Sudden Infant Death Syndrome

Report to the Minnesota Legislature 2004

Minnesota Department of Health

November 2004
Sudden Infant Death Syndrome

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Executive Summary

Sudden Infant Death Syndrome (SIDS) is the sudden death of an infant under 1 year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history. It is the leading cause of death in infants between the ages of one month to one year.

The death of a child alters forever family structure, family dreams and touches the community at large in unique and powerful ways. Such a death requires a public health response – both to support families during this time of crisis as well as to learn from each death how to improve health and well being for all children and families.

SIDS Risk Reduction Campaign
While research has not uncovered the cause/s of SIDS, it has demonstrated infant care practices that can reduce the risk of SIDS. In 1994, the National Institute of Child Health and Human Development (NICHD) and others launched a national SIDS risk reduction campaign entitled Back to Sleep which recommends:

- Always place a baby to sleep on his or her back-even at naptime.
- Don't smoke around a baby.
- Don't smoke if you're pregnant.
- Place a baby on a firm mattress, such as in a safety-approved crib.
- Remove soft, fluffy bedding and stuffed toys from a baby's sleep areas.
- Keep blankets and other coverings away from a baby's nose and mouth.
- Don't put too many layers of clothing or blankets on a baby.
- Make sure everyone who cares for a baby knows that infants should be placed to sleep on their backs and the other ways to reduce SIDS risk.

Relevant Statistics - Affecting Change in Minnesota
Since the beginning of the Back to Sleep campaign in 1994, the Minnesota SIDS incidence has declined from 1.5 deaths per 1,000 live births in 1990 to 0.35 deaths per 1,000 live births in 2002. This decrease in SIDS accounts in part for the significant overall decline in infant mortality in Minnesota from 7.3 per 1,000 live births in 1990 to 5.3 per 1,000 live births in 2002.

Following the 2001 legislation requiring all child care providers to be trained in SIDS risk reduction, the SIDS rate in licensed childcare fell to 3% in 2002 as compared to 23% in 2000. This is the most dramatic decrease in SIDS in childcare in 20 years of data collection.

This noteworthy improvement is the result of the work of the Minnesota Department of Health (MDH) and the Minnesota Sudden Infant Death Center (MN SID Center) of Children’s Hospitals and Clinics and all their state and local partners including the Department of Human Services, child care providers, local public health and tribal health agencies, hospitals, primary care providers, and community and faith-based agencies, all of whom help educate new parents and other infant caregivers on safe infant sleep practices.

Emerging Trends
Other modifiable risk factors for sudden death in infants have also emerged. These include unsafe sleep environments such as pillows, fluffy bedding, adult beds, unsafe cribs, and infant/parent bedsharing. Also, identification of metabolic disorders, as well as pre and postnatal exposure to cigarette smoke are modifiable risk factors.
Disparities
While we recognize that the work of the MN SID Center has helped Minnesota achieve one of the lowest infant mortality rates in the nation for our total statewide population, we also recognize that significant racial and ethnic, economic and geographic disparities in infant mortality persist. As we continue the work to further reduce SIDS deaths, one of our primary goals is to continue to eliminate disparities in SIDS and all other infant deaths in Minnesota.

Actions and Accomplishments
MDH in partnership with the MN SID Center and others has developed several strategies to respond to these public health issues:

1. Bereaved families who experience the sudden death of an infant receive support, information and counseling.
2. Proactive and aggressive public and professional SIDS risk reduction education programs have been conducted.
3. Culturally appropriate risk reduction materials have been developed and broadly distributed.
4. Infant Death Investigation Guidelines have been developed and revised to facilitate a uniform investigation and determination of causes of death for sudden, unexplained infant deaths (deaths under two years of age).
5. In January 2001, MDH established population screening for MCAD (a genetic metabolic disorder that can result in sudden death in infants and children) as part of the expanded metabolic newborn screen.
6. In response to the 2001 legislation requiring all child care providers to be trained in SIDS risk reduction, a statewide training was undertaken and a training curriculum was developed and distributed. Following this training, the SIDS rate in licensed childcare fell to 3% in 2002 as compared to 23% in 2000.
7. In 2002, state money from the Infant Mortality Reduction Initiative (IMRI) was used to pilot a project entitled The Infant Sleep Safety and Baby Bed Project. Cribs were provided to public health agencies throughout Minnesota for families in need. Informational materials on safe sleep environment and bedsharing were developed as an education tool used by public health nurses in their parenting education outreach.

Future actions to be considered include such things as:

- Promoting aggressive public and professional education about safe infant sleep environment including the potential hazards of bedsharing;
- Training hospital newborn nursery staff to follow Back to Sleep recommendations to model best practice for new parents;
- Engaging grandparents who care for grandchildren to support and follow safe sleep practices that may be different from their parenting practices;
- Educating foster parents in risk reduction infant care practices;
- Ongoing training of new child care providers about safe infant care practices;
- Encouraging targeted preconception and prenatal smoking cessation programs.
Background

Sudden Infant Death Syndrome (SIDS) is the sudden death of an infant under 1 year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.

The primary characteristics of SIDS are:

- That SIDS is the leading cause of death in infants between the ages of one month and one year.
- The peak incidence of SIDS occurs between two and four months of age.
- SIDS remains unpredictable and almost always occurs during sleep.
- In most cases, infants appear healthy before succumbing to SIDS.

The rate of SIDS for African American and American Indian infants is two to three times greater than that of white infants.

Diagnosis

As in the case of any sudden, unexpected death, diagnosing SIDS is the responsibility of the County Coroner or Medical Examiner. The diagnosis is made based on the findings of a complete autopsy, scene investigation, and review of the medical and social history. Establishing a SIDS diagnosis requires excluding other recognizable causes of sudden unexpected death in infancy (SUDI). As many as 15-20% of sudden, unexpected infant deaths will be explained by acute infections, congenital malformations, or metabolic abnormalities.

