 20% were unexplained. Early neonatal deaths were generally due to congenital anomaly (51%) or respiratory disorder (33%) - primarily severe pulmonary immaturity. Just 4% were unexplained. Low birthweight was common, below normal range for 53% of stillbirths and 40% of early neonatal deaths. In most cases of early neonatal death, spontaneous respiratory activity was absent or ineffective five minutes following delivery (63%) and death occurred within 24 hours (62%).

**Conclusion:** This audit enhances clinical interpretation of perinatal deaths which will inform clinical practice, public health interventions and counselling of prospective parents.

## O107

### STILLBIRTHS IN SCOTLAND: FOUR DECADES OF IMPROVEMENT

Christopher Lennox

*Healthcare improvement Scotland*

Annual reports on perinatal mortality in Scotland have been published since 1974 through collaboration among providers of health care, national registration and health information analysis.

This paper presents information from the comprehensive population-based data set and describes trends, causes and associated factors influencing stillbirths. Unexpected improvements have occurred in recent years. Key areas susceptible to further improvement are identified.

Stillbirth rates: Following a fall in Scotland's stillbirth rate in the 1970's and 80's, there has been a widely held perception that it has changed little for 20 years.

However, charting the change in the stillbirth rate from 1993 does, in fact, show a steady improvement, with the decline in the last decade (from 5.6 per 1000 births in 2003 to 4.7 in 2012) being statistically significant. There has been particular improvement in the rate of stillbirths in multiple pregnancies, from 21.8 per 1000 multiple births in 2003 to 10.8 in 2012.

Causes of stillbirth: For most of the past four decades, causes of stillbirths were reported using a modified Wigglesworth system and 60% of stillbirths were recorded as "unexplained". A bespoke classification system was introduced in 2011. This, together with a high rate of postmortem (65% of stillbirths in 2012) and placental examinations (97%), improved attribution of a cause of death. Placental abnormality was the most frequent, accounting for 40% of stillbirths. Antepartum haemorrhage and congenital anomaly were other important causes. No specific cause could be assigned in 10%.

Fetal growth restriction (FGR) was identified as a single cause in only 1% of stillbirths. The associations between FGR, birthweight below the 5th centile for gestation and placental abnormality were variable.

Associated factors: Multiple pregnancy is the single biggest risk factor for stillbirth. Other important factors were:

- Maternal age (<20 and >40 years)
- Socioeconomic deprivation
- Obesity
- Smoking
- Lack of employment
- Abuse of alcohol and/or drugs
- Assisted conception
- Previous stillbirth.

No association was found with ethnicity or with the time of birth.

Recent improvements and future possibilities: In the past decade, there has been a rise in multiple pregnancy rates, obesity and women giving birth over the age of 40 years within Scotland. Smoking, alcohol and drug misuse persist, and employment prospects have worsened. The stillbirth rate in Scotland is, however, falling. The improvement has been particularly marked among multiple pregnancies, women aged over 40 years, and those with the highest level of socioeconomic deprivation. Heightened awareness of risk may have improved the care of these women.

Most stillbirths were discussed at a perinatal mortality forum, but in only 15% was a detailed root cause analysis performed. Intrapartum stillbirths were not always accurately defined and in individual cases there was a failure to recognise intrapartum hypoxia.

There are four key areas where efforts to further reduce stillbirths should be concentrated:

- Reduce socioeconomic deprivation
- Improve antenatal recognition of placental dysfunction
- Improve recognition of intrapartum hypoxia
- Improve analysis of the root cause of individual stillbirths.

## O108

**No abstract available**

## O109

### THE POWER OF CHILD DEATH REVIEW TO CHANGE SYSTEMS AND PREVENT SUICIDE DEATHS

Theresa Covington

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The death of an infant is a sentinel event that is a measure of a community's overall social and economic well being as well as its health. In the United States, sudden and unexpected infant deaths remain the leading cause of post neonatal mortality. Over the past 20 years, child death review (CDR) has emerged as a key process to understand the risks factors in these deaths and to catalyze safe infant sleep promotion efforts.

Child Death Review (CDR) is a retrospective review of child death and in some cases may be used as an approach to facilitate a comprehensive, multidisciplinary investigation into the death. Team members usually include broad representation from agencies involved in death investigation, family services and prevention. In the U.S. CDR Teams in all 50 states are reviewing more than 80 percent of all SUIDs.

The U.S. Maternal and Child Health Bureau funds the National Center for the Review and Prevention of Child Deaths to assist states in conducting quality reviews, to collect data from their reviews into a national CDR database and to assist states with prevention. The Center's primary goal is to increase the capacity of child death review teams in all 50 states to translate their case review findings into new and improved policies, practices and programs that reduce the rates of infant, child and adolescent mortality. In the U.S. CDR Teams in all 50 states are reviewing more than 80 percent of all SUIDs. Teams have entered more than 16,000 SUID deaths into the center's database: 29% SIDS, 25% suffocation and the remainder were coded undetermined on the death certificate.



The teams reported that more than half could have been prevented and teams identified prevention recommendations in more than half of their reviews. . CDR programs are becoming more skilled in reviewing SUID cases and in using public health principals to develop effective prevention strategies. More than 400 of the recommendations included providing safe cribs. A large number of CDR teams have worked to establish Cribs for Kids coalitions in their states and communities. Many CDR coordinators have joined CAUSE to obtain additional support in their understanding of SUID and to help them with prevention. This presentation will provide an overview of CDR, including techniques to conduct a high quality case review of a SUID event, describe the National CDR Case Reporting System and offer resources to assist other countries in implementing a CDR program. It will describe how to effectively move from data to action for prevention and provide a description of the myriad of SUID prevention activities occurring throughout the states as a result of the reviews. It will discuss how engagement with Cribs for Kids and CAUSE has assisted states in developing and sustaining their own prevention programs.

## O109

### **Cribs for Kids®....an Infant Safe Sleep Initiative**

Judith Bannon

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Introduction: Deaths diagnosed as Sudden Unexpected Infant Death (SUID) and Sudden Infant Death Syndrome (SIDS) are the number one cause of infant mortality after the first month of age in the U.S. Deaths attributed to SIDS decreased with the introduction of the Back to Sleep Campaign. However, those attributed to asphyxia or suffocation in bed or unknown cause increased. This was due to a diagnostic shift. A review of infant deaths in Allegheny County, (Pittsburgh) Pennsylvania in 1998 by the local Child Death Review Team revealed that 90% of the infants diagnosed as SIDS or SUID were found in unsafe sleeping environments such as adult beds, couches and chairs.

Methods: Cribs for Kids®, a safe sleep education program which includes the donation of safety-approved cribs to families in need, was started by SIDS of PA to address these preventable deaths that were occurring in Allegheny County. Within 3 years, these deaths decreased from 17 in 1998 to 5 in 2001. With the success of the Cribs for Kids® program and through public/private partnerships, Cribs for Kids® has expanded the program to a network of over 450 licensed partners throughout the United States. In the past 16 years, over 200,000 cribs have been distributed nationwide from the Cribs for Kids® Resource Center to partners throughout the country. A partnership with Graco Children's Products and free shipping from Pitt Ohio Express (in their service area) enables most partners to purchase the Graco Pack n Play for only \$49.99. Other programs that have been initiated through the Cribs for Kids® Program include its Infant Safe Sleep Hospital Initiative, Infant Safe Sleep Information App, Infant Safe Sleep Educational Kiosk, Safe Sleep Ambassador Program, Cops N Cribs, national conferences, public service announcements, billboard campaigns and, in some states, legislation that mandates that every mother receive infant safe sleep education before leaving the birthing hospital. Dozens of other initiatives and programs have also been developed by state and local Cribs for Kids® partners.

Results: A study done through the Allegheny County Medical Examiner's office and Cribs for Kids® Program has determined that all 20,000 high-risk infants whose mother was given infant safe sleep education and a safe-sleeping environment lived to celebrate their first birthdays. The same results are being reported by the 450 partners nationwide.

Conclusions: Evidence indicates the need to improve safe sleep programs to reduce SUID. Impact of state programs can be improved by expanded efforts to integrate education with the provision of safety-approved cribs. The Cribs for Kids® Program, offered free to interested organizations throughout the country, will reduce this leading cause of infant death.

## O109

### **CAUSE - THE COALITION AGAINST UNSAFE SLEEP ENVIRONMENTS**

Judy Rainey

*Cribs for Kids®, Vienna, USA*

This presentation will give a history, and show the accomplishments, of a coalition that was formed in the United States of individuals, groups, and organizations that have been involved in stopping the epidemic of infants dying of SIDS/SUID. National, state and local groups are working hard to educate parents about reducing the risk of SIDS and preventing accidental deaths during sleep due to suffocation or entrapment in the sleep environment.

Unfortunately, many groups are not aware that successful programs, education materials, public service announcements, videos and other materials have already been created by others across the nation. There was clearly a need to link these groups together, to share best practices, to avoid redundancy, and to advocate for a simple infant safe sleep message.

The Coalition Against Unsafe Sleep Environments (CAUSE) was formed in July 2011. A partnership was formed with the private, non-profit, consumer and government sectors working on the issue of infant safe sleep. The first group of partners evolved from the United States' child death review system, as many teams were trying to identify safe sleep resources. The National Center for Child Death Review (NCCDR) joined forces with Cribs for Kids (CFK), a national program that specializes in distributing cribs and safe sleep education to high risk families. These two groups worked together with a number of SIDS parents to design the collation. This coalition capitalizes on the broad array of knowledge and experience individuals and organizations bring from the SIDS, child welfare, injury prevention and Maternal and Child Health arenas. This includes SIDS groups, researchers, health departments, coroners and medical examiners, hospital personnel, death investigators, health care professionals, child death review teams, and bereavement groups. Also included are parents, grandparents and other caregivers whose infant has died from SIDS/SUID.

Since 2011 more than 175 national, state, and local organizations and individuals have joined the coalition. The Infant Safe Sleep listserv, CAUSE website, and CAUSE Facebook page were created to share best practices among the coalition members. Since then we have:

- Advocated for national and state legislation that mandates safe sleep education in birthing hospitals and for child care providers, bans the sale of bumper pads, and that supports better infant death investigations, better data collection, and better infant safe sleep education.
- Responded to bedsharing advocates and media depictions of unsafe sleep environments with information about infant safe sleep and have backed it up with accurate statistics and current studies.

- Contacted advertisers and the media to ask that pictures of unsafe sleep be removed from the public domain.
- Shared successful initiatives and materials amongst coalition members.
- Acted as a watchdog for products that have been/should be recalled for safety issues, or for false claims of preventing SIDS.
- Advocated as a group for infant safe sleep with a simple, clear message. We believe that our voice is stronger if we speak together than if we speak alone.

## O110

### IMPLEMENTATION OF CHILD DEATH REVIEW IN THE NETHERLANDS: RESULTS OF A PILOT STUDY

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**Background:** Child mortality in the Netherlands declined gradually in the past decades. In total 1169 children and youth aged 0 to 19 years died in 2012 (i.e. 30.1 per 100,000 live births). In 8 out of 10 cases the death was classified as due to a natural cause. Most children die in their first year, especially due to conditions in the perinatal period and congenital abnormalities. A better understanding of the background and the circumstances surrounding the death of a child as well as the manner and cause of death, may lead to preventive actions and to a further decline of child deaths in the Netherlands.

Child Death Review (CDR) is a method to systematically analyze child deaths by a multidisciplinary team to identify avoidable factors that may have contributed to the death and to give directions for prevention. It has already been introduced in the United States of America, Canada, Australia, New Zealand and the United Kingdom.

Systematic analysis of child deaths in the Netherlands occurs in cases of Sudden Infant Death Syndrome (SIDS), in perinatal deaths and in unexplained deaths in minors since October 2012. Since only these specific child deaths are reviewed, CDR could be a method to further reduce avoidable child deaths. A pilot implementation was performed in the Eastern part of the Netherlands from January 2011 until December 2012.

**Objective:** To explore the strengths, weaknesses, opportunities and threats (SWOT) in the implementation of CDR in a pilot region in the Netherlands and provide recommendations for future development of the CDR method.

**Methods:** According to the CDR protocol, children who lived in the pilot region and died from 29 days after birth until 2 years of age were included for reviewing by a regional CDR team. Logs were made for every signaled child death. If parents gave their consent, information was collected from all relevant healthcare professionals and the child's death was reviewed according to a standard analysis form. Minutes of the case discussions were made to monitor the CDR procedure. The analysis forms and logs of 18 children who died and the minutes of seven meetings were used for analysis. Atlas ti. was used to analyze the logs and minutes. The SWOT framework was used to categorize important themes and provide a basis for a strategic implementation of CDR in the Netherlands.

**Results:** Of the 18 child deaths, 5 were due to an external cause. Parents of 6 deceased children gave their consent for reviewing their child's death. The most important strengths identified were the available materials such as the agency report and analysis form and information for the parents to carry out the reviews and the highly motivated CDR team members. Important weaknesses were found in the complicated procedure to obtain parental consent and in collecting patient information from professionals involved in the child's healthcare. The fact that parents and professionals who have cooperated in the pilot endorse the objective of the CDR method is seen as an important opportunity. The lack of legal basis for the CDR procedure is perceived as a threat.

**Conclusion:** The pilot study of CDR has identified strengths, weaknesses, opportunities and threats which can provide input for further implementation in the Netherlands. The CDR method could be improved in terms of materials and procedures. The social basis of implementing CDR could be enlarged when it is incorporated in professional standards, preferably supported by the management of healthcare organizations and legislation.

## O111

### USING CHILD DEATH REVIEW TO UNDERSTAND AND PREVENT SUDI

Joanna Garstang

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**Introduction:** Since 2008, in England, all unexpected child deaths are investigated jointly by police, health and social services with the aim of determining the complete cause of death and addressing the family's needs. All child deaths are also subject to Child Death Review (CDR) by local Child Death Overview Panels (CDOP). These new processes have yet to be evaluated in routine practice; this is a study of the outcomes of multi-agency investigation and CDR of SUDI cases.

**Aim:** To determine the effectiveness of multi-agency investigation and CDR in establishing the cause of death and risk factors for Sudden Unexpected Death in Infancy (SUDI) in the West Midlands of England.

**Methods:** We obtained the dates of birth and death of all SUDI cases in the region aged between 1 week and 1 year, dying between 1 September 2010 and 31 August 2012, from hospitals conducting all infant post-mortem examinations. We contacted all 10 CDOP for copies of individual case reviews; these are completed using the standard national CDOP Form C. We extracted the following data items for each case from the Form C: age, cause of death (SIDS, unascertained death, medical cause, external cause) and presence of modifiable factors for death.

We recorded the presence of significant risk factors in each domain: intrinsic to the child, family and environment, parenting capacity and service provision. We created a total family and environmental risk factor score ranging from 0- 6 by totalling the number of individual risk factors.

**Results:** Data were available for 65/70 (93%) of SUDI cases.

Most deaths 45/65 (69%) remained unexplained despite complete multi-agency investigation. Of these 21 (47%) were classified as SIDS and 24 (53%) as unascertained. 20/65 (31%) deaths were due to a medical cause of which 12 (60%) were due to infection.

Deaths classified as unascertained had significantly higher total family and environmental risk factor scores with a mean of 2.6 (95% CI 2.0– 3.3) than those classified as SIDS of 1.6 (95% CI 1.2-1.9), or medical causes for death of 1.1 (95% CI 0.8-1.3). Only 3 unexplained deaths had no identified risk factors in the family and environment; however all of these infants were intrinsically vulnerable infants.

Most deaths (51/65, 79%) were deemed to be potentially preventable; this was significantly associated with unexplained deaths rather than medically explained deaths ( $p=0.001$ ).

CDR identified inadequacies in medical provision for a minority of medically explained deaths; these included deaths from vaccine preventable infections in unimmunised infants.

**Discussion:** Multi-agency investigation and CDR are highly effective at determining modifiable risk factors for SUDI thus have the potential to reduce the rates of SUDI in the future. Most unexplained deaths occurred in unsafe sleep environments despite many years of health information campaigns regarding safe sleeping. Frequently deaths occurred in families with mental illness, drug or alcohol misuse and chaotic lifestyles; we need to find ways to better support these families in making the right choices to enable their children to grow up healthily.

## O112

### THREE YEARS OF DEATH SCENE INVESTIGATION IN IN CASES OF SUDDEN DEATH IN INFANTS AND SMALL CHILDREN IN NORWAY

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**Background:** Between 35-40 children under the age of 4 die suddenly and unexpected and every year in Norway. In November 2010 Norway implemented a system of death scene investigation in these cases, offered as a health service. These death scene investigations are voluntary and the parents have to sign a written informed consent. In June 2011 the legislation was changed so that the police from this point on was obligated to start an initial investigation in every case of sudden and unexpected death in children under the age of 18, even in cases with no suspicion of a criminal act. If the police decide to open a full investigation, that excludes the death scene investigation from the health care service.

**Objective:** Give a summary of the three first years of death scene investigation in Norway. The purpose of the death scene investigation is to see if there are circumstances in the child's surroundings that can help understand the cause of death. This in turn will enforce the legal protection of infants and small children, and it may protect the families from gossip. A more long-term goal is to learn more about risk- factors for prevention of future deaths.

**Method:** The family is offered a visit by the forensic pathologist who performed the autopsy and an investigator with education and experience from tactical police investigation. The death scene investigation consists of a conversation with the parents and a reconstruction in the room in which the baby was found dead, using a doll. Finally, a multi-agency case conference is held, where a thorough discussion leads to a final conclusion to the cause of death.

**Results:** In the period from 1. November 2010 to December 2013, 42 death scene investigations have been conducted. The number of parents who does not consent has decreased over the three year period, only 2 families refused the offer in 2013. At the same time, the police open full investigation in an increasing number of cases, 8 cases in 2013.

Almost seventy percent of the total number of unexpected deaths (totally 109 cases) occurred in infants below one year of age. In 38 % of these cases the cause of death was SIDS.

Of the 42 cases with death scene investigations, 30 remained unexplained and was diagnosed with SIDS, 17 boys and 13 girls.

SIDS cases: 50 % of the children were found dead in prone position, 27 had been co-sleeping with one or both parents and in 50 % of the parents said that they smoke daily.

**Conclusions:** There are still every year a few death scenes which are not being investigated, neither by the police nor the team from the health care system. In 2012 death scene investigation was not performed in 10% of the cases. The goal must be that every death scene is looked at, to ensure that information about the circumstances is not lost. A mandatory death scene investigation might be the solution.

## O113

### MODIFIABLE RISK FACTORS FOR SUDDEN INFANT DEATH SYNDROME (SIDS) IN GERMANY: CURRENT PREVALENCE AND TRENDS

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Sudden Infant Death Syndrome (SIDS) remains the major cause of infant death in the post-neonatal period in high income countries. Germany's SIDS mortality rate has dropped substantially in the early 1990s, but for the last decade it has not been falling much further and it remains relatively high compared to other European countries. This may be due to modifiable risk factors such as prone sleeping position, maternal smoking and not breastfeeding.

Current prevalence and trends of modifiable risk factors in Germany were assessed.

Prevalence estimates and 95% confidence intervals were compared from cross-sectional-studies of 1- to 6-month-old babies. Two studies recruited parents from stratified random samples of communities from three German states (1991:  $n= 3007$  and 1995:  $n= 2936$ ). In 2003-2006 and 2009-2012, two waves of a nation-wide cross-sectional study (KiGGS) included parents of 0- to 17-year-old children; prevalences were calculated from subsamples of babies below 7 months ( $n = 413$  and  $n = 289$ , respectively). The sleeping position was not obtained in the survey of 2003-2006.

The prevalence of babies laid prone for sleeping dropped between 1991 (37.6%; 35.9-39.3%) and 1995 (8.7%; 7.7-9.7%), no much further decrease was observed in 2009-2012 (6.8%; 4.4-10.6%). The prevalence of smoking during pregnancy was 21.8% (20.3-23.3%) in 1991/1995 and was 18.9% (14.8-23.8%) in 2003-2006. In 2009-2012, 15.6% (9.2-25.2%) of the mothers still smoked during pregnancy. The prevalence of fully breastfeeding at the time of study increased from 34.7% (33.0-36.4%) in 1991 to 43.9% (42.1-45.7%) in 1995. Ever breastfeeding non-significantly increased from 78.6% (73.0-83.2%) in 2003-2006 to 88.0% (78.7-93.6%) in 2009-2012 ( $p$ -value for trend = 0.065). Although these data show some positive developments towards the more current time periods, the variables obtained on breastfeeding are not fully comparable to the 1990s data.

Despite some improvements in reducing risk factors for SIDS especially in the 1990s, further reduction is required in order to decrease SIDS mortality.

## O114

### DO PRE-BIRTH DEMOGRAPHIC CHARACTERISTICS OF THE FAMILY IDENTIFY POST-NATAL SIDS RISK FACTORS FOR THE INFANT?

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**Objectives:** Longitudinal postal questionnaire data collected between pregnancy and late infancy were used to assess the relationship between a previously developed scoring system of infants at high risk for SIDS based on pre-birth demographic factors and subsequent post-natal SIDS risk factors for infants.

**Methods:** Risk factors scores were based on 4 easy to obtain pre-birth demographics; young maternal age (< 26 years), high parity (> 2 children), maternal smoking and low social class. Data were collected from 591 mothers in South West England from 2003-6 inclusive, who were sent postal questionnaires to collect information at 5 time points from pregnancy to late infancy. Information on infant care practices relating to SIDS was collected including sleeping position, mode of feeding, dummy use and bedsharing. The data were analysed by splitting families into three groups; low (no risk factors), intermediate (1-2 risk factors) and high risk (3-4 risk factors).

**Results:** Babies in the high risk group were more likely to be put down for sleep on the side at 2 months (OR=4.09 [95% CI: 1.48-11.31],  $p=0.004$ ), less likely to be breastfed at all (OR=9.71 [95% CI: 4.97-18.99],  $p<0.001$ ) and more likely to be given a dummy in the first week (OR=4.45 [95% CI: 2.49-7.94],  $p<0.001$ ). There were no significant differences between the groups for bedsharing overall, however mothers in the high risk group were more likely to share covers with the baby while bedsharing (OR= 2.46 [95%CI: 1.24-4.87],  $p<0.01$ ) rather than the baby have covers of their own.

**Conclusions:** These findings demonstrate that identifying infants at high risk of SIDS using distal pre-birth demographics can pick up proximal risk factors in early infancy lending itself to the idea of a targeted approach to SIDS prevention.

## O115

### THE POOREST INFANTS ARE AT INCREASED RISK OF SIDS: EXPERIENCE IN BOGOTA, COLOMBIA

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**Introduction:** The Sudden infant death syndrome, also known as the crib death, is the unexpected death of an infant under one year of age, apparently healthy and without a known cause; that usually occurs during sleep. Bearing in mind that exists a direct association between sudden deaths and risk factors demonstrated in different studies, there has been necessary to carry out important educational and preventive campaigns in order to decline the mortality of SIDS. According to vital statistics, in Colombia in 2010 the infant mortality rate was 12.76%. In Bogotá, by probable cases of SIDS in under one year children, according to ICD10 code, were 120 deaths of 372 occurred throughout the country. For that reason a survey constructed from the review of these risk factors was applied to parents and caregivers of infants in Bogota, showing the ignorance and risk practices with the babies at bedtime, especially the poorest.

**Methods:** A descriptive cross-sectional study of 1,101 parents of babies born in Bogotá in the 12 months prior to the completion of the survey was conducted through a structured survey administered by telephone between September and November 2010, sampling was stratified, representative stratum, with a margin of error of 2.9% for  $p = 0.5$  with 95% confidence. Data were Stata processed, used chi-square and t-test to determine statistical significance.

**Results:** The results reflect the risk that the infants are exposed because erroneous practices associated with knowledge, recommendations given in a lot of cases, by health professionals and practice like cigarette smoking in home, consumption of alcohol by the mother, bed sharing, using pillows and positioning prone of the infant at bedtime. Using an expansion factor, with infant populations (less 1 year old) estimated in 119,679 in Bogota for 2010, it could mean that about 77,000 infants were lying sideways or prone at bedtime; 50,000 children slept in bed with another person and 10,800 were exposed to cigarette smoke.

The study evidenced inequity between the richest and poorest people in Bogotá: there are significant differences between socioeconomic strata ( $p < 0.05$ ). The highest socioeconomic status has greater knowledge and practices of "safe sleep" for example, position prone in which the infant sleeps (40.5% vs. 21.9%), and pacifier use (16,3% vs. 5%). And the percentage of children at risk is lower among the richest population: use of pillows (42.7% vs. 59.7%); bed sharing (19.4% vs. 59%), smoking mother (0.4% vs. 2.7%) and smoke exposure (3.1% vs. 12.5%).

**Discussion:** Colombia shows large inequalities among its population, which have been evidenced in this study. This survey shows statistically significant differences between safe sleep practices by socio economic status, with the higher strata that get more and better information, those who have more knowledge about SIDS and how to prevent and those closer to sleep practices insurance with their babies. It is possible that these differences in knowledge and practices are those that result in more deaths in lower strata and in infants with parents with less education.

## O116

### **A CALL TO GLOBAL ACTION: PROPOSAL FOR MULTIDISCIPLINARY CONSENSUS CONFERENCE TO STANDARDIZE THE CLASSIFICATION OF UNEXPLAINED SLEEP RELATED DEATHS**

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There is a strong evidence base confirming that an unsafe sleep environment is a major risk factor for sleep-related infant deaths and we need to continue to expand and enhance our public health education efforts. Accordingly, it is critical that we more effectively overcome persisting cultural, historical and other behavioral and socio-demographic barriers to safe sleeping for all infants. Regardless of the success of these public health efforts, however, the diagnostic dilemma will remain as to how to accurately assign the cause and manner of sleep-related infant deaths.

This shift in thinking and consequent dilemma have consequences for pediatricians and other health care professionals, scientific investigators, medical examiners/coroners, law enforcement agencies, families and support or advocacy groups. We therefore recommend convening a multidisciplinary proceeding to develop a mutually accepted approach for assigning cause and manner of death for all sleep-related infant deaths. Potential participants could include representatives from the following organizations or constituencies:

- NIH/NICHHD (Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health)
- ISPID (International Society for the Study and Prevention of Perinatal and Infant Death)
- CDC (Center for Disease Control and Prevention)
- AAP (American Academy of Pediatrics)
- NCHS (National Center for Health Statistics)
- NCCDR (National Center for Child Death Review)
- NAME (National Association of Medical Examiners)
- Advocacy and Support Groups (First Candle, CJ Foundation, American SIDS Institute, Head Start, etc.)
- Professionals (Clinicians, Researchers, Medical Examiners)
- Parents and caregivers.

A number of recent publications have recommended a new approach to classification intended to resolve or at least clarify the current diagnostic dilemma. No specific recommended approach, however, has achieved broad-based acceptance. At least in part, this lack of acceptance and utilization can be attributed to the lack of a fully participatory interdisciplinary process having substantially greater potential for broad-based support and implementation.

Implementation of this strategy will require coordination by an organization or group that does not have a vested interest in a particular outcome. We need an approach to classification that is consistent not only with our current understanding of environmental risks contributing to an unsafe sleeping environment but also interactions with maturational and biologic vulnerability including genetic risk factors. Rapidly evolving advances in genetic and biological technologies including next-generation sequencing and metabolomics should lead to progressive expansion of our knowledge of relevant genetic and gene-environment interactions. We thus need an approach that not only addresses our current dilemma but that is sufficiently flexible to accommodate progressive future expansion of our knowledge of the complex interactions resulting in sleep-related infant deaths.

Discussion and Audience Participation: Clinicians, researchers, medical examiners, parents and caregivers, and participants in national and international organizations.

## O116

### **HISTORY OF THE DIAGNOSTIC DILEMMA FOR SUDDEN UNEXPECTED INFANT DEATHS**

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Sudden infant death syndrome (SIDS) is the sudden, unexpected death of an infant that remains unexplained after a thorough postmortem examination including a complete autopsy, investigation of the scene of death, and review of the medical history. Modifications of this definition have been suggested, but there is no agreed upon modification. In association with implementation of back-to-sleep public health campaigns, SIDS rates decreased dramatically. As detailed death scene investigations including “doll reenactments” have become more frequent, however, medical examiners and coroners have become reluctant to assign SIDS (ICD-10 R95) as the cause of death and increasingly assign the cause of death as accidental suffocation or strangulation in bed (ASSB, ICD-10 code W75-W84) or “unknown” (ICD-10 code R99). Some medical examiners and coroners do not consider SIDS a true cause of death and code these deaths as “undetermined” (ICD-10 code R99).

The increased availability of scene investigations has allowed us to better document the varying degrees of unsafe sleep environments to which infants may be exposed. Although in some instances there is incontrovertible evidence of entrapment, wedging, or strangulation, there is no consensus as to whether or when an unsafe sleep environment would be sufficient to cause fatal asphyxia, due to the lack of any objective criteria for assigning suffocation as the cause of death except in the most clear-cut examples. Recently, the term “SUID” (or SUDI) has been used to represent all sudden and unexpected infant deaths, both explained and unexplained. Under this system of classification, SIDS, accidental suffocation or strangulation in bed (ASSB), and unknown are included under the “umbrella” heading of SUID. Since there is no ICD-10 code for SUID, when SUID is listed on the death certificate it is assigned an ICD-10 code of R95 or “SIDS.”

These changes have not only affected the assigned cause of death but also the manner of death. SIDS historically has been considered to result from a medical issue and hence the manner of death was natural. However, suffocation as the cause of death is classified not as natural but as accidental, or as undetermined if one cannot decide between natural and accidental as the manner of death. However, undetermined is also used when homicide is suspected but there is insufficient evidence, and homicide is rarely suspected in sleep-related sudden unexpected infant deaths.

There is also increasing evidence that many infants who succumb to SIDS have genetic risk factors that increases the probability of death in a potentially asphyxiating environment. However, the increasing assignment of the cause of death as asphyxia and not SIDS has occurred without consideration of the role of intrinsic "infant vulnerability." In all but the most extreme examples of asphyxiating environments, most infants exposed to an unsafe sleep environment would likely not die absent an intrinsic vulnerability due to genetic risk factors. However, there is presently no approach to classifying sudden unexpected infant deaths that encompasses genetic as well as environmental risk factors in determining the cause and manner of death.

## **O116**

### **IMPORTANCE OF INFANT VULNERABILITY AND INTERACTION WITH POTENTIALLY ASPHYXIATING ENVIRONMENTS**

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Our current understanding of SIDS or unexplained SUID is that these sleep-related infant deaths result from an interaction between infant vulnerability, a critical stage of development, and some exogenous "trigger" or stressor. This has best been embodied in the "Triple Risk Model" suggested by Filiano and Kinney in 1994. Exogenous stressors encompass many well-documented epidemiological extrinsic risk factors, including prone positioning, over-bundling, bed sharing, and soft bedding. It is noteworthy that these extrinsic risk factors are either singly, or in combination, potentially asphyxiating. Some factors appear to be protective, including breast feeding, pacifier use, and room (not bed) sharing. Although the rationale for room sharing seems clear, the physiology underlying the protective effects of breast feeding and pacifier use are unknown. The concept of a critical maturational or developmental period is derived from the peak incidence of SIDS being in early infancy when many autonomic control systems are undergoing rapid developmental changes. The concept of "vulnerability" can range from factors that might alter normal developmental trajectories such as prematurity or maternal cigarette, alcohol, or other drug use, to an underlying genetic or developmental alteration in brainstem function, or to the presence of an upper respiratory infection or others. These vulnerabilities impair an infant's ability to respond to significant environmental and/or positional asphyxia encountered during sleep. These protective responses include arousal from sleep, cardiorespiratory responses to hypoxia and/or hypercapnia, reflex or learned motor responses required to lift and/or turn the head to clear the airway, the laryngeal chemoreflex, and autoresuscitation. Variations in the ability to respond appropriately may underlie the observation that very few infants placed in mild or moderate asphyxiating environments actually die.

To accurately classify sleep-related SUID, therefore, we must consider the important interactions between infant vulnerability and positional or other environmental asphyxia. This is best visualized as the interaction between at least two continua: 1) the risk of death from a potentially asphyxiating environment, and 2) the risk of death from an underlying vulnerability. Interactions can occur anywhere along the continua. In other words, a completely normal, healthy full term infant has a high probability of death when confronted with in an unmistakably asphyxiating environment (i.e. overlaying, wedging, strangulation or entrapment). On the other end of the spectrum, an extremely vulnerable infant (e.g. a premature infant less than 3 months old with brainstem immaturity, or an infant with a genetic polymorphism affecting brainstem function) might die suddenly in a completely safe sleep environment. Most deaths, however, likely involve interactions between the extremes. Importantly, most of these described genetic and/or biological abnormalities cannot be detected antemortem, due to current limitations in our knowledge base and/or lack of cost-effective methods, and most also cannot be currently be detected postmortem. Current research is poised for the discovery of biomarkers which may identify infants at risk, but this is hampered by a lack of consistency in our classification of these deaths. A classification system that takes into account the interaction between infant vulnerability and the potentially asphyxiating sleep environment is critical to move forward as we strive to prevent these deaths.

