

2012

October 4 - 7, 2012
Baltimore, Maryland



The 2012 International Conference on
STILLBIRTH, SIDS AND INFANT SURVIVAL

HOSTED BY FIRST CANDLE | Helping Babies Survive & Thrive



The development and printing of this Conference Program Book is dedicated in loving memory of baby Sheila Kay O'Sullivan.



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WELCOME

From First Candle

I would like to extend a warm welcome to the participants of the 2012 International Conference on Stillbirth, SIDS and Infant Survival.

Infant survival continues to be among the most significant and challenging public health issues of our time. The need for new research, and the sharing and dissemination of existing research findings, is crucial in order for us to have a substantial positive impact on reducing the rates of stillbirth, SIDS and other unexpected infant deaths worldwide. The International Conference is our opportunity to bring the global community together by uniting the most prominent international researchers, medical professionals and health educators with parent leaders and public policy, safety and product development professionals, to work toward our common goals. I extend my heartfelt thanks to each conference delegate for your valuable contributions to the field, dedication to the cause and participation at this event.



“Infant survival continues to be among the most significant and challenging public health issues of our time.”

As we celebrate our 25th Anniversary, it has been a great honor for First Candle to serve as host to the Conference. Special thanks to the many, many people who have worked tirelessly to make this Conference possible, from our great friends at ISA and ISPID to our many sponsors and supporters. And my personal thanks to the team at First Candle – their diligence and attention to detail ensure that the Conference will be a great experience for all.

As we join together over the four days of the Conference to instruct, learn, network, socialize, and honor, let us always be mindful of the children we have lost and the families whose battle for answers is the foundation of our efforts. You are our inspiration and our motivation.

I hope you will enjoy your time in Baltimore and take away valuable information to assist in your ongoing efforts to ensure that all babies survive and thrive.

Until we meet again.

A handwritten signature in black ink that reads "Kelly Neal Mariotti". The signature is fluid and cursive.

Kelly Neal Mariotti
Chief Executive Officer, First Candle



WELCOME

From the International Stillbirth Alliance (ISA)

On behalf of the Board of the International Stillbirth Alliance (ISA) I would like to extend a very warm welcome to all delegates attending the 2012 International Conference on Stillbirth, SIDS and Infant Survival. I am sure that we are all going to have a very rewarding time in Baltimore, with many interesting and informative presentations from clinicians, researchers and parent organizations from around the globe. The program is truly international and this meeting has attracted delegates from many countries who will come together to learn and share information about the latest in research and care for families experiencing these tragic outcomes of pregnancy and early childhood.



Stillbirth remains a major global public health problem, as clearly described in last year's Lancet series. Although there has been an increasing awareness of this over the last few years there is still a paucity of rigorous research which can provide high level evidence to guide both clinical practice to prevent the tragedy of stillbirth, as well as care for bereaved parents to help them with their loss. It is by coming together at meetings such as this that we can share our research findings, and our stories about dealing with loss. In this we can all become better informed and better equipped to continue our important work.

“It is by coming together at meetings such as this that we can share our research findings, and our stories about dealing with loss.”

First Candle and the various organising committees have done an excellent job in putting together a very fine program and I am sure we will all experience the best of hospitality from our hosts. It will be a time to renew old acquaintances and make new friendships, hopefully forging partnerships which will encourage further research collaborations.

I look forward very much to seeing you all in Baltimore,

A handwritten signature in black ink that reads "David A. Ellwood". The signature is written in a cursive, flowing style.

David Ellwood
Chair, International Stillbirth Alliance



WELCOME

From the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID)

It is with great pleasure that I welcome you to First Candle's 2012 International Conference on Stillbirth, SIDS and Infant Survival, which is held in conjunction with the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) and the International Stillbirth Alliance (ISA). ISPID has a long history of supporting these conferences. Indeed its predecessor SIDS International ran the first truly international conference on sudden infant death in Lake Como, Italy some 25 years ago.



For those who have had the privilege of working in SIDS research and prevention, these last 25 years have been an exciting time, with the recognition of the risk from prone sleeping leading to the various "Back to Sleep" campaigns and the striking reduction in mortality that occurred. With the reduction in mortality new issues have arisen, and we must continue to strive to keep this in front of policy makers. Stillbirth has been described as the "silent epidemic". How can so many cherished babies be lost without there being a national outcry?

This conference is special, as it brings together researchers, health promotion, the voluntary sector and parents. The parents are special. They bring a passion and a painful reminder of why we are here.

"This conference is special, as it brings together researchers, health promotion, the voluntary sector and parents."

The voluntary sector has such an important role, especially supporting bereaved parents, and advocating for their right to be heard.

To all in the SIDS and Stillbirth family, welcome and enjoy this conference.

Yours sincerely,

A handwritten signature in cursive script that reads "Ed Mitchell".

Ed Mitchell
Chair, ISPID





MARTIN O'MALLEY
GOVERNOR

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TTY USERS CALL VIA MD RELAY

A MESSAGE FROM GOVERNOR MARTIN O'MALLEY

Dear Friends:

Welcome to Baltimore for the 2012 International Conference on Stillbirth, SIDS and Infant Survival hosted by First Candle.

First Candle is committed to promoting infant health and survival. By working with parents, caregivers, researchers and partner organizations across the nation, you have helped save lives and provided comfort and support to families who have experienced tragic loss.

The Talmud says that *'to save one life, it is as if you had saved the world.'* In our State, where there is no such thing as a spare Marylander, we are committed to reducing the infant mortality rate. We're working to improve the health of women before they become pregnant, increase the number of women who receive early prenatal care and ensure that mothers and babies receive the follow-up care that they need after delivery.

Thank you for your dedication to our families. Together, we're making progress and must continue to take action to save lives.

Best wishes for a successful conference.

Sincerely,

Governor



STEPHANIE RAWLINGS-BLAKE
Mayor
250 City Hall, 100 North Holliday Street
Baltimore, Maryland 21202

October 5, 2012

A Message from Mayor Stephanie Rawlings-Blake:

It is my pleasure to welcome you to the 2012 International Conference on SIDS, Stillbirth, and Infant Survival, hosted by First Candle. On behalf of the citizens of Baltimore, I want to thank you for your commitment to making strides in the battle against infant mortality.

One of the pillars of my administration is making Baltimore a healthier city; this is especially urgent in the matter of infant mortality. Our *B'More for Healthy Babies* initiative seeks to build widespread involvement in preventing infant deaths through education, community outreach, a media campaign, and other means. The program's guiding mission is to ensure that all Baltimore babies are born at a healthy weight, at full-term, and ready to thrive in healthy families. Collaboration and cooperation are vital to our goal of reducing infant mortality and improving the health of Baltimore's families.

Losing even one infant to a preventable death is a tragedy, and I'm thankful for events like this weekend's conference that shine a light on this critical issue. Best wishes for a great conference. Keep up the good work.

Sincerely,

Stephanie Rawlings-Blake
Mayor
Baltimore City

phone: 410.396.3835 fax: 410.576.9425 e-mail: mayor@baltimorecity.gov

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CONFERENCE COMMITTEES

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Conference Committees

INTERNATIONAL CONFERENCE CO-CHAIRS



Rachel Y. Moon, MD

Associate Chief, General Pediatrics & Community Health, Children's National Medical Center; Professor of Pediatrics, George Washington University, USA



Ruth C. Fretts, MD, MPH

Assistant Professor, ObGyn, Harvard Medical School
Harvard Vanguard Medical Associates, USA

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David A. Ellwood, MD, Chair, International Stillbirth Alliance and Professor, Obstetrics & Gynaecology, Australian National University, Australia

Jan Jaap Erwich, MD, PhD, Associate Professor, University Medical Centre Groningen, Netherlands

Ruth Fretts, MD, MPH, Researcher, Harvard Vanguard Medical Associates, USA

Stephanie Fukui, Executive Director, SIDS Family Association Japan

Kelly Neal Mariotti, CEO, First Candle, USA

Edwin Mitchell, MD, Chair, International Society for the Study and Prevention of Perinatal and Infant Death; Professor, University of Auckland, New Zealand

Rachel Moon, MD, Professor of Pediatrics, George Washington University, USA

Leanne Raven, CEO, SIDS and Kids, Australia

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Mary Adkins, RN, MSW, Tomorrow's Child, ASIP, USA

Aurore Côté, MD, Montreal Children's Hospital, Canada

Fern R. Hauck, MD, MS, University of Virginia, USA

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Rachel Moon, MD, Professor of Pediatrics, George Washington University, USA

David Paterson, PhD, Children's Hospital Boston and Harvard Medical School, USA

Carrie Shapiro-Mendoza, PhD, MPH, Epidemiologist, Centers for Disease Control and Prevention, USA

Marian Willinger, PhD, Special Assistant for SIDS, NICHD, USA

Conference Committees

STILLBIRTH PROGRAM COMMITTEE

David A. Ellwood, MD, Chair, International Stillbirth Alliance and Professor, Obstetrics & Gynaecology, Australian National University, Australia

Jan Jaap Erwich, MD, PhD, Associate Professor, University Medical Centre Groningen, Netherlands

Ruth Fretts, MD, MPH, Researcher, Harvard Vanguard Medical Associates, USA

J. Frederik Froen, MD, PhD, Division of Epidemiology, Norwegian Institute of Public Health, Norway

Dana Kaplin, MPH, Kicks Count Initiative, First Candle, USA

Elizabeth McClure, MD, Research Triangle International, USA

Uma Reddy, MD, MPH, NICHD, USA

Craig Rubens, MD, PhD, Affiliate Professor, Pediatrics, University of Washington and Executive Director, Global Alliance to Prevent Prematurity and Stillbirth (GAPPS), USA

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Nadine Goldberg, PhD, MS, First Candle, USA

Sherokee Ilse, Author and Bereavement Speaker, USA

Jamie King, Executive Director, Canadian Foundation for the Study of Infant Deaths, Canada

Rebecca Sirody, First Candle, USA

Marian Sokol, PhD, MPH, First Candle, USA

Leah Tanner, Seattle Children's Hospital, USA

Dee Moore, First Candle, USA

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CONFERENCE EXHIBITORS

Exhibitors by Booth Number14

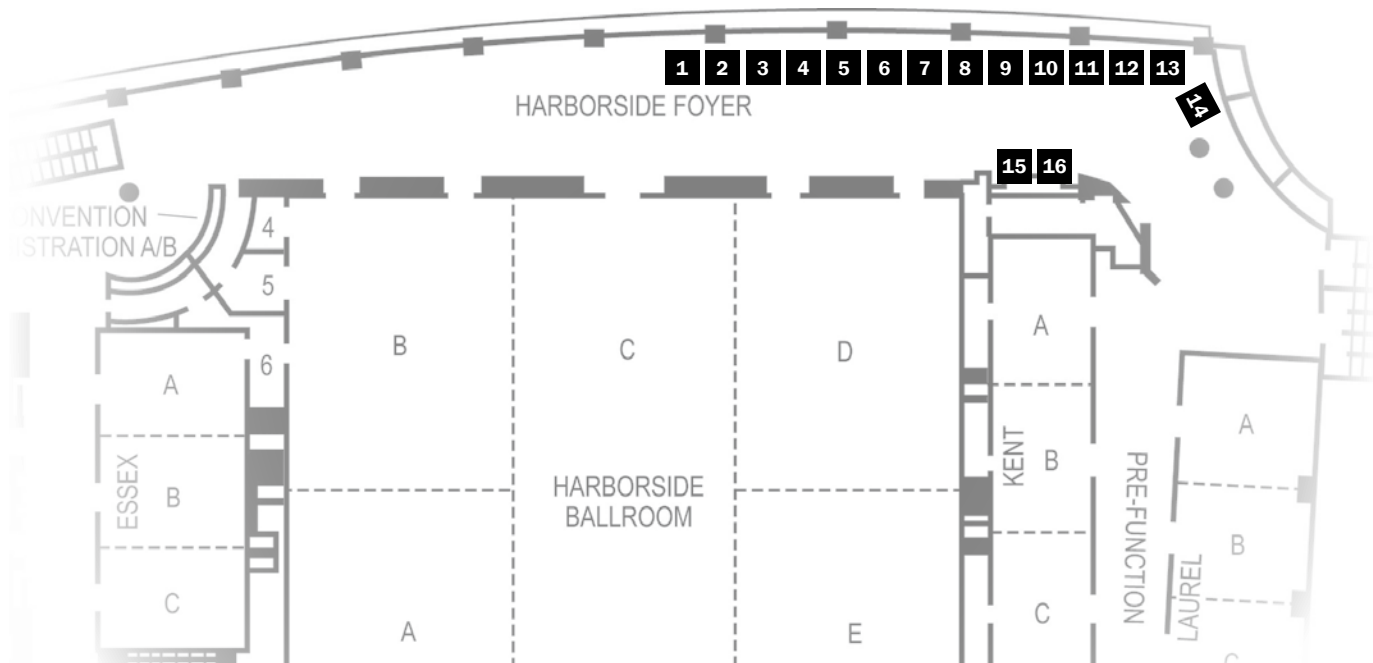
Conference Exhibitors

BOOTH	EXHIBITOR
1	National Center for Review & Prevention of Child Death
2 3	MAM
4	HALO Innovations Inc.
5 6	CDC Division of Reproductive Health
7	March of Dimes

BOOTH	EXHIBITOR
8	Star Legacy Foundation
9	Group B STREP International
10	SIDS & Kids Australia
11	CJ Foundation For SIDS
12	NICHD

BOOTH	EXHIBITOR
13	Cribs for Kids
14	Georgetown University, National SUID/SIDS Resource Center
15	SOOTHETime
16	Project Impact, HRSA

HARBORSIDE BALLROOM LEVEL - HARBORSIDE FOYER, 4TH FLOOR



FIRST CANDLE SALUTES



50th Anniversary 2012

Research, Dedication and Leadership to **Save Infant Lives**

First Candle is a proud founding partner in the *Back to Sleep* and *Safe to Sleep* campaigns. Upon this special occasion we also wish to applaud the National Children's Study and the National Child & Maternal Health Education Program (NCMHEP) for its efforts to prevent preterm birth.

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First Candle Salutes

HRSA Maternal and Child Health Bureau
For National, State and Local Leadership To Save Infant Lives

CONFERENCE AGENDA

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Agenda At-A-Glance

THURSDAY, OCTOBER 4

12:00 pm - 5:00 pm	Registration	Harborside Foyer, 4th Floor
12:00 pm - 6:00 pm	Poster Session A Setup	Laurel Rooms A, B, & C
1:00 pm - 4:30 pm	ISPID Pre-Conference Meetings	Kent Rooms A, B & C
1:00 pm - 10:00 pm	Family Oasis Room	Laurel Room D
6:00 pm - 7:30 pm	Opening Welcome Reception	Harborside Ballroom Salon D

FRIDAY, OCTOBER 5

6:55 am - 8:55 am	Breakfast 🍴	Harborside Foyer D
7:00 am - 7:00 pm	Registration	Harborside Foyer, 4th Floor
7:00 am - 6:00 pm	Family Oasis Room	Laurel Room D
7:00 am - 8:30 am	Breakfast Session I: SIDS/SUID SS	Kent Room A
7:00 am - 8:30 am	Breakfast Session II: Stillbirth S	Kent Room B
7:00 am - 8:30 am	Breakfast Session III: SIDS/SUID & Pacifiers SS	Kent Room C
8:30 am - 9:15 am	Welcome to Baltimore	Harborside Ballroom Salons D & E
9:15 am - 10:00 am	Plenary I: Maternal Life Course	Harborside Ballroom Salons D & E
10:00 am - 10:45 am	Plenary II: What Can Stillbirth Research Learn from SIDS?	Harborside Ballroom Salons D & E
10:45 am - 11:30 am	Plenary III: A Parent's Perspective	Harborside Ballroom Salons D & E
11:30 am - 12:30 pm	Buffet Lunch 🍴	Harborside Ballroom Salon C
12:30 pm - 3:00 pm	Stillbirth Oral Abstract Presentations S	Harborside Ballroom Salon D
12:30 pm - 4:30 pm	SIDS/SUID Pathology Symposium SS	Harborside Ballroom Salon E
3:00 pm - 3:15 pm	Break	Harborside Foyer D
3:15 pm - 4:30 pm	Stillbirth Workshop: Fetal Movement & Kick Counting S	Harborside Ballroom Salon D
4:30 pm - 6:00 pm	Poster Session A: Stillbirth & SIDS/SUID S SS	Laurel Rooms A, B & C
6:00 pm	Poster Session A Breakdown	Laurel Rooms A, B & C
6:00 pm - 8:00 pm	Poster Session B Setup	Laurel Rooms A, B, & C
6:15 pm - 7:30 pm	Remembrance Service	World Trade Center, 21st Floor, Maryland Room

NOTE: Meet in the Marriott Lobby at 5:30 pm.

There will be transportation to and from The World Trade Center. First Candle staff will be available to assist.

SATURDAY, OCTOBER 6

6:55 am - 8:55 am	Breakfast 🍴	Harborside Foyer D
7:00 am - 5:30 pm	Registration	Harborside Foyer, 4th Floor
7:00 am - 6:00 pm	Family Oasis Room	Laurel Room D
7:00 am - 8:30 am	Breakfast Session I: SIDS/SUID SS	Kent Room A
7:00 am - 8:30 am	Breakfast Session II: Stillbirth S	Kent Room B
8:30 am - 9:15 am	Plenary I: Global Perspectives on Stillbirth	Harborside Ballroom Salons D & E
9:15 am - 10:00 am	Plenary II: Fetal Physiology	Harborside Ballroom Salons D & E
10:00 am - 10:15 am	Break	Harborside Foyer D
10:15 am - 11:15 am	Stillbirth Session: Review of GAPPS Initiatives S	Harborside Ballroom Salon D
10:15 am - 11:15 am	SIDS/SUID Oral Abstract Presentations: Physiology & Genetics SS	Harborside Ballroom Salon E

Agenda At-A-Glance

11:15 am - 11:30 am	Break	Harborside Foyer D
11:30 am - 12:30 pm	Stillbirth Session: Placental Insufficiencies S	Harborside Ballroom Salon D
11:30 am - 12:30 pm	SIDS/SUID Workshop: SIDS/SUID Diagnostic Drift SS	Harborside Ballroom Salon E
12:30 pm - 1:30 pm	Buffet Lunch FF	Harborside Ballroom Salon C
12:30 pm - 1:30 pm	Poster Session B: Stillbirth & SIDS/SUID S SS	Laurel Rooms A, B & C
1:30 pm - 3:00 pm	Stillbirth Workshop: Perinatal Audit S	Harborside Ballroom Salon D
1:30 pm - 3:00 pm	SIDS/SUID Oral Abstract Presentations: Diagnosis and Risk Reduction SS	Harborside Ballroom Salon E
3:00 pm - 3:15 pm	Break	Harborside Foyer D
3:15 pm - 5:30 pm	SIDS/SUID Oral Abstract Presentations: Epidemiology SS	Harborside Ballroom Salon E
3:15 pm - 6:15 pm	Stillbirth Oral Abstract Presentations S	Harborside Ballroom Salon D
4:30 pm - 6:00 pm	ISA Board and Annual General Meeting	Kent Room A
7:30 pm - 11:00 pm	Awards Dinner: Special Recognition NICHD	Harborside Ballroom Salon C

SUNDAY, OCTOBER 7

7:00 am - 8:30 am	Breakfast FF	Harborside Foyer D
8:00 am - 12:00 pm	Family Oasis Room	Laurel Room D
8:30 am - 9:15 am	Plenary I: Social Media & Health Messaging	Harborside Ballroom Salons D & E
9:15 am - 10:00 am	Plenary II: Disparities in Stillbirth	Harborside Ballroom Salons D & E
10:00 am - 10:15 am	Break	Harborside Foyer D
10:15 am - 10:45 am	SIDS and Stillbirth, Combined Session: Grief and Bereavement S SS	Harborside Ballroom Salon D
10:45 am - 12:00 pm	Grief and Bereavement Oral Abstract Presentations: Breakout Session I: SIDS/SUID/Neonatal SS Breakout Session II: Stillbirth S	Harborside Ballroom Salon D Kent Room A
10:15 am - 12:00 pm	SIDS Oral Abstract Presentation: Innovative Practices Panel SS	Harborside Ballroom Salon E
12:00 pm - 12:30 pm	Awards and Closing Ceremony	Harborside Ballroom Salons D & E

scan for
conference
agenda



Agenda Detail

THURSDAY, OCTOBER 4

REGISTRATION

12:00 pm - 5:00 pm Harborside Foyer, 4th Floor

POSTER SESSION A SETUP

12:00 pm - 6:00 pm Laurel Rooms A, B & C

EXHIBITOR SETUP

12:00 pm - 6:00 pm Harborside Foyer, 4th Floor

ISPID PRE-CONFERENCE MEETINGS

1:00 pm - 4:30 pm Kent Rooms A, B & C

1:00 pm - 1:45 pm Pre-Conference Meeting Stillbirth - Kent Room A

Pre-Conference Meeting Physiology - Kent Room B

Pre-Conference Meeting Epidemiology - Kent Room C

1:45 pm - 2:30 pm Pre-Conference meeting Joint Session – Kent Rooms A & B

2:30 pm - 3:00 pm Pre-Conference Meeting ISPID - Kent Room B

3:30 pm - 4:30 pm ISPID Board Meeting – Kent Room C

OPENING WELCOME RECEPTION

6:00 pm - 7:30 pm Harborside Ballroom Salon D

Please join us for cocktails, hors d'oeuvres and a special Native American performance.

FRIDAY, OCTOBER 5

BREAKFAST

6:55 am - 8:55 am Harborside Foyer D

REGISTRATION

7:00 am - 7:00 pm Harborside Foyer, 4th Floor

BREAKFAST SESSION I: SIDS/SUID (ROUND TABLE)

7:00 am - 8:30 am Kent Room A

Moderators: Stephanie Cowan, Director, Change for our Children, New Zealand

David Tipene-Leach, Department of Women's and Children's Health, Dunedin School of Medicine, University of Otago, New Zealand

'End Game' SUID Prevention Approaches and the Need for Innovation

BREAKFAST SESSION II: STILLBIRTH

7:00 am - 8:30 am Kent Room B

Moderator: Penny Brabin, PhD, Monash University, School of Psychology and Psychiatry, Australia

Being with Parents after the Loss of a Baby: Guidance from the Experience as the Basis of Appropriate Care

BREAKFAST SESSION III: SIDS/SUID & PACIFIERS

7:00 am - 8:30 am Kent Room C

Moderator: Fern Hauck, MD, MS, Professor of Family Medicine and Public Health Services, Director, International Family Medicine Clinic, University of Virginia, USA

Agenda Detail

Speaker: Peter Weiss, MSc., PhD, Vice-President Research, International Children's Medical Research Society, United Kingdom
Time to Re-evaluate the Role of Pacifiers in SIDS Campaigns

Speaker: Fern Hauck, MD, MS, Professor of Family Medicine and Public Health Services, Director, International Family Medicine Clinic, University of Virginia, USA

Relationship Between Pacifier Usage and SIDS – Review of Epidemiologic Literature

Speaker: Reinhold Kerbl, MD, Professor, Department of Pediatrics and Adolescent Medicine, Hospital of Leoben, Austria
A Trial to Explain the Beneficial Effect of Pacifier Use; Observations and Speculations

Speaker: Peter Weiss, MSc., PhD, Vice-President Research, International Children's Medical Research Society, United Kingdom
The Changes in Attitude Toward Pacifier Use throughout History and a Survey of Current View on the Internet

Speaker: Alejandro Jenik, MD, Associate Professor, Department of Neonatology, Hospital Italiano de Buenos Aires, Argentina
The Effect of Pacifiers on Breastfeeding

OPENING SESSION: WELCOME TO BALTIMORE

8:30 am - 9:15 am Harborside Ballroom Salons D & E

Kelly Mariotti, Chief Executive Officer, First Candle, USA

Oxiris Barbot, MD, Commissioner, Baltimore City Health Department, USA

Joshua Sharfstein, MD, Maryland Department of Health and Mental Hygiene, USA

PLENARY I

9:15 am - 10:00 am Harborside Ballroom Salons D & E

Speaker: Michael C. Lu, MD, MS, MPH, Associate Administrator, Maternal and Child Health, Health Resources and Services Administration, U.S. Department of Health and Human Services, USA

Maternal Life Course

PLENARY II (Session Sponsored in Memory of Baby Jeremy Fine)

10:00 am - 10:45 am Harborside Ballroom Salons D & E

Speaker: Edwin A. Mitchell, MD, Professor of Pediatrics, University of Auckland; Chair, ISPID, New Zealand

What Can Stillbirth Research Learn from SIDS?

PLENARY III (Session Sponsored in Memory of Baby U'Jana Conley)

10:45 am - 11:30 am Harborside Ballroom Salons D & E

Speaker: Tamasine Bogle, Executive Director HR, UBS Investment Bank, USA

Speaker: Steven Scully, Senior Executive Producer and Political Editor, C-SPAN, USA

Speaker: Allison Glover, Bereavement Support Coordinator, First Candle, USA

A Parent's Perspective

BUFFET LUNCH 🍴

11:30 am - 12:30 pm Harborside Ballroom Salon C

Agenda Detail

STILLBIRTH TRACK **S**

STILLBIRTH ORAL ABSTRACT PRESENTATIONS **S**

12:30 pm - 3:00 pm Harborside Ballroom Salon D

Moderator: David A. Ellwood, FRANZCOG, DPhil (Oxon), Chair, International Stillbirth Alliance, Professor of Obstetrics & Gynaecology, Australian National University, Australia

BREAK

3:00 pm - 3:15 pm Harborside Foyer D

STILLBIRTH WORKSHOP: FETAL MOVEMENT & KICK COUNTING **S**

3:15 pm - 4:30 pm Harborside Ballroom Salon D

Speaker: J. Frederik Froen, MD, PhD, Norwegian Institute of Public Health, Norway

Speaker: Brita Askeland, PhD, Norwegian Institute of Public Health, Norway

Speaker: Vicki Flenady, PhD, Director, Translating Research Into Practice (TRIP) Centre, Mater Medical Research Institute, Australia

Speaker: Jan Jaap Erwich, MD, PhD, Department of Obstetrics and Gynaecology, University Medical Center Groningen, Netherlands

Speaker: Ruth Fretts, MD, MPH, Harvard Vanguard Medical Associates, USA

Speaker: Alex Heazell, MBChB, PhD, Maternal and Fetal Health Research Centre, University of Manchester, United Kingdom

SIDS/SUID TRACK **SS**

SIDS/SUID PATHOLOGY SYMPOSIUM – IN CELEBRATION OF THE CAREER OF HENRY F. KROUS, MD **SS**

(Session Sponsored by the American SIDS Institute)

12:30 pm - 4:30 pm Harborside Ballroom Salon E

Moderator: Hannah Kinney, MD, Professor of Pathology, Harvard Medical School, USA

Moderator: Torleiv Rognum, MD, PhD, MHA, Professor, Institute of Forensic Medicine, Norway

Welcome and Introduction/Overview of Program

Speaker: Gabriel Haddad, MD, Departments of Pediatrics and Neuroscience, University of California and Rady Children's Hospital, USA

Mechanisms of Cell Death in Neurons and Glia following Hypoxia/Ischemia

Speaker: Torleiv Rognum, MD, PhD, MHA, Professor, Institute of Forensic Medicine, Norway

Professor Henry Krous' Contribution to More Accurate Definition of SIDS

Speaker: Roger Byard, MD, Professor of Pathology, University of Adelaide, Australia

Standardized Protocols in the Investigation of Sudden Infant Death

Speaker: Bruce Hyma, MD, Director and Chief Medical Examiner, Miami-Dade, University of Miami, Miller School of Medicine, USA

Sudden Unexpected Infant Death (SUID) Tissue Consortia

Speaker: David Paterson, PhD, Children's Hospital Boston and Harvard Medical School, USA

SIDS Brainstem and Genetics Research

Speaker: Eugene Nattie Jr., MD, Department of Physiology, The Geisel School of Medicine Dartmouth, USA

Insights into SIDS Pathogenesis and Possible "Treatment" from Animal Models

Speaker: Laura Crandall, PT, MA, Program Co-Director and Co-Founder, The Sudden Unexplained Death in Childhood Program, CJ Foundation for SIDS, USA

Filling the Void: Envisioning and Fulfilling the Needs of SUDC

Agenda Detail

Speaker: Hannah Kinney, MD, Professor of Pathology, Harvard Medical School, USA
Neuropathologic Research in SUDC: Reflections in Honor of Henry F. Krous

Speaker: Henry F. Krous, MD, University of California - San Diego and Rady Children's Hospital, USA
Career Reflections

Speaker: Betty McEntire, PhD, Executive Director, American SIDS Institute, USA
Closing Reminisces, Thoughts and Comments

POSTER SESSION A: STILLBIRTH & SIDS/SUID ^S ^{SS} (Session Sponsored by the Ryan Wolfe Kossar Foundation)
4:30 pm - 6:00 pm Laurel Rooms A, B & C

POSTER SESSION A BREAKDOWN
6:00 pm Laurel Rooms A, B & C

POSTER SESSION B SETUP
6:00 pm - 8:00 pm Laurel Rooms A, B & C

REMEMBRANCE SERVICE
6:15 pm - 7:30 pm World Trade Center, 21st Floor, Maryland Room

Speakers: Jamie King, Executive Director, Canadian Foundation for the Study of Infant Deaths; Phyllis Williams-Thompson, MS, CIM Associate Director, Prematurity Campaign, March of Dimes; Dr. Leanne Raven, CEO, SIDS and Kids Australia; Sherokee Ilse, Author and Bereavement Speaker; Anat Shatz, MD, Chairperson, ATID - Israeli Foundation for the Study and Prevention of Sudden Infant Death; Patricia Flynn, MD, Founder, 1st Breath; Special Music: Naomi Arnold

There will be transportation to and from The World Trade Center. Meet in the Marriott Lobby at 5:30 pm. First Candle staff will be available to assist.

SATURDAY, OCTOBER 6

REGISTRATION
7:00 am - 5:30 pm Harborside Foyer, 4th Floor

BREAKFAST 
6:55 am - 8:55 am Harborside Foyer D

BREAKFAST SESSION I: SIDS/SUID ^{SS}
7:00 am - 8:30 am Kent Room A

Moderator: Lena Camperlengo, RN, MPH, DrPH, Health Scientist, Sudden Unexpected Infant Death Initiative, Preterm Birth/Infant Health Team, Centers for Disease Control and Prevention, USA

The Sudden Unexpected Infant Death (SUID) Case Registry: Improving Knowledge about SUID and Taking Action

Speaker: Theresa M. Covington, MPH, Director, National Center for Child Death Review and Prevention, USA

Speaker: Lisa Kay Hartmann, Child Death Review Coordinator, Office of Performance Management and Accountability, New Jersey Department of Children and Families, USA

Speaker: Shannon Stotenbur-Wing, MSW, Director, Child & Adolescent Health at the Center for Child and Family Health, Michigan Public Health Institute, USA

Speaker: Arleymah Raheem, MPH, Child Fatality Prevention Specialist, Georgia Office of the Child Advocate, USA

Agenda Detail

BREAKFAST SESSION II: STILLBIRTH **S**

7:00 am - 8:30 am Kent Room B

Moderator: Sherokee Ilse, Author and Bereavement Speaker, USA

Taking Baby Home: International Perspectives on Caring for Parents and Families after the Death of a Baby

Speaker: Ingela Radestad, Sophiahemmet University College, Sweden

Speaker: Vicki Culling, PhD, Chairperson, Stillbirth and Newborn Death Support (SANDS), New Zealand

PLENARY I

8:30 am - 9:15 am Harborside Ballroom Salons D & E

Speaker: Robert Goldenberg, MD, Professor of Obstetrics and Gynecology, Drexel University College of Medicine, USA

Global Perspectives on Stillbirth

PLENARY II (Session Sponsored in Memory of Baby Alexander Williamson-Noble)

9:15 am - 10:00 am Harborside Ballroom Salons D & E

Moderator: Marian Willinger, PhD, Special Assistant for SIDS, Eunice Kennedy Shriver National Institute of Child Health and Human Development, USA

Speaker: William Fifer, PhD, Professor of Psychiatry and Pediatrics, Columbia University, USA

Fetal Physiology

BREAK

10:00 am - 10:15 am Harborside Foyer D

STILLBIRTH TRACK **S**

STILLBIRTH SESSION **S**

10:15 am - 11:15 am Harborside Ballroom Salon D

Speaker: Craig Rubens, MD, PhD, Affiliate Professor, Pediatrics, University of Washington, USA

Review of GAPPS Initiatives

BREAK

11:15 am - 11:30 am Harborside Foyer D

STILLBIRTH SESSION **S**

11:30 am - 12:30 pm Harborside Ballroom Salon D

Speaker: Robert Silver, MD, Professor of Obstetrics and Gynecology, University of Utah, USA

Placental Insufficiencies

BUFFET LUNCH **¶¶**

12:30 pm - 1:30 pm Harborside Ballroom Salon C

POSTER SESSION B: STILLBIRTH & SIDS/SUID **S** **SS**

12:30 pm - 1:30 pm Laurel Rooms A, B & C

STILLBIRTH WORKSHOP: PERINATAL AUDIT **S**

1:30 pm - 3:00 pm Harborside Ballroom Salon D

Speaker: Vicki Flenady, PhD, Director, Translating Research Into Practice (TRIP) Centre, Mater Medical Research Institute, Australia

Speaker: Jan Jaap Erwich, MD, PhD, Department of Obstetrics and Gynaecology, University Medical Center Groningen, Netherlands

Speaker: J. Frederik Froen, MD, PhD, Division of Epidemiology, Norwegian Institute of Public Health, Norway

Speaker: Ruth Fretts, MD, MPH, Harvard Vanguard Medical Associates, USA

Agenda Detail

BREAK

3:00 pm - 3:15 pm Harborside Foyer D

STILLBIRTH ORAL ABSTRACT PRESENTATIONS **S**

3:15 pm - 6:15 pm Harborside Ballroom Salon D

Moderator: Elizabeth McClure, M.Sc., Principle Investigator, Statistics and Epidemiology, RTI International

SIDS/SUID TRACK **SS**

SIDS/SUID ORAL ABSTRACT PRESENTATIONS: PHYSIOLOGY & GENETICS **SS**

10:15 am - 11:15 am Harborside Ballroom Salon E

Moderator: Aurore Côté, MD, Department of Pediatrics, McGill University, Canada

BREAK

11:15 am - 11:30 am Harborside Foyer D

SIDS/SUID WORKSHOP: SIDS/SUID DIAGNOSTIC DRIFT **SS** (Session Sponsored by the SIDS Family Association Japan)

11:30 am - 12:30 pm Harborside Ballroom Salon E

Moderator: Carrie Shapiro-Mendoza, PhD, MPH, Epidemiologist, Centers for Disease Control and Prevention, USA

BUFFET LUNCH **¶¶**

12:30 pm - 1:30 pm Harborside Ballroom Salon C

POSTER SESSION B: STILLBIRTH & SIDS/SUID **S SS**

12:30 pm - 1:30 pm Laurel Rooms A, B & C

SIDS/SUID ORAL ABSTRACT PRESENTATIONS: DIAGNOSIS AND RISK REDUCTION **SS**

An Afternoon of SIDS/SUID Abstracts Presented by the C.J. Foundation for SIDS

1:30 pm - 3:00 pm Harborside Ballroom Salon E

Moderator: David Paterson, PhD, Instructor in Pathology, Children's Hospital Boston and Harvard Medical School, USA

BREAK

3:00 pm - 3:15 pm Harborside Foyer D

SIDS/SUID ORAL ABSTRACT PRESENTATIONS: EPIDEMIOLOGY **SS**

An Afternoon of SIDS/SUID Abstracts Presented by the C.J. Foundation for SIDS

3:15 pm - 5:30 pm Harborside Ballroom Salon E

Moderator: Fern Hauck, MD, MS, Professor of Family Medicine, University of Virginia, USA

ISA BOARD AND ANNUAL GENERAL MEETING

4:30 pm - 6:00 pm Kent Room A

AWARDS DINNER - SPECIAL RECOGNITION AWARD FOR NICHD (Awards Dinner Sponsored by Star Legacy Foundation)

7:30 pm - 11:00 pm Harborside Ballroom Salon C

Welcome: Kelly Marriotti, Chief Executive Officer, First Candle, USA

Shauna Libsack and Lindsey Wimmer, MSN, CPNP, Co-Founders of Star Legacy Foundation, USA

Presentations and Award Ceremony in Honor of NICHD: ISA and ISPID

Agenda Detail

SUNDAY, OCTOBER 7

BREAKFAST 🍴

7:00 am - 8:30 am Harborside Foyer D

PLENARY I

8:30 am - 9:15 am Harborside Ballroom Salons D & E

Speaker: Peter Mitchell, Chairman and Chief Creative Officer, Salter Mitchell Communications, USA
Social Media and Health Messaging

PLENARY II

9:15 am - 10:00 am Harborside Ballroom Salons D & E

Speaker: Uma Reddy, MD, MPH, Eunice Kennedy Shriver National Institute of Child Health and Human Development, USA
Disparities in Stillbirth

BREAK

10:00 am - 10:15 am Harborside Foyer D

SIDS AND STILLBIRTH COMBINED SESSION: GRIEF AND BEREAVEMENT **S** **SS**

(Session Sponsored by the Rhode Island SIDS Alliance)

10:15 am - 10:45 am Harborside Ballroom Salon D

Speaker: Katherine Gold MD, MSW, Assistant Professor, Family Medicine and Obstetrics and Gynecology, University of Michigan, USA

GRIEF AND BEREAVEMENT ORAL ABSTRACT PRESENTATIONS

10:45 am - 12:00 pm

BREAKOUT SESSION I: SIDS/SUID/NEONATAL **SS**

Harborside Ballroom Salon D

Moderator: Joani Nelson Horchler, Executive Director, SIDS Educational Services, USA

BREAKOUT SESSION II: STILLBIRTH **S**

Kent Room A

Moderator: Stephanie Fukui, Executive Director, SIDS Family Association Japan

SIDS ORAL ABSTRACT PRESENTATIONS: INNOVATIVE PRACTICES PANEL **S**

10:15 am - 12:00 pm Harborside Ballroom Salon E

Moderator: Mary Adkins, RN, MSW, Tomorrow's Child, ASIP, USA

AWARDS AND CLOSING CEREMONY

ANNOUNCEMENT OF INTERNATIONAL CONFERENCE 2014

12:00 pm - 12:30 pm Harborside Ballroom Salons D & E

Moderator: Rachel Moon, MD, Professor of Pediatrics, George Washington University, USA

Moderator: Ruth Fretts, MD, MPH, Harvard Vanguard Medical Associates, USA

Closing Remarks: Kelly Marriotti, Chief Executive Officer, First Candle, USA



CONFERENCE SPEAKERS

Invited Speakers & Moderators.....	28
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Invited Speakers & Moderators

(in alphabetical order)

INVITED SPEAKERS & MODERATORS



Mary Adkins, RN, MSW

Program Director, Tomorrow's Child, ASIP, USA

SIDS/SUID INNOVATIVE PRACTICES

Mary Adkins is the Project Director for Project IMPACT, one of four national SUID resource centers funded by HRSA's Maternal Child Health Bureau. She is also the Program Director for Tomorrow's Child, a statewide non-profit organization in Michigan dedicated to the prevention of infant death and support for those affected by it. She has over 25 years experience in maternal child health and public health with expertise in program planning, community coalitions, curriculum development and professional training. She is a past president of the Association of SIDS and Infant Mortality Programs (ASIP) and currently serves as a board member.



Oxiris Barbot, MD

Commissioner of Health, Baltimore City Health Department, USA

Dr. Barbot was appointed Commissioner on July 7, 2010. Her priorities include promoting health equity, maximizing community engagement, and fostering innovation. In the spring of 2011, she unveiled Healthy Baltimore 2015, a comprehensive health policy agenda that articulates 10 priority areas and indicators for action. This plan highlights areas where the largest impact can be made on reducing morbidity and mortality while improving quality of life for all Baltimoreans. Dr. Barbot comes to the Health Department from the Office of School Health at the New York City (NYC) Department of Health and Mental Hygiene and Department of Education, having served as medical director there since 2003. During her tenure she implemented an electronic health record for the City's 1.1 million public school students. In 2010, Dr. Barbot received the Hispanic Health Leadership Award from the National Hispanic Medical Association. Dr. Barbot received a bachelor's degree from Yale University and holds a medical degree from the University of Medicine and Dentistry of New Jersey. She completed her residency at George Washington University's Children's National Medical Center. Dr. Barbot has published several articles on topics as varied as H1N1 response in NYC, school health, and health disparities amongst Latino children.



Tamasine Bogle

Parent Speaker and Executive Director HR, UBS Investment Bank, USA

A PARENT'S PERSPECTIVE

Tamasine Bogle is an Executive Director in Human Resources at UBS Investment Bank in New York. Tamasine's first son was stillborn at term in February 2007 after a healthy, low-risk pregnancy. Since then, Tamasine has partnered with non-profit organization First Candle to help raise awareness of stillbirth and educate expectant parents about the risks and prevention techniques, including kick counting. Originally from Scotland, Tamasine graduated from the University of Edinburgh with an MA in Psychology. Tamasine lives with her husband and two subsequent sons in Westchester, New York.



Penny Brabin, PhD

Adjunct Research Fellow, Monash Medical Centre, Australia

BEING WITH PARENTS AFTER THE LOSS OF A BABY: GUIDANCE FROM THE EXPERIENCE AS THE BASIS OF APPROPRIATE CARE

As a psychologist with over 35 years of practice, Dr. Penny Brabin is also well known for her professional training of colleagues and other professionals in best practice care of parents and their families after the death of a baby. Since the stillbirth of her son in 1984, she has been involved in leadership in Stillbirth and Neonatal Death Society (SANDS) and is currently on the board of ISA. Through SANDS, she has led advocacy for parents beginning with legislative change to enable birth certificates to be provided for stillborn babies and has been a representative on numerous state and national committees.

Invited Speakers & Moderators

(in alphabetical order)



Roger Byard, MD

Professor of Pathology, University of Adelaide, The Sudden Unexplained Death in Childhood Program, Australia

STANDARDIZED PROTOCOLS IN THE INVESTIGATION OF SUDDEN INFANT DEATH

Professor Roger Byard holds the Marks Professor of Pathology at the University of Adelaide and is a Senior Specialist Forensic Pathologist at Forensic Science SA in Adelaide, Australia. He is also a pediatric pathologist. He has an interest in SIDS and sudden childhood death and has published a number of papers and books in this area. He is the Editor-in-Chief of *Forensic Science Medicine and Pathology*.



Lena Camperlengo, RN, MPH, DrPH

Health Scientist, Centers for Disease Control and Prevention, USA

THE SUDDEN UNEXPECTED INFANT DEATH (SUID) CASE REGISTRY: IMPROVING KNOWLEDGE ABOUT SUID AND TAKING ACTION

Lena Camperlengo is a Health Scientist at the Center for Disease Control and Prevention's Division of Reproductive Health. In the Maternal Infant Health Branch, Lena serves as the program coordinator for the Sudden Unexpected Infant Death (SUID) Initiative, which includes managing the nine-state SUID surveillance system. Previous to her role at CDC, Lena has more than 20 years' experience in maternal-child health and has served in diverse settings including county health departments, Florida's state health office and non-profit organizations.



Aurore Côté, MD

Associate Professor of Pediatrics & Associate Chair, Department of Pediatrics, McGill University, Canada

SIDS/SUID PHYSIOLOGY AND GENETICS

Dr. Aurore Côté is Associate Professor of Pediatrics and Associate Chair, Department of Pediatrics, McGill University. She is also Director of the Pediatric Network at the McGill University Health Centre and a member of the Pediatric Respiratory Division of the Montreal Children's Hospital. She received her MD and her training in clinical Pediatrics and Pulmonology in Canada. Her research training was in the Pediatric Pulmonary Division at Columbia University in New York. She is an investigator and a clinician. One of her major interests in research concerns the epidemiology and risk factors for sudden unexpected deaths including sudden infant death syndrome (SIDS). She is working with several National and Provincial organizations in Canada on health-related policies for infants and children. She enjoys living in Montreal and is the proud mother of an adult son.



Stephanie Cowan, PhD

Director, Change for our Children, New Zealand

'END GAME' SUID PREVENTION APPROACHES AND THE NEED FOR INNOVATION

Stephanie Cowan is founding director of Change for our Children, a small social innovation company in Christchurch, New Zealand that is largely health funded. She has 25 years' experience in SIDS prevention, parent education and the design and implementation of innovative infant health education programmes at regional, national and international levels. Stephanie was a long term member of the Education Working Group of the SIDS Global Strategy Task Force, with four years as Chairperson from 1996 to 2000. During this time she led a successful initiative for raising SIDS awareness in Spanish speaking countries (Project Link) with SIDS colleague Dr Alejandro Jenik from Argentina. Since 2000, Stephanie has focussed her efforts on addressing smoking in pregnancy within NZ. A current initiative, propelled into action by the 2011 earthquakes in Christchurch, is the supply of portable sleeping spaces, called pēpi-pods, to protect more vulnerable babies when they sleep in or on adult beds, on couches or away from home.

Invited Speakers & Moderators

(in alphabetical order)



Laura Crandall, MS

Program Co-Director and Co-Founder, The Sudden Unexplained Death in Childhood Program, USA

SUDDEN UNEXPLAINED DEATH IN CHILDHOOD

Laura Crandall is formally trained as a Physical Therapist. She earned undergraduate and postgraduate degrees from NYU and practiced at the Mount Sinai Hospital in NYC. Maria, her first child, was born in April 1996. Maria was a bright and happy child when at the age of 15 months, she died while taking a nap. Her death was eventually ruled "Sudden Unexplained Death in Childhood." Through the death investigation of Maria, Laura was convinced that changes in the system could and should be achieved. She lobbied for new child death investigation legislation in NJ that became laws. Laura is the SUDC Program's Co-Founder and Program Director (sudc.org) and Assistant Executive Director of Advocacy at the CJ Foundation for SIDS. Laura is the secretary of the national Scientific Working Group for Medicolegal Death Investigation (swgmdi.org). Laura advocates for information, awareness, research and support for families who have lost children to a sudden unexpected death. The Crandalls have three subsequent daughters.



Jan Jaap Erwich, MD, PhD

Associate Professor, Department of Obstetrics and Gynaecology, Gronigen University Medical Centre, Netherlands

PERINATAL AUDIT

Professor Dr. Jan Jaap Erwich (1958) is an obstetrician from the Netherlands, trained in Leiden and the Hague and after a two-year period in Adelaide, Australia he now works at Groningen University, Netherlands. As a medical student, he was interested in the amazing process of how two cells develop into an embryo and beyond, as well as in the function of the placenta. A/Prof. Erwich, (JJ) has a PhD in prostaglandins and placenta function. During specialty training he was very touched by women/couples who experienced fetal death or perinatal mortality. Finding the cause and proper bereavement care became one of his major goals. His basic research looks into why some placentas do not function properly to sustain the baby. Not only with fetal death as a consequence, but also with long term effects on the baby as an adult. Presently, JJ is focusing on classification of perinatal mortality, which is needed to give insight into the causes and into the actions that need to be taken for prevention. His clinical work is based on caring for pregnant women in a third level referral center working with the very young pregnancies, very sick women or with babies who have anomalies. JJ has also organised a nation-wide perinatal mortality audit system for identification and repair of substandard factors in the care for pregnant women and their babies as managing director of the Foundation for Perinatal Audit in the Netherlands (PAN) www.perinataleaudit.nl (in Dutch). "I am involved with ISA because every baby counts and I still get nauseated when I do not find a fetal heartbeat when doing an ultrasound". He also writes, "I am very fortunate to have my wife and two boys (12 and 14 yrs), and every time I look at them I wish everybody could have the same experience as a parent."



William Fifer, PhD

Professor of Psychiatry and Pediatrics, Columbia University Medical Center, USA

FETAL PHYSIOLOGY

Dr. William Fifer is a senior research scientist at the New York State Psychiatric Institute, Professor in the Departments of Psychiatry and Pediatrics, and the Associate Director of the Sackler Institute at Columbia University Medical Center and a First Candle/SIDS Alliance Research Awardee. His research interests focus on studies of fetal and infant sleep physiology and neurobehavior and the effects of adverse prenatal exposures on later neurodevelopment. His NIH MERIT Award, the Sackler Institute, and other NIH funding support his current studies of early learning and brain development, measurement of behavioral and cortical activity during environmental challenges, development of autonomic control during sleep, and early assessment of risk for developmental disorders including sudden infant and fetal death, and infant neurobehavioral disabilities. He and his colleagues are currently involved in a large NIH funded fetal/infant cohort, the Safe Passage Study, in North and South Dakota and in Cape Town, South Africa.

Invited Speakers & Moderators

(in alphabetical order)



Vicki Flenady, PhD, MMedSc (ClinEpid)

Director, Translating Research Into Practice (TRIP) Centre, Mater Medical Research Institute, Australia

PERINATAL AUDIT

Associate Professor Vicki Flenady has a background in midwifery and neonatal nursing, has completed a Masters in Medical Science and PhD in stillbirth prevention focusing on risk factors and improving data collection. Vicki's research interests also include preterm birth prevention undertaking systematic reviews on tocolytics for the Cochrane Pregnancy and Childbirth Group. Vicki is a co-founder of the Perinatal Society of Australia and New Zealand Perinatal Mortality Group (PSANZ PMG) and the Australian and New Zealand Stillbirth Alliance (ANZSA) which collaborate in improving standards in clinical practice in maternity care for stillbirth and neonatal deaths through national guidelines and educational programs for clinicians. Vicki is the immediate past chair of the International Stillbirth Alliance (ISA). In her current role of Director, Translating Research Into Practice (TRIP), Mater Medical Research Institute, Brisbane, Vicki is involved in studies to identify novel methods for bridging the gap between evidence and practice. Vicki is a steering committee member for The Lancet Stillbirth Series.



Ruth Fretts, MD, MPH

Harvard Vanguard Medical Associates, USA

FETAL MOVEMENT AND KICK COUNTING PERINATAL AUDIT

Dr. Ruth Fretts is Assistant Professor Obstetrics and Gynecology and Reproductive Biology Harvard Medical School and practices obstetrics and gynecology at Harvard Vanguard Medical Associates in Boston MA, USA. She began her research on stillbirth in her residency at McGill University, in Montreal Canada in 1988-92 with neonatologist Dr Robert Usher. She completed her Master's in the Harvard School of Public Health in 1994. In 2002 she joined International Stillbirth Alliance (ISA) a not-for-profit group formed by parents and was chair of their Scientific Committee until 2010. She is the Medical Director for stillbirth prevention at First Candle (an American non-profit organization). She developed the stillbirth review committee at the Brigham and Women's Hospital in Boston. She has published in Nature, the Lancet, and New England Journal of Medicine on the topic of stillbirth and advanced maternal age. She wrote the Technical Bulletin of Stillbirth for the American College of Obstetrics and Gynecology. She lives in Brookline Massachusetts with her husband and three children and two dogs.



J. Frederick Froën, MD, PhD

Division of Epidemiology, Norwegian Institute of Public Health, Norway

FETAL MOVEMENT AND KICK COUNTING PERINATAL AUDIT

Dr. J. Frederik Froën is a researcher in the Departments of Pediatric Research and Obstetrics & Gynecology at Rikshospitalet University Clinic ("The National Hospital"), University of Oslo, Norway. As an MD graduating from the University of Bergen in 1996, Dr. Froën's research interests have since involved "both sides" of perinatology. His PhD thesis in pediatrics was based on experimental models to explore the effects of inflammation and nicotine on respiratory control and brain injuries in the newborn, while his second PhD thesis, in obstetrics, was based on epidemiological studies of unexplained stillbirths - research that has led to both national and international awards. Today he continues his work on the combined effects of inflammation and hypoxia-ischemia on perinatal brain injuries and unexplained deaths, and on the ability of standard antenatal care programs to detect the babies at risk. Beyond these focused topics, Dr. Froën is committed to promoting stillbirth research in general, and to the support of women experiencing stillbirths, through the parental organizations MISS Foundation and International Stillbirth Alliance, where he has chaired the Scientific Medical Board. Of other research interests, and besides his research in perinatology, Dr. Froën works part-time as a research consultant in the Department of Biostatistics at Rikshospitalet University Clinic, and is a member of the Advisory Board on Quality Improvement in Health Care of the Norwegian Medical Association. Leisure time is also focused on children...his own three children at home.

Invited Speakers & Moderators

(in alphabetical order)



Stephanie Fukui

Executive Director, SIDS Family Association Japan

STILLBIRTH GRIEF AND BEREAVEMENT

Stephanie Fukui has an MA in Anthropology and founded the SIDS Family Association Japan in 1993. Stephanie's first child, Ema, was stillborn in 1986. She has done education on grief issues and researched childcare practices in Japan. Stephanie serves on the boards of SIDS International, ISA and ISPID and has received awards for contributing to Social Welfare from the Maternal and Child Health and Welfare Association and the Japanese Ministry of Health and Welfare.



Allison Glover

Bereavement Support Coordinator, First Candle, USA

A PARENT'S PERSPECTIVE

Allison Glover has served as a Community Health Educator in the public health arena for 19 years. Allison enjoyed working as a Diabetes Educator at Pennsylvania Hospital and moved to Georgia in 1994. On May 11, 2000, Allison and her family lost their firstborn, twin son, Garrett, to SIDS. Three months after losing Garrett, Allison began volunteering with the Georgia SIDS and the National SIDS Alliances. Presently, Allison's passion is serving families as the Bereavement Support Coordinator for First Candle. She also loves teaching parents, caregivers, healthcare professionals and other audiences on infant sleep safety and SIDS risk reduction, bereavement support for adults and children, child abuse prevention, diabetes management, weight loss management, 'Going Green' at home and in child care centers and extreme couponing through her company, *Garrett's Voice*. Allison and her husband reside in Georgia with their tribe of four busy children and two dogs, Stella (Beagle) and Ginger (Jack Russell Terrier).



Katherine J. Gold, MD, MSW, MS

Assistant Professor of Family Medicine and Obstetrics and Gynecology, University of Michigan, USA

MATERNAL BEREAVEMENT AND MENTAL HEALTH AS A PUBLIC HEALTH ISSUE

Dr. Katherine Gold is a board-certified family physician who holds a dual appointment at the University of Michigan in the Department of Family Medicine and the Department of Obstetrics & Gynecology. She has completed two fellowships in research training: the Robert Wood Johnson Foundation Clinical Scholars Program and the NIH K-12: Building Interdisciplinary Research Careers in Women's Health. She holds a Master's Degree in Social Work and has completed another Master's in Health and Health Services Research. Dr. Gold has a particular interest in mental and physical health outcomes for parents after stillbirth and infant death, stillbirth prevention, bereavement training for health professionals, and perinatal mental health. She currently has an NIH K-23 grant to evaluate maternal outcomes after perinatal loss. Dr. Gold has multiple ongoing studies of adverse perinatal outcomes in Ghana, West Africa including stillbirth prevention, maternal postpartum depression, and maternal bereavement after infant death.

Invited Speakers & Moderators

(in alphabetical order)



Robert Goldenberg, MD

Professor of Obstetrics and Gynecology, Drexel University College of Medicine, USA

GLOBAL PERSPECTIVES ON STILLBIRTH

Dr. Robert Goldenberg practiced high risk obstetrics for over 30 years. He has also served as Director of the Department of Maternal and Child Health for the Alabama Health Department. He is a member of the Institute Of Medicine and its Committee on Improving Birth Outcomes in Developing Countries. He has played leading roles in the March Of Dimes Prematurity Prevention Study; the National Institute of Child Health and Human Development (NICHD) - funded study of risk factors for fetal growth retardation; the NICHD Preterm Prediction Study; the Agency for Health Care Policy and Research's Low Birthweight Patient Outcomes Research Team; the NICHD Maternal Fetal Medicine Network and the National Institute of Allergy and Infectious Disease HIVNET 024 study of antibiotics to prevent infection – related Mother To Child Transmission of HIV. He has directed the Office on Smoking in Pregnancy for the Robert Wood Johnson Foundation. He is also Principal Investigator for the Pakistan site for the Gates/NICHD Global Network and chairs the National Institute of Health's Stillbirth Research Network and has just completed a term chairing the Section on Mother to Child Transmission of HIV for the National Institute of Allergy and Infectious Disease-funded IMPAACT Network. He was one of the founders of the Center for Infectious Disease Research in Zambia which now has 200,000 HIV-infected children and adults under antiviral treatment. He is currently chairing a NICHD Global Network multi-country study on Emergency Obstetric and Neonatal Care. He has consulted on pregnancy outcomes in Egypt, Columbia, Zambia, India and Armenia. He has published nearly 550 journal articles. He also served on the steering committee for the Lancet Stillbirth Series and wrote the final paper in that series, "The Call to Action". He is currently working on a Gates funded project creating a model that suggests the strategies for investment in technologies that are likely to have the biggest impact on reducing maternal, fetal and neonatal mortality.



Gabriel G. Haddad, MD

Professor of Pediatrics, University of California - San Diego, USA

BASIC RESEARCH IN SIDS

Dr. Gabriel G. Haddad is the Chairman of the Department of Pediatrics at the University of California, San Diego and the Physician-in-Chief and Chief Scientific Officer at Rady Children's Hospital. UCSD's Department of Pediatrics and Children's Hospital are affiliated programs, with most of UCSD's pediatric training and inpatient care based at Children's Hospital. He is a leading specialist in pediatric respiratory medicine and an accomplished physician-scientist. He is passionate about developing better care through research. In recent years his research has focused on the basis for cell and tissue injury at the molecular level when tissues and organs are deprived of nutrients and oxygen. He leads the development of a comprehensive strategic research plan at Rady Children's with a goal of ensuring San Diego's place on the national map as a leading center for children's health and research. Haddad came from the Albert Einstein College of Medicine in New York, where he served as the Chairman of the Department of Pediatrics, and also as Pediatrician-in-Chief at The Children's Hospital at Montefiore Hospital. Haddad has published over 225 articles and manuscripts, written over 90 chapters, and authored numerous medical texts including the landmark Basic Mechanisms of Pediatric Respiratory Disease. He sits on numerous national committees such as the National Heart Lung and Blood Institute, and is a member of 18 distinguished medical societies, many in a leadership role. Haddad has held numerous editorial appointments; is a reviewer for 28 respected medical journals; is the recipient of numerous awards and honors, and has been invited to speak at over 150 national and international conferences. Haddad received his medical education and initial medical training at the American University of Beirut in Lebanon, followed by additional training at University of Texas in Houston. He then moved to Columbia University in New York to do his fellowship before joining the faculty in 1978. Ten years later he accepted an appointment at Yale to direct the Respiratory Medicine Section and serve as Chief of Clinical Service in Respiratory Medicine, and becoming a Professor of Cellular & Molecular Physiology shortly thereafter at the same institution. He was appointed Chairman at Albert Einstein in 2002. Haddad is married and the father of three children, a daughter and two sons.

Invited Speakers & Moderators

(in alphabetical order)



Fern Hauck, MD, MS

Professor of Family Medicine & Public Health Sciences, University of Virginia, USA

SIDS/SUID EPIDEMIOLOGY SIDS/SUID AND PACIFIERS

Dr. Fern Hauck is Professor of Family Medicine and Public Health Sciences at the University of Virginia. Her medical degree is from St. Louis University School of Medicine and her residency training was conducted at the Maine-Dartmouth Family Medicine Residency. She received fellowship training at Case Western Reserve University and the Centers for Disease Control and Prevention. Dr. Hauck's research has focused on risk factors and protective factors for sudden infant death syndrome and other causes of sudden infant death. Currently, she is interested in developing effective, culturally sensitive methods to disseminate safe sleep and other risk reduction messages to overcome significant barriers to uptake that still exist. Dr. Hauck serves as an advisor to numerous federal agencies and SIDS organizations and she is a member of the American Academy of Pediatrics Task Force on SIDS.



Alex Heazell, MBChB, PhD

Clinical Lecturer in Obstetrics, University of Manchester, United Kingdom

FETAL MOVEMENT AND KICK COUNTING

Dr. Alex Heazell is a Clinical Lecturer in Obstetrics working at the Maternal and Fetal Health Research Centre, University of Manchester. After graduation from the University of Birmingham Medical School in 2000, he commenced clinical training in Obstetrics and Gynaecology. After completing his PhD thesis on placental dysfunction in preeclampsia, he has focussed his research interests around stillbirth and is particularly interested in the role that placental dysfunction plays in this condition. He has also led qualitative research projects to explore professionals and parents' experiences after stillbirth, with a particular focus on investigations following a stillbirth. His research portfolio includes a profile of basic science, clinical and qualitative research studies. His passion for stillbirth research stems, in part, from his personal experience of stillbirth. He is on the board of the International Stillbirth Alliance.