Research

The cause of SIDS is unknown. There are no medical tests or examinations that can detect which children will become victims of SIDS. Research has shown that the most likely cause of SIDS is a combination of factors, related to the infant and his/her environment, possibly developmental, anatomical, or biochemical.

Infants vulnerable to SIDS likely possess developmental abnormalities in heart and respiratory rate control and in arousal. Environmental stresses encountered in early infancy may result in a “short-circuiting” of normal “defense” or arousal mechanisms resulting in sudden death. Several structural and functional nerve cell abnormalities have been identified in SIDS infants, which may increase risk for sudden infant death. Several studies have shown evidence that suggests delayed development of the brain stem, as well as a reduction in the degree of myelination of specific brain regions. Other studies point to neurotransmitter abnormalities in infants with SIDS and fewer receptors or structural deficiencies within the arcuate nucleus, a nerve cell complex thought to be crucial to integrating cardiorespiratory and arousal responses.

Exposure to cigarette smoke has now emerged as one of the most important modifiable risk factors associated with SIDS. Infants exposed to cigarette smoke, both pre- and post-natally have as much as a 5-fold elevated risk of SIDS.

Reducing the Risk of SIDS

While research has not uncovered the cause/s of SIDS, it has demonstrated infant care practices that can reduce the risk of SIDS. In 1994, the National Institute of Child Health and Human Development (NICHD) in partnership with the American Academy of Pediatrics (AAP), the SIDS Alliance, and the Association of SIDS and Infant Mortality Programs (ASIP) launched a national campaign to promote several risk reduction practices including placing babies on their backs for sleep. Since the inception of
this initiative, called the *Back to Sleep* campaign, the rate of SIDS has dropped almost 50% nationally as well as in Minnesota.

The recommendations of the *Back to Sleep* campaign are:

- Always place a baby to sleep on his or her back—even at naptime.
- Don't smoke around a baby.
- Don't smoke if you're pregnant.
- Place a baby on a firm mattress, such as in a safety-approved crib.
- Remove soft, fluffy bedding and stuffed toys from a baby's sleep areas.
- Keep blankets and other coverings away from a baby's nose and mouth.
- Don't put too many layers of clothing or blankets on a baby.
- Make sure everyone who cares for a baby knows that infants should be placed to sleep on their backs and the other ways to reduce SIDS risk.

In addition, research has suggested that certain sleep environments, including a long held practice of adult-infant bedsharing may, in some cases, be unsafe for infants. While the rate of SIDS has declined significantly since the *Back to Sleep* campaign, studies from the Consumer Product Safety Commission and others have suggested that the number of reported deaths of infants who suffocated on sleep surfaces other than those designed for infants are increasing. These preventable causes of death are reflected in such things as entrapment or wedging of an infant, overlying (head or body covered by part or all of another person's body), face or head covered by bedding such as comforters, pillows, blankets etc.

As a result, additional recommendations by the AAP and NICHD to promote a safe sleep environment for infants advise:

- that infants should not be put to sleep on waterbeds, sofas, soft mattresses or other soft surfaces,
- as an alternative to bedsharing, parents should consider placing the infant's crib near their bed,
- parents should never bedshare if they smoke or use medications or drugs that impair arousal from sleep.
SIDS in Minnesota

Data confirm that the SIDS’ characteristics i.e., peak age, incidence etc. described in the medical literature is reflected in the Minnesota population as well.

Most importantly, since the beginning of the Back to Sleep campaign in 1994, the Minnesota SIDS incidence has declined from 1.5 deaths per 1,000 live births in 1990 to 0.35 deaths per 1,000 live births in 2002. This decrease in SIDS accounts in part for the significant overall decline in infant mortality in Minnesota from 7.3 per 1,000 live births in 1990 to 5.3 per 1,000 live births in 2002.

The Minnesota Department of Health (MDH) allocates federal Title V monies to fund in part the Minnesota Sudden Infant Death Center (MN SID Center) of Children’s Hospitals and Clinics. This contract charges the MN SID Center to identify cases of SIDS and other sudden infant deaths in the state, to provide information and counseling to bereaved families, to educate professionals and communities about infant mortality and risk reduction practices, and to participate in research.

This public-private partnership has contributed to positive changes in Minnesota through the:

- support, information and counseling bereaved families receive following the sudden death of an infant,
- information gained about causes of infant mortality and trends in Minnesota,
- aggressive promotion of SIDS Risk reduction messages to the public as well as health and human service professionals via a variety of strategies and outreach activities.

Diagnosis

The 1989 Minnesota Legislature mandated the MDH to develop Infant Death Investigation Guidelines to facilitate the uniform investigation and determination of causes of death for sudden, unexplained infant deaths (deaths under two years of age) throughout the state (Minnesota Statute 145.898). In 1990, MDH established an interdisciplinary ad hoc Committee on Infant Death to advise on the contents of the guidelines.

This committee includes experts representing medical examiners and coroners, law enforcement, emergency medical services, pathology, SIDS, as well as bereavement and culture. These guidelines have been revised periodically with the most recent revisions being completed in 2002.

The cornerstone of the diagnosis of SIDS includes assessing the infant and family medical history, examining the death scene, and a thorough autopsy. It used to be felt that a detailed investigation of the death scene was considered too intrusive for the parents at a time of shock and grief. Investigators and counseling professionals have found that many families want a full investigation not only for themselves but to also help future families from suffering these tragic losses, if possible.

Part of the decrease in the rate of SIDS has been the result of reclassifying some unexpected deaths, as other contributing environmental factors are identified in the postmortem process.