## **O116**

### **SIDS: HOW SHOULD WE REACH THE DIAGNOSIS, AND WHO SHOULD DECIDE? AN ENGLISH PERSPECTIVE**

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In order to understand what may have contributed to the sudden unexpected death of an infant it is important to understand not only what is found at autopsy, the scene, and circumstances of the death, but also to understand how these findings relate to the normal developmental progress of infants. There are normal variations in physiological, metabolic and immunological development, and the range of circumstances in which infants in the same society are routinely put down to sleep and spend their sleeping (and waking) hours. This level of knowledge is not in the professional domain of any one professional group. Whilst paediatric pathologists have knowledge and understanding of the manifestations of both natural disease processes and imposed harm or injury, few have detailed knowledge or understanding of normal physiological development, and fewer have knowledge of the range of "normal" parenting practices in their community. Similarly, whilst many paediatricians have a good understanding of normal motor, cognitive and behavioural development, relatively few extend this to a detailed understanding and knowledge of the range of parenting practices in their community and the ways in which such practices may affect infant development, illness or risk of adverse events.

The approach to the investigation of unexpected infant deaths introduced in 2008 in England as part of the Children Act accepts these limitations on behalf of each professional group, and mandates an investigation and an approach to reaching a “diagnosis” or classification of the deaths that includes input from the police, social care, paediatricians and children’s community nurses, and tries to understand how and why each death has occurred in the light of what is known about pathological findings, the scene and circumstances of the death, and the ways these may have interacted with normal developmental progress and the range of patterns of parenting behaviour prevalent in the community. No one professional group has the final word. The important concept is professional consensus based on a far broader understanding than has previously been the case.

This approach has been in widespread use in the Southwest of England over the past decade, and we will present some of the results arising from this approach – identifying its advantages and limitations in helping to understand what has led to some deaths as a step towards helping to prevent similar deaths in future.

## O117

### DUMMY USE INCREASES BLOOD PRESSURE IN PRETERM INFANTS.

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**Background:** Epidemiological studies have consistently shown that dummy sucking is a protective factor for the Sudden Infant Death Syndrome (SIDS). However, the mechanism by which dummy sucking acts is unknown. It is thought that impaired cardiovascular control accompanied by an uncompensated hypotension may play a major role in the underlying mechanism of SIDS. In support of this hypothesis, major SIDS risk factors such as prone sleeping, are associated with lowered blood pressure, particularly at 2-3 months of age when SIDS incidence is greatest. Preterm infants are at increased risk for SIDS, accordingly, we assessed the effects of dummy sucking on blood pressure and heart rate during sleep across the first 6 months after term corrected age. We hypothesised that in order to be protective dummy sucking would increase blood pressure and heart rate and this would be most marked in the prone position.

**Methods:** 35 preterm infants (21M/14F) born at 26-36 weeks GA (mean gestation 31.2±0.4, mean birth weight 1697±92g) were recruited and studied longitudinally at 2-4 weeks, 2-3 months and 5-6 months corrected age using daytime polysomnography. Infants were divided into those who regularly used a dummy (n=18 at study 1; n=22 at study 2; n=19 at study 3) and those who did not (n=12 at study 1; n=6 at study 2; n=9 at study 3). Heart rate (HR) and mean arterial pressure (MAP) were measured continuously in 2 min epochs during both quiet sleep (QS) and active sleep (AS) in the supine and prone sleeping positions. Only periods of non-sucking were analysed.

**Results:** There was no difference in total sleep time between the groups at any age studied. At 2-3 months MAP was significantly higher in the supine position in those infants who sucked on a dummy compared to those infants who did not in both QS (70 ± 2 vs 60 ± 2 mmHg, p<0.05) and AS (74 ± 3 vs 69 ± 2 mmHg p<0.05). No differences in MAP were identified at either 2-4 weeks or 5-6 months. Heart rate tended to be lower in the dummy users and this reached significance in AS in both the supine (128 ± 2 vs 134 ± 2 bpm) and prone (128 ± 2 vs 136 ± 3 bpm, p<0.05) positions.

**Conclusions:** This study has identified that in preterm infants dummy use increases blood pressure during sleep, at the age of greatest SIDS risk. A higher baseline blood pressure in infants who routinely use a dummy may indicate increased sympathetic tone of the peripheral vasculature which may serve as a protective mechanism against possible hypotension during sleep leading to SIDS, however further analysis is required.

## O118

### DUMMY USE IMPROVES CONTROL OF HEART RATE IN PRETERM INFANTS

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**Background:** Epidemiological studies have consistently identified that fewer infants who regularly use a dummy die from the Sudden Infant Death Syndrome (SIDS). However, the mechanism for this is unknown. It has been suggested that infants who die from SIDS have an impaired ability to recover from a cardiovascular event such as a profound hypotension during sleep. Preterm infants are at four times the risk of SIDS and previous studies have identified that autonomic control of heart rate is impaired in preterm compared to term infants. Accordingly, we assessed the effects of dummy use on cardiac control over the first 6 months of life after term corrected age when SIDS risk is greatest.

**Methods:** 35 preterm infants (21M/14F) born at 26-36 weeks of gestational age (mean gestation 31.2±0.4, mean birth weight 1697±92g) were recruited and studied longitudinally at 2-4 weeks, 2-3 months and 5-6 months corrected age (CA) using daytime polysomnography. Infants were divided into those who used a dummy at time of study (n=18 study 1; n=22 study 2; n=19 study 3) and those who did not (n=12 study 1; n=6 study 2; n=9 study 3). Heart rate (HR) was recorded continuously during both quiet sleep (QS) and active sleep (AS) in the supine and prone sleeping positions. Cardiac control was assessed from spectral indices of heart rate variability (HRV) in the low frequency (LF) range reflecting both sympathetic and parasympathetic activity and the high frequency (HF) range reflecting parasympathetic activity. Total power and the ratio of HF/LF indicating sympathovagal balance was also calculated. Data were compared with 2 way ANOVA.

**Results:** In dummy users, at 2-4 weeks CA LF HRV, the LF/HF ratio and total power were higher overall in AS and this reached statistical significance in both the prone and supine positions in QS (p<0.05 for all). At 2-3 months the LF/HF ratio was higher in QS in both the prone (p<0.05) and supine (p<0.01) positions and overall HF HRV was lower in QS (p<0.05). At 5-6 months the LF/HF ratio was also elevated overall reaching statistical significance in the supine position in both QS and AS (p<0.05 for both). HF HRV was reduced in QS in both positions.

**Conclusions:** Dummy use increases HRV during sleep across the first 6 months after term corrected age in infants born preterm. Dummy use may improve cardiac control in preterm infants, which may serve as a protective mechanism against SIDS.

## O119

### THE STRESS PEPTIDE, PACAP, REGULATES THE AUTONOMIC RESPONSE TO HYPERTHERMIC STRESS IN NEONATAL MICE: RELEVANCE TO SIDS

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**Background:** Neonatal mice lacking the stress peptide, PACAP, display a phenotype that is characteristic of the sudden infant death syndrome (SIDS). These mice die suddenly during the second week of life; the deaths are increased with mild thermal stress and are likely associated with an inability to mount an appropriate protective response when faced with a homeostatic challenge.

**Objectives:** Since hyperthermia has been implicated as a risk factor for SIDS, we investigated whether PACAP is involved in mediating the cardio-respiratory and metabolic responses to hyperthermic stress in early postnatal life.

**Methods:** Using the head-out plethysmograph and surface electrodes, we assessed breathing (minute ventilation), heart rate, the rate of carbon dioxide production (metabolism) and skin temperature (cutaneous heat loss) in 4 day old PACAP-deficient and control mice, under baseline (32°C) and hyperthermic (40°C) conditions.

**Results:** At baseline, both breathing and heart rate were normal in PACAP-deficient neonates, but metabolism was increased (~40%;  $p=0.02$ ), cutaneous heat loss were elevated (skin temperature = ~0.5°C higher;  $p=0.051$ ) and heart rate variability reduced (~59-90%;  $p<0.001$ ) compared to control pups. In response to hyperthermia, breathing, heart rate, metabolism and cutaneous heat loss were all significantly increased in control pups, but in PACAP-deficient neonates, breathing and metabolic rate were significantly decreased ( $p<0.01$ ), and the increase in heart rate and cutaneous heat loss were significantly blunted ( $p<0.01$ ) compared to controls.

**Conclusions:** These findings suggest that PACAP is important in regulating cutaneous heat loss in neonates and matching ventilation and heart rate to metabolism during hyperthermic stress. Abnormalities in these systems might have far reaching implications in the pathogenesis of developmental disorders such as the sudden infant death syndrome.

## O120

### ALTERED GENE EXPRESSION AND POSSIBLE IMMUNODEFICIENCY IN CASES OF SUDDEN INFANT DEATH SYNDROME

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**Background:** A large number of studies have been performed in order to uncover a genetic predisposition for sudden infant death syndrome (SIDS). Despite these efforts, the key to understand the molecular pathogenesis of these deaths is not yet found. Due to new technology the possibility of an alternative approach to identify disease associated genes has become available; i.e. mRNA expression studies. Although investigation of mRNA expression has long been a challenge in forensic casework and research, new and improved methods have opened new doors. A study of mRNA expression may show the concurrent gene transcription and thereby bridge the gap between fixed genomic information and dynamic phenotype.

**Objective:** The purpose of this study was to identify disease associated genes by comparing the levels of mRNA expression in cases and controls.

**Methods:** Tissue from heart, liver and brain from SIDS victims are investigated to uncover whether any genes were up or down-regulated, compared to age matched-controls. Fifteen SIDS cases and 15 controls were included in this study, and mRNA expression was determined using the Illumina whole genome gene expression DASL HT assay. T-test was performed for comparison of the groups, followed by a correction for multiple testing using Benjamini Hochberg false discovery rate (FDR).

**Results:** Out of the 39378 genes analysed, 17 genes showed altered expression compared to the controls. The expression analysis revealed 15 down-regulated and 2 up-regulated genes. The organ with largest alteration in gene expression was liver, in this organ 13 genes were found down-regulated, while one gene was up-regulated. Furthermore one gene was up-regulated and one gene down-regulated in the heart, while one gene was down-regulated in the brain. Three genes involved in the immune system were of particular interest, including the down-regulation of MyD88 in tissue from SIDS brain ( $p=2.7 \times 10^{-5}$ ), as well as the down-regulation of the genes encoding CCL3 ( $6.7 \times 10^{-7}$ ) and UNC13 ( $p=2.0 \times 10^{-6}$ ) in the liver.

**Conclusions:** These findings indicate that there is an altered expression of genes involved in the inflammatory process in a subset of SIDS. This further strengthens the hypothesis that impaired immune response play a role in this syndrome. The study has disclosed genes with altered regulation, and has identified genes that can be the source of the malfunction leading to death.



## O121

### IS GENETIC VARIATION IN AQP1 INVOLVED IN SIDS?

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**Background:** The aquaporins (AQP) are a group of proteins that function as water channels, and so far six different aquaporins have been found in the brain. AQP4 is the most important, but also AQP1 and AQP9 have well established roles, while AQP3, AQP5 and AQP8 are less investigated. The findings of an increased brain weight, brain edema, abnormal cerebral development and hypoxia in some SIDS cases might indicate an involvement of the aquaporins in this syndrome. Several SNPs in the AQP4 gene have been investigated with regard to SIDS, and an association between rs2075575 CC/CT and SIDS has been reported.

AQP1 is located at the apical membrane of the choroid plexus, where it is involved in the formation of cerebrospinal fluid. AQP1 is not expressed in astrocytes in the normal brain, but is up-regulated in several pathological states, including brain tumors and Alzheimer's disease.

**Objective:** The purpose of this study was to further elucidate the involvement of aquaporins in SIDS, by investigating genetic variation in the AQP1 gene in SIDS cases and controls. The  $\chi^2$  test was used for comparison of genotype frequencies between the groups.

**Methods:** The subjects consisted of 172 SIDS cases (median age 19 weeks, range 2-52 weeks, 98 male, 74 female) and 371 adult deceased controls. Twenty-six selected SNPs were investigated using a MassArray technology.

**Results:** Eighteen of the investigated SNPs were homozygous in both SIDS cases and controls, while 8 SNPs showed variation in the investigated populations. One SNP tended to be associated with SIDS; rs17159702. For this SNP, there was a difference in genotype frequency between the groups; the CC/CT genotypes were more frequent in SIDS than in controls (52.3% vs 41.5%,  $p=0.018$ ). The same was true for the C-allele; 31.4% of the SIDS cases had this allele compared to 23.9% of the controls ( $p=0.009$ ,  $\chi^2$ ). If using the Bonferroni correction for the eight SNPs showing variation, there is still a tendency for the C-allele to be more common in the SIDS cases ( $p=0.07$ ).

**Conclusions:** This study indicates that polymorphisms in the AQP1 gene may be a predisposing factor for SIDS. The rs17159702 is a tag SNP, situated in an intron, and is thus not likely of importance as such, but might be a marker for deleterious variants at other sites in the AQP1 gene. One might speculate that an altered expression of the AQP1 gene, together with functional polymorphisms in other genes involved in brain water- and ion-homeostasis, might influence the developing brain both in utero and after birth, leading to increased seizure susceptibility, brain edema and sudden death.

## O122

### SEROTONERGIC BRAINSTEM ANALYSIS IN SIDS INFANTS BORN PREMATURELY

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**Background:** A leading risk factor for SIDS today is premature birth (gestational age <37 weeks) with approximately one-third of SIDS infants born prematurely. There is also an inverse correlation between gestational age and SIDS such that infants born at progressively younger gestational ages have progressively higher SIDS rates. While the biologic basis of SIDS risk in preterm infants is unknown, immature autonomic and respiratory control in relevant brain regions, and/or acquired insult to these regions due to perinatal hypoxia-ischemia (a common complication of preterm birth) have been postulated. The serotonergic (5-HT) network in the medulla (caudal brainstem) plays a key role in autonomic and respiratory control, and we have previously reported multiple 5-HT-related abnormalities in this network in SIDS infants. In this study, we examined various aspects of the medullary 5-HT network relative to the issue of prematurity in SIDS in a database accrued by our laboratory over the last two decades from the San Diego medical examiner's office (unexpected infant death) and Department of Pathology, Boston Children's Hospital (prematurity).

**Objectives:** We tested the following hypotheses utilizing 5-HT<sub>1A</sub> receptor binding with tissue receptor autoradiography: 1) there is a developmental change in 5-HT<sub>1A</sub> binding in the 5-HT medullary network in the non-SIDS cases (controls) with increasing postconceptional age; 2) the levels of 5-HT<sub>1A</sub> binding in the medullary 5-HT network differ significantly between preterm and term SIDS cases adjusted for postconceptional age; 3) there is a positive correlation between 5-HT<sub>1A</sub> receptor binding in medullary 5-HT network such that decreasing gestational age at birth correlates with decreasing 5-HT<sub>1A</sub> binding; and 4) SIDS infants have the same levels of 5-HT<sub>1A</sub> receptor binding in the medullary 5-HT network as preterm infants with hypoxic ischemic brain lesions dying in the perinatal period.

**Results:** 1) There is no significant change with development in 5-HT<sub>1A</sub> receptor binding in any of the 10 nuclei sampled of the medullary 5-HT network. 2) Preterm SIDS infants (n=13) demonstrate 5-HT<sub>1A</sub> receptor binding abnormalities that are essentially the same as those in term SIDS infants (n=36) (with levels in both groups significantly different from infants dying of known causes [controls, n=26]). 3) There is no significant correlation between gestational age and 5-HT<sub>1A</sub> binding levels in the medullary 5-HT system in SIDS infants. 4) There is reduced 5-HT<sub>1A</sub> receptor binding levels in 7/8 medullary nuclei analyzed in the SIDS group (preterm and term combined) (n=32-49) compared to preterm infants with perinatal hypoxia-ischemia and death (n=4-5), with significant differences in 3 nuclei ( $p\leq 0.02$ ) and marginally significant differences in 2 ( $0.05 > p < 0.10$ ).

**Conclusion:** Our data suggest preterm and term SIDS infants share the same 5-HT<sub>1A</sub> pathologic findings in the medullary 5-HT network, and 5-HT<sub>1A</sub> binding does not correlate with gestational age in SIDS infants. Moreover, preterm infants with hypoxic-ischemic injury and perinatal death do not share these same 5-HT<sub>1A</sub> deficits. Thus, it is unlikely that prematurity, including that associated with brain hypoxic-ischemic lesions, influences medullary 5-HT<sub>1A</sub> receptor binding defects in SIDS, and mandates ongoing research into an underlying biologic explanation for SIDS risk in preterm infants.

**Funding:** CJ Foundation for SIDS, NICHD HD-20991.

## O123

### THE DIAGNOSIS OF ANAPHYLAXIS IN UNEXPECTED INFANT DEATH. A BLINDED STUDY

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**Background:** The histopathology of the lungs of SIDS cases may resemble that of death due to asphyxia even when the circumstances of death are such that mechanical suffocation is unlikely to have occurred. Death from anaphylactic shock may represent a form of suffocation. In 1960 Parish, Barrett and Coombs suggested that some cot deaths might be due to a modified form of anaphylactic reaction to cows' milk. Coombs and his colleagues characterised such death as biological suffocation, and suggested that they can be identified histologically by a form of epithelial desquamation (Bodian-Heslop lesion) and mast cell degranulation. Emery and Carpenter showed excess mast cell degranulation occurred in some unexpected infant deaths compared with infant deaths that occurred in hospital. Further analysis by Silverman showed that, for unexpected deaths the distribution of the percentage of degranulated mast cells comprised a mixture of two populations in a 2:1 ratio. The larger group had a distribution similar to that of hospital deaths, and the smaller a similar distribution but with a mean 1.3 SD larger.

**Objective:** To show that unsuspected anaphylaxis is present in SIDS cases.

**Method:** A preliminary blind study of lung tissue blocks from 8 cases of unexpected infant death was conducted by histological examination of the material, and statistical analysis of the proportion of degranulated mast cells.

**Results:** Histology and statistical analysis agreed that 5 of the cases showed clear evidence that an anaphylactic reaction had occurred prior to death. All had cows' milk in their diet.

In 3 cases there was no evidence of anaphylaxis. When the cause of death was revealed, those with evidence of anaphylaxis had all been designated SIDS, while of those without anaphylaxis, death was due to violence in two and in the other to infection.

**Conclusion:** Histological and statistical tests for of anaphylaxis may make it possible to distinguish natural asphyxia from mechanical or imposed asphyxia. This may help resolve cases in which deliberate suffocation is suspected. More work is required.

## O124

### HIPPOCAMPAL PATHOLOGY IN SUDDEN UNEXPLAINED DEATH IN YOUNG CHILDREN: AN EXTENDED SERIES

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**Background:** Sudden unexplained death in childhood (SUDC) is the sudden death of a child older than 1 year that remains unexplained after a review of the clinical history, circumstances of death, autopsy, and ancillary testing; its incidence in children 1-3 years is 1.3/100,000. Previously, we reported a putative new entity of SUDC associated with hippocampal/temporal lobe (TL) maldevelopment with or without a personal and/or family history of febrile seizures (FS) in a subset of children aged 1-6 (Kinney HC et al. *Ped Dev Pathol* 2019; 12: 455-463). Sixty-four SUDC cases were accrued from 2002-2007 in an autopsy study of sudden unexpected death (77% SUDC, 23% explained); of the 49 SUDC cases, 46% with hippocampal sections (12/26) had substantial microdysgenesis. From 2007-2011, we accrued 88 additional cases (SUDC, 88%).

**Objective:** To test the hypothesis that a larger sample size confirms the observation of hippocampal anomalies associated with SUDC.

**Results:** We report combined findings in the cohort of 151 cases (1-6 years) based upon review of clinical records, autopsy and scene reports, microscopic slides, and family surveys. The demise categories were: SUDC, 80% (n=121); explained/known causes, 13% (n=19) (e.g., infection, accidents); undetermined, 5% (n=7), and epilepsy, 3% (n=4). There was no difference in age at death, male gender, or preterm birth among the groups. In the SUDC group, 49% (59/121) had a personal and/or family history of FS compared to 11% (2/19) of known causes (p=0.003). Of the SUDC cases, 97% were discovered after a sleep period, and 86% in the prone position. Hippocampal/TL review revealed 43% (36/83) of SUDC cases had gross and/or microscopic anomalies compared to 13% (2/16) of known causes (p=0.02). Of these SUDC cases, 31% had a personal FS history, and 17%, a family FS history only.

**Conclusion:** Hippocampal anomalies are significantly increased in young children with SUDC compared to children dying suddenly of known causes. Future research is needed towards identifying living young children at risk for sudden death. Presented in part at the American Association of Neuropathology annual meeting, June 2014.

## O125

### MULTICULTURAL VIEWS ON STILLBIRTH AND MATERNITY BEREAVEMENT CARE

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**Background:** There is a paucity of literature on the needs of parents from diverse cultural and religious backgrounds after stillbirth. This study aimed to explore relevant and unique beliefs surrounding stillbirth in the six main religious and cultural groups within the UK, to improve the design and provision of bereavement care.

**Methods:** Structured interviews with male and female representatives from a healthcare support network, expressing Jewish, Christian, Sikh, Hindu, Buddhist and Islamic beliefs. All interviews were digitally recorded, transcribed and analysed independently by 3 researchers using content analysis.

**Results:** Despite differences in belief systems, all representatives emphasised the need for a supportive, empathetic approach to provide holistic bereavement care. Examples of relevant beliefs include:

Jewish (Orthodox) - Too many babies died before, during or soon after childbirth, and mourning had to continue for one year after every death. It was accepted therefore that a baby should not be mourned unless at least 30 days old before dying.

Christianity - Stillborn babies cannot be baptised, but they can be blessed by anyone.

Sikh - The soul leaves the body after the last 'breath', when the heart stops beating, and cremation is preferred to burial. This means that if a post-mortem is required, it would not be seen to interfere with the soul.

Hindu - The baby already has a soul from conception. The soul leaves the body at death. Cremation is preferred but any child less than 10 years old should be buried.

Buddhist - As soon as a baby is stillborn the head must be tapped with the holy book or implement, by the parents, to assist the 'mind' leaving the body and enable rebirth. Afterwards the baby should be disturbed as little as possible. A post-mortem should not take place for at least three days, preferably ten.

Islam - The soul enters the body at 16 weeks of gestation and, does not leave the body until it is buried. Post-mortems are seen to cause harm, and as exposing 'the modesty' of a person to others.

**Conclusions:** These data serve to emphasise the variety of different beliefs that will need to be considered if maternity staff in the NHS are to provide bereavement care that meets both the cultural and religious needs of service users. This unique study will help guide training and improve service provision tailored to parents' needs in a culturally diverse world, for example by considering non-invasive post-mortem investigations such as MRI when appropriate.

## O126

### WHO TELLS A MOTHER HER BABY HAS DIED? RACIAL DIFFERENCES IN DEATH DISCLOSURE

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**Background:** The moment a death is diagnosed is likely to be a permanent memory for parents and become a critical time in their perinatal care. While much literature focuses on the interaction between families and their physician or midwife at the time of a loss, we could identify no studies in the U.S. or internationally which evaluated who actually provides parents news of the death. To improve care for bereaved parents, it is critical to identify the key players and processes of care and to evaluate whether care differs based on patient race or other demographic factors.

**Methods:** We conducted a population-based sample of women in Michigan, USA, in collaboration with the Michigan Department of Community Health. We surveyed women with perinatal death (stillbirth or infant death in the first 28 days of life) and control women with a live and surviving child. The study was sent to 900 bereaved mothers and 500 control mothers to evaluate mental and physical health outcomes. This abstract focuses on disclosure of the perinatal death.

**Results:** 609 women (cases and controls) were eligible to participate and responded to the first survey (response rate 44%). 232 women had a live birth and surviving child; 377 of the mothers were bereaved. 196 mothers experienced a stillbirth and 186 an infant death (women with multiples could have both). Bereaved mothers had a mean age of 29 years (+/-6), 37% had high school education or less, 76% were Caucasian, 19% African-American, and 5% other race, and 51% had public or no health insurance. When asked who first told them that their baby had died, less than two-thirds of women with a stillbirth (62%) reported it had been their physician or midwife, 19% reported they heard from the ultrasound technician, and 15% identified a nurse -midwife. For stillbirths, Caucasian women were significantly more likely than women of other racial groups to be told about the death by a physician or midwife (66% for Caucasian versus 36% for African-American, 57% for Asian and Pacific-Islander, and 40% for biracial women, p=0.019). For women with infant death, less than half (46%) reported a physician or midwife had been the one to break the news of the death while 32% found out from their partner or other family member and 14% from a non-midwife nurse.

**Conclusions:** This is the first research to identify that less than two-thirds of women with stillbirth and less than half of women with infant death in Michigan received this diagnosis from a physician or midwife. Further, maternal race may impact who provides this information. The training and demeanor of professional caregivers plays an essential role in helping families cope with bad news. It is surprising to learn that physicians and midwives who manage prenatal care may not be the ones disclosing perinatal death and raises the question of whether staff who do give the diagnosis are given adequate training and skills for follow-up support and guidance of grieving parents.

## O127

### NARRATIVES ABOUT HAVING A STILLBORN CHILD AND THE SUPPORT FROM THE CHURCH

Juha Itkonen

University of Helsinki, Orivesi, Finland

**Background:** Interactions with caregivers has deep effects on parents with perinatal losses. As many studies point out grieving parents perceive many behaviors to be thoughtless or insensitive. There is a lot of research about parents' experiences about the professional helpers in the context of health care, but not so much in the context of religious caregivers and churches.

**Objectives:** This paper will explore how employees of the Evangelical Lutheran Church in Finland support parents of a stillborn child. It will also compare how support received from the Church contrast with support offered from other agencies. The Lutheran Church is a major agent in the field of bereavement support in Finland and works among people with various religious backgrounds, so the results of this study carry meaning all kinds of caregivers' not just religious ones.

**Methods:** My study is qualitative with a narrative perspective. The data of this paper was collected by narrative interviews. 14

mothers and 10 fathers of stillborn child entered for interviews from peer support websites. These interviews were analyzed with computer assisted NCT –method (notice, collect, think) with help of Atlas.ti –software.

**Results:** The interviews revealed stories about grieving parents trying to get help from the church and health care services. These narratives of loss were seen as a setting to the stories about support, which could be divided five main themes. Those themes were social support (inc. health care provides, peer support and close relatives), the stillborn (fostering and caressing, angel baby, acknowledge humanity and realizing of the death), the burial (the planning and doing, funeral service and traditions), the church (priests, faith and support of the parish) and the grief (reactions, impacts and meaning-making process). These themes were examined with 80 inductive evaluate-codes. It occurred that many of the parents did not feel encounters with employees of the church and the health care services supportive, but rather formal and distant. However, when support was received, the helper did not approach the bereaved parent as a professional but as a human being who had courage to come close and be there. The emotional support was received, if the bereaved parent saw helper as “one of us”, not as some part of a big health care or religious system. To shed more light on this finding, I am using a theory of social identity (Taijfel 1981). Based on my findings, effective emotional support can happen only if a parent sees a caregiver as a member of in-group with her/him. There are many ways to create the in-group-membership with the parent, for example experience of common humanity, womanhood, religious group or loss. It is important though that there is a real link with a caregiver and a parent, in-group-membership should not and probably cannot be created by some kind of trick or false identity.

**Discussion:** When the best practices of bereavement support are considered, the views of social psychology, such as the theory of social identity, should be taken very seriously. Although a caregiver has the ultimate best practice in use, the interaction with the bereaved will most likely fail, if the caregiver is seen as out-group-member.

## O128

### THE SPIRITUAL IMPACT OF STILLBIRTH ON CONSULTANT OBSTETRICIANS

Daniel Nuzum<sup>1</sup>, Sarah Meaney<sup>2</sup>, Keelin O'Donoghue<sup>1</sup>

<sup>1</sup>Anu Research Centre, Department of Obstetrics and Gynaecology, University College Cork, Cork University Maternity Hospital, Ireland, <sup>2</sup>National Perinatal Epidemiology Centre, Cork, Ireland

**Background:** Stillbirth remains amongst the most challenging areas in obstetric practice. In Ireland, consultant obstetricians are ultimately responsible for care provided to mothers following stillbirth.

**Objectives:** This study explores the spiritual impact of stillbirth on consultant obstetricians working in an Irish tertiary maternity hospital (8,500 births per annum) where the stillbirth rate is 4.6/1000.

**Methods:** Semi-structured qualitative interviews lasting 27-58 minutes were conducted in 2012 with a purposive sample of 8 consultant obstetricians and gynaecologists (50% of the consultant obstetrician staff). The study explored how consultants care for parents following stillbirth focusing on the impact of stillbirth on belief and faith of consultants in particular. The data were analysed using Interpretative Phenomenological Analysis.

**Results:** Stillbirth was identified as one of the most difficult experiences for most consultants; describing it as amongst ‘the most devastating news’. All consultants recognised the importance of parents’ spiritual beliefs in their bereavement care. Five consultants said that they are unable to engage with their personal beliefs when dealing with death at work –for some this means “leaving their faith at the door”. The major themes emerging from the data are conflict of personal faith and work, the sense of blame and the avoidance of spirituality. For two consultants their faith is not challenged, seeing perinatal death as being part of the “nature of God”.

**Conclusions:** The tension between personal faith and professional practice is evident for most consultants as they care for parents in the midst of bereavement. This study presents the spiritual impact of death on obstetricians and highlights a gap in how obstetricians see their own faith and feeling able to respond to the faith needs of parents. Consultants did not demonstrate that spirituality was an integrated part of their professional life. How consultants respond to the spiritual needs of parents in stillbirth care warrants further research.

## O129

### HER CHILD WAS A BODY

Jan Bleyen

*KU Leuven, Belgium*

In a reflective, listening way, with attention for action and metaphor, historian Jan Bleyen will retell the hospital experience of two mothers who lost their baby at birth. Whereas in 1966 Lynn’s midwife, nurse and gynaecologist did everything they could to keep her stillborn child at a distance, forty years later, they expected from Sarah the exact opposite: they wanted her to see her baby-son and to hold him with her own hands in order to continue bonds. Her child was a body and this body was her son.

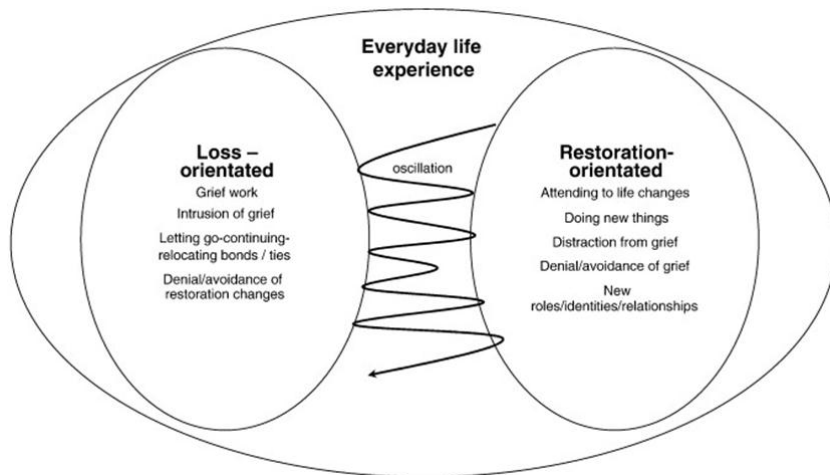
## O130

### DISTANCE AND CLOSENESS. ABOUT THE EFFECTS ON THERAPISTS AND PROFESSIONALS & SELF MANAGEMENT

Paul de Groot

*De Verbindig, Practice for Occupational & Health Psychology, the Netherlands*

The Dual Process Model of Coping with Loss (DPM) (Stroebe,1999), as described by Johan Maes (2007), is a new way to consider the bereavement process, among the more traditional view of stages (Kubler-Ross, Bowlby and Worden). This additional view of coping with bereavement sees bereavement in a more circular way. (see figure).



The model is based on two types of stressors:

- The loss; the reality of the event, the loss of someone / something ( attachment theory)
- The secondary consequences of the loss / the event; the awareness that life goes on without the loss ( stress / transition theory). This model recognizes that grief is a dynamic process, alternating between loss orientation ( the loss itself) and restoration orientation (the real and anticipated life changes).

This means that a grieving person may be strongly oriented towards loss and the deceased, switching to a focus on reality and the future the next. Mankind has both orientations at one's disposal; however individually we all have our own preferred, unique grieving style, which may be either more loss or restoration oriented.

This may be a source of tension in relationships in case of shared loss and bereavement . Sometimes partners with different preferred grieving styles may not be able to fully meet each other's bereavement needs.

As noticed the loss orientation focuses on and is characterized by pre-occupation with the loss, the past, the pain, the sad emotions, avoidance behavior and mental orientation inwards. The restoration orientation deals with the future, positive thinking, problem handling, solution orientation, orientation outwards and the need for contact with others and the outside world. Considering the different focus of the loss- and restoration orientation and the associated mental state of the bereaved person, it is important to keep in mind that we are making a distinction in the used interventions when dealing with bereaved people, as therapists and professionals! In the loss orientation the focus of contact is called "being" ( presence, essence, closeness, giving meaning, involvement) and in the restoration orientation "doing" ( intervention, effectiveness, problem solving, distance). Contact with bereaved people in their restoration mode generally meets little problems; as well in private life as well as a professional. In contrast with interaction in the restoration orientation, interacting in the loss orientation, sometimes characterized by deep distress, is much more difficult. Meeting someone's deep distress does not mean only dealing with the other but also with your own coping style, grieving style, cognitions and emotions. It is a fundamental encounter with yourself.