Joani Nelson Horchler

Executive Director, SIDS Educational Services, USA

SIDS/SUID AND NEONATAL GRIEF AND BEREAVEMENT

Joani Nelson Horchler is co-author of the SIDS and Infant Death Survival Guide. This comforting book (anthology) has been sold or donated to some 37,000 people and organizations in English and Spanish-language editions since its 1994 publication. Joani started writing it a year after the 1991 SIDS death of her son, Christian Gabriel Horchler. She and her husband Gabe have five daughters (ages 16-30), two born after Christian's death. Joani founded and serves as executive director of SIDS Educational Services, a small nonprofit dedicated to grief support; distributing the SIDS book and *Dancing on the Moon*, (a picturebook for grieving children); and providing cribs to needy families. Joani facilitates a SIDS/infant death support group for SIDS Mid-Atlantic in the Washington DC area and helps grieving families through her toll-free 1-877-WeLoveYou /sidses@aol.com. Joani has been a magazine reporter/editor and Congressional aide, and enjoys volunteering for several charities, including FAIR Girls.

Invited Speakers & Moderators

(in alphabetical order)



Bruce A. Hyma, MD

Director and Chief Medical Examiner, Miami-Dade, University of Miami, USA

TISSUE COLLECTION FOR SIDS RESEARCH

Dr. Bruce A. Hyma is the Director and Chief Medical Examiner of the Medical Examiner Department in Miami, Florida, District 11. Concurrent with his duties as Miami-Dade's Medical Examiner, he is the Chairman of Florida's Medical Examiners Commission. Additionally, Dr. Hyma holds a volunteer faculty appointment as Assistant Clinical Professor of Pathology at the University of Miami, Miller School of Medicine. Dr. Hyma was born and raised in Muskegon, Michigan. He received his Medical Doctorate from Wayne State University in Detroit, Michigan. An internship in medicine and surgery was completed at Saint John Hospital in Detroit. Following his internship, Dr. Hyma completed a 4-year residency in Anatomic and Clinical Pathology at Mayo Clinic in Rochester, Minnesota, while serving as a Deputy Olmstead County Coroner. Dr. Hyma came to Miami in 1987 to complete his education in the Medical Examiner Department's forensic pathology fellowship program. After completing his formal education, Dr. Hyma joined the department as an Associate/Assistant Medical Examiner. He was promoted to Department Director in 2001. Dr. Hyma is married and has three children and two grandchildren. His wife is a nurse consultant.



Sherokee Ilse

Author and Bereavement Speaker, USA

TAKING BABY HOME: INTERNATIONAL PERSPECTIVES ON CARING FOR PARENTS AND FAMILIES AFTER THE DEATH OF A BABY

Sherokee is a bereaved mother who has had three losses (Marama, Brennan, and Bryna) and the proud mother of two living sons. For over 30 years, her passion has been to improve the care families receive, to support careproviders who interact with bereaved families, to shift the community from avoidance to one of embracing and empowering families, and to be an active participant in the movement to discover causes working toward prevention of miscarriage, stillbirth, and early infant death. Ms. Ilse is the author of *Empty Arms* and 16 other books/booklets and many articles on perinatal loss and bereavement support. An international speaker/trainer, paradigm shifter, and parent advocate, she founded an international pregnancy loss nonprofit, her own company Wintergreen Press and Babies Remembered Consulting, and with her colleague Dr. Pat Flynn, has recently developed Loss Doula International, a certification program for parent advocates/loss doula who support families from the time of hearing the news and beyond. Active on many boards in the recent past including Star Legacy Foundation and ISA, she is presently a board member for ISPID and is the chair of the Parent Committee of ISA.



Hannah Kinney, MD

Professor of Pathology, Harvard Medical School, USA

SUDDEN UNEXPLAINED DEATH IN CHILDHOOD

Dr. Hannah Kinney is Professor of Pathology at Harvard Medical School, Boston, MA, and a pediatric neuropathologist at Boston Children's Hospital. Her laboratory performs research in developmental disorders of the human brain in early life, with a focus upon brain disorders leading to sudden death in fetuses (stillbirth), infants, and children. Dr. Kinney graduated from Duke University, Durham, NC, in 1970 with a BA degree (major in history), and from Case Western Reserve University School of Medicine, Cleveland, OH, in 1974. She subsequently completed residencies in Pediatrics at the Children's Hospital of Philadelphia, PA, and in Pathology and Neuropathology at Duke University Medical School, Durham, NC. Dr. Kinney is board-certified in pediatrics, anatomic pathology, and neuropathology. She came to Boston Children's Hospital and Harvard Medical School, Boston, MA, for specialized training in pediatric neuropathology and developmental neuroscience in 1981. She then joined the neuropathology staff, and eventually became Professor of Pathology in 2003.

Invited Speakers & Moderators

(in alphabetical order)



Henry Krous, MD

Professor of Pathology, University of California - San Diego, USA

CAREER REFLECTIONS

Dr. Henry Krous is board certified in anatomic pathology and in pediatric pathology. He earned his medical degree from the University of Nebraska College of Medicine and completed his postgraduate training at the University of Washington. Dr. Krous recently retired as the Director of Pathology at Rady Children's Hospital San Diego and Adjunct Professor of Pathology and Pediatrics at the University of California San Diego School of Medicine. Dr. Krous clinical interests include SIDS, sudden unexpected death in infancy and childhood and renal disease. He has chaired the Pathology Working Group, SIDS Global Strategy Task Force, and served as Vice Chair of the California SIDS Advisory Council. Dr. Krous serves on the editorial board of *Pediatric and Developmental Pathology* and reviews for several other journals. Dr. Krous is the author of more than 120 articles and 80 abstracts and has edited three books. He has been invited to give nearly 100 lectures in the United States, Europe, New Zealand and Australia.

See page 42 of this conference guide for more information on Dr. Henry Krous.



Michael C. Lu, MD, MS, MPH

Associate Administrator, Maternal and Child Health, Health Resources and Services Administration, U.S. Department of Health and Human Services, USA

MATERNAL LIFE COURSE

Dr. Michael C. Lu was named associate administrator of maternal and child health of the Health Resources and Services Administration (HRSA) on November 3, 2011. HRSA is an agency of the U.S. Department of Health and Human Services. The mission of the Maternal and Child Health Bureau (MCHB) is to provide leadership, in partnership with key stakeholders, to improve the physical and mental health, safety and well-being of mothers, children and families. Through its Title V program, MCHB serves 40 million women, infants, children, adolescents, and their families each year, including fathers and children with special health care needs. Dr. Lu joined HRSA from the University of California, Los Angeles Schools of Medicine and Public Health, where he was associate professor of obstetrics, gynecology and public health. Dr. Lu brings years of experience in MCH research, practice, and policy to his post at HRSA. Prior to his appointment, Dr. Lu chaired the Secretary's Advisory Committee on Infant Mortality. He has served on two Institute of Medicine (IOM) committees (Committee on Understanding Premature Birth and Assuring Healthy Outcomes, and Committee to Reexamine IOM Pregnancy Weight Guidelines), and the Centers for Disease Control and Prevention Select Panel on Preconception Care. While at UCLA, Dr. Lu was a lead investigator for the National Children's Study and led a project to monitor and improve the quality and safety of maternity care in California. He was best known for his research on racial-ethnic disparities in birth outcomes, and his leadership on the life course. Dr. Lu taught obstetrics and gynecology at the David Geffen School of Medicine at UCLA and maternal and child health at UCLA School of Public Health. He has received numerous awards for his teaching, including Excellence in Teaching Awards from the Association of Professors of Gynecology and Obstetrics. As an obstetrician, Dr. Lu has attended over a thousand births, and has been voted one of the Best Doctors in America since 2005. Dr. Lu received his bachelor's degrees in political science and human biology from Stanford University, master's degrees in health and medical sciences and public health from UC Berkeley, medical degree from UC San Francisco, and residency training in obstetrics and gynecology from UC Irvine.

Invited Speakers & Moderators

(in alphabetical order)



Elizabeth McClure, PhD-c

Principle Investigator, Statistics and Epidemiology, RTI International, USA

STILLBIRTH ORAL ABSTRACT PRESENTATIONS

Elizabeth McClure, PhD-c, is a perinatal epidemiologist at Research Triangle Institute (RTI) who is the principal investigator for data coordinating center of the NIH-funded Global Network for Women's and Children's Health Research. The Global Network has conducted research to improve birth outcomes among pregnant women in low-middle income countries since 2001. In that role, Ms. McClure has led research in Southeast Asia, Sub-Saharan Africa, and Latin America to address birth outcomes, including numerous publications on stillbirth in low-resource settings. Ms. McClure is also the co-PI for the Bill & Melinda Gates-funded Maternal and Neonatal Directed Assessment of Technology (MANDATE), a project initially funded in 2009 to evaluate the impact of interventions in low-resource settings to improve birth outcomes. Prior to joining RTI in 2001, Ms. McClure worked as a program coordinator for neonatal research at the National Institute of Child Health and Human Development, NIH.



Betty McEntire, PhD

Executive Director, American SIDS Institute, USA

SUDDEN UNEXPECTED INFANT DEATH (SUID) TISSUE CONSORTIUM

Dr. Betty McEntire has been the executive director of the American SIDS Institute since 1998, and also serves on the board of directors of AASPP (American Association of SIDS Prevention Physicians). She has held various other SIDS related positions such as director of the Florida SIDS Counseling & Information Project and director of the Florida Statewide Infant Monitoring Project (CMS). Dr. McEntire was also the director of medical education for Healthdyne/Matria. She has a PhD from Florida State University in sociology with an emphasis in research methods and has held academic appointments at the University of NC in Wilmington and Florida State University. In her position with the American SIDS Institute, Dr. McEntire has served as the project director of several research projects (including the PIA Multi-Center Project, the DECAF Pilot Study, and the NICU Discharge Survey Project). She recently is co-director of the Florida SUID Tissue Project. This is a consortium involving medical examiners, the NICHD Brain and Tissue Bank (in Maryland) and the American SIDS Institute. The purpose is to provide infant tissue, along with medical-legal information, to current and future researchers.



Edwin A. Mitchell, MD

Professor of Pediatrics, University of Auckland, New Zealand; Chair, ISPID

WHAT CAN STILLBIRTH RESEARCH LEARN FROM SIDS?

Dr. Ed Mitchell qualified at St George's Hospital Medical School in London and has worked in the UK, Zambia and New Zealand. He completed his paediatric training in New Zealand. From 2001 he has been the Professor of Child Health Research at the University of Auckland. He has published over 300 original papers, particularly on the epidemiology of asthma and sudden infant death syndrome (SIDS). In 1996 the University of London awarded him a Doctor of Science for his work on "The Epidemiology and Prevention of SIDS". He has received several awards for his landmark study of SIDS. Ed is the elected Chair of ISPID. He is married to Hilary and they have two grown-up children, one a doctor too. If you don't find him in his office he'll be either sailing or tramping.

Invited Speakers & Moderators

(in alphabetical order)



Peter Mitchell

Chairman and Chief Creative Officer, Salter Mitchell Communications, USA

SOCIAL MEDIA AND HEALTH MESSAGING

A former journalist and legislative staffer, Peter got into social marketing more than a decade ago when he was asked to direct the marketing campaign for a new anti-tobacco initiative in Florida. The campaign became “truth” – an effort that transformed tobacco control and got replicated on a national scale after Florida showed the first statewide drop in teen smoking in 19 years. Since then, Peter has developed and directed dozens of social marketing campaigns across the globe, first for a large international non-profit and later as a founder of Marketing for Change, which is now part of Salter Mitchell. He’s developed dozens of social marketing campaigns over the years, including one to reduce fertilizer use near Chesapeake Bay that urged homeowners to “save the crabs, then eat ‘em,” and a pandemic-flu preparedness initiative that noted “four out of five people wash their hands after using the rest room. Could someone talk to the fifth guy?” He has won numerous awards (Emmy, Silver Anvil, Gold Davey, Telly, Addy, etc.) and designed behavior-change campaigns domestically and in Bangladesh, India, Jordan and Tanzania for such organizations as the U.S. Environmental Protection Agency, Florida Healthy Kids Corporation, the Massachusetts Institute of Technology, the Planned Parenthood Federation of America, and the U.S. Agency for International Development. A graduate of Colgate University, Peter also spent a decade as a reporter, including covering Florida for The Wall Street Journal, and served as the policy coordinator for Florida’s Senate President.



Eugene Nattie, Jr, MD

Professor of Physiology and Neurobiology, Dartmouth Medical School, USA

BASIC RESEARCH IN SIDS

Dr. Eugene Nattie, Jr. attended Dartmouth College (1962-66), Dartmouth and Harvard Medical Schools (1966-71), interned at the Peter Bent Brigham Hospital, then studied as a postdoctoral fellow with Dr. S. M. Tenney back at Dartmouth, where he has remained as a faculty member. His research has focused on central chemoreception, i.e., how and where does the brain detect CO₂/pH and regulate breathing, fostering the view that there are multiple sites, which vary in importance in a state-dependent manner. About 15 years ago his research broadened to include the pathogenesis of the Sudden Infant Death Syndrome (SIDS) as he joined an NICHD Program Project Grant (PPG) led by Dr. Hannah Kinney. His focus examined the role of serotonin in ventilatory and heart rate responses to hypoxia as well as hypercapnia during postnatal development in rodent models, including transgenic mice created in the lab of Dr. Dymecki, another PPG member, and rats with both dietary and pharmacological manipulations.



David Paterson, PhD

Instructor in Pathology, Children’s Hospital Boston and Harvard Medical School, USA

SIDS BRAINSTEM RESEARCH SIDS/SUID DIAGNOSIS AND RISK REDUCTION

Dr. David Paterson is an Instructor in the Department of Pathology, Children’s Hospital Boston and Harvard Medical School. His doctoral studies concerned neuroscience and pharmacology; he completed post-doctoral training with Dr. Kinney in neuropathology and developmental neuroscience. He is currently the Associate Director of the CJ Murphy Laboratory for SIDS Research, and the Pathology Research Coordinator, Developmental Biology and Pathology Center, PASS Research Network. His research has included major analysis of SIDS brainstems relative to the medullary 5-HT system and has involved cellular and chemical anatomic studies of the brainstem in SIDS cases compared to controls, as well as in brainstem anatomy relevant to cardiorespiratory control. He has also focused upon the relationships between brainstem findings and genetic polymorphisms in SIDS cases, and has spearheaded all SIDS-related genetic studies in the laboratory. He currently has an award from the CJ Foundation for SIDS to analyze copy number variants in SIDS. He has won several awards, including the First Candle Award for Contributions to SIDS in 2008.

Invited Speakers & Moderators

(in alphabetical order)



Uma M. Reddy, MD, MPH

Maternal-Fetal Medicine Specialist, Eunice Kennedy Shriver National Institute of Child Health and Human Development, USA

DISPARITIES IN STILLBIRTH

Dr. Uma Reddy is a board-certified Obstetrician-Gynecologist and Maternal-Fetal Medicine specialist at the *Eunice Kennedy Shriver National Institute of Child Health and Human Development*. After receiving her undergraduate and medical degrees from Brown University, Dr. Reddy completed her residency in Obstetrics and Gynecology at the Johns Hopkins Hospital. Dr. Reddy then obtained her Master of Public Health degree at the Johns Hopkins Bloomberg School of Public Health and was a Robert Wood Johnson Clinical Scholar. Dr. Reddy completed her Maternal-Fetal Medicine fellowship at Thomas Jefferson University in Philadelphia. She is a maternal-fetal medicine attending at Washington Hospital Center, Washington, DC. Dr. Reddy is currently in the Pregnancy and Perinatology Branch, NICHD and manages diverse research studies of clinical obstetrics, reproductive epidemiology and prenatal diagnosis. Dr. Reddy's scientific responsibilities also include serving as the program scientist for large research studies focused on adverse pregnancy outcomes such as the Genomic and Proteomic Network for Preterm Birth Research and the Nulliparous Pregnancy Outcomes Study: Monitoring Mothers-to-Be (nuMoM2b) study of 10,000 women in their first pregnancy to understand the mechanism and to predict women at risk for poor pregnancy outcomes. Dr. Reddy is also a program scientist for the Stillbirth Collaborative Research Network which was established to examine the causes and epidemiology of stillbirth which involved 59 hospitals throughout the U.S. Dr. Reddy has published extensively on the topic of stillbirth as well as presented at numerous national and international meetings.



Torleiv Rognum, MD, PhD, MHA

Professor, Institute of Forensic Medicine, Norway

DEFINING SIDS

Dr. Torleiv Rognum, born 1948, MD 1974, PhD 1982, MHA 1996, full professor of forensic medicine University of Oslo 1991. Research interests: SIDS and cancer. Leader of research group 1987. Together with Saugstad (Pediatrics 1988) based on studies of the hypoxia marker hypoxanthine demonstrated that most SIDS victims had had significant (repeated) periods of hypoxia prior to death. Engaged in immunological and genetic studies in SIDS and since 2010 responsible for all death scene investigations in Norway. Government appointed chairman of The Norwegian Biotechnology Advisory Board 1998-2001. From 1986 member/leader of the scientific board of The Norwegian SIDS Society. Scientific organizer of the third SIDS International Conference, Stavanger 1994, The ESPID Congress Oslo 2003 and the yearly Soria Moria SIDS research meetings, Oslo since 1990. Teacher of the year Oslo University Medical school 2005. "The right to live price" 2007, Knighted The Royal Norwegian Order of St. Olav by King Harald 2007.



Craig Rubens, MD, PhD

Executive Director of GAPPS, University of Washington, USA

REVIEW OF GAPPS INITIATIVES

Dr. Craig Rubens is co-founder and Executive Director of the Global Alliance to Prevent Prematurity and Stillbirth (GAPPS). This initiative was launched by Seattle Children's Hospital to unravel the mysteries surrounding prematurity and stillbirth and to promote an aggressive research and development and advocacy agenda that will lead to prevention of these two significant global perinatal health problems. GAPPS' Mission is to Improve Birth Outcomes Worldwide. Dr. Rubens is Professor in the Department of Global Health, and Professor of Pediatrics at University of Washington School of Medicine. He is a member of several prestigious societies, including the American Society of Clinical Investigators and the American Pediatric Society. Dr. Rubens is a physician-scientist and Pediatric Infectious Disease specialist with a strong background in infectious diseases and microbiology. His research focus is on serious bacterial infections in childhood, primarily perinatal infections that lead to poor pregnancy and neonatal health outcomes. His research, based on the premise that the battle between infectious agents and the immune system is at the heart of disease, has focused on understanding the mechanisms of infection-induced preterm labor and severe neonatal infections. GAPPS is leading a collaborative, global effort to increase awareness and accelerate innovative research and interventions that will improve maternal, newborn and child health outcomes around the world.

Invited Speakers & Moderators

(in alphabetical order)



Steve Scully

Senior Executive Producer and Political Editor, C-SPAN, USA

A PARENT'S PERSPECTIVE

Steve Scully is senior executive producer and political editor for C-SPAN. He also hosts 'Washington Journal,' a daily three-hour public affairs program. Since 1990, Scully has been responsible for planning and editing C-SPAN's campaign programming, including presidential and congressional elections. Prior to joining C-SPAN, Scully covered politics and local government as a reporter with WSEE-TV in Erie, PA. He also worked as a reporter and anchor at WHEC-TV in Rochester, N.Y. In January 2003, he assumed the Amos P. Hostetter Chair at the University of Denver, teaching a course on media, politics, and public policy issues via cable fiber line between Washington, D.C., and Denver. Scully earned a bachelor's degree in communication and political science from American University, and a master's degree in journalism from Northwestern University. Steve and wife Katie, a nurse, have experienced the loss of a baby to SIDS as well as the unimaginable loss of another baby to stillbirth. They have four living children who are the joy of their lives.



Carrie Shapiro-Mendoza, PhD, MPH

Epidemiologist, Centers for Disease Control and Prevention, USA

SIDS/SUID DIAGNOSTIC DRIFT

Dr. Carrie Shapiro-Mendoza holds a Ph.D. in Epidemiology and an MPH from the School of Public Health at University of Texas Health Science Center at Houston and a B.S. in Professional Nursing from the University of Vermont. Dr. Shapiro-Mendoza's public health career began in 1988 as a clinical research nurse at the National Institutes of Health and then served as an Air Force nurse, a Peace Corps volunteer rural health nurse, and a research coordinator for border health research projects in Texas and Mexico. Currently, Dr. Shapiro-Mendoza is the Senior Scientist in the Maternal and Infant Health Branch (MIHB) within the Division of Reproductive Health at the Centers for Disease Control and Prevention. She joined MIHB in 2003 where she began her work on Sudden Infant Death Syndrome (SIDS) and other Sudden Unexpected Infant Deaths (SUID). Since that time, she has established herself as a nationally-recognized leader in the field, and advanced a national initiative to improve death scene investigation for the accurate detection and consistent reporting of SUID. This initiative has included development and dissemination of standardized SUID investigation and reporting forms, national training programs of coroners, medical examiners, and first responders, and development of a state-based SUID Case Registry. She has achieved this work by building large and complex national coalitions that have brought endless visibility and action to this infant health agenda. In addition, Dr. Shapiro-Mendoza has proven to be a rigorous and prolific researcher, completing multiple studies of health risks associated with late preterm birth, fetal death, infant mortality, and trends in SIDS and SUID, as well as leading activities with the Massachusetts Pregnancy to Early Life Longitudinal data system program. She has authored or co-authored over 30 peer-reviewed publications. Dr. Shapiro-Mendoza's research specifically focuses on SIDS, other sudden unexpected infant deaths, and preterm birth. She currently serves as a federal liaison to the Task Force on SIDS for the American Academy of Pediatrics. Dr. Shapiro-Mendoza was the recipient of the 2007 National Maternal and Child Health Epidemiology Award for Effective Practice at the National Level. She was primarily recognized for her leading role in developing and implementing CDC's national Sudden Unexpected Infant Death Initiative which has advanced both research and programs to better understand and prevent SIDS and other infant deaths.

Invited Speakers & Moderators

(in alphabetical order)



Joshua Sharfstein, MD

Secretary of Health, Maryland Department of Health and Mental Hygiene, USA

COMMUNITY HEALTH APPROACHES TO INFANT MORTALITY CHALLENGES

Dr. Joshua M. Sharfstein was appointed by Governor Martin O'Malley as Secretary of the Maryland Department of Health and Mental Hygiene in January 2011. The Department includes Medicaid, public health, behavioral health, and services for the developmentally disabled, with an annual budget of approximately \$10 billion. In March 2009, President Obama appointed Dr. Sharfstein to serve as the Principal Deputy Commissioner of the U.S. Food and Drug Administration, the agency's second highest-ranking position. He served as the Acting Commissioner from March 2009 through May 2009 and as Principal Deputy Commissioner through January 2011. From December 2005 through March 2009, Dr. Sharfstein served as the Commissioner of Health for the City of Baltimore, Maryland. From July 2001 to December 2005, Dr. Sharfstein served as minority professional staff of the Government Reform Committee of the U.S. House of Representatives for Congressman Henry A. Waxman. Dr. Sharfstein is a 1991 graduate of Harvard College, a 1996 graduate of Harvard Medical School, a 1999 graduate of the combined residency program in pediatrics at Boston Children's Hospital and Boston Medical Center, and a 2001 graduate of the fellowship in general pediatrics at the Boston University School of Medicine. In 2008, Dr. Sharfstein was named a Public Official of the Year by Governing Magazine. Dr. Sharfstein now serves on the Health Information Technology Policy Committee, an advisory committee of the U.S. Department of Health and Human Services, and is a member of the editorial board of the Journal of the American Medical Association.



Robert M. Silver, MD

Professor of Obstetrics and Gynecology, University of Utah, USA

PLACENTAL INSUFFICIENCIES

Dr. Bob Silver is a Maternal Fetal Medicine physician in the department of Obstetrics and Gynecology at the University of Utah Health Sciences Center. His expertise is in translational research with a focus on adverse pregnancy outcomes including stillbirth, recurrent pregnancy loss, and abnormal placentation. He has a clinical interest in and has worked closely with families with recurrent pregnancy loss and stillbirth for over 20 years. He serves as the principal investigator for the Utah site of the Stillbirth Collaborative Research Network (SCRN) and the Effects of Aspirin in Gestation and Reproduction (EAGeR) trial, which is a randomized trial of low dose aspirin in patients with early pregnancy loss.



Marian Willinger, PhD

Special Assistant for SIDS, Eunice Kennedy Shriver National Institute of Child Health and Human Development, USA

FETAL PHYSIOLOGY

Dr. Marian Willinger received her Ph.D. in Microbiology from the University of Pennsylvania in 1976. She then conducted research in developmental neurobiology on the faculty of Harvard Medical School and Children's Hospital, Boston. In 1987, she joined the National Institute of Allergy and Infectious Diseases to work on outreach and clinical trials of AIDS therapies. Since 1989, she has been in the Pregnancy and Perinatology Branch at the National Institute of Child Health and Human Development. As Special Assistant for SIDS, she directs the SIDS research program, and related activities in stillbirth and infant health. She is program scientist for the Perinatal Alcohol in SIDS and Stillbirth Network, the Stillbirth Collaborative Research Network, the Nulliparous Pregnancy Outcomes Study, Monitoring Mothers-To-Be and the Study of Attitudes and Factors Affecting Infant Care. She has received numerous awards including the NIH Directors Award and the U.S. Department of Health and Human Services Secretary's Award for Distinguished Service.

FIRST CANDLE THANKS DR. HENRY KROUS

for his decades of dedication to research in the field of unexpected death of infants and children



Henry Krous, MD

Professor of Pathology,
University of California - San Diego, USA

SIDS/SUID Pathology Symposium

celebrating the career of Henry Krous, MD

Friday, October 5 | 12:30 pm - 4:30 pm
Harborside Ballroom Salon E

Speakers: Gabriel Haddad, MD
Torleiv Rognum, MD, PhD, MHA
Roger Byard, MD
Bruce Hyma, MD
David Paterson, PhD
Eugene Nattie, Jr, MD
Laura Crandall, MS
Hannah Kinney, MD
Henry Krous, MD
Betty McEntire, PhD

**Symposium
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Dr. Krous recently retired at the end of June 2012 as Director of the San Diego SIDS/SUDC Research Project, Clinical Professor of Pathology & Pediatrics at the University of California, San Diego School of Medicine, and Director of Pathology Research at the Rady Children's Hospital-San Diego where he also served as Chair of the Pathology Department for 25 years. His 37-year-career was dedicated to research into sudden unexpected death in infancy and childhood. He received his undergraduate and medical degrees from the University of Nebraska and his anatomic pathology residency at the University of Washington in Seattle, WA. The sudden unexpected death of the infant daughter of one of his fellow interns led to his introduction to Dr. J. Bruce Beckwith, who inspired Dr. Krous' research into sudden infant death syndrome (SIDS) career and mentored his fellowship in pediatric pathology at Children's Orthopedic Hospital Medical Center in Seattle. Dr. Krous broadened his interest and experience in forensic pediatric pathology by performing postmortem examinations at the King County Medical Examiner's office during his fellowship, and then at the Naval Regional Medical Center, San Diego, and San Diego County Coroner's Office. His early research into SIDS began while at the University of Oklahoma Health Sciences Center where he pursued the significance of intrathoracic petechiae in the mechanism of death. In 1985, Dr. Krous moved to San Diego, CA where he joined Rady Children's Hospital and the University of California, San Diego School of Medicine. In 1991, he assisted in the development of California legislation aimed at improving case investigations into sudden unexpected infant death and served as chair of a statewide multidisciplinary committee that developed and implemented standardized death scene investigation and autopsy protocols. He subsequently served as Chair of the SIDS Global Strategy Task Force that developed similar protocols for international use.

In 1991, Dr. Krous formed the San Diego SIDS Research Project from which his research focused upon refining the pathology of SIDS and its differentiation from other causes of sudden unexpected infant death. Also recognizing the unique opportunities afforded by the California SIDS legislation, he welcomed the collaboration of investigators world-wide who were pursuing SIDS research. The 25-year collaboration with Dr. Hannah Kinney, Harvard University neuropathologist at Children's Hospital Boston, was particularly important in that the complex role of defective neurotransmitter systems, especially those involving serotonin, in SIDS began to be unraveled. In 2004, he also chaired an international committee that developed the San Diego SIDS definition that is now widely used.

In 1999 Dr. Krous broadened his research to include cases of sudden unexpected death in childhood; this effort began not long after he presented a paper entitled "SIDS: Is the Incidence Increasing in Infants Older than One Year of Age?" at the SIDS Alliance National Meeting in Atlanta, GA. To acknowledge this, he renamed the San Diego SIDS Research Project as the San Diego SIDS/SUDC Research Project to include these latter cases thus initiating the first formal research into this topic anywhere. In his 2005 publication, Dr. Krous and his colleagues provided the first definition of sudden unexplained death in childhood (SUDC), profiled 36 cases, and linked to febrile seizures. Since then, Dr. Kinney and others have joined in this research, the outcome of which has strengthened this association and connected it to gross and microscopic hippocampal abnormalities.

Dr. Krous has been President of the Society for Pediatric Pathology, for which he held numerous offices and had been previously honored with the President's Award. He gave dozens of invited national and international lectures. Among numerous awards and visiting professorships, Dr. Krous was presented with the Senator Daniel E. Boatwright Award for "extraordinary public service on behalf of Californians touched by SIDS." He serves on the editorial boards of Pediatric and Developmental Pathology and Forensic Science Medicine and Pathology, and reviews manuscripts for numerous journals. Dr. Krous has served as the Vice Chair of the SIDS Advisory Council to the California Department of Health Services; as the Pathology Chair of the International Society for the Prevention of Infant Death, and continues to serve as Chair of the San Diego County Child Death Review Committee. His memberships have included numerous pediatric and forensic pathology societies. Dr. Krous has authored/co-authored greater than 200 publications and numerous book chapters, and co-edited several books. Finally, he will always remain grateful to the innumerable and extraordinary families who survived the sudden unexpected death of their infants or children and served as a continual source of inspiration and support throughout his career.

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SIDS/SUID Oral Abstract Presentations

FRIDAY, OCTOBER 5

BREAKFAST SESSION I ☉ 7:00 am – 8:30 am

Moderator: Stephanie Cowan

Cowan SF, Tipene-Leach D.
Founding Director, Change for our Children, New Zealand

'END GAME' SUID PREVENTION APPROACHES AND THE NEED FOR INNOVATION

Overview. In the language of chess, we are now in the 'end game' for preventing sudden infant deaths. There are fewer pieces on the board and their different characteristics require different strategic concerns. To overwhelm the opponent (SUID), pieces must be developed, promoted and centralised to enable strong defence at the heart of play. For SIDS/SUDI/SUID, the end game 'players' are from vulnerable groups, the 'heart of play' is the context of infant sleep, and 'strategic concerns' involve decisions about where the work will focus, who will be communicators and what will enable action.

This round table discussion is led by people with a long experience in breaking through the status quo, championing a new reality and enlisting support from others in the pursuit of increasing survival rates for babies. Specifically, David championed the introduction of the wahakura baby bed, and Stephanie the pēpi-pod, to enable safety in 'same-bed' co-sleeping spaces for more vulnerable babies in New Zealand.

Interactive Discussion. Participants will be encouraged to identify a desired outcome to a current infant mortality related concern in their communities. Discussion will be shaped by 'end-game' thinking and explore these issues for participants:

- People:** Who are your 'end-game' players?
How well do you understand them?
What are their roles in bringing in the new order, winning the game?
- Idea:** Where is the 'heart of play' or context of focus?
How well do you understand it?
Where are the threats (barriers) and opportunities (supports)?
How can 'play' be defended, protected, strengthened?
What would be a winning move (idea to enable safe action)?
- Spread:** What are the 'strategic concerns'?
Who are the decisions makers?
What decisions must be made by whom?
Where is the influence, the need?
How will you 'overwhelm' the opponent (SUID), reach all players?
Who will you enlist to help?

Conclusion. Different thinking gets different results. Rethinking status quo approaches and embracing innovation methodologies is likely to open the way for more precision in prevention efforts and to ending preventable sudden infant deaths completely.

BREAKFAST SESSION III ☉ 7:00 am – 8:30 am

Moderator: Fern Hauck

Weiss P.
Vice-President Research, International Children's Medical Research Society, United Kingdom

TIME TO RE-EVALUATE THE ROLE OF PACIFIERS IN SIDS CAMPAIGNS

The primary objectives of this session are 1) to present data to support the importance of pacifier use as a protective strategy to prevent SIDS, and 2) show that the recommendation for the use of pacifiers as a preventative measure for SIDS is often heavily qualified and not universally accepted, despite this evidence. In 2005 the American Academy of Pediatrics added pacifiers to their recommendations to reduce the risk of SIDS. First, the research evidence leading to this ground-breaking recommendation will be summarised. Secondly, possible mechanisms to explain how pacifiers may reduce the risk of SIDS will be summarised. Thirdly, a brief history of pacifiers will be presented, including the changing attitudes of the medical profession over the millennia. The results of a preliminary survey of advisory web sites where pacifiers are almost universally recommended for SIDS prevention will be presented. This survey shows that the majority qualify the use of pacifiers for SIDS prevention with a variety of negative factors, the most important of these being the possible effect of pacifier use on breastfeeding. Finally, evidence will be presented from 5 randomized controlled trials revealing no difference in breastfeeding

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outcomes with different pacifier interventions. Based on this absence of a causal link between pacifier use and early weaning from breastfeeding, we recommend that breastfeeding promotion programs and international agencies that do not endorse pacifier use as a preventive measure for SIDS re-examine their opposition to this potentially life-saving intervention.

Speakers: Relationship between pacifier usage and SIDS - review of the epidemiologic literature

Fern R. Hauck, MD, MS
Professor of Family Medicine and Public Health Sciences
Director, International Family Medicine Clinic
University of Virginia, USA

A trial to explain the beneficial effect of pacifier use; observations and speculations

Reinhold Kerbl, MD
Professor, Department of Pediatrics and Adolescent Medicine
Hospital of Leoben, Austria
Dr Kerbl's study was co-authored by:
Marie Hausegger, MD, University Children's Hospital, Austria
Heinz Zotter, MD, University Children's Hospital, Austria

The changes in attitude toward pacifier use throughout history and a survey of current views on the Internet

Peter W Weiss, MSc., PhD
Vice-President Research, International Children's Medical Research Society

The Effect of pacifiers on breast feeding

Alejandro Jenik, MD
Associate Professor, Department of Neonatology
Hospital Italiano de Buenos Aires, Argentina

PATHOLOGY SYMPOSIUM - In Celebration of the Career of Henry F. Krous, MD 🕒 12:30 pm - 4:30 pm

Moderators: Drs. Hannah Kinney and Torleiv Rognum

🕒 12:35 pm

Haddad GG.

University of California, San Diego, Departments of Pediatrics and Neuroscience; Rady Children's Hospital - San Diego, USA

MECHANISMS OF CELL DEATH IN NEURONS AND GLIA FOLLOWING HYPOXIA/ISCHEMIA

Over the past half century, SIDS has not suffered from hypotheses aimed at explaining the pathogenesis and determining the factors that lead to the demise of the infant in the first several months of life. More recently, with the help of scientists and clinicians alike, theories have surfaced, favoring the idea of abnormalities in brainstem development resulting in physiologic catastrophies, possibly triggered by environmental events. Dr. Henry Krous was one of the major leaders in SIDS that shaped our current thinking. Our laboratory has been interested in the response of nerve and glial cells to alterations in O₂ and CO₂ and the mechanisms that lead to cell injury (rodents) or cell survival (Drosophila). In this work, we focus on brain hypoxia in mice particularly on cells in the penumbral region. To mimic such conditions, we employ a slice culture system and use an ischemic solution (IS) that resembles the milieu of the infarct rim. Our data show significant cell injury following IS exposure. We also studied the effect of each component in IS (e.g., acidosis, hypoxia) and we isolated the contribution of each of these. Gene expression studies indicated that among 46,000 transcripts tested, chemokine receptor-like 2 (CCRL2) was one of the most significantly up-regulated. In vivo experiments, brain lesions were assessed after middle carotid artery occlusion. There was a smaller infarct volume and reduced neurological deficits in CCRL2 knock-out mice than in control. We conclude that activation of neuro-inflammatory pathways play a critical role in hypoxic/ischemic cell death in the brain.

🕒 12:55 pm

Rognum TO.

University of Oslo, The Norwegian Institute of Public Health, Norway

PROFESSOR HENRY F. KROUS' CONTRIBUTION TO A MORE ACCURATE DEFINITION OF SIDS

The SIDS definition (1969) and the SIDS ICD code (1971) meant an important step forward for research on sudden deaths in infants and small children. However, this definition "per exclusion", caused conflict considering which findings that might cause death, and there has been local "epidemics" due to some pathologists' and researchers' special ideas. After the Back to Sleep campaigns in the early 1990's and even before that, Bruce Beckwith and Henry F. Krous understood that sudden death in infants and small children were different conditions. The classical SIDS deaths in small infants had certain

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characteristics different from sudden deaths in older children (SUDC). In 2003 Henry F. Krous gathered SIDS researchers in San Diego to develop a new definition of SIDS: the category I A Classic SIDS now requires age more than 21 days and less than 9 months of age, normal clinical history, growth and development, and no similar deaths in close genetic relatives. Death should occur during sleep. The reduced SIDS rates after the Back to Sleep campaign is mainly due to reduction in the number of small SIDS victims. This fact should result in new hypothesis in SIDS research. SUDC research needs other hypotheses than SIDS. The work of Henry F. Krous through several decades has had a clear-cut punch line and will contribute to better studies in the future.

🕒 1:15 pm

Byard RW.

The University of Adelaide, Australia

STANDARDIZED PROTOCOLS IN THE INVESTIGATION OF SUDDEN INFANT DEATH

Despite definitions of SIDS being formulated from the late 1960's, a major problem in the areas of both diagnosis and research was the heterogeneity of approaches at the time of first investigation and autopsy. In some cases, death scenes were reviewed in a very perfunctory fashion with parental interviews occurring days after the death and over the telephone. Autopsy examinations were equally variable, with minimal special dissections being undertaken and very patchy use of ancillary studies. Henry Krous, more than anyone, was instrumental in establishing standard protocols and in promoting their use. This began in the early 1990's when SIDS International and the NICHD established the Global Strategy Task Force. Henry as Chair of the GST Pathology Working Group was tasked with developing the International Standardized Autopsy Protocol and accompanying Instruction Manual. This was first published in 1996, and over the ensuing years has been endorsed by many professional bodies, as well as acting as a template internationally for the autopsy examination of the young. If Henry Krous had achieved nothing else in his career (and that is certainly not the case) this one contribution would rank at the highest level in advancing the investigation, understanding and prevention of unexpected infant deaths. It has been one of the most important developments in the field of pediatric forensic pathology in the past decades and has been of global significance.

🕒 1:35 pm

Hyma BA, McEntire B.

Dade Medical Examiner Department, Florida, American SIDS Institute, USA

SUDDEN UNEXPECTED INFANT DEATH (SUID) TISSUE CONSORTIUM

The sudden unexpected death of an infant continues to challenge the forensic science community while bringing untold emotional trauma to parents and extended family members. As a scientific community, forensic pathologists, medical examiners and coroners have investigated these deaths with the assistance of law enforcement and research scientists. Years of research studying the pathology, neurobiochemistry, pathophysiology, neuroanatomy, neurophysiology and the physical environment in which death occurs has yielded a wealth of data without clear, cohesive conclusions. We must rely on an animistic record and its inherent selection bias to interpret this research data. To that end, the SUID Tissue Consortium was created for three purposes: to provide much needed tissue and body fluids for researchers from infants who die suddenly, to help understand the medical abnormalities that may increase the risk of sudden death in infants, and to develop age-matched tissue and body fluid controls. With informed, next of kin consent, body fluids, tissue samples from all organ systems and the brain of infants (1 year of age or less) are collected during the autopsy process and preserved at -80° F or in 10% buffered formalin. These body fluid and tissue samples are banked at the National Institute for Child Health and Development (NICHD) at the University of Maryland. De-identified, investigative data is collected by the American SIDS Institute and attached to each body fluid/tissue set. With time, this tissue consortium will be a valuable, national resource for current and future SUID research.

🕒 2:15 pm

Paterson DS.

Children's Hospital Boston, Harvard Medical School, USA

SIDS BRAINSTEM AND GENETICS RESEARCH

We have reported neurotransmitter and related abnormalities in the medulla oblongata of SIDS infants in four independent datasets over two decades. These data suggest an important SIDS subset have an underlying abnormality in the medullary homeostatic network that: 1) Results in a failure of protective responses to life-threatening stressors during sleep in a critical developmental period; 2) importantly involves serotonin (5-hydroxytryptamine, 5-HT), γ -aminobutyric acid (GABA), and their potential interactions with other neurotransmitter systems and the signal transduction family 14-3-3. The pathogenesis of these abnormalities remains unknown but is proposed to be multifactorial, involving a combination of environmental and genetic risk factors. Epidemiological studies have been very successful in identifying environmental risk factors involved including prone sleep position and maternal cigarette and alcohol use during pregnancy, but much less is known about the associated genetic factors. This presentation reviews the studies that we have performed in our laboratory attempting to identify these genetic factors using a variety of approaches, including analysis of candidate gene polymorphisms (e.g., 5-HT transporter and monoamine oxidase polymorphisms), genome wide association studies (GWAS) of single nucleotide polymorphisms (SNPs), and analysis of copy number variations (CNVs). The results from these studies support the idea that SIDS is oligogenic in nature, i.e., no single gene mutation is responsible, but that multiple gene polymorphisms, that individually are responsible for a small increase in SIDS risk, occur in different combinations simultaneously in an infant and act synergistically to significantly increase the risk of SIDS.

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🕒 2:35 pm

Nattie EE.

The Geisel School of Medicine at Dartmouth, Department of Physiology, USA

INSIGHTS INTO SIDS PATHOGENESIS AND POSSIBLE 'TREATMENT' FROM ANIMAL MODELS

Studies of brainstems from SIDS cases, collected largely due to the industry and dedication of Henry Krous, have uncovered a cluster of abnormalities as described by Drs. Kinney, Paterson, and colleagues. Within our program project on SIDS, the responsibility of the Dartmouth Physiology group, which I represent, has been to define in animal models how these brainstem abnormalities might cause sudden death during a window of development. In rodent pups during early postnatal development, we study three aspects of physiology relevant to SIDS: 1) arousal from sleep, 2) the laryngeal chemoreflex, which powerfully inhibits breathing, 3) responses to various forms of intermittent exposure to hypoxia. In normal rat pups, we have found a 5-HT induced shortening of the time of apnea induced by stimulation of the laryngeal chemoreflex. In rat pups from dams fed a diet deficient in tryptophan, which causes brainstem 5-HT depletion, or in transgenic mice with altered 5-HT function we have found: 1) a delay in the time it takes to arouse from sleep with hypoxic stimulation, and 2) a decreased ability to recover from brief, induced periods of anoxia (autoresuscitation). In this last case, we observe age-specific mortality in pups 90% deficient in brainstem 5-HT (the Pet1 null mouse). Further, we are able to 'rescue' these mice by 'treatment' with caffeine. These findings support the hypothesis that brainstem neurotransmitter abnormalities can cause sudden death during an age-specific window of postnatal development and suggest that treatment of infants identified as at risk may be possible. (Supported by: P01 HD036379).

🕒 2:55 pm

Crandall L.

Sudden Unexplained Death In Childhood (SUDC) Program, CJ Foundation for SIDS, USA

FILLING THE VOID: ENVISIONING AND FULFILLING THE NEEDS OF SUDC

In 1999, the first formal recognition of "post infancy SIDS", now known as sudden and unexplained death in childhood (SUDC), was presented in Atlanta, Georgia by Dr Henry Krous at the SIDS Alliance annual meeting. His presentation highlighted the gaps in knowledge, support and research for these tragedies. Seven affected families were in the audience; they asked many difficult and unanswered questions about sudden death beyond the first year of life, and brought out differences between these deaths and those less than 1 year. What ensued, was a rich collaboration in the planning and creation of the first database and retrospective review of SUDC cases through the formation of the San Diego SUDC Research Project, as well as, the founding of The SUDC Program. The project addressed research needs, whereas the program addressed bereavement services, advocacy, awareness and fundraising. Thirteen years later in 2012, both the SUDC Research Project and the SUDC Program represent a thriving and successful collaboration that has brought to light a rare and under recognized population by: 1) meeting the emotional and informational needs of affected families; 2) improving awareness and collaboration of SUDC in the medicolegal death investigation community; 3) providing private funds to support crucial research and support SUDC needs; and 4) publishing crucial research findings to improve the overall understanding of these tragic deaths and direct future research. Over 500 families from 14 countries have sought the services of the program since its formation. The role of Dr. Krous in SUDC will be forever acknowledged and gratefully appreciated.

🕒 3:15 pm

Kinney HC.

Children's Hospital Boston, Harvard Medical School, Department of Pathology, USA

NEUROPATHOLOGIC RESEARCH IN SUDC: REFLECTIONS IN HONOR OF HENRY F. KROUS

Neuropathologic research in SUDC was greatly facilitated by the founding of the SUDC Research Project by Dr. Henry F. Krous, in conjunction with Ms. Laura Crandall, in the early 2000's. This project has developed a national and international registry of rare SUDC cases that would otherwise take a professional lifetime to accrue a sufficient sample size of cases to ascertain common patterns. I was personally fortunate and honored to be asked by Dr. Krous to serve as the pediatric neuropathologist for this project. In conjunction with Dr. Krous, we have defined a potential new entity that may account for the majority of SUDC in toddlers, defined by sleep-related death in the prone position, individual or family history of febrile seizures, and with or without hippocampal anomalies (Kinney HC et al. *Pediatr Dev Pathol* 2007; Kinney HC et al. *Pediatr Dev Pathol* 2009). The mechanism of death appears analogous to sudden unexpected death in epilepsy (SUDEP), with a putative unwitnessed seizure during sleep leading to airway occlusion and/or cardiac arrhythmia, and death. Moreover, SUDC in toddlers with a personal and family history of febrile seizures (with or without hippocampal anomalies) is associated with an autosomal dominant mode of inheritance in an initial small series (Holm IA et al. *Pediatr Neurol* 2012, in press); the gene defect is under investigation involving families in the SUDC Research Project database. My talk ends with a tribute to Dr. Krous for his foresight, drive, and compassion to develop the unprecedented SUDC Research Project.

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SATURDAY, OCTOBER 6

BREAKFAST SESSION I 🕒 7:00 am – 8:30 am

Moderator: Lena Camperlengo

Camperlengo LT, Covington TM, Hartmann LK, Sotenbur-Wing S, Raheem A.
Centers for Disease Control and Prevention, National Center for Child Death Review and Prevention, New Jersey
Department of Children and Families, Michigan Public Health Institute, Georgia Office of the Child Advocate, USA

THE SUDDEN UNEXPECTED INFANT DEATH (SUID) CASE REGISTRY: IMPROVING KNOWLEDGE ABOUT SUID AND TAKING ACTION

This group presentation will provide an overview of the Centers for Disease Control and Prevention's Sudden Unexpected Infant Death (SUID) Case Registry and the National Center for the Review and Prevention of Child Death's program upon which it was built. Additionally, three states participating in the SUID Case Registry will present information on how they use the SUID Case Registry to improve the investigation of infant deaths and inform SUID prevention programs.

Introduction. In the United States, about 4,200 infants die suddenly, unexpectedly and without an immediately obvious cause. Vital records are important for monitoring trends in sudden unexpected and unexplained infant deaths (SUID), but provide limited information about the circumstances and events surrounding these deaths. The Centers for Disease Control and Prevention (CDC) developed the SUID Case Registry to conduct state-level SUID surveillance. The SUID Case Registry, built upon existing state Child Death Review programs, collects comprehensive information about the characteristics of each SUID case as well as the components of the case investigation.

Methods. Following a 2007 feasibility study, the CDC gathered input from partners to develop a program model for the SUID Case Registry. In July 2009, five states were selected to participate in a 3-year SUID Case Registry pilot program. In 2010, an additional two states were funded. The National Center for the Review and Prevention of Child Death and the CDC worked together to provide training and technical assistance, including site visits with observations of SUID case reviews. Standardized quality assurance activities have been implemented and all state teams are guided by an operations manual.

Results. Colorado, Georgia, Michigan, Minnesota, New Hampshire, New Jersey and New Mexico are collecting information on each SUID case in their state. As of December 2011, these states have reviewed and entered information for 1,003 SUID cases. States report improved collaboration with local and state medical examiner and coroner offices and improved data completeness. SUID Case Registry states have also initiated SUID case investigation improvement strategies and local interventions promoting safe sleep.

Discussion. The SUID Case Registry collects population-based SUID-specific case and investigation information from multiple sources. Together, the CDC SUID Case Registry and Child Death Review programs have catalyzed local and state actions across the spectrum of SUID investigation, SUID cause-of-death determination, services to families and SUID prevention interventions.

SIDS/SUID ORAL ABSTRACT PRESENTATIONS: PHYSIOLOGY AND GENETICS 🕒 10:15 am - 11:15 am

Moderator: Aurore Côté

🕒 10:15 am

Vennemann MMT, Bajanowski T, Cohen M, Mitchell EA, Mage DT, Pfeifer A.
University of Münster, Institute of Legal Medicine, Germany; University of Essen-Duisburg, Germany; Sheffield Children's Hospital NHS Trust Western Bank, United Kingdom; The University of Auckland, New Zealand; National Exposure Research Laboratory, USA; German Research Center for Environmental Health, Germany

GENOME-WIDE ASSOCIATION STUDY OF SIDS-PREDISPOSING GENETIC VARIATION

Background. In SIDS the contribution of monogenic disorders has long been appreciated while the importance of complex genetic predispositions is less clear. To investigate the latter we conducted a two stage GWAS case control study comparing SIDS cases with population based controls. As in developed countries proven cases of SIDS exhibit 50% male excess we included Chr.X markers into our analysis. We also analyzed CNV (Gene copy number variants) markers as chromosomal insertions and deletions may likewise contribute to SIDS.

Patients. We included 446 cases with both information and bio samples available into our study. 346 infants originated from the multi-center German study on sudden infant death (GeSID) and 100 further cases were recruited in the U.K. As controls we used 1,311 population based individuals with genotypes and information available.

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Methods. We performed genome-wide SNP genotyping of 320 cases. After rigid quality control, data from 295 individuals were analyzed. Autosomal SNP- and CNV-markers (Chr.1-22) were analyzed using an additive model adjusted for sex. Markers on Chr.X were analyzed stratified by sex and then meta-analyzed. As age matching is not feasible in SIDS we performed sex matching of controls and geographical adjustment by multidimensional scaling.

Results. In the GWAS markers no marker surpassed the genome-wide significance level ($p < 5 \times 10^{-8}$). Markers from 23 autosomal and 4 Chr.X loci achieved $p < 1 \times 10^{-4}$ and were selected for follow-up in the entire sample of 446 cases and 1311 controls. Here the strongest autosomal marker was located on Chr.4 and achieved an OR=1.6 (95%CI 1.4-2.0) $p = 1.9 \times 10^{-8}$ while the strongest Chr.X marker had OR=1.6 (1.3-2.1) $p = 1.2 \times 10^{-6}$.

Conclusion. The preliminary analysis and follow-up of our GWAS has shown that even samples of about 500 cases can be adequately powered to achieve a genome-wide significant result. In addition we have also found evidence for the association of X-chromosomal markers with SIDS albeit so far only markers with a smaller effect than anticipated under the X-chromosomal recessive-susceptibility locus hypothesis. The preliminary analysis of CNV markers has not yielded reliable association with SIDS.

*Study funded by Foundation for Study of Infant Death (FSID), London, UK

🕒 10:30 am

Randall BB, Paterson DS, Haas EA, Broadbelt KG, Krous HF, Trachtenberg FL, Kinney HC.
University of South Dakota Sanford School of Medicine, Children's Hospital Boston, Rady Children's Hospital, New England Research Institutes, USA

NEUROCHEMICAL BRAINSTEM PATHOLOGY AND POTENTIAL ASPHYXIA IN SUDDEN UNEXPLAINED INFANT DEATHS

Background and Hypothesis. Circumstances consistent with asphyxia in unsafe sleep environments at the time of death are known to increase the risk for SIDS >3-fold, raising the possibility that otherwise normal infants die of asphyxia in these environments. Potential asphyxia-generating circumstances include prone and face-covered sleep position, excessive bed clothing, and bed sharing, the latter with the possibility of overlaying. We postulate that at least some SIDS infants, however, are not completely healthy, but rather, have an underlying brainstem abnormality in neural networks that mediate protective responses to asphyxia, resulting in sleep-related sudden death. Over the last 2 decades, we have reported abnormalities in inter-related neurochemical parameters in the same SIDS cases in such a homeostatic network in the medulla oblongata (lower brainstem). The parameters are related to the neurotransmitters serotonin (5-HT) and γ -aminobutyric acid (GABA) and the signal transduction family 14-3-3 that is involved in 5-HT regulation. In this study, we tested the hypothesis that cases of sudden and unexplained infant death (irrespective of the label "SIDS") were associated with both asphyxia risks and reductions in 5-HT, GABA, and/or 14-3-3 parameters in medullary regions related to cardiorespiratory control as compared to control infants dying of known causes of death.

Methods. The dataset involved 44 cases from the San Diego medical examiner's system in whom neurochemical data were available in the CHB laboratory from samples in the last decade. The neurochemical procedures included tissue receptor autoradiography (5-HT_{1A} and GABA_A receptor binding), high performance liquid chromatography (5-HT levels), and western blotting (14-3-3 subtypes, tryptophan hydroxylase 2). The study causes of death were assigned after review of the reports of the death scene investigation and autopsy records by a long-time medical examiner (BBR) who was blinded to the neurochemical data. No cases of possible hyperthermia were included in order to examine independently the role of potential asphyxia.

Results. Medullary measures of 5-HT_{1A}, and GABA_A receptor binding, and levels of several 14-3-3 subtypes were significantly lower ($p < 0.05$) in the cases with sudden infant death and potential asphyxia-generating conditions ($n=35$) compared to controls with known causes of death ($n=9$).

Conclusion. These data suggest that infants with sudden unexplained death (irrespective of the label of SIDS) who die in circumstances potentially related to asphyxia demonstrate neurochemical abnormalities in the medullary homeostatic network compared to infants dying of known causes. Thus, an intrinsic brainstem abnormality may underlie at least some cases of sudden infant death in association with prone sleep position and bed sharing. This underlying abnormality may put the infant at risk for sudden death possibly triggered by asphyxia. Grant support: NICHD (HD20991), First Candle, CJ Foundation for SIDS, Jacob Neil Boger Foundation for SIDS, and Marley Jaye Cherella Foundation for SIDS.

🕒 10:45 am

Paterson DS, Hoa T, Tran HT, Harty B, Trachtenberg FL, Haas EA, Krous HF.
Children's Hospital Boston and Harvard Medical School, New England Research Institutes, Rady Children's Hospital San Diego and the University of California, San Diego School of Medicine, USA

REDUCED 5-HT_{1A} RECEPTOR BINDING IN THE AUDITORY BRAINSTEM IN SUDDEN INFANT DEATH SYNDROME: IMPLICATIONS FOR NEWBORN HEARING SCREENING AS A DIAGNOSTIC TEST FOR SIDS

Background and Hypothesis. Despite the success of risk reduction messages and the Back-to-Sleep campaign, SIDS remains the leading cause of postnatal infant mortality in the United States; it is also the third most common cause of infant mortality overall. The cause of SIDS remains unknown, and currently there is no diagnostic test to identify at risk infants. Development of such a test and intervention therapies are, therefore, urgently needed. Two important findings have emerged in the last decade: 1) reproducible abnormalities in markers of serotonergic (5-HT) function in regions mediating homeostatic control in the medulla oblongata (i.e., the medullary 5-HT system) in SIDS cases that we propose result in defective modulation and coordination of homeostatic function leading to a chain of events causing sleep-related sudden death; and 2) a preliminary study reporting altered newborn

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oto-acoustic emission (OAE) profile (hearing test scores) in infants who subsequently died of SIDS. Importantly, OAEs are modulated by auditory nuclei that are adjacent to and have reciprocal connections with the cardiorespiratory-related nuclei in the medulla in which we previously observed 5-HT-related abnormalities. Furthermore, lesion/injury of the inner ear or the adjacent vestibular nucleus suppresses the hypercapnic ventilatory response in humans and experimental animals indicating that brainstem cochlear-vestibular nuclei and homeostatic-related nuclei are functionally integrated. Taken together, these observations raise the possibility that altered OAEs are a marker of neurotransmitter pathology in SIDS suggesting that they be used to both identify 'at risk' infants at birth and further our understanding of how these infant die. As a first step towards answering this question, we tested the hypothesis that 5-HT_{1A} receptor binding density was significantly lower in the cochlear and adjacent vestibular nuclei of SIDS cases compared to controls from two independent SIDS datasets on which we have previously reported abnormalities in 5-HT_{1A} receptor binding in the medullary 5-HT system.

Methods. 5-HT_{1A} receptor binding was measured in the cochlear and vestibular nuclei of 30 SIDS cases and 5 controls (infants dying acutely of known causes) accrued through the San Diego Medical Examiner's System. Receptor binding density was determined by quantitative densitometric analysis of previously generated autoradiograms of 3H-8-OH-DPAT binding to 5-HT_{1A} receptors in sections of postmortem human medulla from these cases by an investigator blinded to diagnosis.

Results. We observed 5-HT_{1A} receptor binding density to be significantly lower in both the cochlear ($p=0.02$) and vestibular ($p=0.03$) nuclei in SIDS cases compared to controls.

Conclusions. These observations suggest that a common neurotransmitter defect may be responsible for cardiorespiratory and hearing dysfunction supporting the idea that abnormal OAE responses may be used as a diagnostic test to identify infants with an underlying brainstem abnormality that are at risk of SIDS.

🕒 11:00 am

Horne RSC, Yiallourou S, Witcombe N, Sands S, Walker A
Monash Institute of Medical Research, Monash University, Australia

DEVELOPMENT OF AUTONOMIC CARDIOVASCULAR CONTROL IN PRETERM INFANTS IS ALTERED COMPARED TO TERM INFANTS

Background. Preterm infants are at 3 times the risk for the Sudden Infant Death Syndrome (SIDS) compared with infants born at term. It has been suggested that cardiovascular control may be impaired in those babies who die from SIDS. And thus cardiovascular autonomic dysfunction may explain the increased incidence of SIDS in preterm infants. Currently, little is known about the development of autonomic cardiovascular control in preterm infants after term equivalent age and during the period of greatest SIDS risk. Accordingly, we examined the effects of preterm birth on autonomic blood pressure control during sleep across the first 6 months after term-corrected age (CA).

Methods. Preterm ($n=25$) and term infants ($n=31$) were studied at 2-4 weeks, 2-3 months and 5-6 months CA using daytime polysomnography. Blood pressure was measured during quiet (QS) and active (AS) sleep using photoplethysmography. Autonomic control was assessed using spectral indices of blood pressure variability (BPV) in ranges of low frequency (LF, reflecting sympathetic activity), high frequency (HF, respiratory-mediated changes+parasympathetic activity), total power (LF+HF) and LF/HF ratio (sympathovagal balance).

Results. With advancing age in preterm infants, HF HRV increased, LF/HF HRV decreased and LF BPV decreased ($p<0.05$); these changes were most evident in AS. Compared to age-matched term infants, preterm infants in QS exhibited lower LF, HF and total HRV at 5-6 months CA ($p<0.05$), higher HF BPV at all ages studied ($p<0.05$) and lower LF BPV at 2-4 weeks ($p<0.05$).

Conclusions. In preterm infants, parasympathetic modulation of the heart increases while sympathetic modulation of blood pressure decreases with maturation. Compared to term infants, preterm infants exhibit lesser parasympathetic modulation of the heart along with greater respiratory-mediated changes and lower sympathetic modulation of blood pressure. Impaired autonomic control in preterm infants may contribute to their increased risks of SIDS.

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SIDS/SUID ORAL ABSTRACT PRESENTATIONS: DIAGNOSIS AND RISK REDUCTION 🕒 1:30 pm - 3:00 pm

Moderator: David Paterson

🕒 1:30 pm

Taylor BJ, Engelberts AC, Vennemann MM, Moon RY, Sidebotham P, Garstang J, Freemantle J, Obonai T.
Orbis Medical Center, Netherlands; University of Münster, Institute of Legal Medicine, Germany; George Washington University School of Medicine and Health Sciences, USA; University of Warwick, United Kingdom; University of Melbourne, Australia; National Center of Neurology and Psychiatry, Japan

AN INTERNATIONAL COMPARISON OF UNEXPLAINED SUDDEN UNEXPECTED DEATH IN INFANCY (SUDI) USING A NEWLY DEFINED RANGE OF ICD10 CODES

Introduction. International comparisons are bedeviled by the variation in the interpretation of cause of death between pathologists, coroners or medical examiners and official coders who rely on the reports of pathologists. With increased understanding of "risk factors" for Sudden Infant Death Syndrome, anecdotal reports of changes in how deaths are coded have led to some concern that reported decreases in SIDS rate might be occurring just because the deaths are coded to another cause of death.