Research

Research activities in Minnesota have made significant contributions to the body of knowledge about SIDS and have had impact on the health care of infants and families not only in Minnesota but also nationally. Three examples of this follow:

1. Having additional data available post-mortem has expanded an understanding of the differential diagnosis of sudden, unexpected infant death. There are several cardiac conditions that can
contribute to sudden infant death. One factor is Long QT Syndrome, which may account for as many as 2% of sudden, unexpected infant deaths as reported by studies being done by Mayo Clinic and others.

2. Other disorders that present as sudden death include genetic defects that influence fatty acid beta-oxidation, such as medium-chain acyl-CoA dehydrogenase (MCAD) deficiency. An estimated 25% of children with MCAD deficiency are not identified until sudden unexpected death. It is important to identify these children as early as possible since the preventative intervention is simple, straightforward and effective. Therefore in January 2001 MDH established population screening for MCAD as part of the expanded metabolic newborn screen.

3. Since the launch of the Back to Sleep campaign, products claiming to reduce or prevent SIDS have been marketed to consumers. In 2000, Pediatrics, the peer reviewed journal of the American Academy of Pediatrics, published a study of five such mattress products. This study was conducted by the MN SID Center, Children’s Hospitals and Clinics and St. Louis University School of Medicine. As a result of the study’s findings the Consumer Product Safety Commission took action against several manufacturers to stop distributing these products and to alter marketing on others.

Reducing the Risk
The partnership of the MDH and the MN SID Center at Children’s Hospitals and Clinics has contributed to the decline in SIDS in Minnesota by:

- identifying trends and public health strategies to address infant mortality,
- conducting proactive and aggressive public and professional education programs,
- collaborating with health institutions and public health and human service agencies,
- developing and widely distributing culturally appropriate risk reduction materials, and
- developing targeted materials or initiatives.

Several illustrations of this proactive public health approach follow:

The Minnesota SID Center has been tracking the rate of SIDS deaths in childcare settings. The Center participated in an 11-state study of SIDS in child care conducted by a researcher from Children’s National Medical Center in Washington DC. The results of the study, published in the August 2000 Pediatrics, identified Minnesota as having the highest rate of SIDS in childcare of the 11 states. In 2001, the Minnesota Legislature passed a regulation (Minnesota Statute Sec. 23. [245A.144]) requiring all licensed providers to be trained in SIDS risk reduction immediately and that retraining is required every 5 years. The MN SID Center developed and made available a SIDS Risk Reduction training curriculum and conducted trainings across the state.

Case data from 2002 indicate that only 3% of SIDS deaths occurred in licensed childcare settings as compared to 2001 and 2000 when 13% and 23% respectively occurred in licensed childcare settings. While one year does not define a trend or confirm the impact of training, this decline is the most dramatic decrease in SIDS in childcare in 20 years of data collection.

Another emerging issue reported nationally - the increase in the number of preventable sudden, unexpected infant deaths attributed to an unsafe sleep environment - has also been observed in Minnesota. The MDH-funded Project LID (Lower Infant Death), the infant mortality review project conducted by the Minneapolis Department of Health and the Saint Paul - Ramsey County Department of Public Health, identified 6 sudden infant deaths attributed to bedsharing in their random review of 1996-97 infant deaths. Furthermore, in 2001, 16 deaths reported to the MN SID Center were related to bed-
sharing, and 7 deaths were related to soft bedding or unsafe sleep environments. In 2002, 11 deaths reported to the MN SID Center were related to bedsharing and 6 were related to soft bedding or unsafe sleep environments.

To address this problem, the MDH consulted with the MN SID Center and sought advice from community-based organizations. As a result, in 2002, funding from the state’s infant mortality reduction initiative (IMRI) was used to develop the Infant Sleep Safety and Baby Bed Project. As a pilot project, 760 cribs were purchased and made available to public health agencies throughout the state for families in need. As public health nurses distributed cribs, they also provided education and informational materials on sleep safety. A brochure entitled Safety Tips for Bedsharing with Your Baby was developed and has been broadly distributed. While the crib distribution was a pilot and time limited, the Infant Sleep Safety materials continue to be available and widely used by public health agencies, hospital nurseries and parent educators. The Infant Sleep Safety and Baby Bed project was presented as a model program described in the Fall 2003 publication of the National Center on Child Fatality Review.

Decreasing racial and ethnic disparity in infant mortality is an objective of the national Healthy People 2010 agenda as well as the Healthy Minnesotans: Public Health Improvement Goals 2004. To address these disparities, the Minnesota SID Center with the support of MDH, works closely with Twin Cities Healthy Start and faith-based organizations to train home visitors about safe infant sleep practices and provides culturally appropriate risk reduction materials. Through community health fairs, participation in “baby showers” and community celebrations, the risk reduction messages are taken to diverse communities in a variety of ways.

While much has been accomplished more needs to be done. Families who experience the sudden death of an infant must receive support, counseling and information to help them cope with this devastating loss in as healthy a way as possible. Emerging issues about modifiable risk factors that contribute to sudden death in infants need to be identified and monitored. The risk reduction messages of the Back to Sleep campaign which have been successful must continue to be reinforced and disseminated.

Future actions to be considered include such things as:

- Promoting aggressive public and professional education about safe infant sleep environment including the potential hazards of bedsharing;
- Training hospital newborn nursery staff to follow Back to Sleep recommendations to model best practice for new parents;
- Engaging grandparents who care for grandchildren to support and follow safe sleep practices that may be different from their parenting practices;
- Educating foster parents in risk reduction infant care practices;
- Ongoing training of new child care providers about safe infant care practices;
- Encouraging targeted preconception and prenatal smoking cessation programs.
References

For additional information and references, see http://emedicine.com/PED/topic2171.htm


Appendices

Minnesota Statutes 2004, Table of Chapters

- 144.07 Powers of commissioner.
- 245A.144 Reduction of risk of sudden infant death syndrome in child care programs.
- 145.898 Sudden infant death.