#### Workshop Distance and Closeness:

In this workshop we will give you insight into the Dual Process Model and we will give you tools

- to deal with bereaved people in the loss state,
- to recognize transference and counter transference signals
- to deal with pitfalls and
- to manage distance and closeness

#### Abstracts of Ahmed Hassan, who, unfortunately, was not able to come

### **AN OVERVIEW OF PERINATAL EPIDEMIOLOGY IN DIFFERENT REGIONS OF SUDAN**

Ahmed Hassan<sup>1</sup>, Abd Elrahium Haggaz<sup>2</sup>, Elhassan Elhassan<sup>2</sup>, Omer Mirghani<sup>2</sup>, Magid Abubaker<sup>1</sup>, Elgoni Radi<sup>1</sup>, Elshiekh Bader<sup>1</sup>, Amel Alhaj<sup>1</sup>, Abdel Aziem Ali<sup>3</sup>, Ishag Adam<sup>1</sup>

<sup>1</sup>Faculty of Medicine, University of Khartoum, <sup>2</sup>University of Gezera, Wad Medani, <sup>3</sup>Faculty of Medicine, Kassala University, Sudan

Introduction: Perinatal mortality rate (stillbirths plus early neonatal deaths) is an important indicator of the quality of antenatal and obstetric care. More than 3 million stillbirths occur annually, a disease burden that approaches that of postnatal deaths. The poorest countries have the highest incidences with two regions, sub-Saharan Africa and south Asia, together accounting for nearly 70% of worldwide stillbirths. Methodology: Various cross- sectional, and case –control studies were conducted during the last 10 years, aimed to investigate perinatal epidemiology in different regions of Sudan. This paper summarized all these efforts concerning perinatal epidemiology in one simple paper. Results: In Sudan perinatal mortality rates were recorded in Kassala, Khartoum and Darfur 92, 51 and 30 deaths per 1000 births giving 57.7 deaths per 1000 births in all three regions. Regarding stillbirth rate was found 35.5, 22, 21, 29, 33 and 28.8 per 1000 births in Khartoum, Omdurman, Darfur, Gezira, Kassala and all five areas respectively. The majority of stillbirths were macerated, which is not common pattern in developing countries. The common causes of perinatal mortality were illiteracy, nutrition problems, and lack of antenatal care, low birth weight, malaria, anemia, the conflict in certain areas, preterm delivery, hypoxia and infections and obstetrical malpractice. Conclusion: Based on our research on perinatal epidemiology, perinatal mortality rate are high in Sudan in compare to other countries. Thus, at the current rate, it is unlikely that the Millennium Development Goal 4 (MDG4) will be achieved in Sudan by the year 2015; unless more integrated care should be directed by health care providers and health policy makers based on this basic perinatal data toward Education, nutrition, Antenatal care and malaria prevention.

## **STILLBIRTH SITUATION IN SUDAN, IS IT ALARMING, TO EXTEND TO HAVE A SEPARATE STILLBIRTH SOCIETY?**

Ahmed Hassan

*Sudan Stillbirth Society, Sudan*

About 98% of stillbirths occur in low-income and middle-income countries. And Worldwide, 67% of stillbirths occur in rural families, 55% in rural sub-Saharan Africa and south Asia. Thanks for ISA for conducting the Annual International Stillbirth Alliance (ISA) conference 2013 in Vietnam. Hoping that, soon it will be organized in Africa aiming to high light the stillbirth hazard in its source.

According to our long experience in maternal and perinatal field in the last 10 years, Sudan showed a very high stillbirth rate ranging from 21 to 35.5 per 1000 births. This article discusses the rationale of establishing Sudan Stillbirth Society initiation as one viable body to address and fight stillbirth tragedy in Sudan.

In Sudan there are obstetrics & gynecology society and pediatrics society, which is good, but unfortunately stillbirth gaps were not filled by them completely (till now stillbirth are less recognized, less registered, less actions taken ...).

All these mentioned factors and others ones push us as a group of medical and non medical Sudanese volunteers to lead the Initiation, since June, 2013 to dig deep in stillbirth dilemma aiming to fill stillbirth gaps, with closed collaboration with above mentioned national existing and international bodies. Fortunately stillbirth societies are widely present in many countries and most of them under ISA umbrella.

The responsibly of this body is to document, to investigate the possible direct and indirect causes of stillbirth and to find appropriate management through using our available resources based on voluntary work.

To establish a new body is not an easy task and many challenges faced the idea from them time, to find motivate and committed people, money... In spite of all these challenges we believe we can achieve our ultimate goal is to reduce the stillbirth rate in Sudan and to provide appropriate psychological support to parent who lost their future child. Till now the initiation achieved many things towards our objectives and attending ISA conferences is a good opportunity for us to share our stillbirth knowledge and practice especially in building community volunteers network in rural areas where the bulk of stillbirth is hidden.

## ABSTRACTS - POSTERS

### P1

#### HOSPITAL INITIATIVES TO PROMOTE AND MODEL THE AMERICAN ACADEMY OF PEDIATRICS' SAFE SLEEP RECOMMENDATIONS

Stephanie Kuhlmann<sup>1</sup>, Carolyn Ahlers-Schmidt<sup>1</sup>, Christy Schunn<sup>2</sup>, Brooke Mason, MD

<sup>1</sup>University of Kansas, School of Medicine, Wichita, USA, <sup>2</sup>Kansas Infant Death and SIDS Network, USA

Studies demonstrate modeling by healthcare workers influences parents to place infants supine for sleep. Recently, additional emphasis has been placed on environment; therefore the purpose of this study was to improve sleep position and environment in the hospital. Wesley Medical Center (WMC) is a community teaching hospital in Wichita, Kansas. The hospital has 62 postpartum rooms where well newborns routinely room in with their parents. Average annual deliveries exceed 6000. A Plan-Do-Study-Act cycle was initiated. At baseline, 25% (36/144) of sleeping well newborns were safe; the majority of unsafe sleep was due to environment.

A bundled intervention was implemented, which included the following:

- A) An educational "Policy Poster" was developed including: (1) a new safe sleep nursing policy; (2) our baseline data on sleep environment and position; (3) a Declaration of Safe Sleep Practice; and (4) a place to sign indicating the nurse had read and agreed to practice safe sleep for patients.
- B) Viewing the ABC's of Safe Sleep video was made mandatory for all parents within the first 24 hours of arrival to the newborn unit. Viewing was documented in the medical record.
- C) Posters from the National Institute of Child Health & Human Development (NICHD) showing an infant sleeping on his back, in a bassinet, with no items in the bassinet were placed in rooms. Nurses used this poster to discuss safe sleep with families. Initial discussions of safe sleep were moved from dismissal training to postpartum room orientation.
- D) Nurses were asked to evaluate sleep environment and position of the infant each time they assessed the infant for any reason. If the infant had "safe sleep," the nurse was asked to commend families for following sleep recommendations. If the infant's sleep location or position was unsafe, the nurse was asked to use this as a teachable moment and to instruct families again on the importance of safe sleep.

Post-intervention, significantly more (58%; 145/249) had safe sleep ( $p < 0.0001$ ). Most parents planned to use supine position (95%; 96/101); none planned to bed-share. Many intended to adjust their infants' home sleep environment.

A similar PDSA and bundle were implemented on the pediatric floor. Baseline found 13% of sleeping infants were safe. Post intervention, this number was only 15%, but there was a significant reduction in the number of objects present in the crib. Extra blankets were the most frequent objects post intervention. (Seven hospitals in other states have implemented this bundle, and six had significant improvements in safe sleep).

In conclusion, the bundled interventions in the hospital were successful in improving infant safe sleep, however additional PDSA cycles are needed to further increase our rates. Hospitals are an important part of the continuum for educating parents about safe sleep, however they are only one opportunity along the way.

### P2

#### PHYSICIAN TOOLKIT TO PROMOTE CONSISTENT MESSAGES REGARDING SAFE SLEEP

Carolyn Ahlers-Schmidt<sup>1</sup>, Stephanie Kuhlmann<sup>1</sup>, Zachary Kuhlmann<sup>1</sup>, Christy Schunn<sup>2</sup>, Jon Rosell<sup>3</sup>

<sup>1</sup>University of Kansas School of Medicine, Wichita, <sup>2</sup>Kansas Infant Death and SIDS Network, <sup>3</sup>Medical Society of Sedgwick County, USA

The toolkit was intended for use by Pediatricians, Family Medicine Physicians and Obstetricians. The focal point of the toolkit was a paper-based checklist for caregivers to complete regarding safe sleep, including the following 4 multiple-choice items:

1. How do you lay your baby down to sleep?
2. Where does your baby sleep at home?
3. Please circle the items that are already in your baby's sleeping area at home, or that you plan to get for your baby's sleeping area.
4. Have you talked about safe sleep with others who may put your child down to sleep?

The toolkit also included a brief provider script with suggestions on consistent sleep messages for caregivers based on responses to the questions. A Child Care Checklist that addressed safe sleep, in addition to other topics, was included for parents who had not talked about safe sleep with other caregivers. Additional local and national resources were provided, including links to the ABC's of Safe Sleep video and to order free Safe Sleep items, such as *Infant Sleep Position and SIDS: Questions and Answers for Health Care Providers* booklet, posters, tri-fold brochures and door hangers.

The toolkit was pilot tested at five resident physician clinics in Wichita, Kansas from March to October 2013. Clinics included 3 Family Medicine Clinics, one Obstetrical Clinic and one Pediatric Clinic. Pregnant women completed the paper-based checklist at 28 and 36 weeks gestation based on their intentions for following the safe sleep guidelines after their infant was born. Parents of children ≤6 months of age completed the checklist based on actual sleep practices. Optional demographic questions were added regarding sex, age, education, race/ethnicity and number of children. On the back of the checklist providers could indicate which, if any, of the first three questions were discussed and whether the Child Care Checklist was given to address the fourth question.

Checklists were completed by 652 parents, 23% at Family Medicine, 44% at Pediatric and 33% at the Obstetrical Clinic. Most respondents were female (83%), 4% were male, and the remaining 13% did not respond. A high school diploma or less was reported by 46%. Nearly 44% identified as white, with 16% African American, and 17% mixed race or other; 23% did not respond. In addition, 23% were Hispanic, although 17% did not respond. Number of children ranged from 0 to 9, with the majority reporting ≤2 (59%).

The majority of respondents ( $\geq 80\%$ ) reported both safe sleep location and position. However, only 35% reported a sleep environment with no unsafe items such as loose bedding, pillows, bumpers, etc. Providers engaged in discussion regarding safe sleep with most parents who reported intentions/behavior in opposition of the AAP recommendations for safe sleep. Provider surveys ( $n=11$ ) suggest the toolkit helped promote safe sleep discussion and was easy to implement.

### P3

#### **CHANGING THE PARADIGM REGARDING SAFE SLEEP EDUCATION IN AN OBSTETRICAL CLINIC**

Zachary Kuhlmann<sup>1</sup>, Carolyn Ahlers-Schmidt<sup>1</sup>, Stephanie Kuhlmann<sup>1</sup>, Christy Schunn<sup>2</sup>, Jon Rosell<sup>3</sup>

<sup>1</sup>University of Kansas School of Medicine, Wichita, <sup>2</sup>Kansas Infant Death and SIDS Network, <sup>3</sup>Medical Society of Sedgwick County, USA

A pediatrician pursuing her Master's degree in public health evaluated knowledge and dissemination of safe sleep information by local pediatricians, family physicians and obstetricians. Findings indicated obstetricians were significantly less likely to spend adequate time discussing safe sleep and SIDS risk reduction strategies with their patients (unpublished data used with permission). In fact, while a few reported discussing sleep position (21%), breastfeeding (7%) and pacifier use (6%), no obstetricians reported discussing the peak age for SIDS, safest mattress type, bed sharing, or the safest place to sleep.

Based on this striking data, along with results from the previously described studies, an initiative was undertaken in a private, group obstetrical practice to evaluate the frequency and consistency of safe sleep discussions. Patients (at 28 and 36 weeks gestation) were surveyed regarding discussions about the AAP's Safe Sleep guidelines. Of 70 women approached, 56 completed the 14-item survey (80%). Only 5% had no misconceptions regarding safe sleep. Most (84%) recognized positioning an infant on its back to sleep was safe; however, 34% thought side and 7% thought tummy were also safe. Nearly all (98%) recognized cribs as a safe location, but many unsafe locations were also identified as safe: infant swing (45%), car seat (32%), adult bed with parent (14%), adult bed alone (7%), and toddler bed (7%). In addition, items such as blankets (41%), sleep positioners (27%), bumpers (15%), quilts (7%), and soft mattresses (6%) were identified as safe. Some mothers were unsure about unsafe positions, locations and items (2%-20%).

The most commonly reported sources of safe sleep information were books, newspapers and magazines (56%) or family and friends (46%). However, 33% reported hearing about the AAP's safe sleep recommendations at their obstetrical appointment immediately prior to being surveyed and 20% had received information previously from their obstetrician or other staff; an additional 35% had received information from the hospital. Eighteen percent of respondents had heard advice contradictory to the AAP's. Sources included friends, family, and even a nurse.

Due to this baseline data, it was recommended that the Safe Sleep Toolkit be rolled out at the clinic. There were several barriers to implementation. To begin, the board of directors for the practice had to approve the project. This required the physicians to analyze and discuss national and local data and guidelines. Also, clearly defining an obstetrician's role in anticipatory guidance during prenatal education for safe sleep was a change in culture (i.e. safe sleep is not just the responsibility of the pediatrician). Once approval was granted, the checklist questions had to be added to the electronic medical record and providers needed education on how to utilize the toolkit. Multiple sessions were needed to update all providers. Buy-in from physicians and support staff varied. Post-intervention data will be collected in June 2014.

### P4

#### **RELATIONSHIP SATISFACTION OF THE PARENTS AFTER THE DEATH OF THE CHILD**

Anna Liisa Aho, Katja Joronen, Marja Kaunonen

*School of Health Sciences, University of Tampere, Finland*

**Background:** Death of a child is a crisis situation which either strengthens or weakens the parental relationship. However, there is lack of studies concerning factors related to relationship satisfaction after the child's death.

**Objectives:** The aim of this research is to describe parental relationship satisfaction and to study the factors related to that after the death of a child.

**Methods:** The data were collected by an electronic survey from parents ( $n=461$ ) whose one or more children had died. The respondents were recruited between December 2012 and June 2013 through websites and membership registers of three Finnish non-governmental bereavement organizations providing peer support. Furthermore, participants were recruited through online discussion forums after the permission of the forums' administrator.

**Results:** Findings indicated that 36 % of the respondents were very satisfied and 49 % quite satisfied with their current relationship. Lower relationship satisfaction was reported by older respondents, and those who had worse subjective health and other children than the deceased one. Additionally, another cause of death than stillbirth, need for marriage counseling and perception of moderate or bad marital relationship of the parents were related to lower relationship satisfaction.

**Conclusions:** The most parents were satisfied with their relationship after the death of a child. Higher relationship satisfaction was significantly associated with some background characteristics of the parents, of the death of a child and of the parents' relationship. Parents who have lost their child may need support in their mutual relationship.



## P5

### SUDDEN INFANT DEATH SYNDROME: THE KNOWLEDGE OF NURSES AND MIDWIVES IN ABU DHABI, UNITED ARAB EMIRATES

Sarah Ball, Joanne Jenkinson

*Corniche Hospital, Education Department, Abu Dhabi, United Arab Emirates*

**Background:** Sudden Infant Death Syndrome (SIDS) remains a leading cause of infant mortality. Today the causes of SIDS remain unknown; however factors such as sleeping position and excessive clothing are associated with increased risk of SIDS.

Educational campaigns providing information on safe sleeping position and safe sleeping environment in Europe, Australia and North America have resulted in a 70% decrease in the number of infants dying of SIDS in those countries. In the United Arab Emirates (UAE) where similar educational campaigns have not occurred, the incidence of SIDS is three times that of countries having instigated SIDS awareness campaigns.

Nurses and midwives have a recognized role in health education and are well placed to provide new parents on information to help prevent SIDS. Therefore assessing nurses' and midwives' knowledge on SIDS prevention is essential.

**Objectives:** Following an informal observational audit, revealing inconsistent practices surrounding SIDS preventative strategies, the primary objective of the study was to describe the knowledge of nurses and midwives in relation to SIDS prevention knowledge.

Secondary objectives examined whether there were any relationships for the nurses' and midwives' SIDS prevention knowledge between: level of tertiary education, years of experience, years of employment at the maternity hospital, current job title, type of registration, prior SIDS education and/or their nationality.

Third objective of this study was the implementation of a hospital wide SIDS policy.

**Methods:** The largest stand-alone maternity hospital within the UAE was selected using a descriptive, cross-sectional, quantitative approach. A structured questionnaire was administered to 270 nurses and midwives caring for inpatient newborns within the maternity hospital. A response rate of n=190 was achieved.

**Results:** A majority (92%, n=175) correctly answered that the supine position is the safest sleeping position, however 25.8% (n=49) wrongly answered a dangerous sleeping position in cots, not the advocated feet-to-foot position. Ninety three per cent (n=177) correctly answered that wearing a hat is unsafe whilst 29.4% (n=56) wrongly recommended unsafe linen types. Eighty three per cent (n=158) wrongly answered unsafe room temperatures and 64% (n=122) wrongly answered that pacifiers do not reduce the incidence of SIDS.

To fulfil the secondary objectives of the study, Chi-Squared and Fisher's Exact Test calculations were used. There were statistically significant associations between those having received previous SIDS education and recommending the correct sleep location for an infant ( $p=0.002$ ), stating that the wearing of a hat on a sleeping infant was unsafe ( $p=0.026$ ) and the use of swaddling of a sleeping infant was dangerous ( $p=0.030$ ). Nurses, compared to midwives, were more likely to recommend an incorrect room temperature for a sleeping infant ( $p<0.001$ ). Degree educated nurses and midwives were more likely to recommend the correct sleep location ( $p=0.05$ ) and sleep position for an infant ( $p=0.022$ ). No association was found between years of experience and employment. There were statistically significant associations found between SIDS knowledge and nationality.

**Conclusion:** Significant errors in knowledge regarding sleeping position, room temperature and the use of pacifiers were identified, reflecting the findings of other research studies. Recommendations for practice include hospital wide education.

## P6

### GIVING BAD NEWS

Sheila Broderick, Ruth Cochrane

*University Hospital Lewisham, Women's Health Department; co-authors of 'Perinatal Loss: a handbook for those working women and their families, UK*

**Objectives:**

- Explore fears about giving bad news.
- Insights into how fears can interfere with communication well with a mother and her family.
- The chance to feel more confident about managing their reactions to patients' distress, however this is manifested.
- Strategies to help the family feel more confident about communicating in these difficult situations.
- Opportunities to share examples of good practice.

**Description:** Having to tell a mother and her partner that something has gone wrong with her pregnancy or her baby has died can be very daunting. Often medical staff are afraid of getting it wrong or doing it badly. Many staff fear that they are causing hurt, when in fact they are at the beginning of the process of tending to the wounds that come with pregnancy loss.

## P7

### INNOVATIVE TECHNICAL ASSISTANCE TO IMPROVE SUID SURVEILLANCE

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**Introduction:** In 2009, the U.S. Centers for Disease Control and Prevention (CDC) launched the Sudden Unexpected Infant Death (SUID) Case Registry to conduct state-level SUID surveillance by building upon existing state Child Death Review programs. Before 2009, states collected SUID case information from multiple sources, but did not have the resources to ensure and monitor data completeness; state capacity to analyze and disseminate data was also limited.

**Methods:** To improve SUID surveillance, state grantees receive training and technical assistance from the National Center for the Review and Prevention of Child Death and the CDC using innovative strategies. These improvement strategies include: a common workplan to compare activities between states; state report cards to track data completeness; site visits by CDC and peer state colleagues; and yearly in-person training to address surveillance improvement strategies. In addition, states participate in monthly calls and an annual meeting focused on specific quality improvement issues. A biannual infrastructure assessment is also completed by each state. This survey is used to determine states' capacity to implement and improve their program and to measure a state's progress within their workplan. CDC assigns points to activities such as analysis and dissemination of data, building new partnerships, and taking leadership roles. After twenty five points are awarded in one category, the state receives a badge. There are 5 potential workplan badges and 5 potential infrastructure badges.

**Results:** As of January 15, 2014, ten states have reviewed and entered information for 2,398 SUID cases. The percentage of cases that met the 80% data completeness goal for 32 key variables increased from 44% in 2009 to 94% 2011. In 2013, every state earned points for their workplan or capacity building activities, yet they earned the most points in the partnership category and data analysis category. Point earning activities from states included creating and distributing one page SUID data briefs, presenting at national conferences and attending new partner meetings. Seven badges were awarded to four of the nine states.

**Conclusion:** By implementing innovative technical assistance strategies, data completeness, analysis and dissemination have improved in SUID Case Registry states. In addition, states have learned to use their data and create partnerships to catalyze actions to improve SUID surveillance.

## P8

### **NURSES' PERCEPTION OF THE FACILITATORS AND BARRIERS TO THE IMPLEMENTATION OF SAFE SLEEP RECOMMENDATIONS IN THE HOSPITAL INPATIENT SETTING**

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**Introduction:** The American Academy of Pediatrics recommends specific behaviors for sleeping infants to decrease the risk of sudden and unexpected infant death. Inpatient hospital units can model and teach these recommendations to families.

**Objective:** To identify facilitators and barriers to modeling and teaching safe sleep recommendations in the hospital inpatient setting to guide development of nursing education.

**Methods:** We conducted 5 focus groups with 41 nurses and other staff at 3 hospitals in Connecticut and Virginia, USA. Nurses and staff were from inpatient pediatric, newborn intensive care and postpartum units. Focus groups were facilitated by a trained moderator using a script modified in an iterative process. Discussions were digitally recorded and transcribed. Using standard qualitative techniques, data were organized with qualitative software and analyzed, using constant comparative methods, to identify key themes and subthemes.

**Results:** Three main themes emerged as key facilitators and barriers:

1) Previously held beliefs of families and providers could both facilitate and act as barriers to modeling and teaching safe sleep recommendations. Nurses described many families not wanting to follow recommendations based on their cultural beliefs or previous practices. Nurses doubted their power to change these beliefs and practices. One said: *"We can tell them that is recommended, but in my mind it is almost like they are going to do what they want."*

Nursing practices were also based on their own personal experience. For example, one nurse said: "...I always feel somewhat of a hypocrite because she [my daughter] sleeps on her tummy."

2) Inconsistent provider messages were seen as a barrier. Nursing staff and other healthcare providers were reported to sometimes give mothers messages contrary to AAP recommendations. Nurses felt that messages to families would only be effective if consistent.

3) External forces can drive the success of messaging to providers and families. Nurses cited regulations from outside accreditation bodies as drivers for delivering accurate information. Some hospitals had protocols to guide information delivery. Many nurses noted that media messages and baby products sold in stores (such as bumpers) were often contrary to recommendations. One participant said:

"I mean the media could push families in the opposite direction from what we want because they show all these nice cute baby stuff and then you will have ads."

**Conclusions:** We identified key themes that are important to consider when developing a program to educate nursing staff to teach and model safe sleep messages that included overcoming families' cultural beliefs about infant care practices, the importance of uniform messages, and the influence of external regulations and contradictory media images. Providing consistent messaging language and teaching aids for nursing staff to use in the hospital setting would be expected to enhance their confidence and efficacy in providing safe sleep education.

## P9

### **THE USE OF A SIMPLE TOOL TO ESTABLISH LOCAL INFANT SLEEP PRACTICES**

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**Background:** While the risk factors for SIDS are well known, many health care professionals working with families do not know the prevalence of these risk factors in their community. This may be especially true for bed sharing.

**Aim:** To develop a questionnaire to be used by health visitors at the 6-8 week of age home visit to understand the sleep practices of families with babies in Sheffield UK.

**Methods:** A short questionnaire designed to establish sleep practices was administered (with full parental consent) by health visitors to parents of babies receiving their home visit at 6-8 weeks of age.

**Results:** 292 completed questionnaires were obtained over a predetermined 4 week period in 2013. (Sheffield Term births 2013=6467). The mean age of the mother was 28.9yrs. White British 62.7% and 8.2% from the Indian subcontinent. On the day of the survey 85% of the babies had woken in a Moses basket or cot in the same room as their carer. This was the normal pattern for 95% of them. 10.6% woke in the parental bed 23/32 of them being breast fed. 18/32 white British, 4 Asian subcontinent. 91% were put to bed in Moses basket or cot in the same room as the parents. Only 12 (4%) were put to bed in the parental bed. 45 infants spent some time in the parental bed in 23 of these cases only the mother was present. 70.2 % of babies had received breast milk at some stage and 49% were still partially or totally breast fed. 20% of babies slept in a sleeping sac, 6 (2.7%) were swaddled. 32 mothers admitted to smoking, 5 admitted alcohol the previous evening. 43 fathers admitted to smoking, 16 admitted alcohol the previous evening.

**Conclusions:** This simple survey has informed our local health care professionals of the sleeping circumstances of their families. It can be used as an instructional tool for them in terms of focusing on risky behaviour and will be used facilitate collection of longitudinal data to help evaluate local "safe sleeping" campaigns.

## **P10**

### **CULTURALLY APPROPRIATE AND SUSTAINABLE CAPACITY BUILDING FOR THE ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH WORKFORCE TO REDUCE INFANT DEATHS: AN INDIGENOUS SAFE INFANT SLEEPING ELEARNING PROGRAM**

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**Background:** Aboriginal and Torres Strait Islander peoples of Australia experience poorer health outcomes across the lifespan compared to non-Indigenous Australians, with infant mortality attributed to Sudden Unexpected Death in Infancy (SUDI) three times the rate of non-Indigenous infants. Previous research has demonstrated a) health professional knowledge and attitude gaps may have contributed to the poor uptake of safe infant sleeping messages by Aboriginal and Torres Strait Islander parents; b) and the identified need and request for a specific eLearning program appropriate to the needs of Aboriginal and Torres Strait Islander Health Workers.

**Objective:** To develop and test a culturally appropriate, evidence-based eLearning program which increases the capacity of Aboriginal and Torres Strait Islander health professionals to confidently role model safe sleeping practices in their communities.

**Methods:** An Indigenous Project Officer led consultation with Queensland Aboriginal and Torres Strait Islander networks regarding cultural appropriateness, suitability and acceptability of the program. The program was built in Provetus, the Queensland Health Clinical Skills Development Service (CSDS) designed eLearning platform, which allows for delivery of content in multiple interactive formats. The Aboriginal and Torres Strait Islander Safe Infant Sleeping eLearning Program consists of a course overview including orientation to e-learning environments; personal video address to participants from an experienced Aboriginal Health Worker; pre and post course knowledge and attitude quizzes; four modules each with a post-module quiz which must be successfully passed before advancing to next stage of course; novel interactions, Indigenous artwork and illustrations featuring culturally appropriate drawings and language. Pre-test-post-test changes were analysed using paired t-tests; sample subsets were compared using independent t-tests.

**Results:** During the first 18 months (June 2012-January 2014) this free program attracted over 100 registrations with 39 completions. Participants identified as nursing (n=15), midwifery (n=10), medical (n=5) and Other Indigenous Health Workers (n=9) working in Indigenous communities. Pretest results (n=39) identified deficits in knowledge and application to risk factor assessment and evidence-based parent advice. Participant scores significantly increased posttest [pretest 67% Vs post-test average 91%, p<0.0001). Similar scores were achieved post-test for each of the learning modules indicating consistency in delivery across content (Post-test scores: 91%, 91%, 93%, 95% for Modules 1, 2, 3, 4 respectively). Several organisations have integrated this program into core professional support as part of staff preparation for safe infant sleeping health promotion in communities.

**Conclusion:** Aboriginal and Torres Strait Islander families continue to be underexposed to safe sleeping public health messages. This eLearning program addressed a need identified by Indigenous Health Workers for culturally appropriate resources to assist them in supporting families to use safe sleeping recommendations. The culturally appropriate learning tool was effective in significantly and positively influencing health worker knowledge and knowledge application, and has continued to attract interest and participation with integration into service commitments for health worker support. Culturally appropriate and consistent methods of delivery will assist health workers and parents to use infant care practices that will ultimately reduce the risk of sudden unexpected deaths in infancy.

## **P11**

### **IMPAIRED AROUSAL ASSOCIATED WITH PRENATAL ALCOHOL EXPOSURE IN RAT PUPS IS RELATED TO AN INCREASE IN BRAINSTEM GABA**

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**Background/Objectives:** Prenatal alcohol exposure (PAE) increases the risk for The Sudden Infant Death Syndrome (SIDS). Many SIDS infants are exposed to repeated episodes of hypoxia in the days and weeks before death. Arousal from sleep is an important protective mechanism during hypoxia and is impaired after PAE, and in rodent models, is modulated by medullary raphe GABAergic mechanisms.

There are reports of a decrease in respiration in juvenile rodents after PAE, possibly driven by inhibitory mechanisms. We hypothesized that 1) arousal impairment after PAE is associated with increases in brainstem GABA and 2) respiratory frequency is decreased by PAE also mediated by GABAergic mechanisms.

**Methods:** Five days before mating, throughout the gestation until delivery, pregnant dams received either an ethanol containing liquid diet (ETOH), an iso-caloric pair fed diet (PF) or a standard chow diet (CHOW). PAE consisted of an alternating "binge" diet of 2 days of a high level (7% v/v) and 3 days of a low level (4% v/v) of ethanol. Artificial cerebrospinal fluid (ACSF) or nipecotic acid (NIP), a GABA reuptake inhibitor, was microinjected into the raphe magnus of P15 and P21 pups from each diet group. After recovery, pups were exposed to four 3-minute episodes of hypoxia (10% oxygen) alternating with 4 minutes of normoxia. The time to arousal (latency) from the onset of hypoxia was determined behaviorally; respiratory frequency (RR) was measured during the 5 seconds before the onset of each hypoxic episode. Brainstem GABA concentration was measured (HPLC) in P5, P15 and P21 pups from each diet group.

**Results:** PAE did not affect arousal during hypoxia in P15 rat pups. However, at P21, ACSF injected pups in the ETOH group had longer arousal latencies than those in the PF and CHOW pups combined (CON group) ( $P < 0.001$ ). Moreover, CON pups injected with NIP had arousal latencies similar to those in ETOH pups after ACSF injection and NIP injected ETOH pups had no further increases in arousal latency. Mean pre-hypoxia RR, averaged across all hypoxia trials was not different after PAE (CON/ACSF vs ETOH/ACSF). Moreover, increasing ambient GABA with NIP increased mean RR in the CON pups ( $P = 0.001$ ) but had no effect on RR in the ETOH pups. However, PAE did have an effect on the change in pre-hypoxia RR across trials. Thus the slope of RR across the 4 hypoxia trials was lower in the ETOH/ACSF pups compared to the CON/ACSF pups ( $P = 0.020$ ). Treatment with NIP did not change this relationship. Thus there was a significant interaction between the effects of ETOH, NIP and hypoxia trial on pre-hypoxia RR. Finally, ETOH pups had higher medullary concentrations of GABA compared to CON pups ( $P = 0.013$ ).

**Conclusions:** Arousal impairment after PAE is associated with an increase in brainstem GABA and medullary GABA reuptake mechanisms may be involved. The effect of PAE on pre-hypoxia RR was complicated and was dependent on an interaction between the effects of ETOH, ambient GABA and exposure to intermittent hypoxia. Supported by NIH PO1 HD36379 and R21 AA020279.

## P12

### **<sup>3</sup>H-EPIBATIDINE AND <sup>125</sup>I-BUNGAROTOXIN NICOTINIC RECEPTOR BINDING IN THE MEDULLA OBLONGATA IN SIDS INFANTS WITH IDENTIFIED SEROTONERGIC ABNORMALITIES**

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**Background:** SIDS infants have abnormalities in brainstem networks mediating protective responses to life-threatening challenges. Maternal cigarette smoking during pregnancy increases SIDS risk 2-5-fold, presumably through effects on these networks. Nicotine, which is a major toxic component of cigarette smoke, binds with high affinity to cholinergic neuronal nicotinic receptors (nAChR). Previous analysis of <sup>3</sup>H-nicotine binding to nAChRs revealed no significant changes in the brainstem of SIDS cases compared to non-SIDS cases, except when stratified by history of maternal cigarette smoking, in 2 independent datasets. However as nAChRs can be subdivided into heteromeric receptors comprised of combinations of  $\alpha$  and  $\beta$  subunits (e.g.,  $\alpha 4\beta 2$ ) and homomeric receptors comprised of only a single type of  $\alpha$  subunit (e.g.,  $\alpha 7$ ) and that <sup>3</sup>H-nicotine preferentially binds to heteromeric nAChR subtypes, we wished to investigate whether subunit specific changes in nAChRs are present in the brainstem in SIDS cases. This is supported by the observation that subunit specific changes in nAChRs exist in the brainstem of fetal baboons exposed to nicotine pre-natally. Furthermore, in the current dataset we observed changes to the serotonergic (5-HT) system in the medulla, we thus focused our investigation on this region to observe whether subunit specific changes to nAChRs, even in the absence of <sup>3</sup>H-nicotine changes, correlated to 5-HT abnormalities in the same region.

**Objective:** We tested the hypothesis that nAChR binding would be altered in the medulla in SIDS cases in a subunit specific manner and this would correlate with changes to the 5-HT system.