Methods. In NZ, the child and youth mortality review process agreed to start using an agreed set of ICD10 codes as a definition of unexplained SUDI. In particular this set of codes included R95 (used in most countries for SIDS) as well as W75, a code used by many for accidental suffocation in bed. Other codes that could possibly be used to for unexplained SUDI were also identified. The co-authors from several different countries were asked if they could identify both the number of live births in their country from 2002 - 2010 as well as the number of deaths coded to R95 (Sudden infant death syndrome), R96 (Other sudden death, cause unknown), R98 (Unattended death), R99 (Other ill-defined and unspecified causes of mortality), W75 (Accidental suffocation and strangulation in bed), W78 (Inhalation of gastric contents) and W79 (inhalation of food).

Results. Data will be presented on rates of different categories of SUDI from NZ, Netherlands, Germany, USA, Japan, Australia and England/Wales. They confirm significant differences in coding practices in different countries. For these countries unexplained SUDI rates per thousand live births over this period vary from 0.14 to 1.2 deaths for every 1000 births. Access to the number of deaths attributed to these codes is not always straight forward, and in some countries might only be available for those over 28 days of age.

Discussion. We suggest that these set of ICD10 codes should be used in the future for international comparisons of unexplained SUDI rates, and should be used as well as comparing total post-neonatal mortality rates. Variation in coding can significantly affect international comparisons in the area of sudden unexpected death in infancy.

🕒 1:45 pm

L'Hoir MP, Knoeff-Gijzen S, Vennemann MM, Boere-Boonekamp MM.
University of Twente, Netherlands; University of Münster, Institute of Legal Medicine, Germany

INSTALLATION OF CHILD DEATH REVIEW TEAMS IN THE EASTERN PART OF THE NETHERLANDS

Background. Child mortality in the Netherlands declines gradually. In total 1,275 children and youth aged 0 to 19 years died in 2009. In 8 out of 10 cases the death was classified as due to a natural cause. 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. Child Death Review (CDR) has been introduced in the United States of America, Canada, Australia, New Zealand and the United Kingdom. All child deaths are examined in a systematic way through a multidisciplinary approach with the objective to improve cause of death statistics, to identify risk factors for generating preventive interventions, and to enhance support of families and professionals.

Aim. The objective of this cross-border study is to identify factors that promote or obstruct installation of Child Death Review teams in the Eastern part of the Netherlands. In Germany cot death cases are reviewed.

Methods. (Inter)national experts and institutes for reviewing child deaths were interviewed. In addition to this, two focus groups were held with professionals in child and family care and one with parents of a deceased child. A model for implementation of change in clinical practice is used to analyze the data.

Results. The results provide insights into the perceptions, opinions, beliefs and attitudes among professionals and parents towards Child Death Review. The most important barriers for implementation are the medico legal consequences, issues of confidentiality, time consumption, and the pending procedure to further investigate the cause of death in minors (NODO-procedure). The most important factors that promote CDR are the multidisciplinary approach, reviewing all child deaths with the parents' consent and the ongoing support to the family. Main results will be presented about the Dutch death reviews and the German cot death reviews.

Conclusions. Implementation of CDR in the Eastern part of the Netherlands is feasible. In designing the CDR procedure we made use of knowledge on promoting factors and of solutions that were found for the observed barriers. In January 2011, the implementation pilot has started and results will be presented.

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🕒 2:00 pm

Du Toit-Prinsloo L

University of Pretoria, South Africa

SUDDEN DEATH IN INFANCY: A MULTICENTRE STUDY OF THE MEDICO-LEGAL INVESTIGATION PROCEDURES AND OUTCOMES IN SOUTH AFRICA

Introduction. Little is known about the epidemiology of sudden unexpected death in infancy, in South Africa. A previous study has suggested that lack of standardized protocols of investigation may result in diagnostic discrepancies which may compromise comparability of data between centers and with other countries. A study was undertaken in an effort to evaluate the investigative approach as well as the eventual diagnostic profile of cases of sudden death amongst infants admitted to eight large urban medico-legal mortuaries.

Methods. A retrospective case audit was conducted on infants younger than one year of age who were admitted to eight large medico-legal mortuaries in South Africa as sudden and unexpected or unexplained deaths, over a five year period from 2005 to 2009. The medico-legal investigative protocols which were followed at the various mortuaries, patient demographics and diagnostic outcomes of autopsy, histology and other special investigations were recorded and compared.

Results. Over the study period, 50 549 cases were admitted to the 8 participating mortuaries, which included a total of 3 295 infants under one year of age (6.5% of the total case load). Of the latter, 591 infants had died due to other than natural causes (injuries, drowning, etc), with the remaining 2 704 presenting as cases of sudden, unexpected and/or unexplained deaths (and which constituted the study population). Of these, 199 infants were aged under 7 days, with a further 230 infants being aged between 8 and 30 days and the remaining 2 275 infants aged between 1 month and 12 months. Formal scene of death investigations were conducted in only 17 (0.6%) of the cases. There were distinct differences between mortuaries pertaining to the scope and nature of the autopsy, varying from viewings and partial dissections only to comprehensive dissections with histological examination and other special investigations. A natural disease condition was specified as cause of death in 1976 of cases (76.5%), with bronchopneumonia as the leading cause of death at all participating mortuaries (674 cases or 24.9%). SIDS was diagnosed in only 224 cases (8.7%), although in another 383 (14.8%) cases (where a full post mortem examination with ancillary investigations was conducted), the cause of death was recorded as "unascertained".

Conclusions. There are significant discrepancies in the investigative protocols and diagnostic criteria as applied to cases of sudden death amongst infants at mortuaries in South Africa and it would appear that the diagnosis of SIDS is made with hesitancy. This study would suggest that SIDS is more prevalent than previously reported, as it is certain that not all cases of sudden death amongst infants under one year of age are referred for medico-legal investigation in South Africa. Further studies are called for, whilst standardized protocols of investigation should also be advocated and implemented.

🕒 2:15 pm

Kerbl R, Kurz R, Kenner T, Einspieler C, Roll P, Hausegger M, Sauseng W, Zotter H.

Medical University of Graz, Hospital of Leoben, Austria

STEPWISE REDUCTION OF SIDS RATE IN STYRIA (AUSTRIA). THE CONTRIBUTION OF INDIVIDUAL MEASURES

Introduction. Styria is the south-eastern federal state of Austria and was the first Austrian region to introduce a SIDS prevention program. According to Steinschneider's apnea hypothesis, the first step consisted of the trial to detect infants with sleep apneas and periodic breathing. Numerous oxycardiopneumography investigations were performed, and up to 7% of liveborn infants received home monitoring. Since this intervention did not result in significantly decreased SIDS rates, a SIDS risk questionnaire was developed, based on retrospective evaluations in SIDS victims and controls. This intervention led to a significant reduction of SIDS figures which however appeared to be further reducible. Therefore, broad information campaigns were launched in a third step.

Methods. The period 1981 – 2011 was divided into three phases. Phase A (1981 – 1988) was the polygraphy / monitoring phase, phase B (1989 – 1995) the period during which prevention was shifted towards the use of the SIDS risk questionnaire, and phase C (1996 – 2011) were the years with additional statewide and systematic information strategy. For each period, mean SIDS incidence was calculated based on national registry data, and the rates of the three phases were compared by statistical analysis.

Results. During phase A, the mean SIDS incidence was 1.67 cases per 1.000 liveborn infants. During phase B, the incidence decreased to 0.94, the reduction being statistically highly significant ($p < 0.001$). Broad informational strategies during phase C resulted in a decrease of SIDS rate to 0.19 cases per 1.000 liveborn infants, the differences against phase A ($p < 0.001$) as well as phase B ($p < 0.001$) were both highly significant. During last years, the few SIDS cases that were observed in our region (0-2 cases per year) were almost exclusively infants who were not handled appropriately according to the recommendations of the Styrian SIDS Working Group.

Discussion. The comparison of the three phases clearly reflects the "learning effect" taking place over the last three decades in SIDS prevention. Especially the apnea hypothesis and broad use of home monitoring proved as "wrong turns" in SIDS prophylaxis. The Styrian SIDS prevention program was therefore repeatedly adapted to the updated knowledge, leading to either addition, withdrawal or replacement of measures. During last years, SIDS occurred predominantly in the socially underprivileged population which apparently neglects SIDS prevention recommendations more frequently than higher social classes. Therefore, an additional promotion program for sleeping bags ("bag to sleep") was launched in 2005, and the AAP recommendation of pacifiers

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was adopted in 2007 also in the Styrian program. Since pacifiers are usually well accepted in lower social classes, the latter measure may prove effective for further reduction of SIDS rate in Styria.

🕒 2:30 pm

Dillon EM

National Health Service, Central Manchester Foundation Health Trust, Children's Community Health Directorate, Greater Manchester Public Health Network, Salford University, Foundation for the Study of Infant Deaths, United Kingdom

MANCHESTER VULNERABLE BABIES: TARGETING RISKY BEHAVIOUR

Introduction. In December 2003 Central Manchester Foundation Trust (CMFT) implemented a Vulnerable Baby Service (VBS). The aim of this service is to reduce the risks of Sudden Unexplained Deaths in Infants (SUDI). The population of Manchester is 500,000, with 7,500 births to residents annually. It is a city with high levels of deprivation.

The VBS tackles SUDI using two approaches. In 2005 a Public Health approach was introduced to reduce risk behaviours for all babies born in Manchester. The foundation of this is an embedded Safe Sleeping Practice Message delivered by all practitioners working across the city. The service also facilitates targeted multiagency case planning meetings for any unborn baby or infant under 12 months of age who are identified as being at risk. As a result SUDI have dropped significantly, and health staff and multi agency partners have developed closer and more productive partnerships. The learning has been shared regionally and nationally to support a wider population impact on SUDI. The social marketing campaign BeCotSafe, which supported this work, has also won several regional and national awards.

Methods. Whilst targeting vulnerable families was effective for babies identified with risk factors, there needed to be a general population approach aimed at reducing risk as approximately two thirds of deaths did not have previously identified indicators. A Safe Sleeping Practice Guidance document was created in 2005. In 2008 a social marketing campaign was developed and the learning is used in training of staff and the education of parents and carers. The service oversees multiagency case planning meetings for any unborn baby or infant under 12 months of age living in Manchester who is considered to be vulnerable as defined by the referral criteria, unless they meet the threshold of significant harm.

Results. The numbers of SUDI in Manchester have reduced by 60% since 2004. In approximately 70% cases of SUDI, unsafe sleeping was recorded as an issue. Very few SUDI are now seen in high risk groups e.g. teenage parents and babies who are premature or low birth weight. There has been an increase in staff engagement, as they become stakeholders in baby outcomes, specifically to reduce SUDI. Staff are very motivated by local data. Midwives attend regular update sessions and training as part of their induction. Multi-agency partners and health professionals continue to be members of the VBS Steering Group which helps ensure engagement and two-way communication. Manchester staff work closely with the Foundation for the Study of Infant Deaths (FSID) and share learning and resources nationally.

Discussion. Safe Sleep Practice Guidance is invaluable and should be shared with all multi-agency partners to ensure a consistent message. It is recommended that this is "owned" by health staff, especially midwives. Front line practitioners and specialist services are key stakeholders in embedding practice. Effective communication at all levels of the multi-agency partnership sustains engagement and training and updates are a way of life. Evaluation is crucial, keep looking for gaps and themes.

🕒 2:45 pm

Joyner BL, Oden RP, Moon RY.

Children's National Medical Center, George Washington University of School of Medicine and Health Sciences, USA

BREASTFEEDING INTENTION AMONG AFRICAN AMERICAN WOMEN OF DIFFERENT SOCIOECONOMIC STATUS

Background. Breastfeeding reduces the risk for SIDS. African-Americans have higher rates of SIDS than other racial/ethnic groups in the U.S. Research shows that overall, breastfeeding intent is associated with positive breastfeeding attitudes; higher household incomes; being born outside the US; being Afro-Caribbean as opposed to African American; having family, peer, and partner support for breastfeeding; attending breastfeeding classes and having greater years of education. Many of these factors are not common among African American women, and this may contribute to the low breastfeeding rates in this group. Little research had been done on breastfeeding intention among African American women of different socioeconomic status (SES).

Objectives. To explore the beliefs and reasons breastfeed among African American mothers of both high and low SES.

Methods. Focus groups and individual interviews with lower- and higher-SES African-American mothers were conducted. Mothers were asked about many infant care practices, including breastfeeding.

Results. There were several themes that emerged in regard to the decision to breastfeed. Themes related to reinforcement of breastfeeding included maternal weight or figure, the ability to pump milk after returning to work, convenience, control over baby's appetite, increased bonding, and health and IQ benefits of breast milk. Themes describing barriers to breastfeeding included inability to pump milk at work, inconvenience, maternal weight or figure, perceived inability to supply sufficient milk for the infant, embarrassment or concern about the opinion of others, use of medication, pain associated with breastfeeding, and mother's preferences. Many breast feeding mothers described a lack of support from family and friends for their decision to breast feed. Mothers also discussed their perceptions of whether breastfeeding was important for the infant and for SIDS risk reduction. Matrix analysis of themes

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found that, regardless of SES or interview format, themes were similar in both groups.

Conclusion. Many factors underlie the decision to breastfeed or not, and there are many barriers for African-American mothers. Many barriers, such as the perception of inadequate milk supply and management of breast pain, can be addressed through improved education. Many mothers will respond positively to the health benefits of breastfeeding. Increased education about breastfeeding may improve breastfeeding rates in African-Americans.

SIDS/SUID ORAL ABSTRACT PRESENTATIONS: EPIDEMIOLOGY 🕒 3:15 pm - 5:30 pm

Moderator: Fern Hauck

🕒 3:15 pm

Hayman RM, Dalziel SR, Baker NJ de C (*Nicholas Baker presenting*)
Starship Children's Hospital, New Zealand

THE CONTEXT AND CIRCUMSTANCES OF UNINTENTIONAL SUFFOCATION IN PLACE OF SLEEP IN NEW ZEALAND

Background. Unintentional suffocation is increasingly being recognized as a contributing factor to SUDI and SIDS. However information concerning the contextual circumstances of these deaths is limited.

Aim. To understand the context and circumstances of death of infants who suffocate in a place of sleep.

Method. Police scene of death reports, coroner reports, pathology reports and local mortality committee reviews were examined for 621 deaths in New Zealand children aged less than 25 years from 2002-2009 for 14 ICD10AM codes that potentially included cases of suffocation in place of sleep. Cases of clear unintentional external compression to neck, chest, or oro-pharynx in a place of sleep were extracted. Detailed information concerning the deaths was then extracted by three independent assessors with discrepancies resolved by consensus.

Results. 50 cases were identified (0.42/100,000/year). 48 were aged <1 year (median age 3 months, range 1-10) with the remaining 2 children both developmentally delayed. 20 (40%) deaths were due to entrapment; 11 between mattress and cot/bed/couch, 5 between sleeping surface and wall, 5 between sleeping surface and couch/cushions. 30 (60%) deaths were due to overlay by a co-sleeping partner; 8 while breast-feeding, 4 by a sibling, 17 by a parent and 1 case undetermined. 12 (24%) of the total deaths occurred away from home in temporary bedding arrangements or in faulty cots. 8 (16%) deaths occurred in cots, 7 of which were faulty.

Conclusions. Entrapment attributable to faulty bedding, temporary sleeping arrangements or a co-sleeping partner is a significant factor in the deaths of infants due to suffocation in a place of sleep. SUDI prevention messages need to be reinforced to make both the public and health professionals aware of these increased risks.

🕒 3:30 pm

Shapiro-Mendoza C, Colson ER, Willinger M, Rybin D, Camperlengo LT, Corwin M.
Senior Scientist, CDC, NCCDPHP, Division of Reproductive Health, Maternal and Infant Health Branch, USA

TRENDS AND FACTORS ASSOCIATED WITH THE USE OF SOFT BEDDING IN THE INFANT'S SLEEP ENVIRONMENT, NATIONAL INFANT SLEEP POSITION STUDY, 1993-2010

Introduction. Soft bedding is an important modifiable risk factor for SIDS and sleep-related unintentional suffocation. Understanding infant sleep practices and characteristics associated with these practices is important for developing effective interventions.

Methods. To investigate US trends in the prevalence and characteristics associated with soft bedding use in infant sleep environments, we analyzed 1993-2010 data from the National Infant Sleep Position Study (NISPS). NISPS is an annual US cross-sectional telephone survey of randomly-sampled nighttime caregivers of infants < 8 months old (n~1000/year). Caregivers are asked about demographic factors and about infant sleep practices. We defined soft bedding as any blankets, bean bags, waterbeds, rugs, sheepskins, cushions, sleeping bags or pillows under the infant or blankets, quilts, comforters, sheepskins, or pillows covering the infant. For each survey year, we calculated the prevalence of reported soft bedding use overall and by soft bedding type and race/ethnicity. A multivariable logistic regression model was constructed to assess the independent relationship of caregiver age, education, race and Hispanic origin, parity, geographic region, infant sex, infant age, preterm birth (<37 weeks), and survey year with soft bedding use.

Results. The reported practice of any soft bedding use has declined slowly, but steadily from 1993 through 2010; from 97.4% in 1993 to 72.2% in 2010; yearly statistically significant changes were observed after 1997. In multivariable analysis, selected factors associated with any soft bedding use included age (adjusted odd ratio [aOR] 2.0, 95% Confidence Interval [CI] 1.4, 2.9 for < 20 vs. ≥30 years), race and Hispanic origin (aOR 1.4, 95% CI 1.1, 1.8 for Black vs. White; aOR 1.3, 95% CI 1.1, 1.6 for Hispanic vs. White), education (aOR 2.8, 95% CI 2.0, 3.9 for <high school vs. ≥college), infant age in weeks (aOR 2.6, 95% CI 2.1, 3.1 for <8 vs. ≥16), geographic region (aOR 1.3, 95% CI 1.1, 1.5 for West vs. Midwest), and survey year (aOR 0.06, 95% CI 0.04, 0.10) for 2010 vs. 1993). By soft bedding type, the practice of covering infants with thick blankets or quilts/comforters declined significantly (p-value

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<0.0001) from 1993 through 2010; thick blanket covering was 55.8% in 1993 and 26.1% in 2010; quilt/comforter covering was 41.2% in 1993 and 7.8% in 2010. During 2006-2010, the prevalence of reported quilt covering was 1.9 and 2.6 times higher for Black (18.0%) and Hispanic (13.3%) caregivers compared to Whites (7.0%). For soft bedding under infants, blankets and cushions were reported most often for all study years, with prevalences ranging from 24.1%-33.6% for blankets and 2.5%-5.4% for cushions.

Discussion. In 2010, nearly three-quarters of US infants were reported placed to sleep with some type of soft bedding under or covering them. Thick blanket covering was the most prevalent type of soft bedding. Despite recommendations to remove soft bedding from the infant sleep environment, the use of soft bedding over and under the baby is still common.

🕒 3:45 pm

McDonnell-Naughton MM, McGarvey C, O'Regan M, Matthews T.

Athlone Institute of Technology, National SIDS Register, Children's University Hospital, Trinity College, Ireland

MATERNAL SMOKING AND ALCOHOL CONSUMPTION DURING PREGNANCY: ARE THE RISK FACTORS FOR SUDDEN INFANT DEATH SYNDROME

Introduction. SIDS is a major cause of infant mortality in the Western world with a rate of 0.37 per 1,000 live births in Ireland currently.¹ The Reduce the Risks of SIDS Campaign ran nationally and internationally over the past 18 years, was successful in reducing the SIDS rate. In Ireland the rate fell from 2.2/1000 live births in the 1980's to 0.37/1000 live births currently, resulting in the greatest improvement in infant mortality in 30 years to under 4/1000 live births, since 2006 the equivalent of approximately 100 fewer infant deaths per year.¹ The aim of this study was to review alcohol consumption and maternal smoking during pregnancy and to investigate whether they are risk factors for SIDS.

Methods. A population based case control study was conducted in the Republic of Ireland to examine alcohol consumption and maternal smoking during pregnancy and the risk of SIDS in an Irish population. Each SIDS case (n=287) was compared with control infants (n=832) matched for date and place of birth for infants born from 1994 to 2001. The multivariate analysis was carried out using an additive stepped approach with variables introduced into the model in a sequence of time determined stages starting with pre-pregnancy variables and progressing through history of prior pregnancies, variables related to the current pregnancy, birth related variables, post delivery issues, the week prior to death, the 48 hours before death and the last/reference sleep period. Criteria for inclusion in the multivariate model included having achieved statistical significance at univariate level (P<0.05) and having not greater than 10% of values missing. Conditional logistic regression was used to investigate differences between Cases and Controls establishing Odds Ratio's (OR) and 95% Confidence Intervals (CI).

Results. Mothers who smoked were 3 times more likely to have a SIDS Case, and a dose response effect was apparent, with mothers smoking 1-10 cigarettes/day OR 2.93 (CI 1.50-5.71), and those smoking >10 cigarettes/day OR 4.36 (CI 2.50-7.61). More Case mothers consumed alcohol during pregnancy than Control mothers and, within drinkers, the amount of alcohol consumed was also greater (p<0.05). A dose response with frequency of drinking was apparent. The adjusted odds ratio for those consuming alcohol in all three trimesters was 3.59 (CI:1.40-9.20).

Conclusion. Both of these risk factors are modifiable and need to be incorporated into all antenatal education from a SIDS point of view. Health professionals need to act on this public health challenge. Reducing the SIDS risk by changing levels of social deprivation is not easily amenable to health educational messages. Antenatal advice should incorporate abstaining from alcohol consumption while pregnant. The study although retrospective is a valuable population study. A grieving family, although very emotional can recall accurately those events relating to the death. Although it is not always possible in any study to eliminate systematic bias, the safety measures taken in this study by the design, conduct and analysis of the work have attended to such concerns in detail and thus allow the results to be accepted.

🕒 4:00 pm

McIntosh CG, Chiu K, Tonkin SL, Gunn AJ

University of Auckland, New Zealand

ARE BABY HAMMOCKS SAFE FOR SLEEPING BABIES

Background. Hammocks have been suggested to encourage babies to sleep, Two infants in the United States died while sleeping in their hammocks in 2009, raising international concern. We hypothesized that the semi flexed position of the infant neck while sleeping in a hammock could cause pressure on the infant lower jaw, leading to middle airway obstruction.

Aim. To determine the risk of episodes of desaturation and lower mean oxygen saturation in babies sleeping in an infant sleep hammock compared to sleeping in a bassinet.

Methods. 24 healthy full term 4-8 week old infants were randomised to sleep either in a commercially available hammock or a standard bassinet cot. A limited sleep study was performed over a daytime sleep. Sleep studies were analysed for sleep state, oxygen desaturations (a drop of greater than or equal to 4%, for greater than or equal to 4 seconds in duration from baseline to nadir), apnoea and hypopnoea, and mean oxygen saturation.

Results. There was no significant difference in mean oxygen saturation (both 98.5%) or oxygen desaturation events between the hammock and the bassinet cot (mean 24 ± 20 and 28 ± 23 events per hour respectively). Infants slept for shorter times in the hammock (62±31 vs 90 ± 36 min, P<0.05).

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Substantial flexion of the neck was not seen in any infant in either environment.

Conclusions. This study suggests that, correctly used, hammocks are a reasonably safe environment for sleeping 4-8 week old infants, although unexpectedly hammock sleeping was associated with shorter sleeps. It is possible that in older and more mobile infants there may be a risk that the infant could shift position or roll while in the hammock and so compromise the airway.

🕒 4:15 pm

Thach BT

Washington University School of Medicine, USA

DEATHS AND NEAR DEATHS OF HEALTHY NEWBORN INFANTS WHILE CO-SLEEPING AND BED-SHARING ON MATERNITY WARDS

Introduction. Deaths and especially near deaths of healthy infants on maternity wards during mother infant skin-to-skin contact have been reported in Europe. One such death has recently been reported in the U.S. Here we report 15 additional cases.

Methods. In 2011 we e-mailed 80 persons on the CDC SUID list serve and also 1000 members of the American Association of Medical Examiners requesting information on maternity ward deaths of healthy newborn infants while bed sharing. We received post mortem reports and relevant history in 14 deaths and in one near death (even though near death cases were not solicited). Information on two additional deaths reviewed by Child Death Review Boards were not released to us because of confidentiality agreements. Information on 2 near death events were requested but were not released by hospital personnel.

Results. All infants were deemed healthy prior to their deaths or near death. All infants were successfully breastfed shortly prior to their deaths. In addition to young infant age, the presence of factors that increase risk of bed sharing such as sedating drugs, stated or probable (death <24 hours from delivery) parental fatigue, obesity or "large breasts", multiple bed sharing adults, pillows and maternal smoking were present in 6, 10, 3, 2, 6 and 2 cases respectively. These events occurred between 1999 and 2012, with 9 deaths occurring in the past three years. In 5 cases the mother was awake but assumed her infant was sleeping when attendants found it lifeless. Seven mothers fell asleep while breast-feeding and 7 infants were still "on the breast" when discovered lifeless. Infant age at death was 2.3 hours to 3 days (mean = 26.4 hours). In 6 cases the M.E's diagnosis was accidental suffocation or overlaying. In 9 it was "cause undetermined" or SIDS (1 case). The infant who survived with severe encephalopathy was diagnosed as "apnea of undetermined cause". Metabolic screening was negative in all cases.

Conclusions. Underreporting of cases was probable since reporting was voluntary, near deaths were not solicited and not all such deaths are referred to an M.E. In order to determine the actual incidence of such cases we suggest that reporting be made mandatory. The increased frequency of death over the past 3 years may reflect an increasing emphasis on breastfeeding and skin-to-skin contact. Six mothers were awake but unaware their infants had died. Therefore, wakefulness does not guarantee rapid discovery of a distressed infant. Seven mothers went to sleep with their infants indicating that mothers can't be relied on to remove their infants from bed prior to sleeping. Seven infants were found still "on the breast" when discovered suggesting that oronasal obstruction is a frequent lethal causal mechanism. The presence of multiple factors increasing the risk of bed sharing suggests that these occurrences were likely all, or nearly all, preventable. If in-hospital bed sharing is to be done safely, if at all, it should be done with close continuous observation or electronic monitoring.

FUNDING: The Madison Foundation

🕒 4:30 pm

Fleming P, Blair PS

University of Bristol, United Kingdom

SWADDLING AND THE RISK OF SIDS: A COMPLEX RELATIONSHIP

Introduction. The traditional practice of infant swaddling has been advocated as an effective way to placate unsettled infants, and in western societies has been used increasingly in recent years. Physiological studies have shown that swaddling leads to more settled sleep with preservation of responses to auditory stimuli, but in infants not accustomed to swaddling it may lead to decreased cortical arousals. Swaddling has been associated with decreased risk of SIDS for infants sleeping supine, but it may increase the risk of SIDS in those sleeping prone.

Methods. We have investigated the use of swaddling (defined as infants being put down to sleep wrapped in a layer which completely encircled them at least once) in two large UK population-based case control studies of SUDI, both of which took place after the major fall in SUDI rates that followed the "Back to sleep" campaign of 1991-2: the CESDI study (1993-6) and the SWISS study (2003-6).

Results. In the CESDI study, 47 (14.7%) of SIDS victims were swaddled, compared to 119 (9.2%) of the age matched controls [OR=1.71 (95% CI: 1.17-2.50)] (p .0.003). Amongst these, only 2 SIDS and no controls were placed prone for the last /reference sleep. However 16 SIDS infants were found prone compared to one control. Tog values for bedding and clothing were higher for swaddled infants but the same for cases and controls (non-swaddled SIDS and controls 5.8 vs 4.8 tog, swaddled SIDS and controls both 6.7 tog).

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In the SWISS study, 19 (24%) of SIDS victims were swaddled (including 1 placed prone and 5 placed on the side), compared to 5 (5%) of controls (none placed prone and one placed on the side) [OR=5.28 (95% CI: 1.76-18.96)] (p 0.001). Tog values for bedding and clothing were slightly higher for swaddled infants for both controls and SIDS victims (non-swaddled SIDS and controls 3.3 vs 2.8 tog, swaddled SIDS and controls 3.8 and 3.3 tog respectively).

This is complicated by the fact that the swaddled infants tended to be younger and in the SWISS study most (100% controls and 77% SIDS) were breastfed, and 11/19 (58%) of the swaddled SIDS victims were bedsharing compared with none of the swaddled controls.

Discussion. The relationship between swaddling and the risk of SIDS is complex, and dependent upon where the infant is sleeping and on sleeping position. Swaddling is clearly a significant hazard for infants who are bedsharing. For infants sleeping in a cot, whilst the risk from swaddling is highest for those sleeping prone, in these two large UK studies the risk of SIDS was also increased for swaddled infants sleeping on the side or supine.

🕒 4:45 pm

Mathews A, Oden RP, Joyner BL, Moon RY

Children's National Medical Center, George Washington University School of Medicine and Health Sciences, USA

COMPARISON OF INFANT SLEEP PRACTICES IN AFRICAN-AMERICAN AND U.S. HISPANIC FAMILIES: WHAT CAN WE LEARN?

Background. Although the incidence of sudden infant death syndrome (SIDS) has declined by 50% since 1992, African-American infants remain twice as likely to die from SIDS, accidental suffocation and strangulation in bed, and undetermined causes of death — all of which are frequently associated with bedsharing. African-American and U.S. Hispanic families share similar socioeconomic profiles and high rates of bedsharing. However, Hispanic rates of SIDS, accidental suffocation and strangulation in bed, and other sleep-related deaths are all much lower than the national rates and as much as four times lower than the African-American rates. At the moment little is known about the basis for these observed racial health disparities. It is possible that the sleep practices of U.S Hispanic mothers have a protective effect on their infants.

Objectives. To compare and contrast infant sleep practices, including sleep positioning, bed sharing and use of soft bedding, in African-American and U.S Hispanic families with young infants.

Methods. This is a cross-sectional, multi-modal study, using both quantitative (survey) and qualitative (focus group and individual interview) data. Survey data were collected from a sample of 416 African-American and 100 Hispanic parents from lower and higher socioeconomic status. The data were used to quantify the knowledge, attitudes and practices regarding infant sleep circumstances in an objective manner. Semi-structured in-depth interviews or focus group interviews were conducted among a subset of the study population to develop a better understanding of the sleep practices and the factors influencing decisions about sleep practices.

Results. Out of the 83 African American women and infants that participated in focus groups and individual interviews, 62.6% slept in the supine position, 3.6% slept in supine/side position, 16.9% slept on their side and 16.9% slept in the prone position. Regardless of SES the two predominant themes with regard to parental decisions about sleep position were infant safety and infant comfort. Parental needs, perception of SIDS risk and biological plausibility, and trusted sources influenced whether the parent chose infant safety or infant comfort. With regards to bedsharing, 69.9% reported that they did not bedshare, 15.7% bed shared for part of the night, and 14.4% bedshared for the entire night. Infant safety and infant comfort were also prominent themes for bedsharing. The common themes that emerged for soft bedding, including bumper pads, were comfort, safety and aesthetics. Data from survey and focus groups with U.S Hispanic parents will also be described and compared with the African American data. Particular attention will be given to differences in bed-sharing arrangements in both African American and Hispanic infants.

Conclusion. Despite similar socioeconomic profiles and similarly high rates of bedsharing, U.S Hispanic infants have sleep-related death rates that are four times lower than those seen in African American infants. Understanding the differences in sleep practices may provide insight into which specific behaviors confer higher or lower risk for sleep-related death among infants.

🕒 5:00 pm

Ludvigsen RA, Shapiro-Mendoza C, Howards PP.

Centers for Disease Control and Prevention, Emory University, USA

AGE AT DEATH DUE TO SUDDEN INFANT DEATH SYNDROME FOR TERM AND PRE-TERM INFANTS

Introduction. Sudden Infant Death Syndrome (SIDS), defined as infant death that occurs suddenly and unexpectedly, and whose manner and cause of death are not immediately obvious prior to investigation, is the third leading cause of infant mortality in the United States. Preterm birth is a well-established risk factor for SIDS. Knowledge about how gestational age at birth relates to age at death among SIDS cases may have important implications for understanding physiological changes occurring during the critical developmental period after birth. We compared age at death distributions between infants born preterm and term for all SIDS cases, and also stratified by race and Hispanic origin and sex.

Methods. Data were obtained from the US Birth Cohort Linked Birth/Infant Death Data Sets for 2003-2005. Analysis was restricted to US singleton infants born between 28 and 41 weeks gestation to US-resident mothers from 2003 through 2005 who died of SIDS in the postneonatal period. SIDS cases were identified from the death certificate underlying International Classification of Diseases-10th revision (ICD-10) cause-of-death code, R95. Infants were

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categorized into four gestational age categories in completed weeks: very preterm (28-33 weeks), late preterm (34-36 weeks), early term (37-38 weeks), and term gestations (39-41 weeks). We compared age at death distributions and used Analysis of Variance (ANOVA) to evaluate differences in mean chronological age at death between gestational age categories.

Results. Of all postneonatal SIDS deaths (n=5017), chronological age at death distributions for each gestational age groups peaked at around 9 weeks. Approximately 85% of SIDS occurred before 6 months of age (n=4,368) overall and for all gestational age groups. Mean chronological age at death of SIDS was 15.2 weeks among very preterm infants, 14.6 weeks among late preterm infants, 13.9 weeks among early term infants and 14.3 weeks among term (p<0.0001). Mean chronological ages at death by gestational age group stratified by race and Hispanic origin or sex, were not meaningfully different.

Discussion. In contrast to previous studies (all conducted with data collected before 1997) that have demonstrated shifts towards later chronological age at death in younger gestational age groups, we report no substantial or clinically meaningful difference between gestational age at birth and chronological age at death for SIDS. Similar findings are found for race-specific and sex-specific analyses. Our use of clinically meaningful cut points for gestational age provides an insight into the relationship between gestational age at birth and chronological age at death for SIDS. Caregivers and health care providers should be aware of the increased risk of SIDS in preterm infants, and practice SIDS risk reduction strategies for all infants regardless of gestational age at birth.

🕒 5:15 pm

Colson ER, Rybin D, Lister G, Corwin M.
Yale University School of Medicine, USA

TRENDS AND FACTORS ASSOCIATED WITH BED-SHARING: THE NATIONAL INFANT SLEEP POSITION (NISP) STUDY 1993-2010

Introduction. Bed-sharing increases the risk of Sudden Infant Death Syndrome. We examined the trends in bed-sharing between infants and caregivers and factors associated with this behavior.

Methods. We analyzed data from the NISP Study from 1993-2010, a national telephone survey of caregivers for infants born within the 7 months prior to the interview in the 48 contiguous United States. We conducted 18,986 interviews (~1000/yr). The main outcome variable was usually bed-sharing (sharing a sleep space) with an adult or another person. Trends over time for usual bed-sharing by race were calculated using the three-year moving average. Survey year, maternal and infant characteristics, characteristics of the sleep environment and position placed to sleep, were used in univariate logistic regression modeling to determine individual influence of variables on usually bed-sharing factors and in a multivariate logistic regression model to determine independent contributions. Piece-wise models were constructed to estimate and compare trends for 1993-2000 and 2001-2010 year intervals.

Results. 2128 (11%) participants reported usually sharing a bed with their infants. The overall trend for bed-sharing among all infants increased significantly between 1993 (6%) and 2010 (13%). [see figure]. While there was a significant increase in bed-sharing for White infants from 1993 (5%) to 2000 (12%), there was no significant increase from 2001 to 2010 (10%). Black infants showed a continued significant increase in bed-sharing through the entire period 1993 (24%) to 2010 (40%).

Factors significantly associated with increased bed-sharing included less maternal education, maternal race, region of the country, less household income, infant age, and prematurity. In addition, bed-sharing infants were also more likely have more covers and to use a comforter.

Discussion. We found that the use of bed-sharing has increased since 1993, especially among Black families. This suggests that current messaging advising against bed-sharing has not been effective, and that efforts to improve this messaging, especially for Black mothers are needed.

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SUNDAY, OCTOBER 7

SIDS/SUID ORAL ABSTRACT PRESENTATIONS: INNOVATIVE PRACTICES 🕒 10:15 am - 12:00 pm

Moderator: Mary Adkins

Howard J.

Foundation for the Study of Infant deaths (FSID), United Kingdom

BUBBALICIOUS: ENGAGING VULNERABLE FAMILIES IN A DIGITAL AGE

Introduction. In England and Wales, parents under the age of 20 are at a four times greater risk of experiencing unexplained infant death than older parents. In September 2009 the Foundation for the Study of Infant deaths (FSID) launched a new website, Bubbalicious.org.uk, to specifically target young parents. The website has now been running for almost three years, and has continued to grow steadily and develop resources to support young parents, with the additional aim of reducing infant deaths.

Methods. The traditional format for giving risk-reducing advice in the UK was not tailored to young parents, and was focussed on leaflets and advice from health professionals. Following focus groups with a number of young parents, FSID decided to launch a stand-alone website. Bubbalicious is distinctly different from the main FSID site, and includes the standard reduce the risk information without the obvious focus on infant death. It was designed as a social networking site, and has attracted parents on this basis, whilst also giving advice. The development of a staged Big Sister programme has allowed active members who pass certain tests to give peer-to-peer support.

Results. The website was launched in September 2009, and in the years 2009-2012 the site has shown steady growth of both visitors and registered users. The page views for the latest 12 months are double those of the first year. The average time spent on the site is 10 minutes, with 10 pages being viewed per visit.

Growth has been aided by the development of some supporting materials and promotion through health professionals, but there is no reduce the risk 'leaflet'. Of over 3,000 registered users, 147 have progressed to the top level of 'Big Sister', having shown that they have the required knowledge of reduce the risk advice. The site is moderated daily, but the peer support is a great strength and intervention from a moderator is rarely needed.

Different methods are now being used to encourage and prolong visits. The site is being increasingly used by other organisations to promote parallel services to young parents. Lessons can be learned from the posts made by young parents about other types of support they receive, which could improve practice.

Discussion. Bubbalicious is now the only dedicated networking site in the UK for young parents. Utilising the most popular form of communication for young parents has eliminated the need for traditional methods of healthcare information. To successfully distribute advice we need to think creatively about how information is distributed to those at high risk. Information can also be taken from the interaction between young parents about their infant care practices and decisions which can then inform health professionals. When levels of unexplained infant deaths have plateaued, a new approach is the only way to reduce infant mortality.

Hauck F.

Professor of Family Medicine and Public Health Sciences, University of Virginia School of Medicine, USA

REDUCE THE RISK CAMPAIGNS IN 2012: HOW SEVEN COUNTRIES ARE MEETING THE CHALLENGE

The dramatic success of "reduce the risk" and "back to sleep" campaigns in decreasing infant deaths due to SIDS is well known. However, rates of SIDS in many countries have reached a plateau, and other causes of sudden unexpected infant death, such as accidental suffocation in unsafe sleeping environments, have increased. As a result, campaigns and educational interventions need to be flexible to address the challenges of changing infant mortality patterns and new research findings. Families that have difficulty adhering to safe sleep and other reduce the risk recommendations require innovative and targeted methods to encourage behavior change. This panel will 1) explore the ways in which eight countries (Australia, Canada, Germany, Israel, United Kingdom, New Zealand, the Netherlands, and the United States) are addressing cultural and other challenges in the design of their campaigns; and 2) describe the strategies they have developed to influence those who are hardest to reach and most difficult to engage.

Moderator:

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SIDS/SUID/NEONATAL ORAL ABSTRACT PRESENTATIONS: GRIEF AND BEREAVEMENT 🕒 10:45 am – 12:00 pm

Moderator: Joani Nelson Horchler

🕒 10:45 am

De Groot-Noordenbos M, Erwich JJHM.
University Medical Centre Groningen, Netherlands

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

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)

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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 15 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. 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. Parents are still often encouraged 'to let go' after a certain period of time has passed and to look to the future. Yet, how can anyone deny one has become a parent? 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 despair. 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.

🕒 11:00 am

Sterry L, Bathgate L.

Scottish Cot Death Trust, Scotland

A SCOTTISH RETROSPECTIVE REVIEW OF BEREAVED FAMILIES' OPINION ON THE SUPPORT NETWORK PROVIDED AND EXPERIENCED AFTER SUDDEN UNEXPECTED DEATH IN INFANCY (SUDI)

Introduction. In 2011, the Scottish Cot Death Trust (SCDT) gained funding from Vodafone World of Difference Programme to conduct a survey into bereaved families' perception of the roles played by different professional groups after the death of their child.

Aims.

- To record parents' experience of contact with professionals and to indicate what was helpful and unhelpful
- To seek the families' view of how the services could have been delivered better
- To use the information to aid SCDT better to support families
- To ensure that the findings influence the SUDI Scotland project being launched nationally led by the Scottish Government

Method. The research sought detail in 3 main areas:

- Personal information
- Experience of the professionals
- Role played by SCDT

500 surveys were sent directly to bereaved family members and 109 valid surveys were completed (22.4% response rate).

A range of questions was designed to enable the gathering of information. Quantitative analysis was carried out as well as qualitative/ thematic analysis of each section.

Results. The families impression of the effectiveness of professionals given in descending rank order was as follows: Health visitor; Family physician; Police; Funeral Director; Hospital-based Paediatrician. Only 3/62 respondents listed their Paediatrician as the key professional important to them. The role of the police was understood and difficulties appreciated.

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Contact in relation to SCDT identified that in the first week, 44% of respondents were aware or had contact with SCDT and by the end of the first month, 82%. Family clearly identified the need to support siblings better.

Discussion. Participation in the survey was difficult and distressing for families. However, the high response rate identifies the families desire to influence change.

One of the most striking elements was the clear identification of inconsistency of care and communication across Scotland. This negatively influenced families' ability to recover. Their experiences were recalled in a positive light when they were given factual information and truthful explanations.

Undertaking this retrospective review has not only enabled families to reconnect with SCDT, it has also influenced the strategic plans of the Trust. This includes providing greater support for siblings, focussing on delivery of education to health professionals and the encouragement of greater partnership working to ensure that the lessons of the survey are incorporated within the SUDI guidelines which are available to all key professionals across Scotland.

🕒 11:15 am

Rietberg JC, Pel M.

Academic Medical Centre Amsterdam, Netherlands

EMPIRICAL EXPERT'S ADVICE ON CARE IN SUBSEQUENT PREGNANCY

Introduction. A pregnancy after stillbirth or neonatal death poses an enormous challenge, combining overwhelming fears with sparkles of hope. Pregnancy after a loss can also be a time of grief, healing, courage and hope. Much of the perinatal loss literature focuses on various aspects of the grieving process, while very little has been published related to pregnancy following a perinatal loss.

Methods. Semi-structured in-depth interviews with fourteen mothers who had experienced at least one perinatal loss and a minimum of one subsequent pregnancy. Recruitment was accomplished via the largest internet perinatal loss support group in the Netherlands, via personal contacts and via the Academic Medical Centre Amsterdam. All women currently have living children. The semi-structured approach offered the interviewees an interaction on and acknowledgement of their loss and their subsequent pregnancy. The use of one empirical expert moderator increased the dependability of the study since the threshold to share was exceptionally lowered. One of the main interview questions was: How can health care providers meet the clinical and emotional needs of these women?

Results. The majority of women experienced increased fear, worry and anxiety. Vulnerability and uncertainty about the outcome of the subsequent pregnancy were also shared feelings. Recent research has revealed that feelings of anxiety can be considered normal in a pregnancy after loss. Many health care providers, however, are not able to provide these mothers the extra care they need. The reason for this is probably lack of time and training. The increased fear and anxiety are often wrongfully diagnosed as unresolved or pathological grief. These women expected medical professionals who offered personal, sensitive care, but were often disappointed. The health care system in the Netherlands is not able to offer these women a distinct status. This status should give recognition and acknowledgement to all specific problems relating to a subsequent pregnancy. Furthermore, low threshold additional ultrasound sessions are considered to be of great importance offering extra reassurance. Finally, an individual plan combined with continuity of care is also of great significance.

Discussion. Health care providers should be aware that mourning of the lost child continues in the next pregnancy. There even is a risk that a new grief chapter opens with the birth of the next child. Awareness of this problem is needed. Increased prepartum anxiety should also be considered as a predictor of postpartum problems, such as overprotective parenting after a subsequent pregnancy or postpartum depression and anxiety. Medical professionals should be taught to provide coping strategies to reduce anxiety, offer sensitivity to such women's experiences, and enhance attachment to the subsequent healthy child. A specific protocol could be considered to teach medical professionals how to be supportive to these women, acknowledge their courage to try again, accommodate their clinical needs, offer sensitive care and really understand their anxiety.

🕒 11:30 am

Schrader L, Mathiesen T, Kalstad TG.

Norwegian SIDS and Stillbirth Society, Norway

THE DOUBLE GRIEF – INFORMATION AND BEREAVEMENT SUPPORT FOR GRANDPARENTS

The Norwegian SIDS and Stillbirth Society provides care and support for families who experience the loss of a little child. This presentation will describe how the Society has developed bereavement support to grandparents by including grandparents in our volunteer peer-support program, publishing a booklet to bereaved grandparents and arranging meetings for grandparents.

Despite the fact that grandparents are greatly affected when a grandchild dies, in Norway, they normally receive little support. Grandparents often experience "a double grief" as they grieve both their grandchild and their child. More than anything they want to help their bereaved child, but they often feel helpless. Unfortunately, conflicts, misunderstandings and disappointments often occur between grandparents and bereaved parents. At the same time, social support from the family is known to strengthen the confidence and prevent depression in bereaved people. It is therefore important to provide support for grandparents and to strengthen them as caregivers to their bereaved family.

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In 2005 the Society organized four meetings for bereaved grandparents with the aim to gain more knowledge on grandparent's experiences and needs. This revealed a great need for bereavement support, follow-up and information. From 2006, the Society has therefore invited grandparents to participate in the Society's peer-support training program and thereby providing peer-support to grandparents. In 2010, the booklet *The double grief – Grandparents' grief when a grandchild dies* was published. It is based on interviews, contributions and suggestions from grandparents, the society's experiences, research and literature. It provides information about grandparent's grief, how to support and help their bereaved children and family and at the same time take care of themselves. The booklet can be ordered free of charge, it can be downloaded on internet and it is distributed through hospitals. In 2011, the Society invited bereaved grandparents to a weekend meeting led by a peer-support grandparent. All the participants agreed the meeting was of great benefit to them in their struggle to help their own children and handling their own grief. In 2012 there will be a second weekend meeting led by peer-support grandparents.

There has been a great change in the support for and understanding of bereaved grandparents since the first meetings in 2005. In the beginning it was difficult to reach the grandparents and few of them contacted the Society. Now there are 6 trained peer-support grandparents in the Society and the number of newly bereaved grandparents who contact the Society for support and to become members continues to increase. The grandparent booklet reach out to many newly bereaved grandparents and the feedback is positive. The interest for the second grandparent meeting is high and more participants are expected than in 2011. However the increasing contact with grandparents is challenging as it is time consuming to organize the peer-support. An aim for the next meeting is therefore to gather the peer-support grandparents and for them to work out a functional way of organizing peer-support for grandparents.

🕒 11:45 am

Aho AL, Joronen K, Kaunonen M. (Susanna Uttomaki presenting)
University of Tampere, School of Health Sciences, Finland

PARENTAL RELATIONSHIPS AND PROFESSIONAL SUPPORT AFTER THE DEATH OF A CHILD

Introduction. Death of the child and the grief thereafter create complex changes in parental health and well-being. The purpose of this study was to describe the parental relationships and family functioning after the death of a child.

Methods. The data were gathered by e-questionnaires from Finnish parents who had lost a child. Participants were recruited via Internet closed discussion groups and grief associations. The questionnaire consisted of background variables, and questions concerning parental relationship. Data were analysed statistically.

Results. Participants (N=242) were mothers (N=213) and fathers (N=29). Age ranged from 21 to 67. Participants had mostly college (46 %) or academic degree (18 %). More than half (55%) of the respondents had a fulltime work outside home. More than three of four (77 %) was member of Evangelical Lutheran church which is main religion in Finland. Most of the parents (92%) had lost one child. Fiftysix percent of the lost children were boys. The most common reasons of the deaths included illness (32%) or stillbirth (32 %). The number of other children in the family ranged from 0-9; in every fourth (27%) family there were two living children.

Respondents were mostly (73 %) married, and in most cases (71 %) the marriage was their first one. Fifteen percent of the respondents were divorced from the parents of the lost child. Divorce had occurred between 6 months and 20 years after the death of the child, in most cases 1-2 years. Divorced parents perceived that the death affected on their decision of divorce fairly much (35%) or very much (24%). Almost half of the parents (47%) were satisfied with their current relationship with their spouse, and more than one thirty (36%) were very satisfied. Parents assessed their relationship with the parent of the lost child as good (43%) or as very good (32%). According to the respondents, the death of their child had mostly improved the parental relationship a little (43%) or very much (16%). However, 21 % of the parents perceived that child's death had impaired parental relationship a little; and very much by six percent of the parents. Most of the parents (68 %) had not been participated in marriage counseling or gotten any professional support after the death of a child. However, more than half of the parents (55%) would have needed professional help or support on parental relationships.

Discussion. The death of a child has a positive or a negative impact on parental relationship. Only few parents have received professional support on their parental relationship after the death of their child although more than half of the parents reported to need it.



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FRIDAY, OCTOBER 5

BREAKFAST SESSION II 🕒 7:00 am – 8:30 am

Moderator: Penny Brabin

Brabin PG.

Monash University, School of Psychology and Psychiatry, Australia

BEING WITH PARENTS AFTER THE LOSS OF A BABY: GUIDANCE FROM THE EXPERIENCE AS THE BASIS OF APPROPRIATE CARE

The death of a baby, before or soon after birth is a trauma, its impact typically reaching into, at least, the next pregnancy and baby and often into the next generation.

Changes in the meaning of a child over the last few decades influenced by medical and social changes have impacted on post-natal care practices after a baby dies around the time of birth. The traditional practice of avoidance – to repress, deny, ignore the experience and to conceive again quickly – has been replaced with an approach paradigm – deal with and face the trauma before conceiving again. The therapeutic context, however, has been fraught with contradictions in constructs and practices for dealing with the sequelae of this experience of loss.

Medical practice often supports avoidance – grief being pathologised as anxiety and depression and these emotions being ablated with medication – thus, confusing the reality of the experience of grief. In contrast, the short history of grief counselling recognises grief but often promotes any emotional reaction as a valid expression of grief – validating guilt, anger and depression after the loss, and anxiety in the subsequent pregnancy – failing to distinguish common unhealthy from healthy reactions with their associated long-term outcomes.

Empiricism, relied upon to assess outcomes and an essential component in the recommendation of bereavement care practices, typically fails to incorporate the phenomenology of the grief experience. This results in 'evidence-based' recommendations emanating from data that reflects only a snapshot at one point in the experience rather than the movie of the whole experience.

This workshop, through interactive processes with the participants, explores the changes in the meaning of a child, particularly in the first world context, and the facets of the grief experience in the following decade and beyond after the death of a baby, highlighting the impact of postnatal care practices. An example of the potential damage of promoting the findings of an evidence-based study that failed to account for this experience is described. The impact of postnatal care on the experience of the subsequent pregnancy and options for managing anxiety in this pregnancy are explored highlighting the limitations of reassurance practices typically provided which fail to address the actual fears -'I'll never cope if this baby dies.

Within the context of an 'approach' rather than 'avoidance' paradigm constructive therapy is defined which normalises grief (managed experientially in peer support) and identifies unhelpful reactions like guilt and anxiety, promoting more appropriate cognitions or meaning related to the experience. Finally, a call for the provision of appropriate psychological care is made – care which provides options for management of mid-pregnancy termination and effective tools for addressing anxiety in the next pregnancy impacting on reducing the stress in parenting the subsequent baby and child and into the next generation.

STILLBIRTH ORAL ABSTRACT PRESENTATIONS 🕒 12:30 pm - 3:00 pm

Moderator: David A. Ellwood

🕒 12:30 pm

Raynes-Greenow CH, Gordon A, Ellwood D, McGee Chan K, Morris JM, Ren A, Liu JM, Dibley M.
University of Sydney, Sydney School of Public Health, Australia

PROTOCOL FOR A CLUSTER RCT FOR AN INTERVENTION IN THE THIRD TRIMESTER TO PREVENT LATE PREGNANCY STILLBIRTH

Background. In 2011 Stacey et al reported an association with maternal sleep position and stillbirth (aOR 2.03 (95% CI 1.29, 3.29)[1]. The Sydney Stillbirth study found also found an increased prevalence of back sleeping amongst the mothers of stillborn babies (OR 4.34, 95%CI 1.2, 16.0). There is also evidence of uptake of this message amongst pregnant women in Australia and Internationally. We propose a cluster randomised controlled trial to evaluate the effectiveness of an intervention to encourage left-sided sleeping position.

Aims. In a pilot trial we aim to collect data to finalise the design of a trial for the main planned trial.

Primary Objective. Estimate a realistic recruitment rate for the definitive trial (i.e Total recruitment rate per 100 deliveries). Secondary endpoints: Total recruitment rate per eligible women, adherence to the protocol, measure acceptability of the randomisation among potential participants offered trial entry,

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measure acceptability of the trial among clinicians, measure adherence with the treatment arm, and measure contamination of the intervention into the control arm.

Methods. A cluster RCT in the Hebei province of China. Intervention: An information leaflet and discussion with usual care provider. The intervention message will encourage pregnant women to fall asleep in a left position and following any awakening or sleep disturbance return to the left position to fall asleep. Study Base: Pregnant women ≥ 28 weeks gestation receiving antenatal care in one of the cluster antenatal services in the Hebei province, China. Eligible participants: Pregnant women of ≥ 28 weeks gestation, attending antenatal care in one of the study hospitals. Exclusion Criteria: Pregnant women with (i) fetuses who have any known lethal or chromosomal anomalies, (ii) elective caesarean delivery and any (iii) terminations of pregnancy results. Feasibility and pilot testing is currently underway funded by the Stillbirth Foundation Australia. Results from this data (at the time of submission) are being collected, but will be complete for the conference and will be presented.

Discussion. This presentation will describe the results of the feasibility study currently underway and present the protocol in detail and discuss issues associated with this planned trial.

🕒 12:45 pm

Christiansen-Lindquist L, Gaydos LM, Hogue C, Kramer M, Sahay K.
Emory University, Department of Epidemiology, USA

DEVELOPING A SURVEILLANCE SYSTEM FOR STILLBIRTH: AN EXPLORATORY STUDY TO DETERMINE THE ACCEPTABILITY OF A PREGNANCY RISK ASSESSMENT MONITORING AND SURVEILLANCE (PRAMS)-LIKE SURVEY AMONG WOMEN WHO HAVE RECENTLY EXPERIENCED A STILLBIRTH

Background. Rates of stillbirth (fetal deaths > 20 weeks gestation) in the US have not decreased substantially in incidence since the 1980s. For the last 25 years, the Centers for Disease Control and Prevention (CDC) and state health departments have used the Pregnancy Risk Assessment Monitoring System (PRAMS) to collect data from women who have recently delivered a baby. Questions on the PRAMS survey include risk factors for preterm birth and healthcare related issues. Expanding PRAMS to include stillbirths could provide much-needed data for surveillance of stillbirth trends and risk factors. Women with stillbirth can be identified through vital records, utilizing similar methodologies currently used to sample women with livebirths for PRAMS. Yet, it is not known whether women with stillbirths would be amenable to a PRAMS-like interview. Also, the methods currently used for recruiting and interviewing women may not be entirely appropriate for contacting women with a known pregnancy loss.

Objective. In partnership with the CDC's Division of Reproductive Health, we are conducting formative research to determine the acceptability of a PRAMS-like survey among women who have experienced a stillbirth. We are also interested in learning about the types of questions that women who have experienced a stillbirth and their advocates believe should be included in this survey.

Methods. This study will take place in three phases. During Phase 1 (spring 2012), we will identify and interview 5-10 leaders who advocate for parents who have experienced a stillbirth (Parent Advocacy Leaders—PALs). We will ask PALs about the types of questions they would like to see on a PRAMS-like survey, appropriate language to use in this setting, and how best to recruit women for participation in the second phase of the study. Using input from the interviews with PALs, we will create a draft questionnaire for Phase 2. In Phase 2 (summer 2012), we will conduct in-person interviews with 10-15 women who have experienced a stillbirth in the metro Atlanta area in the last twelve months. In addition to piloting the draft questionnaire, we will ask these women whether they think that women would prefer to answer PRAMS survey questions by mail or telephone. We will also ask them if we should add or remove any questions, and whether the language is appropriate for this setting. Finally, in Phase 3 (August 2012), we will convene a panel of experts in stillbirth research and advocacy to review our study findings and discuss the future directions for a PRAMS-like survey for stillbirth. We will report on results of the formative research at this Conference.

Discussion. Upon completion of formative research by September 2012, CDC plans to pilot the questionnaire in 3-4 states. If successfully implemented, a PRAMS-Stillbirth state-based surveillance system should provide women's health advocates, public health policy makers and private healthcare providers with current information to use for health care quality improvement leading to a reduction in stillbirths.

🕒 1:00 pm

Meaney S, Gallagher S, Lutomski E, Nuzum D, O'Connell O, O'Donoghue K.
National Perinatal Epidemiology Centre, University College Cork, Ireland; Department of Psychology, University of Limerick, Ireland; Cork University Maternity Hospital, Ireland; Department of Obstetrics and Gynaecology, University College Cork, Ireland

WHAT INFLUENCES PARENTS DECISION TO HAVE A PERINATAL AUTOPSY? A QUALITATIVE INVESTIGATION

Introduction. Despite improvements in antenatal care, stillbirth remains 10 times more common than sudden infant death syndrome, and rates have remained constant for decades. The emotional and psychological impact of perinatal death is extensive, and parents often want to be informed of a specific cause of death. Yet, perinatal autopsy rates have been declining internationally, thus inhibiting clinical investigation into the underlying factors for stillbirth. Despite rates being potentially influenced by parents' knowledge and understanding of autopsy procedures, there is a dearth of research in this area. To fill in these critical gaps, this study aims to explore the experiences of parents who were asked to consent to a perinatal autopsy. From this exploration, we aim to gain insight into parents' perception of autopsy and decision-making processes.

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Methods. An interpretative phenomenological analysis (IPA) is being utilised in this study as it has an idiographic approach, and allows for close examination of parents' experiences using a small sample. IPA rigorously identifies themes and then groups them into subordinate themes which will identify not only that which is important to the participant but also identify and detail the meaning of these phenomena in a social context. Purposive sampling was used to recruit parents from a large hospital, where there were 30 stillbirths in 2011. To date 6 parents, who either consented or declined autopsy, have participated in semi-structured interviews.

Results. The parents illustrated that the decision-making process in relation to autopsy was made promptly once approached by a medical professional for consent and the decision was generally made without consultation with family, friends or other supports. Preliminary findings reveal two subordinate themes influencing parents' decision-making; certainty of diagnosis and perception of the invasiveness of the autopsy. In every account, parents talked about the importance of the certainty of the diagnosis as it highly influenced a number of emotional reactions including difficulty in coping with the uncertainty of the outcome of a future pregnancy. Parents' knowledge and understanding of the autopsy process was acquired primarily from public discourse, with particular reference to television programs, which elicited negative responses from parents due to their perception of the invasive nature of the autopsy process. Analysis also indicated disparity between the experiences of men and women. Men were more likely to indicate dissatisfaction with the maternity services, indicating a lack of communication with them at the time of the perinatal death.

Discussion. These findings have implications not only for psychological models of decision making but also clinical practice. Parents illustrated a lack of understanding of the autopsy process which was to be undertaken, and therefore consideration needs to be given to improving communication with parents. The findings of this study underscore the challenges that clinicians face in overcoming public misperceptions of the invasiveness of some autopsy procedures.

🕒 1:15 pm

Erlandsson K, Lindgren H, Malm MC, Davidsson-Bremborg A, Rådestad I.

School of Health, Care and Social Welfare, Mälardalen University, Sweden; Institute of Health and Care Sciences, University of Gothenburg, Sweden; School of Health and Social Science, Dalarna University, Sweden; Department of Woman and Child Health, Division of Reproductive and Perinatal Health, Karolinska Institutet, Sweden; Sophiahemmet University College, Sweden; Lund University, Sweden

MOTHERS' EXPERIENCES OF THE TIME AFTER THE DIAGNOSIS OF AN INTRAUTERINE DEATH UNTIL THE INDUCTION OF THE DELIVERY. A QUALITATIVE INTERNET-BASED STUDY

Introduction. Sometimes parents wish to delay induction, and sometimes, for practical reasons, it takes time to induce labor. A delay of induction carries the risk of disseminated intravascular coagulation and infection, but it is small. There is a lack of qualitative description of mothers' activities and feelings between being diagnosed with a dead baby in utero and the induction of the birth.

Aim. This study aims to describe how mothers spend the period of time between being diagnosed with a dead baby in utero and the induction of the delivery.

Methods. Data were collected using a web questionnaire. Five hundred and fifteen women who had experienced a stillbirth after the 22nd week of gestation answered the open question: 'What did you do between the diagnosis of the child's death and the beginning of the delivery?' A qualitative content analysis method was used.

Results. The results show that some mothers received help to adapt to the situation, while for others, waiting for the induction meant further stress and additional psychological trauma in an already strained situation.

Discussion. There is no reason to wait with the induction unless the parents themselves express a wish to the contrary. Health care professionals, together with the parents, should try to determine the best time for the induction of the birth after the baby's death in utero. That time may vary, depending on the parents' preferences.

