

## Annual Report 2003

This year has been an important one for the SIDS Family Association Japan. We became an official NPO (Non-Profit Organization) and we embarked on an ambitious research project to determine the level of care for bereaved families in Japan. Though the SIDS rate continues to decline in Japan, thousands of families suffer miscarriage, stillbirth and infant death each year. Do they receive adequate psychological care during their painful experience? We designed and distributed questionnaires to determine the kind of care that families are presently receiving. Armed with the results of this survey, we can now start work on finding ways to improve care for the bereaved. We are grateful to the government-related foundation WAM (Welfare and Medical Service Agency) that partially funded this project.

We have also been working steadily on creating plans for the SIDS International Conference that will be held from June 1-4, 2006 in Yokohama. The conference will be a fabulous opportunity to share information with our constituents from overseas, ensuring that exciting strides will continue to be made towards preventing infant death.

I would like to offer sincere thanks to all of our members and supporters whose hard work and generous donations have made it possible to continue our work and achieve our goals in 2003.

Sincerely,  
Stephanie Fukui, Executive Director

# Recent Projects

## Publicity and Fundraising

The SIDS Family Association Japan (SIDSFAJ) is a not-for-profit, volunteer organization that operates its projects and activities by raising funds through membership fees and donations. The SIDSFAJ works to constantly keep the organization and SIDS issues in the newspapers and magazines. We also regularly contribute articles to scientific magazines about the psychological care of bereaved families.

Our Head Medical Advisor, Dr. Hiroshi Nishida, started a “Running Journey” in February of 2004. In three months he ran the 2500 kilometers from Rome to Istanbul. He will continue his run from the spring of 2005 from the interior of China. He eventually plans to run the length of the Silk Road from Rome, Italy to Nara, Japan, stopping at various places along the way to give lectures on nurturing babies and small children. This project is sponsored by Aprica and the theme is “Warm-heartedness to Children.” Dr. Nishida will be collecting funds for the SIDS Family Association Japan through pledges per kilometer. We wish him luck and strength on his incredible journey!

SIDSFAJ maintains a website in Japanese to give information about our organization and to disseminate information on SIDS. The address is: <http://www.sids.gr.jp> (only for systems that can read Japanese characters). Information in English on the **2006 SIDS International Conference** can be found at <http://www.sids.gr.jp/invi/>.

## Survey of Bereaved Families in Japan

Though the SIDS rate continues to decline, there are thousands of families that suffer miscarriage, stillbirth and infant death in Japan each year. Do they receive adequate care during their painful experience? We designed questionnaires to determine the kind of care that families are presently receiving. The first questionnaire was given to our bereaved family members. The results showed what they experienced at the time their babies died. Using this as a base, we designed other questionnaires that were sent to obstetricians, pediatricians and daycare centers. The results of these surveys confirmed the results of the bereaved parent survey and taught us about the attitudes and the problems that caretakers face when a baby dies. The results of all of these surveys showed clearly 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, we can now start work on finding ways to create a system for follow-up care. The results of the surveys to caretakers (obstetricians, pediatricians and daycare workers) taught us about the problems we will face as we work on implementing a system. Most medical professionals do not feel comfortable introducing a counselor or support group because most do not have training in dealing with bereaved families. Also they do not have official permission from their administration to introduce counselors or support groups. There are also some cultural constraints. There was an attitude among some participants that a family's privacy should not be invaded, especially at such a painful time. This might be related to the Japanese cultural taboo on dealing with problems outside of the family. It is also possibly related to the common perception that counseling is for extremely ill people. It was felt that bringing up the topic of follow-up psychological care might embarrass or insult the bereaved family. However, the results of the parent survey showed that the bereaved did indeed want follow-up care. Part of our job will be to respect these attitudes while helping to set up a system of care.

## The SIDS Prevention Campaign

The SIDS Family Association Japan launched a SIDS prevention campaign in June of 1996 targeting medical professionals. In early 1997 a pamphlet was released that educated new parents about SIDS risk factors. These were distributed to hospitals and daycare centers. The pamphlet encouraged parents to do the following to lower the risk for their baby:

- Sleep the baby on the back
- Do not smoke near the baby or during pregnancy
- Breastfeed as much as possible
- Do not leave the baby alone when asleep



The pamphlet urges parents to sleep the baby in the same room with parents, to avoid leaving the baby alone, to avoid sleeping the baby in unusual places like a sofa, and to avoid soft toys and pillows in the sleep area. The pamphlet also reassures parents that SIDS is relatively rare so parents should not feel stressed about the child care environment but should do what they can to keep it risk free and enjoy parenting as much as possible.