Graph of Minnesota SIDS Incidence, 1986-2002

Graph of Minnesota SIDS Incidence in Child Care, 1994-2002

Resources

- *Minnesota Sudden Infant Death Center* Brochure
- Minnesota Sudden Infant Death Center Newsletter
- *Safe Sleep for Your Baby* Brochure
- *Safety Tips for Bedsharing with Your Baby* Brochure
- How to Reduce the Risk for Sudden Infant Death Syndrome: What Parents Can Do
144.07 Powers of commissioner.

The commissioner may:

(1) make all reasonable rules necessary to carry into effect the provisions of this section and sections 144.06 and 144.09, and may amend, alter, or repeal such rules;

(2) accept private gifts for the purpose of carrying out the provisions of those sections;

(3) cooperate with agencies, whether city, state, federal, or private, which carry on work for maternal and infant hygiene;

(4) make investigations and recommendations for the purpose of improving maternity care;

(5) promote programs and services available in Minnesota for parents and families of victims of sudden infant death syndrome; and

(6) collect and report to the legislature the most current information regarding the frequency and causes of sudden infant death syndrome.

The commissioner shall include in the report to the legislature a statement of the operation of those sections.

HIST: (5343) 1921 c 392 s 4; 1977 c 305 s 45; 1984 c 637 s 1; 1985 c 248 s 70; 1986 c 444

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245A.144 Reduction of risk of sudden infant death syndrome in child care programs.

License holders must ensure that before staff persons, caregivers, and helpers assist in the care of infants, they receive training on reducing the risk of sudden infant death syndrome. The training on reducing the risk of sudden infant death syndrome may be provided as orientation training under Minnesota Rules, part 9503.0035, subpart 1, as initial training under Minnesota Rules, part 9502.0385, subpart 2, as in-service training under Minnesota Rules, part 9503.0035, subpart 4, or as ongoing training under Minnesota Rules, part 9502.0385, subpart 3. Training required under this section must be at least one hour in length and must be completed at least once every five years. At a minimum, the training must address the risk factors related to sudden infant death syndrome, means of reducing the risk of sudden infant death syndrome in child care, and license holder communication with parents regarding reducing the risk of sudden infant death syndrome. Training for family and group family child care providers must be approved by the county licensing agency according to Minnesota Rules, part 9502.0385.

HIST: 1Sp2001 c 9 art 14 s 23; 2002 c 375 art 1 s 16; 2002 c 379 art 1 s 113

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145.898 Sudden infant death.

The Department of Health shall develop uniform investigative guidelines and protocols for coroners and medical examiners conducting death investigations and autopsies of children under two years of age.

HIST: 1989 c 282 art 2 s 36
Minnesota SIDS Incidence

Deaths/1000 Live Births

Minnesota SIDS Incidence

Minnesota SID Center Data
The Minnesota Sudden Infant Death Center is available for information guidance and support. The Center directs a statewide information and counseling network. It is dedicated to supporting all those who experience the sudden death of an infant by providing counseling, broad-based education and information.

The goals of the center are to:
1. Identify SIDS cases in Minnesota
2. Reach out with information and support to bereaved families
3. Educate professionals and the public about sudden unexpected infant death
4. Participate in research

The Center coordinates an extensive statewide consultation and information network so local resources are better equipped to serve families.

Services
- Support groups
- Contact with other parents, grandparents and child care providers affected by sudden unexpected infant death
- Referral to trained public health nurses
- Counseling
- Physician consult
- Quarterly newsletter
- Education programs and materials

Concerned community members, family physicians, funeral directors, nurses and friends can refer individuals and families to the Minnesota Sudden Infant Death Center.

For information or assistance please contact:

Minnesota Sudden Infant Death Center
Children's Hospitals and Clinics
2525 Chicago Avenue South
Minneapolis, MN 55404
(612) 813-6285
1-800-732-3812 (toll-free)
FAX (612) 813-7344

A seemingly normal healthy infant dies suddenly and unexpectedly. The baby is a victim of Sudden Infant Death Syndrome (SIDS), sometimes called “crib death.” Each year, an estimated 3,000 babies in the U.S. die of SIDS—50 of them in Minnesota. The death of a child is the most painful loss a family can experience. When the child is an apparently healthy infant, the tragedy leaves family members with intense feelings of shock, grief and guilt. They are victims of SIDS as well.

The Minnesota Sudden Infant Death Center is funded in part by a grant from the Minnesota Department of Health, Division of Maternal/Child Health, and by private donations.
Because a SIDS death is unexpected and tragic, the grief of surviving family members is intense and painful.

Parents. Many parents experience guilt, anger, fear, shock, denial and depression. Their suffering is a very personal experience and can appear in many different ways. To all parents, though, the loss of their baby is devastating.

Children. Other children in the family are also deeply affected by the death. Their mourning will be as individual as that of their parents. If very young, these brothers and sisters may express their feelings through actions and play rather than talking. They may develop physical symptoms or regress to less mature behavior. Older children are more prone to the development of problems in the school setting, or they may suddenly develop extreme fears. Like their parents, the children's reactions can include anger, guilt, anxiety and great sadness. All these feelings are normal.

Many others. Often, the death touches family, friends, neighbors, co-workers and relatives as well. The grandparents' grief, especially, may be intensified by the grief for their own child as well as the loss of a grandchild. Occasionally a SIDS death may occur while the infant is in the care of a child care provider. They, too, are significantly affected by the death.