🕒 1:30 pm

Warland J.

University of South Australia

IS IT FEASIBLE TO TELL PREGNANT WOMEN TO SLEEP ON THEIR LEFT?

Following recommendations from Stacey et al (2011) that if women were advised to sleep on their left in late pregnancy that the incidence of stillbirth could be halved. A follow up feasibility study to explore the success of instructing women to sleep on their left in late pregnancy was conducted.

It is well known that people shift position many times during sleep when they are not pregnant. However, nothing is known about whether or not pregnant women shift position to the same degree when they are asleep in late pregnancy. A large pregnant abdomen and the fact that many pregnant women sleep supported by pillows may reduce the number of times women change position as they sleep. Furthermore, Stacey's study was based on retrospective self report. Evidence as to whether or not self reported sleep position is well correlated with actual sleep position is warranted.

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Instructing pregnant women to settle to sleep on their left may be an important step in reducing the risk of stillbirth, however, research is needed in order for maternity care providers to be confident that advising women to settle on their left will actually result in them spending more time on their left as they sleep.

This paper will report preliminary findings from a study which is currently underway. Women were asked to keep a sleep position diary (three days) in which they recorded their settling position, wake position and Re-settling. During the same time period she was filmed as she slept via night capable (infra-red (IR)) camera. Demographic information such as marital status, and current gestation as well as sleeping habits such as, usual sleeping position, use of pillows and side of the bed she slept on relative to her partner was also collected.

Please note: Data Collection is currently occurring (Jan – May 2012) Data will be analysed (July-Sept) and be 'hot off the press' ready for the conference in October.

🕒 1:45 pm

Flenady V, Charles A, Ellwood D, Gordon A, Jennings B, Kent A, Khong Y, Teale G, Thomas S, Gardiner P.
Mater Medical Research Institute and The University of Queensland; Princess Margaret Hospital; King Edward Memorial Hospital and University of Western Australia; Canberra Hospital and Australian National University; Royal Prince Alfred Hospital and The University of Sydney; Women's and Children's Hospital and University of Adelaide; Sunshine Hospital; Western Health; Royal Darwin Hospital; Flinders University, Australia

UPSKILLING THE WORKFORCE IN CLINICAL PRACTICE AROUND STILLBIRTH: EVALUATION OF IMPROVE (IMPROVING PERINATAL REVIEW AND OUTCOMES VIA EDUCATION) WORKSHOPS

Introduction. Stillbirth is globally recognised as a major public health problem, however almost one third of cases remain unexplained. The dearth of quality information about stillbirth remains a major barrier to prevention. The Perinatal Mortality Group of the Perinatal Society of Australia and New Zealand (PSANZ-PMG) developed a clinical practice guideline for perinatal mortality audit, to include a stillbirth investigation protocol and a classification system for causes of death. The PSANZ-PMG developed an educational program (IMPROVE; IMproving Perinatal Review and Outcomes Via Education) to assist with the implementation of the PSANZ perinatal mortality guidelines into practice. This study evaluates IMPROVE for quality of teaching and perceived learning outcomes.

Method. Questionnaires were administered before and after each workshop session to assess knowledge and confidence related to six stations: consenting for autopsy (3 items); placental and post mortem examination (3 items); investigation of perinatal deaths (3 items); examination of the deceased baby (3 items); perinatal mortality classification (2 items); and psychological and social aspects of perinatal bereavement (7 items). Participants who agreed or strongly agreed with each of the individual items for each station were categorized as confident in that station. Additional questions on the quality of the teaching sessions were administered at the conclusion of the workshop.

Results. In 2010 and 2011, 647 doctors, midwives, nurses and other health professionals attended an IMPROVE workshop, with 84.1% providing data for this evaluation. The workshops were associated with an improvement in confidence in relation to each domain. The proportion of participants confident at each station (pre, post-workshop) were: consenting for autopsy (15.2, 93.3%); placental and post mortem examination (8.8, 79.9%); investigation of perinatal deaths (0.0, 90.4%); examination of the deceased baby (13.7, 88.3%); perinatal mortality classification (14.5, 87.7%); and psychological and social aspects of perinatal bereavement (22.8, 70.9%). Only 1.4% of participants were confident in all 21 items before the workshop, with over half of the participants (53.9%) confident in all 21 items at the completion of the workshop. Over 99% of participants were satisfied or very satisfied with the workshop.

Discussion. The IMPROVE workshops are successful in increasing knowledge and confidence of participants about the PSANZ perinatal mortality guidelines and maternity and newborn care following perinatal death. The next phase of this study is to assess how the upskilling of the workforce translates into clinical practice by assessing implementation of the guidelines in the clinical setting.

🕒 2:00 pm

Duke W, Gilboa S.
National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, USA

THE UTILITY OF USING AN EXISTING BIRTH DEFECTS SURVEILLANCE PROGRAM TO ENHANCE SURVEILLANCE DATA ON STILLBIRTH – ATLANTA, GEORGIA, 2006

Background. In the United States, the prevalence of stillbirth was 6.2 per 1,000 births (live births + stillbirths) in 2005, with approximately 26,000 stillbirths occurring overall. Historically, stillbirth surveillance data have come from fetal death certificates (FDC), which may underestimate true stillbirth prevalence. In 2005, CDC initiated pilot studies to evaluate the feasibility of expanding existing birth defects surveillance programs to conduct active surveillance on stillbirth. The objectives of this study were to: 1) evaluate the completeness of ascertainment of cases of stillbirth identified through an existing birth defects surveillance program, the Metropolitan Atlanta Congenital Defects Program (MACDP), and 2) compare the prevalence of stillbirths obtained through active case finding (MACDP) with corresponding data available from FDC in 2006.

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Methods. Stillbirth cases (intrauterine fetal death at ≥ 20 weeks of gestation or ≥ 350 grams) were independently ascertained by both FDC and MACDP in 2006 for mothers residing in the 5 central counties of metropolitan Atlanta. Cases were linked to FDC to assess the number of cases captured by both sources and the number of cases ascertained by either source alone. Capture-recapture methodology was used to estimate the total number of cases in the surveillance population, from which the sensitivities of FDC, MACDP, and both sources combined were estimated. Prevalence estimates of stillbirth stratified by data source and maternal characteristics were calculated.

Results. In 2006, an estimated 581 stillbirth cases occurred in metropolitan Atlanta. MACDP captured 446 cases; FDC captured 456 cases. Ninety-six cases captured by MACDP were not reported by FDC, and 106 cases found in FDC were not identified by MACDP. The estimated sensitivities were 78.5%, 76.8%, and 95.0% for FDC, MACDP, and both sources combined, respectively. Overall, the stillbirth prevalence rate using FDC data alone was 8.2 per 1,000 births, and 9.9 per 1,000 births with both sources combined.

Conclusions. Incorporating stillbirth surveillance into MACDP improved stillbirth case ascertainment when linked to data in FDC. Leveraging the resources of existing birth defects surveillance programs, combined with FDC data, could improve population-based estimates of stillbirth prevalence.

🕒 2:15 pm

Silver RM.

University of Utah Health Sciences Center, Maternal Fetal Medicine, Eunice Kennedy Shriver National Institute of Child Health and Human Development Stillbirth Collaborative Research Network (SCRN), USA

BILE ACIDS AND STILLBIRTH

Introduction. Intrahepatic cholestasis of pregnancy (ICP) has been associated with an increased risk of stillbirth. However, it is unknown whether bile acids are elevated in women with stillbirth in the absence of clinical symptoms of ICP. Thus, our objective was to compare bile acids in women with and without stillbirth in a population-based study.

Methods. Prospective, multicenter, population-based case-control study of all stillbirths (fetal deaths >20 weeks) and a representative sample of live births enrolled at delivery in 5 geographic areas at 59 hospitals averaging $>80,000$ deliveries/year. Maternal sera were obtained at the time of enrollment and frozen at -80°C until assay for bile acids.

Results. Assays were performed in 588 women with stillbirth and 1,183 women with live births. None of the women had clinical evidence of ICP. The mean level of bile acids were higher in women with stillbirth ($5.3 \text{ umol/L} \pm 0.5$) compared to livebirths ($4.4 \text{ umol/L} \pm 0.2$; $p = 0.0294$). However, the proportion of women with elevated levels of bile acids ($\geq 10 \text{ umol/L}$) was similar in stillbirths and livebirths (7.1 versus 6.1%; OR 1.17; 95% CI, 0.78 – 1.74). Results were similar when the analysis was limited to all stillbirths versus term livebirths ($N = 1062$). Bile acid levels were higher in stillbirths (5.3 ± 0.5) versus term livebirths (4.2 ± 0.2 ; $p = 0.236$). The proportion of women with levels $\geq 10 \text{ umol/L}$ was similar in both groups; 7.1% versus 5.6% for stillbirths and term livebirths, respectively (OR 1.29; 95% CI, 0.85 – 1.96). Non-anomalous stillbirths ($N = 457$) also were compared to term livebirths. Mean levels were higher in stillbirths compared to livebirths (5.4 ± 0.7 versus $4.2 \pm 0.2 \text{ umol/L}$, respectively; $p = 0.0176$). Again, the proportion of women with elevated levels of bile acids was similar among groups (7.1% versus 5.6% for stillbirths and livebirths, respectively (OR 1.30; 95% CI, 0.83 – 2.03).

Conclusion. Mean levels of bile acids were elevated in women with stillbirths compared to livebirths. Given the association between ICP of pregnancy and stillbirth, this has implications for the pathophysiology of some cases of stillbirth. However, our data do not support routine testing for bile acids in cases of stillbirth in the absence of clinical evidence of ICP.

🕒 2:30 pm

Ostlund, M.

Commissioned by the Swedish National Infant Foundation, Sweden

FILM 1: IN TIMES OF BEREAVEMENT.

Introduction. I am a member of the board of the Swedish National Infant Foundation. I am also a film director (worked with Ingmar Bergman) and I have made two short films (2 minutes and 14 minutes) in the field of grief. By commission of the Swedish Infant Foundation and SAMS (Swedish co-operation of organizations of grief support).

This film is about siblings' sorrow. How the parents should handle the situation with the brothers or sisters when an infant dies in the family. The other film is about how the world around them treats a person in grief. Target group is the family, friends, fellow workers, neighbors, insurance staff, banks etc.

This film has been produced with special care and feeling to affect the viewer. The film is also about important and often unspoken questions.

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Aim with the Movie.

- To help parents to see and take time for the children in the family experiencing a loss. Give advice and tools to handle the brothers and sisters sorrow to the lost infant.
- To reach people in general and give them an insight how to behave when you meet a person in grief.
- Show the films in seminars, congresses, websites and broadcasting.
- Inspire other countries to produce film about these unspoken questions.

Method.

- Grief of Siblings: A research of siblings in families in grief has been the ground. Interviews of families, priests, psychologist and therapist.
- In times of Bereavement: Interviews of twenty-five families with different experience of grief. Five cases were selected. Interviews of priest, psychologist and therapist. And organizations in the grief field.
- The choice of film producer, director and the team with experience of art and music has been important to the character of the film. The goal was to create a sensible and beautiful film with an important message than too much lecturing.

Conclusion. Film delivers important message, when it takes the way through the heart.

Result. Film as a media has reached our target group efficiently. It has also been a good medium to reach a broader audience such as politicians, authorities and people in society in general.

🕒 2:45 pm

Nuzum DR.

Anu Research Centre, Department of Obstetrics and Gynaecology, University College Cork, Cork University Maternity Hospital, Ireland

WEAVING SACRED THREADS: REMEMBERING SPECIAL LIVES. AN EXPERIENTIAL WORKSHOP TO CREATE MEANINGFUL CEREMONIES OF NAMING, BLESSING, LEAVE-TAKING/FUNERAL.

Introduction. Perinatal death brings together the liminal worlds of saying 'hello' and 'goodbye' at painfully short intervals. At a time of expected joy, longing and expectation, families are often plunged into the depths of heart-rending pain as they hear the news that their baby has died or is unlikely to survive. Responding to this pain requires a depth and breath of skill, tenderness and compassion on the part of all who provide care in the healthcare team. As part of the Bereavement and Loss Team at Cork University Maternity Hospital, chaplains journey with each family to create meaningful ceremonies of naming, blessing, and leave-taking/funeral using a co-constructive approach. These ceremonies weave together the distinctive threads of each couple through word, action, symbol and ritual to express their deep emotional and spiritual journey of birth, death and hope.

Intended Audience. This interactive workshop is aimed at all staff working in perinatal bereavement support both in hospital and in the community.

Learning Objectives.

- To identify spiritual, pastoral, and cultural wishes and needs of families in the midst of crisis bereavement.
- To understand the importance of spiritual and cultural sensitivity.
- To explore ceremony and ritual with creativity and diversity with particular emphasis on the use of texts, music, symbol, art and action.
- To understand the process of co-construction in the creation of services.
- To explore the involvement of children.
- To explore the creation of mementos and practical advice on the creation of ceremony/service booklets.
- To learn from the wisdom of the group and to draw this wisdom, experience and skill together to create services as an experiential exercise, including the creation of a booklet.

Workshop Activities. A presentation input from Daniel Nuzum will outline the principles involved in identifying the needs and wishes of parents and family members as they start the process of creating a ceremony to acknowledge, remember and say 'good-bye' to their baby.

- The opportunity in smaller groups to explore the use of music, word, symbol, art, religious and secular texts.
- Small groups will draw on the experience and traditions of the group to create a service of naming, thanksgiving, remembrance and funeral/leave-taking.
- This part of the workshop will be flexible and responsive to the needs of the participants so that it can be of most practical use.
- Each group will be invited to create a memento booklet as part of their work.

Facilitator Qualifications. Daniel Nuzum is a Registered Nurse, Anglican Priest, Practical Theologian and Accredited Healthcare Chaplain. Daniel has twelve years parish ministry experience and started work in perinatal healthcare ministry in early 2009. Daniel has a specialist professional and academic interest in perinatal bereavement care and is a member of the Miscarriage, Stillbirth and Neonatal Death Committee at CUMH. Daniel has completed the RTS Perinatal Bereavement Training Program and RTS Co-Ordinator training and is currently a postgraduate student at University College Cork, researching the spiritual and pastoral needs of parents who experience stillbirth.

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SATURDAY, OCTOBER 6

BREAKFAST SESSION II ☉ 7:00 am – 8:30 am

Moderator: Sherokee Ilse

Ilse SL, Radestad I, Culling V, Lindgren H.

Babies Remembered Consulting, USA; Sophiahemmet University College, Sweden; Chairperson, Stillbirth and Newborn Death Support (SANDS), New Zealand; Department of Health & Care Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden

TAKING BABY HOME: INTERNATIONAL PERSPECTIVES ON CARING FOR PARENTS AND FAMILIES AFTER THE DEATH OF A BABY

This group thematic panel presentation will address the topic of care following the diagnosis of a stillbirth or impending death of a baby and the practice of taking the deceased baby home from the hospital prior to a funeral or service. Presenters from the USA, Sweden and New Zealand will discuss approaches to care for bereaved parents and families from their country's perspective with an emphasis on taking baby home.

SI: This presentation sets the stage for helping parents gain control and decision-making time prior to hospital admittance. The video, I Hardly Knew You...What happens next? a tool to aid caregivers and families at this time, will be shown along with a discussion of the new concept of Perinatal/Baby Loss Doulas. It concludes with explanations on how they can be used to promote the ultimate gift of helping families have their baby home for some time.

IR: When a child is stillborn, the parents' meeting with the baby is also the time of parting, and the parents need time for saying farewell. A dead body is affected by temperature, and if the baby is being kept in warm room temperature, then changes in the body will take place more quickly; the baby's skin color changes and the body can begin to smell. On the basis of our research findings, a helpful device, Cubitus Baby (Cubitus, is the Latin word for lie down and rest), has been developed. This device has a dignified design and employs a technique that ensures that temperature is kept low enough to keep the baby intact as long as needed before burial. Cubitus Baby can be used in the hospital and it makes it possible for the parents to keep the baby in their room for a longer time than would otherwise be possible. At present the baby is usually taken from the parents during the night. The baby is transferred to a pathology department and placed in a cold room. If there is an aid available that can maintain the baby at below room temperature, it is no longer necessary for the parents to be separated from their child. Cubitus Baby may also be used if the parents want to take their baby home for awhile before the funeral. This presentation will describe the research that is the basis for the development of Cubitus Baby and will also explain how the device has been developed through material testing and clinical tests that must precede implementation of use in the health-care system.

VC: Increasingly there is interest from around the globe about the practice of taking our deceased babies home for a short period prior to a service or funeral. In New Zealand, this is a common practice for all of our deceased loved ones, adults or children. In this presentation, bereaved parents talk about taking their precious baby home and the impact it has had on their grief and their continued relationship with their deceased baby or child.

HL: Background. When a baby has died during pregnancy the first encounter between mother and child occurs when the baby is already dead. Despair, emptiness and grief characterize the encounter, which is also a gradual farewell to the child and the planned future for the family.

Aim. This study describes mother's experiences of the farewell of their stillborn baby at discharge from hospital.

Method. Twenty-three mothers who suffered stillbirth were interviewed. Semi-structured questions were used and the replies were analysed using content analysis.

Results. The mothers describe the separation from the child when leaving hospital as unnatural and that the separation ruins the motherhood they felt during pregnancy. Five categories were identified: Unnatural to leave the baby; Going home empty-handed; Access to the child; Security and insecurity in the separation; To let go. The overarching theme that we recognized from these responses we have formulated as: You don't leave your baby.

Conclusion. Leaving the baby at the hospital goes against the biological instinct to care for and protect the offspring. Routines for a dignified goodbye including designating a deputy guardian into whose arms the mother can place the baby can help to facilitate the separation.

Implications. The possibility of leaving the baby in the arms of someone known to the parents should be an option for parents who choose to take farewell of the child at the hospital. The place and time for the farewell should be decided on by the parents, taking the baby home for a personal farewell could be an alternative.

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STILLBIRTH ORAL ABSTRACT PRESENTATIONS 🕒 3:15 pm - 6:15 pm

Moderator: Elizabeth McClure, M.Sc., Principle Investigator, Statistics and Epidemiology, RTI International

🕒 3:15 pm

Erlandsson K, Lindgren H, Davidsson-Bremborg A, Radestad I.

School of Health, Care and Social Welfare, Mälardalen University, Sweden; Institute of Health and Care Sciences, University of Gothenburg, Sweden; School of Health and Social Science, Dalarna University, Sweden; Centre for Theology and Religious Studies, Lund University, Sweden; Sophiahemmet University College, Sweden

WOMEN'S PREMONITIONS PRIOR TO THE DEATH OF THEIR BABY IN UTERO AND HOW THEY DEAL WITH THE FEELING THAT THEIR BABY MAY BE UNWELL

Background. There is limited knowledge of women's premonitions before an intrauterine death, and general guidelines are often missing. Data indicate that mothers may hesitate to contact the antenatal clinic or hospital when they have concerns about their unborn baby.

Objective. To identify whether mothers of stillborn babies had had a premonition that their unborn child might not be well and how they dealt with that premonition.

Design. A mixed method approach.

Setting. One thousand and thirty-four women answered a web questionnaire.

Sample. Six hundred and fourteen women fulfilled the inclusion criteria of having a stillbirth after the 22nd gestational week and answered questions about premonition.

Methods. Qualitative content analysis was used for the open questions and descriptive statistics for questions with fixed alternatives.

Main Outcome Measure. The premonition of an unwell unborn baby.

Results. In all, 392 of 614 (64%) of the women had had a premonition that their unborn baby might be unwell; 274 of 614 (70%) contacted their clinic and were invited to come in for a check-up, but by then it was too late because the baby was already dead. A further 88 of 614 (22%) decided to wait until their next routine check-up, believing that the symptoms were part of the normal cycle of pregnancy, and that the fetus would move less towards the end of pregnancy. Thirty women (8%) contacted their clinic, but were told that everything appeared normal without an examination of the baby.

Conclusions. Women need to know that a decrease in fetal movements is an important indicator of their unborn baby's health. Healthcare professionals should not delay an examination if a mother-to-be is worried about her unborn baby's wellbeing.

🕒 3:30 pm

Hogue CJ. (Robert Silver, MD presenting)

Emory University, Rollins School of Public Health, Department of Epidemiology for the Eunice Kennedy Shriver National Institute of Child Health and Human Development, USA

EXPERIENCES OF SUPPORT FOR WOMEN WITH STILLBIRTH: REPORT FROM THE STILLBIRTH COLLABORATIVE RESEARCH NETWORK FOLLOW-UP STUDY (SCRNFS)

Introduction. To describe women's experiences of grief support during hospitalization for stillbirth and for 2 months after delivery.

Methods. Prospective, multicenter, population-based case-control study of all stillbirths (fetal deaths ≥ 20 weeks) and a representative sample of live births enrolled at delivery in 5 geographic areas at 59 hospitals averaging $>80,000$ deliveries/year. Follow-up contact was attempted for women who had consented; time from delivery to contact attempt varied from < 12 months to > 3 years. For women with stillbirth, follow-up interview included detailed questions about support they had received from professionals, family, and others.

Results. Of 953 women with stillbirths eligible for the study, 663 (70%) consented both to participate and be contacted later. Of these, 296 (45%) were located and interviewed at < 12 months (12%), 12-23 months (47%), 24-35 months (40%), or > 36 months (1%). Most women lost to follow-up had moved and could not be located. Followed and non-followed women did not differ by maternal age, gestational age of stillbirth, time to follow-up, or whether the index pregnancy had been wanted. Followed women were more likely than non-followed women to have insurance, be college-educated, married, and non-Hispanic White race ($p < 0.001$). Followed women were also less likely to have moved during the index pregnancy ($p = 0.02$). 291 women (44% of the original sample) provided information on post-stillbirth support. Most (91%) received in-hospital support from their physician (65%), nurse (78%), grief counselor (55%), religious counselor (53%), or support group (16%). Hospital staff discussed seeing or holding the baby with most (93%) women, and most either held (72%) or saw but did not hold (20%) their baby. 93% also indicated that they would recommend that women with similar loss also hold or see their baby. The stillbirth was memorialized with mementos (94%), service (63%), and other (46%) ways. In the first 2 months post-delivery, 91% of women

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received support; however, sources of support varied considerably, with no one source predominating. While support groups provided slightly more support during the first months following loss (22%) than during hospitalization, support from other professionals was less frequently reported post-hospitalization than during the hospital stay. The largest percentage of women reported post-hospitalization support from their physician (41%), followed by religious counselor (38%), hospital nurse staff (34%), and hospital grief staff (32%).

Discussion. To our knowledge, this is the largest, population-based study of stillbirth with follow-up information. Our findings may be more generalizable than prior hospital-based studies or studies with small sample sizes. While most women received support from care providers, fewer were supported by grief counselors during or after their hospitalization. There is much need for outreach and continued support during the first months following loss.

🕒 3:45 pm

Silver RM.

University of Utah Health Sciences Center, Maternal Fetal Medicine, Eunice Kennedy Shriver National Institute of Child Health and Human Development Stillbirth Collaborative Research Network (SCRN), USA

ANTICARANTICARDIOLIPIN AND ANTI-BETA-2-GLYCOPROTEIN I ANTIBODIES AND STILLBIRTH

Introduction. Antiphospholipid antibodies have been associated with pregnancy loss but have not been assessed in a large cohort of well-characterized stillbirths. Our purpose was to compare antiphospholipid antibodies in women with and without stillbirth in a population-based study.

Methods. Prospective, multicenter, population-based case-control study of all stillbirths (fetal deaths >20 weeks) and a representative sample of live births enrolled at delivery in 5 geographic areas at 59 hospitals averaging >80,000 deliveries/year. Maternal sera were obtained before hospital discharge at the time of enrollment and frozen at -80°C until assay for anticardiolipin (aCL) anti-beta2-glycoprotein-I (β 2-GP-I) IgG and IgM antibodies. These two antiphospholipid antibodies are characteristic laboratory features of the antiphospholipid syndrome.

Results. Assays were performed in 589 women with stillbirth and 1,184 women with live birth. A higher proportion of women with stillbirth (3.7%) had elevated levels of IgG aCL (≥ 20 GPL) than controls (1.1%; OR 3.37; 95% CI, 1.76 - 6.49; $p = 0.0003$). Similar results were obtained for IgG anti- β 2-GP-I antibodies; 2.0% of women with stillbirth had elevated levels (≥ 20 SGU) compared to 0.6% with live births (OR 3.36; 95% CI 1.40 - 8.07; $p = 0.0067$). However, the proportion of women with elevated levels of IgM aCL and anti- β 2-GP-I were similar among stillbirths and controls; 3.4% versus 3.4% for aCL (OR 1.08; 95% CI, 0.62 - 1.89) and 2.6% versus 1.9% for anti- β 2-GP-I (OR 1.40; 95% CI, 0.72 - 2.71). Results were similar when the analysis was limited to all stillbirths versus term livebirths ($N = 1,063$) and non-anomalous stillbirths ($N = 457$) versus term livebirths ($N = 1,063$). For example, 4.4% of women with non-anomalous stillbirths had elevated levels of IgG aCL compared to 1.0% of women with term livebirths (OR 4.67; 95% CI, 2.27 - 9.61; $p < 0.0001$). 2.0% of women with non-anomalous stillbirths had elevated levels of anti- β 2-GP-I antibodies compared to 0.6% of women with live births (OR 3.14; 95% CI 1.20 - 8.20; $p = 0.0194$).

Conclusion. Elevated levels of IgG but not IgM aCL and anti- β 2-GP-I antibodies are associated with a 3 - 4 fold increased risk of stillbirth.

🕒 4:00 pm

Heazell AE, Mistry H, Vincent O, Roberts TE.

Maternal and Fetal Health Research Centre, University of Manchester, United Kingdom; University of Birmingham, United Kingdom; Health Economics Unit, University of Birmingham, United Kingdom

ASSESSING THE ECONOMIC IMPACT OF STILLBIRTH USING MODELS OF CARE IN SUBSEQUENT PREGNANCY

Introduction. Despite advances in obstetric care, the incidence of stillbirth in the UK is not any lower than it was 20 years ago. One in 200 pregnancies after 24 weeks gestation end in a stillbirth; in 2008, there were 3,617 stillbirths in England and Wales. 86% of women will go on to conceive again within 18 months of the previous loss. This is likely to have significant resource implications for instance UK RCOG Guidelines suggest serial ultrasound scans in the next pregnancy following stillbirth, even though approximately 20% of stillbirths have a non recurrent cause. The psychological and emotional impact of stillbirth means that women may demand more health care resources including antenatal visits and tests in their subsequent pregnancy even in the absence of evidence of clinical benefit.

Objectives. To explore the trade-off that exists between the cost of investigation to determine the cause of stillbirth and the additional cost of managing pregnancy following stillbirths where the cause was not determined.

Methods. Alternative care pathways for four cohorts of pregnant multiparous women were developed using guidelines from NICE and expert opinion: (1) Women with a previous healthy child; (2) Women classed as high risk eg diabetes or hypertension with a previous health child; (3) Women classed as high risk but with a previous stillbirth; (4) Women with a previous stillbirth of known or unknown causes. Using published data we obtained information on prevalence rates, resource use, and unit cost to populate each of the care pathways.

Results. Cost of antenatal care ranged from £724 (group 1) to £2,181 (group 3), where group 1 had 9 antenatal visits and 2 ultrasound scans compared with group 3 who had 15 antenatal visits and 9 ultrasound scans. For women who had experienced a stillbirth and had underlying conditions such as diabetes, antenatal care costs were £770 higher, compared to women who previously had a healthy child. The cost of care in a subsequent pregnancy for a

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woman who had a previous stillbirth due to unknown cause was approximately £500 more than a woman who experienced a stillbirth as a result of a non recurrent cause.

Discussion. In addition to the emotional and medical benefits of determining a cause for stillbirth there is a potential economic benefit in a subsequent pregnancy. Rather than performing antenatal test(s) that may have no value, in the subsequent pregnancy, this cost saving could be more appropriately spent providing good quality psychological support.

🕒 4:15 pm

Haine Vijayvergiya D.
Stillbirth Parent

TAKING THE SOCIAL TABOO OUT OF STILLBIRTH

Fetal demise isn't a common household concept. I wasn't familiar with the term until July of 2011, now it has become interwoven in the fabric of my life ever since. When we first learned that our baby had died, we were completely caught off guard. We were then required to suffer through a labor and delivery. The hospital did very little to help prepare us for what lay ahead as we stepped out into this new and unfamiliar world. As I was being discharged, a nurse handed me a sheet which outlined the different phases of grief, a pamphlet on a monthly support group, and a nice pat on the back wishing me good luck. We shut out the world. Family and friends tried to reach out and offer comfort, but we thought that silence and privacy were what we needed to heal.

When I realized that I needed help coping, I found myself disappointed. I couldn't find a book or a blog that felt right to me. That is actually surprising because my experience wasn't as rare as you might think: according to an 2009 ACOG practice bulletin, there are approximately 25,000 stillbirths a year, or 1 in 160 deliveries, practically as many as the number of infants who die in their first year of life. That number is therefore greater than SIDS, NICU deaths, and infant deaths from congenital anomalies combined. The little information that I was able to find wasn't easy to relate to – which made me feel even more isolated and hurt.

Stillbirths/fetal demise and miscarriages are a taboo topic in our society. And because of its taboo nature we as a society are often unprepared to handle such situations, as patients, friends and family, or even health care professionals. Being able to create a social dialogue around this topic is the first step in addressing unmet needs in this area. Just as mental illness was a taboo subject 50 years ago, talking about it has opened a social dialogue that's created considerable change in how we talk about, deal with and treat patients with mental illness.

The objective of this presentation/panel is to initiate a community dialogue that explores the individual experiences of women who have suffered fetal demise in order to identify consistent areas of unmet need that can serve to inform the implementation of programs and infrastructure designed to create relevant support for women who suffer this (currently) unspeakable tragedy.

🕒 4:30 pm

Throsten VR, Engmann , Garcés AL, Jehan I, Ditekemena J, Phiri M, Mazariegos M, Chomba E, Pasha O, Tshefu A, Wallace D, McClure B, Goldenberg R, Carlo WA, Wright L, Bose C.
RTI International, USA; The Aga Khan University Departments of Community Health Sciences & Family Medicine, Pakistan; University of North Carolina-Chapel Hill School of Medicine, USA; Hospital General de Kinshasa, Kinshasa School of Public Health, DRC; University Teaching Hospital, Zambia; Center for Studies of Sensory Impairment Aging and Metabolism, Guatemala; Department of Obstetrics/Gynecology Drexel University College of Medicine, USA; University of Alabama at Birmingham Department of Pediatrics/Division of Neonatology, USA, Center for Research of Mothers and Children Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health, USA

BIRTH ATTENDANTS AS PERINATAL VERBAL AUTOPSY RESPONDENTS IN LOW-INCOME COUNTRIES: A VIABLE ALTERNATIVE?

Introduction. Perinatal Verbal Autopsy (VA) is a technique used to assign cause of death (COD) where health registration systems are weak or unavailable. During VA, a systematic description of the signs, symptoms and circumstances preceding the death is recorded from an interview. Subsequently, a physician panel, removed from the site of death, assigns COD from the interview data.

The conventional perinatal VA respondent is the mother whose baby or fetus has died, however birth attendants (BA) might make preferable VA respondents for a number of reasons: 1) BA may have a greater awareness of the circumstances surrounding the birth compared to the mother; 2) BA are often the 'first responders' to attempt resuscitation and thus may have greater insight into the events resulting in a subsequent death. Often the circumstances surrounding such deaths are indelibly imprinted in the mind of the BA present. In light of these reasons, our group undertook a prospective study to investigate whether BA could serve as a viable alternative to bereaved mothers. We hypothesized that there would be greater than 80% agreement between mothers' and BA' responses on selected close-ended items on the VA questionnaire.

Methods. The study included deliveries resulting in perinatal death (stillbirth or early neonatal death (END)) from 38 communities in the Democratic Republic of the Congo, Guatemala, Pakistan and Zambia. Data describing the circumstances surrounding the deaths were collected separately from each

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mother and BA, using a standardized VA questionnaire of 64 questions for END and 48 questions for stillbirth. The mother was considered the reference standard. Concordance across all questions, groups of questions, and individual questions were calculated. Measures of sensitivity and specificity were obtained.

Results. Overall, concordance across all questions was 94% for END. Over 50% of the time, concordance for BA responses was 95% or greater for categories grouped under maternal medical history, birth attendance and newborn characteristics. All questions had a concordance of 80% or greater. Sensitivity and specificity varied across individual questions. Over 80% of questions on ENDS had sensitivities 80% or greater, and 80% of the time, specificities of 90% or more.

Overall concordance across all questions was 93% for stillbirths. Over 50% of the time, concordance was 95% or greater for categories grouped under birth attendance, site of delivery, and stillborn characteristics. Similarly, sensitivity and specificity varied across stillbirth questions. Over 60% of questions had sensitivities of 80% or greater, and over 80% of questions specificities 90% or greater.

Conclusion. Mothers and BA reported comparable circumstances surrounding the deaths. Since the physician coders use these data to code the causes of death, the high concordance suggests that the cause of death derived from the BA's responses would be similar to the cause coded from the mother's responses. Since there are significant public health, economic, logistic and ethical advantages to using BAs as VA respondents, using BA as the source for VA should be considered. Further refinements of questions on existing verbal autopsy questionnaires.

🕒 4:45 pm

Nuzum DR.

Anu Research Centre, Department of Obstetrics & Gynaecology, University College Cork and Cork University Maternity Hospital, Ireland

SPIRITUAL AND PASTORAL CARE FOLLOWING STILLBIRTH: A REVIEW OF SERVICES IN IRELAND

Introduction. Stillbirth is a devastating experience for parents and their families. Research has consistently shown that how parents are cared for during this difficult time has a significant bearing on their healing and recovery which is a lifelong journey. Great strides have been made in recent years to improve the care provided to parents following the diagnosis that their baby has died. This has led to a marked improvement in the experiences of parents and the positive shaping of hospital policies and procedures in this area and a greater emphasis on integrative care provided by the multidisciplinary healthcare team. Parents receive optimal care when the emotional, physical, social and spiritual dimensions of the impact of stillbirth are met holistically.

The aim of this review is to evaluate the level of spiritual and pastoral care that is provided following stillbirth in maternity facilities in Ireland.

Methods. A mixed-methods approach is used involving the collection of data and semi-structured qualitative interviews with the providers of spiritual and pastoral care in each of the maternity facilities in Ireland (n=20). Interviews will be conducted during March and April 2012. Data analysis will take place in May 2012.

Results. This study will be the first to identify the level of spiritual and pastoral care that is currently provided in Ireland following stillbirth. The study will draw together the provision of spiritual and pastoral care and practice to give an overall view of how bereaved parents have their spiritual and pastoral needs met from the perspective of the providers of care. In addition the study will identify what providers of spiritual and pastoral care consider to be the greatest spiritual and pastoral challenges in this delicate area. Recommendations for practice development and the greater harmonisation and consistency of spiritual and pastoral care for all families following stillbirth will be suggested as best practice in holistic care.

Discussion. Every maternity facility in Ireland experiences stillbirth; however, only the larger units have the services of a dedicated spiritual/ pastoral care provider. This review will highlight how spiritual and pastoral needs of families are met and how best practice can be standardised across all units to provide a consistently high provision of care for all families. It will also identify what the providers of spiritual and pastoral care consider to be the spiritual and pastoral needs of parents following stillbirth.

This information will contribute to the overall multidisciplinary care provided to all families following the death of their baby before birth.

🕒 5:00 pm

Waelput A, Eskes M, Bremmer-Bolhuis WTL, Erwich JJHM, Van Swigchum FM.

Foundation Perinatal Audit in the Netherlands (PAN)

AUDIT OF TERM PERINATAL DEATHS IN THE NETHERLANDS

Introduction. All term perinatal deaths in 2010 in the Netherlands are audited.

Methods. Multidisciplinary internal audit meetings were organized by obstetric collaborative groups, which consist of all professionals involved. They discussed cases of term perinatal mortality in a structured way. The sessions were chaired by an independent chairperson.

Results. Audit of term perinatal deaths was organized in 91 out of all 93 obstetric collaborative groups. All professional groups, involved in perinatal care,

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participated in these sessions. More than 4,000 professionals were present. All sessions were attended by professionals of different groups, such as midwives, GP's, gynecologists, pediatricians, nurses, pathologists and others.

They audited 87% of the (359) term perinatal deaths in 2010. In 222 cases all audit results were registered (62%). Stillbirths accounted for 63% of all term deaths: 115 antepartum and 11 intrapartum. In 48% of them no substandard factors (SSF) were identified. In the other 116 cases the groups identified 212 SSF's. A total of 390 professionals were involved in these SSF's.

In 67% of all SSF's actions to improve care were reported (n=186). They address different domains, such as the development of proper protocols or guidelines (27%) and training and education (8%) and the improvement of the organization of care (35%), of documentation (11%) and communication (12%) and "other" (7%)

In 10% (n=20) of all cases discussed the mortality was (very) probably related to the SSF. This matches with results of former external audits.

Discussion. The nationwide introduction of internal perinatal audit is feasible. Identifications of local factors to promote and secure audits are still needed, as well as strategies to implement actions to improve care.

🕒 5:15 pm

Gordon A, Raynes-Greenow CH, Bond D, Jones R, Rawlinson WR, Iwasenko J, Morris JM, Jeffery HE.
RPA Newborn Care, Royal Prince Alfred Hospital, Australia; University of Sydney, Australia; South Eastern Area Laboratory Services, Prince of Wales Hospital, Australia; The University Clinic, Royal North Shore Hospital, Australia

RISK FACTORS FOR LATE PREGNANCY STILLBIRTH: THE SYDNEY STILLBIRTH STUDY

Background. The proportion of stillbirths classified as unexplained increases near term, often despite investigations. There is a need to identify new or emerging risk factors for stillbirth and to identify what is potentially modifiable.

Aims. To identify potentially modifiable risk factors for late pregnancy stillbirth.

Method. Population-based matched case control study of pregnant women ≥ 32 weeks gestation booked into tertiary maternity hospitals in metropolitan Sydney between Jan 2006 and Dec 2011. Data collection was performed using a semi-structured interview based on the PSANZ perinatal mortality guideline clinical history and included validated questionnaires for specific risk factors. Interviews were performed as soon as possible following recruitment to minimise recall bias and women were blinded to the specific study hypotheses. Controls were matched to expected delivery date of cases and interviewed during pregnancy. Infection investigations were performed at delivery and included standard microbiology plus multiplex PCR and placental histopathology. Odds ratios (OR) were calculated for a priori specified risk factors and multivariate analysis performed.

Results. There were 103 cases and 192 controls. Mean gestation was 36 weeks. Significantly more cases were identified as having fetal growth restriction during pregnancy (aOR 7.4 95% CI 2.0 – 28) as well as being small for gestational age at birth (aOR 3.1 95% CI 1.1 – 8.8). Antibiotic treatment for a proven urinary tract infection (UTI) was more common in cases (aOR 2.2 95% CI 1.0 -5.5). Cases were more likely to sleep on their back in late pregnancy (aOR 4.34, 95%CI 1.2, 16.0). Results for infection and placental pathology are currently being collated and will be presented.

Conclusions. Interview data provides detailed information on known and potential risk factors for stillbirth and is acceptable to families. Infection is underestimated using standard techniques and UTI in late pregnancy may not be benign. Identification and management of growth restriction in late pregnancy remains a significant opportunity for stillbirth prevention and maternal sleep position deserves further investigation.

🕒 5:30 pm

Hoffman-Sage Y, Fretts R.
Brigham & Women's Hospital, Boston, USA

CHARACTERISTICS AND PREGNANCY OUTCOMES OF WOMEN PRESENTING WITH DECREASED FETAL MOVEMENT

Introduction. Women presenting with decreased fetal movement (DFM) in the third trimester are believed to be at increased risk of growth restriction, preterm birth, and stillbirth. We wished to evaluate the pregnancy characteristics and outcomes of women presenting to our triage unit for DFM.

Methods. All women who presented in the third trimester from October 1, 2010 to September 30, 2011 at our institution's triage were identified if the initial complaint was DFM. Demographics, pregnancy characteristics, and obstetric outcomes were compared to all women delivering at our institution during the same time period.

Results. Three-hundred and seventy-one women presented for DFM, representing 5% of the 7595 deliveries during this period. 7 were diagnosed with fetal demise on presentation. Women were at a mean of 35, and median of 37, weeks' gestation on presentation. They delivered on average at 39.0 weeks, similar to the average gestational age of 38.8 weeks for our population. 10% delivered prior to 37 weeks, similar to 12% overall. 60% with DFM, compared with 47% of the total population, were nulliparous ($p < 0.01$). Of those presenting with DFM, 38% were white, compared with 52% of the total obstetric population ($p < 0.01$). 23% were black and 26% Hispanic, compared with 17% and 16%, respectively, in the general population ($p < 0.01$ for each).

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Mean birth weight was similar to the entire population: 3188 compared to 3229 grams ($p=0.30$). However, 16% of neonates born to women experiencing DFM weighed <10 th percentile for gestational age at birth, compared with 10% of the total population ($p<0.01$). 30% of babies born to mothers with DFM required neonatal intensive care admission, compared with 15% of neonates overall ($p < 0.01$). 47% with DFM were induced, compared with 23% rate overall ($p < 0.01$). Cesarean delivery rate was 32% among women with DFM, identical to the rate for the entire institution during those months. The rate of cesarean following induction was 19% for those experiencing DFM, compared to 23% overall.

Conclusions. Women presenting with DFM were more likely to be nulliparous and black than in our total obstetric population. While mean birth weight was similar to the general population, the 16% rate of small for gestational age was significantly higher than our population rate. 30% of neonates born to mothers experiencing reduced fetal movement required an intensive care admission; this was despite an average gestational age at delivery comparable to our entire obstetric population. Though their providers were more likely to induce them, their cesarean delivery rate was unchanged. This study demonstrates that, at our institution, women presenting with DFM tend to be at elevated risk of adverse pregnancy outcomes based on their demographics and baseline characteristics. Considering this cohort at higher risk of stillbirth, a tendency towards more liberal use of induction of labor for these pregnancies, without an increase in cesarean rates, appears warranted.

🕒 5:45 pm

Ray JG, Urquia ML.

University of Toronto, Canada

RISK OF STILLBIRTH AT EXTREMES OF BIRTHWEIGHT BETWEEN 20 TO 41 WEEKS GESTATION

Introduction. We determined the risk of stillbirth between 20 to 41 weeks gestation, at highly detailed weight percentiles, including extreme degrees of small (SGA) and large (LGA) for gestational age birthweight.

Methods. We completed a population-based study of all births in Ontario, Canada between 2002 and 2007. We included 767,016 liveborn and 4,697 stillborn singletons delivered between 20 and 41 weeks gestation. Smoothed birthweight percentile curves were generated for males and females, combining livebirths and stillbirths. Quantile regression was used to calculate sex-specific absolute birthweight differences and 95% confidence intervals (CI) between stillborns vs. liveborns at various gestational ages. Logistic regression was used to calculate the odds ratios (OR) for stillbirth at various sex-specific birthweight percentiles, including < 1 st and ≥ 99 th percentile. OR were adjusted for maternal age and parity.

Results. At the 10th percentile, stillborns weighed significantly less than liveborns starting at 24 weeks gestation. By 32 weeks, this difference was 590 g (95% CI 430-750) for males and 551 g (95% CI 345-448) for females. A reverse J-shaped association was observed between birthweight percentile and risk of stillbirth across all gestational ages. Relative to the 40-60th percentile referent, the adjusted OR for stillbirth was 9.63 (95% CI 8.39-11.06) at a birthweight < 1 st percentile. At ≥ 99 th percentile, the adjusted OR was 2.24 (95% CI 1.76-2.86). The risk of stillbirth at extreme birthweight percentiles was robustly observed across gestational ages.

Discussion. Substantial birthweight differences exist between stillborns and newborns. As a possible hallmark of impending intrauterine death, severe SGA and LGA may each be potential targets for future stillbirth prevention initiatives.

🕒 6:00 pm

Tinsley JM, Swanson-Kubaska S, Rollins JL, Humm P, Nelson K, Franklin HL.

Women's and Children's Center of the Rollins School of Public Health and School of Medicine, Emory University, USA, Division of Research, Women & Infant's Hospital, Brown University, USA; University of Texas Medical Branch, Galveston, USA; Intermountain Healthcare and University of Utah, USA; RTI International, USA

MAXIMIZING ENROLLMENT TO A STILLBIRTH RESEARCH STUDY

Yearly about 26,000 women experience a stillbirth, defined as a baby dies after 20 weeks gestation. For most the cause of the baby's death is unknown. The SCRIN study was a multi-site, population-based, cohort and nested case-control study, with prospective enrollment of stillbirths and live births at the time of delivery. The population was racially, ethnically, and geographical diverse. This study of stillbirth included: 1) population-based controls; 2) controls oversampled for preterm births; 3) prospective enrollment at delivery; 4) uniform fetal and placental pathology in stillbirths and placental pathology in live births; 5) review of medical records; 6) a maternal interview conducted after the delivery for mothers of cases and controls; 7) collection of placenta, blood, and fetal tissue biospecimens from the mother and the still- or live born infant. Enrollment occurred between 2006-2008 with surveillance for all stillbirths in 59 tertiary care and community hospitals in 5 geographically defined catchment areas with access to at least 90% of deliveries. This abstract describes the strategies implemented by the research personnel that lead to a high participation rate among women with stillbirths.

Methods. Training and recruitment - All research staff attended standardized multidisciplinary training for interview and bereavement care (RTS Bereavement Services). The research protocol included maternal interview, medical record review, and biospecimen acquisition (placenta and maternal blood and requesting consent for postmortem examinations of the stillborn babies.) Participants were invited to participate in all appropriate aspects of the research. Clinical partnerships were developed between the research staff and obstetric providers, staff on inpatient units, and pathology departments. The research staff educated inpatient staff on the purpose and scope of the study. Each unit was contacted daily by phone to identify qualified subjects. Additionally, research staff visited each facility regularly to reinforce knowledge about the study, and to answer staff questions. Individualized bereavement support was provided to mothers as needed during enrollment, interview, and follow-up. Investigators actively communicated with community providers and

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to families requesting additional information.

Discussion. Researching current practice, integrating the study into their existing protocols for stillbirth, educating and building relationships with our study hospitals was key to our enrollment success. Having research staff available 24/7 was another key for successful enrollment. Initial and ongoing education of hospital staff on the protocol was critical for the research staff to identify potential participants. Study personnel actively engaged community practitioners as well.. Additional strategies that lead to increased enrollment included the research staff flexibility, willingness to spend time with families, knowledge, and cultural sensitivity to our study families.

Recommendations for future studies include spending the time to educate and engage hospital staff and community providers, and continuous contact to maintain relationships. Ensuring the research staffs are flexible, culturally sensitized, trained in bereavement, and willing to tailor biospecimen collection to each hospital. Finally, one of the most important recommendations is allowing research staff to spend time (6-8 hours) with grieving families.

SUNDAY, OCTOBER 7

STILLBIRTH ORAL ABSTRACT PRESENTATIONS: GRIEF AND BEREAVEMENT 🕒 10:45 am - 12:00 pm

Moderator: Stephanie Fukui

🕒 10:45 am

de Groot P.

De Verbindig, Practice for Occupational and Health Psychology, Netherlands; Department of Obstetrics and Gynaecology, University Medical Centre, Netherlands

GRIEVING AFTER STILLBIRTH - HOW DOES A BABY'S DEATH AFFECT THE PARENTS? ABOUT THE DUAL PROCESS MODEL OF COPING WITH LOSS

Grieving after stillbirth is a highly individual process for a family and individually for the mother and the father, siblings and grandparents. The traditional models of grief (Freud, Murray-Parkes, Bowlby, Kübler-Ross: Stages model and Worden: tasks model) consider grief as a linear process through which bereaved people move in a specific sequence and some health workers are considering different kind of losses to have different time periods in which grief ends.

Other new developed and evidence-based theories, like the Dual Process Model of Coping with Loss (Stroebe & Schut, 1999) and the Model of Reconstruction of Meaning (Neimeyer, 2001) focus more on the individual, unique way of grieving, within a general framework.

The Dual Process Model of Coping with Loss (DPM) (figure 1.) is developed by Stroebe and Schut in the late 1980s and published in their seminal article of the model in 1999.



Figure 1. Dual Process Model of Coping with Loss (DPM)

According to the DPM bereaved persons typically alternate between two modes: the “loss orientation “ mode and the “restoration orientation” mode. The key-word here is “oscillation”. The model is an acknowledgement that grief is a very personal, usually experienced in an iterative manner rather than as a sequence of pre-ordained stages.

While all bereaved persons shift between the two modes (“oscillation”; sometimes very rapidly, sometimes with great intervals and sometimes due to external stimuli, sometimes due to internal stimuli), according to the model, everybody has a “personal, preferred mode”. Some scientists even speak of

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“female and male modes” of coping with loss.

The individuals way of grieving and one’s individual preferred mode of coping with loss can be a serious source of (very strong) tension in mixed gender relationships in which both parties are bereaved.

It is important for both parties to recognize that grief is experienced and expressed differently for each person and that sometimes help and support for a bereaved parent must be sought outside the relationship.

Loss orientation	Restoration orientation
Confrontation of the loss	Adjustment to the loss
Talking	Evading
“Being” / “I am the pain”	“Doing” / “I feel the pain”
Denial and avoidance of recovery	Denial and avoidance of loss
Involvement	Distance
Closeness	Alloofness
Need for emotional support	Need to problem-solve
Complication: “Chronic mourning”	Complication: “Postponed mourning”
Dangers: Complaining, over-involvement, drowning in emotion	Dangers: Escapism, distance, over-control, feeling nothing

Table 1. Characteristics of the Dual Process Model of Coping with Loss

Since its inception over two decades ago, the model has been applied to grief and bereavement in a variety of contexts. Of greatest relevance to stillbirth, one study focused on the applicability to perinatal-related parental bereavement.

The study compared the coping strategies of over 200 bereaved parents and their partners in terms of the Dual Process model of Coping with Loss. It found that “loss orientation” was predictive of negative psychological adjustment, while “restoration orientation” was related to better adjustment. Furthermore, high levels of “restoration oriented” coping buffered the negative effect of high levels of “loss orientation” on depression.

The study concluded that “in coping with the loss of their child, intra-personal as well as inter-personal processes are relevant for the adjustment process of parents after the loss of their child”.

🕒 11:00 am

Radestad IJ, Erlandsson K, Warland J, Cacciatore J.

Sophiahemmet University College, Sweden; School of Health, Care and Social Welfare, Mälardalen University, Sweden; School of Nursing and Midwifery, University of South Australia, Australia; School of Social Work, Arizona State University, USA

SEEING AND HOLDING A STILLBORN BABY: MOTHERS’ FEELINGS IN RELATION TO HOW THEIR BABIES WERE PRESENTED TO THEM AFTER BIRTH – FINDINGS FROM AN ONLINE QUESTIONNAIRE

Objective. To determine if the way caregivers offer opportunities to see and hold a stillborn baby impacts a mother’s feelings about the experience of seeing and holding her newborn.

Design and Setting. A web questionnaire hosted by the Swedish National Infant Foundation from March 2008 to April 2010. Participants: 840 eligible participants who had experienced a stillbirth after the 22nd gestational week from 1955 to 2010 and completed an online questionnaire about their experiences.

Methods. Descriptive and inferential statistics.

Findings. When mothers were presented the baby as a normal part of birth without being asked if they wanted to see, they more often reported that the experience was comfortable compared to mothers who were asked if they wanted to see the baby 86% vs. 76% ($p < 0.01$). The incitation of fear in mothers was 70% vs. 80% ($p = 0.02$) in favor of mothers who were not asked. Furthermore the mothers who were not asked more often stated that it felt natural and good when compared to those who said staff asked if the mother wanted to see, 73% vs. 61% ($p = 0.07$) and (78%) vs. (69%) $p = 0.19$, respectively. A trend was seen toward more mothers feeling natural, good, comfortable, and less frightened if the provider engaged in “assumptive bonding”, that is the baby is simply and naturally presented to the mother without asking her to choose.

Key Conclusions. Mothers of stillborn babies felt more natural, good, comfortable, and less frightened if the staff supported assumptive bonding by simply offering the baby to the mother.

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Implications for Practice. Care providers should approach caring for grieving mothers with tenderness and humility, assuming that they wish to see and hold their stillborn baby.

🕒 11:15 am

Gold KJ, Marcus SM, Copeland G.

Department of Family Medicine & Department of Obstetrics and Gynecology, University of Michigan, USA; Department of Psychiatry, University of Michigan, USA; State of Michigan, Division for Vital Records and Health Statistics, Michigan Department of Community Health, USA

DEPRESSION AND PTSD AMONG MOTHERS WITH STILLBIRTH AND EARLY INFANT DEATH COMPARED TO MOTHERS WITH LIVE BIRTH: THE MICHIGAN MOTHERS STUDY

Background. Stillbirth and infant death are traumatic events with profound and lasting impacts on bereaved families. Mothers with perinatal loss are at high risk for depression, anxiety, and PTSD although this has rarely been assessed in a representative epidemiologic cohort. In addition, virtually all studies on mental health outcomes after loss have focused on white mothers, and there is virtually no data on loss among African-American women (who face more than twice the risk of both stillbirth and infant death in the United States).

Methods. The Michigan Mother's Study is a two-year longitudinal survey of all mothers in Michigan with stillbirth and infant death, matched with control mothers with live birth. The broader study evaluates mental health (anxiety, post-traumatic stress disorder, obsessive-compulsive disorder, eating disorders, complicated grief, phobias), physical health, and subsequent reproductive choices. Data collection is ongoing with the first full year of data available in May 2012. The Patient Health Questionnaire-8 (PHQ-8) was used to assess mood with a score of 10 or higher suggestive of depression, and the Post Traumatic Stress Disorder Checklist, Civilian Version (PCL-C) was used to screen for PTSD.

Results. Preliminary results for the first 509 returned 6-month surveys (data still being collected) included 200 (39%) live birth mothers 169 (33%) mothers with stillbirth, and 140 (27%) mothers with infant death. Mean maternal age was 29 and 62% of respondents were married. Nine percent of live birth moms reported African-American race compared with 17% of mothers with stillbirth and 28% of mothers with infant death. While only 8% of mothers with live birth had scores concerning for depression, 25% of mothers with stillbirth and 21% of mothers with infant death had scores >10. PTSD results still pending as data collection for the first wave of surveys is still being completed (but will be available by the time of the conference).

Discussion. This on-going population-based study is the first to describe epidemiologic data of depression and PTSD among perinatal bereaved mothers compared to mothers with live births. The study is the first to include a large cohort of African-American mothers who are at particularly high risk for adverse pregnancy outcomes in the United States.

🕒 11:30 am

Braben PJ.

Monash University, School of Psychology and Psychiatry, Australia

HASTY CONCEPTION AFTER PERINATAL LOSS: THE SALVE FOR MATERNAL GRIEF OR PERPETUATION OF ANXIETY FOR MOTHER AND SUBSEQUENT CHILD?

The pregnancy and postnatal period following perinatal loss is typically fraught with anxiety related to fears that 'this baby will die too', often entailing maternal depression and guilt. The notion of a replacement child syndrome, when a hastily conceived new baby distorts or delays mourning (Poznanski, 1972), and a vulnerable child syndrome (Davis, Stewart & Harmon, 1989), where over-protection or unrealistic expectations of the infant due to the fear of forgetting the previous child and/or of losing this child, have been described. Hughes et al. (2001) suggested that the experience of perinatal loss can trigger a past-learned insecure or disorganised coping style in the mother impacting on the relationship with the new baby - a mechanism of inter-generational transmission of emotional problems. Little empirical research has been reported on these subsequent child syndromes beyond descriptive, qualitative studies.

Hughes et al. (1999), however, undertaking one of the first comparison studies, found that mothers whose subsequent pregnancy was conceived less than 12 months after a stillbirth had higher levels of anxiety and depression at one year post delivery than mothers who had conceived after 12 months. They concluded (Hughes et al., 2001) that infants next-born after a stillbirth may be at greater risk of increased psychological problems in later childhood as a result of maternal unresolved grief.

This paper confirms these data detailing research findings from a large Australian stillbirth study (Brabin, 2004) linking contact with the baby and timing of the subsequent pregnancy with maternal and subsequent child outcomes. These outcomes highlight conception within five months as the critical factor, particularly when the mother had contact with the stillborn baby.

Research evidence is also cited describing the impact of anxiety on foetal development, a universal experience in a subsequent pregnancy. Attendance in mother-baby units appears to be common now for mothers coping with a subsequent baby, particularly after a quickly conceived subsequent pregnancy, and this experience not always differentiated from post-natal depression as a grief-related issue. While grief is not depression it can be a sequel to chronic anxiety and impact on the developing relationship with the new living infant. These issues are discussed with two case study examples of girls conceived quickly after a perinatal loss where anxiety impacted, unrecognised, on their educational experience.

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The paper further discusses the need for women in pregnancies subsequent to a perinatal loss for better psychological care that goes beyond obstetric reassurance and concludes with a plea for further well-designed research in this important area of early childhood development.

🕒 11:45 am

Johnson S, Warland J. (*Jane Warland presenting*)

University of South Australia, Australia

OUR BABY DIED: ADOLESCENTS' RECOLLECTIONS OF BEING RAISED IN A FAMILY AFTER THE LOSS OF A BABY

This paper reports on a study where the primary aim was to improve our understanding of the experience of being a child living in a family when a baby sibling dies. This knowledge is expected to facilitate many opportunities for intervention at various levels of health-care, with the anticipated outcome of reducing mental health problems in both bereaved parents, child/ren alive at the time and subsequent children.

It is now well known that bereaved parents in their subsequent pregnancy after the death of a baby often delay emotional attachment to their new baby for fear of another loss. It is also understood that the child born after a sibling's death, may be subject to increased risk of psychopathology because of parental anxiety. However, little is known of the experiences of children alive in the family when the loss occurs. This study gives adolescents a voice to share their subjective experiences of living in a family when a baby dies.

This paper will present the preliminary findings of a recently completed doctoral study. 10 Adolescents were interviewed and asked to describe their experiences of living in a family after the death of an infant sibling. The four main themes arising from these interviews will be shared followed by a short discussion of the implications of these findings for those working with bereaved families.



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FRIDAY, OCTOBER 5

POSTER SESSION A 🕒 4:30 pm - 6:00 pm

➡ **A-02**

Radestad, IJ

Sophiahemmet University College, Sweden

CUBITUS BABY GIVES TIME TO TAKE FAREWELL

When a child is stillborn, the parents' meeting with the baby is also the time of parting, and the parents need time for saying farewell. A dead body is affected by temperature, and if the baby is being kept in warm room temperature, then changes in the body will take place more quickly; the baby's skin color changes and the body can begin to smell. On the basis of our research findings, a helpful device, Cubitus Baby (Cubitus, is the Latin word for lie down and rest), has been developed. This device has a dignified design and employs a technique that ensures that temperature is kept low enough to keep the baby intact as long as needed before burial. Cubitus Baby can be used in the hospital and it makes it possible for the parents to keep the baby in their room for a longer time than would otherwise be possible. At present the baby is usually taken from the parents during the night. The baby is transferred to the pathology department and placed in a cold room. If there is an aid available that can maintain the baby at below room temperature, it is no longer necessary for the parents to be separated from their child. Cubitus Baby may also be used if the parents want to take their baby home for awhile before the funeral. This presentation will describe the research that is the basis for the development of Cubitus Baby and will also explain how the device has been developed through material testing and clinical tests that must precede implementation of use in the health-care system.

➡ **A-03**

O'Donoghue K, Smith M, Verling AM, O'Connell O.

Anu Research Centre, Department of Obstetrics and Gynaecology, University College Cork, Cork University Maternity Hospital, Ireland

THE INVESTIGATION OF STILLBIRTH - ARE WE COMPLYING WITH GUIDELINES?

Introduction. In the developed world, one in 200 infants is stillborn, a devastating outcome for parents and clinicians. In Cork University Maternity Hospital (CUMH), of 26,699 babies delivered from 2008 to 2010, 124 were stillborn (4.6 per 1000 births).

Purpose of Study. We aimed to audit the performance of CUMH in relation to the new National Clinical Practice Guidelines for Investigation of Stillbirth, published in October 2011. We examined how many mothers had a complete medical work-up, including the use of placental pathology, and then focused on how many were offered or consented to a post-mortem examination (PM).

Methods. We performed a retrospective audit of stillbirths from 2008 to 2010. We searched the Pregnancy Loss Clinic databases, and supplemented this with medical correspondence as well as individual chart review. The electronic laboratory database and pathology reports were also searched.

Results. We reviewed 112 cases. Of these all were offered a PM, bar two for reasons that are unclear from the case-notes. Of the couples offered PM, 53% accepted. Only 1.8% of placentas were not sent for pathological examination. 55% of Mothers had the full series of blood tests recommended by the guidelines. Of the remainder, 42% had a prior antenatal diagnosis, e.g fetal congenital malformation .

