

International SIDS/Infant Death

Program Highlights



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The international SIDS/Infant Death and stillbirth community provides numerous risk reduction and bereavement support programs and research in the areas of sudden infant death syndrome (SIDS), other infant death, and stillbirth. This booklet highlights the services and research activities of several member countries of SIDS International (and one non-member country, Ireland). SIDS International is also highlighted as the driving force behind global collaboration that has saved many infant lives.

This information is provided to assist SIDS and Infant Death programs in the United States to continue to collaborate and develop new ties with the international SIDS, infant death, and stillbirth community.

Table of Contents

Canadian Foundation for the Study of Infant Deaths (CFSID).....	1
SIDS and KIDS/National SIDS Council of Australia	2
Foundation for the Study of Infant Deaths–UK (FSID).....	3
SIDS Family Association Japan (SIDSFAJ)	4
Irish Sudden Infant Death Association (ISIDA).....	5
Scottish Cot Death Trust.....	6
SIDS International (SIDSI).....	7
International Stillbirth Alliance (ISA).....	8
The International Society for the Study and Prevention of Infant Death (ISPID).....	9
Other Members of SIDS International	10
Other International Contacts	10

Canadian Foundation for the Study of Infant Deaths (CFSID)

The CFSID is dedicated to solving the mystery of sudden and unexpected infant deaths and to providing emotional support to those who are affected. CFSID promotes and supports high-quality and innovative research into the causes of SIDS and its effects on families; conducts public education and awareness programs about issues relating to infant deaths; and provides current and accurate information and emotional support to families who have suffered the devastating experience of an infant death.

In recent years, CFSID has expanded its mandate to include all infant and perinatal deaths with respect to peer support, public education, and fundraising. Research remains SIDS-focused.

Programs:

- STEPS (Special Teen Education Program SIDS) is a supportive, educational training program that provides risk reduction information for teen moms and dads, expectant parents, and all who may become parents in the future.
- Over the years, SIDS volunteers have made hundreds of presentations on parenting and risk reduction to students throughout Canada. Public education is an important part of the mandate of the CFSID.
- CFSID provides discussion forums on its web site highlighting various topics related to SIDS. The web site also includes a FAQ section and risk reduction public service announcements.

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SIDS and KIDS/National SIDS Council of Australia

SIDS and Kids organizations provide safe sleep education and grief/bereavement counseling services to families who have experienced stillbirth, SIDS, and sudden unexpected death of a child up to 6 years of age. SIDS and Kids funds research, both nationally and regionally, and provides information on research efforts aimed at reducing mortality in infants (2 years and under) who die suddenly and unexpectedly from stillbirth, neonatal death, SIDS, and other infant death.

Programs:

- SIDS and Kids Safe Sleeping is an evidence-based health promotion campaign developed for health professionals, child care providers, parents, and anyone who cares for babies, to inform them about the evidence around SIDS risk reduction. The campaign has been developed in conjunction with researchers from Australia and internationally. Since its inception in the early 1990s, the campaign has saved the lives of more than 4,500 Australian babies.
- “Red Nose Day” is the cornerstone of SIDS and Kids fundraising efforts throughout Australia and is widely acknowledged as the first “signature” day of its kind in Australia. The campaign raises funds for the wide range of family support programs, community education, and research into sudden unexpected death, from 20 weeks gestation to 2 years of age. A range of quality novelty merchandise forms the basis of fundraising through partnerships with key retailers.
- Nine member organizations provide bereavement support and counseling for families who have experienced stillbirth or the sudden unexpected death of a child, whatever the cause, from 20 weeks gestation to 6 years of age. SIDS and Kids provides bereavement publications and links to “Pen Parents of Australia,” a non-profit correspondence network of parents who have suffered the tragedy of pregnancy loss or the death of a child.
- The web site provides FAQ’s, information on risk reduction, and topics such as plagiocephaly, bedsharing, and pacifiers and is targeted to parents, child care providers, and health professionals. Risk reduction information is provided in several languages. The site also provides information on upcoming research grant cycles.