SIDS is often misunderstood partially because its cause is still unclear. Research has proven many long-standing beliefs about SIDS to be false. This research shows that SIDS is not:

- predictable
- contagious
- suffocation or smothering
- caused by choking or vomiting
- caused by immunizations/baby shots
- caused by allergies
- caused by abuse or neglect
- related to how or what an infant eats

For more information or assistance, call the Minnesota Sudden Infant Death Center at 612-813-6285 or toll-free 1-800-732-3812.
Annual Meeting 2003

On Saturday November 8 please join us for this year’s annual statewide family meeting at the Minnesota Landscape Arboretum in Chanhassen. Hosted by the Minnesota SID Center, this is a day for those who have experienced the sudden death of an infant or young child from any cause. Bereaved parents, grandparents, extended family, friends and child care providers can come together for a time of education, fellowship and support. The Arboretum offers a comforting setting amidst beautiful grounds. The eeting center includes a fireplace, conservatory and warm, friendly sitting rooms which lend themselves to a comfortable and welcoming atmosphere. Registration begins at 9:30 am with the opening session at 10:00 a.m.

We are pleased to welcome Patsy Neary Keech, M.A. as this year’s keynote speaker. A bereaved parent herself, Patsy has intimate knowledge of the grief journey parents experience. Patsy’s son, Derian died at the age of 2 1/2 years following multiple surgeries to manage a syndrome called C.H.A.R.G.E which affects eyes, ears, heart, nose, as well as physical and mental development. Author of the book *Mothering an Angel… A Story of Love, Loss, and Rediscovery*, it sy tells of her life with Derian, her journey with grief and the miracles that led her and her husband, Robb, to create the non-profit Spare Key Foundation to help provide mortgage payments for Minnesota parents with critically ill children.

Patsy was a professional teacher who taught for thirteen years. During her teaching career, she looked for the teachable moments in each day. It was because of this approach that she was nominated for Teacher of the Year at the middle school where she taught.

2000, Patsy and her husband Robb appeared on *Oprah* where they received an Angel Network “Use Your Life” award for drawing on their experience to create the Spare Key Foundation. A follow up *Oprah* story was done in 2001. At the same year the Keeches were nominated for a CNN National Heroes Segment for their work with Spare Key.

Ceremonies from Keech’s book, *Mothering An Angel…*, have been included in both *Chicken Soup for the Couple’s Soul*, and *Chicken Soup for the Volunteer Soul*. Patsy has appeared on many local TV and

(Annual Meeting 2003 continued on page 4)

Details, map, and mail-in registration form for the annual meeting are on page 7. Please complete the form and return it to the Minnesota SID Center by Wednesday, October 29.
Establishing a SIDS diagnosis requires excluding other recognizable causes of sudden unexpected death in infancy (SUDI). SIDS remains the single leading cause of death among categories of unexpected deaths in infancy. However, since the beginning of the Back to Sleep campaign in 1994, the incidence of SIDS has declined in Minnesota from 2.3 deaths per 1,000 live births in 1986 to 0.52 deaths in 2000. Nationwide, The National Center for Health Statistics reported that the SIDS rate for 1998 was 0.72 per 1000 live births.

As many as 15-20% of sudden, unexpected infant deaths, however, will be explained by acute infections, congenital malformations or metabolic abnormalities. Part of the decrease in the rate of SIDS has been the result of reclassifying some unexpected deaths, as other contributing environmental factors are identified in the postmortem process.

SIDS likely represents an intersection of factors related to the infant and its environment. Infants vulnerable to SIDS likely possess developmental abnormalities in heart and respiratory rate control and arousal mechanisms. Environmental stresses encountered in early infancy may result in a "short-circuiting" of normal “defense” or arousal mechanisms resulting in sudden death. Several structural and functional nerve cell abnormalities have been identified in SIDS infants, which may increase risk for sudden infant death. Some studies have shown evidence that suggests delayed development of the brain stem, as well as a reduction in the degree of myelination of specific brain regions. Other studies point to neurotransmitter abnormalities in the brain of infants with SIDS and fewer receptors or structural deficiencies within the arcuate nucleus, a nerve cell complex thought to be crucial to integrating cardiorespiratory and arousal responses.

Sleep position and SIDS incidence

Rebreathing of carbon dioxide happens more frequently in infants who tummy sleep; with one sleep study showing that two-month-old infants tummy sleeping on a soft surface may spend as much as 33 percent of sleep time with face straight down on the bed. Some of the initial resistance of parents to place their child in the back position came from observations, later confirmed during sleep studies, that babies seem to sleep more soundly when placed on their tummies. There have been several sleep studies that show distinct differences between the tummy and back sleep positions. Infants who sleep on their tummies experience more quiet sleep, have fewer arousals and require more stimulation to become aroused. However, these sleep position factors may disadvantage normal arousal mechanisms. Tummy sleeping also may result in temperature stresses for the infant.

Exposure to cigarette smoke has now emerged as one of the most important modifiable risk factors associated with SIDS. Infants exposed to cigarette smoke, both pre- and post-natally have as much as a 5-fold elevated risk of SIDS.

Questions sometimes arise about the role of cardiorespiratory monitors in "at-risk" infants. These infants may include the healthy subsequent siblings of prior SIDS victims or premature infants. Studies have shown that monitors will not "prevent" SIDS and the use of monitors is best reserved for those with documented abnormalities of cardiorespiratory control.

Unraveling the mystery of SIDS

The cornerstone of the diagnosis of SIDS includes assessing the infant and family medical history, examining the death scene and a thorough autopsy. It used to be felt that a detailed investigation of the death scene was considered too intrusive for the parents at a time of shock and grief. Investigators and counseling professionals have found that many families war a full investigation not only for themselves but to also help future families from suffering these tragic losses, if possible. The staff of the Minnesota SIDS Center have participated in the development of state and federal guidelines for infant death scene investigation as well as for the autops examination so that this information is obtained in a way that is sensitive to the bereavement needs of families.