Discussion. Overall CUMH performed well in the investigation of stillbirth. There were several cases in which a cause for stillbirth had been identified during pregnancy; these did not require the full work-up. The majority of couples were offered a PM examination. Recommendations for the investigation of stillbirth in the new guideline should be incorporated into clinical practice and regularly audited to ensure compliance.

➡ **A-04**

O'Connell O, Verling AM, O'Donoghue K.

Cork University Maternity Hospital, Ireland; Anu Research Centre, Department of Obstetrics and Gynaecology, University College Cork, Ireland

PROVISION OF CARE AT THE TIME OF STILLBIRTH

Introduction. Cork University Maternity Hospital opened in 2007. It is a busy tertiary referral centre with an annual birth rate of around 8,800. Over these 5 years there has been a concerted and ongoing commitment to meet the needs of bereaved families at the time of perinatal death. The multi-disciplinary team focuses on all aspects of care including emotional, medical and spiritual, in accordance with international evidence-based practice. Our concern however, is that while there are universal norms in terms of the pain of grief involved in perinatal death there will also be specific needs relating to individual culture and values. We needed to hear from the parents to establish the extent to which we were meeting their needs or even causing additional distress, so we determined to survey our 2011 stillbirth group to discover what they felt about the care they had received.

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Aim. To refine our practice based on the detailed feedback of our specific patient group.

Method. There were 30 stillbirths in CUMH in 2011. Two cases were excluded on the grounds that one had just had another baby so we felt it would be inappropriate to introduce a detailed questionnaire on stillbirth, and the other had previously requested to have no contact with the hospital. The remaining 28 mothers were contacted by telephone to explain the objectives of the survey and obtain their verbal consent. All agreed to participate. Two copies of the questionnaire were sent to each home, one for each partner. It was clearly stated both verbally and in writing that support from the bereavement team was available should the material open up painful memories.

Results. Within 3 weeks we received 18 responses i.e. 10 from mothers and 8 from fathers. We then sent a generalised thank you/reminder via text message. We are currently awaiting further responses.

Of the 18 responses received to date:

- Each parent within a couple seemed to concur with the other's perception of care
- 2 out of 8 fathers specifically valued support with funeral arrangements
- Spending time with their baby was very important for 12 of the 18 responders
- The 2 unanimously "strongly" important aspects of care were "kindness and sensitivity of staff" and "medical management"
- 3 responders highlighted their distress relating to having buried their babies prior to receiving notification that certain organs had been retained at autopsy
- When receiving bad news regarding the death of their baby, all 18 said it had been delivered with sensitivity, 4 said it was somewhat unclear and ambiguous and 7 did not receive adequate written information/contact sources.
- 9 respondents didn't meet or didn't know if they had met the consultant in charge of their care

Discussion. These findings and others clearly identify routes for modifying the care we provide. By prioritising our bereaved parents' views, we consider that this initiative, in itself supports and expands an open culture in which we collaborate with and empower our parents in their continuing grieving process.

➔ A-05

Almeida M, Alencar GP, Ortiz Flores LP, Pereira da Silva Z, dos Santos PC, Raspantini PR. (Gizelton P. Alencar presenting)
University of São Paulo; Fundacao SEADE, Brazil

CONTRIBUTION OF FETAL DEATHS TO THE INCREASE OF PRETERM BIRTHS IN SÃO PAULO STATE, BRAZIL

Introduction. Preterm births have increased in recent years in the state of São Paulo, in a scenario expanding access to prenatal care and childbirth and reduction of fertility rate. One possible explanation is the reduction in fetal mortality rate.

Materials and Methods. We obtained the total number of pregnancies by the sum of live births and fetal deaths according to gestational age (GA). We excluded live births and fetal deaths with gestation length ignored. The prenatal care was evaluated based on the number of appointments of live births. The study period was from 2000 to 2009. We obtained specific rates of fetal mortality by gestational age. We employed exponential regression to evaluate time trend of preterm births and fetal mortality rates.

Results. The number of pregnancies rose from 672,767 in 2000 to 599,336 in 2009. The proportion of preterm births grew by 2.1% per year ($y = 9E-18e0,0206x$; $R^2 = 0,9476$) during this period reaching 8.6% in 2009. During this period the fetal mortality rate decline of 4% per year ($y = 7E+35e-0,0401x$; $R^2 = 0,8986$), it was 13.1 per thousand births in 2000 and 8.9 in 2009. There was a reduction of 16% in the participation of fetal deaths in pregnancies of gestational age less than 28 weeks between 2000 and 2009, the reduction was 6.5% for pregnancies of subgroup of 28-31weeks length and in pregnancies 32-36 weeks of 2.1%. Virtually there was no change of fetal deaths participation in full-term pregnancies (37-41 weeks). There was a reduction of the specific fetal mortality rate of 32% in the gestational age group of less than 28 weeks of gestation, 33.5 % in GA group 28-31 weeks and 21.1% GA group of 32-36 weeks. As a result of these reductions there was an increase of preterm survivors. Prenatal care data was available only for live births in this period. There was a decreased in the proportion of live births with no access to prenatal care of 1.9 % to 1.2 %, with 4 a 6 consultations 30.6% to 18.5% and an increase of live births with 7 or more visits, it rose from 60.9% to 76.7%.

Discussion. Vital statistics data may help to identify change patterns of pregnancies. The reduction of fetal mortality may contribute to the increase in preterm births in São Paulo. Increased access to prenatal care may also have played a role in reducing fetal mortality and increased survival in preterm pregnancies. Although the effect of health services alone could not lead these pregnancies to be full term, others risk factors are also present, as maternal affections, multiple births and changes of maternal reproductive profile.

➔ A-06

Almeida M, Schoeps D, Alencar GP, Minucil EG, Pereira da Silva Z, Ortiz LP, Dutilh Novaes HM, Alencar AP, Raspantini PR, dos Santos PC. (Zilda P. Silva presenting)
University of Sao Paulo, Brazil; Fundacao SEADE, Brazil

AUTOPSY AND INFORMATION QUALITY OF FETAL DEATH CERTIFICATES IN SÃO PAULO CITY, BRAZIL

Introduction. High proportion of fetal deaths occurred in Public Health System hospitals are sent to coroners' office to be autopsied in São Paulo City,

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Brazil. Autopsy is supposed to furnish information of better quality to death certificates.

Methods. A sample of 40% of the deaths certificates (212) from fetal deaths occurred in public system hospitals was studied. Data completeness and underline cause of death of the deaths certificates fulfilled by hospitals and CO were compared. Interviews were performed with hospital and coroners office professionals. The fetal deaths certificates were issued in the 1st semester 2008.

Results. Public System Hospitals respond for 57.5% of all deliveries in São Paulo city in the 1st semester 2008; 78.5% of fetal deaths from these hospitals were sent to coroners' office (CO) to be autopsied. CO issued 140 death certificates and hospitals 72.

The removal of the fetuses from the hospital to CO occurs after a police report issued by the police station near to the hospital. The families are sent to the police station to request police reports to transport the fetuses. On the sample of fetal deaths studied 90% of the police reports were requested by family members and 10% by hospitals professionals. Two causes of deaths respond up to 90% of death certificates issued by CO: fetal death unspecified cause (65.8%) and intrauterine hypoxia (24.3%). The main causes from hospital death certificates were: intrauterine hypoxia (41.7%); fetus affected by maternal complications of pregnancy (19.4%); fetal death unspecified cause (18.1%). CO death certificates showed a significant lower completeness for mother's age (39.2%); parity (29.9%); type of gestation (3.9%) than those fulfilled by hospitals. A high completeness of gestational age and sex (over 95%) was found and there was no statistical difference between death certificates issued by CO and hospitals. Birth weight completeness was significant higher in CO death certificates (99.3%) than deaths certificates fulfilled by hospital.

Discussion. The high proportion of fetal death certificates emitted by CO can be related to the combination of three factors: a) performance of fetal autopsies is thought to improve the identification of cause of death by obstetricians; b) the high proportion of antepartum fetal deaths (approximately 90%) combined with the lack of integration between prenatal care and delivery, in the woman's health records not being sent to the delivery hospital; c) the reluctance of health professionals to report unfavorable outcomes. These factors can incentivize obstetricians to judge antepartum fetal deaths as undefined deaths and to refer them to autopsy. CO does not have accesses to hospital records, resulting in poor data quality, regarding causes of deaths and other variables. Instead of receiving social support to face fetal loss, families were sent to police offices to get authorized file to transport fetus from hospitals to CO.

➡ A-07

Ilse, SL, Steen, S.
ISPID, ISA

TAKING CHARGE AFTER NEWS DELIVERY: BIRTH PREFERENCE PLANNING AFTER STILLBIRTH AND OTHER PERINATAL LOSS

This interactive workshop will invite parents and professionals to understand and discuss why having some control after hearing the news the baby has died or will die decreases shock and helps minimize regrets, promoting healing. The speakers will walk participants through a Birth Preferences Planning process that honors cultural, spiritual, and personal beliefs and needs. Various models hospital, clinic, and community models of pre-planning will be discussed including Loss Doulas, Birth Planners, Clinic-hospital staff collaboration and more. Audio-visuals, Birth Preferences Plans, and research on the importance of rituals in healing will be utilized during the session.

➡ A-08

MacGuire FAS, Renfrew M, McFadden A.
NHS Airedale, Bradford and Leeds; University of York

PREVENTION OF STILLBIRTHS IN HIGH INCOME COUNTRIES: LOCAL UNDERSTANDING IS NEEDED TO DRIVE LOCAL ACTION

The UK's stillbirth rate is relatively high compared to other high income countries. This year, for the first time, stillbirth has been specifically included in the NHS Outcomes Framework. In 2011 the Lancet's Series on Stillbirths called for greater local understanding of causes and risk factors. This study reports on stillbirth rates in Bradford, a post-industrial city in England, where rates are higher than the national average at around 7.5 per 1000. This case-study featured as part of a review of the evidence base for the prevention of stillbirth.

Methods. Structured literature reviews were carried out to assess the evidence base for the prevention of stillbirth, particularly late stillbirth and to examine guidelines for the management of stillbirth with a focus on investigations in unexplained stillbirth.

Data on stillbirth rates in Bradford District from 1996-2009 were compared to England and Wales rates and analysed by gestational age (pre-term and term), maternal age, socio-economic deprivation, ethnicity and baby gender.

A case series of stillbirths in the Born in Bradford (BiB) cohort, a recently established cohort study of 13,766 births, were analysed as part of a pilot study to explore local rates, causes and risks, in order to inform prevention strategies at a local level. Data on fetal and maternal characteristics were extracted from patient records and analysed. Cause of death data were analysed for District stillbirths and the BiB cohort. The BiB data were considered in the context of stillbirth rates for the whole of Bradford District.

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Results. There are no systematic reviews specifically on the prevention of stillbirth although one is underway under the Cochrane Collaboration. Numerous guidelines on antenatal and intrapartum care contribute to the prevention of stillbirth at term. Several countries have specific guidelines for the management of stillbirth, including investigations and bereavement care.

Stillbirth rates in Bradford are higher than the national average and stillbirths at term have increased over the period 1996-2009. The reasons for this are not known.

There were 68 babies stillborn in the BiB cohort. From a statistical perspective only limited analysis could be undertaken. Twenty eight stillbirths were premature (41.2%) and 40 were born at term (58.8%). The higher proportion of term stillbirths reflects the findings for Bradford District. Ethnicity, socio-economic deprivation, and post-dates gestation appeared to be risk factors.

Cause of death was coded as unspecified in around 70% of District cases and in 78% of BiB cases. This is higher than is usually reported in the literature.

Discussion. A range of obstetric and public health guidelines are relevant to the prevention of stillbirth. However, these need to be consolidated to enable practitioners to focus on prevention. Bradford's higher than national average stillbirth rates and the increase in stillbirth rates at term require further investigation.

Local information on cause of death is poor. Bradford is a multi-cultural city and this may reflect cultural concerns about post-mortem. However, further exploration of why there is so little information on cause of death is needed, particularly among babies stillborn at term.

➔ A-09

Warland, J.

University of South Australia, Australia

KEEPING BABY SAFE IN PREGNANCY PROJECT

Background. In the Lancet Stillbirth series' (April 2011) Flenady et al demonstrated wide variation in stillbirth incidence (28+ weeks) in high income countries and suggested this meant there is potential for stillbirth rates to lower. One recommendation for achieving this is "public awareness."

Aims and Objectives. This project sought to increase pregnant women's awareness of stillbirth and provide them with protective behaviours to help reduce their risk.

Project Description. In 2010 SIDS and Kids South Australia in collaboration with UniSA conducted a pilot health promotion project titled "Keeping baby SAFE in pregnancy." The pilot sought to establish what women knew about incidence and modifiable risk factors for stillbirth, before and after reading an information brochure.

Results. This poster outlines findings of the pilot project in which there was significant improvement in both, awareness of the incidence of stillbirth, as well as participant's understanding of things they can proactively do to keep baby SAFE. After the pilot study the brochure was revised and the acronym SAFE, (Sleep left, Attend all appointments, Feeling baby move, Early expert advice) used to simplify the message.

Implications. The value of giving written information about stillbirth to pregnant woman and her partner will also be raised. Improving women's knowledge about preventable risk factors for stillbirth may also reduce their risk of suffering this tragedy. However, further quantitative research is required to determine the extent that improving women's knowledge also improves perinatal outcome in the long term. The brochure encourages pregnant women to take a proactive role, in partnership with their care provider, to help keep her unborn baby safe. Copies of the brochure will be available for Delegates.

➔ A-10

Warland, J.

University of South Australia, Australia

DISCUSSING STILLBIRTH WITH PREGNANT WOMEN

Recent research suggests that maternity care-providers often avoid discussing the possibility of stillbirth with women in their care. For example, Pullen and Nalos (2009), miscarriage is presented as a possibility by the care-provider only 48% of the time and stillbirth only 11%. The reluctance to discuss this kind of poor outcome often is from a wish to avoid "scaring the woman" however, not to do so is missing an opportunity to educate and alert the woman to adopt behaviours to help keep her baby safe.

Maternity Care providers should provide women with sufficient and accurate information to enable them to be have freedom to be self-determinant and autonomous when making choices in relation to their care. This type of care ensures women are informed and given every opportunity to be advocates of their own experience with the knowledge and understanding to make informed decisions.

However, raising and discussing sensitive topics such as stillbirth during antenatal care can be problematic. Walking the fine line between informing the

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woman and scaring her with too much information is often a challenge. Rather than having a conversation on what can go wrong during pregnancy, more beneficial would be for midwives to have an ongoing dialogue that encourages parent's sense of empowerment, awareness, and intuitive knowing of their unborn baby. Antenatal visits would then shift concentration from maternity care providers imparting knowledge; to parents sharing what they are learning about their baby with their provider at each visit.

This paper will suggest a method for sensitively raising and discussing the possibility of stillbirth with pregnant women. By using the keeping baby SAFE in pregnancy brochure (see poster) provides one means to raise and discuss Stillbirth with women. In particular the suggestion will be made that if maternity care providers raise the topic of stillbirth as important and also give information to women about what they can actively do to minimise their risk of stillbirth then this information will empower and enable women to keep her baby safe.

➡ A-12

Lindgren H, Rådestad I, Malm, MC. (*Ingela Rådestad presenting*)

Sahlgrenska Academy, University of Gothenburg; Sophiahemmet University College; Dalarna University, Sweden

YOU DON'T LEAVE YOUR BABY – MOTHER'S EXPERIENCES AFTER A STILLBIRTH

Introduction. When a baby has died during pregnancy the first encounter between mother and child occurs when the baby is already dead. Despair, emptiness and grief characterize the encounter, which is also a gradual farewell to the child and the planned future for the family.

Aim. This study describes mother's experiences of the farewell of their stillborn baby at discharge from hospital.

Method. Twenty-three mothers who suffered stillbirth were interviewed. Semi-structured questions were used and the replies were analysed using content analysis.

Results. The mothers describe the separation from the child when leaving hospital as unnatural and that the separation ruins the motherhood they felt during pregnancy. Five categories were identified: Unnatural to leave the baby; Going home empty-handed; Access to the child; Security and insecurity in the separation; To let go. The overarching theme that we recognized from these responses we have formulated as: You don't leave your baby.

Discussion. Leaving the baby at the hospital goes against the biological instinct to care for and protect the offspring. Routines for a dignified goodbye including designating a deputy guardian into whose arms the mother can place the baby can help to facilitate the separation. The possibility of leaving the baby in the arms of someone known to the parents should be an option for parents who choose to take farewell of the child at the hospital. The place and time for the farewell should be decided on by the parents, taking the baby home for a personal farewell could be an alternative.

➡ A-13

Itkonen, JMO.

University of Helsinki, Finland

EFFECTIVE SUPPORT IN THE LIGHT OF COMMUNICATIVE ACTION THEORY - NARRATIVES ABOUT HAVING A STILLBORN CHILD AND HELP OF THE CHURCH

This paper aims to find out how employees of the Evangelical Lutheran Church in Finland support parents of a stillborn child. My study is qualitative with a narrative point of view. The data was collected by 15 interviews. The interviews revealed stories about grieving parents trying to get help from the church and health care services. In some cases help and support were received and in some cases they were not.

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. To support this finding and to shed more light on supporting bereaved parents, I am using a theory roughly based on Jürgen Habermas' theory of Communicative Action (Habermas 1987). I apply this theory to the situation of having a stillborn child.

The basic idea of Habermas' theory is that the systems of politics and economics have become so complex that they have alienated from the life-world of ordinary people. The system-world and the life-world do not communicate with each other. The only place where communication between life-world and system-world can be successful from the life-world point of view is in a hierarchy-free zone of communication. Habermas' original theory operates in the level of society and tries to find a way to enhance civil activity. In my research I apply it to the field of social support in a manner that Habermas has not done.

Institutions such as traditional churches and big hospital units could be seen as systems that function with their own ways and needs of communications. Based on my findings, effective emotional support of these kinds of systems can happen only in a hierarchy-free zone of communication. Some other forms of support (e.g. medical, information based, financial) could probably be given although the communication is not hierarchy-free, but it may leave emotional wounds and increase the need of emotional support at a later stage. Thus, it could be wise to employ a hierarchy-free zone of communication in giving other forms of support as well, if possible.

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This theoretical perspective does not give ideas of support only to churches and parishes, but also to hospitals and other institutions or communities that are aiming to help bereaved people regardless of the age of the deceased child or the manner she/he died.

➔ A-14

Perhach M, Russell D.

Group B Strep International, USA

THE POWER OF PARENT ADVOCACY: A ROADMAP FOR 1) MOBILIZING PARENTS AND OTHER ADVOCATES WORLDWIDE TO REDUCE FETAL AND NEONATAL MORBIDITY AND MORTALITY CAUSED BY GROUP B STREPTOCOCCUS INFECTION, AND 2) PROVIDING TOOLS AND LESSONS LEARNED THAT CAN BE APPLIED TO SIMILAR ADVOCACY EFFORTS TO IMPROVE MATERNAL, FETAL, AND NEONATAL HEALTH OUTCOMES.

Introduction. Group B Streptococcus (GBS) is now recognized to be an important cause of maternal and neonatal morbidity in both developed and developing countries (Joachim and Matee, 2009). Further, it is estimated that between 10% and 25% of stillbirths in developed countries may be caused by infection; in developing countries, it is thought the contribution of infection is much greater (McClure and Goldenberg, 2009).

This workshop will 1) show how parents in the United States successfully influenced the adoption of new national guidelines in 2002 for screening all pregnant women for GBS and treating GBS positive women during labor and delivery, resulting in a 65% reduction in cases, and 2) provide tools and lessons learned that can be applied to GBS advocacy efforts in countries around the world as well as to similar advocacy efforts aimed at improving maternal, fetal and neonatal health outcomes.

Intended Audience. Parents and Advocates for Healthy Babies

Objective. To share what has been learned to facilitate the efforts of parents and other advocates worldwide in improving maternal, fetal, and neonatal outcomes.

Key Discussion Topics.

How to engage stakeholders and gather data to support your effort

How to mobilize other parents

What is more powerful: stories or data?

How do we initiate efforts in low-resource settings where data are often missing?

How to implement effective awareness campaign strategies

➔ A-15

Waelput A, Eskes M, Bremmer-Bolhuis WTL, Erwich JJHM, Van Swigchum FM.

Foundation Perinatal Audit in the Netherlands (PAN)

THE IMPLEMENTATION OF PERINATAL AUDIT IN THE NETHERLANDS NATIONWIDE INTRODUCTION OF PERINATAL AUDIT IN 93 CENTERS IN THE NETHERLANDS

Introduction. In the Netherlands the perinatal mortality is relatively high compared to other European countries. The use of perinatal audit as a quality instrument for the improvement of the quality of obstetric care has been a longstanding wish of all professionals involved.

Methods. From 2007 onwards, the Ministry of Health funded the implementation of perinatal audit. In 2010 (internal) perinatal audit was introduced nationwide, through the obstetric collaborative groups (n=93). These groups of professionals in primary, secondary and tertiary obstetric care are responsible for the provision and quality of perinatal care in the Netherlands.

An audit methodology, which was piloted in the Northern provinces of the Netherlands, is introduced in these groups. Professionals are trained in the basics of audit and a registry, based on the Netherlands Perinatal Registry, is set up for the case notes.

Results are registered in a web-based application. Nine regional teams support the local groups during the preparation of cases to be audited and provide the independent chair of these sessions.

Results. It was possible to introduce formal perinatal audit sessions, at least twice-yearly, in all obstetric collaborative groups. Midwives, GP's, gynecologists, pediatricians, nurses and others involved identified substandard factors (SSF) in the care and the relation between the SSF and perinatal death. Actions for improvement are formulated and acted upon within the groups.

Conclusion. Motivated professionals, training, methodology and support succeeded in successful implementation of perinatal audit in all obstetric units in the Netherlands.

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➔ A-16

McGregor JA, French JI, Perhach M.

USC Keck School of Medicine; LA Best Babies Network; Group B Strep International, USA

PRIMARY AND SECONDARY PREVENTION OF FETAL DEATH CAUSED BY INFECTION AND/OR INFLAMMATION

Introduction/Background. Preventable reproductive tract infections are increasingly recognized as direct causes of death in the 20-40% of fetal deaths and stillbirths worldwide.

Objective. Develop “gedenken” (thought-based) strategies to prevent infection-caused fetal loss.

Methods. Medical knowledge review and synthesis. Perinatal lethal infections are known to be caused by various potentially preventable pathways:

- 1) bloodborne (via maternal circulation) infection of placental tissues, umbilical cord, amniotic fluid,
- 2) ascending infection through the cervix, decidua, and amniochorion,
- 3) iatrogenic infection (amniocentesis, membrane stripping),
- 4) preexisting (prepregnancy) endometrial infections, and
- 5) zoonic bloodborne infections.

More recently recognized or unfamiliar “pathogenic pathways” include:

- 1) combined bacterial and viral infections in which viral infection or maternal-fetal “mismatch” sensitized the placenta to the effects of LPS (lipopolysaccharide),
- 2) “graft vs. host” phenomena by which prior infections could amplify production of HSPs (Heat Shock proteins) and other “immune molecules”, and
- 3) sterile inflammation or “autophagic” stimuli (caused by small particles or increased cell death from any cause).

Results/Discussion. Successful primary and secondary prevention strategies include:

- 1) recognition and documentation of stillbirth; implicated microorganisms,
- 2) development of simple, inexpensive, accurate means to identify causal agents and boost host response mechanism,
- 3) formulate means to prevent infections, such as GBS and/or STI pregnancy infections,
- 4) recognize how systematic vaccination programs may prevent intrauterine infections (influenza, measles, rubella), and
- 5) formulate evidence-based strategies to systematically prevent infection-caused late miscarriage, stillbirth, or neonatal infection.

➔ A-17

McGregor JA, Parsons AK, French JI, Perhach M.

USC Keck School of Medicine; LA Best Babies Network; Group B Strep International

HOW DO MICROORGANISMS GAIN ACCESS INTO THE UPPER REPRODUCTIVE TRACT?

Introduction/Objective. Provide insight into how microorganisms may gain access to the upper reproductive tract (uterus, fallopian tubes) in order to develop primary prevention strategies against infection-caused late miscarriage and/or stillbirth or perinatal infection-mediated neonatal death.

Materials. Vaginal ultrasonography with ultrasound contrast media

Methods. We conducted timed vaginal ultrasound observation using Albuminex™ ultrasound contrast media composed of bacteria-sized air bubbles. Five cc's of Albuminex™ were placed in the mid-vagina of a 24 year old woman on day 14 of her ovarian cycle and the midvagina of a second woman at 38 weeks gestation with an intact mucous plug who was similarly examined.

Results. The ovulatory woman demonstrated easily observed active uterine transport of ultrasound media through the cervix and into the uterus and fallopian tubes. Similarly, there was an easily observable passage of ultrasound contrast media through the cervix and into the lower uterine segment when the pregnant woman's cervix was lightly touched.

Discussion/Conclusion. These timed observations confirm “active transport” of microbe-sized particulate matter into the upper reproductive tract during both late pregnancy and midovulatory cycle. This phenomenon of “upsuck” was well documented in animal models and fertility patients. Strategic risks of ascending infection could include:

- 1) Screening and treating for abnormal microflora prior to preconception or EARLY in pregnancy; or
- 2) Empiric antimicrobial or probiotic treatments

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➔ A-18

Gardiner PA, Humphrey M, Cooke L, Panaretto K, Woodgate P, Middleton P, Flenady V. (*Vicki Flenady presenting*)
Ipswich Hospital and Mater Medical Research Institute; University of Queensland and Queensland Aboriginal and Islander Health Council; The University of Adelaide and Women's and Children's Hospital, Australia

ADDRESSING THE CALL TO ACTION: DISPARITIES IN STILLBIRTH AND NEONATAL DEATH BETWEEN INDIGENOUS AND NON-INDIGENOUS AUSTRALIANS

Introduction. In Australia, Indigenous babies have significantly worse perinatal mortality rates when compared with non-Indigenous counterparts, e.g. Australia has the 15th lowest rates of stillbirth internationally; however Indigenous babies have twice the risk compared to non-Indigenous women. This study answers the call to action for priority research in high income countries in the Lancet's Stillbirth Series. It investigates the disparity in stillbirth rates and neonatal deaths between Indigenous and non-Indigenous babies in Queensland, Australia.

Methods. Queensland perinatal mortality data from 1995-2008 were examined for rates of stillbirth and neonatal death. Obstetric antecedent factors and neonatal conditions, using Perinatal Society of Australia and New Zealand perinatal and neonatal death classifications (PSANZ-PDC and PSANZ-NDC) were reviewed to assess clinical differences between the two groups.

Results. In Queensland, during the years 1995 to 2008, 40,001 Indigenous babies were born in a total of 724,585 births; 5.5% of births. The perinatal mortality rate for Indigenous babies was 19.8 per 1,000 births, compared with a non-Indigenous perinatal mortality rate of 10.1 per 1,000 births (RR 1.97, 95% CI 1.83, 2.12). The stillbirth and neonatal mortality rates were both raised to a similar extent (12.0 vs 6.5, 7.9 vs 3.5 respectively). Spontaneous preterm birth (2.5 vs 0.8, RR 3.06, 95% CI 2.47, 3.78) and unexplained antepartum death (3.3 vs 2.0, RR 1.60, 95% CI 1.34, 1.91) showed the most marked differences for stillbirth, while almost all PSANZ-PDC categories were approximately double or more for neonatal death. Extreme prematurity was the standout difference in PSANZ-NDC classification (3.2 vs 0.9, RR 3.46, 95% CI 2.86, 4.20) but all classification groups were increased for Indigenous babies. For stillbirth, the greatest contributors to disparity were unknown/unspecified for no obstetric antecedent, syphilis, and essential hypertension (all RR > 3.8).

Discussion. Stillbirth and neonatal death rates for Indigenous babies was increased in almost all PSANZ-PDC categories. Preterm birth and preventable maternal conditions are important contributors to the disparity in perinatal mortality rates for Indigenous births in Queensland. The higher proportion of unexplained stillbirths for Indigenous women suggests the need for improved data quality.

Data Source. Perinatal Data Collection, Queensland Health (extracted 12 September 2011) Prepared by: Statistical Output, Health Statistics Centre, Queensland Health

Data Analysis and Interpretation. Queensland Maternal and Perinatal Quality Council

➔ A-19

Hoffman-Sage Y, Fretts R.
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CHARACTERISTICS AND PREGNANCY OUTCOMES OF WOMEN PRESENTING WITH DECREASED FETAL MOVEMENT

Introduction. Women presenting with decreased fetal movement (DFM) in the third trimester are believed to be at increased risk of growth restriction, preterm birth, and stillbirth. We wished to evaluate the pregnancy characteristics and outcomes of women presenting to our triage unit for DFM.

Methods. All women who presented in the third trimester from October 1, 2010 to September 30, 2011 at our institution's triage were identified if the initial complaint was DFM. Demographics, pregnancy characteristics, and obstetric outcomes were compared to all women delivering at our institution during the same time period.

Results. 371 women presented for DFM, representing 5% of the 7595 deliveries during this period. 7 were diagnosed with fetal demise on presentation. Women were at a mean of 35, and median of 37, weeks' gestation on presentation. They delivered on average at 39.0 weeks, similar to the average gestational age of 38.8 weeks for our population. 10% delivered prior to 37 weeks, similar to 12% overall. 60% with DFM, compared with 47% of the total population, were nulliparous ($p < 0.01$). Of those presenting with DFM, 38% were white, compared with 52% of the total obstetric population ($p < 0.01$). 23% were black and 26% Hispanic, compared with 17% and 16%, respectively, in the general population ($p < 0.01$ for each). Mean birth weight was similar to the entire population: 3188 compared to 3229 grams ($p = 0.30$). However, 16% of neonates born to women experiencing DFM weighed <10%ile for gestational age at birth, compared with 10% of the total population ($p < 0.01$). 30% of babies born to mothers with DFM required neonatal intensive care admission, compared with 15% of neonates overall ($p < 0.01$). 47% with DFM were induced, compared with 23% rate overall ($p < 0.01$). Cesarean delivery rate was 32% among women with DFM, identical to the rate for the entire institution during those months. The rate of cesarean following induction was 19% for those experiencing DFM, compared to 23% overall.

Conclusions. Women presenting with DFM were more likely to be nulliparous and black than in our total obstetric population. While mean birth weight was similar to the general population, the 16% rate of small for gestational age was significantly higher than our population rate. 30% of neonates born to

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mothers experiencing reduced fetal movement required an intensive care admission; this was despite an average gestational age at delivery comparable to our entire obstetric population. Though their providers were more likely to induce them, their cesarean delivery rate was unchanged. This study demonstrates that, at our institution, women presenting with DFM tend to be at elevated risk of adverse pregnancy outcomes based on their demographics and baseline characteristics. Considering this cohort at higher risk of stillbirth, a tendency towards more liberal use of induction of labor for these pregnancies, without an increase in cesarean rates, appears warranted.

➔ A-30

Ward, J.

Foundation for the Study of Infant Deaths, United Kingdom

PROJECT INDIGO: DETAILED ANALYSIS OF UNEXPECTED INFANT DEATHS IN LONDON

Introduction. Project Indigo, launched in 2004, is the Metropolitan Police's response to the unexpected death of all children under two years of age within Greater London. The Project provides a sensitive, professional response to incidents of infant death by the police, but also involves a comprehensive data collection process through the use of a standardised form, completed by trained officers. Regular analysis of this dataset is also conducted as part of Project Indigo, exploring a range of geographic and demographic variables in cases of SUDI. Existing and emerging trends from the data, including medical and behavioural risk factors, are investigated to try and prevent future infant deaths.

Methods. Data was analysed from 464 deaths over a 5 year period, from January 2005 to December 2010. Of these deaths, 256 were SUDI (Sudden unexplained Death in Infancy) and 208 medically explained. The focus of the analysis is on SUDIs, but comparison with medically-explained deaths has also proved useful. Particular areas of focus in relation to SUDIs include medical issues, social factors such as deprivation and household structure, and also issues of care practice.

Results. London data highlights a strong deprivation correlation, with 1 in 3 cases of SUDI taking place in the most deprived 20% of London. Decreases in infant death have largely been apparent in the least deprived areas, with a 9% increase in the most deprived areas over the study period. Geographical variations largely highlight deprivation, with 42% of all SUDIs occurring within 7 of London's 32 Boroughs.

Ethnic minorities are disproportionately represented in London's most deprived areas, yet the black population is significantly over-represented in cases of SUDI, with the Asian population less so. This may reflect the presence and absence of risk factors amongst these households.

Established risk factors for SUDI are visible within London. 50% of deaths are in a co-sleeping environment, 54% are linked with parental smoking, and 43% with alcohol. Of the co-sleeping deaths, less than one third slept the baby in the parental bed in normal practice, highlighting a range of situational factors. It is also observed that at least one parent had a criminal conviction in 44% of SUDI cases. A range of theories concerning this are addressed.

Discussion. The dataset generated by Project Indigo is one of the largest and most detailed available in the United Kingdom. It is also collected as part of a comprehensive partnership strategy in relation to SUDI in London and there is immense value in being able to collect and disseminate findings from the data so quickly. Indigo provides an evidence base for a range of public and third sector organisations, enabling those working within London to highlight key behaviours and communities to target and work in relation to. Additional work needs to be done to develop channels of communication to these often hard to reach populations, particularly in relation to the need for consistent infant care practices, even as the families experience difficult circumstances. Joint working with other agencies is essential to reduce infant deaths.

➔ A-31

Aho AL, Jaana M, Uittomachi S, Marja K. (*Susanna Uittomachi presenting*)

University of Tampere, School of Health Sciences, Finland

PARENTS' TRAUMATIC STRESS AND THE FACTORS ASSOCIATED WITH IT BEFORE AND AFTER A FAMILY-WEEKEND

Introduction. Parents have experienced peer-support as positive after the death of their child. However, the research is lacking from the effect of peer-support on parents' grief and coping. In Finland, Child Death Families (KÄPY ry.) organizes family-weekends, during which parents who have lost a child have a possibility to meet each others. The program consists of thematic peer groups, expert lectures about different grief topics, collective family memorial service, and also time to socialize. The aim of this study was to describe the effect of the family-weekend intervention for parents' traumatic stress and the factors associated with it.

Methods. A pre- and posttest control group design was used to evaluate the differences in traumatic stress reactions between parents two weeks before and two weeks after the family-weekend. The sample consisted of 110 parents, who participated in the family-weekend. Data were collected by using the Impact of Event Scale-R -measure and background variables. The data were analyzed statistically.

Results. Two weeks after the family-weekend the parents traumatic stress reactions in Intrusion or Avoidance scales were not statistically significantly different than before the intervention. However, almost half of the parents reported larger scores in Intrusion and smaller scores in Avoidance after the family-weekend. In addition, almost half of the parents experienced the family-weekend supporting them much or very much. The results will be presented in the conference.

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Discussion. The results suggested that the family-weekend has an effect on parents' traumatic stress reactions and they experience it positively. There is a need for a longer follow-up study to indicate the effect of the family-weekend.

➔ A-32

Aho AL, Savolainen SI, Kaunonen ME. (*Susanna Uttomachi presenting*)

University of Tampere, School of Health Sciences, Finland

FACTORS THAT HELP AND FACTORS THAT HINDER THE COPING OF PARENTS WITH A CHILD'S DEATH

Introduction. The purpose of the study is to describe factors that helps and factors that hinders the coping of parents with a child's death. The aim of the study is to generate knowledge of the parents' coping that can be used in the development of nursing practice.

Methods. The study participants (n=245) were grieving mothers (n=143, 58%) and fathers (n=102, 42%) whose child had died at the age or three years and younger (including perinatal deaths at 22 weeks gestation or fetuses over 500 g) at University hospitals (N=5) in Finland. The data were collected by a questionnaire with two open-ended questions: (a) What helped you to cope with your grief; (b) What hindered you from coping with your grief. The questionnaires were posted to the participants six months after the child's death. The consent to participate was obtained both from the mothers and the fathers.

The data were analysed with inductive content analysis. Altogether 3404 expressions of the factors that helped or hindered the coping of parents were found, including 2579 (76%) from the mothers and 824 (24%) from the fathers. The expressions were organised into themes by seeking similarities and differences. The themes were classified into subcategories and further combined into categories and main categories.

Results. The preliminary results indicate that good care of the child's disease and facing the child's death, social support after the child's death, and active grieving were factors that helped parents' coping. Factors that hindered parents coping were the unsatisfactory care of the child's disease and facing the child's death, missing or inconvenient social support after the child's death, and clinging to the grief. The final results of the study will be presented at the conference.

Discussion. This study provides knowledge of the coping of parents to all who face a child's death. Challenges for the future are developing practice that takes parents' needs into consideration, developing different forms of social support, and developing interventions that promote parents' active grieving.

➔ A-33

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University of Louisville, USA

A PSYCHOMETRIC EVALUATION OF THE PERINATAL GRIEF INTENSITY SCALE

Introduction. The Perinatal Grief Intensity Scale (PGIS) has been developed as a clinical instrument to assist healthcare providers to determine which parents are most likely to experience significant grief after a perinatal loss and to feel angry and victimized by their loss experience, which may complicate their grief. It is based on the notion that parents experience more significant feelings of grief when the pregnancy and baby are perceived as real (high Reality); there is little congruence between the actual loss experience and how a parent perceives it should unfold (low Congruence); and there is limited ability to make decisions or act in ways to increase this congruence (low Confront Others). This is the second psychometric evaluation of the PGIS.

Methodology. A web-based survey was used to collect data from 447 primarily white, middle-class women. 192 (42.9%) participants completed the PGIS. Of these, 81 had a miscarriage, 69 had a stillbirth, and 42 had a neonatal death in the previous pregnancy. The PGIS was used to evaluate grief extending into the subsequent pregnancy.

Results. Exploratory factor analysis suggested a three factor solution, retaining all 14 items of the PGIS, and accounting for 66.94% of the variance. Factor 1 accounted for 34.62% of the variance and included eight items (8/14) which loaded in the original factor analysis as Congruence and Confront Others. Factor 2 included three (3/14) items associated with whether the pregnancy felt real to the mother. Factor 3 included three items (3/14) associated with the degree to which parents had assigned personhood to the baby, accounting for 10.19% of the variance. Factor 2 and 3 items loaded in the original factor analysis on the Reality subscale.

Cronbach's alphas for the PGIS scale and subscales were 0.75 (PGIS Total), .80 (Reality), 0.80 (Congruence), and 0.82 (Confront Others), indicating good reliability.

The previous neonatal death group reported a higher PGIS mean score ($X^2=3.97$), indicating a more significant grief response when compared to the stillbirth group ($X^2=3.92$; $P=0.002$) and the miscarriage group ($X^2=3.84$; $P=0.007$). No differences were found in the significance of the grief response when the stillbirth ($X^2=3.92$) and miscarriage ($X^2=3.84$) groups were compared ($P=0.08$).

Conclusions. This instrument is needed to help clinicians more easily identify parents in need of follow-up after perinatal loss. The PGIS demonstrated acceptable reliability and validity in identifying grief in this sample of women in subsequent pregnancy after loss, and supported the conceptual relationships of the PGIS. Further testing in a longitudinal study directly after perinatal loss is needed.

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➔ A-34

Cowan SF, Reardon C, Houston J.

Change for our Children, SmokeChange, New Zealand

WOMB FOR IMPROVEMENT: WHERE IS THE ACTION ON SMOKING IN PREGNANCY?

Introduction. Smoking in pregnancy is well-established as a major preventable risk factor for adverse outcomes in pregnancy, infancy and childhood. Of specific concern to delegates of this conference is reducing stillbirths and sudden infant deaths. Both are likely to reduce significantly from increasing smokefree pregnancies, with a resulting cascade of other benefits, too. Why then is the level of action on smoking in pregnancy far from its priority status as a risk to infant life? Is it that smoking is considered 'non-modifiable' and attention is placed on interventions considered more amenable to change, such as safe sleep initiatives? With an estimated 1 in 4 pregnancies exposed to smoking in New Zealand, there is considerable room for improvement in enabling effective action. This presentation uses the framework of programme logic (need, action, impact, outcome) to describe two replicable approaches to changing smoking in pregnancy.

Method. A) A personalised programme of intensive smokefree support for pregnant women and their partners operates in Christchurch and South Auckland, New Zealand. It is designed to 'bring in the new (smokefree) alongside what it will replace (smoking)' as a strategy for building self-efficacy in 'low ready' participants. An eight item readiness tool is used to monitor personal progress and service effectiveness. B) More recently, a complimentary intervention taking a 'whole of community' approach was implemented into South Auckland where smoking in pregnancy rates and health inequalities, generally, are the highest in the country. As part of this approach, identified family members of women referred to the intensive service, were trained as champions of smokefree pregnancies and supported to influence two key conversations within their networks of family and friends: why a smokefree pregnancy is so important, and how to support smokefree change. Programme data from both approaches were analysed and are presented in this talk. **Results.** Over three years the personalised service enrolled a total 1139 participants who were pregnant and smoking at the time. A total 324 (28.5%) of these were smokefree at exit (> 7 days) six months on, at a cost of USD\$2250.00 per mother-baby pair. Sixty per cent of this smokefree group were women assessed as 'low ready' at enrollment. While smokefree rates at exit were higher for 'high ready' versus 'low ready' women (50% vs 23%), actual numbers of 'high ready' women were lower (129 vs 195). In its first year, the 'whole of community' approach recruited more than the goal of 80 family members into the champion programme. Champions were required to provide evidence of their first ten conversations and more than 800 were recorded.

Results. Over three years the personalised service enrolled a total 1139 participants who were pregnant and smoking at the time. A total 324 (28.5%) of these were smokefree at exit (> 7 days) six months on, at a cost of USD\$2250.00 per mother-baby pair. Sixty per cent of this smokefree group were women assessed as 'low ready' at enrolment. While smokefree rates at exit were higher for 'high ready' versus 'low ready' women (50% vs 23%), actual numbers of 'high ready' women were lower (129 vs 195). In its first year, the 'whole of community' approach recruited more than the goal of 80 family members into the champion programme. Champions were required to provide evidence of their first ten conversations and more than 800 were recorded.

Discussion. Smoking in pregnancy is about two people, one of whom is in a critical process of rapid development. It can and must be changed if we are serious about reducing infant loss from stillbirth and sudden infant death. Action on smoking in pregnancy needs to be elevated to a level that matches its status as a major threat to infant life. There is considerable room for improvement in addressing this priority health issue.

➔ A-35

Cowan SF, Clarke J, Bennett S.

Change for our Children, New Zealand

PEOPLE HAVE SPOKEN: THE RAPID SPREAD OF A SAFE SLEEP SOLUTION FOR BABIES

Introduction. The drives for a baby to be close and a parent to protect are primal. The 'same bed' co-sleeping debate pitches these two drives against each other. When 'close' means 'touch' for a baby, and the need to be held or stroked, then 'in a bassinet beside your bed' will not be close enough. Nor was it safe enough for parents in earthquake ravaged Christchurch in 2011, where two babies were killed in their cots and others toppled from bassinets. Increased risk posed by the aftermath of the earthquakes, led to the supply of 'protected sleeping spaces' (PSS) to safeguard babies when sleeping in unsafe settings, especially when 'same bed' co-sleeping. This presentation describes how recipient families received and used these devices (called pēpi-pods), their rapid spread as a health-funded intervention and recommendations for replication.

Method. The pēpi-pod package was quickly assembled using a general purpose polypropylene storage container. It was fitted with an attractive cover, mattress, and bedding to transform the box into a baby bed that could be used in, or on, an adult bed, on a couch or when away from home. A personalised safety briefing was central to the package, as was the expectation that recipients help spread safe sleep education to others in their networks. The initiative attracted national media attention which facilitated awareness amongst professionals and demand by families. A lead agency coordinated training, communication, supply and demand. A sub-group of early recipients was invited to give feedback on usage via an online survey.

Results. There were 642 PSSs distributed in Christchurch in the first four months. Survey responses were received from 100 (72%) of 139 recipients invited to participate. Respondents included, as risk factors for their babies, bed sharing (41%), smoking before (36%) and during (26%) pregnancy, and prematurity or low birth weight (11%). They reported being thoroughly briefed when they got their PSSs, and had spread safe sleep education to an average 3.5 others per respondent. PSSs were used as instructed with no reported accidents and usage was highest between the ages of eight (70%) and twelve weeks (36%). They were used widely for 'same bed' co-sleeping (87%), for all or most sleeps (44%), and in a variety of places that included beds (89%),

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couches (35%) and floors (33%). Features most appreciated by families were 'having baby close by' (90%), 'peace of mind with the earthquakes' (88%), 'easy to move about' (74%), 'safer bed sharing' (62%) and 'help with settling' (34%). Its value was rated highly by users, at 7-9/9 for 91%, and this value has spread to the health service. By April 2012, there were ten health-funded pēpi-pod services within New Zealand, a collective 3500 PSSs committed as standard issue support for more vulnerable babies and interest growing from other regions and countries.

Discussion. Ordinary time thinking can be a barrier to innovation. In populations and settings where the stakes are high from failed approaches, we need to trade caution for courage and pursue real solutions for safe sleep options for families and health services.

➔ A-36

Mathiesen T, Schrader L.

Norwegian SIDS and Stillbirth Society, Norway

"TELL ME YOUR STORY!"- LEARNING STORYTELLING TECHNIQUES TO COMMUNICATE EXPERIENCES OF LOSS

Introduction. All members of the Norwegian SIDS and Stillbirth Society carry stories about the loss of a child and the impact of such a loss on their lives. These stories are of course significant to the parents themselves, but can also be seen as important resources that can be used as a tool in our efforts to improve the quality of bereavement support services offered by health personnel and other professionals. In addition, the stories can be used as a door-opener to address other issues, for example the prevention of SIDS and stillbirths. A personal story adds credibility and substance, and it takes the listener beyond facts and research findings. To tell a story that touches the listener and at the same time conveys a clear message is however demanding – both emotionally and technically.

Objective. Empower members of the Norwegian SIDS and Stillbirth Society in oral storytelling and engage them as volunteers in communication activities.

Method. In order to increase members' competence and to create a stronger confidence in oral communication of their personal stories of loss, the Norwegian SIDS and Stillbirth Society has organized storytelling courses for members. These courses were led by a professional storyteller. Storytelling as a method differs from what can be called "everyday stories". Storytelling involves prepared and consciously shaped stories that have a special purpose. Thus in storytelling it is important to make choices between what to include and exclude in order to make the story both interesting and effective. Furthermore, it is important to reflect about the purpose when developing the story. The participants learned a range of specific techniques and methods, e.g. how to form a story, creating mental images, using metaphors and symbols, finding the story's turning point and building a plot.

Results. The course in storytelling was very well received by the 15 members who attended the course. The participants reported to have become more confident in sharing their stories and most of them have been engaged as storytellers, either in external settings or within the organization. Some of them have also contributed in fundraising activities. We've received positive feedback from health professionals and other professionals who report to have become emotionally affected by the storytellers. Thanks to the storytellers the Norwegian SIDS and Stillbirth Society has also become more visible in society, specifically among health personnel.

➔ A-37

Mathiesen T, Schrader L.

Norwegian SIDS and Stillbirth Society, Norway

EDUCATIONAL SEMINARS FOR HEALTH PROFESSIONALS; IMPROVING CARE AND FOLLOW-UP OF BEREAVED FAMILIES

Introduction. The Norwegian SIDS and Stillbirth Society is a nationwide organization with activities in the areas of bereavement support, education, prevention and research. The organization's members have experienced the loss of a child in pregnancy, at birth, in infancy or in toddler age. A priority in the Norwegian SIDS and Stillbirth Society is to educate professionals about grief and bereavement support in order to improve their expertise on how to follow-up bereaved individuals and families. The Society has for this purpose developed an educational seminar for professionals addressing care and follow-up of people experiencing grief and crisis. Participants pay a registration fee in order to attend the seminar. Indeed, another ambition has been to make a profit from these seminars.

Target Groups. The seminar is aimed at health professionals (including physicians, nurses, midwives, psychologists and psychiatrists), educators (teachers in schools and kindergartens), social workers, priests, deacons, burial agents, etc.

Content. The main goal of the seminar is to contribute to an increased understanding of grief and the impact of grief on daily life activities. Therefore, the participants learn about how grief and crisis affect people, how it manifests itself and what constitutes good psychosocial follow-up after deaths. We address both a short-term and long-term perspective of follow-up routines. More specifically, the seminar focuses on how you can communicate with and care for bereaved families, how grief can affect sexuality and a couple's relationship, how to support sibling and contribute to a greater understanding of the importance of your professional help and support for bereaved persons. In addition, we address criteria of normal and complicated grief (ref. complicated/prolonged grief is considered as a new diagnosis).

Results. Approximately 670 professionals have attended the five seminars we've so far arranged in various locations in Norway. According to the evaluation, the participants have strengthened their expertise in psychosocial follow-up of people experiencing grief and crisis. In addition, the Norwegian

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SIDS and Stillbirth Society has also become a more known organization among various categories of professionals. We have also made a profit from arranging these seminars.

➔ A-38

Joseph DV, Chong N, Taub N, Rosato E, Shanks M, Petersen S, Wailoo M.
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INFANT CIRCADIAN RHYTHMS – FACTORS AFFECTING THE DEVELOPMENT OF RHYTHMS IN THE POSTNATAL PERIOD

Introduction. In utero, foetal biological rhythms are largely influenced and determined by the mother. In the first postnatal months the infant undergoes a series of rapid physiological changes which result in the development of fully mature circadian rhythms, culminating in sleep consolidation. Infants who demonstrate a delay in physiological maturation, combined with a genetic predisposition are at increased risk of cot death.

The aim of this study was to determine the effect of family factors and those related to sleep environment on the development of physiological maturity and the effect on infant sleep in normal term infants.

Longitudinal measurements of core body temperature were used as a marker of physiological maturity, with concurrent measurements of melatonin, cortisol and circadian gene expression.

Methods. Full term, normal birth weight infants were recruited from 6 weeks of age till 18 weeks. Overnight core body temperature recordings were made in the home setting on a fortnightly basis. Urine was collected for melatonin estimation, and cortisol. Sleep patterns of infants (paired with mothers) were recorded using actigraphy. Mothers collected six hourly buccal swabs from their infants on two consecutive days for each week of the study, for peripheral circadian gene expression estimation. Details of infant sleeping arrangements (bedding, tog value, location, and sleep position) were recorded and validated by direct observation by a trained researcher. Demographic data was collected by form of questionnaire.

Results. 35 infants were recruited into the study. Retention into the study was 100%. Infants in the study were more likely to be breast fed ($p < 0.001$) and were from families from higher socioeconomic class ($p = 0.034$). Fifty six percent of infants were non-smoking households. Three infants had a family history of cot death or apparent life threatening event. Eighty percent of infants room shared $p < 0.001$; $\chi^2 = 12.6$. One infant routinely bed shared. No infants slept prone.

Young maternal age delayed physiological maturation as well being from a poorer economic background. Having a period of minor illness had a deleterious effect on night time melatonin secretion. No factors affected morning cortisol levels. Infants who room shared with the main care giver had increased sleep efficiency. Achieving physiological maturity, using temperature as a marker also increased efficiency.

Discussion. Twenty four hour bio-rhythms are not present at birth. They develop over the first few postnatal months and the rate at which this occurs can be used as an indicator of increased risk to illness and death. Factors, such as young maternal age and being from poor socioeconomic background, cause a disruption to different facets of physiological development. Protective measures such as room sharing have a direct and measurable effect on infant sleep. The interaction between infant physiology and sleep environment as well as the contribution of other factors may offer a possible basis for the further physiological investigation of modifiable risk factors for cot death.

➔ A-41

Lockey, CLM.
Bournemouth, United Kingdom

LIFE AFTER A COT DEATH: A MOTHERS PERSPECTIVE

In November 2004, Chantal Lockey lost her six week old baby daughter to SIDS or "cot death". This devastating loss stemmed a varying degree of emotions in the form of a rollercoaster ride for many years: Anger, denial, shock, guilt, loss, remorse and bitterness. Upon her tremendous loss in 2004, Chantal Lockey sought out support. She was saddened to find that any books on the market were wholly consumed by medical terminology that she did not understand or that were not child specific so very simply, she wrote her own book on her journey after the death of Marnie Mae. The book is real. It is a brutally honest account of the utter devastation in finding her daughter not breathing. The emotional journey that followed and subsequently, the final part of the book that was written almost six years after Marnies death. This part focused on hope and the feelings and experiences associated with having another baby, as well as the utter fear of having to go through it all again. It touches on CONI - Care of the Next Infant, an invaluable service offered in the United Kingdom to parents who have lost babies to cot death. The book has been sent to varying hospitals, coroners offices and funeral homes in their hundreds and the author has befriended many parents who have read the book and have said - quite overwhelmingly, that what parents need who have lost babies to cot death is not leaflets or booklets that are filled with terminology that the average person cannot understand, nor specific information relating to general death and the grieving process. Coping with the loss of a cot death is not the same as losing an elderly relative. The grief and utter devastation at a loss cut short requires a feeling of the parent not "feeling alone", not feeling that they are going insane at the constant rollercoaster emotions that change from minute to minute and being able to relate to somebody else who has gone through the same experience. The Author also found that many parents who have lost children; sometimes do not want to talk face to face or by the telephone. The internet and email seems to be an ever increasing popular way of communicating thoughts and feelings. With this in mind the Author set up a facebook page with an electronic version of Marnies story and this has attracted several hundred people already (<http://www.facebook.com/groups/12325830308/>) and acts as a forum where by the Author

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talks to parents who have lost and where by parents can easily find a group of people who know EXACTLY how they are feeling. The Author strongly believes that this is a vital element in outletting a parents grief and ultimately assisting parents in coming to death with their devastating loss.

➡ A-42

Lang SD, Gilman D, Lang M.

University of Redlands; Guild for Infant Survival, Inland Empire, USA

COPING WITH SIDS DEATH: PERSPECTIVES FROM A JEWISH FAMILY

This talk provides a multi-generational anthropological study of SIDS loss and familial bereavement from a Jewish perspective. The ethnoscientific point of view holds that reality is subjective and conditioned on the mental categories through which one thinks and perceives the world. Thus the journey of a bereaved family is at once a universally devastating human experience that crosses all cultural divides, and a uniquely individual process situated within and dependent on the individual's social and cultural contexts. The contradiction holds; SIDS bereavement entails universal emotions, yet is truly a culturally constructed experience shaped by religious and cultural frameworks. How is Jewish loss different from that of other (Christian) families in the United States? This study looks at an instance of Jewish SIDS loss to gain insight into the culturally constructed processes and unique experiences of bereaved families.

This presentation is also a very much a personal quest; my daughter Micaela died of SIDS on August 27th, 2003. Thus, for this talk, my mother, my daughter, and myself come together to share personal thoughts and insights on nearly a decade of coping with a SIDS death, and, in particular, how our journey has been influenced by our Jewish identity, understandings, and cultural frameworks.

➡ A-43

Colen L, Reynolds J. (*Jessica Reynolds presenting*)

Healthy Start Coalition of Hillsborough County, USA

SAFE BABY: HOSPITAL-BASED EDUCATION PROGRAM TO REDUCE SUIDS AND SIDS

Safe Baby offers hospital and community-based education to teach parents about direct actions that they can take to protect their babies from the main causes of preventable infant deaths in Hillsborough County in Florida. Protective practices include how to choose a safe caregiver, prevent Shaken Baby Syndrome, and promote safe sleep practices. The curriculum is accompanied by an educational DVD and brochure to reinforce parents' understanding of these topics. Parents are also asked to read and sign the "Promise to Protect My Baby" letter to solidify their commitment to keep their baby safe.

Safe Baby was developed in 2009 with funding through the Florida Department of Health acquired to address the findings and recommendations of Hillsborough County's Fetal Infant Mortality Review Committee (FIMR). Findings indicated that more prevention efforts needed to be targeted in the areas of Sudden Unexpected Infant Deaths and Sudden Infant Death Syndrome because of the increase in infant deaths due to suffocation resulting from unsafe sleep environments.

This funding allowed the Coalition to develop a comprehensive, research-based curriculum, a DVD and brochures in English and Spanish, Promise to Protect letters, a Website, and a formal training module for nurses and hospital staff. The campaign was developed to be implemented in hospitals, and then expanded in the community utilizing partnerships to help stop these preventable infant deaths. Safe Baby was written by the Healthy Start Coalition of Hillsborough County based on American Academy of Pediatrics recommendations and modeled after a similar curriculum developed by Dr. Mark Dias' program was implemented in birthing hospitals in Pennsylvania and upstate New York to reduce the incidence of abusive head trauma (AHT) and homicides due to Shaken Baby Syndrome. The program resulted in a 50% reduction in infant AHT.

More than 600 nurses in labor and delivery, pediatrics, mother and baby units and neonatal intensive care units in Tampa General Hospital, Florida Hospital Tampa, Brandon Regional Hospital and St. Joseph's Women's Hospital have also been trained and to use Safe Baby curriculum with patients. Education is delivered to patients postpartum either bedside or through discharge classes. Hillsborough County has more than 16,000 births annually and Safe Baby proposes to reach nearly 100 percent of these parents utilizing broad public/private partnerships.

Currently, Healthy Start Coalition is applying for IRB in three hospitals and has approval for one. Evaluation design and protocol has been determined by an outside evaluation consultant and the agency's Associate Executive Director Leisa Stanley, Ph.D., an epidemiologist who also leads FIMR. Preliminary evaluation results and program design will be reviewed in this presentation.

➡ A-44

Rubens DD, Davis A, McAlpine J, Paterson D, Fleming P, Blair P, Ewer A.

University of Washington, USA; University College London, United Kingdom; Children's Hospital Boston, USA; University of Bristol, United Kingdom; University of Birmingham, United Kingdom

A PROPOSED POPULATION BASED STUDY OF NEWBORN HEARING SCREENING AND THE RISK OF SIDS

Introduction. Despite a 55% reduction in sudden infant death syndrome (SIDS), it remains the leading cause of post-neonatal infant mortality in the US. The ability to detect high risk cases at birth with a currently utilized non-invasive test would be a key breakthrough; targeted monitoring and for the first

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time, therapeutic strategies could be applied to susceptible infants well before a crisis. The response of the inner ear to sound presented via headphones (oto-acoustic emissions, (OAEs)) are routinely measured in the United States and United Kingdom as part of their universal newborn hearing screening programs. The proposed study is based upon two important findings in the last decade: 1) Our initial study demonstrating a suppressed and asymmetrical newborn OAE profile in 31 infants who subsequently died of SIDS compared to 31 control infants^{ref1}; and 2) Reproducible abnormalities in brainstem neurotransmitter systems in SIDS cases related to homeostatic control, particularly in the medullary serotonergic (5-HT) system^{ref2}. Importantly, OAEs are mediated by auditory nuclei that are adjacent to cardiorespiratory-related nuclei in the brainstem and that share the same neurotransmitter systems as those that regulate homeostatic responses. The primary goal is to evaluate in depth, the strength of association between SIDS and newborn OAEs by conducting a population based case-controlled study. The secondary objective is to determine whether the hearing difference is a marker of identified neurotransmitter abnormalities in the auditory and cardio-respiratory brainstem nuclei of SIDS cases.

Methods. The OAE results of babies born in England are stored in an accessible national database; there is no centralized newborn hearing database in the United States at this time. Our proposal is to employ the UK database to undertake a large scale definitive comparison of OAE profiles between controls and SIDS cases. We will include a sample of well-defined SIDS cases (projected n=120) with that of surviving control infants (projected n=360) over a two year period (2013-2014). We will additionally control for a number of epidemiological risk factors including prematurity and maternal smoking during and after pregnancy. Brainstem samples are routinely taken as part of the national postmortem sampling protocol for SIDS cases in England. In addition to obtaining their hearing tests, we aim to accrue postmortem brainstem tissue samples from 25 SIDS cases and 5 autopsy comparator cases (who died suddenly of other known causes) for neurotransmitter receptor analysis over the 2 years of the study.

Conclusion. If we establish a robust association between SIDS and newborn OAEs in the outlined study, we plan in the future to assess the potential implementation of a novel scoring system that would identify infants at high risk for SIDS at birth based upon the newborn hearing test result combined with a comprehensive assessment of identifiable risk factors. This would allow monitoring and intervention strategies to be applied well before a fatal crisis.

➔ A-45

Rubens DD, Allen T, Garcia F, Tang J, Ramirez J-M.

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DOES IMPAIRMENT OF THE HEARING AND BALANCE ORGANS OF THE INNER EAR PLAY A KEY ROLE IN SIDS? EVIDENCE FROM AN ANIMAL MODEL

Introduction. Sudden Infant Death Syndrome (SIDS) remains the leading cause of post-neonatal infant mortality in Western societies. Our 2008 pilot study^{ref1} indicated a suppressed and asymmetrical newborn hearing profile in 31 infants that later died of SIDS compared to 31 surviving control infants. We hypothesize that a pre/perinatal inner ear insult is associated with predisposition for SIDS: An insult may lead to i) cochlear dysfunction resulting in a hearing alteration at birth and ii) vestibular dysfunction precipitating later susceptibility to a fatal event. Previous human and animal studies support an integral relationship between vestibular function and respiration; stimulation of the semicircular canals by alterations in posture precipitate acute respiratory adjustments. Furthermore, approximately half of patients with inner ear dysfunction from symptomatic labyrinthitis exhibit compensated respiratory acidosis (hypercarbia).^{ref 2} Risk factors for SIDS may precipitate a hypercarbic environment; hence a suppressed hypercapnic ventilatory response (HCVR) from vestibular dysfunction could play a critical role in SIDS.