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Foundation for the Study of Infant Deaths– UK (FSID)

The FSID is one of the United Kingdom's leading baby charities working to prevent SIDS and promote baby health. The FSID carries out its aims by funding vital research into the causes of cot death, supporting families who have been devastated by cot death, and promoting lifesaving baby safety advice to parents, caregivers and health professionals.

Programs:

- A help line is provided for bereaved parents, anyone affected by SIDS, and parents seeking information on SIDS. Free phone cards are available to bereaved families wishing to use the help line.
- The Network of Befrienders comprises volunteers who are family members of SIDS infants, and they work with recently bereaved parents and family members. Volunteers attend three “preparation days” to become a befriender.
- A bereavement conference for parents and professionals, and continuing education programs for health care professionals are provided.
- The Care of Next Infant (CONI) program helps SIDS parents work through some of their fears with the birth of a subsequent infant. CONI is run in hospitals and community health centers and involves midwives, pediatricians, general practitioners, and health visitors.
- The web site highlights current and completed research funded by FSID.

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SIDS Family Association Japan (SIDSFAJ)

The SIDSFAJ has three main goals: 1) to support families in Japan who have lost a baby for any reason; 2) to educate Japan about SIDS and how to care for bereaved families; and 3) to support research on SIDS and care for the bereaved. Japan hosted the 9th Annual International SIDS Conference in Yokohama, Japan in June 2006.

Programs:

- SIDSFAJ coordinates a network of more than 100 befrienders nationwide. A befriender is a SIDS parent who provides understanding and information to recently bereaved parents.
- SIDSFAJ produces pamphlets and booklets in Japanese that help to support bereaved families. SIDSFAJ also produces pamphlets for health care professionals working with bereaved families.
- SIDSFAJ maintains a web site in Japanese with information about the organization and SIDS (only for systems that can read Japanese characters).
- Recent surveys of bereaved parents and family members were conducted to determine the attitudes and problems that caretakers face when a baby dies. The results of the survey clearly showed that there is virtually no follow-up care for families after the death of a baby in Japan. Armed with the results of this survey, SIDSFAJ will start work on finding ways to create a system for follow-up care.

Contact information:

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Japan

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Irish Sudden Infant Death Association (ISIDA)

The ISIDA provides the following services: 1) offers support to families bereaved by SIDS and others affected by it; 2) provides information on SIDS to parents, health care professionals, the media, and the public at large; 3) promotes and supports research into the causes and prevention of SIDS, and 4) raises funds to support the above.

Programs:

- ISIDA provides a variety of support and information services for bereaved parents and families. These services are provided by trained staff and volunteers who have themselves experienced the feelings of grief, loss, and isolation that follow the death of a child. The services include a befriending network and nationwide support helpline.
- A Book of Remembrance, commemorating children who have died suddenly and unexpectedly, is kept at ISIDA's national office where parents and relatives are welcome to visit, read, and contribute.
- ISIDA's support services include a Nationwide Support Helpline that puts parents in touch with befrienders.
- A training video for professionals, entitled *Sudden Infant Death Syndrome: A Co-ordinated Approach for Professionals* can be ordered through the web site. Also available on the website is another resource for professionals entitled *Sudden Infant Death: a National Model of Care for Professionals*.
- A comprehensive document targeted to bereaved parents entitled *A Precious Past: a Hopeful Future* is available for download from the website.
- The web site provides information on a National SIDS Registry and risk reduction for caregivers.

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Scottish Cot Death Trust

The Scottish Cot Death Trust is a charity that aims to find the cause of cot death, to support the families affected by this tragedy, and to provide education on the topic for both the public and health care professionals. The Trust funds research into the possible causes of cot death in a wide variety of fields, including physiology, pathology, epidemiology, biochemistry, microbiology, virology, and genetics.