Having additional data available post-mortem has expanded an understanding of the differential diagnosis of sudden unexpected infant death. There are several cardiac conditions that can contribute to sudden infant death. One factor is the Long QT Syndrome, which may account for as many as 2% of sudden, unexpected infant deaths. Other disorders that present as sudden death include genetic defects that influence fatty acid beta-oxidation, such as medium-chain acyl-CoA dehydrogenase (MCAD) deficiency. An estimated 25 percent of children with MCAD deficiency are not identified until sudden unexpected death. Population screening for MCAD now part of the expanded metabolic newborn screen.

SIDS and ALTE

Research has shown that there is a lack of association between an infant having a history of an Apparent Life Threatening Event (ALTE) and SIDS. For this reason, ALTE’s should not be considered as near-miss SIDS events. ALTE’s are defined as an episode that is frightening to the observer and includes some combination of marked changes in color, oxygenation, muscle tone and gagging or choking. The risk of SIDS in infants that experienced an ALTE is 1 to 2 percent. The risk of mortality increases to 4 percent if the ALTE is associated with RSV and increases to 8-10 percent if the ALTE occurs during sleep or required CPR intervention. Overall, about percent of infants who die of SIDS have a history of an ALTE. Further prospective population-based studies are needed to examine this association in further detail. About half of infants who have an ALTE have a recognizable disorder which when treated, reduces their risk of sudden death. The main causes of ALTE include apnea of infancy, gastroesophageal reflux disease, RSV bronchiolitis, pertussis, sepsis/meningitis, seizure, and pallid/cyanotic breath-hold spells. Less common causes include cardiac dysrythmia (lor QT syndrome), anemia, structural CNS, and cardiac or airway anomaly.

This article is reprinted in part from Inform, Vol.9 #1, Spring 2003, the professional staff newsletter of Children's Hospitals and Clinics.
Grief Memoirs
By Patsy Neary Keech

Derian's Third Birthday
Dear Derian,

There are no balloons,
no invitations were sent.
Guest are not lined up outside the door.
A few cards will be in the mail.

What does one say to a mother on
the day her child was born, when you’re dead?
His was such a life-changing day for me.
Life will never, and can never be the way
it was when you were here.
My first born-stolen from my arms, before
you outgrew them.
Will not ponder the what if’s, only what
was.

I have to be honest and tell you the
well in my soul has dried up,
the laughs that used to send me rolling,
have quieted.
I carefree worries I would love to
have, are another world away.
Our birthday pierces my heart,
or it was too short of a hello,
ever ending good-bye.

Winter
The winds of grief
last a raw chill
the quick of my being.
I am bare and vulnerable
A tree in the middle of a wicked winter storm,
tree on the open plain.

Nothing protects me,
can cushion the rawness.
My tears freeze,
casing me in a sorrow so deep
The roots of my being
Ach and uproot from the soil
At once harbored me.

Am looking for a new place to grow.
searching for a new soil that will transplant the loss of
you.

Nothing can replace you.
But something needs to nourish the loss.
The soil becomes life-giving through decay and death.
Will I too?
Will I grow to be a stronger, more beautiful being?
Will I take this loss
And better the world around me?
Will I bear fruit again?
Help me take these withered roots and find a new place to
grow.

Five Months
Five months ago,
I said good-bye to you.

I miss you,
and I think of you,
at least five times a day.

A Mountain Before Me
A mountain erupted in the pathway of
My life.
It’s huge and frightfully wide.
I have a choice as to how I will deal with
this mountain.
It can stand before me,
and I can set up my camp beneath its
large shadows.

OR,
I can decide to tackle this obstacle.
I cannot move the mountain but I can walk around it, even
if it takes years.
I can dig underneat it if I use the correct tools
Or, perhaps I slowly and deliberately climb over it.

It is with great determination and good planning that I
begin to journey onward.
I realize this will not be an easy task.
I will know every nook and cranny of this mountain.
I will touch all of its solidness,
I will taste the wetness of its snow and rain,
I will cleanse myself with freshness of new air as I reach
higher ground.

But, I WILL PASS
And once I do,
I will turn my head and gaze
as the sun slowly sets over my mountain.
It will be then that I will marvel at its greatness
And the strength I received from climbing over it.
It is with this newfound strength
That I will face the mountains that will erupt on my path
From now on.
International Children's Memorial Day...
that their light may always shine

December 14, 2003 is the date for the seventh annual international candle lighting by those who have experienced the death of a child. This international commemoration begins at 7 p.m. in each time zone when parents all over the country are invited to light a candle in memory of their child. A wave of light will encircle the earth marking the 24 hours of the day. Designated National Children's Memorial Day, this event is organized in the United States by The Compassionate Friends.

In promoting the significance of such the day, supporters state that "by establishing a day to remember children that have passed away, bereaved families from all over the country will be encouraged and supported in the positive resolution of their grief. It is important to families who have suffered such a loss to know they are not alone. To commemorate the lives of these children with a special day would pay them honor and would help to bring comfort to the hearts of their bereaved families."

Winter Newsletter Deadline
October 20, 2003

PLEASE NOTE: If you would like to have your name taken off the SID Center mailing list, notify the Center at (612) 813-6285 or 1-800-732-3812.

We welcome letters, poems and pictures from parents, grandparents, relatives, childcare providers and friends. Because of space limitations, we must sometimes edit these submissions. The editors attempt to give as many parents as possible the opportunity to share memories of their children.
Place your baby on his or her stomach for "tummy time" when he or she is awake, and someone is watching. This helps your baby's neck and shoulder muscles get stronger.

Minnesota Sudden Infant Death Center
Children's Hospitals and Clinics
2525 Chicago Avenue South
Minneapolis, MN 55404
612-813-6285 or 1-800-732-3812
FAX: 612-813-7344

Back to Sleep campaign sponsors include:
National Institute of Child Health and Human Development
Maternal and Child Health Bureau
American Academy of Pediatrics • SIDS Alliance
Association of SIDS and Infant Mortality Programs

National Institute of Child Health and Human Development
NIH Pub. No. 02-7040
August 2003

U.S. Department of Health and Human Services
National Institutes of Health
What is SIDS?
SIDS stands for Sudden Infant Death Syndrome. It is the sudden and unexplained death of a baby under 1 year of age.