Methods. Gentamicin precipitates irreversible inner ear hair cell damage. We generated cochlear and vestibular dysfunction in 17 day old CBa/CaJ mice with bilateral intra-tympanic gentamicin injections. Hearing and vestibular function were tested one week later to confirm presence of inner ear insult, following which the animal's respiratory response to inhalation of 8% CO₂ was examined.

Results. Mice that received tympanic gentamicin (n = 60) displayed a significantly diminished HCVR as well as suppressed hearing. This contrasted with the normal HCVR seen in control mice that had not undergone tympanic injections (n = 30), controls that received tympanic injections with saline (n = 5), and controls that had gentamicin administered systemically (n = 5). In response to inspired CO₂, the mean respiratory frequency of control mice increased by an average of 50% over their baseline values. In contrast, the ear-damaged group values increased by only 2-11%. Tidal volume did not compensate for the decreased respiratory rate response. Vestibular hair cell damage was confirmed with immuno-flourescent microscopy. It is noteworthy that experimental mice fed, preened and mobilized as controls. This is analogous to SIDS cases that are grossly indistinguishable from other babies before they die.

Discussion. In a new project, we recently found a reversible suppression of the HCVR in mice by utilizing intra-tympanic lidocaine instead of gentamicin. This is important as it demonstrates a suppressed HCVR from inner ear effect without possible lasting or secondary effect on brainstem respiratory centers. In a further preliminary study we found a considerably weaker arousal (defensive body movement) response from hypoxia in animals with inner ear dysfunction compared to controls. This could be a key missing piece to SIDS and we are pursuing the new findings in greater detail. We describe elsewhere the plan to investigate the association between inner ear dysfunction (hearing test abnormalities) at birth and subsequent histological injury in infants who later died of SIDS.

Conclusion. We propose that mice with suppressed HCVR from induced inner ear damage are a credible model for SIDS.

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➔ A-46

Tipene-Leach DC
University of Otago, New Zealand

THE WAHAKURA: A BED-SHARING 'SAFER' SLEEPING ENVIRONMENT FOR SIDS PREVENTION

There is an almost six fold (RR= 5.66) disparity in SUDI between Māori and European infants with no evidence of any decrease since 1996 and the fall in Māori SUDI mortality over the 1996 to 2002 period has come to a plateau. Knowing that 21% of Māori mothers both smoke in pregnancy and bed-share with their infant compared to only 1% of a largely European sample and understanding the interacting risk(s) of 'smoking in pregnancy and bed-sharing' is key to the huge disparity in SUDI mortality in New Zealand. The difficulties of population level smoking cessation among Māori women and the abject failure of Ministry of Health and health professional advice to not bed-share are common knowledge and creative attention, therefore, to modification of the shared sleeping environment seems the obvious move.

Working with the current knowledge that the removal of one of two interacting risk factors will remove the risk associated with the interacting pair, a Māori SIDS/SUDI prevention initiative uses the American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome 2011 report's advice around a 'separate sleep surface' advice but ignores that relating to 'a device promoted to make bedsharing safe'. A separate sleep surface that is able to be deployed almost anywhere, including in or on the adult bed has been developed.

The wahakura, developed in the Māori community is the form in which this 'safer separate sleep surface' first appeared in 2006. A 36 x 72 cm bassinet-like structure woven from flax, it is culturally attractive and has a particular appeal in its ability to maintain the valued proximity at night. This proximity also makes for easy return to wahakura after night feeding, and its mobility provides a consistent safer sleep environment for use at any time by any caregiver in any place. The 'safe sleep rules' that accompany the wahakura include: back sleeping, keeping the face clear, using a firm mattress without pillows, maintaining a smoke free environment, keeping inebriated or excessively tired people and younger siblings at bay and, ensuring adherence to the 'return to wahakura after feeding' and 'every place-every sleep' messages.

This presentation outlines the development and deployment of the wahakura in New Zealand communities.

➔ A-47

Mage DT, Donner EM.
World Health Organization (retired), US Environmental Protection Agency (retired), DuPont Haskell Centers for Health & Environmental Sciences, USA

THE ROLE OF PHYSIOLOGICAL ANEMIA AND ASYMPTOMATIC PRODROMAL RESPIRATORY INFECTION IN SIDS

Introduction. Given that SIDS autopsies do not identify a sufficient cause of death and parents or care-givers of SIDS infants had no idea before the final sleep that the infant was at imminent risk of dying, we look at all risk factors to see which are not measured at autopsy and which could have changed precipitously to make that night different from all other nights. Asymptomatic physiological anemia is not an acknowledged SIDS risk factor because hemolysis after death leads to lividity and renders postmortem hemoglobin (Hb) measurements meaningless, and Genetic (DNA) testing is not routinely performed so an X-linkage that could explain the 0.60±0.01 male fraction is not looked for.

Methods. The risk factor literature is reviewed to identify a possible transient risk factor capable of triggering or causing SIDS.

Results. Almost all physiological risk factors (e.g., neurological prematurity; anemia; genetics) are virtually the same from night-to-night and most non-physiological risk factors (e.g., parity; maternal age, sleep position and bedding; bottle feeding) are the same from night-to-night due to parental custom or habit. An exception is an asymptomatic prodromal respiratory infection, unnoticed by the parents/care-givers before it would invoke a physician's treatment.

Discussion. Infant physiological anemia (IPA) is Hb <10g/dL or Hb <-2σ g/dL, that minimizes between 2-3 months for term infants. Table 1 shows -2σ Hb with infant age (Koenig & Lightsey, 1982). SIDS also has seasonality maximizing in winter and minimizing in summer matching respiratory disease mortality (RDM 10ICD J00-J98). Table 2 shows seasonal U.S. 1999-2008 SIDS and RDM with joint winter maxima and summer minima (wonder.cdc.gov).

Table 1.

-2σ H g/dL	12.5	11.5	10.0	7.8	7.9	8.0	8.2	8.5	8.9	9.3	9.6	9.9	10.1	10.2	10.3
Weeks	0	2	4	6	8	10	12	14	16	18	20	22	24	26	28

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Table 2.

Month	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Total
SIDS R95	2,197	1,986	2,082	2043	1,968	1,813	1,728	1,775	1,859	1,926	2,000	2,090	23,467
RDM J00-98	837	778	657	544	477	434	435	410	422	430	520	650	6,594

Given infants catch respiratory diseases from family members, we tested the hypothesis that rates of RDM and SIDS are proportional to number of family members living with the infant. We assume this equals 2 parents or partners plus [live birth order (LBO) - 1] older siblings = LBO+1. Table 3 lists the SIDS and RDM rates per 10,000 as a function of LBO+1. Transport vehicle accident (TVA) mortality which must be independent of LBO is shown for comparison as a negative control. Data are U.S. 1995-2007, wonder.cdc.gov.

Table 3.

Rate/10,000						
Disease↓ LBO+1→	2	3	4	5	6	Rate/10,000 = k (LBO + 1)
SIDS R95	4.48	6.33	7.49	9.14	10.42	k = 1.846, R2 = 0.976
RDM J00-J98	1.27	1.49	1.77	2.49	2.87	k = 0.486, R2 = 0.975
TVA V1-V99	0.393	0.333	0.362	0.453	0.382	Rate = 0.345 + 0.01 (LBO+1), R2 = 0.12

Conclusion. Anemia and Respiratory Infections are important SIDS risk factors, leading to a respiratory death.

➔ A-48

Mage DT, Donner EM.

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THE 50% MALE EXCESS OF SIDS AND OTHER INFANT RESPIRATORY DEATHS

Introduction. SIDS, Sudden Unexpected Infant Death (SUID), and infant Sudden Respiratory Deaths (SRD) are characterized by ~50% male excess (male fraction of $\sim 0.60 \pm 0.01$) that has not changed with the back-to-sleep campaign. It is the same for all causes of death composing SIDS, SUID, SRD and other non-SUID respiratory deaths such as infant Respiratory Distress Syndrome (RDS) and Inhalation of Food or Foreign Object (IFFO). A genetic explanation for the gender distribution is discussed that provides a basic clue towards unraveling the cause of SIDS and a possible means for its prevention.

Methods. The world's literature on gender distributions of SIDS, SRD and SUID components has been reviewed and representative supporting data are presented here.

Results. Table 1 shows representative values of SIDS, SRD (SUID), RDS and IFFO gender data.

Table 1.

Data Set	Male	Female	Male Fraction
36 Global SIDS data sets Mage & Donner 1997	41,238	26,140	0.612
U.S. RDS 1979-2008 wonder.cdc.gov	41,181	26,405	0.609
England & Wales SRD At home 1965-1976 Carpenter & Gardner 1982	11,212	7,443	0.601
England & Wales SRD In hospital, 1969-1976 Carpenter & Gardner 1982	2,375	1,564	0.603
U.S. SRD at Home 2003-2008 wonder.cdc.gov	3,685	2,441	0.602

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U.S. SRD in Hospital 2003-2008 wonder.cdc.gov	1,506	1,057	0.588
U.S. Suffocation by IFFO 1979-2008 wonder.cdc.gov	2,089	1,385	0.601
San Diego, SIDS 1991-2008 Trachtenberg et al., 2012	345	223	0.606

Discussion. The only published explanation in the medical literature for the mathematical consistency of the male excess mortality shown above is that a presently unknown X-linkage is responsible (Naeye et al., 1971; Mage and Donner, 1996, 2004). The ~50% male excess in SIDS and all other respiratory deaths is explainable by an X-linked gene with a dominant allele protective against neuronal apoptosis from acute anoxic encephalopathy with frequency $p \approx 1/3$, like GATA1 involving erythropoietin. The XY male will not have it with probability $1-p \approx 2/3$ and the XX female will not have it with probability $(1-p)^2 \approx 4/9$, the ratio $2/3:4/9$ is 1.5:1 or 0.60 male. Examination of the Table shows that male gender cannot be a risk factor for SIDS alone because it is a factor for all respiratory deaths in infancy. Although sudden infant death from an autosomal SNC5A cardiac channelopathy (Long QT syndrome) may be possible and rare, there is no gender difference observed for it, and it is virtually impossible at autopsy to tell whether an infant died of SIDS from SNC5A or died of SIDS with SNC5A. In conclusion, the SIDS/SUID ~0.60 male fraction has not changed with the back-to-sleep campaign and it is a characteristic of all infant sudden and unexpected respiratory deaths from virtually all causes. If this hypothesized gene and its dominant allele can be identified (see our GWAS abstract at this meeting), the protein involved with protection against cerebral anoxia could be found and possibly open a route for prophylaxis in the infants at greatest risk of SIDS or SUID.

➔ A-49

Mage DT, Donner EM, Vennemann MM, Fleming P, Sol-Church K, Drake R, Gulino S.
World Health Organization (retired), US Environmental Protection Agency (retired), DuPont Haskell Centers for Health & Environmental Sciences, USA; University of Münster, Institute of Legal Medicine, Germany; University of Bristol, United Kingdom; Al Dupont Hospital for Children, USA; Philadelphia Medical Examiner's Office, USA

ALMOST ALL SUID AND SRD SUBSETS HAVE THE SAME TERMINAL EVENT REACHED BY DIFFERENT PATHS.

Introduction. What CDC now considers Sudden Unexpected Infant Deaths (SUID) were all called SIDS in the U.S. prior to 1991 and Sudden Respiratory Deaths (SRD) in England & Wales by Carpenter and Gardner (1982). We show that all those SUID, SIDS and SRD have the same 4-parameter lognormal age distribution and gender binomial distribution with $p \sim 0.60$. We also show physiological anemia and prodromal respiratory infections are likely involved. Therefore these sudden unexpected infant deaths (SUID, SIDS, SRD) may have identical respiratory cause of death reached by different risk-factor paths.

Methods. Published summary age distributions, detailed age distributions provided by coauthors, and a detailed age distribution extracted from autopsy files of SIDS/SRD/SUID are presented.

Results. Table 1 shows that all such monthly (m) data sets are well fit by the same 4-parameter lognormal distribution $y = \text{Log}[(m + 0.31)/(41.2 - m)] = \mu + \sigma z$ where μ (median) and σ (standard deviation) vary between data sets as they are collections of independent random samples of different sizes (N) with different racial mixes (z is a standard-normal-deviate).

Table 1.

Data Set fit to $y = \text{Log}[(m+0.31)/(41.2-m)] = \mu + \sigma z$	N*	μ	σ
Australia 1981-1990 SIDS = SUID SIDS&Kids 2003	4,893	-1.04	0.284
Australia 1991-2000 SIDS = SUID SIDS&Kids 2003	2,086	-1.05	0.294
Global 15 sets pre-1991 Mage, 1996	19,975	-1.05	0.287
England&Wales 79-83 SUID male Osmond&Murphy 1988	3,814	-1.04	0.289
England&Wales 79-83 SUID female O&M	2,507	-1.02	0.304
England&Wales 79-83 SIDS male+female O&M	5,240	-1.05	0.290
England&Wales 79-83 SUID - SIDS male+female O&M	1,081	-1.00	0.293
England SIDS+SUID CESDI/SWISS Leach et al. 1999	548	-1.03	0.441

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Germany GeSID Findeisen et al. 2004, SIDS and SUID	499	-0.92	0.391
England&Wales OPCS 1986-1992 SUID - SIDS	703	-0.98	0.286
SRD England&Wales 1965-1976 Carpenter&Gardner 1982	19,318	-1.00	0.316
ASSB U.S. 2002-2004, Shapiro-Mendoza et al. 2006	1,386	-1.12	0.367
SUID Philadelphia 1995-2009 Mage et al. submitted 2012	681	-1.12	0.392
SIDS San Diego 1991-2008. Trachtenberg et al., 2012	573	-1.06	0.278

*Includes extrapolated SIDS between 12 and 41

Discussion. The 14 data sets summarized above all represent various sets of respiratory infant deaths that CDC currently includes as subsets of SUID. The fact that all these data sets have the same 4-parameter lognormal distribution with different mean and variance from sampling variability is predicted by Cramér's Theorem (Cramér, 1936). That is, if SUID is bounded and lognormally distributed then all the subsets of SUID must also be similarly bounded and lognormally distributed. In conclusion, SIDS or SUID are collections of deaths from a common terminal mechanism of acute anoxic encephalopathy that can be reached by different paths as shown by Emery at the Baltimore SIDS 1982 meeting and supported by Byard (1995). We suggest that all these subsets, such as Cause Unknown (UNK) and 'positional asphyxiation' or non-mechanical Accidental Strangulation and Suffocation in Bed (ASSB), be reclassified as Tenth International Classification of Diseases (ICD) subsets of R95 (e.g., R95.1, R95.2) to show the same deaths reached by different pathways.

➔ A-50

Badriah F, Abe T, Risahmawati DR.

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ASSOCIATIONS OF TYPE ASSISTANCE AT DELIVERY WITH MATERNAL-NEONATAL OUTCOMES AND NEWBORN CARE FOLLOWING HOME DELIVERY

Background. As part of Indonesia's intensive efforts to improve access to professional care during delivery, which reflects Indonesia's commitment to reducing maternal and neonatal mortality rates, more than 50,000 midwives had been placed in villages around the country in 1996. This improvement increased the proportion of deliveries at which skilled birth assistance was available from 43% in 1997 to 79% in 2007. However, maternal and neonatal mortality and morbidity rates remain surprisingly high, further research is needed. The aim of this study was to compare quality of care provided by midwife with that provided by unskilled birth assistance during home deliveries.

Methods. Design of research is a retrospective cohort study. Data on 9,862 home deliveries from 2003 to 2007 were obtained from the Indonesia Demographic Health Survey (DHC 2007). Logistic regression analyses with backward elimination were used to examine association of cause (type of assistance at delivery) and all independent variables such as socio-demographic, characteristic of mothers and prenatal care during pregnancy with maternal-neonatal outcomes (complication at time of birth and after birth, stillbirth, neonatal death and child survival) and newborn care of babies (immediate breastfeeding, breastfeeding for a minimum of 6 months, fed nothing during first 3 days, postnatal check-ups and received vaccinations).

Results. The results showed significantly higher risk with the use of midwife than the use unskilled assistance; adjusted odds ratio: 1.54 (95% CI: 1.36-1.62) for complication at time of birth, 1.42 (95%CI: 1.28-1.56) for complication after giving birth and; 1.62 (95% CI 0.90 - 2.89) stillbirth. However, use midwife at delivery statistically significant better outcomes in term of postnatal check-ups; adjusted odds ratio: 22.72 (95% CI: 20.30-25.44) and receiving vaccinations (adjusted odds ratio: 2.00; 95% CI: 1.76-2.29). We found no significant associations between type of assistance at delivery and others outcomes. Despite, higher number of neonatal mortality rate use unskilled assistance than use midwife. Neonatal mortality rate at 1-28 days with use unskilled assistance were 1420 per 100.000 infants live birth than midwife were 727 per 100.000 infants live birth and neonatal mortality rate at 1-7 days with use unskilled assistance were 1470 death per 100.000 infants live birth than use midwife; 519 infant death per 100.000 infants live birth .

Discussion. Ironically, a high risk for complication at birth and stillbirth was associated with availability of skilled versus unskilled assistance. This indicates that midwives have limited abilities to manage deliveries at home due to lack of clinical training and experience. These results mean that simply increasing number of skilled assistance at delivery is not sufficient to reduce maternal morbidity and stillbirth in the absence of adequate of care. This may reflect the limitations of home based care. However, midwife better outcome for neonatal mortality rate, postnatal check-ups and receiving vaccinations. Further research is needed to verify the findings of the present study.

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➔ A-51

Combs J, Wardick K.

Healthy Mothers, Healthy Babies Coalition of Broward, Inc., Broward County Medical Examiner's Office, USA

BROWARD WE HAVE A PROBLEM: AN OVERVIEW OF SLEEP RELATED DEATHS IN BROWARD COUNTY, 2006-2010

Problem Identified. In 2010, through our FIMR process, there were 17 babies identified that died in unsafe sleep environments or positions in Broward County. This number was up from nine babies in 2009. In response, the FIMR CRT recommended a retrospective review of all infant deaths that had come through the Medical Examiner's office from 2006-2010. The purpose of this review was to identify which babies, regardless of the cause of death listed on death certificate, actually were in unsafe sleep environments or positions at the time of death. The results would allow us to make recommendations to improve the process of classification of these infant deaths, which in turn would allow us to better target needed areas of community education. A retrospective review of all infant deaths that had been examined by the Medical Examiner's office from 2006-2010 using FIMR methodology was conducted by the FIMR abstractor. The findings showed that 81 babies died of sleep related deaths in Broward County from 2006-2010, with 23% of these deaths classified as something other than a sleep related death. Problems identified: inconsistent safe sleep education being disseminated by delivering hospitals to new parents, continued racial disparity with 62% of the deaths being black babies, inconsistent and incomplete crime scene investigations, incomplete documentation by the ME office and inconsistent and inaccurate documentation of unsafe sleep environment/positions on the death certificates.

Recommendations. It was recommended by the CRT that a public awareness and education campaign be implemented in Broward County that would focus on all aspects of safe infant sleep as recommended by the American Academy of Pediatrics. It was recommended that all delivering hospitals model safe sleep practices and provide consistent safe sleep education to all families. Recommendations for the Medical Examiner's office included: consistent and thorough scene investigations, completion of SUID forms and accurate and consistent documentation of unsafe sleep environments on the death certificates.

Action/Interventions. The "Best for Broward Babies" project was launched on October 1, 2010 with three key components: "Model Behavior", "Fatherhood Mentorship Program" and "Community Voice". All three of the programs have a common element of promotion of safe sleep practices for infants. Within the Medical Examiner's office, a single Medical Examiner has been identified to solely be responsible for examination of the infant deaths. This ensures that there will be consistency in the review of these deaths.

Outcomes. "Model Behavior" has been launched in three of the eight delivering hospitals. The culmination of our efforts was the county wide Safe Sleep Summit held on September 29, 2011. This event has led to county wide interest from other organizations in promoting safe sleep. We are already seeing improved documentation and consistency from the Medical Examiner's office. Other FIMR programs can utilize FIMR methodology to look at all of the infant deaths that come through the ME office to ensure that all sleep related deaths are being correctly classified. This will allow them to enhance and better target their community efforts.

➔ A-52

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FROM FRAGMENTED VOICES TO A PROVINCIAL CHOIR – SINGING FROM THE SAME SONG BOOK IN PREVENTING INFANT DEATHS

This workshop will give participants an opportunity to explore challenges and potential solutions to providing consistent Safe Infant Sleep messages across a large geographic area and diverse populations. It will be of interest to front-line staff, educators, policy makers and administrators responsible for promoting best practices in preventing infant deaths in large or small health organizations.

As a result of attending this workshop, participants will:

- 1) have the opportunity to discuss the challenges of promoting a consistent safe infant sleep message across populations
- 2) have the opportunity to share and learn about potential solutions with colleagues
- 3) be aware of the critical components of a successful campaign through the examination of the experience in Alberta, Canada.

Small and large group discussions, a provincial case study of the Alberta experience, and a question and answer session will provide participants with ample opportunity to discuss challenges and solutions to effectively promote a consistent message on safe infant sleep.

Alberta is Canada's only province to have a single health service-providing organization. Formerly nine separate health regions, the province reorganized in an unprecedented merger into one single service, Alberta Health Services (AHS), in 2009. AHS has responsibility for Acute Care (Primary to Tertiary), Public Health, Health Promotion, Disease and Injury Prevention, Community and Home Care, and Long Term Care. AHS serves a diverse population of 3,645,257 over an area of 255,541 sq. miles.

The task of bringing a consistent safe infant sleep message to such a diverse population over a huge geographical area has been challenging, but a dedicated team of professionals from acute care, public health, and provincial organizations have successfully defined the scope of the issue. In two years,

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we have standardized the message and resources, with supporting policies to ensure sustainability and accountability. AHS is the major source of health information in the province, thus looked to by community agencies and families alike for reliable, current health information. No matter where a baby is born today in Alberta, his or her parents now receive the same messages about safe infant sleep.

➔ A-53

Cox HJ

Hulls Royal Infirmary, United Kingdom

THE SUDI BOX

A tearful call to the Duty Biochemist of "can you do acylcarnitines on bone marrow" prompted the creation of an easy to use system to collect relevant samples for laboratory investigations following sudden unexpected death in infancy (SUDI).

Guidance from the 2004 RCPATH & RCPCH protocol for care and investigation in SUDI was used as a basis of ascertaining the utility of various samples in the investigation of potential causes of SUDI including metabolic and malicious causes. Meetings involving consultants in the Biochemistry, Microbiology & Virology, Neuropathology, Histopathology, Emergency Paediatric & Women and Children's Medicine were held to seek views and experiences from previous cases.

A SUDI box (and spare) was created that would facilitate the collection of samples and information from deceased infants in the setting of the paediatric resuscitation department of our teaching hospital. The yellow 'carry' box contains a protocol to record demographics, samples to be taken and opportunity to list observations useful to aid the Paediatric Pathologist undertaking the post mortem examination. The box is divided into 8 sections each containing relevant containers for the samples to be taken including 1) Guthrie Card, 2) Aerobic blood culture bottle, 3) 2 lithium heparin tubes 4) fluoride oxalate 5) 60mL urine pot + plastic bag for a nappy 6) a sterile 60mL pot with saline vial & scalpel and forceps to obtain a axilla skin sample for fibroblast culture. The box is sealed with a temper proof tag and sent immediately to the blood sciences laboratory for processing. On receipt of the SUDI box in the lab, a set of 7 chain of custody forms is assigned to the SUDI box enabling processing of the samples and despatch to the relevant discipline for analysis or stored securely until analysis if deemed necessary by the Pathologist/Coroner.

A spare complete SUDI box is maintained in the lab which is then sent to the paediatric resuscitation area to replace the one used. The box in place is checked monthly for integrity and any short-dated sample containers replaced.

The provision and use of the SUDI box has been welcomed by both clinicians and laboratory staff and will hopefully remove some of the understandable stress and anxiety experienced by those dealing with a SUDI and help to ascertain both cause of death of an infant and also potentially help to influence decisions regarding further siblings.

➔ A-55

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NICOTINIC (nACh) AND SEROTONERGIC (5-HT) RECEPTOR BINDING IN THE BRAIN OF FETAL BABOONS EXPOSED TO MATERNAL NICOTINE IN UTERO

Introduction. SIDS infants have abnormalities in brainstem networks that mediate protective cardiorespiratory responses to life-threatening challenges. Prenatal exposure to smoking 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 $\alpha 4$ nicotinic receptors (nAChR) and is known to affect brain development. Previously, we reported alterations to nAChR binding in rostral brainstem regions in SIDS infants exposed to maternal smoking. These infants also demonstrated serotonergic (5-HT) changes in caudal brainstem regions critical for cardiorespiratory regulation. These findings raise the possibility of neurotransmitter and regionally specific effects of prenatal exposure to cigarette smoke. We tested the hypothesis, in a fetal baboon model, that prenatal nicotine-exposure causes differential changes to nAChRs and 5-HT parameters in the caudal brainstem (medulla) and cerebral cortex (visual (BA 17) and associative (BAs 18 and 19) cortices). The findings have been published in part (Duncan et al., 2009).

Methods. At 87 days gestation (dg) pregnant baboons were infused with saline (n=5) or nicotine (0.5 mg/hr, n=5). Fetuses were surgically instrumented (129dg) to monitor heart rate (ECG) and breathing activity. Fetal brain tissues (including one unoperated control, n=6) were collected (161dg) for autoradiography of nACh, 5-HT_{1A}, and 5-HT_{2A} receptors, and 5-HT transporter (5-HTT) binding in 6-8 medullary nuclei and 3 occipital regions. Statistical analysis included student t-tests or Wilcoxon-rank sum tests (failed normality) with correction for multiple testing.

Results. Prenatal nicotine-exposure altered fetal physiology and affected binding to 5-HT parameters and nAChRs in a region-specific manner. In nicotine-exposed fetuses, high frequency heart rate variability, which indirectly reflects parasympathetic activity, was increased 55% (p<0.05). In the medulla 5-HT_{1A} binding was increased 219% (p=0.04) in the raphe obscurus (RO), with a trend towards increased 5-HTT binding (134%, RO, 0.05).

Discussion. Prenatal nicotine-exposure results in altered 5-HT_{1A} receptor binding in the RO (nucleus critical in protective responses) but not robust changes in 5-HT parameters in the cerebral cortex. This occurred in conjunction with generalized alterations in binding to $\alpha 2$ -4, $\beta 2$ or $\beta 4$ nAChRs but not $\alpha 7$. These data indicate a regional and receptor vulnerability to prenatal nicotine-exposure that may help to explain the differential outcomes related to

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maternal smoking during pregnancy, ranging from brainstem abnormalities in SIDS infants to potential long-term cognitive (cortical) impairments beyond infancy. Understanding the molecular mechanism(s) whereby prenatal nicotine-exposure alters these parameters in the developing brain is critical.

➔ A-56

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ALIGNING WITH INDUSTRY TO STRENGTHEN SAFE SLEEP AWARENESS

Introduction. This presentation builds on previous work in assessing how well the baby product industry aligns with safe sleep evidence. It addresses the identified gap between information parents receive from health professionals about safe sleep, and what they see on infant sleep products and packaging at point of sale. The aim of this work was to align parents and retail staff with safe sleep principles at point of sale and point of use, and to influence sleep product design to be consistent with developmentally appropriate care.

Method. A three pronged approach was taken to support industry in aligning with safe sleep evidence:

- A “safe sleep star” education mark was developed to direct attention to safe sleep recommendations. It was made available to manufacturers and retailers in New Zealand to incorporate into infant sleep related packaging and products. A website was developed to further support parents, retailers and the wider industry.
- A relationship was built with a large New Zealand manufacturing company and distributor of infant sleep products. Working in collaboration with the company, an innovation process was applied to influence product design and to integrate safe sleep education at point of sale and point of use.
- An interactive education programme was initiated to strengthen retail staff knowledge and was offered to baby product retail organisations within New Zealand.

Results. Once it became known that a retail specific education mark had been developed, companies approached our organisation wanting to participate; creating ‘pull’ for the initiative. To date, the mark has been used on product packaging, product labels, swing tags and promoted on company websites and blogs.

The collaboration with the manufacturing company resulted in the design and marketing of a baby bed enabling parents to sleep safely and closely to their babies. Safe sleep advice was a key element of the promotional and point of use materials.

The interactive education programme has been taken up by a leading retailer of baby products, who has committed to implementing the programme throughout its stores. An update and impact analysis on the rollout of the above will be given in the presentation.

Discussion. This work is about more than just ‘messages’ on products. It sits within a broader context of aligning evidence with practice, creating approaches of value and developing networks that influence. It provides an opportunity for socially responsible companies to demonstrate their commitment to infant safety. By creating an approach of value to retailers, we have strengthened alignment of safe sleep recommendations for retail staff and parents, and aligned evidence with practice to influence communities and conversations.

➔ A-57

Filonzi L, Magnani C, Nosetti L, Vaghi M, Marzano FN. (*Cinzia Magnani presenting*)

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COMMON MOLECULAR BASIS OF SUDDEN INFANT DEATH SYNDROME AND APPARENT LIFE THREATENING EVENTS

Considering previous molecular studies on the role of LL genotype of serotonin transporter (5HTT) and correlated genes (MAOA and DAT) in unexpected death in infancy (SIDS), an investigation was carried out to verify their possible involvement in apparent life threatening events (ALTE). In particular, the main objective was to verify whether or not SIDS and ALTE (including idiopathic ALTE) are a different phenotype expression of a common genetic base. The differential diagnosis was made in 76 generally defined ALTE with the aim of discriminating ALTE with aspecific cause from idiopathic ALTE. Genotypes and allelic frequencies of DAT, MAOA and 5HTT were determined in ALTE and IALTE infants and compared with data obtained from 150 healthy controls and 25 SIDS. No association was found between DAT polymorphisms and ALTE/IALTE groups either at genotype ($P=0.25$; $P=0.112$) or allelic ($P=0.94$; $P=0.88$) level. MAOA genotypes and allele data comparison between ALTE and control group was not significant, on the opposite data on IALTE was statistically significant for genotypes ($P=0.09$) and a tendency for allele ($P=0.036$). Analysis of 5HTT polymorphisms in IALTE remarked the role of LL genotype ($P<0.00001$) and L allele ($P<0.00001$) as previously demonstrated in SIDS. Considering strict correspondence between 5HTT and MAOA genotypic and allelic data in IALTE and SIDS (but not in ALTE), we hypothesize that the two syndromes are different expressions of a common ethiopathogenesis. In particular, molecular data suggest that SIDS events could basically be IALTE episodes occurred during sleep, and therefore out of parental control. On the opposite, IALTE crisis during daytime are usually promptly managed with emergency assistance, avoiding SIDS events. Despite its functional role, results highlight the usefulness of 5HTT as a valuable tracer of SIDS risk in IALTE infants.

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➔ A-58

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NEWBORN VITAL SIGNS AND SYMPTOMS IN SIDS AND CONTROLS, RESULTS OF THE NIH COLLABORATIVE SIDS EPIDEMIOLOGY STUDY.

Introduction. Findings of various abnormalities in the Serotonergic system in multiple areas of the brain responsible for heart rate, respiratory rate and autonomic control have raised the question of whether abnormalities in vital sign control could be identified during early life. Adaptation to life outside the womb provides a challenge test for such systems.

Methods. The NIH Collaborative SIDS Epidemiology Study collected extensive vital sign data over the first 96 hours of life for 714 SIDS Cases, 735 unmatched controls (Control A) and 740 birthweight (within 250 grams below 2500 grams) and race (black versus non-black) matched controls (Control B). Infants were classified as Preterm (<37 weeks), Term IUGR (Intrauterine Growth Restricted) and Term non-IUGR. Within birth type and race categories, values were compared by non-paired t-test. For total groups, Multiple Regression Analysis was performed adjusting for several factors.

Results. Differences between vital signs and symptoms in the SIDS group and Control A were accounted for by the high rate of prematurity and IUGR in the SIDS group. In the Term non-IUGR infants no differences were seen between SIDS and both Control A and Control B groups for the highest heart rate, lowest heart rate and the greatest heart rate difference as a measure of crude heart rate variability. Respiratory rates were significantly ($P < .01$) higher in non-black SIDS compared to non-black Control B at 25-48 hrs and 49-72 hrs but were not different from Control A and no differences were seen when comparing black infants only. There were no significant differences in high or low temperature. There were no differences in the number of infants reported to have an abnormal cry, lethargy, irritability or tremors. Also no differences were seen in reports of poor feeding, vomiting, or jaundice.

Discussion. Although the high incidence of prematurity and IUGR in SIDS leads to reports of multiple symptoms, adequately grown term infants who die of SIDS do not seem to differ in symptoms and vital signs in the first four days of life. Prediction of SIDS risk from newborn vital signs and symptoms is probably not possible.

➔ A-59

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SUDDEN INFANT DEATH SYNDROME (SIDS): A PUBLIC HEALTH PROBLEM IN BOGOTÁ, COLOMBIA?

Sudden infant death syndrome (SIDS) in the United States and other developed countries it is between the first causes of post neonatal infantile mortality which has led to multiple studies to investigate its cause. Although, in Bogota, Colombia there had been no investigation or study directed to this issue, in 2010 an investigation was started based on increase the knowledge of SIDS behavior in our country and why it is not considered a health public problem. In this basis it has never been proposed a surveillance protocol or a program directed to assess risk factors and conditions related to SIDS. It is necessary a combination between clinical research and public health investigation to have more accurate results. As methods and procedure we evaluated death certificates provided by DANE which classifies SIDS according to ICD-10 as R95X; between 2005 and 2006 it was found 229 cases associated to colt death; 280 deaths in infants under one year old classified as R98 unassisted death; 499 cases in infants under one year old classified as R99 undefined cause, the last one mentioned by the United States Center for Disease Control and Prevention as Sudden Unexpected Infant Deaths (SUIDS) for infants under one year old which die without explanation and the cause of it cannot be detected before the investigation. Data base revision were made in Bogotá between years 2005 to 2009 with 135 (2005), 109 (2006), 127 (2007), 84 (2008), 120 (2009) deaths respectively, compatibles with SIDS with an average of 115 cases per year. As presented in other studies association between gender, age, season and social security affiliation (contribute regimen vs. subsidized) were made; males under six months of age which belong to subsidized regimen were almost 20% of the deaths found.

In 2010, a survey directed to parents and child supervisors, to enquire about modifying risks and most common practices that can affect the incidence of SIDS in the most prone population in Bogota. Relevant outcomes were low socioeconomically condition, mother education level, daily habits of the mother like smoke or alcohol, and misconception like sleeping facedown, also it was found that the more affected were males (56.67%) older than one month and under one year 27.5% in 2009. According to the previous data search and evaluation of the results it can be determined that if the average continue to be 1.08 SIDS cases per 1,000 born life, a number which is statistically significant, it will end having 700 cases of sudden death per year; A concerning sum for a situation that can be controlled with simple public health interventions over the population at risk, so it can be decision making steps that lead to basic constitutional laws that proclaimed the right to life and the right to a decent health attention, even more if the population treated are children under 1 year old who possesses special protection (artículo 44. Children rights prevail upon others).

➔ A-61

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HOW RISK FACTORS FOR SIDS ARE PERCEIVED IN GERMANY?

Introduction. Many risk factors for SIDS are known for many years now, some of them as long as 25 years i.e. the prone sleeping position. In Germany,

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never a German-wide campaign for “Back to sleep” was conducted, but rather local initiatives were taken. The authors wanted to examine the reason why the biggest state in Germany with nearly 18 million inhabitants has a ten-fold higher incidence of SIDS in comparison to the neighboring country the Netherlands with nearly 17 million inhabitants. Therefore we did a survey in a normal population in three cities in North Rhine-Westphalia.

Methods. The first questionnaire was filled in at birth to examine the intention of the parents and the second one at the highest risk with 3 months.

Results. From the 872 parents who were questioned at birth, 652 filled in the second questionnaire as well (response rate 75%). Of the 872 mothers at birth only 82% said they were informed about the risk factors for SIDS, despite the fact that they were all first informed about the risk factors with a flyer and then filled in the questionnaire.

At birth only 1% of the parents are planning to put their baby to sleep prone, 9% side and 87% only on his/her back. At the age of three months 11% of the babies are placed prone as a usual sleeping position. At birth 81% of the parents are planning to put their baby only in a sleeping bag, with three months this numbers are stable and nobody uses duvets anymore.

The immunization recommendations for Germany are: the first immunization with 8 weeks, then every 4 weeks. Despite these recommendations with 12 weeks 27% of the infants were not immunized, at the age of 16 weeks still 10% are not immunized. At birth 62% of the mothers are exclusively breast feeding their babies, at the age of three months only 33% of the babies are fully breastfed. Only 70% of the babies are living in a smoke free environment. We will present further data in comparison to the Netherlands and Austria.

Discussion. Despite the fact that many risk factors are known for many years now, many parents do not follow the recommendations. In Germany a major obstacle seems to be the lack of communication between the midwives and the pediatricians.

➔ A-62

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SAFE SLEEPING ADVICES: NEW SURVEY SHOWS THE EFFECTIVENESS OF CHILD HEALTHCARE IN WESTERN AND NON-WESTERN PARENTS

Objective. In the Netherlands, the cot death incidence for infants was 0.059 per 1.000 live births in 2006, 0,092 in 2010 (17 infants/184.397 live born infants) and since 2004 the prevalence is less than 20 infants a year (Central Bureau of Statistics, 2011). No diagnostic shifts seem to occur and the total child death is declining. International advices are similar to the Dutch preventive advices.

Due to an on-going stream of information from the Dutch Cot Death Association, healthcare workers provide unequivocal prevention advices to young parents. In 2006 a national focus was on parents with a non-Western background and in 2003, 2005 and 2010 a national survey had been conducted and new data on non-western inhabitants are collected.

Methods. In a random sample survey, parents completed a questionnaire, either at home or at the well-baby clinic. The questionnaire is equal to the once used in the earlier surveys.

Results. A total of 1748 Dutch mothers and 194 mothers with a non-western background and an equal amount of fathers completed the questionnaire.

Table 1. Differences in infant care practices between mothers with a western and non-western background (p-value n=1748 n=192)

	Western	Non-Western	Difference
Supine sleeping during the night	83%	64%	< 0,001
Supine sleeping during the day	78%	59%	< 0,001
Side sleeping during the night	4%	5%	ns
Side sleeping during the day	4%	6%	ns
Sleeping sack	49%	42%	ns
Sleeping sack, blanket, sheet	25%	11%	< 0,001
Sleeping sack with duvet	1%	3%	ns
Swaddling	10%	18%	< 0,006
Child care	49%	32%	< 0,001
Totally breast feeding	21%	23%	ns
Totally bottle feeding	65%	51%	< 0,001
Own bed, parental sleeping room	26%	13%	< 0,001

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Bed sharing	1%	4%	< 0,001
Duvet use	3%	7%	< 0,001
Dummy use sometimes	35%	40%	ns
Dummy use always	21%	20%	ns

Conclusions. In 2006 a campaign was launched for non-Western parents and 71% had changed their infant care behaviour due to the campaign advices. In 2010 there are still some differences in child care practices between parents with a western and non-western background, but in the Netherlands we are closing the gaps. Furthermore, details on swaddling of infants in western and non-western infants will be presented.

➔ A-63

Hauck FR.

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ASSOCIATION BETWEEN PRIOR CHILD ABUSE REPORTS AND POSTNEONATAL INFANT MORTALITY FROM ALL CAUSES

Introduction: U.S. deaths among infants one month to one year of age (postneonatal infant mortality) total almost 10,000 annually. Since many of these deaths are preventable, it is important to identify factors that may distinguish at-risk families so that appropriate interventions can be offered. The objective of this study was to determine 1) if there is an association between prior reports of child abuse in families and subsequent postneonatal deaths, and 2) if there are differences by cause of death.

Methods: The Chicago Infant Mortality Study used a case-control design, with one living infant matched to each case infant on race-ethnicity, age, and birth weight. Chicago residents one month to one year of age who died suddenly and unexpectedly between November 1993 and April 1996 were included. Controls were identified from birth certificates. Standardized protocols were used to investigate characteristics of the family and infant, environment, and circumstances of death. Information on prior contact with the Illinois Department of Children and Family Services (DCFS)—the state agency for child protective services—was obtained through the DCSF State Central Registry. Only “founded” allegations of neglect or abuse were included.

Results: Analyses were conducted for 469 case infants and 472 control infants. DCFS allegations had been made for 119 (25.4%) of cases and/or their families and 35 (7.4%) of controls (odds ratio 4.25, 95% confidence interval 2.83-6.36, P=0.001). When frequency of allegations was analyzed by cause of death, no clear patterns emerged: highest rates were for prematurity-related deaths (50%), dehydration (40%), undetermined cause (40%), malnutrition/neglect (33%), and respiratory tract infections (29%); and intermediate for infants dying from abuse/homicide (26%), injury (25%), sudden infant death syndrome (24%) and asphyxia (20%).

Discussion: A strong association was found between prior contact with child protection services and subsequent sudden unexpected infant death, regardless of the cause of death. Clinicians should pay special attention to infants from families with a history of child abuse, including referral of at-risk families for appropriate interventions, to help reduce the incidence of potentially preventable deaths of infants. Additionally, child protection agency staff can play an important role in educating parents about safe sleep and other preventive strategies.

➔ A-64

Moon RY.

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THE POTENTIAL DANGERS OF SWADDLE BLANKETS: A CASE SERIES

Background. Swaddling has recently become increasingly popular as a strategy to calm infants and to potentially encouraging supine sleeping. “Swaddle blankets,” which incorporate bands of fabric that can be wrapped around the infant, have become popular in the U.S. However, there are concerns about the safety of swaddling, and both epidemiologic and physiologic studies have documented these.

Objective. To review cases of incidents and deaths associated with swaddle blankets that have been reported to the Consumer Product Safety Commission (CPSC), in order to better understand potential risks of swaddling and use of swaddle blankets.

Methods. We conducted a retrospective review of all incidents and deaths occurring in association with swaddle blankets that were reported to the CPSC. Reporting to the CPSC is voluntary and can be done by any citizen. Cases were obtained through a search of 3 CPSC databases: Death Certificate, Injury and Potential Injury Incidents, and In-Depth Investigations. Cases were reviewed for demographic information, medical history, circumstances of the incident or death, including position of the infant.

Results. 19 cases (including 4 deaths, 7 injuries, and 8 incidents without injury) between 2005 and 2011 were reviewed. Brands and manufacturers of swaddle blankets were redacted. The mean age of the infants was 3 months (range, 1 week-11 months); only 4 infants were less than 2 months of age. 10 infants were male. Hazard patterns described: swaddle wrap entangled around head/neck, swaddle wrap covering face; blanket material bunched up around mouth/nose. With regard to the 4 deaths, 3 were male and 1 female. All infants were between 5 and 7 months of age. All were placed supine for sleep, spontaneously rolled over, and were found prone.

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Conclusions. Swaddle blankets may, under certain circumstances, create a suffocation or strangulation risk for infants. For older infants, death can occur if the infant rolls into the prone position while swaddled. Swaddling should not be used past the age of 2-3 months, when there is a higher likelihood of the infant rolling spontaneously. The AAP has stated that there is insufficient evidence to recommend routine swaddling as a strategy to reduce SIDS risk and that swaddling must be correctly applied to avoid head covering and strangulation.

➡ A-65

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CHANGES IN SLEEP PATTERNS AND STRESS IN INFANTS ENTERING CHILD CARE

Background. Approximately 20% of infants who die of SIDS die while in child care. Many of these deaths occur in the first week of child care. Infants who die in child care have "low risk" demographics: Caucasian; older, more educated parents; more likely to be in a crib without pillows or blankets; and less likely to have secondhand or in utero smoke exposure. It is unclear why infants are at increased risk for SIDS during the transition into child care. We hypothesize that infants undergo a period of increased stress and disruption of sleep patterns during this transition, which may increase SIDS risk.

Objectives. To investigate changes in infant sleep patterns during the transition into child care and to determine if there are measurable differences in stress and circadian rhythm hormones between infants transitioning to child care and infants staying at home.

Methods. Using a case-control design based on parental intentions for child care, infants younger than 3 months entering a licensed child care center were matched by age, gender and race/ethnicity with infants who remained at home. Actigraphy data were collected on all infants for 30 days (during which half of the infants were transitioning to child care). Urine was collected from the mother and infant on specified days during this 30 day period. Urine levels of cortisol and 6-sulphatoxymelatonin (a melatonin metabolite) were measured by gas-chromatography mass spectrometry-validated radioimmunoassay (Stockgrand Ltd, Surrey, UK).

Results. The preliminary results demonstrate differences in sleep patterns in the 2 groups. Infants, during the first 2 days of the transition to child care, had decreased sleep efficiency during the day, decreased waking after sleep onset, increased wake periods during the day, decreased wake periods during the night, and longer sleeper periods during the night, when compared with infants not entering child care. Cortisol levels were higher in infants during the transition into child care. In addition, while infant staying at home began to show development of circadian rhythm (as demonstrated by a diurnal cycling of melatonin), this development was less marked in infants entering child care.

Conclusion. Our preliminary data suggest that infants transitioning into child care experience disruption in sleep patterns, increased stress, and delayed maturation of circadian rhythm. These data may help to explain why the period of transition into child care is one that places the infant at higher risk for SIDS.

➡ A-66

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IS THERE ANY CORRELATION BETWEEN HLA-DR EXPRESSION IN LARYNGEAL MUCOSA AND INTERLEUKIN GENE VARIATION IN SUDDEN INFANT DEATH SYNDROME?

Introduction. The mucosal immune system and the interleukin cascade are activated in a large proportion of SIDS cases. It is hypothesised that SIDS might be due to an uncontrolled cytokine storm induced by slight infection, and that a certain genetic make-up pre-dispose to such overreaction. The HLA-DR determinants play an important role in the body's defense against infection, HLA-DR expression may be used as a marker for an activated immune system. In this paper, the intensity of HLA-DR expression in laryngeal mucosa in SIDS was studied and related to cytokine gene polymorphisms as well as to CSF levels of various cytokines.

Method. Laryngeal sections from 97 SIDS cases were investigated with regard to HLA-DR expression. Both mucosal glands and surface epithelium in the larynx were evaluated and given a score according to intensity and extension of staining. The score obtained from the two areas were pooled. Score 0-1 were taken as negative, score 2-4 were assigned medium and score 5-8 as strong. Positive HLA-DR expression were taken as a risk factor for SIDS, and a total risk factor score were calculated by adding HLA-DR positivity (1), prone sleeping position (1) and fever prior to death (1), giving a maximal risk score of 3.

The concentration of IL-1 α , IL-1 β , IL-6 and IL-10 in the cerebrospinal fluid was measured by ELISA technique. The gene frequencies of functional SNPs were taken from previous studies of the same SIDS cohort.

Results. HLA-DR expression was seen in 70% of the cases, 30 % were scored as negative. Of the positive cases 63% had been scored as medium and 7 % scores as strong staining. The IL-6 -176CG/CC genotype was found in 92.3% of the SIDS cases with positive score for all risk factors (HLA-DR positive, prone sleeping and fever prior to death) ($p=0.01$). A significant correlation was found between the CSF IL-6 level and laryngeal gland HLA-DR score. Furthermore, IL-8 -781 CT/TT ($p=0,003$) genotypes and -251 AA/AT ($p=0,016$) genotypes were observed in 93% of the SIDS cases with one or more risk factors present compared to SIDS cases no risk factors. Also, IL-6 levels in CFS were found to be elevated in infants with high HLA-DR score ($p=0.005$), whereas a tendency to an inverse relationship was seen for IL-1 α ($p=0.09$). None of the other cytokine polymorphisms evaluated was found to be related to the laryngeal

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epithelial HLA-DR expression or the other risk factors in the SIDS cases studied.

Discussion. The main finding of this study is that a total of 92.3% of the SIDS cases with positive score in all the evaluated risk factors (HLA-DR positive, prone sleeping and fever prior to death) were found more often to have the IL-6 -176CG/CC genotype ($p=0.01$). The study also showed a significant correlation between the CSF IL-6 level and laryngeal gland HLA-DR score, which confirms previous studies. Furthermore, both SNPs in the IL-8 gene included in the study showed significant association with SIDS. Interestingly previous studies have shown that the production of IL-8 is genetically determined and individuals who are homozygous for the A/A genotype at the -251 position tended to have higher levels of IL-8 in response to lipopolysaccharide than others. In theory, the high output of IL-8 in SIDS cases with the A/A genotype at the -251 position, might be related to high HLA-DR expression.

Conclusion. In conclusion, the study suggests that in some SIDS infants there might be a genetic disturbance of the immune system.

➔ A-67

Ferrante L, Opdal SH. (*Torliev Rognum presenting*)
Norwegian Institute of Public Health, Norway

THE ROLE OF CYTOKINE POLYMORPHISM IN SIDS, A CUSTOM DESIGNED CHIP STUDY.

Introduction. Several studies indicate that the immune system is stimulated in a significant proportion of cases of sudden infant death syndrome (SIDS). This immune activation could be the result of an unfavorable combination of functional polymorphisms in genes encoding components in the immune response, which the most important might be the cytokine genes. Several studies have investigated the cytokine genes in cases of SIDS, and association in the genes encoding IL-1, IL-6, IL-10 and TNF- α have been found. Our hypothesis is that the immune reaction seen in SIDS is due to an unfavorable combination of functional polymorphisms in the cytokine genes, giving an unbalanced immune response.

Method. The subjects included in this study were examined at the Institute of Forensic Medicine, University of Oslo, during the period 1988-2011. All individuals were Caucasians from the south-eastern part of Norway. The subjects included 171 SIDS cases, 67 borderline SIDS cases, 44 cases of infectious death, and 419 adult diseased controls. The SNPs were genotyped using MassARRAY™ on a SEQUENOM® platform, in cooperation with CIGENE, Norwegian University of Life science, Ås. Based on previous studies SNPs the genes encoding interleukin 1 β , interleukin 10 and TNF α were selected for this study.

Results. From a total of 110 SNPs were 82 SNPs able to fit the multiplexes. The main finding of this study is an association between 3 SNPs in the IL-10 gene and SIDS. In rs 1800872, located in position -572 in the promoter of the gene, (69%) of the SIDS cases had the AA/AC genotypes, compared to 45% of the controls ($p=0.001$). For the other 2 SNPs, the rs146520891 ($P=0.004$) and the rs1554286 ($P=0.01$), showed no association after further calculation. No other SNPs showed any association between neither the SIDS cases, the borderline SIDS cases, nor the cases of infectious death.

Discussion. The main finding in this study is that almost 70% of the SIDS victims were observed to have the AA/AC genotype of rs 1800872, located in position -572. The CC genotype is reported to be the most common genotype in the Caucasian population, this was also the observation in our control group. Studies have shown that the A allele produce less IL-10 than the C allele. The findings of this study add evidence to the theory that unfavorable genetic variants in the interleukin 10 gene may be involved in SIDS. This may result in low levels of IL-10, which could cause the infant to suffer toxic shock like symptoms due to inability to down-regulate pro-inflammatory cytokines. This may give a deleterious immunological imbalance in an infant which are at a vulnerable developmental stage of both the central nervous system and the mucosal immune system, and thus contribute to SIDS.

Interleukins has a special physiological significance in limiting and preventing an excessive immune response and in limiting collateral damage. Down-regulation caused by specific gene variations in the interleukin genes might influence this and thus provide a molecular explanation for the unbalanced immune response seen in most SIDS cases.

➔ A-68

Bennett SM, Cowan S, Clarke J.
Change for our Children, New Zealand

THE POWER OF NETWORKS - ALIGNING A NATION ON SAFE SLEEP ACTION FOR BABIES

Introduction. To have a population effect, public health initiatives need scale. This means broad participation and extensive reach. While sudden infant death rates have fallen by 80% in New Zealand since the mid-1980s, for the sub-groups in which these tragedies now cluster, current rates match those of the epidemic twenty-five years ago. This presentation describes how networks and the internet were used to power a simple education approach and small resource, in an effort to align our nation on safe sleep action for ending sudden infant death completely.

Method. A national network of health and community professionals was developed and supported, to champion safe infant sleep locally. Called Safe Sleep Champions (SSC) members were individually prepared to facilitate education sessions with peers using a standard program - 'Baby Essentials'. Program materials included a 24 slide MS PowerPoint presentation that was fitted with voice over and adapted for online access, to extend participation options. Program content was designed to align participants with current knowledge, attitudes and actions for a blitz approach to preventing sudden infant death in New Zealand. Both facilitated and online sessions were certificated and attracted continuing education points. The online version was embedded in a

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template for monitoring usage, enabling targeted promotion in low using regions and easy evaluation. Evaluation data for facilitated sessions was from activity reports (optional after July 2010) that were provided by SSCs and, where available, from the session feedback of participating peers. The impact measure for the education was self-rated increased confidence (IC) to discuss safe sleep with others within one's sphere of influence. High IC ratings were defined as 7-9/9.

Results. One practitioner prepared and supported 65 SSC to facilitate the 'Baby Essentials' education and more than 6000 people participated between September 2009 and January 2012. 2949 participated in peer facilitated group sessions and 3313 completed online sessions. IC ratings were available for 3790 people and were high for 77.9% of these (2953 of 3790). IC ratings were higher for participants of facilitated sessions (91%) where there was

Discussion. and skill practice as well as the presentation, than it was for the 'bare bones' online sessions (68.7%) where 30% gave as their reason for participating 'personal interest' rather than 'to educate others'. The online tool reached beyond the health sector with 35.2% of participants in non-health roles, 29.2% of whom were parents or relatives of a baby.

Discussion. Networks enable the spread of ideas. When nurtured and supported they are a force to be reckoned with. Through the power of networks and the use of the internet, the work of a few reached to 6000 people, across social and professional groups, and into families. As well, there is the unquantifiable effect from unreported sessions and flow-on conversations. Champions and participants across the country reported increased confidence to address what had previously been a problematic issue. Coincidentally, but of interest, is the fact that during 2011, the total infant mortality rate in New Zealand steepened its downward trend and was the lowest on record.

➔ A-69

Artis SM.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), National Institutes of Health (NIH), USA

SIDS RISK-REDUCTION ACTIVITIES FOR AMERICAN INDIAN AND ALASKA NATIVE COMMUNITIES: THE HEALTHY NATIVE BABIES PROJECT

Introduction. American Indian and Alaska Native (AI/AN) infants are nearly three times more likely to die of Sudden Infant Death Syndrome (SIDS) as white infants making it the leading cause of post-neonatal deaths for Native babies. SIDS rates for AI/AN are particularly high in the Northern Tier of the United States, which includes Aberdeen, Alaska, Billings, Bemidji, and Portland. The Healthy Native Babies Project is focused on providing SIDS risk-reduction messages to AI/AN in the Northern Tier of the United States via culturally and regionally appropriate training and outreach materials.

Methods. The *Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)* of the National Institutes of Health (NIH) convened work group meetings with AI/AN stakeholders and federal partners to develop an approach for assisting local programs with SIDS risk-reduction efforts in Northern Tier Native communities. Focus groups in each of the five Northern Tier Indian Health Service (IHS) Areas were conducted to determine how SIDS risk-reduction messages resonated with young parents and what approaches were most effective for communicating the messages. The NICHD and work group members used this information to develop and implement the innovative Healthy Native Babies Project.

Results. The NICHD's Healthy Native Babies Project includes a Workbook Packet and a Facilitator's Packet. The Workbook Packet shares facts about SIDS and provides strategies for reaching AI/AN communities and their specific audiences and explains how to plan and sustain a community-based Healthy Native Babies Project. The Workbook Packet also includes a toolkit disk program, which allows users to tailor outreach materials for their community with photographs, Native languages, and text. The Facilitator's Packet includes training guides, presentations, group activities for both full-day and 2-hour training sessions, and a resource disk for health professionals to conduct their own training sessions. The Healthy Native Babies Project provided resource stipends for 35 Tribes and organizations for outreach materials; and held 24 training sessions to explain culturally tailored SIDS risk-reduction messages to about 350 community partners, health care providers, and other stakeholders. As a result of the training sessions, over half of the training attendees surveyed provided community-level training and outreach after participating in the training session.

Discussion. The Healthy Native Babies Project represents an effort to add AI/AN-specific cultural competence to recognized SIDS risk-reduction practices. The project materials and training encourage further development of community-specific cultural competence. Each outreach coordinator, health educator, and community partner can choose the most appropriate outreach approach for his or her specific audience. This project provides a model framework and lessons learned on how to build strong collaborative relationships with other communities to help make safe infant sleep education and outreach more personal and effective.

➔ A-70

Artis SM, Scott SD. (*Stacy Scott presenting*)

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), of the National Institutes of Health (NIH), In Black Print, Inc, USA

REDUCING SIDS IN MISSISSIPPI'S AFRICAN AMERICAN COMMUNITIES BY UTILIZING CULTURALLY APPROPRIATE OUTREACH

Introduction. As part of the *Eunice Kennedy Shriver National Institute of Child Health and Human Development's (NICHD)* "Back to Sleep" campaign,

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the Mississippi Sudden Infant Death Syndrome (SIDS) African American Outreach Project was launched in 2006. This project was a statewide effort to reduce SIDS among African Americans through education and awareness. The project consisted of working with the Mississippi Department of Health, local organizations, churches and community groups to promote the use of culturally tailored SIDS risk-reduction materials developed by the NICHD for the African American community.

Methods. The major goals of the NICHD's Mississippi SIDS African American Outreach Project were to build alliances within communities to assist in SIDS risk-reduction activities and create collaborative models and resources that can remain within communities. Project staff provided technical assistance to organizations to implement effective SIDS training. Through a series of capacity-building activities, community-based organizations participated in outreach and research-learning opportunities.

Results. There were 128 mini-grants awarded to faith- and community-based organizations to promote the use of NICHD's culturally tailored SIDS risk-reduction materials in all nine health districts in Mississippi. The project staff conducted a total of 57 train-the-trainer sessions throughout the state. According to the Mississippi Child Death Review data, in 2009, 44 infants in Mississippi died of SIDS and SUID (Sudden Unexplained Infant Deaths – a new category) combined, compared to 68 infant deaths due to SIDS in 2006. The number of SIDS deaths appeared to have dropped by at least 35% in just three years – those years in which the NICHD project was active in the state.

Discussion. Working collectively with state and community organizations, there has been a significant reduction in the incidence of SIDS across the state. It's recognized that capacity-building opportunities benefit not only the community, but also major institutions in the development of outreach and research projects. It is expected that the participating organizations and mini-grant recipients now have the skills to conduct intervention activities to increase awareness about the importance of safe infant sleep practices, which will continue to reduce the number of infants who die suddenly and unexpectedly in the state of Mississippi.

SATURDAY, OCTOBER 6

POSTER SESSION B 🕒 12:30 pm - 1:30 pm

➡ B-01

Erlandsson K, Rådestad I, Davidsson-Bremborg A.

Sophiahemmet University College, Sweden; Mälardalen University School of Health, Care and Social Welfare, Sweden

EVALUATION OF CARE AFTER STILLBIRTH IN SWEDEN BASED ON MOTHERS' GRATITUDE

Introduction. Caring routines in many countries for parents following the death of a baby have shifted over the last 40 years, from initial recommendations that parents should not see their baby, to the opposite in present day. This study aims to describe mothers' gratitude for the actions taken by health professionals in connection with the birth of their child. The study also examines whether the aspects of care for which they were grateful differed between mothers whose children died before and after 1990.

Methods. Data was collected from 799 women via a questionnaire posted on the homepage of the Swedish National Infant Foundation.

Results. Women who gave birth to a stillborn child after 1990 expressed gratefulness more often than women who gave birth to a stillborn child before 1990, for several reasons including the help received in creating memories of their baby.

Discussion. The mothers were thankful for being supported in their motherhood, and that the staff encouraged them to see, hold and be with their baby.

➡ B-02

Erlandsson K, Radestad I.

Mälardalen University, School of Health, Care and Social Welfare, Sweden; Danderyd Hospital, Karolinska Institutet, Sweden; Sophiahemmet University College, Sweden

SUPPORT AFTER STILLBIRTH AND ITS EFFECT ON PARENTAL GRIEF OVER TIME

Introduction. There appears to be little longitudinal work on the topic of parental grief and its relationship to professional encouragement and support from family, friends, and support groups for parents of a stillborn. This study aimed to describe parents' experiences of support over a 2-year period after a stillbirth 90 and its effect on parental grief. The research question guiding this study is: How do parents emotionally cope with the stillbirth of their child?

Methods. In this study, the authors describe parents' experiences of support over a 2-year period after a stillbirth and its effect on parental grief. Data was collected by questionnaire from 33 mothers and 22 fathers at 3 months, 1 year, and 2 years after stillbirth.

Results. Midwives, physicians, counselors, and priests—at the hospital 15 where the stillbirth occurred—are those on the front line providing professional

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support. The support from family and friends was seen to be important 2 years after the stillbirth.