**Methods:** Autopsy study conducted to analyze tissue receptor binding for the nAChR subunit specific ligands <sup>3</sup>H-epibatidine ( $\alpha 2-4$ ,  $\beta 2$ ,  $\beta 4$  subunits) and <sup>125</sup>I-bungarotoxin ( $\alpha 7$  subunits) in the medulla oblongata. Data was then correlated to our findings of changes to the 5-HT system in the same region in SIDS cases as published previously (Duncan et al., 2010). The dataset was accrued between 2004 and 2008 and consisted of 37 infants dying from SIDS (cases), 5 infants with acute death from known causes and 3 infants with chronic illness (n = 8 controls).

**Results:** Binding for both <sup>3</sup>H-epibatidine and <sup>125</sup>I-bungarotoxin varied across the 12 medullary nuclei analyzed. While we found no compelling differences between SIDS and non-SIDS cases, there were significant positive correlations between nAChR binding and markers of the 5-HT system (primarily 5-HT<sub>1A</sub> receptor binding) ( $p < 0.05$ ).

**Conclusion:** Brainstem networks mediate protective cardiorespiratory responses to life-threatening challenges. We have previously demonstrated that 5-HT neurons express nAChRs and that 5-HT systems are altered in the medulla oblongata in SIDS cases. Contrary to our initial hypothesis, we did not observe compelling differences in nAChR binding between SIDS and non-SIDS cases in this study, we did observe positive correlations between nAChR binding and markers of the 5-HT system. This suggests interactions may occur between the cholinergic and 5-HT systems such that while altered nAChR binding does not appear to be an underlying vulnerability in SIDS infants, exposure to cigarette smoke which is known to alter nAChR expression, may further compromise 5-HT abnormalities that are known to exist in these infants.

## P13

### BED-SHARING IN THE ABSENCE OF HAZARDOUS CIRCUMSTANCES: IS THERE A RISK OF SIDS?

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**Objective:** The risk of sudden infant death syndrome (SIDS) among infants who co-sleep in the absence of hazardous circumstances is unclear and needs to be quantified.

**Methods:** Combined individual-analysis of two population-based case-control studies of SIDS infants and controls comparable for age and time of last sleep. Parents of 400 SIDS infants and 1386 controls provided information from five English health regions between 1993-6 (population: 17.7 million) and one of these regions between 2003-6 (population: 4.9 million).

**Results:** Over a third of SIDS infants (36%) were found co-sleeping with an adult at the time of death compared to 15% of control infants after the reference sleep (multivariate OR=3.9 [95% CI: 2.7-5.6]). The multivariable risk associated with co-sleeping on a sofa (OR=18.3 [95% CI: 7.1-47.4]) or next to a parent who drank more than two units of alcohol (OR=18.3 [95% CI: 7.7-43.5]) was very high and significant for infants of all ages. The risk associated with co-sleeping next to someone who smoked was significant for infants under 3 months old (OR=8.9 [95% CI: 5.3-15.1]) but not for older infants (OR=1.4 [95% CI: 0.7-2.8]). The multivariable risk associated with bed-sharing in the absence of these hazards was not significant overall (OR=1.1 [95% CI: 0.6-2.0]), for infants less than 3 months old (OR=1.6 [95% CI: 0.96-2.7]), and was in the direction of protection for older infants (OR=0.1 [95% CI: 0.01-0.5]). Surprisingly dummy use was associated with a lower risk of SIDS only among co-sleepers whilst prone sleeping was associated with a higher risk only among infants sleeping alone.

**Conclusion:** These findings do not support an approach of advising against all bed-sharing in any circumstances, but support a public health strategy that underlines specific hazardous co-sleeping environments parents should avoid.

## P14

### BEREAVED PARENTS' UNDERSTANDING OF WHY THEIR BABY DIED

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**Aims:** Since 2008, in England, all unexpected infant deaths must be investigated jointly by police, health and child welfare services aiming to establish the full cause and relevant contributory factors for the death. This study aims to learn of bereaved parents' experiences of this joint agency approach (JAA) and parents understanding of the cause and contributory factors for their infant's death.

**Methods:** Bereaved parents, whose unexpected infants' deaths were investigated by a JAA were eligible to participate in the study. Case records from all agencies were analysed, JAA professionals were interviewed and parents invited to complete questionnaires or in-depth interviews. All parents completed the Hospital Anxiety and Depression Scale (HADS). Data were analysed using a Framework Approach.

**Results:** There were 111 eligible families, of whom 23 were recruited giving theoretical saturation. 16 families had in-depth interviews, 5 completed questionnaires and 2 allowed case note access only. 27 Professionals were interviewed. The median time between infants' deaths and study participation was 33 weeks; data collection took place between 2011-3. 7 cases had a medical cause for death, 16 cases remained unexplained being classified as SIDS or unascertained deaths.

The JAA determined modifiable risk factors in 15/16 unexplained deaths but in only 1 medically explained death. 14/16 unexplained deaths occurred in unsafe sleep environments.

Learning the cause for the death was very important for families; unexplained deaths were a source of continuing grief. While most parents understood medical causes for death; the concept of SIDS or unascertained deaths was more difficult to comprehend. Despite this, several parents did have a good understanding of the relevant modifiable risk factors for their infant's death even when these related to parental actions such as co-sleeping. However some parents seemed either not to understand the role of contributory factors or failed to mention these at interview.

Paediatricians' practices varied; some had detailed discussions with parents about modifiable contributory factors while others deliberately avoided these conversations worrying that the parents would feel blamed for the death.

Some parents talked of blame: of themselves, for health care professionals or feeling blamed by professionals. Mothers often blamed themselves for the death even when it was unpreventable; this could be considered part of normal grieving. A minority of mothers had extreme feelings of self-blame; this did not relate to understanding the causes of death but was associated with clinically significant scores on HADS (> 11) with mean anxiety score of 17.0 (95% CI 14.5 – 19.5) and mean depression score of 18.3 (95% CI 15.5 – 21.2).

When parents blamed health care professionals or felt blamed it often seemed that parents were using this to deflect their own responsibility.

**Conclusion:** Parents want to know why their infant died; they can understand the complexities of contributory factors even when these relate to their own actions. Paediatricians need to be honest with parents and explain the role of contributory factors in deaths; withholding this information to protect parents from blaming themselves is not justified.

## P15

### THE IMPACT OF LEGISLATIVE EFFORTS TO IMPROVE HOSPITAL BASED INFANT SLEEP SAFETY (ISS) IN PENNSYLVANIA (PA)

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**Background:** Proper modeling of a safe infant sleep environment has a positive impact on parental behaviors in the home. A 2009 study of PA birthing hospitals revealed that although 94% of respondents felt their nursery staffs were well-educated on the topic of infant sleep safety (ISS), there were significant inconsistencies with the modeling of a safe sleep environment. In 2010 PA passed the Sudden Infant Death Syndrome Education and Prevention Act (Act 73) which mandated the Department of Health to generate educational materials and provide a foundation for consistent ISS education across the state. (All parents must receive ISS education prior to hospital discharge and sign an acknowledgment form that they understand the material.)

**Objective:** To determine if effective communication and educational materials regarding ISS are utilized consistently by birthing hospitals in accordance with PA law.

**Design/Methods:** Cross-sectional survey of maternity ward nurse managers of all PA hospitals providing birthing services. Questions were designed to assess ISS program materials and staff modeling of ISS behaviors. Data were analyzed using z-test of proportions.

**Results:** We received responses from 69 hospitals of 95 (73%) with delivery services, representing 101,000 deliveries of approximately 142,000 yearly births in PA (71%). The mean deliveries per center were 1401 with a range of 13 to 10,000.

Question	2009	2014	p-value
Written ISS hospital policy	48%	76%	0.004
Standard parental ISS education	67%	100%	<0.001
Written parental information	87%	100%	0.009
Verbal parental instruction	96%	100%	0.37
Use of DVD for education	28%	58%	0.003
Healthy babies maintained supine	81%	100%	0.001
Ever use the side position	48%	64%	0.14
Ever use the prone position	8%	21%	0.047
Propping the bassinet	65%	61%	0.81
Washcloth near face for regurgitation	43%	41%	0.98
Parents allowed to sleep with the baby	0%	0%	1
Any staff promote bed sharing	4%	9%	0.26
Staff ask family if they have crib	69%	91%	0.005
Staff well educated on AAP guidelines	94%	81%	0.08
Ongoing staff education	21%	63%	<0.001
More education wanted for staff	67%	55%	0.27
Nursery audits	N/A	20%	N/A

Nurses are involved in providing ISS at 97% of the sites, while doctors never exclusively perform this task. The most common reasons given for using a position other than supine or for propping the bassinet were concern over regurgitation (58%/73%), retained fetal lung fluid (14%/8%), and nursing preference (14%/23%). Although propping the bassinet is still common, there has been a significant decrease in its use always or commonly (61% vs. 2%,  $p < 0.001$ ).

**Conclusions:** The passage of ACT 73 has led to significant improvements in the standardization of parental education on ISS. However this has not translated into the uniform modeling of safe sleep behaviors by staff. Achieving cultural change on ISS in the hospital requires on-going educational efforts to reinforce the safe sleep message. Future legislative efforts should consider standardizing provider education, with a focus on infant transitional physiology and airway protective mechanisms to promote universal modeling of supine sleep positioning.

## P16

### EXPLORING THE BELIEFS AND PERCEPTIONS OF NEW PARENTS: 'I'M OLDER ..WISER..KNOWLEDGEABLE.. SIDS? IT WON'T HAPPEN TO ME'

Jill Green

*SIDS and Kids Australia*

**Background:** Sudden Unexpected Death in Infancy (SUDI) remains the main cause of unexpected infant mortality in Australia. The presence of known and modifiable risk factors has been reported in many SUDI.

Given that the mothers in this cohort were well educated, from professional backgrounds, over 30 years of age and in stable relationships, the demographic profile appears consistent with features associated with a positive transition to the role of being a parent. Considering the majority of the literature in the context of safe sleeping speaks to the experiences of women from low socio-economic or specific target populations of ethnic origin, this research identified findings unique to this specific older, educated and professional demographic. The social context of how or why parents select particular infant sleep care practices is a significant, if a somewhat neglected, perspective.

**Objectives:** This exploratory study aimed to draw on the life experiences of parents to understand:

- Why they choose certain sleeping practices;
- Their perception of what is a safe sleeping environment;
- Who or what influenced their practice;
- What role health professionals play in conveying the key safe sleeping messages.

**Methodology:** This qualitative study was conducted within a phenomenological framework. Semi structured interviews were conducted with 15 parents living in Victoria with infants under the age of one.

**Conclusions and Practice Implications:** Findings revealed an overarching theme influencing perception of safe sleeping centred on the parents' own sense of confidence gained by their age, high level of education and professional working background. Thus, a sense of being independent, being able to control the situation initially by acquiring knowledge through research and 'planning' pervaded. However, although parents were aware of the Safe Sleeping recommendations a range of barriers hindering parents' ability to follow them was evident. Parents' initial perceptions of safe sleeping was often questioned and contradicted by what actually works in practice with no apparent ill effect. Parents spoke of resistance particularly to 'place baby in the cot to sleep'. The desire to co-sleep was framed within a construct to create closeness, safety, social connectedness and move away from western societal expectations. Barriers evident for those who chose to co-sleep included lack of information how to co-sleep safely, feeling isolated, outcast and perceived negativity from others.

Lack of social acceptance had been accentuated by recent media reporting deaths of infants in cosleeping situations. The findings highlight a sense of frustration by parents that their ability to 'plan' was impeded by messages directing risk elimination versus risk minimisation. Additionally, few parents acknowledged a known association between the recommendations to sleep infant in the same room to reduce the risk of SIDS.

This study emphasises that empowerment from one's own intellectual capabilities, on its own, is not enough to deal with the social reality of parenting. Further, this study raises concerns of inconsistency, lack of information and role modelling by health professionals and the need for further collaboration between researchers, policy makers, health professionals to ensure parents are supported with consistent messages.

## **P17**

### **SUDDEN UNEXPECTED DEATH STUDY UNDERLINES RISKS OF INFANTS SLEEPING IN SITTING DEVICES**

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**Background:** Although deaths in sitting devices are relatively uncommon, guidelines on SIDS prevention recommend that infants should not sleep in a seated position. Airway occlusion has been identified as a contributory mechanism in SIDS and may be relevant in deaths occurring in seating devices.

**Objective:** To describe sudden unexpected deaths in the Republic of Ireland which occurred while seated, with the aim of identifying any potentially modifiable risk factors.

**Methods:** Data from the National Paediatric Mortality Register of Ireland was examined for cases of sudden unexpected deaths in infancy (SUDI) in sitting devices over a twelve year period from January 1999 to December 2010.

**Results:** There were 387 cases of SIDS in the Republic of Ireland during the study period. Eight deaths (2%) occurred in infants while they were in a sitting device. Infants who died in the seated position were more commonly term and outside the peak age range (4-16 weeks) for SIDS deaths. Death more commonly occurred during daytime hours.

**Conclusions:** This may point to a distinct biologic mechanism of sudden death in this position which needs to be confirmed in larger studies and confirmation of these associations would facilitate the introduction of risk reduction strategies for this group.

## **P18**

### **SHARING A SLEEP SURFACE WITH INFANTS - RAISING AWARENESS OF RISKS. CAN THE DISCUSSION BE RATIONAL?**

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Co-sleeping or sharing a sleep surface has never been more controversial. However, as more risk factors become apparent, particularly in the neonatal period, it is increasingly important to provide information in a clear and consistent, but realistic way to new parents. This information is primarily provided by Health Professionals both in the ante-natal and post-natal period. Appropriate education is important if parents are to be equipped to make an informed decision.

In recent years there have been several reports tabled relating the deaths of infants who are sharing a sleep surface.

In NSW in 2010 a report was tabled entitled: "A preliminary investigation of Neonatal SUDI in NSW 1996-2008: opportunities for prevention". Many factors were outlined including the number of deaths in neonatal period and the relative high incidence of deaths of babies who were sharing a sleep surface with adults. In 2012 the Child Death Review Team identified inappropriate sleep environments for a majority of infants who died under one year of age (SUDI). SIDS & Kids in Australia has a proud history of developing & implementing a Safe Sleeping program to reduce the risk of SIDS. This program has contributed significantly to an 85% reduction in infant deaths over a 20 year period.

SIDS & Kids NSW has developed an education program which is used to raise awareness to Health Professionals & parents across NSW of the risks to a neonate and post-neonatal infant who is sharing a sleep surface with an adult. This presentation highlights the education program & some of the difficulties that arise in discussing this "controversial" topic.

## P19

### PERINATAL FINDINGS IN NIH COLLABORATIVE SIDS EPIDEMIOLOGY STUDY (1980) FINAL 757 CASES, RANDOM CONTROLS AND MATCHED CONTROLS

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**Objective:** The NIH Collaborative Epidemiology Study of SIDS carried out in 1980 was a prospective study of all SIDS cases that occurred at 6 sites paired with a random control (control A) and a control matched for birth weight below 2500 gm within 250 gm and race (Control B). Parents of cases and both controls were interviewed soon after the death and medical records abstracted. The results of the first 400 SIDS cases and their random and matched controls were analyzed to guide final analysis of the 757 cases and controls and results were published. However, results from all the cases and controls have not been published.

**Methods:** Medical records from 748 cases, 757 random controls and 757 matched controls were abstracted to assess prenatal and delivery factors. The significance level of factors were determined using Chi Square tests and for adjusted Odds Ratios, \*P<0.05, \*\* P<0.01, \*\*\* P<0.001.

**Results:** No significant differences between cases and either control were found in the percent of subjects experiencing toxemia, preeclampsia or hypertension, protein urea, or vaginitis. Urinary tract infection was found in 15.8% of SIDS, 8.6%\*\*Control A and 9.3%\*\*Control B. Weight gain <20lb was found in 35.5% of SIDS, 22.1%\*\*\*Control A and 25.6%\*\*\*Control B. Hemoglobin of <10mg was only slightly greater in SIDS than Control B in the lower risk groups of >20 years\* and non-smokers\*and was only slightly different from Control A for the total groups\*. At 24 and 28 weeks gestation maternal systolic and diastolic blood pressure was significantly lower\*\* in SIDS than Control B but only diastolic was lower than Control A\*\*. Use of illegal drugs was 25.6% in SIDS, 11.4% \*\*\* Control A and 14.4% \*\*\* Control B. Smoking had an Adjusted Odds Ratio of 1.72\*\*\*Control A and 1.63\*\*\* Control B. No differences were found in prenatal and delivery complications including premature rupture of membranes, amnionitis, maternal fever, meconium in fluid, vaginal bleeding, placenta previa or placental abruption. Delivery data was not different except for an increase in second stage <10 min, SIDS 30%, Control A 19.0%\*\*\*, Control B 22%\*\* . No differences were seen in heart rate abnormalities; tachycardia, bradycardia, type 2 (late) decelerations. 1 and 5 minute Apgar scores in SIDS were significantly lower than the random control A, 1 minute\*\*\*, 5 minute\*\* but not different from the birth weight matched control .

**Conclusion:** The study provided some support for the previously described risk factors of urinary tract infection, mild anemia, <20lbs weight gain, decreased third trimester blood pressure and increased use of illegal drugs and smoking. Delivery differences were not found and apgar scores were consistent with the increase in premature and low birth weight births in SIDS and Control B. A unifying hypothesis such as the Chronic In-utero Hypoxia Theory, popular in 1980s, is only minimally supported.

## P20

### REPORT OF CASE OF SUDDEN INFANT DEATHS IN VALENCIA (SPAIN)

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**Background:** Sudden Infant death syndrome (SIDS) occurs in infants less than one year while they are sleeping and we can't obtain an explanation after a methodic investigation. It includes autopsy, review of the scene and the clinical history. In Valencia (Spain) we have a special work group for the study of this patients and their family.

**Objectives:** The main objective is the study and classification " San Diego" of this infants to obtain the cause of death. Like secondary objectives we have studied the risk factors.

**Methods:** Retrospective and descriptive study of infants less than one year who died suddenly in Valencia since September 2006 to December 2012. We have obtained the information with an interview of the parents. We have used a model of logistics regression.

**Results:** We had 86 cases (50 boys). The most frequently age was between the first and the fourth month. The major part of the deaths were during the night at home. There are an elevation of incidence in January. In 39 infants (45.3%) we know the explanation of the death. The first cause of death was cardiology diseases, secondly pneumonia and finally sepsis. 4 of this 39 were doing bedsharing (10.2%) and 2 of them were sleeping in prone position (5.1%). 41 (41.6%) cases have been diagnosed by SIDS. 15 (36.5%) of this SIDS were doing bedsharing and 11 of this cases were sleeping in prone position (26.8%). 17 cases (19.7%) occurred in the neonatal moment, 6 were SIDS (3 bedsharing + 1 prone position) and the other were explained. The congenital heart disease was the most frequently cause of death and second was the sepsis. Our results show an statistical association between the risk factor (bedsharing) and the probability of SIDS (p=0.02) with a relative risk of 1.75 (IC 95% [1.15-2.66]).

**Conclusions:** The study of every death is complex and It needs a multidisciplinary team. However, the work of this group is important to obtain the reports and to do the study the family if It would be necessary. In our data collection we have found an statistical association between bedsharing and SIDS. For this reason is necessary another studies. This fact would be considered to create prevention campaigns.



## P21

### CORRELATION BETWEEN HEART RATE VARIABILITY AND AROUSALS IN INFANTS WITH FUTURE SUDDEN DEATH

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**Background:** In the study of heart rate variability, we reported the characteristics of sudden death of newborn or infants, decreased heart rate dynamics by detrended fluctuation analysis (DFA). We have previously reported that victims of sudden death of infant have a decreased arousability during sleep with fewer cortical arousals and more frequent subcortical activations, especially during active sleep, suggesting an incomplete arousal process. Prematurity or incompleteness of the autonomic nervous system may account for the pathogenesis of their decreased arousability.

**Objectives:** To examine the relationship between lower arousals and decreased heart rate dynamics in sudden death infants, we evaluated the correlation between the frequency of arousals and heart rate dynamics in future sudden death of infants.

**Methods:** Fifteen infants died suddenly some days or weeks after a night-time polysomnographic recording (PSG). In these PSG data, arousals were differentiated into subcortical activation or cortical arousal, according to the presence of autonomic and/or EEG changes from the PSG data. In the same data, heart rate variability and nonlinear heart rate dynamics by detrended fluctuation analysis during the whole night were analysed. The correlation between arousals and heart rate dynamics during sleep was evaluated.

**Results:** Average total sleep times were 391.9 min (active sleep 223.2 min, quiet sleep 168.6 min). Mean frequencies of arousals were 15.4 /hr. sleep during whole night, 22.1 during active sleep and 5.8 during quiet sleep. In the study of heart rate dynamics, mean normal-to-normal R-R (N-N) interval or standard deviation of all N-N intervals (SDNN) were 461.3, 56.6, respectively. A lower short-term (4-11 beats) scaling exponent (alpha 1) of DFA was 0.7, a long-term (>11 beats) scaling exponent (alpha 2) was 1.0.

The significant correlation was observed between frequency of arousals during active sleep and DFA alpha 1 (Spearman's rank correlation coefficient: 0.649,  $p < 0.05$ ). No significant differences were observed in total sleep and quiet sleep.

**Conclusion:** DFA alpha 1 primarily reflects the influences of autonomic and respiratory interactions on heart rate dynamics. The decreased alpha 1 may reflect their beat-to-beat heart rate instability caused by impaired autonomic neural regulations of the cardiorespiratory systems. The significant correlation between lower arousability and decreased DFA alpha 1 may reflect the autonomic dysfunction in future sudden death infants. From these results, it is suggested that decreased arousability in infants with sudden death may proceed from impaired autonomic regulations.

## P22

### SIDE-SLEEPING POSITION AND CO-SLEEPING - HARDLY MODIFIABLE RISK FACTORS FOR SIDS?

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**Objective:** To investigate whether there was a significant decline in side sleeping position and co-sleeping in Tyrol over the last five years due to a prevention campaign, and to assess factors associated with these risk predictors.

**Methods:** In an ongoing cohort study data on child care practices including sleeping position, co-sleeping, breastfeeding and use of a pacifier as well as smoking during and after pregnancy have been collected by questionnaire for all infants born in the Tyrol (study period 2008-2012,  $n = 22.390$ , response rate 64%).

**Results:** Prevalence rate for side sleeping decreased from 21.8% in 2005 to 18.1% in 2012 ( $p < 0.001$ ), but is still at a high level. Parents who laid their infant side were more likely to smoke during and after pregnancy and to practice co-sleeping. Moreover, despite the prevention program co-sleeping prevalence remained stable (24.7% in 2005 vs. 27.6% in 2012;  $p = 0.08$ ). Co-sleeping parents were more likely to put their baby in the prone or side sleeping position.

**Conclusions:** Although information on side sleeping position and co-sleeping being risk factors for SIDS became known among the population prevalence rates of both risk predictors are still high. Further efforts have to be made to achieve a safer sleeping position and environment for all infants.

## P23

### SIDS RISKS FACTORS IN SUDI CASES WITH LONG-QT SYNDROME GENETIC VARIANTS IN THE LYON AREA

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**Introduction:** Long-QT syndrome (LQTS) has been linked to a higher risk of sudden cardiac death. A molecular screening of the 5 most prevalent LQTS genes was performed in SUDI cases in all cases referred to the SUDI Reference Centre in Lyon since 2002.

**Aim:** To document SIDS risk factors in cases with LQTS genetic variants in our SUDI population in the Lyon area, especially age of occurrence, gender, tobacco exposure, viral infections and sleep environment at the time of death.

**Method:** We reviewed the clinical data of all the cases in which a genetic variant was identified on *KCNQ1*, *KCNH2*, *SCN5A*, *KCNE1* or *KCNE2* genes in our SUDI cases over a 10-year period. Fourteen cases (10 boys and 4 girls, aged 1 month 20 days to 18 months 1 day) qualified for this clinical study, out of 165 cases. Six cases had a genetic variant on *SCN5A*, 4 on *KCNH2*, 2 on *KCNQ1*, 1 on *SCN5A* and *KCNQ1*, 1 on *SCN5A* and *KCNE1*.

**Results:** Seven boys and 3 girls died before one year of age; their mean age of death was 4 months 3 days [1 month 20 days, 7 months 25 days]. Twelve deaths occurred during sleep: 4 infants were in a prone position, and 4 others had their face covered (2 were on their side and 2 were supine). Two deaths occurred during a loud crying spell. Eight infants were exposed to second-hand smoke. In 6 cases there was evidence of a viral or bacterial infection in the autopsy findings.

**Conclusions:** Three of the major risks factors for SIDS (masculine gender, inadequate sleeping environment, tobacco exposure) were present in most of our SUDI cases carrier of genetic variant on LQTS genes. A viral or bacterial infection may have been the trigger for the accident in some cases.

Our findings suggest that a genetic variant in one of the LQTS genes may not be the only cause of death but may constitute an additional risk factor that predisposes the infant to death in a critical situation. Besides specific preventive intervention (for example, medical treatment if indicated), SIDS prevention measures should be explained to families with a history of LQTS.

## P24

### FINDINGS AT NECROPSY IN INFANTS IN BOGOTA: DESCRIPTIVE STUDY

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**Introduction:** In 2010 in Colombia occurred 8.355 deaths in children under one year and 654.627 live births, and infant mortality rate of 12.76 x 1.000 live births. The probable cases of sudden and unexpected deaths in under one year children, according to vital statics, using CIE-10 code R95-R99, W75-76 and 83-84 were 372 occurred throughout the country and 120 in Bogota DC. Of the 120 cases, 115 (95.8%) were diagnosed by necropsy. This study shows the findings in autopsies performed on infants older than 1 month and less than 1 year who were admitted in 2010 to the National Institute of Legal Medicine and Forensic Sciences (INMLCF) in Bogotá.

**Methods:** This research is an observational cross-sectional descriptive, in the population of children older than one month and less than one year, who died in 2010 whose deaths have been investigated or are being investigated at the INMLCF, in Bogotá, Colombia. The total (150) of infants admitted to INMLCF, to whom he made a necropsy were taken. The autopsy reports and minutes of removal of the bodies were reviewed. A database was constructed to approach the diagnosis of SIDS / SUDI and characterize these deaths.

**Results:** Of the 150 infants were 86 men (57.3%) and 64 (42.6%) women. All children were older than 1 month and younger 1 year. The place of death was at home 91 (60.6%), hospital 22 (14.6%), other 9 (6%) without information 28 (18.6%). As for the activity during the recorded fact, reported that 39 children died while resting, sleeping, eating or performing other vital activity; in 22 children reported activity in the home, 84 had no information, and 5 cases were reported as other. As to the manner of death, the results were: natural 72 (48%) in study 58 (38.6%), indeterminate 8 (5.3%), violent accidental 3 (2%), violent homicide 1 (0.6%) and undetermined violent eight (5.3%).

The cause of death at the end of necropsy, 8 were by trauma, they including 2 cases of suffocation by upper airway obstruction. Other diagnoses were pneumonia (22 cases), intestinal infectious disease, liver, meningitis, influenza, congenital malformations (7) and most have cause of death in study (107). Not all 150 cases have complete information cadaver lifting, but co-sleeping and the prone position is found mentioned.

**Discussion:** In Colombia the children who die at home or in unknown circumstances should be subject to forensic necropsy. However, only about half (53.7%) have an autopsy. Compared children who die in Bogota, on average between 2005 and 2010, had an autopsy in 93% of cases. But in Colombia does not exist a protocol to study the possible cases of SIDS / SUDI so it is not possible to make a complete study and a definitive diagnosis. We hope the results of this study serve to draw attention to the importance of having a protocol for the study of cases of SIDS / SUDI, and also to strengthen SIDS prevention campaigns.

## P25

### SIDS/SUDI: COLOMBIA VITAL STATISTICS FINDINGS BETWEEN 2005-2011

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**Introduction:** In Colombia, a medicine doctor completes all death certificates. The codes are assigned by ICD 10 specialized technicians in the National Department of Statistics - DANE. Colombia's Death certificates have 46 items of which 12 are specific to children under 1 year.

We reviewed the death certificates of children under 1 year in Colombia, between 2005 and 2011, with underlying cause of death classified by the ICD 10 codes compatible with the diagnosis of SIDS/SUDI according to the WHO definitions: R95: sudden infant death syndrome; R98: Death without assistance. Found dead. Death in circumstances where the deceased's body was found and the cause could not be discovered; R99: Unknown cause of death; W75: accidental suffocation and strangulation in bed (includes suffocation and strangulation due to pillows, the body of the mother or bedding); W76: Other strangulations and accidental hangings; W83: Other specified obstructions of breathing; and W84: unspecified obstruction of breathing.

We found a total of 2,664 deaths in children under 1 year at any of these diagnoses and we characterized these deaths by sex, age, seasonality, department of residence, how to determine the cause of death, place of death and other variables.

**Methods:** This research is a descriptive case series, in the population of children less than one year old; who died in Colombia Between 2005 and 2011 whose deaths have been classified with ICD-10 codes R95, R98, R99, W75, W76, W83 and W84. With the information of vital statistics, these deaths were characterized by comparing the findings by year and department of residence, in order to find social determinants such as poverty that were affecting the outcome. A correlation between socioeconomic indicator and mortality from these diagnoses was conducted.

**Results:** By vital statistics between 2005-2011 we found 2,664 infants deaths with cause compatible with SIDS/SUDI.

During these 7 years there is a tendency to decrease, especially in the year 2011. Few cases with W75, 76 and 83 codes (1.31%) were found. Of the total of cases, 482 were R95 and necropsy was performed in less than half (43.77%). With the R98 code a large number of cases were found, in contrast to findings in other countries. The largest number of cases corresponded to W84, which are very few cases in Bogotá DC, though this city has 30% of all cases diagnosed by autopsy in more than 90%. 57% were male and 43% female; 58% patients underwent autopsy; 57% died at home and 34% in health institution; 77% were younger than 6 months; the month in which the events took place was between 7 and 8. Differences between the departments are not directly related to the level of poverty in the Department, but it is possible that difference does exist within each.

Cases of SIDS/SUDI Colombia 2005-2011

	2005	2006	2007	2008	2009	2010	2011	Total
<b>R95</b>	150	79	47	47	65	51	43	<b>482</b>
<b>R98</b>	71	105	99	101	145	131	100	<b>752</b>
<b>R99</b>	43	60	67	57	90	106	80	<b>503</b>
<b>W75</b>	6	2	6	1	2	2	0	<b>19</b>
<b>W76</b>	1	1	1	1	0	2	0	<b>6</b>
<b>W83</b>	2	2	2	1	1	1	1	<b>10</b>
<b>W84</b>	136	183	164	126	120	80	83	<b>892</b>
<b>Total</b>	<b>409</b>	<b>432</b>	<b>386</b>	<b>334</b>	<b>423</b>	<b>373</b>	<b>307</b>	<b>2664</b>

**Discussion:** The ICD- 10 codes that we chose and presented in this work are considered the best approach to measuring the impact of this event in our country. A standardization of codes that can be used would be an important step in being able to compare statistics from different countries and also to follow up in the future. In the next revision of the ICD it is important to ask again how these events should be ranked, especially the R95(SIMS), and also define how to group some codes, as shown in this study, are associated with SUDI.

## P26

### MANAGEMENT OF SUDDEN INFANT DEATH SYNDROME IN REFERENCE CENTERS IN FRANCE IN 2013

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In France, nearly 500 infants still die each year unexpectedly. In 2009, the French Institute for Public Health Surveillance published a survey showing a great heterogeneity in the management of sudden unexpected infant death (SUID) cases.

The aim of our work was to evaluate the actual diagnostic approach to sudden unexpected infant death in the different reference centers in France and to determine in which degree the recommendations' of the French National Authority for Health (Haute Autorité de Santé, HAS) are applied.

We conducted a multicenter cross-sectional epidemiological study by email send to the 36 reference centers for SIDS with questions about examinations usually performed in SIDS cases. We also submitted six SUID test cases for death classification to the different reference physicians.

Twenty nine of thirty six centers (81%) responded. Among recommended tests, only blood cultures, analysis of cerebrospinal fluid and autopsy proposal are performed in 100% of the centers. Other investigations are not carried out systematically: skeleton radiography: (65%), cranial CT scan (58%), eye fundus (21%), metabolic analysis (65%) and blood toxicology (62%). Main reasons for non-completion of these tests were hospital practice, lack of resources, technical difficulties, cost of tests and difficulty in interpreting results (50% reported not knowing the post mortem biological standards). None of the institutions apply the HAS recommendations entirely. The classification of causes of death test cases also varied between the centers with a maximum of 63% concordance in their responses.

In 2013, in France, there is still an important heterogeneity in the diagnostic set up of SIDS, a non exhaustive implementation of the recommendations of the French National Authority for Health and a non satisfactory SIDS classification tool because of a great discordance between physicians. These results explain the current difficulties in obtaining reliable epidemiological data, as many teams do not use all the investigations recommended to find the cause of death. Thus, the establishment of a national registry would provide accurate and up to date epidemiological, environmental, medical and biological data in order to identify the events causing death, and propose appropriate means of prevention.