Because many SIDS babies are found in their cribs, some people call SIDS “crib death.” But, cribs do not cause SIDS.

Facts About SIDS
Doctors and nurses do not know what causes SIDS, but they do know:

- **SIDS is the leading cause of death in babies after 1 month of age to 1 year of age.**
- Most SIDS deaths happen in babies under 6 months old.
- Babies placed to sleep on their stomachs are much more likely to die of SIDS than babies placed on their backs to sleep.
- Babies are more likely to die of SIDS if they are placed to sleep on top of soft bedding or if they are covered by soft bedding.
- African American babies are 2 times more likely to die of SIDS than white babies.
- American Indian babies are almost 3 times more likely to die of SIDS than white babies.

Even though there is no way to know which babies might die of SIDS, there are some things that you can do to make your baby safer.

What Can I Do to Help Lower the Risk of SIDS?

**Always place your baby on his or her Back to Sleep, even for naps.**
This is the safest sleep position for a healthy baby to reduce the risk of SIDS.

**Place your baby on a firm mattress, such as in a safety-approved crib.**
Research has shown that placing a baby to sleep on soft mattresses, sofas, sofa cushions, waterbeds, sheepskins, or other soft surfaces greatly increases the risk of SIDS.

*For more information on crib safety guidelines, call the Consumer Product Safety Commission at 1-800-638-2772 or visit their website at www.cpsc.gov.*
Remove soft, fluffy and loose bedding and stuffed toys from your baby's sleep area.
Make sure you keep all pillows, quilts, stuffed toys, and other soft items away from your baby's sleep area.

Make sure everyone who cares for your baby knows to place your baby on his or her back to sleep and about the dangers of soft bedding.
Talk to childcare providers, grandparents, babysitters and all caregivers about SIDS risk. Remember, every sleep time counts. So, for the least risk, remind every caregiver to place your baby on his or her back to sleep on firm bedding at both nighttime and naptime.

Make sure your baby's face and head stay uncovered during sleep.
Keep blankets and other coverings away from your baby's mouth and nose. The best way to do this is to dress your baby in sleep clothing so you will not have to use any other covering over the baby. If you do use a blanket or another covering, make sure that the baby's feet are at the bottom of the crib, the blanket is no higher than the baby's chest, and the blanket is tucked in around the bottom of the crib mattress.

Do not allow smoking around your baby.
Don't smoke before or after the birth of your baby and make sure no one smokes around your baby.

Don't let your baby get too warm during sleep.
Keep your baby warm during sleep, but not too warm. Your baby's room should be at a temperature that is comfortable for an adult. Too many layers of clothing or blankets can overheat your baby.

Babies Sleep Safest on Their Backs.
One of the easiest ways to lower the risk of SIDS is to put your baby on his or her Back to Sleep, even for naps. Until a few several years ago, doctors told mothers to place babies on their stomachs to sleep. Research now shows that fewer babies die of SIDS when they sleep on their backs.

If you use a blanket, place the baby with his or her feet at the foot of the crib. The blanket should reach no higher than the baby's chest and the ends of the blanket should be tucked under the crib mattress.
Frequently Asked Questions

Q. Is there a risk of choking when my baby sleeps on his or her back?
A. No, babies automatically swallow or cough up fluids. Doctors have found no increase in choking or other problems in babies sleeping on their backs.

Q. What about side sleeping?
A. To keep your baby safest when he or she is sleeping, always use the back sleep position rather than the side position. Babies who sleep on their sides can roll onto their stomachs. A baby sleeping on his or her stomach is at greater risk of SIDS.

Some infants may have health conditions that require them to sleep on their stomachs.

If you are unsure about the best sleep position for your baby, be sure to talk to your doctor or nurse.

Some products claim to be designed to keep a baby in one position. These products have not been tested for safety and are NOT recommended.

Q. Are there times when my baby can be on his or her stomach?
A. Yes, place your baby on his or her stomach for “tummy time,” when he or she is awake and someone is watching. When the baby is awake, tummy time is good because it helps your baby’s neck and shoulder muscles get stronger.

Q. Can I bring my baby in bed with me to breastfeed?
A. Bringing your baby into bed could be risky for your baby. An adult bed usually has a soft mattress and bedding such as comforters, quilts, and pillows. If you choose to bring your baby in bed with you to breastfeed, it is safest to return your baby to his or her crib.** One way to keep your baby close to you is by having the baby’s crib in the room with you.

**If you do not have a crib, check with your state health department about a crib donation program.

Q. Can my baby share a bed with her brother or sister?
A. Bed-sharing with other children, including brothers and sisters is unsafe for your baby. It increases the risk for SIDS as well as suffocation. There have been reports of infants being suffocated from overlying by an adult, brother, sister, or other family member that was sharing a bed with an infant.

Q. Will my baby get “flat spots” on his or her head from back sleeping?
A. For the most part, flat spots on the back of the baby’s head go away a few months after the baby learns to sit up. Tummy time, when your baby is awake, is one way to reduce flat spots. Another way is to change the direction you place your baby down to sleep. Doing this means the baby is not always sleeping on the same side of his or her head. If you think your baby has a more serious problem, talk to your doctor or nurse.

Enjoy Your Baby!
In Association With:

Minnesota Sudden Infant Death Center
Children’s Hospitals and Clinics
2525 Chicago Ave. South
Minneapolis, MN 55404
phone: 612-813-6285
toll free: 1-800-732-3812

References:


Babies have died accidentally from suffocation, smothering, or being trapped under someone or in bedding while sleeping in the same bed with adults or other children.