Discussion. The need for professional support after stillbirth can differ, depending on the support provided by family, friends, and social networks. They may not fully realize the value of their support and how to be supportive. Printed educational materials given to individuals in the social network or family might therefore be helpful.

➔ B-03

Gordon A, Raynes-Greenow C, Bond D, Jones R, Morris J, Jeffery H.
School of Public Health, University of Sydney; Royal Prince Alfred Hospital, Australia

MATERNAL PERCEPTION OF FETAL MOVEMENTS: QUALITY VS QUANTITY? THE SYDNEY STILLBIRTH STUDY

Background. Decreased fetal movements (DFM) are a common cause for maternal concern and are associated with poor pregnancy outcomes. Randomised trials of movement counting however show no reduction in stillbirth and there are no universally agreed definitions. Most previous studies have focused on the number of movements and there is minimal qualitative data.

Aim. To assess maternal perception of fetal movements in women with late pregnancy stillbirth compared with gestationally matched control pregnancies.

Method. Population-based matched case control study of pregnant women ≥ 32 weeks gestation booked into tertiary maternity hospitals in metropolitan Sydney between Jan 2006 and Dec 2011. Quantitative and qualitative data on maternal perception of fetal movement are collected during face-to-face interviews. Standardised questions regarding fetal movement are transcribed and independently coded. Contingency tables were used for the quantitative data and qualitative data was thematically analysed

Results. There were 103 cases and 192 controls recruited. Women who had a late pregnancy stillbirth (cases) were significantly less likely to report an increase in strength or frequency of fetal movements as the pregnancy progressed compared with control women (OR 0.12 95% CI 0.04 – 0.33). Cases were also significantly more likely to report a sudden unusual change in the perception of fetal movement (OR 5.05, 95% CI 1.0 – 26). Active and passive themes were identified from the qualitative data. Passive themes were more commonly identified in the cases and demonstrate several potential “alert words”. Only 44% of both groups were given any specific information regarding fetal movements. Cases were more likely to have contacted a health care provider regarding concerns over movements prior to their actual diagnosis of a stillbirth.

Conclusions. Identification of compromised babies using description of fetal movements needs to be further explored. An increase in strength or frequency of movements with the progression of pregnancy appears reassuring. Advice from health professionals regarding fetal movements is not routine.

➔ B-04

Verling AM, O’Connell O, O’Donoghue K.
Cork University Maternity Hospital, Ireland; Anu Research Centre, Department of Obstetrics and Gynaecology, University College Cork, Ireland

FACTORS THAT INFLUENCE CLINICIANS IN THEIR CARE OF FAMILIES WHO EXPERIENCE STILLBIRTH

Introduction. Surveys of clinicians are an important data collection method in Health Service research. Previous surveys have noticed a strong reluctance of doctors to know, notice or remember anything about patients who have experienced a stillbirth. Are attitudes of clinicians to stillbirth created by lack of training, education, personal experience or clinical experience? Do doctors experience feelings of failure when asked to support this patient group?

Aim. We wanted to find out what influences clinicians in their care of women and their families at the time of stillbirth.

Method. Clinicians, including junior and senior trainees, consultants and specialists were surveyed from February to March 2012. We asked questions to elicit more in depth information on their knowledge of factual details of stillbirth cases and the pregnancy loss services available in CUMH. We also questioned their personal experiences and feelings encountered when dealing with families of stillborn babies. Finally we examined the impact caring for this patient group had on them. Anonymised data was analysed.

Results. When asked clinicians irrespective whether they are senior or junior agreed that caring for women who experience stillbirth takes an emotional toll on them personally.

- Of the group surveyed 14% strongly agreed that they had received adequate training to cope with stillbirth, while 36% partially agreed that training was adequate.
- 50% had personal experience (self, close family member or friend) of perinatal death.
- 36% were parents themselves.

Conclusion. Clinicians feel this patient group are challenging and that talking to senior colleagues, trainers or friends and family is used by 98% of clinicians to cope with the emotional impact of stillbirth. There is a continual need for ongoing staff education and support.

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➔ B-05

Verling AM, O'Connell O, O'Donoghue K.

Cork University Maternity Hospital; Anu Research Centre, Department of Obstetrics and Gynaecology, University College Cork, Ireland

THE VALUE OF A PREGNANCY LOSS CLINIC IN MATERNITY SERVICES; SUPPORTING AND ENHANCING PRACTICE

Introduction. The current pregnancy loss clinic in CUMH has been developed from a gynaecology clinic in the out patient's department to a dedicated consultant led clinic. It is in existence now for 4 years. The clinic provides medical investigation and treatment, as well as bereavement support to 200 women annually. The accumulated data from these care episodes is a valuable tool in critically analysing and supporting our practice.

Aim. The aim of the clinic is to investigate the medical causes of pregnancy loss and to provide information and support to couples who experience pregnancy loss. At the clinic a medical history is taken. Investigations are carried out and plans for a future pregnancy are discussed. Ongoing support is provided if required.

We aim to enhance practice throughout the service via:

- Maintaining and auditing patient database
- Identifying areas for further research
- Education and training
- Allocating resources

Method. Having established criteria for referral to the clinic, we identified which data was relevant for our purpose. A shared spreadsheet folder was designed to allow those involved in running the clinic the ability to update each patient entry as new information was received e.g. investigation results or new pregnancy. The data is then collated on an annual basis and reviewed.

Results.

- In 2010 – 188 women attended the clinic of these, 21.3% were late miscarriages and 10.7% Stillbirth.
- In 2011 – 210 women attend clinic with 20% experiencing late miscarriage and 5.2% experiencing Stillbirth.
- Between 2008 and 2010, 209 women attended the clinic for recurrent miscarriage, 89.5% had the complete set of recommended investigations.

Conclusion. Audit of the database has provided evidence supporting the value of our practice in identifying explanations for perinatal loss and has highlighted areas in which its value is more equivocal, prompting review of the use of resources.

➔ B-06

Verling AM, O'Connell O, O'Donoghue K.

Cork University Maternity Hospital, Ireland; Anu Research Centre, Department of Obstetrics and Gynaecology, University College Cork, Ireland

LABELLING STILLBIRTH - DOES IT MAKE A DIFFERENCE?

Introduction. Stillbirth remains one of the most common adverse pregnancy outcomes, affecting 1 in 200 pregnancies. A subsequent pregnancy following stillbirth is extremely difficult for the couple involved, and feelings of anxiety, failure, guilt, apprehension and reduced attachment are all present. For parents, re-attending the same hospital where they previously experienced a stillbirth can be traumatic. They may meet a variety of healthcare professionals who are not familiar with their history. Being asked to explain the loss of a baby causes distress and also leads parents to question the quality of care being offered in the new pregnancy.

Aim. We wanted to enhance best practice by improving the communication of previous stillbirth outcome across the multidisciplinary team. This intervention needed to be applied in a sensitive manner that was acceptable to parents but would provide a clear yet discreet alert to all staff. To improve quality of care in the treatment of parents who experienced stillbirth we introduced a sticker to be displayed on all hospital records to alert staff to the patient's history. Use of the sticker commenced as soon as an intrauterine death was confirmed or as early as possible in a subsequent pregnancy and then was consistently used on all records relating to the pregnancy. Finally we examined whether the use of the sticker alerts staff and helps them in attending appropriately to the needs of bereaved parents, and whether the parents noticed a difference in the quality of care.

Method. Audit showed the teardrop sticker was consistently used on all records relating to the new pregnancy, with 98% placement on medical case notes in 2010. Staff and patients were then surveyed a year after the sticker was implemented. A high level of satisfaction with the use of the sticker was reported from both groups.

- Positive comments included, "I find the sticker of great benefit, a necessity"
- Negative comments included, " would help if staff saw it"
- The mother and baby teardrop sticker is now a Trademark Registered to the Pregnancy Loss Services at CUMH.

Conclusion. Our vision for tomorrow for these families is that even in the middle of a large tertiary – referral maternity hospital we can alert the whole team

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in an effective and discreet way to deliver sensitive and appropriate care for these vulnerable families, resulting in a better antenatal experience, bonding and attachment experience and decreased risk of adverse outcomes in the next pregnancy.

➔ B-07

Malm MC, Lindgren H, Rubertsson C, Hildingsson I, Rådestad I.

School of Health and Social science, Dalarna University College; Department of Women and Childrens Health, Uppsala University; Institute of Health and Care Science, the Sahlgrenska academy, University of Gothenburg; Sophiahemmet University College, Sweden

QUALITY OF FETAL MOVEMENTS IN FULL TERM PREGNANCY - A SWEDISH POPULATION-BASED STUDY AMONG PREGNANT WOMEN WITHIN STANDARD ANTENATAL CARE

Background. Decreased fetal movements are associated with adverse outcome. Besides the frequencies of fetal movements, enhanced knowledge about the quality of fetal movements may contribute to the development of tools to identify fetus at risk.

Aim. The aim of this study is to investigate the perceptions of the quality of fetal movements among women in full term pregnancy and within standard antenatal care.

Method. 393 women with uncomplicated pregnancies participate in this study. Data were collected by questionnaires, the women answered one open question: "Could you describe how you perceive your child's movements usually been during the current week of pregnancy". The answers were analyzed using content analysis.

Results. 315 (78 %) of women in gestational week 37-42 describe the movements in terms of power and in equal words irrespective of parity.

Conclusion. A fetal movement anamnesis can besides the frequencies also include questions about the quality of the movements.

➔ B-08

Malm MC, Rådestad I, Erlandsson K, Lindgren H.

School of Health and Social Sciences, Dalarna University College; Department of Women and Childrens Health, Uppsala University; Sophiahemmet University College; School of Health, Care and Social Welfare, Mälardalen University; Department of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden

WAITING IN NO-MAN'S-LAND – MOTHERS' EXPERIENCES BEFORE THE INDUCTION OF LABOUR AFTER THEIR BABY HAS DIED IN UTERO

Objective. Carrying death instead of life is beyond understanding and a huge psychological challenge for a pregnant mother. The aim of this study was to investigate the mothers' experiences of the time from the diagnosis of the death of their unborn baby until induction of labour.

Method. In this qualitative study, in-depth interviews were conducted with 21 mothers whose babies had died prior to birth. The interviews were then analysed using content analysis.

Results. The overall theme that emerged from the mothers' experiences is understood as "waiting in noman's-land", describing the feeling of being set aside from normality and put into an area which is unrecognized. Four categories were established: 'involuntary waiting' describes the sense of being left without information about what is to come; 'handling the unimaginable' concerns the confusing state of finding oneself in the worst-case scenario and yet having to deal with the birth; 'broken expectations' is about the loss not only of the baby but also of future family life; and 'courage to face life' describes the determination to go on and face reality.

Conclusions. The mother's experiences during the time after the information of their baby's death in utero until the induction of labour can be understood as a sense of being in no-man's-land, waiting without knowing for what or for how long.

➔ B-09

Avelin P, Radestad I, Gyllenswärd G, Erlandsson K.

Karolinska Institute, Department of Women's and Children's Health; Mälardalen University, School of Health, Care and Social Welfare; Sophiahemmet University College, Sweden

SIBLINGS' GRIEF AND EXPERIENCES OF SUPPORT AFTER LOSING A SISTER OR BROTHER IN STILLBIRTH

Introduction. To have a stillborn baby in the family can affect older siblings more than realized. To experience loss in adolescence can be particularly difficult when young people cannot always take a break in life to mourn, because the physical and mental developments are driving. The study aimed to describe siblings' experiences in connection with the loss of a stillborn little sister or brother. It is important to investigate the adolescents' own experiences since studies more often is focusing on the siblings' situation though from their parents' perspective.

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Methods. 15 adolescents aged 13-17 years was interviewed, and the transcripts was analyzed using content analysis.

Results. Siblings of stillborn babies suffer in two ways, firstly they mourn the loss of the expected baby and in that grief it is important that they can be involved and share the experience, secondly they mourn the loss of their parents who in their own grief in some way cannot be the parents as the siblings knew them prior the loss. So in some way the adolescents grieve the effects loss brings, as the family after the death is not the same.

Discussion. Teens often struggle to maintain balance in life, peers become increasingly important, sometimes more important than parents on many issues. But it is important that they share the experience with others who see them, listening and confirming.

➔ B-10

Avelin P, Radestad I, Erlandsson K.

Karolinska Institute, Department of Women's and Children's Health; Mälardalen University, School of Health, Care and Social Welfare; Sophiahemmet University College; Department of Clinical Sciences, Danderyd Hospital, Karolinska Institutet, Sweden

GRIEF AND RELATIONSHIP AFTER THE LOSS OF A STILLBORN BABY – MOTHERS AND FATHERS PERSPECTIVE

Introduction. The grief that results after stillbirth has been described as a complex and unique loss. Bereaved mothers and fathers tend to have different grieving styles, roles, and their emotional expressions of the loss differ. This study aimed to describe the grief of mothers and fathers and its influence on their relationship after the loss of a stillborn baby.

Methods. The sample consisted of 55 parents, 33 mothers and 22 fathers, who received a postal questionnaire three months, one year and two years after their loss. Data were analysed numerically for multiple choice questions and content analysis was used for comments and answers to open-ended questions.

Results. Both mothers and fathers state that they become closer after the loss, and that feeling is strengthened after one year. The parents described that they were grieving immediately and gradually as individuals, and together as a couple. In this immediate and gradual grieving movement their expectations, expressions and needs for themselves and each other could be a threat towards their togetherness as a couple, in that they feel alone in a movement of withdrawal. While some mothers and fathers find similarities in grieving styles, the intensity and expression of grief vary, and the effects are profound and unique from person to person.

Discussion. By awareness of the variation in intensity of grief along with understanding and acceptance of one another's grieving style and giving each other space in grief, parents will be able to better share their loss together. Anticipating and being able to acknowledge the different aspects of grief will enable professionals to implement more effective interventions in helping couples grieve both individual and as a couple.

➔ B-11

Heazell AE, Smith A, Garrod A, Batra G, Sibley C.

Department of Histopathology, Royal Manchester Children's Hospital; Maternal and Fetal Health Research Centre, University of Manchester; Academic Health Science Centre, United Kingdom

QUANTITATIVE ASSESSMENT OF PLACENTAL MORPHOLOGY IDENTIFIES SPECIFIC CAUSES OF STILLBIRTH AND REDUCES THE PROPORTION OF STILLBIRTHS OF "UNKNOWN CAUSE"

Introduction. Stillbirth is frequently the end result of a pathological process involving the placenta. Many associations with stillbirth alter placental structure or function including: infection, fetal growth restriction (FGR), placental abruption, diabetes, hypertension and anti-phospholipid syndrome. Despite advances in the classification of stillbirths, a significant proportion remain "unexplained".¹ There are few robust studies of placental phenotype in stillbirth. Basic histopathological examination of the placenta reduced the proportion of stillbirths from an "unexplained" cause (Odds Ratio 0.17, 95% CI 0.04-0.70).² It was hypothesised that application of quantitative assessment of placental morphology would find altered placental structure and morphology in different causes of stillbirth. Furthermore, it was proposed that if placental morphological assessment was applied to a group of stillbirths of "unknown" cause, morphological changes associated with a specific cause could be identified.

Methods. Placental tissue blocks (n=3 per placenta) were obtained from stillbirths who had full post-mortem examination with an established cause of death (cord accident n=8; diabetes n=5; hypertension n=8; infection n=9; FGR n=10) and those in which a cause of death was not identified (n=10). For comparison placental tissue from matched pregnancies with live births was used. Syncytial nuclear aggregates were assessed on 5µm sections stained with haematoxylin and eosin. Immunoperoxidase staining was used to highlight proliferative cells (anti-Ki67), villous blood vessels (anti-CD31), leukocytes (anti-CD45) and trophoblast area (anti-cytokeratin 7). Five areas of each section were photographed and subjected to image analysis (ImagePro Plus, Media-Cybernetics). The number of syncytial nuclear aggregates, trophoblast area were normalised to total villous area and the number of proliferative nuclei expressed as a proportion of total nuclei. The median value for these indices was calculated for normal placenta, this was compared to different causes of stillbirth using Wilcoxon signed rank test.

Results. Syncytial nuclear aggregates were increased in stillbirths from cord accidents and hypertensive disorders (p<0.05). Proliferation was decreased in

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all groups of stillbirth ($p < 0.05$), but was particularly reduced in cord accidents and FGR ($p < 0.01$). Trophoblast area was increased in FGR and was reduced in stillbirths from infection ($p < 0.05$). Villous vascularity was significantly reduced in FGR ($p < 0.001$). The proportion of avascular villi was increased in cord accident ($p < 0.01$), hypertension ($p < 0.05$), infection ($p < 0.05$) and most strongly in FGR ($p < 0.001$). Different causes of stillbirth, particularly FGR, cord accident and hypertension had different patterns of placental morphology. When these patterns were applied to stillbirths of “unknown cause”, two cases had identical morphological pattern to FGR (Table 1).

Conclusion. Quantitative assessment of placental morphology using image-analysis software can distinguish between different causes of stillbirth. When these criteria are applied to stillbirths of unknown cause, 20% had a similar pattern to FGR. Therefore, applying quantitative assessment in addition to expert qualitative assessment might reduce the proportion of stillbirths classified as “unexplained”. A greater proportion of pregnancies may be affected by FGR than previously thought.

This work was funded by Tunbridge Wells Sands, UK made possible by support from Eden Financial.

➔ B-12

Gold KJ, Sen A, Xu X.

HOSPITAL COSTS ASSOCIATED WITH THE DELIVERY OF STILLBORN INFANTS

Objectives. Fetal deaths account for nearly one percent of all births in the United States. The cost of hospital care associated with fetal deaths may be substantial. However, there is very limited data on the economic burden of fetal death.

Methods. We conducted a retrospective medical chart review of stillbirths at three large hospitals in Michigan over a ten-year period and identified medical complications, hospital costs, and length of stay for these deliveries. Mothers with stillbirth were matched with mothers of same age who delivered a live-born infant at the same hospital during the same year.

Results. Our final sample was comprised of 533 stillbirths and 1053 matched live births. Average hospital cost for stillbirth was \$7495 (± 7015) and the average length of stay was 2.8 days (± 2.8). Having a serious maternal medical complication was associated with higher costs and longer length of stay among women with stillbirth. Early stillbirths between 20-28 weeks gestational age, epidural/spinal/general anesthesia, and cesarean delivery were also associated with longer length of stay. For women with stillbirth, average hospital costs were more than \$750 higher than women with live births but length of stay was not significantly different.

Conclusions. This study suggests that stillbirths were associated with substantial maternal hospital costs. Future research examining economic impact of stillbirths beyond labor and delivery such as increased costs associated with additional testing and care in subsequent pregnancies will help better understand the overall economic impacts of stillbirths.

➔ B-14

Nuzum, DR.

HOW DO WE AS PROFESSIONALS MEET THE SPIRITUAL NEEDS OF BEREAVED PARENTS?

Introduction. Discovering the joy and expectation of new life in pregnancy is one of life’s most exhilarating moments in which the expectation of a new baby is present in a very real way from the time of that discovery. Plans are made and a future is imagined. When the devastating news that your baby has died or will not survive is broken, suddenly projected dreams of the future are shattered and are replaced by a reversed trajectory of a long and bewildering journey of what might and should have been.

For parents, life will never be the same again. Their grief is one that reaches forward into the future unlike any other grief. The deep beliefs and values that sustain us through life can be shaken to their very core. Certainties can fade, supports can lose their safety and parents can feel like they navigate on their own. Likewise, a life crisis such as this can awaken strong impulses of spirituality in a new way. These spiritual experiences are not dependent on religious faith.

As healthcare professionals how do we respond to these deep needs?

Intended Audience. Healthcare professionals working in the area of perinatal death and bereavement.

Objectives.

- To acknowledge the place of spirituality as an integral part of every person
- To name and identify spiritual needs
- To explore how we as staff can identify spiritual needs in bereaved parents
- To explore how spiritual needs are met in various facilities
- To discover new and deeper ways of addressing spiritual concerns of bereaved parents based on the experience of all around the table
- To have a greater awareness of the role of faith and spirituality in the healing space between carer and bereaved parents

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List Key Discussion Topics.

- What are spiritual needs?
- How do we recognise them?
- Are there specific spiritual needs in bereaved parents?
- How do we come alongside parents in their grief that embodies 'being' rather than 'doing'?
- What about our own spiritual needs?

Facilitators Qualifications. Daniel Nuzum is a Registered Nurse, Anglican Priest, Practical Theologian and Accredited Healthcare Chaplain. Daniel has twelve years parish ministry experience and started work in perinatal healthcare ministry in early 2009. Daniel has a specialist professional and academic interest in perinatal bereavement care and is a member of the Miscarriage, Stillbirth and Neonatal Death Committee at Cork University Maternity Hospital, Ireland. Daniel has completed the RTS Perinatal Bereavement Training Program and RTS Co-Ordinator training and is currently a postgraduate student at the Anu Research Centre, Department of Obstetrics & Gynaecology, University College, Cork researching the spiritual and pastoral needs of parents who experience stillbirth.

Orla O'Connell is a Bereavement and Loss Midwife Specialist at Cork University Maternity Hospital, a member of the Miscarriage, Stillbirth and Neonatal Death Committee at Cork University Maternity Hospital and an Accredited Psychotherapist.

➡ B-15

Nuzum DR, O'Donoghue K, Morris H.

Anu Research Centre, Department of Obstetrics & Gynaecology, University College Cork, Cork University Maternity Hospital; Queen's University Belfast, Ireland

NATIONAL STILLBIRTH GUIDELINES: DOES SPIRITUALITY OR FAITH MATTER?

The provision of national/regional guidelines of care for parents following stillbirth has contributed significantly to a standardised level of care. Most guidelines have woven the strands of best practice, personal experience and latest scientific research as part of an increasing global awareness of the importance of consistent care following stillbirth.

Holistic or 'total' care acknowledges the importance of recognising and attending to the emotional, physical, social and spiritual elements of every person. Stillbirth brings each of these areas into a sharp and painful focus that become part of the story of a family for the rest of their lives. The focus of this review is to evaluate the perceived importance of spiritual and pastoral/faith needs in National/Regional Guidelines for Stillbirth from seven regions of the world.

Methods. A review of National/Regional Guidelines (Australia/New Zealand, Canada, Ireland, Sri Lanka, Sweden, United Kingdom, United States of America) produced in recent years (2006-2011) was conducted to assess the place of faith and spiritual care needs as part of the recommended standards of care.

Each guideline (n=7) was reviewed to establish if spiritual or faith needs were included by the presence of key words such as ceremony, chaplain, faith, pastoral, religious, ritual, spiritual.

Where spiritual and faith needs are mentioned these were explored further to establish if this area is treated as an integral aspect of care or as fleeting reference.

Results. Whereas obstetric, midwifery and scientific practices are generally consistent across the National/Regional Guidelines -with the exception of an agreed definition of stillbirth (20+ -24+ weeks gestational age or 350g+ -500g+ weight)- this review highlights considerable variance in how spiritual and pastoral/faith needs are identified and met. This varies from no inclusion of spiritual or religious care (n=2), a functional religious referral (n=2), an integrated approach where spiritual and pastoral care is offered to all families (n=3). These findings correlate with how each guideline approaches the 'personhood' of a stillborn baby. Guidelines where spiritual care is not included refer to a 'fetus' and in doing so create distance. Guidelines that use the term 'baby' have a more holistic approach.

Discussion. Birth and death are pivotal life events; in stillbirth both are inextricably entwined resulting in deep existential questions that continue long after parents have left our care. These questions raise deep spiritual and theological concerns about meaning and identity and are usually 'Why?', 'Why us?', 'Why our baby?'.

How these deep spiritual questions are recognised, identified and met can contribute significantly to the recovery of parents following stillbirth.

The results of this review contribute a greater awareness of the importance of spirituality and faith beyond a functional 'checklist' approach. This review highlights this important aspect of care for families as they seek to access their spiritual resources and use ceremony/ritual and faith to find meaning and healing. Recommendations for practice include the consistent provision of high quality spiritual and pastoral care for all families.

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➔ B-31

Amoroso A, Skinner A.

Isabella's Giraffe Club, USA

Good Grief to Go - A Giant HeART Bereavement Workshop™

This workshop is to help train bereavement facilitators using leading scientific information and ancient wisdom that is partnered with creative music and art activities. All are welcome.

ABSTRACT GOOD GRIEF TO GO! A 5-WEEK, GIANT HEART WORKSHOP™

Beyond the 5-week workshop optional monthly gatherings are suggested.

Background/Introduction. Unresolved Grief could very well be described as the origin for the human emotional, mental and physical imbalances that lead to dis-easement and suffering of unimaginable proportions. Until now, the vast chasm that has existed between the leading edge science and ancient wisdom has contributed to the agony of those experiencing incomprehensible loss. This is all about to change. Where once grieving individuals found themselves "nowhere" a bridge is "NowHere." This workshop provides a creative and gentle way for facilitators to utilize the leading scientific information regarding brain neuroplasticity, paralleled by ancient wisdom. Together, we can begin to create a blueprint that positions the bereaved to awaken to a new normal, where they can tell a new story to create a happily ever after. Developing emotional intelligence via integrative medicine is becoming a positive Health Care System that is the new frontier for trauma intervention. Leading science and the discovery of brain neuroplasticity is demonstrating what ancient wisdom has known all along. A holistic approach is necessary in an effort to achieve new pathways of communication in the brain as we journey back through the sympathetic to the parasympathetic nervous system. A journey we call grief. Up until now this journey, for many, has led to a dead end. However hope is on the horizon. Life will be joyful once again and to merely survive will be replaced by thriving and joy. We can look back at history and recognize the challenges that have developed people making decisions from a place of fear or anger. Modern day, we recognize the impact that stress has on our health and well-being. Recent studies have shown how meditation, and a variety of alternative medicines from acupuncture to Qigong have had a positive effect on healing. Now we even know that exercise training increases the size of the hippocampus and improves memory. Simply, our thoughts influence our outcome. How we tell our stories and support a healthy system of body-mind can make all the difference in the world, especially for a grieving parent.

Methods. This workshop will provide a sampling of how each facilitator can prepare a trusting and calm environment for the weekly material that builds upon itself. Utilizing the latest techniques in mindfulness, creative approaches for music and art activities we begin to offer relief for the bereaved. This moment of relief is the necessary first step for healing. We will demonstrate the benefits of a consecutive 5-week workshop where facilitators will present weekly topics including: "noticing a coincidence," reframing your story, self-care, unfinished business, reflecting love, honoring your path and being of service. Each week, correlating activities will offer ways for everyone to participate in a gentle and nurturing environment inspiring new perspectives.

Results. A sample of our results have been awe-inspiring:

- * Best Quote from Jaxson's Grandpa - "We came here wondering how in the world we were going to live without our boy - you showed us that we don't have to!"
- * "Laugh for SIDS" - a stand up comedian whose baby passed of SIDS takes it on the road.
- * Alpine Family - creating a musical album
- * A mom created a volunteer group called, "SHINE"
- * Anonymous donor - gave \$400,000 to UCSD Medical Center Infant Special Care Center

Conclusion. We are not individuals but trillions of individual cells living in community under one skin. Fractal geometry demonstrates that we extend that community to our family, our neighborhood, our country and our world. When we allow ourselves to participate in the whole, we experience that together we are greater than the sum of our parts.

➔ B-32

Geisler ME, Verling AM, O'Connell O, O'Donoghue K. (*Keelin O'Donoghue presenting*)

Anu Research Centre, Department of Obstetrics and Gynecology, University College Cork, Cork University Maternity Hospital, Ireland

THE OUTCOME OF PREGNANCY AFTER STILLBIRTH

Introduction. In the developed world pregnancy results in stillbirth in 1 in 200 cases. The subsequent pregnancy following stillbirth is an anxious time for parents and their obstetricians. Antenatal management is complex, involving increased antenatal surveillance and intervention.

Aim. To analyze the antenatal management of the subsequent pregnancy after stillbirth and to study the maternal and neonatal outcomes.

Methods. A retrospective study of subsequent pregnancies in patients who had a stillbirth that occurred between the years 2007-2011.

Results. One hundred women were identified in a new pregnancy after a prior stillbirth. The charts of 51 patients have been analyzed to date. The median maternal age was 32 years (range 20-43). The majority, 88 %, were White Irish. The median gestational age at prior stillbirth was 34 weeks (range 22+6 - 41+4) and all infants were greater than 500g in weight.

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The mean number of antenatal clinic attendances in the new pregnancy was 10 (range 3-21), which compares to 5 in a routine 'low risk' pregnancy in our unit. The mean number of formal ultrasound scans was 6 (range 0-22). Sixteen women (31%) were prescribed low-dose aspirin, 6 were commenced on low-molecular weight heparin and 11 patients were prescribed high-dose folic acid. Four patients required transvaginal ultrasound for cervical length surveillance. Eight women (16%) had a first trimester miscarriage in the subsequent pregnancy. Four women were diagnosed with gestational diabetes and two had gestational hypertension. One woman experienced a recurrent intrauterine fetal death (IUFD) at 26 weeks gestation, and both were characterised by non-immune hydrops. One patient had a placental abruption at 31 weeks gestation with a liveborn infant delivered by emergency cesarean section; her prior IUFD was due to placental abruption at 37 weeks.

Five women (9.8%) delivered preterm (<37 weeks gestation), while six had an elective cesarean section at term. The majority, 73%, had a term delivery (37+0- 40+5 weeks) and of these, 62% (23/37) underwent induction of labor, with 87% delivering vaginally. Five infants were admitted to the neonatal intensive care unit, two for prematurity/low birth weight, one for hypoxia/prematurity following placental abruption and one for cyanosis on day one of life.

Conclusion. The pregnancy following a stillbirth involves more intensive surveillance with a resultant greater demand on hospital resources. Medical intervention is increased, in particular with increased rates of induction of labor. However, the majority of women in our series delivered a liveborn infant, and the rate of vaginal delivery was high with a low occurrence of maternal morbidity.

➔ B-33

Schrader L, Mathiesen T, Dyregrov A, Kalstad TG.
Norwegian SIDS and Stillbirth Society, Center for Crisis Psychology, Norway

CARING FOR EMPLOYEES EXPERIENCING GRIEF AND CRISIS; INFORMATION BOOKLET AND EDUCATIONAL SEMINARS

Introduction. The Norwegian SIDS and Stillbirth Society has activities in the areas of bereavement support, education, prevention and research. The loss of a child affects both physical and mental health and many bereaved experience reduced working capacity and ability. At the same time we know that returning to work is important for the bereavement process, provided a working climate based on respect, care and flexibility. Employers with knowledge about grief are more capable of helping employees to return to work, prevent lack of working capacity and reduce absence from work. One priority of the Society is to spread knowledge about grief to the population in general and to the social network of the bereaved in particular. Colleagues are often an important part of bereaved parents' social network. Knowing that care and support from the social network is important, we have developed the information booklet "When employees experience grief and crisis". Now we also organize educational seminars addressing how workplaces can support and follow-up bereaved employees.

Target Groups. The target groups are employers, leaders, managers and others who have responsibilities and tasks related to occupational safety and health.

Content. Despite the fact that most working places at some point have employees experiencing grief there is often a lack of knowledge about how to handle these situations. Both the booklet and the seminar focus on how grief is expressed, how grief and crisis can affect the working life, characteristics of good follow-up and care, and important leadership tasks.

The booklet is written by psychologist Atle Dyregrov and sociologist Kari Dyregrov in cooperation with staff members in the Society. Some bereaved parents have also contributed by sharing their experiences. The booklet is nicely illustrated, easy to read and contains lots of advices and concrete proposals. It is free of charge and also available at our website. The seminar has a practical approach and is mainly based on the booklet. A bereaved father opens the seminar by telling about how he experienced going back to work. The main speaker is Atle Dyregrov. He addresses the needs of employees and the employer's responsibility and tasks regarding care and follow-up to the best of both the company and the employee. The last speaker is a manager in a big company in Norway. She describes three follow-up cases with employees in grief. At the first seminar there were 80 participants, and we expect a lot more on the next seminar in Oslo.

Results. Employers and working places have become an important target group for The Society. The feedback on both the booklet and the seminar is very good. This is information and knowledge work places have lacked and need. The booklet is distributed regularly to both bereaved parents and companies. Through the booklet and the seminars we are able to spread both parents' experiences and scientific knowledge about grief and returning to work. The Society has as a consequence also become a more visible organization in general. Another good consequence is that the Society benefit economically from the seminars.

➔ B-35

McConnell T, Bishop L, Harrison L, Morris J, Lauder R. (*James Morris presenting*)
Lancaster University, United Kingdom

TEMPERATURE DEPENDENT TOXIN PRODUCTION BY STAPHYLOCOCCUS AUREUS STRAINS

Introduction. Staphylococcus aureus is a pathogenic bacterium capable of producing a range of pyrogenic toxins recognised as superantigens. The bacterium and its toxins have been implicated in cases of sudden infant death. The peak incidence of sudden infant death syndrome is between two and three months of age when circulating anti-toxins are at their nadir. We have hypothesised that if the toxins are not neutralised by specific anti-toxin IgG

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some will be eliminated by the kidneys and excreted in the urine.

A recent retrospective review of autopsy reports from cases of sudden infant death found that *S. aureus* was isolated more commonly from cases of unexplained death compared to an explained non-infection group. Another study detected the toxins in the tissues of over 50% of cases from three different countries. However, the significance of *S. aureus* and its toxins in individual cases is unclear because the presence of the pathogen could be:

- Genuine infection which has caused or contributed to death.
- Genuine infection which is incidental
- Contamination

We hypothesise that there will be differential secretion of bacterial toxins depending on temperature, and that the precise pattern and dose of toxin secretion will help to differentiate between the above three possibilities.

Methods. A TSST-1 producing strain and an SEB producing strain of *Staphylococcus aureus* were cultured for 24 hours at 41 °C, 37 °C, 30 °C, 22 °C or 4 °C in either Brain Heart Infusion broth (BHI) or clean catch mid-stream urine. The OD600 of the suspensions was measured prior to centrifugation at 900g. Toxin levels in the resulting media supernatants were determined by Enzyme Linked Immunosorbent Assay (ELISA), gel electrophoresis and western blotting (WB).

Results. Maximum bacterial growth was observed between 30°C and 37°C. Growth was diminished at 22°C and 41°C and undetectable at 4°C. In contrast, maximal toxin release occurred at 41 °C (0.10µg/ml, XXXX) with less at 37 °C (0.052µg/ml, XXXX) for TSST-1 and SEB respectively, while at 4 °C, 22 °C and 30 °C toxin release was undetectable.

Conclusions. Contamination of urine samples stored at room (22°C) or refrigerated (4°C) temperatures is unlikely to result in the release of significant levels of toxin.

These results support the interpretation of our parallel findings that the detection of *S. aureus* toxins in infant urine results from a transient bacteraemia rather than contamination.

Furthermore, the use of ELISA and WB for the detection of bacterial toxins in body fluids taken at autopsy could be used to distinguish between genuine infection with *S. aureus* and contamination.

➔ B-36

Harrison L, Morris J, Lauder R, McConnell T, Bishop L, Telford D. (James Morris presenting)
Lancaster University, United Kingdom

STAPHYLOCOCCAL PYROGENIC TOXINS IN URINE: A POSSIBLE MARKER OF TRANSIENT BACTERAEMIA

Introduction. Transient bacteraemia occurring in otherwise healthy individuals may cause acute life threatening events due to bacterial toxemia, even though the bacteraemia is rapidly cleared (< 20 minutes). We hypothesise that this can happen in infancy and also later in life. Circulating toxins will normally be neutralised by specific anti-toxin IgG but some will be eliminated by the kidneys and excreted in the urine. The risk of bacterial toxemia is greatest in infancy at around 2 to 3 months of age when anti-toxin IgG reaches its nadir and the incidence of sudden infant death syndrome (SIDS) is greatest. A bacterium implicated in SIDS cases is *Staphylococcus aureus*. The bacterium secretes a range of pyrogenic toxins.

This work reports the examination of urine samples, from infants in the age range most at risk of SIDS, older infants with a cold and adults suffering an acute life threatening event, for the presence of staphylococcal toxins as a marker of transient bacteraemia.

Methods. We have developed an enzyme-linked immunosorbent assay (ELISA) method for the detection of staphylococcal toxins in urine samples. Urine samples from two population groups were analysed for the presence of the staphylococcal toxins; staphylococcal enterotoxin B (SEB), staphylococcal enterotoxin C (SEC) and toxic shock syndrome toxin (TSST-1). Samples were collected from 30 infants at 2 weeks, 10 weeks and 7 months of age when the infants were healthy and from infants of 7 months of age when they had a cold. One hundred adult patients, diagnosed with myocardial infarction, had urine samples collected on admission to the coronary care unit (CCU) and after they had been discharged and recovered from the acute episode. To identify contamination, all samples were cultured and toxin producing *S. aureus* isolates identified. Urine samples were analysed for the presence of the staphylococcal toxins.

Results. The bacterium *S. aureus* was cultured from 10% of infant urine samples and 5% of adult samples. *S. aureus* toxins were detected in 9 of 101 infant urine samples analysed by ELISA. The proportion of positive samples was increased with infection and at 10 weeks of age. All the samples from the adults tested negative for *S. aureus* toxins. There was no evidence that *S. aureus* contamination of urines was associated with toxin positivity.

Discussion. Measuring staphylococcal toxins in urine is a useful marker of transient bacteraemia in infants but not in adults; probably because adults have sufficient circulating specific IgG to neutralise the bacterial toxins whilst levels are low/absent in the infant population. In practice, bacterial contamination is not a problem.

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➔ B-37

Tonkin SL, McIntosh CG, Gunn AJ. (*Christine McIntosh presenting*)
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DOES TONGUE SIZE CONTRIBUTE TO THE UNIQUE AGE DISTRIBUTION OF SUDDEN UNEXPECTED DEATHS IN INFANCY?

Background. The incidence of sudden unexpected deaths in infancy (SUDI) peaks between 2 and 4 months of age - and deaths are rare after 6 months. Although multiple factors have been associated with risk this remarkable age specificity is not hitherto explained.

Methods. Retrospective analysis of previously reported timed lateral radiographs of the upper airways of 17 infants, taken first in car seats whilst asleep with their heads upright and then with their heads slumped forward (when their chins usually rested upon their own chests). Radiographs were scored for the amount of air space around the tongue, as a measure of the relationship between the size of the tongue and the oral space. The oro-pharyngeal airway space was measured along 5 lines of skull definition. Comparisons were made between tongue-oral relationship and airway size.

Results. A smaller airspace around the tongue was significantly associated with greater narrowing of the oro-pharyngeal airway when the head was flexed forward ($p < 0.002$).

Conclusion. The present study suggests that the age of vulnerability of infants to SUDI may in part at least be related to a combination of mobility of the jaw before 6 months and growth in tongue size relative to their oral cavity. After 6 months of age SUDI deaths are rare. Then the temporo-mandibular joint is stable and the jaw cannot be pushed back during head flexion or by direct pressure on the chin.

➔ B-38

Baddock SA, Tipene-Leach D, Tangiora A, Williams S, Jones R, Taylor B.
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METHODOLOGY AND RECRUITMENT INTO A RANDOMISED CONTROL TRIAL TO EVALUATE SLEEPING OPTIONS FOR NEW ZEALAND BABIES

Despite significant improvements, the rate of Sudden Unexpected Death in Infancy (SUDI) in New Zealand remains at 1.1 deaths/1000 live births and 2.4/1000 for Māori (indigenous New Zealanders) babies – five times the rate for non-Māori, non-Pacific babies. These babies are often exposed to multiple risks eg maternal smoking and bedsharing and these behaviours are difficult to change. A novel intervention has been developed by Māori with the potential to reduce bedsharing in these high risk situations. This is a wahakura (a flax bassinet able to be used in bed) that offers a potentially safer sleeping option.

The aim of this study is to evaluate the risks and benefits of wahakura. 240 families will be recruited from midwifery practices supporting mainly Māori families. Diverse strategies, such as discussions with the wider family, are used to recruit “hard to reach” participants. Mothers are randomised to receive a wahakura or bassinet at the antenatal visit. Overnight sleep-video, oximetry, infant body temperature, maternal salivary oxytocin and infant urinary cotinine are monitored at one month; and breastfeeding, attachment and sleep data is collected from interviews at 1, 3 and 6 months of age.

To date 90 families have consented to participate and 30 sleep studies have been completed. Analysis of the video data identifies time in the sleep device, head covering, maternal –infant interactions, sleep duration, time bedsharing and potentially dangerous events which are correlated with infant SaO₂ and peripheral temperature. Time in the infant thermal comfort zone and overnight hypoxic events at 1 month are compared between wahakura and bassinet sleep, as is breastfeeding at 3 and 6 months, mother-infant attachment and regular use of the sleep device.

Results will inform our evaluation of the risks and benefits of wahakura as an infant sleeping option. If the wahakura proves to be an acceptable sleeping environment, and there is sufficient support by health authorities to provide such a device to families in high risk groups, it could be lifesaving by reducing SUDI deaths.

➔ B-39

Bagley R, Hamer B.
Florida SIDS Alliance, USA

FLORIDA'S “TRAIN THE TRAINER - SAFE SLEEP WORKSHOP”

The Florida SIDS Alliance has provided continuous service to parents, education to health professionals, and raised funds for research since our formation in March 1992.

The Florida SIDS Alliance received a grant in 1996 to test the hypothesis that placing and Infant for sleep on its back will reduce the Incident of SIDS. The results were statistically significant and we began delivering a presentation to health professionals with focus on the County Public Health Nurses who work with and provide service to infants and families. Florida experienced a significant decline in SIDS deaths and a parallel decline in infant mortality.

Over the past few years we have seen a small but significant increase in infant mortality especially in counties where back to sleep is less practiced.

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As a result of this and in cooperation with Healthy Start Coalitions throughout Florida, the Florida SIDS Alliance developed a “Train the Trainer” program to promote the steps of healthy infant care practices recommended by the American Academy of Pediatrics. The training program has reached 116 health professionals and they have presented the information to more than 1,500 new and expectant parents.

The program uses a series of activities that allow the participant to experience learning through many different methods and has the AAP recommendations presented in four different presentations.

Incorporated in the training are power point presentations as well as the description of how the other presentations are presented. Trainers return to their home community to teach parents of other professionals and submit the class information for a one year period.

Our program is evaluated through a group process as well as written format and the use of pre-post tests.

➔ B-40

Richardson R.
SIDS and Kids NSW, Australia

RETROSPECTIVE ANALYSIS OF REFERRALS TO SIDS AND KIDS NSW FOR BEREAVEMENT SUPPORT FROM 2007 TO 2011

Introduction. SIDS and Kids NSW was an organization that resulted from the merge in 2004 of two other organizations, SANDS NSW (Stillbirth and Neonatal Death Support of NSW) which had provided services for families who had experienced pregnancy and neo-natal loss and SIDS NSW (Sudden Infant Death Association of NSW) which had provided services to families whose babies had died from SIDS.

Method. To analyze the patterns in referrals for bereavement support from families bereaved by the death of their baby or child during pregnancy, birth, infancy or early childhood from 2007-2011 to determine if there was any change in the frequency, type and purpose of referrals. The SIDS and Kids NSW database was analyzed to ascertain: who made the referral; the types of losses; the location of the family; which services they accessed; how long they received services; and the outcome.

Results. Various patterns emerged from the data about the families who sought bereavement support from SIDS and Kids NSW. Preliminary findings will be presented.

Discussion. With the more recent merge of SIDS and Kids NSW and SIDS and Kids Victoria this is a timely reminder of the need to employ creative methods for meeting the bereavement support needs of all families who experience the death of their baby at any time during pregnancy, birth, infancy or early childhood.

➔ B-41

Richardson R, McSpedden ML.
SIDS and Kids NSW, Australia

ADDRESSING COMPASSION FATIGUE IN TWO BEREAVEMENT COUNSELING TEAMS

Introduction. Providing support for traumatized families may have an adverse impact on counselors. When SIDS and Kids NSW and SIDS and Kids Victoria decided to merge their organizations it was discovered that there was Compassion Fatigue (CF) occurring in both teams of the bereavement counselors who support families that have had a baby or child die at any time during pregnancy, birth, infancy or early childhood. The merge provided an ideal opportunity to address the CF in these teams.

Method. A correlational, non-experimental design was used in a multi-phase study using quantitative and qualitative methods to measure the level of CF and address it within these teams as they merged.

Phase I: Quantitative survey using ProOQL and other instruments to gauge the level of CF.

Phase II: Semi-structured interview about the experience of CF

Phase III: Training in strategies to manage CF

Phase IV: Committing to and Implementation of individual programs to manage CF

Phase V: Review of implementation

Results. Team members participated in the program to reduce and manage CF. An interim report on the first three phases will be presented.

Discussion. Bereavement support organizations need to monitor and manage CF with counselors because of the potential for adverse outcomes from continuous exposure to traumatic experiences.

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➔ B-43

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PARTIAL SILENCING OF MEDULLARY SEROTONIN (5HT) VESICULAR NEUROTRANSMISSION INHIBITS RESPIRATORY LONG TERM FACILITATION (LTF) AND INCREASES TOTAL APNEA IN MICE AT A CRITICAL AGE IN POSTNATAL DEVELOPMENT: RELEVANCE TO SIDS

Introduction. LTF, a sustained increase in ventilation (VE) after repeated exposure to intermittent hypoxia, is 5HT dependent and is thought to prevent apneas. The sudden infant death syndrome (SIDS) is associated with 5HT deficiency and some SIDS infants had increased and prolonged apneas prior to death. In this study we used the Pet1:flpe 'silenced' mouse to test the hypothesis that partial inhibition of 5HT secretion inhibits LTF and leads to increased apneas in early postnatal life. In these mice, the dual activity of Cre and Flpe recombinase activates expression of tetanus toxin light chain in 5HT neurons, which cleaves the VAMP2 protein that anchors synaptic vesicles to the synaptic membrane, thereby inhibiting synaptic vesicular neurotransmission in ~35% of these neurons.

Methods. In 'silenced' and control pups at postnatal days (P) 5, 8 and 12, we used head-out plethysmography to measure VE before, during and after intermittent hypoxia and the apnea index in the pre- and post-hypoxic periods.

Results. VE normalized to metabolic rate (VE/VO₂) was normal in 'silenced' pups at baseline, but was 27% greater than controls during hypoxia at P12. At 90 min post-hypoxia, VE/VO₂ increased 6-fold in control pups at P5 and P8 compared to 5 min post-hypoxia, indicative of LTF, but was unchanged in 'silenced' pups. The apnea index was 2-fold greater in 'silenced' compared to control pups during the post-hypoxic period at P8, and this increased apnea index was directly associated with the absence of LTF.

Discussion. We conclude that 5HT deficiency in early postnatal life might alter the ventilatory response to intermittent hypoxia and inhibit LTF, thus contributing to the increased incidence of apnea documented in SIDS infants.

➔ B-44

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EARLY SUDDEN INFANT DEATH SYNDROME - REPORT OF THREE CASES AND REVIEW OF THE LITERATURE

Background. Early sudden infant death syndrome (ESIDS) is a rare but fatal cause of death in newborns during the first hours of life. With only a few cases described in literature, additional data are required for the identification of risk factors and potential establishment of prevention strategies.

Methods. We describe three cases of ESIDS between 2006 and 2011 and discuss their presentation along with the existing literature.

Results. ESIDS affected term-babies after normal postnatal adaptation, within the first four hours of life (3.5, 2, 1.5 respectively). Gestational age was 40+4, 41+1 and 38+2 and birth weight was within normal range in all infants (3050g, 3790g and 3480g). Mode of delivery was spontaneous in two cases and vacuum-assisted in one case. Maternal ages were 29, 36 and 34 years. Mothers were primiparous and of normal weight. All three events happened during unobserved early skin-to-skin contact. Autopsy and post-mortem metabolic screening revealed no evident cause of death. Searching 'MEDLINE' database, we found several cases of ESIDS in literature. Concurrent with our observations, first parity as well as unobserved early skin-to-skin contact seem to be prime risk factors for ESIDS. Other pre-described risk factors (mode of delivery, birth-weight, mother's age and body mass index) were not present in our patients.

Conclusion. To better understand the cause of ESIDS a special focus needs to be put in identifying further ESIDS risk factors to warrant special observation in the at-risk newborns during the early skin-to-skin contact phase.

➔ B-46

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BED-SHARING ADVICE – AN ALTERNATIVE STRATEGY?

Introduction. With the dramatic fall in SIDS rates the proportion of bed-sharing deaths has increased and several countries have adopted a strategy to simply advise against this infant care practice. However this strategy has not been shown to have any effect upon numbers of such deaths, and undermines the delivery of potentially more important risk reduction messages. Recent data suggests parental alcohol consumption, illegal drug consumption and the use of sofas are implicated. An alternative strategy launched by UNICEF UK acknowledges the existence of bed-sharing but underlines specific hazardous conditions in which bed-sharing can occur.

Methods. Data will be presented from a longitudinal cohort of 300 SIDS deaths between 1984 and 20031 and a population-based case-control study of 80 SIDS deaths and 87 randomly selected age-matched controls between 2003 and 20062.

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Results. Over a 20 year period the proportion of bed-sharing deaths has increased from 11% to 39% although the actual number of these deaths in this cohort has fallen by 50%. Both the proportion (1% to 11%) and number of sofa-sharing deaths has significantly increased over this same period. In the case control study 38% of the SIDS infants were found bed-sharing and 16% sofa-sharing (compared to 20% and 1% of the controls respectively). There was a significant multivariable interaction between co-sleeping and recent parental use of alcohol and drugs (31% SIDS vs. 3% controls).

Discussion. Although more than half of the SIDS deaths occurred whilst the infant slept next to a parent, for nearly a third of these the sleeping surface was a sofa, a particularly hazardous environment to co-sleep with a young infant. For three fifths of these co-sleeping deaths the parent sleeping next to the infant had consumed more than 2 units of alcohol (equivalent to 3 or more glasses of wine) or taken drugs such as marijuana, methadone or amphetamines. Parents need to be reminded that these hazardous practices are simply unacceptable. For the last 3 years we have been working with UNICEF to develop an evidence based leaflet for parents 'Caring for your baby at night' and guidelines for health professionals. This leaflet underlines the message that the cot beside the parental bed is the safest place for infants to sleep but acknowledges that some parents choose to sleep with their baby in bed and some will fall asleep with their baby whether they intend to or not. Specific hazards are therefore highlighted. This leaflet was launched in January 2012 and available to download from the UNICEF website (www.unicef.org/uk/caringatnight).

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➔ B-47

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SOFA-SHARING: A META-ANALYSIS

Introduction. The risk associated with sofa-sharing deaths has only been reported in SIDS case-control studies since the fall in rates after intervention campaigns conducted in the early 1990's. It is not clear whether these deaths went unreported or were previously rare amongst SIDS victims. Longitudinal data from 300 consecutive SIDS deaths in Avon from 1984 to 20031 suggest a numerical and proportional increase in these deaths from 1% to 11%. A systematic review of sofa-sharing deaths in SIDS case-control studies is currently being conducted; the preliminary findings are reported here.

Methods. A preliminary search was conducted using the terms (SIDS, SUDI or SUID) and (sofa, chair, couch, settee, bed-sharing or co-sleeping) and so far over 200 references have been found.

Results. From these references 6 case-control studies have been identified that specifically ask whether the SIDS victims or controls were found sofa-sharing with at least one parent at the time of death or reference sleep. In these studies sofa-sharing was rare amongst the control infants (prevalence between 0% and 1.4%) but more common amongst the SIDS victims (4.2% to 16.3%). All 6 studies suggest a highly significant univariable risk but this factor could often not be modelled in the multivariable analysis because of the low or non-existent prevalence amongst the controls. The pooled risk shows a ten-fold difference between SIDS victims and controls (6.6% vs. 0.6%) and an odds ratio far in excess (pooled OR=11.69 [95% CI: 7.15-19.27]) of many other SIDS risk factors.

Discussion. The difference in prevalence of sofa-sharing amongst SIDS deaths in different studies may in part be due to the diagnostic criteria used by different pathologists. In some countries a sofa-sharing death may often be ascribed as 'unascertained' or 'possible over-laying' rather than SIDS in which case our findings are an underestimate of the potential risk to all infants who die suddenly and unexpectedly. Even if we just use the lower confidence limit of the pooled risk from those studies from which we have data there is a 7-fold increased risk of SIDS amongst infants who slept with a parent on the sofa. This risk reduction message needs to receive more prominence from current intervention campaigns.

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➔ B-49

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THE BACK-TO-SLEEP MESSAGE: HEALTHCARE WORKERS' KNOWLEDGE AND RECOMMENDATIONS FOR THE 1990S TO DATE

Introduction. After discovering in 1985 that the sleep position had an important influence on the risk of SIDS, the diffusion of the Back-to-Sleep message became crucial in all SIDS prevention campaigns run across the world. Their main objective was to deliver the message to infants' parents, who are responsible for the implementation of this recommendation at home during everyday life. Even though parents might try to gather information on this topic

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through several sources, the healthcare workers that they deal with are still one of their most important sources of advice. Nowadays, once many national campaigns came to an end, the role played by healthcare workers became even more crucial, as they represent the most important link in the chain linking the latest scientific evidence and parents.

Methods. In this paper, the data belonging to 28 different surveys about healthcare workers' knowledge attitude towards supine sleeping positioning are analyzed together. The interest of the study focuses on the following indicators: knowledge about the correct sleep position, recommendations given to parents about the position to put their children to sleep in, and usual behavior in positioning the children. Given that most of the considered surveys have been carried out in the US (22 out of 28), all the results are presented both for the aggregate set of surveys and for the American ones alone. The preliminary results of a similar survey carried out for the first time in England and Spain in 2012 will also be presented.

Results. The most interesting finding of this paper relates the percentage of healthcare workers aware that infants should not be put to sleep in a prone position. Surprisingly, this percentage seems to be slowly decreasing over time, from a level about 97% at the end of the 1990s to less than 88% at the end of the 2000s. Moreover, this result holds true both when the data refer to whole set of surveys and when they refer only to the American ones. The percentage of healthcare workers aware that infants should be put to sleep in a supine position, instead, tends to increase over time in both cases, even if with a smaller pace in the US. Increasing trends can be observed for recommendations to parents and behavior. In these cases, the pace of growth does not vary much between the whole set of surveys and only the American ones.

Discussion. The effectiveness of Back-to-Sleep campaigns is confirmed by this paper, which shows that healthcare workers' knowledge of the recommended sleeping position is increasing (in both the whole set of surveys and the American set). However, the decrease in the awareness that infants should not be put to sleep in a prone position shows that this aspect may have been slightly neglected by the last campaigns. A reason may have been a focus on the advantages of the supine position and without stressing enough the dangers of the prone position.

➔ B-50

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THE EFFECTIVENESS OF THE BACK-TO-SLEEP MESSAGE AND OF OTHER SIDS PREVENTION MESSAGES. THE RESULTS OF THE ITALIAN CAMPAIGN "GENITORIPIÙ"

Introduction. This paper analyses the data resulting from the Italian Campaign for newborns' parents, "GenitoriPiù" and focuses on the assessment of healthcare workers' knowledge about Sudden Infant Death Syndrome (SIDS) and its risk factors. The first objective of the paper is to determine which demographic and professional healthcare workers' characteristics influence their knowledge and recommendations about infants sleep positioning. The second objective is to show which of their characteristics influence their overall knowledge of seven factors affecting the risk of SIDS: supine position, smoking in the room where the newborn sleeps, use a soft mattress for the cot, breastfeeding, high temperature of the room where the newborn sleeps, the newborn touching the bottom of the cot with her/his feet, and ECG screening.

Methods. The data were retrieved through a cross-sectional survey of 6,081 healthcare workers who chose to participate in a training campaign for the prevention of major childhood risks. To achieve the first objective, relative risks were used to examine the demographic and professional variables as predictors of healthcare workers' knowledge and compliance with the AAP recommendations. To achieve the second objective, Rasch models were used to develop two composite indices of knowledge about the considered risk factors, and regression analysis was used to analyze which healthcare workers' characteristics influenced the indices.

Results. Overall, 88% of respondents were aware that the supine position has a protective effect towards SIDS, a percentage that reached 97% for pediatricians and only 79% for physicians other than pediatricians and obstetricians. Only 58% of respondents recommended exclusively the supine sleeping position to infants' parents, while 78% recommended a nonprone position. Pediatricians were more likely to have a correct knowledge and give correct recommendations, while healthcare workers belonging to medical clinics, hospitals, districts, and departments of public health presented worse results than all the others. Geographical differences also existed, with professionals from the North performing better than their colleagues from the Center and the South and Islands. When the overall knowledge of seven risk factors was considered, significant differences among different regions were still evident, and the effect of training initiatives was proven as a way to rectify these differences. With regard to professional background, the best-prepared healthcare workers were the pediatricians and those healthcare workers working in birth centers and family planning clinics.

Discussion. The overall knowledge about infants' sleep positioning is encouraging, especially among pediatricians, who are the most important source of information for infants' parents. However, more needs to be done in order to raise the percentage of professionals recommending exclusively the supine position. When seven risk factors were considered altogether, a disparity in knowledge emerged between professionals working in birth centers and family planning clinics and professional operating in other workplaces. This is worrying because after birth newborns' parents do not seek care for their child in birth centers and family planning clinics, but at vaccination centers, hospitals, and medical clinics. Training in the risk factors for SIDS should be intensified at these care locations.

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THE FORMATION OF AN ME (MEDICAL EXAMINER) BASED SUID (SUDDEN UNEXPECTED INFANT DEATH) TISSUE PROJECT

Purpose. Establish an ME based infant tissue project to enable successful conduct of SUID-related research. The American SIDS Institute (ASI) and the ME office in Miami, Florida identified 9 issues that had to be addressed and then initiated a pilot project to address them. The MEs in Miami, Ft. Lauderdale, West Palm Beach and Naples, FL participated. We resolved identified issues in the following ways:

1. To provide vital control cases as well as SUID tissue, ME cases < 1-year of age, regardless of manner and cause of death, are included.
2. Tissue is banked with NICHD Brain and Tissue Bank in Maryland. They have extensive expertise with such cases and were willing to assist.
3. With the help of the San Diego SUID program and NICHD Bank we detailed 9 specimens with comprehensive preparation instructions. (CSF, blood, lung, heart, heart ventricles, kidney, liver, thymus and brain.)
4. Since the U. of Miami Tissue Donor specialists routinely scan cases in these 4 ME offices for transplants they were asked to approach the family regarding the need for research tissue. If interested, NICHD Bank contacts them for consent.
5. Freezers (sub -800), lab equipment, specimen kits, and shipping materials are needed resources. ASI provided freezers and various lab equipment for 3 of the ME offices. Specimen kits, shipping materials and pre-paid overnight-shipping labels are provided by NICHD Bank
6. The ME investigation takes precedence over research tissue, therefore in some cases not all listed specimens can be provided, and in other cases none can be provided. The consent process must proceed quickly to not delay autopsy. The NICHD Bank provides a neuropathology report to the ME for each case
7. When the infant is a potential tissue or organ donor this takes precedence over research tissue. By having donor services involved, such cases are quickly identified. Most SUID cases involve young infants who die at home making them inappropriate for live recipients.
8. ASI databases legal investigation and autopsy results and provides to NICHD Bank.
9. The ME offices provide ASI information on all infant cases (consented or not). ASI then tracks each case to determine if consent was obtained, if tissue was shipped to NICHD Bank and if a neuropathology report was provided to the ME. A task force meets monthly to review case management data and implement methods for improvement.

Results. The pilot project launched mid-August 2011. Although numerous problems occurred, none were insurmountable. Our consent rate is approximately 25%, with a target of 50%. In 6 months 6 sets of tissue were banked. We are now expanding the project to other Florida districts and eventually other states.

Summary. Because all unexpected infant deaths are ME or coroner cases, a SUID tissue project must be layered within the death investigation system. This project has demonstrated that it is possible to establish and fund an infrastructure that will allow the banking of infant tissue linked with necessary data to enable the next generation of SUID/SIDS-related research.

➔ B-52

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A NEW BOTTLE DESIGN DECREASES HYPOXEMIC EPISODES DURING FEEDING IN PRETERM INFANTS AND MAY CONTRIBUTE TO REDUCE THE RISK FOR SIDS

Background. The repetitive hypoxic episodes in preterm infants may contribute a certain risk for Sudden Infant Death Syndrome. Oxygen saturation (SpO₂) is lower during bottle feeding than during breastfeeding in preterm infants. There is interest in developing strategies to improve the bottle feeding performance minimizing oxygen desaturation episodes.

Aim. To compare two different bottle systems in healthy preterm infants before discharge in terms of SpO₂ and oral feeding efficiency (rate of milk intake).

Methods. NICU infants without supplementary oxygen needs were evaluated twice on the same day during two consecutive feeds, by the same nurse. Infants served as their own controls for comparison of two systems of bottles, the order of which was randomized. The new bottle's nipple design (MAM Ultivent Bottle) mimics mom's breast in shape and feel, and the bottle vents to air when the child sucks on the nipple. The other system was the Hospital's standard plastic bottle with silicone nipple. The rate of milk intake was calculated as the total volume transferred minus volume lost during a feeding; mL/min. SpO₂ was assessed during feedings by using the Edentrace II device (Nellcor, USA) and data analyzed electronically.