A reduction in these risk factors in countries overseas has led to a dramatic decrease in the number of SIDS deaths. In Japan in 1998 a decrease in the SIDS rate by 25% was achieved as the message of the campaign began to change childcare practices. The SIDS Family Association was awarded funds from the Japanese Ministry of Health and Welfare to co-produce a new version of the prevention pamphlet.

This was followed by a new version of the booklet “Guidelines for Care of Bereaved Families” and an 18-minute video “How to Protect Against SIDS” that covers the risk information about SIDS and

information on feelings of bereaved parents. Over 7000 copies of this video were distributed to health care centers across the nation in late 2000. Over two million copies of the prevention pamphlet have been distributed since 1998. By 2001, the SIDS rate in Japan had been reduced by almost 50%. The latest version of the prevention pamphlet gives information on the falling SIDS rate:

**SIDS RATE JAPAN (Per 1000 live births, birth to 1 year)**

Year	1995	1996	1997	1998	1999	2000	2001
SIDS Rate Japan	0.44	0.395	0.416	0.299	0.31	0.265	0.248
Number of Deaths	526	477	496	360	365	315	290
IMR	4.3	3.8	3.7	3.6	3.4	3.2	3.1

Source: Maternal and Child Health Statistics of Japan: Boshi Eisei Kenkyuu Kai , 2003

# About Us

## Membership

The SIDS Family Association Japan was founded in 1993 and now has 13 chapters nationwide. The membership consists of 564 bereaved families, 33 supporting members and 52 advisors (medical professionals, counselors, etc.) SIDSFAJ is a volunteer organization governed by an executive committee whose positions are filled by bereaved parent members. We presently have two hired staff members.

Our membership of bereaved families includes families who have suffered a loss through miscarriage (5%), stillbirth (26%), neonatal death (21%), infant death (38%) and child death (10%). About 31% of our bereaved families are SIDS families.

## Statement of Purpose

SIDSFAJ has three main goals:

- to support families in Japan who have lost a baby for any reason
- to educate Japan about SIDS and about how to care for bereaved families
- to support research on SIDS and care for the bereaved

## Care for Bereaved Families

In order to care for bereaved families SIDSFAJ has set up a self-help system that allows bereaved families to care for each other. The support families can give to each other is extremely valuable. Parents feel comfortable in each other's presence and feel that they are not being judged when expressing their deepest feelings and fears. Families also can show each other practical ways to deal with grieving. In order to support bereaved families SIDSFAJ offers a network of befrienders and group meetings throughout the country as well as publications that help them through their loss.

### *Befriender Network*

There is a network of over 100 Befrienders nationwide. When a newly bereaved parent first contacts our organization, she will talk to a befriender. A befriender is a person who has lost a baby and has taken our Befriender Training Course at least a year after her own loss. A befriender

is not a professional counselor but is a bereaved person who will befriend the caller, listen to and understand the pent-up feelings that the caller needs to express. The befriender is also a source of information.

Befrienders are extremely effective in supporting the newly bereaved. Since they too have suffered a loss, they are immediately trusted by the caller. Also they act as a role model and give hope to the caller by showing that it is possible to continue on with life after the devastating loss of a child.

### ***Meetings in Local Communities***

Each chapter holds regular meetings that are organized by befrienders. At these meetings the local members get together to support each other. The meeting is a forum for the bereaved families to express their feelings openly and to cry and talk about their beloved baby in a non-judgmental environment. Topics of discussion and meeting schedules are decided by each individual chapter.

### ***Publications***



The SIDS Family Association Japan produces pamphlets and booklets in Japanese that help to support bereaved families. We also produce pamphlets that explain SIDS and booklets that help professionals to help bereaved families. The titles translate roughly to English as follows:

- When Birth is a Sad Event (pamphlet to help professionals to care for stillbirth parents)
- Little Baby, I Will Never Forget You (for parents suffering the loss of a child through miscarriage, stillbirth or perinatal death)
- Do You Know about SIDS? (pamphlet explaining what is known about SIDS)
- To Hold You in my Arms Once Again (for parents who have lost a baby to SIDS, Medika Publishing)
- Light Glimmering through the Trees (for parents who are having a subsequent child after a loss)
- Protect a Little Life- how to prevent SIDS (pamphlet teaching SIDS prevention)
- Guidelines for Care of Bereaved Families (booklet to help professionals care for SIDS parents)