If you share the same bed with your baby, here are some safety tips:

Always place baby on his or her back to sleep.
- This makes sure that your baby can breathe better while sleeping and helps to protect the baby from Sudden Infant Death Syndrome (SIDS).

Make sure baby sleeps on a mattress that is firm.
- A baby's head and face can get stuck in soft furniture (such as a sofa, waterbed, or recliner) or in a sagging, soft mattress. The baby may not be able to breathe.

Babies need lots of air to breathe.
- Stuffed toys, pillows, heavy blankets, quilts and fluffy comforters can block your baby's breathing.

Keep baby away from smoke.
- Don't let anyone smoke anything around your baby.
- Babies who breathe smoke or who sleep with parents who smoke have a greater risk of SIDS.

When sleeping with your baby, be sure he doesn't get too warm.
- Getting too warm puts the baby at more risk of SIDS.

Consider having baby sleep in his own crib next to your bed.

Prevent your baby from getting trapped in small spaces:
- Don't place your baby on a mattress pushed up against the wall—baby can get trapped between the wall and the mattress.
- Check that there are no spaces where your baby could scoot, crawl, roll or fall between the mattress and bed frame.
- Don't use bed rails on adult beds.
- Don't put your baby to sleep alone in an adult bed.

Prevent your baby from getting trapped under a sleeping parent or an older child:
- Don't sleep with your baby if you have taken medicine that makes you drowsy.
- Don't sleep with your baby if you are overly tired or a heavy sleeper.
- Don't sleep with your baby if you have been drinking alcohol, smoking marijuana, or are high.
- Don't let a child sleep with your baby.
- Pull back long hair in a braid or ponytail when sleeping with your baby.
How to Reduce the Risk of Sudden Infant Death Syndrome (SIDS): What Can Parents Do?

Recently, the media has reported several stories on Sudden Infant Death Syndrome (SIDS), such as: SIDS deaths that occur in child care, dangers of soft bedding, babies with flat heads from too much time on their backs..... It may be both confusing and upsetting for parents. One of the most frightening thoughts new parents may have is that their healthy baby could die unexpectedly while sleeping.

*Back To Sleep is good news for parents:* The *Back To Sleep* campaign began in this country in 1994 to promote the message that babies should sleep on their backs, not on their stomachs, to reduce the risk of SIDS. Since then, the number of babies dying from SIDS has decreased by more than 40 per cent.

*Here is what parents can do to reduce the risk that their baby will die of SIDS:*
- Place healthy babies on their backs to sleep.
- Use a firm mattress in a safe crib.
- Remove all heavy blankets, fluffy comforters, pillows, and stuffed animals from the baby’s sleeping space. Don’t place the baby on a waterbed, bean bag cushion, or sheepskin pad.
- Avoid overdressing or overheating the baby.
- Do not allow smoking around the baby.
- Keep baby’s well child check ups and immunizations on schedule.

*SIDS risk reduction can begin before birth:*
- Women should begin prenatal care early in pregnancy—during the first three months— and continue regular care throughout the pregnancy.
- Do not use drugs, alcohol or tobacco while pregnant.
- Plan to breastfeed.

Recent research reports that babies who normally sleep on their backs are at much greater risk of SIDS if someone places them on their tummy for sleep for the first time. Researchers believe that back sleepers do not learn to raise their heads and turn them from side to side and may end up in the face down position during sleep. *It is very important that parents insist that everyone who cares for their baby use the Back To Sleep position. Parents should discuss Back To Sleep with child care providers, relatives, babysitters, friends, and neighbors!*

*Frequently Asked Questions:*
*At what age does SIDS usually occur?* Most SIDS deaths occur between one month and one year of age. The highest risk period for SIDS is between two and four months. That is why it is so important for parents not to switch their baby from back to tummy sleeping and to make sure child care providers don’t switch either. When the baby is old enough to roll from back to tummy or tummy to back easily on his own, usually at six months or older, the risk of SIDS is greatly reduced.
If I follow these recommendations, can I be sure that my baby won’t die of SIDS?
Unfortunately, the answer is no, SIDS sometimes occurs even when all recommendations are followed. Research is continuing to determine the exact cause of SIDS so that screening and prevention may be possible in the future. Parents should remember, though, that SIDS has always been a rare event and, since Back To Sleep, it is even more rare.

What about side sleeping? Side sleeping is not recommended because it is not a stable position for babies. They often roll to their tummy from the side position. Babies should not be propped or wedged in the side position. Devices used to wedge babies in this position have not been tested for safety. Pillows or rolled up blankets used to prop babies on their sides pose a risk of covering the baby’s face when she moves around during sleep.

What about vomiting and choking? The American Academy of Pediatrics has found no evidence that babies sleeping on their backs are in any greater danger of choking even if they vomit.

What about flat or misshapen heads? Newborn’s skulls are soft to allow the growing brain to expand. If a baby spends all his time on his back either in an infant carrier, swing or bed, he may develop a flat spot or a “favorite position”. Parents and other caregivers should rotate the baby’s sleeping position so he doesn’t always face in the same direction. Babies should not spend too much time in carriers that keep their weight on the back of their heads. Infant carriers worn by parents are a better option: the baby will be upright with no weight on his head. He will also be strengthening his neck muscles as he is carried. When babies are awake and supervised, they should spend daily time on their tummy. Tummy time promotes neck and shoulder strength and helps the baby develop the ability to roll over and crawl.

But what if my baby doesn’t sleep well on her back? Most babies will prefer the position they got used to in the early days of life. However, some parents report that their babies don’t sleep very soundly on their backs. They may startle easily and wake up frequently. Researchers have identified that these are healthy components of normal infant sleep. Parents are encouraged to talk about sleep concerns with their health care providers.

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