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Results. Thirty-four infants (BW: 1,163 ± 479.1 g) were studied at 35.4 ± 1.3 weeks post-conception. Infants did not differ in PCA at the time of the study (range 35 -36 weeks) and were near discharge (mean 2.4 days). Baseline SpO2 was within a clinically acceptable range.

Desaturations Events (*Wilcoxon signed-rank test)

Oxygen desaturation events, expressed as median and interquartile range are shown in the Table	Standard bottle	New bottle design	p*
Percentage of feeding time SpO2 < 90%	8% (3-13)	5% (2-11)	< 0.004
Percentage of feeding time SpO2 90%-94%	13% (6-21)	8 % (2-18)	< 0.0007
Number of desaturation events per infant	5 (2-10)	4 (1-8)	< 0.001
Time with SpO2< 90% (s)	46s (8.3-150)	30s (6-96)	< 0.001
Mean SpO2 during feeding	94 (91-96)	96 (93-98)	< 0.0008

Oral Feeding Outcomes

Average rate of milk intake (Figure 1 mL/min) was significantly higher with the new bottle design than with the standard bottle (6.9 ± 2.6 vs 5.5 ± 2.2 mL/min, respectively, p < 0.001). Percent milk loss (Figure 2) decreased with the new bottle design when compared to the standard bottle (3.5 ± 4.3 vs 5.4 ± 5.6%, respectively, p < 0.0001).

Figure 1

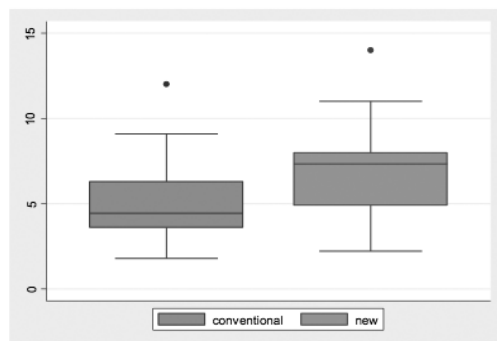
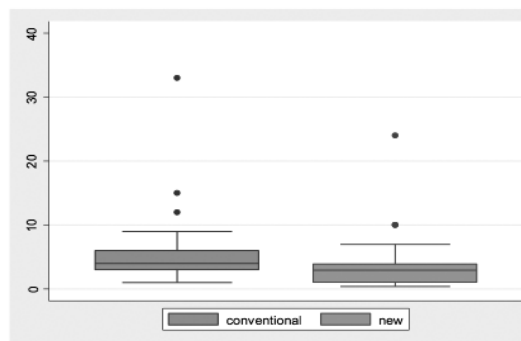


Figure 2



Conclusion. Although breast feeding is clearly best for infants, it may not always be possible. The use of the new-design bottle when compared to that of standard bottle, improves oral feeding performance in infants born with 27 weeks gestation or more in terms of oxygen saturation and oral feeding efficiency, i.e., greater rate of milk intake and less percent milk leakage/loss. Lower oxygen saturation during feeding impacts the infant’s ability to organize and maintain oral feeding skills and may increase the risk of SIDS.

➔ B-54

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MORE THAN THE ABC’S...A PRACTICAL DISCUSSION ON HOW TO ADDRESS SAFE SLEEP IN YOUR COMMUNITY

Introduction. The Upstate Cribs For Kids Program was the first Cribs For Kids charter for safe sleep education program in South Carolina. The program was established after Greenville County detected a rise in infant deaths attributed to unsafe sleep environments. The program has been in existence since 2008 and has provided safe sleep education and distributed Pack N’ Plays to 934 families. Since October 2010 Upstate Cribs For Kids has provided over 100 physician ordered safe sleep education consults; conducted 25 workshops; and trained 821 pediatricians, obstetricians, healthcare professionals and community members. In addition the program reached over 1.5 million listeners in 2011 over 8 weeks through radio with PSA’s on safe sleep. Upstate Cribs for Kids enlisted the help of the Greenville County Coroner’s Office; Greenville County Department of Social Services; and Greenville County First Steps to help create a Safe Sleep Coalition which is actively looking at ways to assess and evaluate the needs of our youngest children. Each of the above agencies is looking at how they address the issue of safe sleep from the way the an infant’s death is coded to assessing that families with infants who receive social services have a safe place for their babies to sleep to educating families with infants on what a safe sleeping environment looks like. Due in large to the efforts of Upstate Cribs for Kids the South Carolina Joint Citizens and Legislative Committee on Children has made Safe Sleeping for

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Infants a major priority for the state “to encourage an emphasis to more effective, less costly preventive services...” To date the program has had no reported deaths of the infants of program participants. This information has been confirmed via two follow up contacts with every family that participates in the program and by the Greenville County Coroner’s Office that conducts the Child Fatality Review Committee.

Audience. The target audience is public health professionals, medical professionals, first responders, community organizations, and parents/primary caregivers.

Objectives.

1. Knowledge of the 3 W’s.
 - a. Where? (Where does your baby sleep?)
 - b. What? (What does your baby sleep on or in?)
 - c. Who? (Who does your baby sleep with?)
2. Identify the role each agency plays in the safe sleep messaging.
3. Identify conflicting messages through media & product advertisement

Topics.

- I. The Role of the Community & Professionals in Increasing the Awareness of the Consequences of Unsafe Sleep Practices
 - a. Who’s Responsible & What Can We Do?
 - i. First Responders
 - ii. Coroners & Medical Examiners
 - iii. Social Services
 - iv. Health Care Professionals
- II. Safe Sleep Images in the Media & Product Advertisement

➔ B-55

Fryer DF, Greco MM, Jewell MA, Frazier KA. (Michelle Greco presenting)

Children’s Hospital of Greenville Hospital System University Medical Center; Upstate Cribs For Kids; Greenville Hospital System University Medical Center, Greenville County Department of Social Services; Safe Kids Upstate, USA

BEYOND BACK TO SLEEP... SAFE SLEEP

Introduction. After Greenville County detected a rise in infant deaths attributed to unsafe sleep environments, Upstate Cribs For Kids was the first Cribs For Kids charter for safe sleep education in South Carolina. The program has been in existence since 2008 and has provided safe sleep education and distributed Pack N’ Plays to 934 families. Since 2010 the program has provided over 100 physician ordered safe sleep education consults; conducted 25 workshops; and trained 821 pediatricians, obstetricians, healthcare professionals and community members. In addition the program reached over 1.5 million listeners in eight weeks through PSA’s on safe sleep. Due in large to the efforts of Upstate Cribs for Kids the South Carolina Joint Citizens and Legislative Committee on Children has made Safe Sleeping for Infants a major priority for the state “to encourage an emphasis to more effective, less costly preventive services...”

The flexible curriculum is tailored to various settings from one-on-one sessions with caregivers, prenatally or after birth, to healthcare professionals and community members from DSS to daycare workers. The successful train the trainer model has been replicated throughout the state and the curriculum which addressed SIDS/SUID, safe sleep and products/devices as well as real life sleep environments and situations. The program has had no reported deaths of the infants of program participants. Information confirmed via two follow up contacts with each of the families and by the four advisory board members who sit on the Child Fatality Review Committees for the counties served.

Audience. The intended audience is parents, caregivers, researchers, health professionals, medical professionals, faith based and community organizations.

Objectives. Using Upstate Cribs For Kids as the model participants will be able create a quality Safe Sleep Education program with minimal funding by:

- I. Identifying educational need of community
 - a. Detection of trends in SIDS/SUID and unsafe sleep deaths in the state & community
 - b. Child Death Review
- II. Identify agency partners
 - a. Identification of who needs to be involved
 - b. Bringing them to the table
- III. Develop & Implement the program.
 - a. Establishment of Advisory Board/Team
 - b. Train the trainer model
 - c. Trainers’ requirements
 - d. Procedures
- IV. Create a Safe Sleep Awareness Campaign
 - a. Media Campaign

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b. Product advertisement/display

Activities. Participants will develop a time line for creating a safe sleep education program and implementation process that best fits their community need with minimal funding. The success and effectiveness of Upstate Cribs for Kids with the participants who have received intervention through this program is the model for this session.

➔ B-56

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SAFE SLEEPING TO REDUCE SUDDEN UNEXPLAINED INFANT DEATH; BELIEVING AND COMMUNICATING THE MESSAGE

Introduction. This roundtable focuses on the delivery of safe sleeping messages and will share the learning from Manchester's journey. In December 2003 Central Manchester Foundation Trust (CMFT) implemented a Vulnerable Baby Service (VBS). The aim of this service is to reduce the incidence of Sudden Unexplained Deaths in Infants (SUDI).

The population of Manchester is 500,000, with 7,500 births to residents annually. It is a city with high levels of deprivation. The VBS tackles SUDI using two approaches. In 2005 a Public Health approach was introduced to reduce risk behaviours for all babies born in Manchester. The foundation of this is an embedded Safe Sleeping Practice Message delivered by all practitioners working across the city. This requires an effective, strategic, and integrated communications model that consistently represents and transmits the vision.

The service also facilitates targeted multiagency case planning meetings for any unborn baby or infant under 12 months of age who are identified as being at risk.

As a result SUDI have dropped by 60%, and health staff and multi agency partners have developed closer and more productive partnerships. The social marketing campaign BeCotSafe, which supported this work, has won several regional and national awards

Intended Audience. Health care providers, health educators and stakeholders interested in translating knowledge into effective safe sleeping practices in families with increased vulnerability.

Objectives.

- To explore communication routes in order to deliver messages
- To enable delegates to actively explore the challenges
- To consider possible strategies to overcome challenges
- To share ideas and cultivate new solutions

Key Discussion Topics.

- How do we ensure the same message is delivered by all agencies?
- What do we need from stakeholders?
- What are the risky behaviours?
- Where can we find the families who are hard to reach?
- What are the barriers to embracing safe sleeping practices?
- When are the important opportunities?
- What does success look like?

➔ B-57

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SUSTAINABLE CAPACITY BUILDING: SAFE INFANT SLEEPING EARNING PROGRAM FOR ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH WORKERS

Introduction. Indigenous infant mortality is twice the rate for non-Indigenous infants in Australia while Queensland Aboriginal and Torres Strait Islander infants die suddenly and unexpectedly at 3.3 times the rate of non-Indigenous infants. Previous research has demonstrated a) suboptimal infant care practices contributing to these deaths; b) the effectiveness of a Safe Sleeping eLearning program in significantly improving knowledge of safe sleeping recommendations by health professionals; c) the need for a specific program for Indigenous Health Workers identified through focus group feedback. The aim of this project was to produce a culturally appropriate, evidence-based eLearning program which meets the needs of Aboriginal and Torres Strait Islander Health professionals responsible for the delivery of safe infant sleeping messages in their communities.

Methods. A culturally appropriate eLearning program for Aboriginal and Torres Strait Islander Health Workers about sudden unexpected death in infancy and safe sleeping recommendations was developed by an Indigenous Project Officer in collaboration with the Clinical Skills Development Centre and

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in consultation with Indigenous Health Workers. The process for the development of this resource was seven-fold: 1) review of original Safe Sleeping E-learning program content to determine cultural and educational appropriateness for target audience; 2) development of culturally specific material and inclusion of Indigenous artwork; 3) broad and targeted consultation with community members and specific health worker groups; 4) community visits and consultation with regional and rural communities; 5) testing of content; 6) launch of new program with built-in electronic evaluation to measure knowledge and knowledge application of risk factors and safe sleeping messages; 7) evaluation of effectiveness.

Results. The development of an culturally specific eLearning resource to support Indigenous Health Workers in their health promotion activities with families in their communities has been achieved. The process and development of this interactive resource is an example of Queensland Health's commitment to closing the gap in health outcomes for Indigenous peoples through addressing the specific target to halve the gap in mortality rates for Indigenous children under five within a decade (2018). Steps 1-5 have been completed with the public launch of the Indigenous eLearning program on schedule for April 2012. The original program achieved significant increases in participant post-test scores of knowledge and application [n=1949, pretest 69.5% vs post-test average 87%, p<0.0001]. It is anticipated that this program will achieve similar results.

Discussion. Aboriginal and Torres Strait Islander families continue to be under exposed to public health messages. The process and development of this interactive resource is an example of Queensland Health's commitment to closing the gap in health outcomes for Indigenous peoples through addressing the specific target to halve the gap in mortality rates for Indigenous children under five within a decade (2018). This eLearning course seeks to increase the capacity of Aboriginal and Torres Strait Islander staff to confidently role model safe infant sleeping practices in their communities. Collaborative networks and new methodologies need to be developed to educate parents about preventable risks associated with sudden infant death. Reducing infant death is everyone's business.

➔ B-58

Young J, Higgins N, Raven L.

University of Queensland, Royal Brisbane and Women's Hospital, SIDS and Kids Australia, Australia

SUPPORTING HEALTH PROFESSIONALS IN DELIVERING EVIDENCE-BASED SAFE SLEEPING RECOMMENDATIONS: EFFECTIVENESS AND SUSTAINABILITY OF A SAFE INFANT SLEEPING E-LEARNING PROGRAM

Introduction. Sudden unexpected deaths in infancy (SUDI) remain one of the leading causes of infant mortality in Australia. Health professionals caring for families with young infants have a key role in supporting parents to use safe sleeping recommendations demonstrated to reduce infant death. This study has evaluated the sustainability and effectiveness of an evidence-based e-learning program in positively impacting health professional knowledge and knowledge application relating to SUDI and safe sleeping recommendations.

Methods. A pre-test/post-test design evaluated knowledge and knowledge application in a sample of health professionals completing the Safe Infant Sleeping E-learning program. The three-module program covers key content related to international and Australian perspectives on sudden unexpected infant death, risk factors associated with SUDI, evidence underpinning Australian public health recommendations related to safe infant sleeping, and strategies for parents and health professionals to improve uptake and utilisation of safe infant sleeping messages. The program contained interactive audio and visual components to reinforce learning objectives. The program has an in-built evaluation to benchmark prior knowledge, and post-module quizzes to complete following each module. Participant test scores were calculated, including a mean post-test score. Pre-test-post-test changes were analysed using paired t-tests; sample subsets were compared using independent t-tests.

Results. The program was officially launched in June 2010. During the first 20 months in operation (June 2010–March 2012) the program has attracted 4600 registrations with 1949 participants completing the program. Although the program has targeted Queensland health professionals (n=1913 completed participants) it has attracted attention from other states and territories (n=23) and overseas (n=13). Participants completing the program have been predominantly nurses and midwives (n=1794) however includes participants identifying as allied health, medical, student, parent, child health worker, Indigenous Health worker and SIDS and Kids employees. Pretest results (n=1949) identified deficits in knowledge and application to risk factor assessment and evidence-based parent advice [mean pretest score 69.5%(±SD13.3)]. Similar scores were achieved post-test for each of the learning modules indicating consistency in delivery across content (Post test scores of 87%, 86% and 88% for Modules 1, 2 and 3 respectively). Nurses and midwives had a higher mean pretest score [69.9%(±SD12.9)] compared to other health professionals [64.6%(±SD15.3), p<0.0001]. Participant scores significantly increased posttest [pretest 69.5% Vs post-test average 87%, p<0.0001]. Public sector staff were significantly higher pretest than private sector (69.9% vs 64%, p<0.0001), however post-test scores were similar (86.7%vs87.4%, p=0.2). Post-test mean scores for nurses and midwives compared with other health professionals were also similar (87% Vs 87%, p=0.5).

Discussion. This innovative e-learning program has been sustainable over a 20-month period and has been effective in significantly improving relevant knowledge and knowledge application relating to safe sleeping public health recommendations for health professionals who care for families with young infants. The program has been endorsed by key professional organisations and underpins state policy in Queensland. Consistent delivery of evidence-based information relating to safe sleeping will support midwives in their key role as parent educators about public health initiatives that promote infant health and reduce mortality.

SIDS/SUID/Stillbirth Poster Presentations

➔ B-59

Green JP.

SIDS and Kids Australia, Deakin University, Australia

EXPLORING THE BELIEFS AND PERCEPTIONS OF PARENTS REGARDING CREATING A SAFE SLEEPING ENVIRONMENT TO REDUCE THE RISK OF SIDS AND SLEEPING ACCIDENTS

Introduction. Australia, many SUDI reviewed report the presence of known and modifiable risk factors that may have increased the risk of death occurring. This qualitative study explored the lived experiences of parents, to understand;

- why they choose certain sleeping practices for their infants, particularly co-sleeping;
- their perception of what is a safe sleeping environment
- who influences their practice
- what role health professionals play in conveying the key messages to reduce the risk of SIDS and sleeping accidents.

Conducted within a phenomenological framework, semi-structured interviews were used to gather the data. Drawing upon aspects from a phenomenological theoretical perspective allowed us to explore this every day practice and gain an insight into the informants first hand experiences. Fifteen participants living in Victoria with infants under the age of one were interviewed. This included fourteen mothers and one father who were the main carers of the infant. A thematic analysis was undertaken in line with a phenomenological investigation and process.

The findings revealed that there is no greater travail for a new parent than an unsettled infant that will not sleep. The decision-making process for parents was complex and influenced by many factors. Although the informants were familiar with the Safe Sleeping Recommendations, the majority of informants did not perceive room sharing increased or decreased the risk of SUDI but was practiced more so due to necessity (lack of space), accessibility for night time feeds and because it 'felt instinctive'. There was a lack of understanding why supine sleeping was recommended and certain practices were adopted even though they had been advised to the contrary. This was exacerbated by the inconsistency of messages and role modelling from health professionals and the media. Co-sleeping was perceived by many to be a 'natural and nurturing practice' and beneficial as a settling technique. Co-sleeping in bed was more likely to be adopted with younger infants under 4 months of age and continued until the infant started rolling over. Those who intentionally co-slept in bed each night with their infant were more likely to place their infant to sleep alone in the adult bed at the beginning of the night till one partner went to bed. Mothers who chose not to adopt a co-sleeping practice cited their partner as the major deciding influence.

An unexpected outcome of the study was the overwhelming vulnerability felt by parents. Co-sleeping parents were more inclined to 'hide' this practice from health professionals, family and other mothers and felt at times isolated in their decision. Concurrently, those who had difficulty settling their infant felt isolated and on their own. All informants agreed that the immediate needs of the infant and a good night sleep for parents can take priority over the recommendations advised. This paper presents a 'wish list'- a compilation of recommendations by informants of ideas how to better support and promote safe sleeping practice for new parents by health professionals in the future.

➔ B-60

Green JP.

SIDS and Kids Australia, Deakin University, Australia

PROMOTING SAFE SLEEPING TO REDUCE THE RISK OF SIDS AND SLEEPING ACCIDENTS: WORKFORCE DEVELOPMENT WITHIN THE VICTORIAN MATERNAL CHILD HEALTH SERVICE

This paper illustrates the development and implementation of an effective workforce project within the Victorian Maternal Child Health(MCH) Service. This program received a highly commended State award for the '2010 Australian Safe Communities Awards' in recognition for its contribution to building a safer, more resilient Victorian community.

The goal of this project was to promote safe sleeping to reduce the risk of SIDS and sleeping accidents by focusing on the advantageous position Maternal Child Health(MCH) nurses hold in the community to educate and promote safe sleeping given their position to reach new families.

During preliminary and informal discussions held with Victorian MCH nurses during the planning phase, it was apparent that many were not familiar with the current SIDS and Kids Safe Sleeping recommendations and were not routinely sighting the sleeping environment of the infant at the home visit. Hence, it was determined that parents may be receiving inconsistent messages or no information at all regarding safe sleeping environments, placing infants at risk. In light of this, it was important that health promoting messages should be conveyed by people well placed in the community working with new families and who have the ability to build strong relationships, ideally Maternal Child Health nurses.

Women give birth to over 70,000 babies each year in Victoria, Australia. The MCH Service provides universal primary care to families with children from birth to school age. This service also provides 10 key appointments with new parents and includes visiting the home environment two weeks post discharge from hospital. Ninety-eight per cent of Victoria's infants are enrolled in this free service in their first weeks of life, placing MCH nurses in a key position to provide evidence-based messages that support safe sleeping for new families within their community.

This paper discusses the inclusion of Safe Sleeping as a priority health promotion program imbedded into the Victorian Maternal Child Health Framework.

SIDS/SUID/Stillbirth Poster Presentations

The main objectives of the program included:

- All Maternal Child Health nurses sight the sleeping environment of the infant at the first home visit at two weeks post discharge from hospital,
- empower families with knowledge about safe sleeping practices ,
- consistent and evidence based messages given by all maternal child health nurses
- develop resources and tools to support MCH nurses and their community

Mixes of strategies were selected to ensure a greater impact and positive outcome for this project. These strategies addressed individual knowledge, attitude and behaviour, created environmental changes to support nurses and achieve accessibility for new parents. In particular, the Safe Sleeping Checklist was developed and implemented to support MCH nurses to document the sighting of the sleep environment of the infant and to prompt discussion between family and nurse.

More than 1300 MCH nurses have undertaken effective training since 2009. This has positively impacted on their knowledge and attitudes. The implementation of this project within the MCH workforce is unique in Australia and will ultimately contribute to parents being more aware of safe sleeping for their infants.

➔ B-61

Garstang JJ, Sidebotham P, Griffiths F.
University of Warwick, United Kingdom

THE WEST MIDLANDS SUDI STUDY; AN EVALUATION OF THE JOINT AGENCY APPROACH TO INVESTIGATING UNEXPECTED INFANT DEATHS

Introduction. Since 2008, in England, it is mandatory that all Sudden Unexpected Death in Infancy (SUDI) cases are investigated jointly by police, health and social services. The aim of this new Joint Agency Approach (JAA) is to establish the complete cause of death including modifiable risk factors and address the needs of the family. Currently, there are only limited data showing the effectiveness of this intensive approach and no data on parental experiences. This study is an evaluation of the JAA, aiming to assess its effectiveness and learn of parents' experiences.

Methods. This a mixed methods research project, using surveys and qualitative interviews with bereaved parents and case note analyses of SUDI records from health, police, social services and Coroners. Families are recruited after the completion of the JAA investigation; it is an ongoing project in the West Midlands region of England.

Results. By March 2012 there had been 42 eligible SUDI cases for recruitment; 12 of these families have been recruited. 8 Families had not been approached about participating in the study by their local paediatrician, 3 families were lost to follow-up, 8 cases were still being investigated. 6 families declined to participate in the study when asked and 4 families initially agreed to participate then changed their minds.

10/12 cases had a joint home visit by police and paediatrician , with death scene analysis. Social services data were available for 7 cases, only 2 cases were investigated.

The median time between the death and final case report was 21 weeks (range 6 to 36 weeks). All parents were offered follow-up home visits by the paediatrician but in 7/12 cases this was only one single visit after the final case report.

The cause of death is currently available for 11 cases. 5 infants died of SIDS, 4 of these had modifiable risk factors identified, 2 deaths were deemed unascertained, both having modifiable risk factors identified. 4 deaths were due to fully explained medical causes. All but 1 parent understood why their baby had died.

12/19 parents rated the paediatrician visit as helpful, the remainder were of neutral opinion. 18/19 rated the paediatrician visit as not at all or a very little intrusive. 5/16 parents rated the police visit as helpful, 7/16 neutral and 4/16 unhelpful. 13/16 rated the police visit as not at all or a very little intrusive, but 3/16 rated it as quite or very intrusive.

All parents completed Hospital Anxiety and Depression scores; the mean maternal score for anxiety 12.1 (95% CI 10.0-14.1) and depression 10.8 (95% CI 7.5-14.2) were clinically significant.

Discussion. This study shows that the JAA is not being implemented fully, with some families not having a joint home visit and a widespread lack involvement by social services. The aim of the JAA is not being fully met; whilst it often determines the complete cause of death, it offers only limited support to families. Most are waiting several weeks for information about the death, then having a single paediatric follow-up visit.

SIDS/SUID/Stillbirth Poster Presentations

➔ B-62

Nishida H. (*Toshimasa Obonai, MD presenting*)
Tokyo Women's Medical University, Japan

HISTORY OF COLLABORATIVE ACTIVITIES BETWEEN MEDICAL PROFESSIONALS AND BEREAVED FAMILY ON PREVENTING SIDS AND PROVIDING GRIEF CARE IN JAPAN

Initially SIDS research group sponsored by the ministry of health and welfare was founded in 1981 for the purpose to elucidate actual figure of SIDS which were almost unfamiliar even to the medical professionals in Japan. In 1985, Japan SIDS Family Association (JSFA) was born to provide appropriate grief care to the bereaved family and to work together with medical professionals to prevent SIDS by propagating SIDS risk factors to the public. Because of the collaborative works, incidence of SIDS has reduced from 0.5 per 1,000 live birth in 1981 to 0.2 in 2010. The late Professor Andre Kahn was providing support from the very beginning in regard to grief care and research work. We hosted the 9th international SIDS conference which is the first joint meeting with international stillbirth alliance at Yokohama with big success. Currently 2/3 of members of Japan SIDS association are families of perinatal loss due to the decline of SIDS and of the awareness of the importance of grief care to the family of perinatal loss including still birth. This presentation will cover more in details on the changing pattern of JSFA activity and prospect for future as well.

➔ B-63

Marom T, Cinamon U, Castellanos PF, Cohen M.
Tel Aviv University Faculty of Medicine, Israel; University of Alabama at Birmingham, USA; Sheffield Children's NHS Foundation Trust, United Kingdom

OTOLARYNGOLOGICAL ASPECTS OF SUDDEN INFANT DEATH SYNDROME

Introduction. Sudden infant death syndrome (SIDS) is characterized by the sudden death of an apparently otherwise healthy infant, typically during sleep, and with no obvious cause after a thorough post-mortem and scene death examination.

Objective. To address the problem from the otolaryngologist's perspective, describe relevant pathologies, discuss controversies and suggest preventive measures in high-risk populations.

Methodology. A MEDLINE search and hand search were conducted to identify reports published between 1969 and 2011 in the English language on the pathophysiology of SIDS related to the head and neck organs. Search terms included SIDS (MeSH term), SIDS and pathophysiology (text words), and SIDS and autopsy (text words).

Discussion. A growing number of reports suggested head and neck organs involvement in SIDS autopsies. Laryngeal, oropharyngeal, maxillofacial, otologic, cervical vascular abnormalities and infectious etiologies, were recognized and discussed.

Conclusions. Otolaryngologists should be aware of relevant pathologies, as some are treatable, if identified early enough in infancy. A proactive risk-management approach is warranted in infants presenting with certain abnormalities reviewed here.

➔ B-64

Toyofuku M, Toshimasa O, Kono C, Niida M, Kondo S.
Tama-Hokubu Medical Center, Japan

CENTRAL SLEEP APNEA AT CONVALESCENCE OF INFECTIOUS DISEASE: A CASE REPORT

Background. Apnea is one of the common symptoms of Respiratory Syncytial Virus (RSV) or Bordetella Pertussis infection. Apnea reflects the severity of inflammation. However it is well recognized that some sudden unexpected death victims (SUDI) were convalescing from a respiratory tract infection, though the mechanisms of sudden death are still unknown. We report the clinical details of two infants who showed severe apnea during convalescence of infectious disease, that was neither RSV nor Bordetella Pertussis.

Case.

Case 1. A 22-day-old girl, who was delivered at 38 gestational weeks with no significant medical history, suffered from an infection disease by an unidentified pathogen. She had high fever for two days. After alleviation of fever, she developed apnea with severe cyanosis. Her laboratory findings exhibited hypoproteremia and her chest x-ray showed bilateral pulmonary oedema. Polysomnography (PsG) findings revealed central apnea (CA) in active sleep phase. Oxygen was supplied to her for four days because oxygen saturation (SpO₂) frequently decreased below 90% during sleep. It took eleven days to normalize PsG findings. After normalized breathing during sleep, chest x-ray and blood examination data also improved.

Case 2. A 16-day-old girl, delivered at 41 gestational weeks with no significant medical history, suffered from an upper air way infection. Two days after alleviation of a fever and accompanying respiratory tract infection, she was sent to hospital as apparent life threatening event. Clinical cause and the findings of examination closely resemble those of Case 1. The characteristic finding of Case 2 was that the pulmonary oedema was dominantly recognized in the right-side lung. Both patients have recovered fully.

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Discussion. The common findings of these two cases were central apnea during convalescence of infectious disease, pulmonary oedema, and hypoproteremia. The oedema which was limited to one side of lung suggests it is the result of neurogenic pulmonary oedema. Pulmonary oedema was identified in RSV infected animal model. In this study substance P (SP) was considered one of the important candidates for developing both lung oedema and hypoproteremia. Furthermore it was known that elevation of SP level in medulla oblongata became a cause of apnea. We speculated that elevation of SP level, not only peripheral sensory nerve but also central nerve system especially in medulla oblongata, plays an important role in developing such critical symptoms. In these cases, apnea occurred after alleviation of fever. Generally speaking, alleviation of fever is a significant sign of recovery from infection. Most caregivers do not imagine the risk of apnea once baby is recovering. In some cases, baby is considered well once the fever has subsided and is taken to nursery school. Our observation of these two cases shows that even if fever is alleviated, intense observation is required for several days.

➔ B-65

Volpi-Wise MA, Gaebler S.

SIDS and Kids Western Australia, Australian Breastfeeding Association, Nursing and Midwifery Board of Australia, Australian College of Neonatal Nurses, St Johns Ambulance Service Western Australia, Australia

IMPLEMENTATION OF AN EVIDENCED BASED CO-SLEEPING E-LEARNING PACKAGE AND STATE WIDE POLICY TO REDUCE CO-SLEEPING RELATED INFANT DEATHS

Introduction. Co-sleeping is a controversial issue with opposing views on the benefits and risks of the practice. Despite evidence of the benefits for the parent and infant when the baby co-sleeps, studies have shown that more than 50% of infants who died suddenly and unexpectedly were co-sleeping at the time of their death. The apparent correlation of co-sleeping and infant deaths has been recognized in recent Coronial Inquests throughout Australia. Evidence of the need for interventions in Western Australia (WA) to reduce the risk posed by infants co-sleeping has been demonstrated in the following data and recommendations: two WA Coronial Inquests recommending implementation of state-wide policies to raise professional awareness and compliance with directives related to co-sleeping; 2011 audit of WA coronial 2008 data showing 42% of babies < 12 months of age were co-sleeping at the time of their death; WA Telethon Institute of Child Health Research study highlighting the confusion of community members and health professionals to perceived mixed messages regarding co-sleeping; and WA Ombudsman Office review recommending a collaborative whole of government approach to reduce the risk of co-sleeping related deaths.

The purpose of the project is to reduce the risk of babies dying suddenly and unexpectedly in relation to co-sleeping by facilitating a state wide approach and increasing knowledge of risks in professionals and community members including cultural considerations of Aboriginal and Culturally and Linguistically Diverse (CALD) populations.

Method. A partnership with SIDS and Kids WA (SKWA) and the WA Women's and Newborn's State Obstetrics Support Unit (SOSU) was formed. A comprehensive literature review and incorporation of local and international mortality data and also input from community and professional focus groups inclusive of Aboriginal and CALD was undertaken. A train the trainer approach and interactive e-learning modules incorporating coronial cases is utilised. Package review performed and endorsed under hospice of national and local Scientific Advisory Committees.

Dissemination is state wide at a government and non for profit community level. An accredited Co-sleeping Certificate of Professional Development is received upon passing a survey testing learnt knowledge. Evaluation of the education package is ongoing and monitors the number and results of participant's survey. A process to systematically review co-sleeping related infant mortality data.

Results. The online participant's surveys demonstrate an increasing knowledge on how to manage the risks of co-sleeping related deaths in a culturally appropriate manner. There is also a demonstration of collaborative policy development and implementation to facilitate behavioral change in saving babies lives throughout WA. Results of the evaluation of the co-sleeping education package and the outcomes of the implementation of state-wide co-sleeping policies and directives will be presented.

Discussion. A blue print for a comprehensive process to assist with the complex issue of co-sleeping. A significant potential contributor in helping other communities potentially reduce co-sleeping related infant mortality.

➔ B-66

Maruyama NL, Cullotta R.

Sudden Infant Death Services (SIDS) of Illinois, Inc, USA

PREVENTING SLEEP RELATED INFANT DEATHS WITH THE HELP OF CONCERNED SIDS PARENTS AND STATE LEGISLATION

Sleep related infant deaths are on the rise in Illinois.

In July 2010 and with the help of bereaved parents and a dedicated Illinois State Representative, SIDS of Illinois, Inc, was the first to have a law passed in that mandates all birthing hospitals in Illinois provide verbal and written infant safe sleep information to parents of newborns prior to hospital discharge. In July 2011, the same dedicated team had another first. They were successful in passing a law that mandates all licensed childcare providers in Illinois, to have infant safe sleep education every three years in order to obtain and maintain their license.

SIDS/SUID/Stillbirth Poster Presentations

In September 2011, SIDS of Illinois, Inc. was part of group that successfully lobbied the Chicago City Council to place an ordinance that bans the sale or lease of all crib bumper pads. The ordinance states that violators will be fined not less than \$100 nor more than \$500 for each infraction. This ban became effective April 1, 2012.

This poster will show how the process began and the survey tools used to gather information from Illinois birthing hospitals on infant safe sleep education. The poster will discuss barriers and confounders to the process and the outcomes.

➔ B-67

Maruyama NL, Colloton E, Rowe K.
Sudden Infant Death Services (SIDS) of Illinois, Inc, USA

PROJECT SAFE SLEEP: ILLINOIS

Generous funding from Servants of Mary and the Mary Alphonse Bradley Foundation, SIDS of IL, Inc. was able to begin the pilot program, Project Safe Sleep. This program provided a portable crib to Illinois families that were 200% below the federal poverty level and that were unable to provide a safe sleep place for their newborns. Each family was recommended by a social service or public health agency. The family also completed a two-page application as a part of the process. The crib set-up included a portable safety-approved crib, a fitted crib sheet, a wearable blanket for baby, a onesie tee shirt with the message, "Put me on my back to sleep," a pacifier and safe sleep brochures. Proper crib set up and break down were demonstrated to the parents with a return demo. One-on-one education on specific risk reduction techniques available to prevent sleep-related infant deaths was given. The SIDS of IL, Inc. educator discussed infant safety challenges that the family faced or cultural issues that the parents had regarding their ability to follow the "Safe Sleep" recommendations. Follow up phone calls were made at 3, 6, 9, and 12 months after the crib was delivered to see how the baby was doing and if parent was still using crib. Data were collected; however, some families were lost to follow up.

This poster will take the reader from the initial crib request to the first birthday of one child as an example. Data collected on all recipients will be displayed.

During 2010, SIDS of IL, Inc. gave over 200 cribs to families of some of the highest risk babies throughout Illinois. Unfortunately, the demand for cribs far outstripped the funds available. In talking with families that received cribs, we have learned that there is excellent compliance with the use of the portable crib for all of their babies' sleep times. Best of all, to our knowledge, none of the babies that received a portable crib from SIDS of IL, Inc. died due to unsafe sleep practices. Project Safe Sleep has helped to provide Illinois' most vulnerable infants a safe sleeping environment. This project has continued through 2011 into 2012, but in a greatly diminished capacity. While we know that providing cribs is not the only answer to preventing sleep related infant deaths, we feel it definitely helps.

➔ B-68

Hausegger M, Pansy J, Sauseng W, Kerbl R, Pichler G, Müller W, Urlesberger B, Zotter H. (Reinhold Kerbl presenting)
Medical University of Graz, Hospital of Leoben, Austria

SPONTANEOUS AROUSABILITY IN PRONE AND SUPINE POSITION

Introduction. Infants' arousals from sleep reflect the activation of various brain stem and cortical structures. Arousals are associated with changes of physiological parameters, such as heart rate and respiratory frequency, as well as with body movements. Dependent on the presence or absence of EEG changes, cortical arousals (CA) and subcortical arousals (SCA) are distinguished.

Arousals represent important survival mechanisms during sleep. Increased arousability lowers the risk for Sudden Infant Death Syndrome (SIDS), which has been postulated as possible pathomechanism for the protective effect of the supine sleep position. The aim of our study was to compare the frequency and duration of spontaneous arousals between prone and supine sleep.

Methods. Daytime polysomnography was performed in 15 healthy term infants (mean age 47.5 ± 17.9 days) sleeping in prone position. Spontaneous arousals were scored according to the criteria of the "International Pediatric Work Group on Arousals". We evaluated the mean number of arousals per 10-minute-period as well as the mean duration of arousals. Furthermore, the analysis was performed separately for CA, SCA and unclassifiable arousals (UCA). The control group consisted of 15 healthy term infants (mean age 50.4 ± 15.8 days) sleeping in supine position.

Results. In prone position, mean total sleep time was 117.7 ± 29.4 minutes. Altogether, 277 arousals were analysed (127 CA, 88 SCA, 62 UCA). The mean number of arousals per 10-minute-period was 1.5 ± 0.6 (0.7 ± 0.3 CA, 0.5 ± 0.2 SCA, 0.4 ± 0.3 UCA). The mean duration of arousals was 13.7 ± 2.3 seconds (CA 15.2 ± 3.2 s, SCA 8.8 ± 2.1 s, UCA 15.9 ± 5.8 s).

In supine position, mean total sleep time was 98.2 ± 16.4 minutes. Altogether, 320 arousals were analysed (186 CA, 75 SCA, 59 UCA). The mean number of arousals per 10-minute-period was 2.2 ± 1.1 (1.3 ± 1.9 CA, 0.6 ± 0.4 SCA, 0.4 ± 0.4 UCA). The mean duration of arousals was 13.2 ± 3.1 seconds (CA 14.9 ± 5.0 s, SCA 7.0 ± 2.2 s, UCA 17.5 ± 3.8 s). The mean number of arousals altogether as well as of CA per 10-minute-period was significantly higher in supine position when compared to prone position. No significant difference was evaluated for SCA. Concerning the duration of arousals, we found significantly longer SCA in prone position, but no differences in the other groups.

Discussion. Our results support the hypothesis that the supine position increases arousability from sleep, which might contribute to its protective effect

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Practical Information

Admission to the Conference

Please make sure you wear your conference ID badge at all times, as this is your admission ticket to the conference sessions.

Concierge

The Baltimore Marriott Waterfront concierge service is available for your assistance. Please feel free to contact the Marriott Concierge Service at 410-385-3000 or by email at cfserver@stayatmarriott.com.

Meals

The full conference registration fee includes:

- Welcome Reception on October 4th
- Breakfast on October 5th
- Lunch on October 5th
- Breakfast on October 6th
- Lunch on October 6th
- The Awards Dinner on October 6th (if you wish to bring a guest, there is a \$90.00 charge)
- Breakfast on October 7th

Evaluation

An overall conference evaluation will be emailed to you shortly after the conclusion of the conference.

Internet

For attendees staying at the Baltimore Marriott Waterfront, internet access is available for \$12.95. For all other attendees, you can purchase an internet connection for \$75 per day or feel free to use the lobby where the Baltimore Marriott Waterfront has complimentary internet connection.

Remembrance Service

The Remembrance Service is scheduled for Friday, October 5th beginning at 6:15 pm.

The Remembrance Service will be held at the World Trade Center in Baltimore, 401 E. Pratt Street. Complimentary transportation to the service will meet in the Baltimore Marriott Waterfront lobby beginning at 5:30 pm on the evening on October 5th.

Poster Sessions

Poster Sessions A and B will be held in Laurel Rooms A, B, and C.

Poster Session A Friday, October 5 4:30 pm – 6:00 pm

Poster Session B Saturday, October 6 12:30 pm – 1:30 pm



Practical Information

The Family Oasis Room

The Family Oasis Room is a quiet resource room for bereaved parents during the conference. For those who require some time away for reflection, prayer or simply relaxation this room is available. The Family Oasis Room will be set with tables for any parent that wishes to eat breakfast in this area. The Family Oasis Room will be staffed with members of the First Candle support team.

Registration Desk

The registration desk is located on the 4th floor as your exit the escalator.

Registration Hours:

Thursday, October 4	12:00 pm - 5:00 pm
Friday, October 5	7:00 am - 7:00 pm
Saturday, October 6	7:00 am - 5:30 pm
Sunday, October 7	Closed

FAMILY OASIS ROOM

Open Thursday, October 4 - Sunday, October 7

Thursday 1 pm - 10pm | Friday: 7 am - 6 pm
Saturday: 7 am - 6 pm | Sunday: 8 am - 12 pm
Laurel Room D

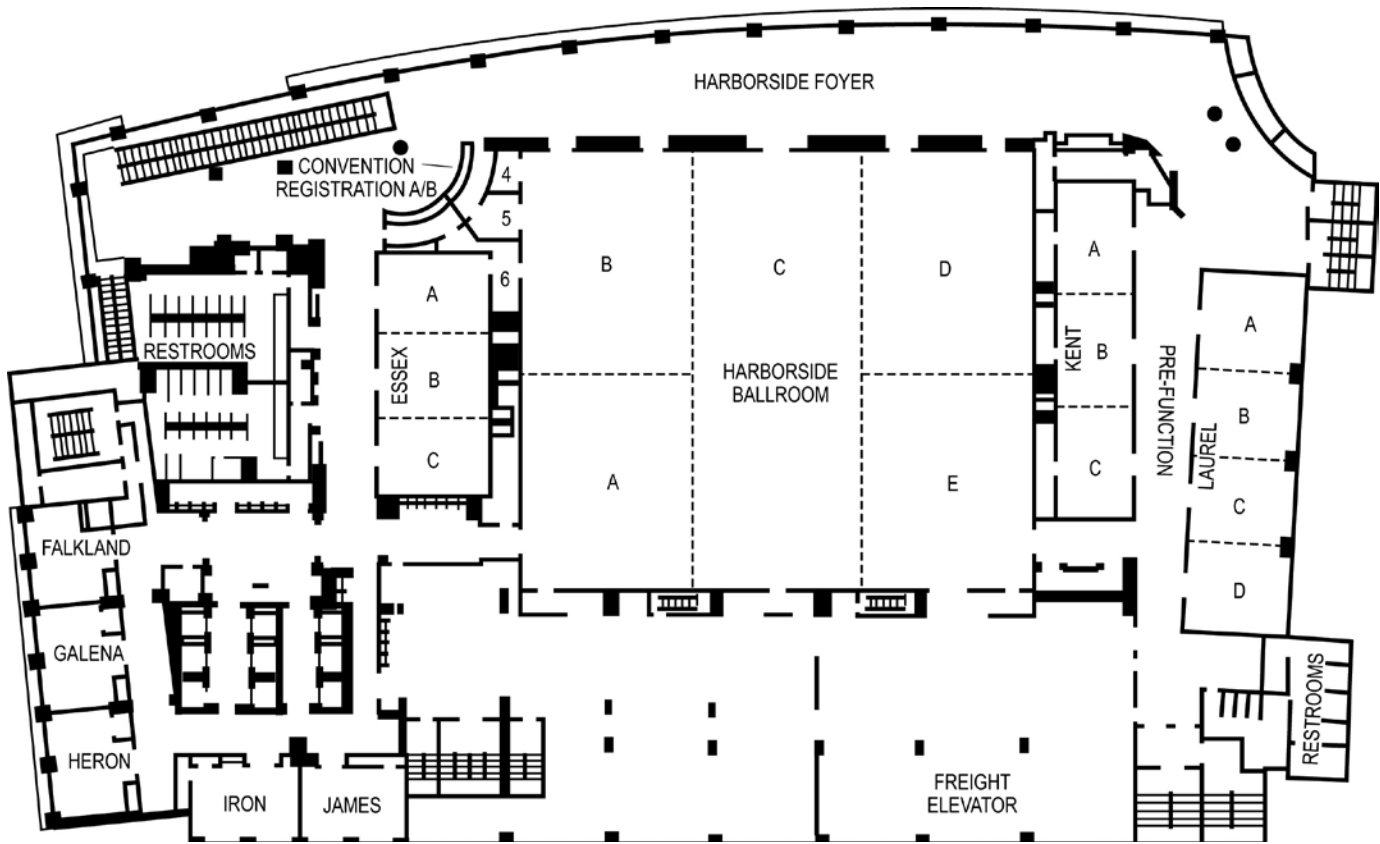
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Emma & John Rooney in honor of baby Fiona

A heartfelt thank you to Dr. Patricia Flynn, Executive Director
of 1st Breath, for the handmade ribbons for parents.



Conference Center Map

HARBORSIDE BALLROOM LEVEL



Index of Invited Speakers

Alphabetical by Last Name

Barbot, Oxiris

Opening Session: Welcome to Baltimore
Friday, October 5; 8:30 am - 9:15 am
Harborside Ballroom Salons D & E

Bogle, Tamasine

Plenary III: A Parent's Perspective
Friday, October 5; 10:45 am - 11:30 am
Harborside Ballroom Salons D & E

Brabin, Penny

Breakfast Session II: Stillbirth
Friday, October 5; 7:00 am - 8:30 am
Kent Room B

Byard, Roger

SIDS/SUID Pathology Symposium
Friday, October 5; 12:30 pm - 4:30 pm
Harborside Ballroom Salon E

Camperlengo, Lena

Breakfast Session I: SIDS/SUID
Saturday, October 6; 7:00 am - 8:30 am
Kent Room A

Côté, Aurore

SIDS/SUID Oral Abstract Presentations: Physiology & Genetics
Saturday, October 6; 10:15 am - 11:15 am
Harborside Ballroom Salon E

Cowan, Stephanie

Breakfast Session I: SIDS/SUID (Round Table)
Friday, October 5; 7:00 am - 8:30 am
Kent Room A

Crandall, Laura

SIDS/SUID Pathology Symposium
Friday, October 5; 12:30 pm - 4:30 pm
Harborside Ballroom Salon E

Erwich, Jan Jaap

Stillbirth Workshop: Fetal Movement & Kick Counting
Friday, October 5; 3:15 pm - 4:30 pm
Harborside Ballroom Salon D

Stillbirth Workshop: Perinatal Audit
Saturday, October 6; 1:30 pm - 3:00 pm
Harborside Ballroom Salon D

Fifer, William

Plenary II: Fetal Physiology
Saturday, October 6; 9:15 am - 10:00 am
Harborside Ballroom Salons D & E

Flenady, Vicki

Stillbirth Workshop: Fetal Movement & Kick Counting
Friday, October 5; 3:15 pm - 4:30 pm
Harborside Ballroom Salon D

Stillbirth Workshop: Perinatal Audit
Saturday, October 6; 1:30 pm - 3:00 pm
Harborside Ballroom Salon D

Fretts, Ruth

Stillbirth Workshop: Fetal Movement & Kick Counting
Friday, October 5; 3:15 pm - 4:30 pm
Harborside Ballroom Salon D

Stillbirth Workshop: Perinatal Audit
Saturday, October 6; 1:30 pm - 3:00 pm
Harborside Ballroom Salon D

Froën, J. Frederick

Stillbirth Workshop: Fetal Movement & Kick Counting
Friday, October 5; 3:15 pm - 4:30 pm
Harborside Ballroom Salon D

Stillbirth Workshop: Perinatal Audit
Saturday, October 6; 1:30 pm - 3:00 pm
Harborside Ballroom Salon D

Glover, Allison

Plenary III: A Parent's Perspective
Friday, October 5; 10:45 am - 11:30 am
Harborside Ballroom Salons D & E

Gold, Katherine

SIDS and Stillbirth Combined Session: Grief and Bereavement
Sunday, October 7; 10:15 am - 10:45 am
Harborside Ballroom Salon D

Goldenberg, Robert

Plenary I: Global Perspectives on Stillbirth
Saturday, October 6; 8:30 am - 9:15 am
Harborside Ballroom Salons D & E

Haddad, Gabriel

SIDS/SUID Pathology Symposium
Friday, October 5; 12:30 pm - 4:30 pm
Harborside Ballroom Salon E

Hauck, Fern

Breakfast Session III: SIDS/SUID & Pacifiers
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Kent Room C

SIDS/SUID Oral Abstract Presentations: Epidemiology
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SIDS/SUID Pathology Symposium
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Ilse, Sherokee

Breakfast Session II: Stillbirth
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Kinney, Hannah

SIDS/SUID Pathology Symposium
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Krous, Henry

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Lu, Michael

Plenary I: Maternal Life Course
Friday, October 5; 9:15 am - 10:00 am
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McClure, Elizabeth

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McEntire, Betty

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Mitchell, Edwin

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Mitchell, Peter

Plenary I: Social Media and Health Messaging
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Nattie, Jr, Eugene

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Paterson, David

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Reddy, Uma

Plenary II: Disparities in Stillbirth
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SIDS/SUID Pathology Symposium
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Rubens, Craig

Stillbirth Session: Review of GAPPS Initiatives
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Opening Session: Welcome to Baltimore
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STILLBIRTH ORAL ABSTRACT PRESENTATIONS

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- 12:30 pm Developing a Surveillance System for Stillbirth: An Exploratory Study to Determine the Acceptability of a Pregnancy Risk Assessment Monitoring and Surveillance (PRAMS)-Like Survey Among Women who have Recently Experienced a Stillbirth
- 12:45 pm What Influences Parents Decision to have a Perinatal Autopsy? A Qualitative Investigation
- 1:00 pm Mothers' Experiences of the Time after the Diagnosis of an Intrauterine Death until the Induction of the Delivery. A Qualitative Internet-Based Study
- 1:15 pm Is it Feasible to Tell Pregnant Women to Sleep on their Left?
- 1:30 pm Upskilling the Workforce in Clinical Practice around Stillbirth: Evaluation of IMPROVE (Improving Perinatal Review and Outcomes Via Education) Workshops
- 1:45 pm The Utility of Using an Existing Birth Defects Surveillance Program to Enhance Surveillance Data on Stillbirth – Atlanta, Georgia, 2006
- 2:00 pm Bile Acids and Stillbirth
- 2:15 pm Film 1: In Times of Bereavement.
- 2:30 pm Weaving Sacred Threads: Remembering Special Lives. An Experiential Workshop to Create Meaningful Ceremonies of Naming, Blessing, Leave-taking/Funeral.
- 2:45 pm

Saturday, October 6

- 7:00 am - 8:30 am Taking Baby Home: International Perspectives on Caring for Parents and Families after the Death of a Baby
- 3:15 pm Women's Premonitions Prior to the Death of their Baby in Utero and How They Deal with the Feeling that their Baby May be Unwell
- 3:30 pm Experiences of Support for Women with Stillbirth: Report from the Stillbirth Collaborative Research Network Follow-up Study (SCRNFS)
- 3:45 pm AnticarAnticardiolipin and Anti-beta-2-glycoprotein I Antibodies and Stillbirth
- 4:00 pm Assessing the Economic Impact of Stillbirth Using Models of Care In Subsequent Pregnancy
- 4:15 pm Taking The Social Taboo Out Of Stillbirth
- 4:30 pm Birth Attendants as Perinatal Verbal Autopsy Respondents in Low-Income Countries: A Viable Alternative?
- 4:45 pm Spiritual and Pastoral Care following Stillbirth: A Review of Services in Ireland
- 5:00 pm Audit of Term Perinatal Deaths in the Netherlands
- 5:15 pm Risk Factors for Late Pregnancy Stillbirth: The Sydney Stillbirth Study
- 5:30 pm Characteristics and Pregnancy Outcomes of Women Presenting with Decreased Fetal Movement
- 5:45 pm Risk of Stillbirth at Extremes of Birthweight between 20 to 41 Weeks Gestation
- 6:00 pm Maximizing Enrollment to a Stillbirth Research Study

STILLBIRTH ORAL ABSTRACT PRESENTATIONS: GRIEF AND BEREAVEMENT

Sunday, October 7

- 10:45 am Grieving After Stillbirth - How Does a Baby's Death Affect the parents? About the Dual Process Model of Coping with Loss
- 11:00 am Seeing and Holding a Stillborn Baby: Mothers' Feelings in Relation to How their Babies were Presented to Them After Birth – Findings from an Online Questionnaire.
- 11:15 am Depression and PTSD among Mothers with Stillbirth and Early Infant Death Compared to Mothers with Live Birth: the Michigan Mothers Study
- 11:30 am Hasty Conception after Perinatal Loss: the Salve for Maternal Grief or Perpetuation of Anxiety for Mother and Subsequent Child?
- 11:45 am Our Baby Died: Adolescents' Recollections of being Raised in a Family after the Loss of a Baby

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SIDS/SUID ORAL ABSTRACT PRESENTATIONS

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- 7:00 am - 8:30 am End Game' SUID Prevention Approaches and the Need for Innovation
Time to Re-evaluate the Role of Pacifiers in SIDS Campaigns
Relationship between Pacifier Usage and SIDS - Review of the Epidemiologic Literature
A Trial to Explain the Beneficial Effect of Pacifier Use; Observations and Speculations.
The Changes in Attitude Toward Pacifier Use throughout History and a Survey of Current Views on the Internet
The Effect of Pacifiers on Breast Feeding
- 12:35 pm Mechanisms of Cell Death in Neurons and Glia following Hypoxia/Ischemia
- 12:55 pm Professor Henry F. Krous' Contribution to More Accurate Definition of SIDS
- 1:15 pm Standardized Protocols in the Investigation of Sudden Infant Death
- 1:35 pm Sudden Unexpected Infant Death (SUID) Tissue Consortium
- 2:15 pm SIDS Brainstem and Genetics Research
- 2:35 pm Insights into SIDS Pathogenesis and Possible "Treatment" from Animal Models
- 2:55 pm Filling the Void: Envisioning and Fulfilling the Needs of SUDC
- 3:15 pm Neuropathologic Research in SUDC: Reflections in Honor of Henry F. Krous

Saturday, October 6

- 7:00 am - 8:30 am The Sudden Unexpected Infant Death (SUID) Case Registry: Improving Knowledge about SUID and Taking Action.
- 10:15 am Genome-Wide Association Study of SIDS-Predisposing Genetic Variation
- 10:30 am Neurochemical Brainstem Pathology and Potential Asphyxia in Sudden Unexplained Infant Deaths
- 10:45 am Reduced 5-HT_{1A} Receptor Binding in the Auditory Brainstem in Sudden Infant Death Syndrome: Implications for Newborn Hearing Screening as a Diagnostic Test for SIDS
- 11:00 am Development of Autonomic Cardiovascular Control in Preterm Infants is Altered Compared to Term Infants
- 1:30 am An International Comparison of Unexplained Sudden Unexpected Death in Infancy (SUDI) using a Newly Defined Range of ICD10 Codes
- 1:45 am Installation of Child Death Review Teams in the Eastern part of the Netherlands
- 2:00 am Sudden Death in Infancy: A Multicentre Study of the Medico-Legal Investigation Procedures and Outcomes in South Africa
- 2:15 am Stepwise Reduction of SIDS Rate in Styria (Austria). The Contribution of Individual Measures
- 2:30 am Manchester Vulnerable Babies: Targeting Risky Behaviour
- 2:45 am Breastfeeding Intention Among African American Women Of Different Socioeconomic Status
- 3:15 am The Context and Circumstances of Unintentional Suffocation in Place of Sleep in New Zealand
- 3:30 am Trends and Factors Associated with the Use of Soft Bedding in the Infant's Sleep Environment, National Infant Sleep Position Study, 1993-2010
- 3:45 am Maternal Smoking and Alcohol Consumption during Pregnancy: Are the Risk Factors for Sudden Infant Death Syndrome
- 4:00 am Are Baby Hammocks Safe for Sleeping Babies
- 4:15 am Deaths and Near Deaths of Healthy Newborn Infants While Co-Sleeping and Bed-Sharing on Maternity Wards
- 4:30 am Swaddling and the Risk of SIDS: a Complex Relationship
- 4:45 am Comparison of Infant Sleep Practices in African-American and U.S. Hispanic Families: What Can We Learn?
- 5:00 am Age at Death Due to Sudden Infant Death Syndrome for Term and Pre-Term Infants
- 5:15 am Trends and Factors Associated with Bed-Sharing: The National Infant Sleep Position (NISP) Study 1993-2010

Sunday, October 7

- 10:15 am Bubblicious: Engaging Vulnerable Families in a Digital Age
- 10:30 am Reduce the Risk Campaigns in 2012: How Eight Countries are Meeting the Challenge

SIDS/SUID/NEONATAL ORAL ABSTRACT PRESENTATIONS: GRIEF AND BEREAVEMENT

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- 11:00 am A Scottish Retrospective Review of Bereaved Families' Opinion on the Support Network Provided and Experienced After Sudden Unexpected Death in Infancy (SUDI)
- 11:15 am Empirical Expert's Advice on Care in Subsequent Pregnancy
- 11:30 am The Double Grief - Information and Bereavement Support for Grandparents
- 11:45 am Parental Relationships and Professional Support after the Death of a Child

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| A-06 | Autopsy and Information Quality of Fetal Death Certificates in São Paulo City, Brazil | A-46 | The Wahakura: a Bed-Sharing 'Safer' Sleeping Environment for SIDS Prevention |
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| A-10 | Discussing Stillbirth with Pregnant Women | A-50 | Associations of Type Assistance at Delivery with Maternal-Neonatal Outcomes and Newborn Care following Home Delivery |
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| A-19 | Characteristics and Pregnancy Outcomes of Women Presenting with Decreased Fetal Movement | A-59 | Sudden Infant Death Syndrome (SIDS): A Public Health Problem In Bogotá, Colombia? |
| A-30 | Project Indigo: Detailed Analysis of Unexpected Infant Deaths in London | A-61 | How Risk Factors for SIDS are Perceived in Germany? |
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- B-04 Factors that Influence Clinicians in their Care of Families who Experience Stillbirth
- B-05 The Value of a Pregnancy Loss Clinic in Maternity Services; Supporting and Enhancing Practice
- B-06 Labelling Stillbirth - Does it Make a Difference?
- B-07 Quality of Fetal Movements in Full Term Pregnancy - A Swedish Population-Based Study among Pregnant Women within Standard Antenatal Care
- B-08 Waiting in No-Man's-Land - Mothers' Experiences before the Induction of Labour after their Baby has Died in Utero
- B-09 Siblings' Grief and Experiences of Support after Losing a Sister or Brother in Stillbirth
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- B-12 Hospital Costs Associated with the Delivery of Stillborn Infants
- B-14 How do We as Professionals Meet the Spiritual Needs of Bereaved Parents?
- B-15 National Stillbirth Guidelines: Does Spirituality or Faith Matter?
- B-31 Abstract Good Grief to Go - A 5-Week, Giant HeART Workshop™
- B-32 The Outcome of Pregnancy After Stillbirth
- B-33 Caring for Employees Experiencing Grief and Crisis; Information Booklet and Educational Seminars
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- B-37 Does Tongue Size Contribute to the Unique Age Distribution of Sudden Unexpected Deaths in Infancy?
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- B-40 Retrospective Analysis of Referrals to SIDS and Kids NSW for Bereavement Support from 2007 to 2011
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- B-43 Partial Silencing of Medullary Serotonin (5HT) Vesicular Neurotransmission Inhibits Respiratory Long Term Facilitation (LTF) and Increases Total Apnea in Mice at a Critical Age in Postnatal Development: Relevance to SIDS
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First Candle welcomes the International SIDS Memorial Quilt back to the United States!



The International SIDS Memorial Quilt was completed by families from various SIDS organizations worldwide and first displayed at the 1996 conference in Washington, DC. After that conference, a tradition started of passing the Quilt and the Flags of country attendees on to the country that was hosting the next international conference. Since that time the quilt has been hung at conferences in Auckland, New Zealand; Rouen, France; Florence, Italy; Edmonton, Canada; Yokohama, Japan; Portsmouth, United Kingdom; and Sydney, Australia.

HEALING JAPAN

"Nights were never this dark, and I never realized how beautiful the stars are."



In 2006, ISPID and ISA convened in Yokohama for a highly successful international conference with more than 550 participants, graciously hosted by the SIDS Family Association Japan. The Japanese families and physicians remain very close in spirit to our international community and have a delegation of four attending this year in the United States. They are a sponsor of this conference.

Last year the Japanese people were devastated by the triple disaster of earthquake, tsunami and nuclear meltdown. The SIDS Family Association would like to share their experience with our international community. Much as healing after the loss of a precious child is a process, so too is healing after loss

of this magnitude, where thousands upon thousands have lost their homes and almost 20,000 Japanese are dead or unaccounted for...

During this time, messages from overseas came pouring into Japan and have been like a light in the darkness to them. The triple disasters may seem long ago but the incredibly hard work of rebuilding, cleaning up radiation and working through the grief has only just begun. Please take a moment to share thoughts with the members of our long-time and steady partner, the SIDS Family Association Japan.



Please stop by the HEALING JAPAN table in the networking area beside registration to sign a note to our friends in Japan.



CDC's Division of Reproductive Health **Where Science Meets Society**

During the meeting, stop and visit us
in the exhibit area at **Tables 4 and 5.**

Visit us online 24/7/365 at:

www.cdc.gov/SIDS or www.cdc.gov/reproductivehealth

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Babies Our Mission. Your Mission.

Infant survival continues to be among the most significant and challenging public health issues of our time.

While progress has been made during the past two decades, there is still much work to be done if we are to continue to have a significant impact on the alarmingly high rates of stillbirth and SIDS/SUID.

Thank you for all of your efforts on behalf of babies and families worldwide!

Working together we can ensure that every baby celebrates his or her first birthday.



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We thank you for your support and participation . . . safe travels!