

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

Strategic Directions and Goals for 2015-2016

Introduction

The death of a baby is a tragedy for parents, siblings, the extended family, friends and work colleagues.

Sudden Unexpected Infant Death (SUID) encompasses all instances of sudden infant death, including death attributed to the Sudden Infant Death Syndrome (SIDS). The definition of SIDS is “the sudden, unexpected, death of an infant less than one year of age, with the fatal episode apparently occurring during sleep, which remains unexplained after thorough investigation, including performance of a complete autopsy and review of the circumstances of death and clinical history”¹. SIDS incidents have declined dramatically--by 50%-90% in Organisation for Economic Cooperation and Development (OECD) countries) following worldwide “safe sleeping” campaigns introduced in the 1990’s. However, SIDS remains the leading cause of post-neonatal infant mortality in these countries. Despite intensive research, the mechanisms underlying SIDS remain unknown. However, what is known is that a number of infant care practices and prenatal conditions increase the probability of an infant dying from SIDS. That knowledge has been the basis of advice to parents on how to reduce the risk of SIDS. The success in reducing incidents of SIDS has been driven by collaboration between researchers in many countries studying the risk factors and mechanisms associated with SIDS.

Perinatal death is the death of an infant which occurs at or around the time of birth, the term encompassing death due to stillbirth and early neonatal death. The World Health Organisation (WHO) defines stillbirth as the death of a baby with a birth weight of at least 1 kilogram, or a gestational age of at least 28 weeks, occurring prior to or during birth. It is estimated that every day over 7,300 babies are stillborn and stillbirth affects at least 2.6 million families every year, with 98% of stillbirths occurring in low and middle-income countries². There is increasing focus on stillbirth research, awareness and prevention, areas that have been largely neglected until now. In developing countries many stillbirths are preventable through improvements in care, health policy, and dedication of additional resources. In OECD countries, recent research and new technologies are revealing stillbirth risks and lead to education campaigns, similar to the SIDS campaigns, that may decrease the incidence of stillbirth.

¹ Krous HF, Beckwith JB, Byard RW, Rognum TO, Bajanowski T, Corey T, Cutz E, Hanzlick R, Keens TG, Mitchell EA, 2004, ‘Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach’, *Pediatrics*, vol. 114 no. 1, pp. 234-238.

² Stillbirths an Executive Summary for The Lancet’s Series, 24 April 2011

ISPID - Who we are.

The International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) is a global organisation that draws researchers, health professionals and parents together from around the world to advance the efforts to further reduce the incidence of SIDS and perinatal death and to provide answers and support to bereaved families.

ISPID is a not-for-profit organisation that is leading the world in discovering evidence-based preventive measures for perinatal and unexpected post-neonatal infant death. ISPID is also working to promote improved support for bereaved families and others impacted by these deaths.

For over 25 years, ISPID has been bringing together researchers and support organisations from over 20 countries, combining the passion of bereaved parents with the world's leading experts on baby survival. ISPID is an amalgamation of the International Society for the Study of Infant Death (ISPID), the SIDS Global Strategy Task Force (GSTF), SIDS International and the European Society for the Study and Prevention of Perinatal and Infant Death (ESPID).

Our Mission – why we exist

To save the lives of babies through increasing knowledge on prevention and advancing research in areas of perinatal, infant health and mortality.

Our Vision – what we aspire to

As an international leading body ISPID is dedicated to the exchange of information among families, scientists and other specialists in the field of perinatal and infant health and to educating the global community at large on prevention of perinatal, and unexpected infant death.

Our Values – what we believe

Research

- ISPID fosters collaborative research through working parties comprised of international scientists working in the fields of physiology, epidemiology, and pathology as they apply to perinatal and unexpected infant death.

Collaboration and information exchange

- ISPID promotes international collaboration by bringing together researchers, health professional and parents at biennial international conferences at which working groups are established to deal with the changing issues associated with these deaths. The ISPID website also provides some of the evidence underlying the different risk reduction messages.

Prevention

- ISPID plays a major role in prevention of unexpected infant and perinatal death by providing up-to-date findings of evidence-based research, providing consensus documents for the ISPID web page, and a forum for researchers from around the world to debate, discuss and collaborate. This enhances research progress and provides ISPID member organizations with the science on which to base and organize prevention campaigns.

Bereavement support

- ISPID provides support for bereaved families through information provided on our web site and also through special sessions devoted to grief and bereavement held at each of our biennial international conferences.

Expansion of partnerships and membership

- ISPID membership is open to individual scientists, health professionals, parents and organisations focused on research, health promotion education and support of bereaved families.
- ISPID seeks partnerships with other international health organisations that will enhance our ability to fulfil our mission.

SWOT Analysis

Strengths

1. Wide array of professionals and parents from diverse backgrounds involved in ISPID at Board level and within the membership. This mix fosters shared collaboration and acts as a catalyst for progressive thought, new theories and breakthroughs in knowledge.
2. International scope. Collaboration between people from many countries working towards the same goals, experiencing the journey and celebrating successes along the way.
3. Institutional knowledge built-up over 25 years by the organizations that merged in 2006 : ISPID (established 1991), SIDS International (established 1985), the Global Strategy Task Force (established 1992), and the European Society for the Study and Prevention of Perinatal and Infant Death (ESPID).
4. Shared experience with life-and-death issues is a solid platform for open-mindedness, humble appreciation, flexibility to embrace change and a willingness to learn from each other.

Weaknesses

1. Geographical dispersion, lack of central location and language barriers create logistical and communication challenges.

2. Reliance on goodwill of others and on in-kind contributions due to ISPID's limited financial base and difficulties in raising funds to support operations.
3. Limited resources to produce multi-language information and support.
4. Lack of standardized approach to the diagnosis of SIDS and definition of perinatal death in various countries make it difficult to collect and compare global data.

Opportunities

1. The ISPID website is an ideal platform to communicate evidence-based education messages aimed at reducing the global incidence of sudden unexpected death in infancy and perinatal death.
2. ISPID can foster more collaborative international research to conduct epidemiologically sound rigorously conducted studies.
3. ISPID should leverage our international presence and members' connections around the world to expand knowledge regarding perinatal and unexpected infant death and to spread the messages for prevention, awareness and risk reduction.
4. ISPID can partner with other international organizations with complementary health goals such as UNICEF, WHO and the International Stillbirth Alliance (ISA).

Threats

1. Dependence on goodwill and ability of members to host international conferences every two years.
2. The financial sustainability of many of our members, especially internationally, is threatened by deteriorating economic conditions.
3. Lack of regular communication among members, adversely impacting on perceptions regarding ISPID's achievements.

Goals and Strategies

1. Research Goals

- Establish international collaborations to investigate the risk factors involved in perinatal and unexpected infant death.
- Promote collaboration internationally with working parties and during the Biennial international conference.

2. Collaboration and Information Goals

- Disseminate relevant information to parents and carers.
- Provide new information as soon as it comes to hand.
- Provide informed opinions on new research in the early stages of its dissemination.

3. Prevention Goals

- Raise awareness and further the education of the public in general and health professionals in particular.
- Support research by collaborating and sharing of information on how to further decrease the incidence of perinatal and unexpected infant death.

4. Bereavement Support Goals

- Support organisations offering bereavement support/counselling and provide a forum for sharing information.

5. Growth in Partnerships and Membership Goals

- Increase membership, both individual and organisational particularly in Asia, Africa and Latin America.
- Increase collaborative working arrangements with like-minded international health organisations.