## P27

### THE INTERACTION BETWEEN INFECTION AND INCREASED ENVIRONMENTAL TEMPERATURE ON NEONATAL RAT BREATHING

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**Background:** SIDS is one of the most common causes of post-natal infant mortality in the developed world. There are a number of identified risk factors such as prenatal cigarette smoke exposure, hyperthermia due to over-wrapping of the child and infection, but the mechanisms underlying SIDS remain elusive. It is believed that a combination of a failure of sufficient cardio-respiratory response to multifaceted environmental stress during a critical period in a vulnerable infant may result in SIDS. This study examines a double hit model of exposure to high environmental temperature and/or infection on cardio-respiratory outcomes.

**Objective:** To examine the interaction between lipopolysaccharide (LPS)-induced infection and hyperthermia on cardio-respiratory outcomes of neonatal rats during normoxia (21% O<sub>2</sub>) and hypoxia (10% O<sub>2</sub>).

**Methods:** Male and female Sprague Dawley neonatal rats were studied at P6-P8. Rats were examined under either a) thermoneutral (33°C) or b) hyperthermic (38°C) conditions. Within each group, rats were allocated to control, saline or LPS (200µg/kg) treatments, (n=5 for each group). Breathing was examined using head-out plethysmography and metabolism, ECG and body temperature were recorded simultaneously throughout the experiment. The protocol included a 10min settling period, followed by 5min baseline recording at normoxia (21%O<sub>2</sub>) and 5min hypoxia (10% O<sub>2</sub>) exposure, followed by a 10min recovery period in normoxia.

**Results:** Our data suggests that a combination of hyperthermia and LPS blunts hypoxic ventilatory response in neonatal rats.

**Conclusion:** These observations provide evidence that infection and hyperthermia may lead to poor respiratory outcomes when challenged with low oxygen and may place infants at higher risk for sudden infant death syndrome.

## P28

### THE EFFECTS OF EARLY LIFE EXPOSURE TO CHRONIC INTERMITTENT HYPOXIA ON ISOLATED STERNOHYOID MUSCLE FORCE

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**Introduction:** Chronic intermittent hypoxia (CIH) is observed in a number of conditions but most notably in obstructive sleep apnoea syndrome (OSAS) and apnea of prematurity (AOP). There is a little information on the effects of CIH during early life on respiratory muscle physiology, despite the clinical relevance. Skeletal muscle has enormous capacity for re-modelling, as evident in various physiological and pathophysiological settings. Stimulus pattern, intensity and duration are important factors driving phenotypic plasticity in skeletal muscle; moreover age and sex are important factors in determining the capacity of the muscle to re-model.

**Aim:** We sought to investigate the effect of CIH during a) *in utero* and b) *neonatal* development on the functional properties of respiratory muscles of developing male and female rats at postnatal day (P) 22.

**Methods:** 3-4 pregnant Wistar dams were exposed in commercial environmental chambers to intermittent hypoxia (21%-5% O<sub>2</sub>; 12 cycles per hour; 8hr/day for 21 consecutive days) a) from the first day of gestation (G0) until G20 before litters dropped b) from the first neonatal day of life (P0). Sham experiments (continuous normoxia) were run in parallel. The offspring of the dams were then allowed to develop and half were studied at P22 and the other half at P42. The Wistar rats were killed humanely and the diaphragm and sternohyoid (a representative pharyngeal dilator) muscles were surgically removed. Isometric contractile properties of isolated muscle strips were measured in tissue baths containing Krebs salt solution at 35°C under hyperoxic (95%O<sub>2</sub>/5%CO<sub>2</sub>) conditions. Force-frequency relationship and fatigue index (*ie* ratio of force at 5min of fatigue to initial force) were examined. Fatigue was assessed in response to repeated tetanic contractions (40Hz, 300msec train duration) every 2 seconds for 5 minutes.

**Results:** *In utero* CIH caused a significant decrease in sternohyoid force-frequency relationship in female and but not male rats (female P< 0.05 vs. male P=0.39; 2-way ANOVA). Peak sternohyoid muscle force was significantly decreased in female (16.0±0.7 vs. 12.8±0.6; mean±SE; sham vs. CIH) but not male rats (14.1±0.6 vs. CIH 13.72±0.6); N=9 for all groups. Impairment in female sternohyoid muscle was reversed by time and was not apparent at P42. Neonatal CIH caused a significant decrease in sternohyoid force-frequency relationship in male and female rats (P< 0.05; 2-way ANOVA). Peak sternohyoid muscle force was significantly decreased in male (14.1±0.6 vs. 11.6±1.0; mean±SE; sham vs. CIH) and female rats (16.0±0.7 vs. CIH 11.5±0.4); N=8-9 for all groups. The impairment of force persisted to P42 in male but not female sternohyoid muscle

**Conclusion:** CIH exposure during gestation causes airway dilator muscle weakness in female offspring. Neonatal CIH exposure causes sternohyoid muscle weakness in both male and female rats, which in human infants could increase the propensity for airway narrowing or collapse.

## P29

### NOVEL METHOD FOR CONSCIOUS AIRWAY RESISTANCE AND VENTILATION ESTIMATION IN NEONATAL RODENTS USING PLETHYSMOGRAPHY AND AN ARTIFICIAL LUNG

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**Background:** Measurement of breathing parameters in neonatal rodents is a mainstay in fundamental research aimed at determining the physiological abnormalities underlying respiratory disorders such as Sudden Infant Death Syndrome (SIDS). To date we have lacked a method of determining airway resistance in conscious neonatal rodents and have relied heavily on whole body plethysmography (WBP) to measure tidal volume. In WBP, tidal volume measurements are based on the 'barometric method', which assumes that warming and humidification of air entering the lungs is responsible for chamber pressure oscillations during breathing. However, chamber pressure is also influenced by a 'mechanical component', the rarefaction and compression of air with each breath that is dependent on airflow and airway resistance. In adults, the mechanical component is believed to be a negligible contributor to the chamber pressure signal compared to the barometric component; however, in neonates this may not be the case, potentially invalidating the use of WBP as a method for measuring neonatal tidal volume.

**Objective:** Using a novel device to simulate the mechanical properties of a neonatal lung and airway, we aim to: (a) determine the contribution of the mechanical component to the chamber pressure signal produced by breathing of neonatal mice within a WBP chamber; and (b) develop a novel method for determining the airway resistance of conscious neonatal mice.

**Method:** A mechanical lung device was constructed to replicate the neonatal WBP signal. Using two computer-controlled syringes to oscillate a fixed tidal volume of gas through a glass chamber at fixed frequency, with increased resistance at one piston simulating the lung compartment, we assessed the contribution of the mechanical component to the neonatal WBP pressure signal. [Tidal volume, respiratory frequency, and airway resistance could be independently manipulated in our apparatus.] Secondly, using tidal volume measurements derived from head-out plethysmography and the WBP pressure signal amplitude at 100% humidified [and warmed] airflow we derived the airway resistance of PD 6 neonatal mice (n=6).

**Results:** We confirm the mechanical component of neonatal breathing dominates chamber pressure fluctuations in WBP. Furthermore, we describe a novel method for conscious airway resistance and ventilation estimation (CARVE) in neonatal mice.

**Conclusion:** Our data highlights the need for caution when applying the barometric method on neonatal rodents, with important implications for investigations into childhood respiratory disease. Furthermore, our novel CARVE method could aid in the assessment of developmental, genetic and pharmaceutical therapies on neonatal airway resistance.

## P30

### REVIEW OF NATIONAL PAEDIATRIC MORTALITY STATISTICS IN IRELAND 2006-2011; ARE SOME DEATHS PREVENTABLE?

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**Introduction:** Unexplained deaths in children under 15 years are increasing, while rates of SIDS are falling. Previous studies of SIDS in Ireland have identified preventable factors with a successful reduction in SIDS numbers over the past two decades. This study aimed to establish accurate figures on mortality in children under 15 years in Ireland over a 6 year period; to define the current main causes of death in this age group and to determine what proportion of deaths are potentially preventable.

**Methods:** All cases of sudden unexpected deaths in infants and children are reported to the National Paediatric Mortality Register. Basic cause of death information coded as per the ICD-10 coding system was obtained from the Central Statistics Office of Ireland. International statistics from the Eurostat and WHO websites were retrieved and compared to Irish data.

All certified deaths in children under 15 in Ireland between 2006-2011 were reviewed by specialist paediatric pathologists.

**Results:** 2353 paediatric deaths were registered with the CSO during this period with complete information available on 2280. The leading cause of death in children >1yr was "External Causes" which category included suicide, accidental and non-accidental injury (NAI), (205/707 - 29%). 2% of deaths in the 1-14yr age group were classified as NAI. In 23 of 2280 cases there was ambiguity as to the cause of death-recorded as "Undetermined or Open Verdict". A discordance rate of 4% in cause of death coding was identified in this review. Death rates due to infection on review increased by 1%.

**Conclusions:** This study shows that a significant percentage (29%) of deaths in children aged 1-14yrs were potentially avoidable. It also highlights the importance of accuracy in coding systems for national statistics, particularly in relation to preventable deaths.

## P31

### INFANTS AND SAFE SLEEP: WHAT DO PARENTS SEE IN STORES?

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**Background and rationale:** There is clear evidence that safe sleep environments can reduce the risk of sudden unexpected infant death. Parents and caregivers have access to professional advice, directly and via websites on what is a safe sleep environment. Parents are also exposed to multiple sources of informal information on the same topic. Displays in retail stores may be a visual example of what might be acceptable safe sleep practice to those who are planning for an infant.

We investigate what proportion of retail stores are upholding sleep environment recommendations put forth by the Public Health Agency of Canada.

**Methods:** We assessed elements of sleep environments in retail stores. Stores were visited and every sleep environment that was on display was analyzed and photographed (n=79). These photographs were later reviewed and standardized questions about each sleep environment were answered. It was also assessed whether the store sold items that could potentially clutter a sleep environment (quilts, heavy blankets, positioning devices and bumper pads).

**Results:** The cribs as furniture pieces all met Canadian standards. In other words, all sleep environments contained a crib that had a firm and flat mattress that was no more than 15cm thick, a tight fitting bottom sheet, and slats that were no more than 6cm apart. Portrayed sleep environments for the most part did not meet recommendations and demonstrated unsafe practices. 87.3% had at least one extra item such as a pillows quilt, heavy blanket, toy, or bumper pads in the sleep environment. The most common item to clutter a sleep environment was a heavy blanket or quilt, which were seen in 75.9%. This was followed by bumper pads (40.5%), toys or stuffed animals (27.8%) and pillows (20.3%).

**Interpretation:** The infant sleeping environments displayed in retail stores do not presently reflect the Public Health Agency of Canada's recommendations. Most egregiously, 87.3% of displays had at least one item in a crib associated with infant death and 87.5% of stores had potentially unsafe items for sale. The infant sleep displays portrayed may be influencing individuals to believe that cluttered sleep environments are appropriate and safe. Action is needed to have retail stores follow evidence-based sleep environments in their displays. At the least, there should be a clear, highly visible statement listing current safe sleep recommendations.

### **P32**

#### **TODAYS BABY: A QUALITY IMPROVEMENT CAMPAIGN FOR SAFE INFANT SLEEP IN BIRTH HOSPITALS**

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**Background:** Physicians and nursing staff are important trusted sources of health information for parents. When physicians and nursing staff do not correctly model safe sleep behavior or address safe sleep recommendations with parents, parents are less likely to follow these recommendations at home. Effectively delivering such information can improve the quality and safety of care to infants and could lead to improvement in infant mortality. However, health professionals frequently have poor understanding of the rationale for the recommendations and/or do not routinely deliver the information. Therefore, nurse education interventions modeled after other successful programs that address the rationale and common misconceptions about safe sleep guidelines may be very effective. Since all U.S. hospitals are required to document efforts in improving quality of health care delivery to maintain accreditation and to be eligible for federal payments, using quality improvement (QI) methodology may be an innovative way to deliver and evaluate this education.

**Objectives:** To use QI techniques in birth hospitals to 1) improve the proportion of infants being placed supine; 2) decrease the proportion of infants bedsharing with the mother; 3) decrease the proportion of infants with soft bedding in their sleep environment; and 4) improve education regarding safe infant sleep for all mothers.

**Methods:** QI programs were initiated on a rolling basis in 2014 in 8 hospitals throughout the U.S. All units received basic QI training and introduction to Plan-Do-Study-Act cycles (a well-established QI method). A team of safe sleep experts visited each participating hospital nursery to review safe sleep measures and provide a Safe Sleep toolkit (PowerPoint presentations and teaching tools, with specific emphasis on frequently cited barriers to adherence, such as concerns about infant choking, comfort, and warmth). Each unit submitted biweekly, unannounced practice audits (documenting infant sleep position, sleep location, presence of soft bedding, and safe sleep education), using standardized practice audit tools and methodology. Data were validated and posted online, so that nurseries could view their biweekly performance data compared to aggregate data for all participating units. Participants could receive continuing education units and maintenance of certification credits.

**Results:** We will present preliminary results from the PDSA cycles. Hospitals were universally receptive to and enthusiastic about receiving tools for implementing QI programs in safe sleep.

**Conclusions:** Quality improvement programs are an effective tool to improve healthcare provider knowledge and understanding of safe sleep recommendations, and may result in enhanced parent education.

### **P33**

#### **THE GENOMIC LOAD OF HETEROZYGOUS DELETERIOUS MUTATIONS: RELEVANCE TO FETAL, INFANT AND CHILDHOOD DEATH**

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**Background:** Post mortem examination in the cases of fetal, infant and childhood death using standard techniques does not always lead to an adequate explanation of the cause of death. When standard techniques fail we need to employ modern molecular techniques which include whole genome screening and proteomic analysis.

**Objectives:** In this poster we present evidence, based on a mathematical model, that introducing the molecular autopsy is likely to yield valuable results.

**Methods:** The model envisages genes acting in complex networks in order to perform essential functions. Heterozygous deleterious mutations in the genome will interact synergistically to degrade performance. Thus individuals with the most deleterious mutations will be most at risk when exposed to an environmental stress such as bacterial infection. Rare recessive disease is more common in the offspring of cousin marriages than in the general population; but over 90% of the children of cousin unions do not have any recognizable recessive disease and are as healthy as the offspring of non-consanguineous unions.

We have used this information to estimate the mean number of heterozygous deleterious mutations in the genome of normal healthy adults (M) and the mean number of new deleterious mutations arising in gametogenesis and entering the genome of zygotes (N). The nature of meiosis indicates that the number of deleterious mutations will show a Poisson distribution. Furthermore there must be strong selective pressure against the zygotes at the upper end of the distribution otherwise the mean of the distribution would rise with each generation.

**Results:** The best estimates obtained using the model are that M is between 5 and 9 and N between 0.5 and 1.5 assuming that the number of functioning genes in the human haploid genome is less than 30,000. The total zygote loss to maintain M constant over succeeding generations is of the order of 30%. Most of the loss will occur at a very early stage in development but if the normal rules of biology apply some will occur later with the risk of death falling through fetal and infant life and into early childhood. The main mechanism according to this model will be synergistic interaction of heterozygous deleterious mutations acting in complex redundant genetic systems but single lethal mutants will also have a role, as will X linked recessives.

**Conclusions:** We suggest that whole exome or whole genome screening should be used in every fetal, infant and childhood death that is not explained after a conventional autopsy. The technology to undertake genome screening is now available and the cost, although not inconsiderable, is comparable to that of some of the standard investigations that are currently used.

### P34

#### **THE MALE EXCESS OF FETAL, INFANT AND CHILDHOOD DEATHS; A POSSIBLE ROLE FOR X LINKED DELETERIOUS MUTATIONS**

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**Background:** Males are more likely to die than females at every stage of *in utero* development and throughout life. We suggest that this is because males have only one X chromosome and suffer the equivalent of inbreeding depression on 5% of their genome. Inbreeding depression occurs in animals in which brother sister mating through several successive generations leads to loss of genetic heterogeneity. In this condition recessive disease will be expressed at any locus with a deleterious mutation and there will be a loss of heterozygous advantage. Inbred animals are sickly with increased morbidity and mortality *in utero*, in early development and in later life.

**Objectives:** To explore the potential value of the molecular autopsy (genomics and proteomics) in males based on the hypothesis that males are at a disadvantage relative to females because they have only one X chromosome.

**Methods:** We have estimated the expected number of deleterious mutations on X using data from the frequency of recessive disease in cousin marriages (see previous poster). This information has then been combined with the observation that the male to female ratio of deaths in sudden unexpected death in infancy (SUDI) is 3 to 2 (Mage's ratio).

**Results:** We have calculated that between 5% and 25% of males are likely to have a deleterious mutation on X and this will raise their risk of sudden unexpected death in infancy (SUDI) by between 3 and 11 times if the male excess is a consequence of X linked recessives. If the male excess of deaths is due to loss of heterozygous advantage then the effect of X linked recessives will be less marked.

**Conclusions:** 1. Whole exome or whole genome screening of male infants who have suffered SUDI is likely to have a high information yield and its feasibility should be explored. Similar arguments also apply to fetal and childhood deaths although Mage's ratio does not necessarily apply. 2. Heterozygous advantage aids in fighting infection and if the male excess of death is due to loss of heterozygous advantage then this strengthens the argument for the role of infection in infant death. Proteomic analysis of body fluids (urine, CSF and blood) obtained at autopsy in order to identify bacterial toxins should also be undertaken. This is the other half of the molecular autopsy.

### P35

#### **'BRIDGING THE GAP' - OVERCOMING THE BARRIERS TO EFFECTIVE ENGAGEMENT WITH FAMILIES AT HIGHER SUDDEN UNEXPECTED DEATH IN INFANCY RISK**

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**Aim:** To describe the experiences of Community Health workers (CHW) overcoming the barriers for effective engagement with whanau (family) with a higher risk of Sudden Unexpected Death in Infancy (SUDI) in South Auckland, New Zealand.

**Background:** Sixty-one percent of births in South Auckland are of Maori or Pacific infants, and 52% of the births occur in families living in deciles 9 and 10 (most deprived) areas. The SUDI rate ratio is 4.46 in Maori and 2.49 in Pacific infants compared with European New Zealand infants. Fifty percent of Maori mothers are reported to have smoked in pregnancy. Community health workers are an integral part of maternity services in CMDHB. They facilitate the interaction between clinical staff and pregnant women, mothers, babies and their families when optimal care may be hindered, for example; by a lack of transport to clinic, or a perception by the family that antenatal care is not required. CHW's are very experienced in negotiating the path to good care for high risk families.

The Haumaruru Moe o te Pepe - South Auckland Safe Sleep study utilised the skills Kristine Day and Eseta Nicholls, both as CHW's but also as experienced research assistants, to recruit 240 high risk Maori and Pacific whanau to participate. They were trained to deliver a comprehensive safe sleep programme associated with the Pepi-pod safe sleep device, and to perform the baseline and follow up interviews at two and four months after the baby was born.

**Discussion:** We will discuss the challenges in engaging with high risk Maori and Pacific families and describe how these were negotiated, with examples under the following headings;

1. Initial contact and staying in contact - establishing a rapport with the mother and whanau
2. Ways of negotiating conflicts between ideal situations and practical realities –adapting to conditions whilst preserving the integrity of safe sleep
3. Cultural compatibility
4. Responding to a need

The experiences shared in this presentation promise to be provide insights and practical strategies to engage with families at higher risk of SUDI. Safe sleep interventions can only result in positive changes in behaviour if effective engagement occurs.

### **P36**

#### **SUDDEN UNEXPECTED DEATH AND BRONCHITIS**

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Sudden Infant Death Syndrome (SIDS) is one of the leading cause of infant death under one year old. Though the various cause and mechanism are speculated, pathogenesis and mechanisms of sudden death is still unknown. Recently the concept of Sudden Unexpected Death in Infant (SUDI), which grasped sudden death comprehensively, is widely accepted. The sudden death accompanying respiratory tract infection occupied large space in SUDI. Especially Respiratory syncytial virus (RSV) is recognized one of major pathogen. Apnea is the most common symptom of RSV infection that is recognized intensively up to 6 month after birth. On the other hand, sudden death often recognized in the child beyond 6 month after birth. The clinical aspect of sudden death which was witnessed is that a cardiopulmonary arrest occurred suddenly and no to react intensive resuscitation. The mechanism of sudden death is suspected cardiac arrest not to be leaded by apnea.

We performed pathological investigation 4 cases infant who identified SUDI accompanied by RSV infection. They were ranged seven month after birth to 2 years old.

In this study Substance P (SP) was targeted to reveal the expression site and level in central nerve system, lung and heart. We performed it with immunohistochemical technique.

SP expression was recognized in N. solitaries, N. ambiguus and N. Dorsalis nervi vagi in the medulla oblongata. The immunoreaction to anti SP was recognized infamation cells, wall of vessels and the cell of bronchial glands in the lung. Especially positive vessel's wall was recognized in the area of pulmonary edema. Although the reaction was observed in the nerve fiber in the atrioventricular node with the heart, it did not accept to a cardiac muscle cell.

Previous studies revealed that the expression of SP was greatly increased by RSV infection. Our study revealed the SP expression was up regulated in neurons in brainstem which concerned the cardio-respiratory control. Over expressed SP directly projected from N ambiguus to atrioventricular node that may become a cause of cardiac arrest. It is not clear why such a phenomenon happens to the child whom not a young baby but age followed.

### **P37**

#### **TEXT MESSAGING VS TELEPHONE CALL: WHICH IS MORE EFFECTIVE FOR REACHING YOUNG MOTHERS?**

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**Background:** Obtaining follow-up data from participants can often be a challenge. Classic methods (telephone calls, postcards, etc.) can require much time and effort, and multiple attempts are often required to contact participants.

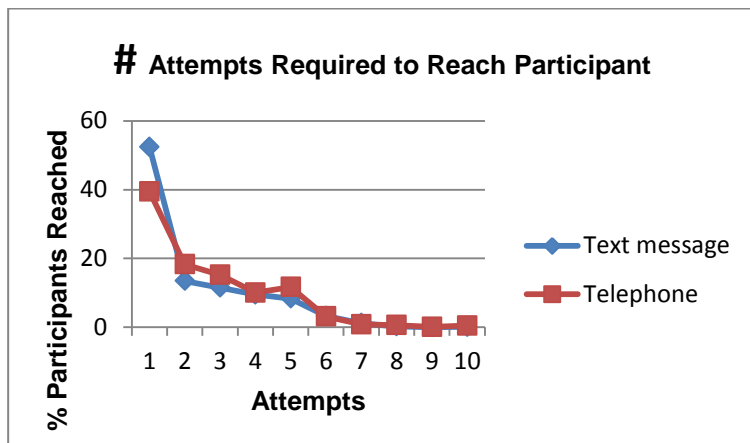
**Objective:** To determine if text messaging is more effective than telephoning as a method of contacting study participants.

**Methods:** This study was part of a larger study of African-American mothers (n=1201) of infants 0-6 months of age who required follow-up interviews 2-3 weeks, 2-3 months, and 4-6 months after the infant's birth. Mothers were initially contacted by telephone or text message, based on staff member assigned. Number of contact attempts, duration of time required to contact participants, and participant demographics were recorded. Statistics were calculated using Stata 9.

**Results:** There were 2346 initial contact attempts between July 2011 and July 2014. 1000 (42.6%) were at 2-3 weeks, 788 (33.6%) at 2-3 months, and 558 (23.8%) at 4-6 months. Mothers had a mean age of 26.5 (range, 18-43) years; 77.9% were unmarried, 21.1% married, and 0.9% divorced/separated. 50% had at least a high school diploma or GED certificate. Approximately 60% were of low socioeconomic status (SES), as determined by eligibility for Medicaid (public health insurance) and WIC (nutritional supplement program for mothers, infants, and children). The initial contact attempt was by text message in 853 (36.4%) and by telephone in 1493 (63.6%). Successful contact (i.e., follow-up survey completed) was more likely if the initial contact was by text message (86.0% vs. 76.2%, p<0.001). This was true regardless of participant marital status, educational status, socioeconomic status, and age. This was also true whether the interview was at 2-3 weeks, 2-3 months, or 4-6 months after the infant's birth. If the initial contact was by text message, fewer attempts were required before the participant completed the follow-up interview; mean 2.2 vs. 2.6, median 1 vs. 2, p<0.01).

**Conclusions:** In this sample of African-American mothers, successful contact was more likely if the initial contact was by text message rather than by telephone. Although this finding is specific for African-American mothers participating in a research study, this may have implications for other settings in which outreach is required.





### P38

#### SEARCHING FOR GENE VARIANTS IN SUDDEN DEATH IN CHILDHOOD WITH FEBRILE SEIZURES (SUDC-FS), SUDEP AND SIDS USING WHOLE EXOME SEQUENCING IN “TRIOS”

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**Background:** Sudden unexplained death in childhood (toddlers) associated with febrile seizures (SUDC-FS) is the unwitnessed sudden death of a child greater than 12 months of age with individual and family history of febrile seizures. These children have many features in common with individuals dying of sudden unexplained death in epilepsy (SUDEP) and sudden infant death syndrome (SIDS), including sudden, sleep-related death and discovery in the prone position. A subset of SUDC-FS brains also exhibit hippocampal and temporal lobe anomalies similar to those observed in temporal lobe epilepsy (TLE), suggesting that a fever induced seizure with focus in the hippocampus causes the sudden death of the toddler during sleep-consistent with mechanisms proposed for SUDEP. Familial evidence strongly supports a genetic component to SUDC-FS as there is a both a personal and a family history of febrile seizure in each case, including autosomal dominant inheritance in 3 families. However, the genetics of SUDC-FS are completely unknown. These observations suggest it is a new genetic disorder that may provide novel insight into the mechanism of all sudden, seizure-related deaths.

**Objectives:** To identify genetic variants that underlie the pathogenesis of SUDC-FS, SUDEP and SIDS using whole exome sequencing (WES) and genetic linkage analysis on SUDC-FS family “trios” (i.e., case and both parents). We seek to identify de novo or inherited rare variants with clear functional significance (e.g., mutations residing within coding, splice-site, or regulatory regions of genes), including those previously associated with febrile seizure, SUDEP, and SIDS, e.g., neuronal and cardiac ion-channel mutations that are present in the case and one or both of the parents are likely to be pathogenic.

**Methods:** Purified genomic DNA (200 ng) from “trios” was submitted to Axseq Technologies (Korea) for processing for WES. Exon enriched DNA libraries were generated from genomic DNA using Agilent SureSelectXT All Human V4 capture kit before being analyzed by 100x (50x on target) paired-end sequencing with Illumina HiSeq 2000. Sequencing data was then analyzed using a custom build, rule based “Variant Explorer” pipeline that integrates family linkage and variant screening using publicly available variant databases such as EVS and the 1000 genome project to identify variants of interest.

**Results:** WES identified an average of 19,754 SNPs affecting gene-coding regions including 8,800 non-synonymous SNPs and 459 indels per sample analyzed. Confirmation analysis of rare potentially pathogenic variants identified all three trio members is underway.

**Conclusions:** In this study, we report our genetic “approach in families with SUDC-FS, and initial results from the analysis of our first SUDC-FS trios analyzed by WES. This approach has the potential to identify gene variants that underlie the pathogenesis of SUDC-FS, SUDEP and SIDS. Importantly, these gene variants may ultimately be used as part of a genetic screening test to identify individuals at risk of seizure-related death regardless of age including living toddlers with FS at risk for death among the thousands of toddlers with benign FS in the United States each year.

### P39

#### A SUCCESSFUL INTEGRATED APPROACH TO SUDDEN UNEXPECTED INFANT DEATHS (SUDI) IN TUSCANY

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A global approach to the Sudden Infant Death Syndrome (SIDS) should necessarily include health policies intended to promote both the 'safe to sleep' campaigns and the timely and correct performing of autopsies in every case of Sudden Unexpected Infant Death (SUDI).

In Tuscany, the SIDS Risk Reduction Campaign has been actively carried out since 2003, whereas in 2009 a project aimed at implementing the multiagency management of SUDI was also initiated. Starting from 2004 the Regional Health Agency, with the collaboration of the Meyer Children's Hospital, introduced a multiple choice questionnaire on the infant sleeping position in three different surveys. The purpose of the first survey was to specifically investigate the risk factors for SIDS, while the second and the third focused on the birth pathways and breastfeeding. The first survey involved 1,427 parents of children aged two to three months who were asked to fill out a questionnaire at the time of the first immunization of their infants. The second was conducted in 2005 and involved 2,324 women who had delivered in the hospitals of Tuscany and who received a questionnaire by mail about three months after delivery. In the last survey conducted in 2010, the questionnaires were administered in 44 immunization centres to 2,670 parents of children aged 2-3 months at the time of the first dose of vaccine. The results showed that the proportion of children put to sleep in the supine position gradually increased from 2004 to 2010, rising from 55.0% to 72.0%. The largest increase was due to the reduction of the side sleeping position, which dropped from 38% in 2004 to 20% in 2010. The prone position showed a slight increase from 6% to 9% during the same period. Interestingly, in the 2010 survey no differences were observed in the supine position between children born to foreign and Italian mothers, while in the previous survey (2005), only 60% of children who were born to foreign mothers were put to sleep on their backs compared to 66% of children of Italian mothers. The SUDI cases were managed by a multiagency task force which included the Regional SIDS Centre, the emergency services, and a group of selected pathologists. The infant deaths were classified as SIDS, SUDI of known origin, and Unclassified Sudden Infant Deaths (USID). In five years there have been 35 sudden unexpected infant deaths which account for an overall mortality rate of 0.22‰ per 1,000 live births. Seventeen of these were SIDS cases (48%), ten were SUDI (28%) and eight were USID (24%). Autopsies were performed in 86% of cases and 7 audits were performed in cases in which the post mortem examinations were either not carried out, or carried out incorrectly in procedural terms. Conclusions: The low mortality rate and satisfactory impact of the 'safe to sleep' message in our region, encourage us to continue our efforts towards achieving a greater reduction of sudden deaths in infants in the future.

#### **P40**

### **IMPROVING SAFE SLEEPING PRACTICES IN CHILD CARE SETTINGS IN AUSTRALIA: EVALUATION OF THE SIDS AND KIDS "SAFE INFANT SLEEPING KIT"**

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<sup>1</sup>SIDS and Kids Australia, <sup>2</sup>Health Promotion and Bereavement Support, SIDS and Kids Australia

**Background:** Since 1999, there has been an increasing demand by parents for the use of informal and formal child care services in Australia and the forecast purports this demand will increase to over 500,000 children aged 0-12 years needing care by 2020. In 2008, 53% of women with infants less than 5 years of age had returned to the workforce and 9% of children aged less than 12 months were in formal child care.

Given SUDI remains the main cause of unexpected infant mortality in the post-neonatal period in Australia it is imperative for staff employed in child care settings to ensure that children in their care are safe at all times and that service policy and procedures reflect evidence based research. Child care professionals can also play a vital role to educate, support and influence parents and other caregivers, are powerful role models to prevent the risk of these deaths occurring and are in a key position to play a supportive role to family members in bereavement care.

This project to evaluate the SIDS and Kids 'Safe Infant Sleeping Child Care Kit' was timely due to the implementation in 2012 of The National Quality Framework (NQF) for Early Childhood Education and Care Services in Australia and the recent review of SIDS and Kids program 2010-2011 which resulted in the launch of our 'Sleep Safe, My Baby' and new messaging underpinning this public health program. SIDS and Kids Australia have advocated for safe infant sleeping to be included as an essential component embedded in the framework and recognise the unique position carers have to inform parents, role model safe sleeping practices and support families within their community.

**Objectives:** This evaluation was undertaken to investigate the benefit/value, usage, content and efficacy of the child care kit and other available resources and explore the specific needs child care educators perceive are necessary to support and grow their knowledge around infant care practices. This evaluation would identify and provide recommendations to further develop resources specific for use within the broad child care settings.

**Method:** The evaluation utilised both interview-led research combined with survey data analysis conducted with National Child Care regulatory bodies, co-ordinators and teaching staff of Child and Family studies, students, SIDS and Kids educators and 36 childcare centres.

**Conclusions and Practice Implications:** This presentation provides findings related to the evaluation outcomes, and key recommendations that have led to the development of an innovative resource.

Overall feedback was positive with a particularly high level of satisfaction around the available information in the existing resource; however feedback clearly identified deficits around training components, understanding why certain safe sleeping recommendations needed to be followed, keeping up to date and sustaining knowledge, developing and implementing safe sleeping policies and guidelines and how to influence parents attending care who do not want to follow the recommendations.

#### **P41**

### **STRATEGIC COMMUNICATION STRATEGIES OF A NATIONAL CAMPAIGN TO REDUCE THE RATES OF SIDS AND OTHER SLEEP-RELATED CAUSES OF INFANT DEATH**

Stacy Scott

*Eunice Kennedy Shriver National Institute of Child Health and Human Development, USA*

The Safe to Sleep<sup>®</sup> campaign started in 1994 as the Back to Sleep campaign, with the goal of educating parents, caregivers, and health care providers about ways to reduce the risk of sudden infant death syndrome (SIDS). Since the start of the campaign, SIDS rates in the United States (U.S.) have decreased by nearly 50 percent, both overall and within various racial/ethnic groups.

Despite the decline, American Indians/Alaska Natives and African Americans infants still are at increased risk for SIDS. SIDS remains the leading cause of death for U.S. infants age 1 month to 1 year. In 2011, the American Academy of Pediatrics released updated recommendations for reducing SIDS and other sleep-related causes of infant death, such as accidental suffocation and strangulation. Now, the Safe to Sleep® campaign aims to promote safe infant sleep messages to reduce SIDS, as well as other sleep-related causes of infant death.