Programs:

- The Trust publishes a range of information leaflets for general practitioners, health visitors, clergy, police and funeral directors who are involved with cot death.
- The Trust's helpline provides expert advice for concerned parents and health care professionals on reducing the risks of cot death. The web site provides an "Info and Advice" section for parents and caregivers, including a Q & A area.
- Leaflets have been produced for bereaved families, and a bereavement support worker is available to visit the family in their home or provide telephone support. If desired, parents can be connected with a befriender, a parent who has suffered a cot death in the past and who is now willing to offer support and hope to the newly bereaved family.
- Each year, "Roadshows" are organized in different parts of the country. These are 2-hour sessions providing an update on cot death for health care professionals, police, social workers and other professionals, and parents.
- SIDS International has completed the third year of a national pilot of case review of Sudden, Unexpected Death in Infancy (SUDI) in Scotland. A multidisciplinary steering group will examine and make recommendations on the way in which SUDI cases are reported and bereaved parents supported. The goal is to agree on a standard that is rigorous but achievable, and supported by all agencies involved, including the Scottish Departments of Health and Justice.

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SIDS International (SIDSI)

The aim of SIDSI is to better understand the causes of, and thereby reduce the incidences of, SIDS and other Sudden Unexpected Deaths in Infancy (SUDI). With 13 member countries, SIDSI acts as a worldwide voice and facilitates the international sharing of information on SIDS and SUDI-related issues pertaining to statistical information, research, counseling, support, education, and service provision. SIDS International conducts an International Conference every 2 years to facilitate sharing of research, education, and program efforts. See the SIDSI web site for information on the conference held June 1 to 4, 2006, in Japan. First Candle/SIDS Alliance is among the active members of SIDSI.

Programs:

- SIDSI funds and promotes research to find answers to why SIDS and stillbirth occur, with the goal of eliminating these infant deaths.
- SIDSI provides a forum through which researchers can share findings and discuss future implications.

Contact information:

Deb Boyd, USA, Chair
First Candle/SIDS Alliance

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International Stillbirth Alliance (ISA)

The ISA, a non-profit coalition of organizations founded by stillbirth parents, is dedicated to understanding the causes of stillbirth and how it can be prevented. The ISA exists because of a collaborative effort between First Candle/SIDS Alliance (United States), Perinatal Research Center (Norway), and SIDS & Kids (Australia). The ISA mission is to raise awareness, educate about recommended precautionary practices, and facilitate research on the prevention of stillbirth. ISA serves as a centralized resource for sharing information and connecting organizations and individuals.

Programs:

The ISA philosophy is to unite groups around these issues and use these strengths to make a difference. ISA believes that having a centralized place for stillbirth issues and sharing information will accelerate progress. Together, groups can provide the public with accurate and validated information about stillbirth.

- ISA promotes and supports research on stillbirth and the development of evidence-based strategies for stillbirth prevention and care worldwide. Recruitment of young professionals into stillbirth research is needed to increase our knowledge and ability to prevent stillbirths. ISA presents the Young Investigator's Awards at the stillbirth conference.
- On the ISA web site, a list of the latest stillbirth research can be found by following the link "Research Reports."
- Extensive information about the MOMS (Maternal Observation and Memories of Stillbirth) Study is highlighted on the web site, including an on-line questionnaire to be completed by mothers of stillborn infants, and a FAQ section.

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

The ISPID exists to promote the exchange of information among scientists who have special experience in the field of infant health and death. The society promotes research and training. ISPID holds close ties with groups of parents and organizations of health professionals around the world. Associations of parents and professionals alike may support the society by becoming members of ISPID.

The web site lists publications related to SIDS/Infant Death research and scientific meetings.

The web site includes information on stillbirth, and completed and ongoing research. Researchers interested in collaboration may submit materials and contact information for posting in the “Ongoing Research” section.

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Other Members of SIDS International

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**Web site not in English*



**National
SIDS/Infant Death
Resource Center**

This booklet was developed by the U.S. Department of Health and Human Services, Health Resources and Services Administration (www.hrsa.gov), Maternal and Child Health Bureau under a contract with the National Sudden Infant Death Syndrome (SIDS)/Infant Death Resource Center, Contract No. NIHIDIQ-263-01-D-0208. The National SIDS/Infant Death Resource Center is operated by Circle Solutions, Inc.

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