Getting messages about safe infant sleep to parents and caregivers in diverse communities throughout the United States takes the concerted effort of many organizations and individuals who share an interest in promoting infant health. Reaching out to different groups of people to help them learn and practice strategies for safe infant sleep has been a cornerstone of the Safe to Sleep® campaign since it began as the Back to Sleep campaign 20 years ago. Community members -including parents and caregivers, community-based organizations, health care providers, and others- play a vital role in spreading safe infant sleep messages and practices within all communities and in getting messages to diverse audiences. The campaign works closely with and within communities to spread safe infant sleep messages and help reduce the risk of SIDS. The Safe to Sleep® campaign and its collaborators continue to work with various partners, including those communities whose infants are at high risk for SIDS and other sleep-related causes of infant death.

This panel will highlight the strategic efforts of the Safe to Sleep® campaign, including its renaming and expansion in 2012, and culturally tailored outreach to American Indian/Alaska Native and African American populations.

## **P42**

### **MOVING BEYOND BACK TO SLEEP TO SAFE TO SLEEP®**

Stacy Scott

*In Black Print, USA*

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) launched the Back to Sleep campaign in 1994 to raise awareness of SIDS. Since then, the overall SIDS rate in the United States has declined by 50 percent across all racial/ethnic groups, and the rate of back sleeping among infants has increased by more than 40 percent. In October 2011, the American Academy of Pediatrics released updated recommendations for reducing SIDS and other sleep-related causes of infant death, such as accidental suffocation and strangulation. In response, the NICHD expanded its Back to Sleep campaign, originally focused on reducing the risk of SIDS, to encompass all sleep-related, sudden unexpected infant deaths. The NICHD solicited feedback on the new campaign name, logo, messages, and campaign activities through a series of 14 focus groups with racially, ethnically, and geographically diverse parents, caregivers, and childcare professionals as well as 10 in-depth telephone interviews with pediatricians and nurses in states with high SIDS rates. The expanded campaign name-Safe to Sleep® reflected a natural evolution from Back to Sleep, in the words of focus group participants. To stimulate behavior change, the new Safe to Sleep® campaign conducts tailored outreach efforts to specific underserved audiences and high-risk communities. Research has shown that different communities and racial and ethnic groups respond differently to messages about safe infant sleep. New campaign materials include culturally tailored products for general audiences, African Americans, American Indians and Alaska Natives, and Spanish-speaking Hispanic populations; tailored resources for grandparents; and a new website. To roll out the new campaign messages, the NICHD created the Safe to Sleep® Champions Initiative, drawing on the power of community leaders to improve health outcomes. This effective public health strategy harnessed the credibility of community members and local health experts to localize a public health issue. The Safe to Sleep® Champions served as the voice of the Safe to Sleep® campaign by speaking with local media and community members to raise awareness about the campaign and key messages about SIDS and other sleep-related causes of infant death. The Champions comprised pediatricians and other health care professionals, community health educators, representatives from state and county health departments, maternal and infant health advocates, and other community leaders. By relying on the expertise of community members, organizations, and governments, Safe to Sleep® continues to get effective, tailored safe sleep messages deep into communities in ways that would not be possible for national campaign outreach alone.

## **P43**

### **THE HEALTHY NATIVE BABIES PROJECT**

Kendra King Bowes

*Native American Management Services, Reston, USA*

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) met with AI/AN stakeholders and other federal partners beginning in 2002. The NICHD formed a workgroup to create an outreach initiative to focus on areas with the highest SIDS rates: the five U.S. Northern Tier Indian Health Service Areas (Aberdeen/Great Plains, Alaska, Bemidji, Billings, Portland). Focus groups were conducted in each of these areas to determine what messages about SIDS risk reduction resonated with young parents and what approaches were most effective for communicating the messages. Consultants met with community members and asked questions regarding practices when taking care of babies, knowledge of SIDS, traditional practices for keeping babies safe, and sources of information about baby care, parenting, and SIDS. The consultants also showed the focus groups a variety of educational materials and asked participants to identify which materials they preferred and the reasons for their selections. Out of those stories and data, the NICHD developed a report, *American Indian Mortality: Community-Driven Strategies*. The NICHD and workgroup members used this information to develop and implement the innovative *Healthy Native Babies Project*.

To date, the project deliverables include the *Healthy Native Babies Project* Workbook Packet, which includes a Workbook and Toolkit Disk. The Toolkit Disk allows users to develop community-tailored materials, including posters, postcards, brochures, and flyers. The Workbook encourages further development of community-specific strategies and messaging. A *Healthy Native Babies Project* Facilitator's Packet was designed for step-by-step preparation to teach classes in reducing the risk of SIDS.

The Facilitator's Packet includes facilitator's guides, slide presentations, and additional materials for full-day and 2-hour training sessions. The training sessions include background information on SIDS and other sleep-related causes of infant death, information about ways to reduce the risk, and resources related to safe infant sleep. These tailored materials have been used for three rounds of training sessions, including introductory trainings, interactive trainings, and train-the-trainer sessions. Resource stipends also have been awarded to tribes and tribal organizations to provide customized outreach and training materials at a community and regional level.

The *Healthy Native Babies Project* blends values and beliefs and draws on existing strengths and traditional practices for the conception of project materials. The project represents an effort to add AI/AN-specific cultural competence to recognized practices for reducing the risk of SIDS.

#### **P44**

### **BUILDING SUSTAINABLE INFRASTRUCTURE: REDUCING SIDS IN AFRICAN AMERICAN COMMUNITIES**

Stacy Scott

*In Black Print, USA*

A disproportionate gap remains in the incidence rate of SIDS among African American infants, who are more than twice as likely as white infants to die of SIDS. The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) formed the Partnerships for Reducing the Risk of SIDS in African American Communities. This national effort established a collaborative that included government partners, key stakeholders, infant health organizations, and diverse communities. The partnerships between the NICHD, the Alpha Kappa Alpha Sorority, 100 Black Women, and Women in the NAACP were prime examples of how a national organization with broad-based trust and respect within the community is well positioned to promote SIDS risk reduction messages to African American communities. These partnerships allowed the NICHD to benefit from the resources and experiences of organizations already working in the community to educate parents, caregivers, and community members about ways to reduce the risk of SIDS among African American infants. The partnership emphasized the importance of responding to a community's diversity, infusing cultural competence, and engaging community leaders. Following the success of the national initiative, the NICHD implemented community-based risk reduction activities on the state level. Mississippi had the highest SIDS rate in the United States and, as a result, became a major focus for NICHD's outreach efforts to contribute to the reduction of SIDS rates in African American communities. A total of 108 mini-grants, up to \$2,000 each, were awarded to community- and faith-based organizations from 2006 to 2012 within each of Mississippi's nine health districts. Mini-grantees conducted outreach activities -including health fairs, community baby showers, community walks, mother and daughter teas, and luncheons- to disseminate information on SIDS risk reduction. In the fall of 2012, the NICHD moved its efforts to Arkansas, another state with a high rate of SIDS. As of 2014, the NICHD has awarded 65 mini-grants, up to \$2,000 each, throughout Arkansas to organizations such as sororities, community health centers, health coalitions, childcare and youth development agencies, hospitals, and universities. Local organizations used the mini-grants to support community educational initiatives to increase public awareness about techniques to reduce the risk of SIDS and other sleep-related causes of death. The NICHD's public health outreach strategy emphasizes educating community leaders about safe infant sleep, providing materials, offering training on the use of campaign resources, and providing ongoing technical assistance for community leaders to educate their communities.

#### **P45**

### **THE INNER EAR AND AROUSAL RESPONSE TO HYPOXIA DURING SLEEP; POTENTIAL IMPLICATIONS FOR THE SUDDEN INFANT DEATH SYNDROME**

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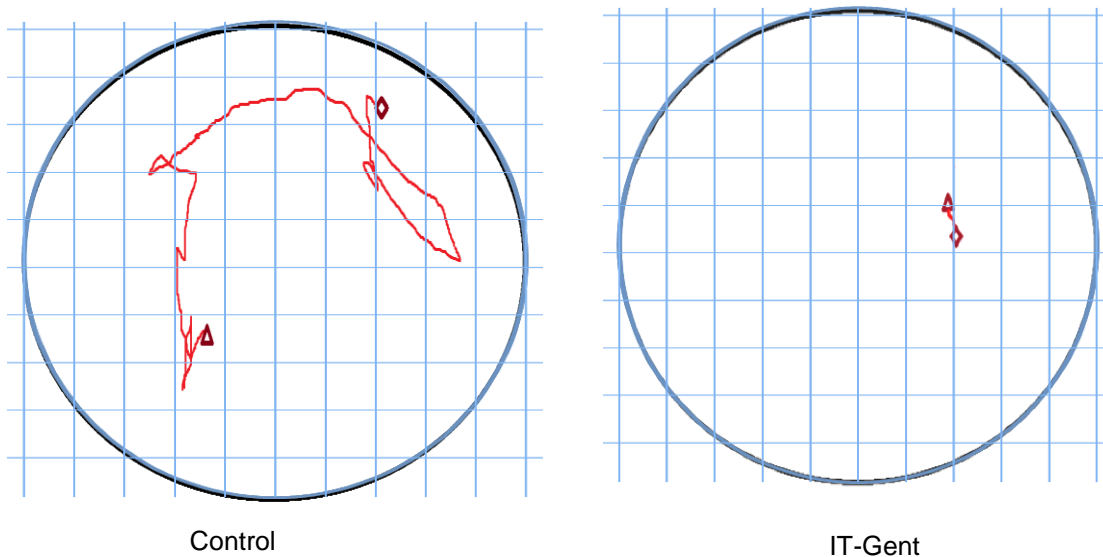
**Introduction:** A suppressed newborn hearing profile has been identified in infants that later succumb to Sudden Infant Death Syndrome (SIDS) and post-mortem analysis of SIDS cases has revealed bleeding and inflammation in the inner ear. In addition to being a potential marker for SIDS at birth, we previously set out to evaluate whether inner ear dysfunction might play a role in the mechanism of SIDS death. We consequently identified that animals with inner ear dysfunction displayed significant suppression of the arousal response to a combined hypoxic-hypercarbic gas mixture under light anesthesia. Mice with bilateral or unilateral inner ear dysfunction did not adequately arouse and move from the suffocating environment compared to control animals that vigorously moved away to access fresh air. In the current study we investigated the interaction between inner ear dysfunction and arousal to hypercarbia and hypoxia individually to establish the role of each gas in the arousal response.

**Methods:** Wild type mice received intra-tympanic gentamicin (IT-Gent) injections bilaterally or unilaterally to precipitate inner ear dysfunction. Controls included wild type mice with no intervention and mice that received intra-tympanic saline (IT-Saline) unilaterally (right or left). The body movement arousal response to hypercarbia alone or hypoxia alone were tested under light anesthesia four days after injections. Adequate body movement arousal responses were defined as movement of the head >4cm away from the suffocating environment.

**Results:** Hypercarbia alone did not stimulate body movement arousal responses in test or control animals. In contrast, hypoxia alone triggered more powerful and prolonged arousal movement responses in control animals compared to their response to the combined hypoxic-hypercarbic gas mixture ( $p < 0.05$ ). Unilateral IT-Gent animals exhibited an adequate arousal response to hypoxia alone; this contrasted with their absent arousal response to hypoxia-hypercarbia combined. Bilateral IT-Gent animals did not make any significant arousal movements to hypoxia alone or hypoxia-hypercarbia combined ( $p < 0.05$ ).

**Conclusions:** Three key points can be summarized from these findings. First, it appears that some intact inner ear function is a prerequisite for instigating a body movement arousal response to suffocation during sleep. Second, hypoxia alone is a potent arousal stimulus. Thirdly and most notably, the addition of hypercarbia suppresses the arousal response to hypoxia.

Further studies of the role of the inner ear in arousal and its potential association with SIDS is warranted. The early detection of inner ear dysfunction could be instrumental in alerting and preventing a fatal event due to suffocation.



cm  
 Figure 1: Arousals movements (in cm) of controls versus animals with inner ear dysfunction in response to the hypoxia-hypercarbia stimulus during sleep

**P46**  
**IDENTIFYING THE CAUSES OF NEONATAL DEATH: RECORD REVIEW IN THE HEALTH FACILITIES OF 24 DISTRICTS OF BANGLADESH**

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**Background:** Despite significant achievement in child survival, neonatal death accounts for 57% of the total under-five mortality in Bangladesh. This study mainly reviewed the records of neonatal deaths occurred in the health facilities of 24 districts in the last 12 months from date of interview. The study documented the significant causes of neonatal death and explored the relevant history that was available in the files.

**Methods:** An emergency obstetric and neonatal care (EmONC) need assessment survey was conducted in the health facilities of 24 districts from March to October 2012 by contextualized averting maternal death and disability tools (AMDD). Particularly for this section of neonatal death review, 3 cases from each facility where neonatal death occurred in the last 12 months were selected by systematic random sampling. Out of 3006 neonatal death cases, total 271 cases were selected from 790 health facilities of 24 study districts.

**Results:** Among all the reviewed files, asphyxia (44.6 %) was documented as the principal cause of neonatal death in the health facility. Low birth weight and aspiration pneumonia followed the next leading causes that account for 10% and 9% respectively. In majority of the cases, documentation records of birth history of cases were significantly poor. Only 13% deaths were recorded as preterm, 17% as term babies whereas about 69% review cases had no information of records on gestational age. Regarding the information on place of delivery the scenario was almost similar to gestational age. In more than half (56%) of the cases no information on delivery place were documented but one-third of the cases (34%) were identified as facility delivery and one-tenth (10%) as home delivery. Although among the reviewed cases, only about 7% death cases had been documented as caesarean delivery and 29% as vaginal delivery, majority (60%) cases had no information regarding the mode of delivery. However, the information on time of death is fairly available which showed that about 33% of death occurred within 24 hours of birth, 48% after 24 hours to 7 days of birth and 19% after 7 to 28 days of birth.

**Discussions/Conclusions:** For improved management of neonatal care in the health facility, proper documentation of the causes and its relevant history is very significant. The evidence in this study indicates that different causes with relevant history that are important for the management of neonatal care services were significantly absent. Therefore, to provide quality neonatal care services, health facility should be strengthened with appropriate record keeping mechanisms by addressing the needs for skilled manpower, availability of drugs and logistics, and training of the staff on emergency management of neonatal condition. Moreover, adoption of cost effective community based intervention programme such as evidence based home care practices, cord cleansing, and breast feeding promotion need to be encouraged to reduce neonatal death.

## P47

### ACCEPTABILITY AND FEASIBILITY OF A SAFE INFANT SLEEP ENABLER FOR ABORIGINAL AND TORRES STRAIT ISLANDER FAMILIES OF HIGH RISK FOR SUDDEN INFANT DEATH: PILOT OF THE PĒPI-POD PROGRAM

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**Background:** Aboriginal and Torres Strait Islander babies currently die suddenly and unexpectedly at a rate three times higher than non-Aboriginal and Torres Strait Islander infants. Sharing sleep with babies is the cultural norm in many Indigenous communities; however infant deaths are associated with hazardous co-sleeping environments. Valued practices, including co-sleeping, need recognition in order to make public health messages effective. Positive findings have been reported from a New Zealand-based safe sleep enabler program. Use of portable sleep spaces for co-sleeping Indigenous families have not been previously reported in Australia; Indigenous families have identified this area as being important for investigation.

**Objectives:** The key objective was to pilot a culturally appropriate adaptation of the Pēpi-pod Program in Queensland Aboriginal and Torres Strait Islander communities to determine acceptability and feasibility.

**Methods:** An exploratory descriptive design was used to report parent experiences of using the Pēpi-pod Program to support safe infant sleep practices. Five families were purposively selected through health services providing maternity care to Aboriginal and Torres Strait Islander families in metropolitan, rural and remote areas of Queensland. Eligible participants were parent/s of babies (target recruitment <1 month of age) with one or more known SUDI risk factors. Health care workers identified eligible families through usual health assessments and referred to the Program, with family permission. The Pēpi-pod Program is delivered as three interlinked components: 1) Safe Space: a polypropylene box transformed into an infant bed through addition of appropriate bedding; 2) Safe Care: Parent education; 3) Family commitment to spread what they had learned about protecting babies as they sleep. Data collection included acceptability and use of the Pēpi-pod Sleep Space. Parent questionnaires were administered within 2 weeks of receiving the Pēpi-pod; then monthly thereafter until Pēpi-pod use ceased; (approximately 4-6 months dependent on baby's growth and development).

**Results:** Five eligible families (infant age 8 days to 9 weeks) were recruited and followed-up each month. Demographic characteristics included: 2 of 5 families were single parents; all babies identified as Aboriginal; all families intended to bed share with two or more risk factors for SUDI present. Four of five families identified they had utilised the Pēpi-pod. The fifth family elected to co-sleep without the Pēpi-pod. The acceptability of the Pēpi-pod as a safe sleep space for babies was supported by parent responses that related to three key themes: safety, convenience and portability.

**Conclusions:** Parent responses highlighted that the Pēpi-pod Program was acceptable to families. Study design and methodology proved feasible through engagement with existing maternal and child health services demonstrating the potential for long term support and sustainability. Pilot results have informed a larger trial (n=300) within six communities across Queensland during 2013-2015. Innovative strategies which allow for benefits of bed-sharing, respect cultural norms and infant care practices, whilst enabling the infant to sleep in a safe environment are necessary if a reduction in Sudden Unexpected Deaths in Infancy (SUDI) is to be achieved amongst Aboriginal and Torres Strait Islander communities.

## P48

### SLEEP SAFETY IN DAY CARE CENTERS : A CAMPAIGN TO INCREASE AWARENESS IN FLANDERS

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The relative number of sleep-related deaths amongst infants is higher in day care centres than at home. The higher risk is explained to be the result of stress experienced by the child as a reaction to sudden changes.

On average, every month a child dies whilst asleep in a day care centre. Kind en Gezin (Child and Family), a governmental agency in Flanders, places great emphasis on efforts to increase day care providers' awareness and knowledge about the importance of safe sleep. In recent years we saw the number of cot deaths drop dramatically. Nevertheless, prevention continues to play a crucial role because the population of parents, grandparents and day care providers changes every few years. Additionally, new research and reports from our field staff continually re-focuses and refines the prevention message.

Although there is no sure way of preventing all sleep-related deaths, by following published international prevention measures, day care providers can reduce the risk to the baby. Since 1994, when our first campaign "Back to sleep" was introduced, the death rate dropped by 60% the following year. This trend continued downwards and but has now stabilized.

In 2009 Kind en Gezin launched the campaign "Open your eyes" in day care centres, based on study of the current scientific literature. The importance of an adjustment period is introduced, also after a period of long absence like a holiday and illness. Because we wanted to reach as much day care providers as possible, we developed a range of materials to disseminate the prevention message in different media, including brochures for daycare providers, a booklet for parents in day centre, a game, a movie, ...

It becomes increasingly obvious that sleep-related deaths in day care occur within the first days after a child starts day care. Therefore in 2011, Kind en Gezin focused on just two prevention measures:- together with parents, day care providers should work out an introductory adjustment period and should also organize extra supervision the first few days, also after a long period of absence like a holiday or illness. Several examples are given in the material as a model for day care providers to use in developing their own programmes.

Following the successful introduction of this pedagogic material, Kind en Gezin began the development of an e-learning module. It is designed as an interactive, easily-accessible training tool, using images and videos. Using this online application, day care providers are informed and, hopefully, convinced about the importance of creating a safe sleeping environment, about how to communicate with parents and introducing an adjustment period.

Following our input over the past few years, we notice that the day care providers are paying significantly greater attention to safe sleep. We are also aware that we are, in many cases, preaching to the converted. Therefore, we have made several rules compulsory for those day care providers who remain sceptical or indifferent.

#### **P49**

### **INFLUENCE OF MOTHER'S EDUCATION ON SMALL FOR GESTATIONAL AGE PROPORTION IN FETAL DEATHS IN AREAS OF SAO PAULO CITY, BRAZIL**

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**Introduction:** Fetal mortality is usually associated to mother's health conditions and prenatal care. The risk of intrauterine fetal death (IUFD) in small-for-gestational-age (SGA) fetuses is known. The aim of this study is to evaluate the influence of education on small for gestational age (SGA) for fetal deaths in Sao Paulo City, Brazil.

**Material and methods:** Sao Paulo City has 96 administrative districts and it were grouped into 5 quintiles according to the mother's education (proportion of less than 4 years of schooling), obtained from the national Census 2010. Fetal weight was obtained from the national mortality information system (Ministry of Health). SGA (weight below the 10th percentile) were identified using the Alexander's curve.

**Results:** The proportion of SGA is 21.1% in the city of Sao Paulo (2012). Vulnerability in education increases from the center to distant districts of the city and group 1 is formed by districts at the central area and group 5 concentrates the more peripheral districts. The mean proportion of low schooling ranged from 5.0% to 17.7% among the groups 1 to 5. There was a gradient of increased proportion of SGA with the decrease of schooling. The difference in SGA proportions showed a gradient from the lowest to the highest education quintile (8.3% in group 1; 10.5% in group 2; 14.5% in group 3; 28.5% in group 4; 38.2% in group 5 ( $p < 0.001$ )). The more vulnerable districts showed 4.6 more SGA in fetal deaths than the less vulnerable area.

**Conclusions:** The vulnerability in districts can be expressed through the mother's education. The heterogeneity of living conditions and spatial concentration of poverty is also expressed by the gradient of the proportion of SGA on fetal deaths.

#### **P50**

### **HOSPITAL CARE AND FOLLOW-UP AFTER STILLBIRTH: LESSONS FROM PARENTS**

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**Background:** The death of an infant is recognised as one of the most stressful life events an adult may experience. Despite this, there is a lack of quality research on which to base best practice in the care and management of stillbirth. The aim of this study was to identify which strategies are the most valued by parents regarding their caregivers, hospital management and follow-up care following stillbirth.

**Method:** Questionnaires were sent to all the bereaved participants of the Sydney Stillbirth Study in 2012. Questionnaires included a combination of fixed and open ended responses regarding three critical areas: the participants' perceptions of their caregivers, their hospital management and their follow up care. Closed ended questions utilised a 5-point Likert scale ranging from Strongly Disagree to Strongly Agree. Qualitative data were analysed using thematic analysis.

**Results:** Of the 103 women who experienced a stillbirth, 36 completed questionnaires were returned. Responders were more likely to have consented to autopsy (OR 3.5 95% CI 1.4 - 8.5), have private obstetric care (OR 4.7 95% CI 1.7 - 12.7) and be tertiary educated (OR 6.2 95% CI 2.3 - 16.8). Key themes relating to Emotion, Education and Environment were identified. These included professionalism and care provided by hospital staff, continuity of care, freedom of choice to make decisions, the hospital environment, the impact of creating memories and the importance of information, guidance and longer-term follow-up. Families preferred not to be seen in an antenatal setting on follow up.

**Conclusions:** There are several simple key components of care that are valued by families experiencing a stillbirth. Incorporating these into practice using an integrated approach to care should be achievable and could benefit both families and caregivers.

#### **P51**

### **A DEMONSTRATION OF SIMPLE COLOUR CODED SIDS RISK CALCULATOR**

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**Background:** Eva Colson has reported that safe sleeping practices may be plateauing and, unsurprisingly, SIDS rates are not declining either. Odds ratios for risk factors are often reported, but few appreciate that risk factors combine multiplicatively, or even interact, as with smoking and bed sharing.

**Objective:** To construct a risk predictor that is simple to use and is both clinically useful and instructive.

**Methods:** Using the adjusted ORs reported by Carpenter et al, and some other studies, an EXCEL spreadsheet has been constructed to calculate an infant's absolute risks from 18 risk factors. By taking account of the age distribution of the deaths, the risk can be age related.

**Results:** The risk of any particular baby is calculated and displayed. The results are colour coded to highlight the level of risk, and the number of avoidable risk are also displayed in red. A demonstration website has been developed: <https://nz.teamdf.com/fmi/webd/#Risk%20Calculator>

**Conclusion:** Presentations of the work sheet and the demonstration website have been warmly welcomed by health professionals. We plan on making this available as an app for use on iPad etc. Feedback will be welcome.

## P52

### **UNDERSTANDING AND IMPROVING BEREAVEMENT CARE FOR PARENTS WHO EXPERIENCE STILLBIRTH; THEIR BABY STILL MATTERS TO THEM: A MIXED METHODS MULTI-CENTRE STUDY IN THE UK (INSIGHT)**

Caroline Chebsey<sup>1</sup>, Sue Jackson<sup>2</sup>, K. Gleeson<sup>2</sup>, C. Winter<sup>1</sup>, Claire Storey<sup>3</sup>, J. Hillman<sup>1</sup>, J. Lewis<sup>1</sup>, R. Cox<sup>1</sup>, Alexander Heazell<sup>4</sup>, R. Fox<sup>5</sup>, T. Draycott<sup>1</sup>, Dimitrios Siassakos<sup>1</sup>

<sup>1</sup>North Bristol NHS Trust, <sup>2</sup>University of Surrey, <sup>3</sup>Bristol SANDS Group, <sup>4</sup>University of Manchester, <sup>5</sup>Musgrove Park Hospital, Taunton, UK

**Background:** Poor bereavement care is associated with poor long-term psychological and social outcome after perinatal death. Robust research to improve bereavement care for families has been identified as a priority in the Lancet stillbirth series.

**Objectives:** To perform an in-depth investigation and understand the main issues in bereavement care experienced by women who experienced stillbirth and their partners: What was already done well? How could current care be improved?

**Method:** Case study analysis of parents' perceptions including: Semi-structured interviews with bereaved parents from three maternity hospitals in England, using a unique staged-recruitment process beginning immediately after their stillbirth - prioritising four main areas; diagnosis and breaking bad news; mode of birth; post-mortem consent process; consultant follow-up appointments. Mixed-method approach involving thematic analysis of qualitative findings alongside detailed investigation of local statistics and service provision data, to provide an in-depth understanding of current maternity bereavement care and how it impacts on parents.

**Results:** 90% (30/33) of couples approached accepted the initial information and were sent more detailed information at 6 weeks after the birth. A final recruitment rate of 64% exceeded our expectations, with 21 out of 33 sets of parents agreeing to participate. 16 mothers chose to be interviewed with their partner present and all but three interviews took place in their homes.

While the majority of parents were positive about their experience, they also identified weaknesses and proposed solutions to improve training and care. Examples of care that distressed some parents were an incomplete awareness of their needs, a lack of time staff were able to spend with the family, and an unwillingness to involve them in decision-making. When being given the news that their baby had died, parents valued an individual and empathetic approach from healthcare professionals that avoided either pity or "cold calculated" communication. Whereas staff appeared to automatically shift care priorities to the mother and their potential future pregnancies, parents continued to focus their concerns on caring for their baby. In contrast to other areas of care, parents felt that taking consent for post-mortem was usually done well because staff were "back in their comfort zone".

We will present the final analysis of the interview findings, alongside a detailed investigation of the service provision data, to improve our understanding of the parents' responses and the context of bereavement care. We will also present a cross-case comparison of findings across different maternity hospitals and different case presentations (e.g. early versus late stillbirth).

**Conclusion:** Understanding the perspective of bereaved parents is a prerequisite for designing training and service improvements. The InSight study explored the parents' perceptions in-depth, and across geographical boundaries. The case study methodology employed helped understand the way the provision of care influences and shapes these perceptions. The lessons learnt are directly applicable to service and training provision to improve bereavement care today and tomorrow.

## P53

### **STAFF WHO PROVIDE CARE FOR BEREAVED PARENTS SHOULD NOT JUST MAKE IT UP AS THEY GO ALONG: A MIXED METHODS MULTI-CENTRE STUDY IN THE UK (INSIGHT)**

Caroline Chebsey<sup>1</sup>, Sue Jackson<sup>2</sup>, K. Gleeson<sup>2</sup>, C. Winter<sup>1</sup>, Claire Storey<sup>3</sup>, J. Hillman<sup>1</sup>, J. Lewis<sup>1</sup>, R. Cox<sup>1</sup>, Alexander Heazell<sup>4</sup>, R. Fox<sup>5</sup>, T. Draycott<sup>1</sup>, Dimitrios Siassakos<sup>1</sup>

<sup>1</sup>North Bristol NHS Trust, <sup>2</sup>University of Surrey, <sup>3</sup>Bristol SANDS Group, <sup>4</sup>University of Manchester, <sup>5</sup>Musgrove Park Hospital, Taunton, UK

**Background:** The Lancet stillbirth series identified better maternity bereavement care as a global priority. Key to improvement is whether healthcare staff provide sensitive and engaged care to meet the emotional and physical needs of parents. However, large surveys have shown that healthcare professionals are not optimally trained to provide such care, which takes a toll not just on parents but also on staff.

**Objectives:** To conduct an in-depth investigation, of the main challenges and deficiencies in training for staff who care for bereaved parents (alongside an exploration of parents' perspectives reported separately): What is already done well from the staff's perspective? How might problems be addressed?

To contrast the two perspectives and obtain lessons for training and service improvement

**Method:** Multidisciplinary focus groups with senior maternity staff from three different maternity hospitals who regularly care for parents following stillbirth. Four main areas were prioritised for discussion: diagnosis / breaking bad news; mode of birth; post-mortem consent process; consultant follow-up.

Mixed-method case study analysis involving thematic analysis of qualitative findings alongside detailed investigation of local statistics and service provision data, to provide an in-depth understanding of maternity bereavement care provision.

**Results:** Staff willingly participated in the focus groups, attending in their own time. The table below demonstrates the composition of each focus group.

Whereas the majority of staff were positive about caring for bereaved families, many identified weaknesses and proposed solutions including better training.



Staff reported learning bereavement care 'on-the-job', often unsupported: "make it up as I go along", "picking it up when you're on call". Some staff actively sought to care for parents who had experienced a stillbirth so that they could learn as much as possible about how to do it right.

Negotiating mode of birth with families was a debated topic. Staff reported that parents often asked for a Caesarean section, it was the most common initial response; "the hardest bit is actually talking them round" to having a vaginal birth.

Post-mortem was not associated with regrets: "I don't find any women regret it, who have it....even when their results are normal", although staff were concerned that parents might regret not having one later on.

**Conclusion:** Lack of evidence-based training is having an impact on maternity staff and the quality of care they provide for bereaved parents. Healthcare professionals have to learn 'on-the-job', often by trial-and-error. This is hampered as examples of poor care are not always fed back to staff. The Insight study explored in-depth both parents' and staff perspectives and their recommendations for change.

We discuss staff perspectives and how they compare with what bereaved parents from the same hospitals reported in a concurrent study of parents' perspectives. We also contrast these findings with service provision data to provide a full context, which will enable other hospitals to understand and improve bereavement care today and tomorrow.

	<i>Hospital A</i>	<i>Hospital B</i>	<i>Hospital C</i>
<i>Obstetric Consultants</i>	2	3	2
<i>Senior Hospital Midwives</i>	4	2	2
<i>Senior Obstetric Trainees</i>	3	2	2
Total Participants	9	7	6

## **P54**

### **STILLBIRTH. DOES PATHOLOGY MAKE A DIFFERENCE?**

Margaret Evans

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**Background:** "The chief purpose of a classification of deaths is to assist prevention" (Baird and Thomspson 1969) Stillbirth remains one of the most frequent and devastating complications of pregnancy in the developed world. At present the rate of stillbirths across Scotland is around 4.2 per 1000 births. The rate has fallen slowly over the past few years but remains higher than many other European countries.

**Objectives:** The aim of this paper is to examine how pathology impacts on the classification of such deaths in order that the underlying causes may be better understood and hence prevented. Further, to examine the role of array CGH in stillbirth autopsies.

**Methods:** I examined post mortem reports, from Edinburgh and referring hospitals, on all stillbirths and neonatal deaths within the first 24 hrs, between 1<sup>st</sup> Jan 2010 and the 31<sup>st</sup> Dec 2013, presenting after 24 completed weeks of gestation and in whom there was no known fetal anomaly, incompatible with life, at the time of delivery.

**Results:** In total 201 reports were reviewed. 61% of stillbirths had a post mortem performed with >80% of neonatal death undergoing autopsy. Nearly all post mortem cases presented with a placenta and, in total the placenta was examined in >97% of cases in 2011 -2013 compared to just 80% in 2010. The number of cases with "cause unknown" fell from 64% to 8.3% with placental pathology accounting for 54% of cases. IUGR was noted in the majority of cases. Where IUGR and placental pathology occurred together >50% showed placental pathology suggestive of underlying thrombus. Over the time period examined, there was a marked increase in cases undergoing genetic investigation with Array – CGH replacing traditional G-banded chromosome analysis. Despite the higher resolution this affords abnormalities were found in <1%. 1 infant carried the same deletion as the mother and the deletion was therefore thought unlikely to have been a factor in the death. 4 (0.2%) cases showed undiagnosed Trisomy 21.

**Conclusion:** From our results it would appear that the vast majority of stillbirths and early neonatal deaths result from placental pathology, many showing associated IUGR. This accords with the clinical view that increased screening for IUGR will identify the "at risk" population with the possibility of early intervention reducing the number of deaths. Genetic investigations have, to date, revealed no definite cause. Comparative Genomic Hybridisation Array (array-CGH) is a relatively new technique, providing a whole genome screen which compares the patient's genome with a reference genome, thereby detecting differences between the two genomes and therefore genomic imbalance in the form of deletion or duplications in the patient's sample. In order to understand the changes observed it is necessary to compare results with the parent's genome. It is assumed that if the duplication or deletion is carried by a phenotypically normal parent then it is unlikely to be disease causing but a normal variant. Future studies may include diagnostic exome sequencing of stillbirths where there is no history of IUGR or placental pathology.

## P55

### PARENTS CONCERNS FOR PREGNANCY AFTER STILLBIRTH

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**Background:** Despite improvements in antenatal care, stillbirth remains 10 times more common than sudden infant death syndrome, and rates have remained constant for decades. Given the devastating impact of stillbirth, it is imperative to understand the importance of clinical and emotional care after stillbirth and how this influences subsequent pregnancies. UK studies have indicated that 50-80% of women become pregnant between twelve and eighteen months following a perinatal death. These studies highlight that during the subsequent pregnancy parents experience high levels of anxiety due to concerns of possible negative outcome in the pregnancy.

**Methods:** In this qualitative study, purposive sampling was used to recruit parents from a large hospital, where there were 30 stillbirths in 2011. Ten parents, six mothers and four fathers consented to the interview process. The interviews were conducted by a health sociologist and a health psychologist. The expertise of the health psychologist was sought after some of the fathers expressed a preference for their interviews to be carried out by a male interviewer. All interviews were conducted on a one-to-one basis. Data were transcribed and the process of inductive thematic analysis was utilised to interpret the data

**Results:** Analysis revealed that in the days following stillbirth both mothers and fathers experience a range of emotions including shock, distress and disbelief. Findings indicate that during this time consideration of a subsequent pregnancy are reflected upon by parents however there was disparity between the aspirations of men and women. Preliminary findings reveal that mothers start planning their next pregnancy in the days following their stillbirth. The fathers interviewed expressed a clear reluctance to consider any future pregnancies identifying grave concerns for the possible impact of another pregnancy on their partners both physically and emotionally. Fathers also indicated an unwillingness to reveal these concerns to their partners. The cause of death in the infants was largely unknown, which could account for the concerns relating to future pregnancies and highlights the importance of investigation and follow-up in the postnatal period.

**Conclusion:** These findings have implications not only for psychological well-being of parents but also for clinical practice, counselling and social work, especially in the area of follow up and future care. The findings of this study underscore the far reaching and contrasting effects of stillbirth on parents. The mothers and fathers interviewed illustrated very differing needs and concerns relating to future pregnancies, which challenges healthcare professionals to individualise the care that they provide. The complex needs of both the mother and the father illustrate the importance of a multidisciplinary team approach. Early intervention in a future pregnancy is vital for a couple's emotional wellbeing.

## P56

### SUDDEN INTRAUTERINE UNEXPLAINED DEATH (SIUD): TIME OF MOLECULAR PATHOLOGY

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**Background:** The frequency of intrauterine death, defined as unexplained death after examination of foetus and its placenta, and exclusion of placenta, maternal, obstetrical or foetus causes of death, range between 15 to 75% of all causes of death. This wide variation reported in the literature can be ascribed mainly to the absence of thorough anatomic-pathological evaluations. Recently few papers have pointed to the possible role of genetic cardiomyopathies in causing sudden death in utero.

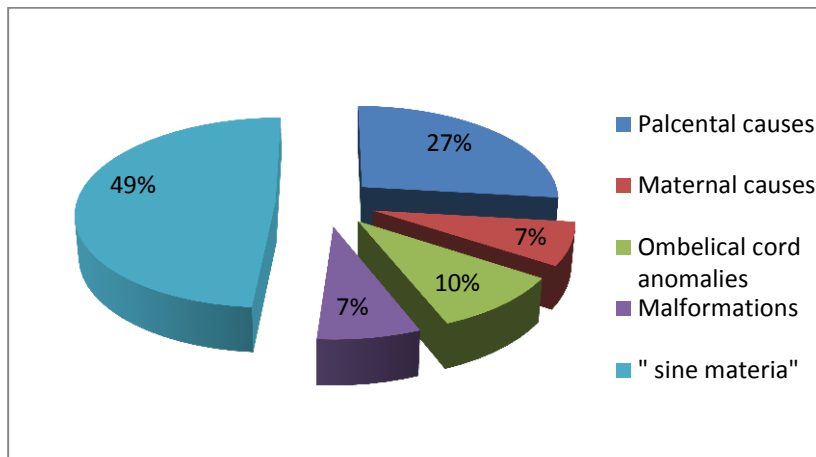
**Objective:** The aim of the study is to create a data base to collect clinical, pathological, genetic data of SIUD cases in the Veneto Region of Northern Italy.

**Methods:** In 2006 the Italian government defined the Sudden intrauterine Death(SIUDS) and Sudden Infant Death Syndrome's Low to study all cases of SIUDS and SIDS, with autopsy protocols including molecular and genetic assessment. In 2012 the Cardiovascular Pathology Unit at University of Padua became Core Centre of Veneto Region for the SIUD and SIDS.

We prepared detailed protocols to perform molecular autopsy, to collect clinical data and make clinic-pathological correlations. The parents consensus was obligatory required for autopsy.

**Results:** From June 2012 to December 2013 we collected 48 cases, median 33 gestation weeks (range 26-40 gws). We performed 44 autopsy in our centre while 4 cases were performed in peripheral hospital and referred later to the core lab. The results of this preliminary experience of molecular autopsy are reported in fig 1. In 49% of the cases the macroscopic and microscopic evaluation were unable to identify a cause of death.

Fig.1



**Conclusions:** This preliminary experience indicates that: 1) Macroscopic and microscopic evaluation per se were unable to identify the cause of death in nearly half of the cases; 2) The molecular autopsy is nowadays mandatory and should be performed in referral centers. This is in the light of what is reported in Sudden deaths in the neonates and youth in whom in cases of absence of macro and microscopic abnormalities (death "sine materia") channelopathies (QT syndrome, Brugada, CPVT) have been identified. 3) In cases of "mors sine materia" genetic counselling for both parents and first degree relatives are recommended to identify cardiovascular diseases responsible of malignant arrhythmias leading to intrauterine unexpected death.

## P57

### **MATERNAL VASCULAR UNDERPERFUSION OF THE PLACENTA IS ASSOCIATED WITH DELAYED CEREBELLAR MATURATION IN STILLBIRTH**

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**Background:** The Safe Passage Study is an ongoing prospective study of maternal alcohol exposure and the risk of sudden infant death syndrome (SIDS) and stillbirth in the Northern Plains (United States of America [USA]) and Republic of South Africa (RSA). The study is population-based and includes American Indian and white patients in the Northern Plains, and a mixed ancestry group in the Western Cape, RSA. While blinded to alcohol exposure, our Pathologists review all fetal and infant losses (including those with autopsies and placental examinations) to determine cause of death. Thus far, we have encountered 2 stillborn fetuses delivered at 30 and 33 gestational weeks (wks) with histologic evidence of delayed cerebellar development.

**Objectives:** To characterize stillbirths with delayed cerebellar maturation.

**Methods:** Complete autopsy and medical records review.

**Results:** In Case 1, visits at 13 and 20wks were unremarkable; at 29wks, the fetus showed oligohydramnios, poor fetal growth, and reverse flow in the ductus venosus by ultrasound. At delivery at 30wks, the fetus was growth-restricted (weight 472g); autopsy showed dehydration, joint contractures, and pulmonary hypoplasia. The placenta weighed 152g (<3<sup>rd</sup> percentile) and showed distal villous hypoplasia, increased syncytial knots, decidual arteriopathy, increased perivillous fibrin, and fetal vascular thrombosis (all components of maternal vascular underperfusion [MVUP]). In Case 2, the mother had normal prenatal visits until 33wks, when she presented with decreased fetal movements; demise was confirmed by ultrasound. Birth weight was 1466g. Autopsy revealed fetal squames in the lung, and thymic atrophy. The placenta weighed 247g (<10<sup>th</sup> percentile) and had histologic features of MVUP. Neuropathologic examination of both fetuses disclosed cerebral cortical development appropriate for gestational age. The cerebellar cortex, however, showed a persistent lamina dissecans, a structure normally present only through the 29th week of gestation. Purkinje cell development, normally well-established by 30wks, was inconspicuous.

**Conclusions:** We speculate that placental perfusion abnormalities may lead, at least in some cases, to a relatively selective delay in brain (i.e., cerebellar) development. Of note, delayed cerebellar maturation (but specifically of granule cells, in contrast to Purkinje cells) has been described in SIDS, cases of which are also included in our study population. Thus, full analysis of our cohort, with eventual data on alcohol exposure, will provide additional clues to the mechanism behind our observations, as well as potential links between SIDS and stillbirth.

## P58

### PARENTAL EXPERIENCES INCLUDED IN NEW PROTOCOL FOR MANAGING STILLBIRTHS IN NORWAY

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**Background:** A collection of protocols from all hospitals in Norway reveals variations regarding the managing of stillbirths. All hospitals do have still birth protocols, but they differ both regarding medical tests to be taken of the mother, child and placenta, the clinical examination of the baby and the follow up of the stillbirth parents. The Norwegian SIDS and Stillbirth Society therefore wanted to develop a standardized clinical still birth protocol for health care providers. To ensure the best possible psychosocial support to bereaved parents, the protocol must be based on both evidence-based knowledge and parental experiences with grief and bereavement support. As the first non-governmental organization in Norway, the Norwegian SIDS and Stillbirth Society now has provided a high quality still birth protocol describing both medical and psychosocial issues.

**Goals:** We wanted to develop a new standardized still birth protocol to be used in all hospitals in Norway. In addition to include updated and standardized medical tests, the protocol should incorporate both evidence-based and parental experiences of psychosocial support after stillbirths. This protocol should emphasize the importance of psychosocial follow-up of families after stillbirths.

**Target group:** Midwives, doctors and other healthcare professionals involved in stillbirths.

**Method/Implementation:** The primary objective of this protocol is to describe clearly the health professionals responsibility and tasks when stillbirths happen. The protocol has two parts, the first part guides the healthcare providers in managing medical tests of the mother, baby and placenta and clinical examination of the baby. The second part describes how to provide psychosocial support to the families. Both parts include check lists. A midwife and member of the Norwegian SIDS and Stillbirth Society and the society's director of bereavement support have worked out the protocols. In the reference group there has been a pediatrician, a pathologist, one midwife and a stillbirth mother. In the review group there has been midwives and obstetricians from nine hospitals in Norway.

Preparation of the protocol requires a systematic approach defined by the Norwegian Knowledge Centre for the Health Services. Literature review has been done in cooperation with a specialist librarian at a hospital, and all evidence-based articles, reviews, guidelines etc. have been discussed and considered. The protocol will now be implemented in all the Norwegian hospitals.

## P59

### FIRST- AND SECOND-TRIMESTER TESTS TO PREDICT STILLBIRTH IN UNSELECTED PREGNANT WOMEN: SYSTEMATIC REVIEW AND META-ANALYSIS

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**Objective:** To assess the accuracy of tests performed during the first and/or second trimester of pregnancy to predict stillbirth in unselected women with singleton, structurally and chromosomally normal fetuses.

**Design:** Systematic review and meta-analysis.

**Data sources:** Medline, Embase, Cinahl, Lilacs, and Medion from their inception to January 2014, plus conference proceedings, Google scholar, and bibliographies.

**Study selection:** Observational studies that evaluated the predictive accuracy for stillbirth of biophysical and biochemical tests performed during the first two trimesters of pregnancy, and that allowed construction of 2x2 tables.

**Review methods:** Two reviewers independently selected studies, assessed risk of bias, and extracted data. Summary receiver operating characteristic curves, pooled sensitivities and specificities, and likelihood ratios were generated for the various tests and their thresholds. Data were synthesized separately for stillbirth as a sole category and for specific stillbirth categories.

**Results:** Sixty-nine studies, evaluating 16 single and five combined tests, met the inclusion criteria. Overall, fetoplacental proteins, first- and second-trimester screening for Down syndrome, multivariable prediction models, uterine artery Doppler velocimetry, nuchal translucency, fetal growth, flow in ductus venosus, thyroid function-related tests, maternal haemoglobin levels, cervicovaginal infection, and 25-hydroxyvitamin D serum levels had a low predictive accuracy for stillbirth as a sole category with pooled sensitivities, specificities, and positive and negative likelihood ratios ranging from 1-70% (median, 13%), 61-99% (median, 95%), 0.7-6.1 (median, 2.5), and 0.4-1.0 (median, 0.9), respectively. A uterine artery pulsatility index >90th percentile and low levels of pregnancy associated plasma protein A had a moderate to high predictive accuracy for stillbirth related to placental abruption, small for gestational age or pre-eclampsia (positive and negative likelihood ratios from 6.3-14.1, and from 0.1-0.4, respectively).

**Conclusions:** Currently, there is no clinically useful first- or second-trimester test to predict stillbirth as a sole category. Uterine artery pulsatility index and maternal serum pregnancy associated plasma protein A levels appeared to be good predictors of stillbirth related to placental dysfunction disorders.

## P60

### TEMPORAL TRENDS AND CAUSES OF STILLBIRTH AMONG INDIGENOUS AND NON-INDIGENOUS WOMEN IN AUSTRALIA BY GESTATIONAL AGE: IS THE GAP CLOSING?

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**Background:** Progress with reduction in stillbirth rates has slowed in recent times in many high income countries and Australian national reports suggest rates may be increasing. The *Lancet Stillbirth series* highlighted the need to address disparity across population subgroups as a means of further reducing rates in these countries. It has been established that Indigenous women in Australia have higher rates of stillbirth than non-Indigenous women. Examination of temporal trends in rates and underlying cause of death is important to gaining an understanding of the scope for further reductions and to direct further clinical and research efforts.

**Objectives:** To assess whether the disparity gap is closing in stillbirth rates between Indigenous and non-Indigenous women; and to assess cause-specific stillbirth rates to determine where the greatest disparities lie in order to identify focal areas for future prevention efforts.

**Methods:** Data on singleton livebirths and stillbirths of at least 400g birthweight and/or 20 weeks gestation in Queensland, Australia (a region of approximately 50,000 births each year) between 1995 and 2011 were obtained. Prospective stillbirth rates (i.e., stillbirths per 1000 ongoing pregnancies) by gestational age ( $\geq 24$ ,  $\geq 28$  and  $\geq 37$  weeks) were calculated for Indigenous and non-Indigenous women. Cause-specific prospective stillbirth rates using the Perinatal Society of Australia and New Zealand Perinatal Death Classification (PSANZ-PDC), relative risk and 95% confidence intervals were also calculated for Indigenous women relative to non-Indigenous women by gestational age.

**Results:** Over the study period, prospective stillbirth rates for Indigenous women decreased from 13.3 to 9.1/1000 while rates remained steady at 5.9/1000 for non-Indigenous women. There was a 57.3% reduction in the disparity gap between Indigenous and non-Indigenous women. These reductions were more pronounced for women birthing at  $\geq 24$  weeks (66.9%) and  $\geq 28$  weeks (76.6%), while at term ( $\geq 37$  weeks), there was an 18.0% increase in the disparity gap. Between 2001 and 2011, the disparity gap at term was steady around 1.2/1000 ongoing pregnancies. Major conditions contributing to the disparity in stillbirth rates at term were: maternal conditions (diabetes), perinatal infection, fetal growth restriction and unexplained antepartum fetal death. Higher rates of undetermined causes may have been driven by lower autopsy rates.

**Conclusion:** The gap in stillbirth rates between Indigenous and non-Indigenous women is closing; however, Indigenous women continue to be at increased risk of stillbirth due to a number of potentially preventable conditions. High quality antenatal care at all levels using culturally appropriate service delivery models which incorporate diabetes management, smoking cessation, STI screening and treatment, folic acid and fetal growth monitoring hold some promise of helping to improve pregnancy outcomes for Indigenous women.

## P61

### A TRIENNIAL ANALYSIS OF STILLBIRTHS WITHIN GLOUCESTERSHIRE HOSPITALS NHS FOUNDATION TRUST, 1<sup>ST</sup> APRIL 2011 - 31<sup>ST</sup> MARCH 2014 : A REPORT ON THE KEY FINDINGS AND THE VALUE OF THE ANALYSIS PROCESS

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**Background:** The stillbirth rate in England and Wales is 5.2/1000 total births. A cluster of stillbirth cases at Gloucestershire Hospitals NHS Foundation Trust between 2010-2011 led to a perceived increase in the rate of this tragic outcome. Though the rate of 6.2/1000 was not statistically significantly higher than the national rate, this prompted audit and review of all stillbirth cases that year. A report of findings was produced and actions monitored. This report gave valuable information about stillbirth in Gloucestershire and is now produced annually. This is our first triennial report.

**Objectives:** The key findings of the triennial analysis of stillbirths at GHNHSFT will be presented. The data collection and analysis process will be described, and potential values of this process discussed.

**Methods:** A detailed case note review of every stillbirth within the trust during the study period was performed. An extensive excel database was used to collate the data.

A detailed annual and triennial analysis of the data was performed. Key findings were compared year-on-year to both local and national data.

**Key Findings:** The key results of the triennial stillbirth report, performed between 2011 and 2014, will be presented. IUGR is a topical subject with the recent publication of the RCOG Green-top guideline 'The investigation and management of the small-for-gestational-age fetus'. The 2011-12 data showed that IUGR (as the primary cause) accounted for higher rates of stillbirth at GHNHSFT (16.7%) than the national average of 10.2%. Analysis showed that serial measurement and documentation of symphysis-fundal height (SFH) had not been reliably performed in several cases. In response the trust guideline was reviewed and a local educational programme was implemented. By 2012-13 documentation of SFH had improved, though the proportion of cases with IUGR as the sole cause of stillbirth was still higher than the national average at 23%. In light of the review's findings key local policies are being reviewed and updated to optimise maternity care. Nationally post-mortem uptake rates remain below the recommended level. Local analysis found rates of uptake of post-mortem examination at GHNHSFT are below national average. Implementation of a training programme for staff on taking consent for post-mortem is now a local priority.

**Conclusions:** Through the process described above each individual case of stillbirth undergoes review at departmental or trust level. Results from each case are collated and compared to look for key themes highlighting potential improvements in care. Key findings and lessons learnt from these case reviews are used to develop action plans.

This is an enormously valuable process. On a personal level affected parents are ensured of an independent review of their case. At a trust level, trends in deficiencies of care were identified which may not have been obvious with individual case reviews being disparate in time.

Creation of a detailed continuous database of stillbirth cases has enabled GHNHSFT to improve identification of local stillbirth trends and implement targeted changes to improve local maternity care. We would encourage other trusts to perform similar analysis of their own stillbirth data.

## **P62**

### **CASE STUDY ANALYSIS FOR STILLBIRTH RESEARCH: BRINGING QUALITATIVE AND QUANTITATIVE DATA TOGETHER**

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<sup>1</sup>University of Surrey, <sup>2</sup>InSight study, UK

Case study research involving study numbers greater than one is notoriously difficult. Many different types of data from many different sources are required. Yin (2009) likens the process to a police investigation where important points (facts) arising from the research are thoroughly verified and validated with relevant data. The workshop will start with a short presentation by Dr Jackson detailing the main principles of case study research.

Workshop participants will then be briefed on their task for the workshop. Participants will be provided with the InSight study research question and aims, and some information on the main points arising from the study interviews and focus groups. Their task will be to plan out what kinds of data they think they would need in order to be able to verify and validate the possible facts, as well as identifying where these data might be located, and how easy or difficult they feel they would be to access.

This task will be followed by another short presentation by the member of the InSight team detailing how the case study methodology was employed in the *InSight* multicentre study, focusing on describing the types of data that were identified as being necessary to access during the process of data collection and analysis.

The authors acknowledge that whilst the methodology is transferable, the types & availability of data may be different in different settings. In light of this, the workshop will end with a group discussion, where workshop participants compare their ideas with the actual data arising from *InSight*. Key learning points about the utilization of qualitative case study as a methodology for such a sensitive topic as stillbirth will be shared as part of the discussion.

## **P63**

### **STILLBIRTHS IN RURAL HOSPITALS IN THE GAMBIA: A CROSS-SECTIONAL RETROSPECTIVE STUDY**

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**Objective:** We determined the stillbirth rate and associated factors among women who delivered in rural hospitals in The Gambia.

**Method:** A cross-sectional retrospective case review of all deliveries between July and December 2008 was undertaken. Maternity records were reviewed and abstracted of the mother's demographic characteristics, obstetric complications and foetal outcome

**Main Outcome Measure:** The stillbirth rate was calculated as deaths per 1000 births.

**Results:** The hospital-based stillbirth rate was high, 156 (95% CI 138–174) per 1000 births. Of the 1,519 deliveries, there were 237 stillbirths of which 137 (57.8%) were fresh. Severe obstetric complication, birth weight <2500 g, caesarean section delivery, and referral from a peripheral health facility were highly significantly associated with higher stillbirth rates, OR = 6.68 (95% CI 3.84–11.62), 4.47 (95% CI 3.04–6.59), 4.35 (95% CI 2.46–7.69), and 3.82 (95% CI 2.24–6.51), respectively. Half (50%) of the women with stillbirths had no antenatal care OR = 4.46 (95% CI 0.84–23.43).

**Conclusion:** We observed an unacceptably high stillbirth rate in this study. As most of the stillbirths were fresh, improved intrapartum care supported by emergency transport services and skilled personnel could positively impact on perinatal outcomes in rural hospitals in The Gambia.

## **P64**

### **BARRIERS TO EMERGENCY OBSTETRIC CARE SERVICES IN PERINATAL DEATHS IN RURAL GAMBIA: A QUALITATIVE IN-DEPTH INTERVIEW STUDY**

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**Objective:** The Gambia has one of the world's highest perinatal mortality rates. We explored barriers of timely access to emergency obstetric care services resulting in perinatal deaths and in survivors of severe obstetric complications in rural Gambia.

**Method:** We applied the "three delays" model as a framework for assessing contributing factors to perinatal deaths and obstetric complications. Qualitative in-depth interviews were conducted with 20 survivors of severe obstetric complications at home settings within three to four weeks after hospital discharge.

Family members and traditional birth attendants were also interviewed. The interviews were translated into English and transcribed verbatim. We used content analysis to identify barriers of care.

**Results:** Transport/cost related delays are the major contributors of perinatal deaths in this study. A delay in recognising danger signs of pregnancy/labour or decision to seek care outside the home was the second important contributor of perinatal deaths. Decision to seek care may be timely, but impaired access precluded utilization of EmOC services. Obtaining blood for transfusion was also identified as a deterrent to appropriate care.

**Conclusion:** Delays in accessing EmOC are critical in perinatal deaths. Thus, timely availability of emergency transport services and prompt decision-making are warranted for improved perinatal outcomes in rural Gambia.

## **P65**

### **REGISTRATION OF FETUS POPYRACEUS - UNNECESSARY DISTRESS FOR PARENTS AND CARE PROVIDERS?**

Kathryn Kenny

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When fetal death occurs beyond the first trimester in twin pregnancies, a fetus papyraceus (mummified) may develop and will be "delivered" when the surviving twin is born. Medical complications associated with fetus papyraceus have been well documented in the literature for both the mother and surviving co-twin. Reporting of a fetus papyraceus is required by vital statistics law. Gestational age is recorded at time of expulsion from the mother not actual gestational age at death. In the province of Alberta, any fetus papyraceus must be recorded if delivery occurs after 20 weeks gestation, and is considered a stillbirth. Registration is considered important for research, counselling for future pregnancies, and parenting.

In Alberta, parents are required to register stillbirth records for the fetus papyraceus. In addition, they are legally responsible for dealing with the remains of the infants once pathological examination is complete. This presents a significant emotional and psychological problem for many families as they often have dealt with the loss of the fetus at the time it occurred, not with the delivery of the surviving co-twin. This practice often creates moral distress for Obstetricians, Pathologists and nursing staff as many feel current reporting practice leads to psychological harm for families and ultimately may result in incorrect reporting.

We present three cases from our centre in which the current registration process caused significant emotional distress for the families and moral distress for the care providers involved.

In conclusion we argue that although reporting of fetus papyraceus is necessary for research purposes, parents should not be required to sign register such a child as a stillbirth records nor should they be responsible for dealing with the remains of the fetus unless specifically requested.

## **P66**

### **INTRODUCTION TO THE SAFE PASSAGE STUDY: A PROSPECTIVE STUDY OF STILLBIRTH AND SIDS**

Hannah Kinney

*PASS Research Network, USA*

**Background:** Prenatal alcohol exposure (PAE) is a major global public health concern. In the United States, 54% of women report drinking alcohol during their childbearing years and 12% report drinking during pregnancy. While PAE has long been linked to a continuum of neurodevelopmental disabilities and somatic anomalies, emerging reports suggest an association between PAE, stillbirth and sudden infant death syndrome (SIDS), indicating that fetal and infant *mortality*, as well as *morbidity*, are part of the spectrum of adverse outcomes.

**Objective:** The purpose of this abstract is to alert the communities at this meeting who are focused upon fetal and infant mortality worldwide to the NIH Safe Passage Study that is currently underway. This study is a large, prospective, and multi-institutional study designed to determine the relationship of PAE to the fatal outcomes in early life of stillbirth and SIDS, and the inter-relationships among PAE, stillbirth, SIDS, and fetal alcohol spectrum disorders (FASD) in infancy. The primary hypothesis is that prenatal exposure to alcohol is associated with stillbirth and/or SIDS; secondary hypotheses concern the impact of genetic and environmental factors in determining the specific phenotypic outcomes of PAE. The study focuses upon populations known to be at high risk for maternal drinking during pregnancy, stillbirth, SIDS, and FASD including American Indians in the Northern Plains and women of mixed ancestry in Cape Town, South Africa.

**Methods:** Here we report an overview of the study design, methods and recruitment experience of the study, now in its 7<sup>th</sup> year of targeted 7.5 years of participant enrollment toward a goal of 12,000 maternal/fetal dyads. The design is based upon a common protocol that is implemented across sites. Importantly, this protocol allows for the integration of diverse types of human data on a large scale in the same maternal/fetal dyads from epidemiology, nutrition, neurophysiology, obstetrics, pediatrics, neurology, psychiatry, neuroscience, genetics, and placental pathology, and in the those cases of fetal/infant demise, pediatric pathology, neuropathology, and forensic pathology.

**Results:** As of March 31, 2014, the study has successfully enrolled 10,589 pregnant women with an overall compliance rate for all visits, including prenatal, delivery, newborn, and postnatal contacts, of 88%, a high capture rate of pregnancy outcomes (99%), and low overall study withdrawal rate (3%). Moreover, the consent rates for the use of DNA and placental and brain tissues for research are high (90-99.6% of those approached and eligible). An essential component of the study design is its foundation in community-based research.

**Conclusion:** While the focus of the study is upon high-risk populations, for PNAE the information to be gained, we believe, will be applicable to all pregnant women, given the commonality of cellular and molecular mechanisms of alcohol toxicity upon the developing fetus and placenta. Importantly, the information to be gained in high-risk populations is critical, as SIDS, stillbirth, and FASD disproportionately afflict socioeconomic disadvantaged populations and racial/ethnic minorities, including those in the SPS. The study is on target to provide comprehensive information towards fully elucidating the role of PAE in SIDS, stillbirth, and FASD.

## P67

### RECURRENCE RISK OF UNEXPLAINED STILLBIRTH: SYSTEMATIC REVIEW AND META-ANALYSIS

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**Objective:** To evaluate the evidence from the available literature on the risk of recurrence of stillbirth where previous stillbirth was unexplained in high-income countries.

**Design:** Systematic review and meta-analysis of observational studies.

**Data Sources:** Embase, Medline, Cochrane Library, Pubmed, CINHAL and Scopus were searched systematically with no date, publication or language restrictions to identify relevant studies. Supplementary efforts included searching relevant internet resources as well as hand searching the reference lists of relevant studies. Where published information was unclear or inadequate corresponding authors were contacted for more information.

**Review methods:** Cohort and case-control studies were included if these investigated the association between unexplained stillbirth in an initial pregnancy and risk of stillbirth in a subsequent pregnancy in high-income countries and used a definition of stillbirth as either occurring at 20 weeks gestation or more or a birth weight of at least 400g. Two reviewers independently screened titles to identify eligible studies based on inclusion and exclusion criteria agreed *a priori*, extracted data and assessed the methodological quality using critical appraisal skills programme scoring. Random effects meta-analyses were used to combine the results of the included studies. Sub-group analysis was performed on studies that examined unexplained stillbirth.

**Results:** 14 studies met the inclusion criteria 12 of which were included in the meta-analysis. Data were available on 3,635,200 women of whom 3,609,761 (99.30%) had had a live birth and 25,440 (0.70%) a stillbirth. There was a total of 15,016 stillbirths in the subsequent pregnancy, 620 (2.43%) occurred in women who had a history of stillbirth and 14,396 (0.40%) among women with no such history. When considering only unexplained stillbirths data were available on 521,255 women comprising 517,161 (99.21%) who had a live birth and 4094 (0.79%) who had a stillbirth. There was a total of 1,713 stillbirths in the subsequent pregnancy, 60 (1.47%) occurred in women who had a history of stillbirth and 1653 (0.32%) among women with no such history. Both stillbirth and unexplained stillbirth were associated with an increased risk of stillbirth in a subsequent pregnancy. Compared with women who had a live birth in a first pregnancy the pooled unadjusted and adjusted odds ratios of stillbirth recurrence for women with a previous stillbirth were (4.79, 95% confidence interval 3.75 to 6.12) and (2.34, 1.53 to 3.57) respectively. Risk of stillbirth recurrence for women with a previous unexplained stillbirth was (1.83, 1.38 to 2.44).

**Conclusions:** Women who have a stillbirth in their first pregnancy have a higher risk of stillbirth in a subsequent pregnancy. Even when the previous stillbirth is unexplained, this increased risk remains. Adding to the body of evidence on stillbirth recurrence these findings can be used by clinicians to counsel parents who are considering conceiving after a previous unexplained pregnancy loss on effective strategies to modify lifestyle factors, such as obesity and smoking known to be implicated with occurrence and recurrence of stillbirth.

## P68

### THE RELEVANT CONDITIONS OF INTRAUTERINE FETAL DEATH IN THE TURKU UNIVERSITY HOSPITAL BETWEEN THE YEARS 2001 AND 2011 ACCORDING TO THE RELEVANT CONDITION OF DEATH (RECODE) CLASSIFICATION SYSTEM

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**Objectives:** We examined temporal trends in the pathophysiology of intrauterine fetal death (FDIU) in Finland (in the district of Southwest Finland). Our main object was by selecting a suitable classification system to analyse through the conditions leading to FDIU and the association of specific maternal conditions to it in Turku University Hospital in Finland Proper. We wanted to examine the importance of postmortem examination and the selection of a suitable classification system to classifying FDIU.

**Study design:** We conducted a hospital-based cohort study of singleton FDIU to study the underlying causes of death. The data was collected from clinical fetal autopsy reports in the pathology department of the Turku University Hospital during 2001 through 2011. We analysed fetal death rates at 24 or more weeks of gestation or patients weighing 500g or more if the gestational age was not known.

**Results:** A total of 98 patients went through careful post-mortem examination in the Turku University Hospital Department of Pathology. A relevant condition determining the FDIU was found in 76 (77.6%) patients according to the Relevant Condition of Death (ReCoDe) classification system. Lethal congenital malformations accounted for 19.4% of all underlying causes of FDIU, being the most common primary relevant condition of FDIU. The second most common primary relevant condition of FDIU was placental insufficiencies, mainly fetal thrombotic vasculopathy and desidual vasculopathy, accounting for 16.3% of all causes of FDIU. The third most common primary relevant condition of FDIU was constricting loops or knots of the umbilical cord when severe enough to be considered relevant with 16.3% of all causes of FDIU. The primary relevant condition of FDIU was left unclassified in 22.4% of cases. Out of these all together three patients were unclassified as "no information available" due to missing placenta and hence no cause of death could be determined. Fetal growth restriction (small for gestational age) was recorded in 42.8% of the patients but this was not listed as a primary relevant condition of FDIU in the present study as it has been listed in the original ReCoDe classification system.



**Conclusion:** With an appropriate classification system, such as the ReCoDe classification, we can classify most of the FDIU and find the most relevant conditions of FDIU. Even if the death is left unexplained after careful clinical, macroscopic and microscopic evaluation, many other harmful conditions such as external trauma and infection may be excluded with the help of post-mortem examination and ancillary studies, thus benefiting both the parents and the health care unit.

## P69

### **CHARACTERISTICS, EVALUATION OF PRESENTATION AND OUTCOMES OF WOMEN WITH REDUCED FETAL MOVEMENTS IN A TERTIARY LEVEL CENTRE**

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**Background:** Reduced Fetal Movements (RFM) affect up to 15% of pregnancies, and have been associated with fetal growth restriction, pre-term delivery and other adverse perinatal outcomes. There are varied practices for evaluation and management of RFM.

**Objectives:**

- To assess demographics of those presenting with RFM.
- To investigate patients admitted and delivered on primary presentation
- To evaluate pregnancy outcomes of those presenting with RFM.

**Methods:** In this prospective study, we recruited all pregnant women over 28 weeks gestation with a singleton pregnancy, without a known fetal anomaly, presenting to the Emergency Department (ED) of a tertiary level hospital with the complaint of RFM from April 1 2013 until October 31 2013. Full data was available on 234 patients for analysis. Telephone records were analysed over two non-consecutive months of the study period to assess advice offered to those who contacted the ED about RFM.

**Results:** 294 women over 28 weeks gestation presented with RFM during the study period (approximately 42 per month), comprising of 4.2% (294/6989) of all patients assessed in the ED. Seventeen women presented on more than one occasion, and 3 women (1.3%; 3/234) were diagnosed with an intra-uterine death on presentation. The mean maternal age was 31.2 years, and 37.9% (n=105; 105/277) were primigravidae. 31.2% (n=73; 73/234) of all patients had a previous history of pregnancy loss. The average gestational age at presentation with RFM was 35+6 weeks (range 28 to 41+1 weeks). 12.3% (n=34; 34/277) of patients were current smokers, with 8.5% (n=20; 20/234) having a current or previous history of fetal growth restriction. 7.3% (n=17; 17/234) had pregnancy induced hypertension or pre-eclampsia diagnosed in the index pregnancy.

On primary presentation with RFM, 7.2% (n=17) had non-reassuring characteristics on their cardiotocograph. 64.9% (n=177; 163/251) had an assessment of amniotic fluid on initial presentation. 24.8% (n=68; 68/274) were admitted on presentation following assessment by a medical practitioner. 60.2% (n=41; 41/68) delivered on admission with RFM; 31.7% (n=13; 13/41) of whom had an induction of labour for reduced fetal movements.

Of patients delivered on their primary presentation with RFM, 31.7% (n= 13/41) had a Caesarean Section, compared to 32.9% (n=77; 77/234) of the total cohort. Mean infant birth weight was 3398g (range 1050-4620g); mean gestational age at delivery was 39+3 weeks (range 28+4 to 42 weeks). 10.2%(n=24; 24/234) of infants were admitted to the neonatal unit following delivery. There were 1912 telephone consultations over two months, with 74(3.9%) patients complaining of RFM, 53(71.6%) of whom were advised to attend for assessment.

**Conclusions:** This study demonstrates that 4.2% women with RFM present to our antenatal services, with a high admission and subsequent delivery rate. Women who delivered on their primary presentation with RFM also had a marginally lower caesarean section rate than the rest of the cohort. The rate of IUFD was higher than expected (at 1.3%). Telephone consultation rates are also similar to presentation rates. It is necessary to compare perinatal outcomes with a control group of patients, to assess if there is a significant difference.

## P70

### **CONGENITAL ANOMALIES IN A COHORT OF STILLBORN INFANTS; A REVIEW FROM 1996-2010 IN THE CORK AND KERRY REGION**

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**Introduction:** Over the past decades the perinatal mortality rate has reduced internationally but this decline is associated with reductions in early neonatal deaths as the rate of stillbirths remains relatively static. In Ireland the rate of stillbirth in 2011 was 4.3 per 1,000 births of which 26% were attributed to major congenital anomaly. Congenital anomalies are structural abnormalities, which are diagnosed in the antenatal period, at delivery or after birth. The local context informs the management as termination for fetal abnormality is not legal in the Republic of Ireland.

**Objective:** The objective of this research was to provide a cohesive analysis of the EUROCAT Cork/Kerry congenital anomaly data on stillbirths from 1996 to 2010, focusing on the epidemiological information and potential maternal risk factors.

**Methods:** A retrospective cohort study was undertaken on stillbirths with a congenital anomaly occurring between 1996 and 2010. All recorded cases of congenital anomalies in Cork and Kerry were identified using the European Surveillance of Congenital Anomalies (EUROCAT) database. The EUROCAT is a network of 41 population based congenital anomaly registries in 21 European countries.

**Results:** From 1996 to 2010 3408 infants diagnosed with congenital anomalies were recorded in the EUROCAT Cork and Kerry database. Of these 148 cases were stillborn which equates to a rate of 1.12 per 1,000 births across the 15 year period. Of these cases 71.4% (n=104) were identified during the antenatal period.

Almost half of stillborn infants were identified as having nervous system anomalies (43.2%; n=64) such as neural tube defects, hydrocephalus, microcephaly and arhinencephaly. 31.7% (n=48) of cases were diagnosed with a chromosomal disorder, of which 27.7% (n=13) were identified as Edwards syndrome. Of the 148 stillbirths 89.1% (n=132) were diagnosed with a malformation of which one in four cases (25.7%; n=34) were identified with anencephaly.

**Conclusions:** Knowledge of the prevalence of congenital malformations and their trend is crucial to identifying and managing new potential causative and preventative factors and also in the provision of adequate services for those affected by congenital anomalies.

## **P71**

### **PREGNANCY AFTER LOSS: COMPARATIVE LITERATURE REVIEW OF COUPLES' EXPERIENCES**

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**Background:** Notwithstanding advances in maternity care, babies still die before or at the time of their birth and the reasons can be varied. While the overwhelming majority of the estimated 3.2 million global perinatal deaths annually occur in low resource countries statistics show that 1:200 births in high resource countries will end in stillbirth or perinatal death. The majority of couples who experience perinatal death will have subsequent pregnancies and births, often very soon after their initial loss. There are implications for all who care for couples in their subsequent pregnancies as uncertainty, fear and anxiety mean that additional supportive measures are required and increased maternity services utilisation is common. Expectant parents, pregnant after loss, have important additional needs to those who have not experienced such loss. By exploring experiences of pregnancy after loss, the care required by couples' can be understood.

**Methods:** In-depth, systematic review of literature performed using Whitemore and Knaf's Integrative Review Framework. Search Terms: Woman OR women OR mother OR female OR parent AND Man OR men OR father OR male OR parent AND Pregnancy loss OR stillbirth OR still birth OR perinatal loss OR intrauterine death OR fetal death OR foetal death OR miscarriage AND Subsequent pregnancy OR next pregnancy OR pregnancy after loss. Databases: EBSCO: CINAHL, PsycINFO, PsycARTICLES, Psychology and Behavioral Sciences Collection, SocINDEX and Pub Med. 167 studies examined in depth.

**Findings:** Mental Health Issues: Reported on-going mental health issues for women including depression, prolonged grief, Post Traumatic Stress Disorder. Women pregnant again can continue to experience symptoms of depression in their subsequent pregnancy. Women reported having greater levels of depression than control groups and fathers who experienced stillbirth in the studies where both were questioned. Depressive tendencies decreased following the birth of a healthy baby in some studies.

Fear, Anxiety, Coping: Pregnancy specific anxiety was higher in women than in men and greater among the stillbirth group. Loss was seen as a threat and was anxiety producing. Coping was correlated to emotional status with problem focused coping. Women describe a fear that did not leave them until after the birth of their subsequent baby, though some women reported the fear never really subsided fully. There was an unexpected intensity of grief reactivation during subsequent pregnancy.

Restrained Expectations: Women reported feeling fearful and anxious to trust in a positive outcome. Women may need to relinquish the safety of old ways of coping to embrace the possibility of their new baby. If adaptation does not occur emotional cushioning may result whereby women actively protect themselves emotionally, by not bonding with their babies until the baby is born.

Intentional Parenting: Parents have been shown to engage in intentional parenting and connectedness with others as ways of interacting with their subsequent unborn children. Parents aware that a positive outcome is not a guarantee and make the most of the interactions that they may have taken for granted prior to their pregnancy loss.

**Conclusion:** Parents are forever changed or transformed by loss and subsequent pregnancies are forever coloured by their experience of stillbirth. Couples, pregnant after loss, have important additional needs to those who have not experienced such loss. Healthcare professionals should expect anxiety, feelings of threat and fear in subsequent pregnancies and should be aware that women and men grieve very differently and provide appropriate, inclusive care.

## **P72**

### **HOW ACUTE IS THE PROBLEM OF UNAVAILABILITY OF HUMAN RESOURCES IN PUBLIC EMERGENCY OBSTETRIC AND NEWBORN CARE HEALTH FACILITIES IN BANGLADESH?**

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**Background:** Although Bangladesh has made remarkable progress in achieving the targets for MDG 4 and 5, the current levels of maternal (194 per 100,000 live births) and neonatal (32 per 1000 live births) mortalities are still high which indicate that there are several challenges for improving Maternal and Newborn Health (MNH) status in the country. Shortage of trained human resources (HR) in public emergency obstetric and newborn care (EmONC) facilities has been identified as one of the major challenges for maternal and newborn survival in Bangladesh. For attaining standard EmONC services, adequate number of competent medical doctors such as obstetricians, anaesthesiologists, paediatricians and trained nurses are crucial to ensure round-the-clock (24/7) EmONC services. Therefore, for further reduction of maternal and neonatal mortalities in the country, there is an urgent need for in-depth assessment of current HR situation in public health facilities at district and sub-district levels. The objective of this paper is to assess the HR gaps at district and sub-district level EmONC facilities in selected districts of Bangladesh.

**Methods:** A health facility assessment was undertaken (March–October, 2012) in all the designated public EmONC facilities from district to sub-district levels in 24 districts of Bangladesh using contextualized Averting Maternal Death and Disability (AMDD) tools, originally developed by Columbia University, USA. For this paper, data was extracted from the contextualized HR module of the tools.

**Results:** In district hospitals (DHs) though almost 90% of the sanctioned posts of the obstetricians were occupied, about 40% posts of the anaesthesiologists were vacant. Approximately, 13% of the DHs and 20% of the mother and child welfare centres (MCWCs) did not have a pair of obstetrician and anaesthesiologist to provide surgical interventions; while about 77% of the upazilla health complexes (UHCs), designated as comprehensive EmONC facilities did not have a pair. Overall, in the UHCs, post occupancy for paediatricians was below 40%. Moreover, in DHs nearly 20% to 50% and in UHCs about 30% to 60% of the sanctioned posts for the nurses of different categories were vacant. Besides, about 30% to 50% in DHs and about 15% to 40% in UHCs medical technologists' posts were vacant.

**Discussion:** All provider categories have substantial vacant posts at both district and sub-district level facilities that need to be filled-up to ensure service availability for round-the-clock EmONC services. This problem is more acute in sub-district level facilities (UHCs) than those in district level. Different innovative (financial and non-financial) incentivized models including public-private-partnership could be adopted to address the problem of retention of the providers, particularly in rural areas. Also initiatives should be taken to identify strategic CEmONC facilities (based on substantial geographical coverage and accessibility) and ensure availability of pair of providers by reallocating providers from other non-functional EmONC facilities.

### P73

#### **BREAKING BAD NEWS: THE IMPACT ON PARENTS**

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**Background:** Communicating bad news in an obstetric setting is challenging for both clinicians and parents. How bad news is communicated is a sensitive and important aspect of overall care for bereaved parents.

**Objectives:** This study explores the impact of bad news on parents diagnosed with stillbirth or fatal fetal abnormality who were cared for in an Irish tertiary maternity hospital (8,500 births per annum) where the perinatal mortality rate is 5.2/1000.

**Methods:** Semi-structured qualitative interviews lasting 31-104 minutes were conducted with 12 mothers and 5 fathers bereaved following stillbirth. The participants were purposively sampled from each of the years 2008, 2010 and 2013. The data were analysed using Interpretative Phenomenological Analysis.

**Results:** The diagnosis of a fatal fetal abnormality or confirmed stillbirth had a profound and enduring impact on each of the parents interviewed. The data revealed a forensic recollection of the context of how news was communicated. Diversionary techniques while awaiting another opinion to confirm a diagnosis were identified by parents. These interactions resulted in a sense of mistrust when it was felt information was purposefully withheld. The remaining major themes were: language used, timing and sensitivity. How and where bad news was communicated had a considerable impact on parents.

**Conclusions:** How professionals communicate bad news to parents is remembered in painstaking detail, often revisited as parents seek to understand their loss. This study reveals in parents' own words examples of how and how not to break bad news. These findings are of interest to clinicians, sonographers and midwives as they continue to refine communication skills in one of the most challenging areas of obstetric practice.

### P74

#### **DEVELOPMENT IN STILLBIRTH CARE IMPROVING PARENTAL EXPERIENCES: A QUALITATIVE STUDY**

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**Background:** Stillbirth is recognised as one of the most difficult bereavements for parents with life-lasting impact. How parents are cared for following stillbirth sets the stage for their grieving process and recovery.

**Objectives:** This study explores whether the experiences of parents following stillbirth have changed over a period of seven years during which various improvement initiatives were implemented in an Irish tertiary maternity hospital (8,500 births per annum) where the stillbirth rate is 4.6/1000.

**Methods:** Semi-structured qualitative interviews lasting 31-104 minutes were conducted with 12 mothers and 5 fathers bereaved following stillbirth. The participants were purposively sampled from each of the years 2008, 2010 and 2013. The data were analysed using Interpretative Phenomenological Analysis.

**Results:** Stillbirth had a profound and enduring impact on each of the parents interviewed. Bereaved parents were able to recall in precise detail both their experiences of care from professionals and their overall hospital experience. The data revealed an incremental improvement in experience of care over the seven years. These improvements are in the area of facilities and accommodation and are linked to the improvement in facilities and care pathways during that time in the hospital. The physical environment where bad news is communicated and the location of where bereaved parents are accommodated during their inpatient stay were significant issues for parents.

**Conclusions:** The improvement of facilities and care pathways following stillbirth has had a direct impact on the expressed experiences of bereaved parents. These improvements have included the provision of a dedicated area of the hospital where scans are performed, the introduction of a stillbirth identification sticker in 2010 and the provision of private room accommodation for all bereaved parents and their partners in a dedicated ward in the hospital away from other pregnant mothers and babies. This study, the first of its kind in Ireland, highlights the importance of providing appropriately sensitive accommodation and care pathways for bereaved parents.

## P75

### **INCOMPATIBLE WITH LIFE BUT NOT WITH LOVE. PREPARING FOR STILLBIRTH IN CASES OF PRENATAL LETHAL DIAGNOSIS**

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**Objective:** Technology increasingly enables diagnosis of lethal fetal conditions prenatally. Termination of these pregnancies is generally assumed to be best practice by both parents and health professionals. In the Republic of Ireland however, where termination is not a legal option, skilled experience in caring for parents who choose to continue their pregnancies has developed. There is little published research exploring the benefits of continuing the pregnancy as an alternative to termination or how best to provide prenatal lethal diagnosis palliative care.

**Study design:** We conducted an interpretative phenomenological analysis examining the parents' experience of pregnancy, birth and postnatal period of a baby diagnosed with anencephaly and the factors contributing to the process in both helpful and hurtful ways. Two primigravida, two multigravid mothers and one couple with a twin pregnancy discordant for anencephaly were sampled.

**Results:** A profoundly emotional journey represented an adaptive grieving process which culminated in rich experiences of transformative growth for all the parents. The data exposed a common theme amongst the parents of an evolving relationship with their baby following prenatal diagnosis. This adjustment process progressed through several stages, starting with rejection and objectification of the baby through to reattachment. A parallel theme was noted as the parent's sense of identity changed from "failed parent" at the time of diagnosis and became re-established as a loving protective parent who cared for their baby through stillbirth, neonatal death and burial. The role of the multidisciplinary team was pivotal to the parents' experience of psychological trauma, decision making and the development of a meaningful parenting relationship with the baby. Insensitive interactions were associated with chronic morbidity.

**Conclusions:** Offering the provision of dynamic individualised prenatal care for those who have had a prenatal diagnosis of lethal abnormality is a beneficial alternative to termination for some families. This care may have the potential to facilitate a 'good death' at the time of stillbirth or neonatal death and so support the parents in their grief process. The role of relationship with health professionals may be vital to this experience and consideration must be given to training, resource provision and a comprehensive team approach.

## P76

### **INCREASED PROPORTION OF SUDC AND EQUALITY IN SEX DISTRIBUTION IN SIDS/SUDC PURPOSE**

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**Purpose :** The rate of sudden infant death syndrome (SIDS) in Norway has been decreasing from about 150 victims per year (rate 0.25 per 1000 live births) in the late 1980s to 15 cases per year in the last decade (rate 0.03 per 1000 live births). This reduction is mainly due to the effective back-to-sleep campaign that was introduced in Norway in 1989/1990. According to the San Diego definition, the SIDS syndrome is confined to sudden unexplained deaths during the first year after birth, whereas sudden unexpected death in childhood (SUDC) is the sudden and unexpected death of a child over the age of 12 months which remains unexplained after a thorough case investigation is conducted. During the SIDS epidemic in the 1970'ties and 1980'ties, SIDS most often occurred between the second and the fourth months after birth. However, an important question is whether the drop in number of SIDS victims may have altered the age distribution of sudden unexpected deaths during the first years after birth. One of the aims of this study was to examine whether the decreased number of SIDS in infants has been followed by an increase in SUDC (age 1-3).

SIDS is known to have a male predominance with male/female ratio of 67/33. Thus an unknown x-linked disease as a risk factor for SIDS/SUDC has been postulated. The other aim of this study was to examine whether the sex distribution has changed.

**Methods:** Department of Forensic Pathology and Clinical Forensic Medicine in Oslo serves South –east Norway which has a population of 2.7 million inhabitants. Information concerning age, sex and diagnose of death has been registered during post-mortem examinations in all cases of sudden unexpected death in infants and children under the age of 4 in South-east Norway. Two time periods (from January 2001 to March 2004 and from November 2010 to December 2013) were compared. In both periods voluntarily death scene investigation was conducted.

**Results:** Between January 2001 and March 2004 the share of SUDC of the total number of SIDS and SUDC was 4 of 27 (15%). Between November 2010 and the end of 2013 the number of SUDCs comprise 8 of the total 22 SIDS/SUDC (36%). The increase in the number of SUDC in that last period was probably significant, applying the chi square test the difference had a p-value of 0.04 with Yates correction the p-value was 0.07. Regarding the sex distribution the first period shows a classical "SIDS-distribution" where 18 of a total 27 cases were boys (67%). The next period (2010-2013) does however have an even 50-50 distribution (11 of 22 in each group). The result from the examined material does in other words indicate that there has been an increase in the number of SIDS/SUDC among girls.

**Discussion:** There is a tendency towards an increase in the rate of SUDC on the expense of SIDS. One possible explanation may be that the reduction of environmental risk factors for SIDS may delay the mortality of fatal conditions not yet explained. In contradiction to the male predominance that is a typical finding in previous studies, our figures show no sex related differences in the in the distribution of SIDS/SUDC in Southeastern Norway in the last period studied. Larger studies are needed to confirm this observation.

## P77

### “THE OFFICIAL RECORD” STILLBIRTH REGISTRATION

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**Background:** It is a legal requirement in the Republic of Ireland that a record is kept of all births, marriages and deaths that occur in the state. Since 1995 parents of a stillborn infant have been able to register their infant’s birth. The information collected in hospital settings helps determine economic and social policy therefore record keeping and accuracy of data collected in hospitals is of utmost importance.

**Objective:** The aim of this study was to compare the concordance between hospital recorded data and the official data recorded on the Medical Certificate of stillbirth issued to parents and the Civil Registration Office of births, marriages and deaths.

**Method:** The internal stillbirth data recorded by the hospital was reviewed and compared against the ‘official record’ data submitted to and recorded in the local Civil Registration Office which is part of the National Government Body responsible for recording stillbirths. Data from the hospital setting were collected from the Hospital Annual Data Report. Hospital data and Civil Registration Office data were reviewed over a five year period; from 2008 to 2012.

Over the five year period we reviewed and compared 94 of the stillbirth cases. In order to assess the accuracy of these data key variables such as gestation, weight, gender, date and cause of death were compared. The cause of death was recorded descriptively and not using classification codes so there were discrepancies in exact phrasing however cause of death was similar in both sets of data.

**Results:** Over the 5 year period discrepancies were noted with regard to gestation, gender and weight see table 1 below. 28% (n 26) had no medical certificate of stillbirth issued. We also noted that our data collection accuracy improved over the 5 year period.

Discrepancies noted between sets of data:

	Gestation	Weight	Gender
2008	10%(n 4)	19%(n 8)	0% (n 0)
2009	9% (n 4)	7% (n 3)	Not recorded in hospital data
2010	7% (n 3)	9% (n 4)	Absent in 1 case
2011	3% (n 1)	10% (n 3)	7% (n 2)
2012	0% (n 0)	0% (n 0)	3% (n 1)

**Conclusion:** Mortality data is one of the key health statistics and therefore is of the utmost importance for policy development and implementation. Incorrect recording of data results in false interpretation of these details. Hospital data are recorded manually and consequently its accuracy is dependent on the recorder. Therefore the education of all health care staff of the importance of completing accurately the often complex paperwork that is associated with patient care is essential. The data submitted for official registration purposes should be concordant with internal hospital records. Monthly multidisciplinary team discussion meetings around perinatal death help provide clarity to the details, facts and diagnosis of cause of death.

## P78

### A NEW OPTION FOR PREVENTING STILLBIRTH VIA OBJECTIVE ASSESSMENT OF FETAL MOTILITY

Rik Vullings, Massimo Mischi

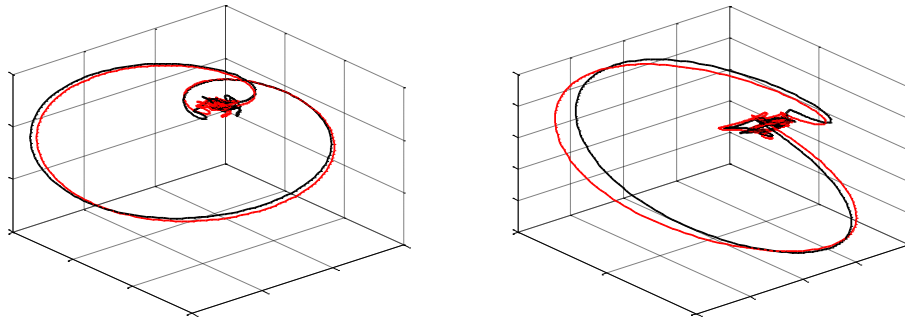
<sup>1</sup>Eindhoven University of Technology, the Netherlands

**Background:** Women that experience a decrease in fetal motility have an increased risk of adverse outcomes, such as stillbirth. Monitoring fetal movements and intervention based on decreased motility has been shown to reduce stillbirth rates. Unfortunately, maternal perception of fetal movements is liable to significant inter-patient variability, e.g. due to the position of the placenta. Consequently, clinical actions based on fetal movement counting performed by the mother do not necessarily improve fetal outcome and an urgent need exists for objective assessment of fetal motility.

**Objectives:** In this study, we aim at developing an unobtrusive method for objective assessment of fetal motility, based on fetal electrocardiographic recordings.

**Methods:** We record a multi-lead fetal ECG with adhesive electrodes on the maternal abdomen, in singleton pregnancies. For validation purposes, the ECG recordings are complemented with simultaneous ultrasound imaging. Using dedicated signal processing techniques and models of the feto-maternal physiology, we extract the fetal ECG from the non-invasive abdominal recordings and subsequently determine the fetal vectorcardiogram (VCG).

When the fetal thorax moves, the fetal heart will move as well. Specifically, the heart will move and/or rotate with respect to the abdominal electrodes and, as a result, the determined fetal VCG will move as well (see Figure 1). By tracking movement of the fetal VCG, again using signal processing and models of fetal physiology, we can assess movement of the fetal thorax. We compared the movement classified from the VCG tracking with annotations based on visual analysis of the ultrasound recordings in 8 patients with gestational ages ranging between 24 and 40 weeks. The ultrasound annotations were not restricted to movement of the fetal thorax alone, but included all fetal movements.



**Figure 1:** Fetal VCG from two consecutive heartbeats. The black line indicates the VCG of the first heartbeat, the red one that of its successor. In the left panel, the VCGs were recorded during an episode of fetal rest. In the right panel, the VCGs for the same fetus were recorded during fetal movement.

**Results:** The performance of our method for fetal movement assessment compared to visual ultrasound analysis yielded a sensitivity of 47% and specificity of 90%. In other words, not all fetal movements were detected by our method; this can easily be explained by the fact that our method can only detect movements that extend to movement of the fetal thorax. More importantly from a clinical standpoint, our method was able to reliably detect lack (or decrease) of fetal movement, as evidenced by the 90% specificity.

**Conclusions:** Our method can be used for unobtrusive and objective assessment of decreased fetal movement and can become a promising tool for preventing stillbirth. The performance of our method in ambulatory settings and in a larger study population will be object of further studies.

## P79

### AN INTERNATIONAL INTERNET SURVEY OF 1,310 MOTHERS WHO HAVE EXPERIENCED A LATE STILLBIRTH: THE STARS STUDY

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**Background:** Late stillbirth rates vary between 2-5 per 1,000 births in high-income countries. Many of these deaths are unexplained or are not adequately investigated, which leaves parents searching for answers.

**Objective:** The objective was to provide an opportunity for women who had experienced a late stillbirth (28+ weeks), to share their experiences with the aim of identifying any common themes.

**Methods:** A web based study was used. Participants had to be 18 years of age and be able to respond to the questions in English. The survey was designed to elicit established risk factors for stillbirths, to assess the prevalence of emerging risk factors and identify novel factors that could be explored in more depth in formal case control studies.

**Results:** In total 1,310 women who had experienced a stillbirth >3 weeks prior to enrolment completed the survey. Median duration of time since the stillbirth was 18.0 months (range 1.0-187.0 months). The median gestation at the time of the stillbirth was 37 weeks (range 28-41 weeks).

Common experiences identified were: Perception of changes in fetal movement, reports of a "gut instinct" that something was wrong, perceived time of death occurring overnight and a reported difference between what the mother believed was the cause of death (COD) versus what she was told.

Of participants who responded to questions about their baby's movement, two thirds (67%) reported a change in their baby's behaviour prior to death, either an increase or decrease in fetal movements. Of concern is that 25% did not realise the significance of this change, and so did not seek care provider consultation until after their baby had died. Two thirds also reported that they had experienced a "gut instinct" that something was wrong. With many indicating that they had felt this way from the beginning of the pregnancy.

When asked to indicate their perception of time of death, 52% of those who estimated a time perceived this to be during the night.

There was a notable difference between the cause of death as told by their care provider and the COD as believed by the mother with many more than expected (24%) believing that there was a cord problem. Unfortunately, 5% of women indicated that they considered they had played a role in their baby's death.

**Conclusions:** Whilst it is clear that more research is needed to answer questions raised by this current study it is also apparent that maternal perception of fetal movements and a maternal report of a sense of impending doom may need closer scrutiny and follow-up by maternity care providers. It is also noteworthy that many women perceived that their baby died overnight perhaps suggesting that events that occur during sleep may impact stillbirth rates. Further, it is important that parents are properly counselled as to the COD which addresses their own beliefs so they can be adequately prepared for another pregnancy and relevant interventions.

## P80

### THE BENEFITS OF A CHECKLIST IN A MULTIDISCIPLINARY TEAM

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Who can say what parents need when they have experience a stillbirth, "geen blote voetjes in het gras".

The emphasis is how to make this time special, unique and memorable for parents and family when saying good bye to their child in their own way. We appreciate that parents are sometimes overwhelmed at this time. To make it easier we provide information on what the possibilities are. We also listen to what parents may want themselves. Our clients comes from a diverse multi cultural background with different cultural beliefs, thus our aim to accommodate all our clients. Our aim is to help the parents create a memory of their child and to be proud that they are parents despite not being able to see their child grow up and become adults. This is where our expertise and experience are helpful.

The expertise of the multidisciplinary team are assessed and changes are implemented on a regular basis with the changes in society and medical care.

A Care Plan: When it is apparent that a woman is going to deliver a baby that is stillborn or not going to survive we ensure that we enlist the expertise of different professional (nurses, doctors, midwives, anesthetist, social worker and health care assistance). We provide a list of practical information and things for parents to think about before the birth. It is an emotional and draining time for the parents which is why we suggest that they enlist the help of a third person to help with practical things. The list has information over practical things (such as parking), route hospital admission, stay in the hospital, information about the birth, pain relief, after the birth and what to expect, making memories of the baby that they can keep (footprint, lock of hair, photos), and postnatal care.

Indeed if parents want more information they are given a folder with additional information. In practice we see that this information is used differently by different family. This confirms that not everyone needs the same information at the same time that the grieving is individual.

It is clearly documented what is discussed.

List of things for nurse to think about: The nurse makes use of the list to help ensure that the parents are physically and mentally prepared for the birth. Although we use a check list to ensure that nothing is forgotten we aim to provide individualized care to all our parents and family.

## P81

### THE RELATIONSHIP OF INTRAPARTUM AND ANTEPARTUM STILLBIRTH RATES IN LATVIA: A RETROSPECTIVE COHORT STUDY

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Introduction: In Latvia according to World Health Organization Health for All (HFA) database, the total stillbirth rate has decreased by 23 % from 2000 to 2010, 7.3/1000 to 5.6/1000. Moreover, stillbirth rate of Latvia exceeds the European average indicators for 14% in 2010. According to Medical Birth Register of Latvia (MBR) 9.3% of stillbirth associated with congenital anomalies (2000-2010).

Objective: to assess the association between intrapartum and antepartum stillbirths and various risk factors.

Materials and methods: Data source - The Medical Birth Register of Latvia. In total 1424 cases of singleton birth (from 22 gestational weeks and 500 grams weight) had been selected, but 17 cases were excluded from data analysis due to no information about stillbirth period. Chi-square test and OR were calculated in data analysis.

Results: There were 70% (n=997) antepartum stillbirth. The average maternal age was 26.8 (SD 9.2), there was difference by gestational age (p<0.05) and birth weight (p<0.01). Intrapartum stillbirth have lower rates - 31.6 GW (SD 6.7) to 33.1 (SD 5.4) and 1981.3g (SD 1300.0) to 2035.7g (SD 1026.2). Higher proportion ( $\chi^2=41.0$ ; p<0.01) with late first antenatal visit (after 12<sup>th</sup> GW) was observed in antepartum stillbirth group - 32.3% (n=322) to 29.7% (n=121), but without antenatal care higher proportion was for intrapartum stillbirth ( $\chi^2=95.4$ ; p<0.01) - 16.4% (n=67) to 15.3% (n=153), as well as abortions in anamnesis ( $\chi^2=23.6$ ; p<0.01) - 53.4% (n=281) to 46.2% (n=461). In total 3.3% (n=47) cases stillbirth have been registered in maternal medical histories, but there is no difference between groups. Mother who have antepartum stillbirth have 2 times higher odds (OR=1.9; 95%CI 1.2-3.8; p<0.05) for fetal growth retardation than other complications due to pregnancy, there were no statistically significant difference due to other complications due to pregnancy (int. al. placental dysfunction - placental abruption). The main death cause for stillbirth was registered - different perinatal period conditions, most of them intrauterine hypoxia - 79.7% (n=1026), congenital anomalies were observed in 9.6% (n=136).

Conclusions: The results indicate about indirect association with late and inadequate antenatal care and poor pregnancy outcomes. The single largest risk factor for antepartum stillbirth is fetal growth restriction. Preventive strategies need to focus on improving antenatal detection of it. The intrapartum stillbirth rate could be more closely related to various measures of obstetric care than the antepartum stillbirth rate.

## P82

### Development of Putative Working Definitions of Prenatal-onset Group B Streptococcal (P-OGBS) Invasive Disease Using “Internet Commons” Group B Strep (GBS) Parent and Provider Sources

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<sup>1</sup>University of Colorado Denver, <sup>2</sup>Group B Strep International, <sup>3</sup>LA Best Babies Network

**Background:** Classification of early-onset GBS disease is defined as death after birth which misses fetal demise caused by GBS before birth. Therefore, fetal demises caused by GBS are not counted as being due to group B strep disease.

**Objective:** Develop and justify epidemiologic, clinically graded (“Proven,” “Likely,” “Possible,” or “Atypical”) case definitions of previously unclassified invasive prenatal-onset group B streptococcal (P-OGBS) invasive disease in order to inform research, advocacy, public policy, clinical care, and social support.

**Methods:** We used quasi-experimental and qualitative techniques (“gedanken” research) to collect, record, and analyze GBS-related questions (FAQ’s) submitted to Group B Strep International’s website ([www.gbs-intl.org](http://www.gbs-intl.org)) or at medical professional meetings from 2000-2012. Questions or requests for information arrived unbidden over the worldwide web (“Internet Commons”) or in response to “Survey Monkey” style inquiries to personal contacts made at professional meetings and through the internet from 2000 to 2012. Language was not restricted, but all analyzed responses were in English to prompt spontaneity. No written consent was obtained and the process and analysis were not IRB-approved.

**Results:** Twelve years of inquiries and contacts were analyzed. There were no measured differences in question types or topics among parents or providers. (At professional meetings as many as 500 questions were submitted daily making detailed analysis unreliable.) Queries mainly fell into three categories:

- 1) clinical “anecdotal cases,”
- 2) procedural, e.g., how to facilitate communication of GBS status cards, and
- 3) informal non-evidence-based advice for uncommon or unstudied clinical circumstances, e.g., severe penicillin allergy, prior GBS-associated stillbirth.





## **REQUEST FOR PARTICIPATION IN RESEARCH**

First Candle is supporting researchers at Harvard Medical School who want to understand the grief mothers experience after a sudden, unexpected loss. This will be a large international study examining the feelings parents have after a loss and the ways they typically adapt their memories. Participation in this confidential survey can be done on-line. We are interested in the participation of mothers who have lost their babies to SIDS within the past 48 months. They will complete a 31 question on-line questionnaire and answer some background questions. Participants will be asked to complete this survey once.

Please consider participating and telling mothers who might want to be involved about this research.

If you are interested in learning more, please go to the First Candle website at <http://www.firstcandle.org> or log on directly to the study website at: [www.bereavementstudy.com](http://www.bereavementstudy.com). The study website will be active after 18 September 2014.

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