



Iowa SIDS Foundation

Support

Education

Hope

Volume 14, Issue 3

Fall 2005

From My Perspective

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I remember many of the comments and advice I received after the death of my first-born child. Some comments hurt deeply; some were filled with words of wisdom that I did not believe were true until much time had passed; other words I clung to in order to save myself from joining my son.

I can not place names or faces with any of the words I remember being spoken to me. That fateful day, the next week and much of the month are a blur of bad memories. It is a time I would much rather have forgotten. I never have.

One phrase that saved me was spoken by, I think, an older woman from our church. She approached me at the funeral and said, "Heaven could not be Heaven without the babies. Think what Heaven would be like if it was filled only with old people."

Even though that phrase was one that saved my life, that phrase was not the first I spoke when I tried to console my sister when she was in the same situation a little over a year later. "Time heals," or words to that effect, were the words I spoke.

I was told those words over and over again by many people. None of those people could convince me that any amount of time would remove the numbness from my brain and the needles from my heart. I believed I would continue to feel that heart-wrenching pain for the rest of my life. But life did go on and the pain subsided and became bearable most of the time. There are days when it all comes back to me—but never at the same intensity of the initial experience.

I had to go through a grieving process to get over the initial shock and despair. The process had many stages, and as each stage passed, a new one began—a milestone of sorts. The milestones were not marked by calendar days, instead they were marked by happenings, like the first day I realized I forgot to cry for the one I lost or when I no longer bargained with God to trade me or my husband or anyone else for my child. Some milestones took only weeks for me to get to; others I struggled to pass and did within a few months; still others took years for me to finally lay them to rest. It took me about two weeks after my son's death before I could bear to be home alone and after about six months my arms no longer physically ached to hold my son, but it took me nine years to go to work on the day of his birthday.

My life did continue and eventually I healed. But, just as if I had received a deep cut, I was left with a scar. It is a scar that will always be a part of me. It has changed my appearance and outlook on life. Scars are what is left after the healing process is finished, and, like many scars that are covered by clothes, mine is also covered—exposed only to those I want to see it. Even though I despise the scar and wish I had

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From My Perspective

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never been subjected to the pain that caused it, I have since realized it is just another part of my life and has shaped who I am today. Now, after more than twenty-five years, I do not say I would trade everything I have for my son, like I would have in the first few months after his death. Time Heals.

-Submitted by Mary Giffin

For my son, Kenneth Edward Giffin (2/8/80 – 4/29/80)
and
my niece, Melissa Sue Lemon (6/30/81 – 9/30/81)

*I was left with a scar.
It is a scar that will
always be a part of
me.*

*Scars are what is left
after the healing
process is finished.*

Research Update and Report from SIDS Conference

Iowa SIDS Foundation Board members, Jennifer Atzen, RN and SIDS parent, and Karen Doughan, Nurse Consultant, represented the Foundation at, “Together: Making a World of Difference- 2005 Conference”. This global meeting was a joint effort of First Candle/SIDS Alliance/International Stillbirth Alliance and convened in Arlington, Virginia, in September.

A safe sleep symposium reviewed the effectiveness of controlling environmental risks for infant sleep and examined how effective our risk reduction efforts have actually been. Researchers revealed that our latest measured USA SIDS death rate currently matches the 1950’s rates when all of the death review changes that have been implemented for collecting statistics during this timeframe were examined. Their data concluded that we may have reached a limit on how much we can reduce death rates via control of environmental factors.

Two particular research projects inspired us as conference participants, offering significant hope for impacting infant death rates in the future.

Dr Hannah Kinney, MD and her research team from Harvard School of Medicine and the Kinney Lab at Children’s Hospital, Boston, presented several sessions about neuropathology. They have focused on the subtle autonomic and respiratory dysfunction in SIDS associated

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New Arrivals:

Congratulations to the following families on their new additions:

Pacey Michael and Cheyanna Jo Lynn Dauen were born June 17, 2005 to Jennifer Newsom.



Colton Lee was born on December 27, 2003 to Melissa and Aaron Balvin.



William Allen was born on September 23, 2005 to Kori and Lee Cusick.



Is there a new little one at your house? If so, we would love to share your happiness. Please phone or mail all pertinent information or e-mail info@iowasids.org.

Research Update and Report from SIDS Conference

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Note: Darnall's research can be re-viewed in the *Journal of Neuroscience*. 2005 Sep 7; 25(36): 8322-32; Darnall RA, Harris MB, Gill WH, Hoffman JM, Brown JW, Niblock MM.
Or visit the web site: www.jneurosci.org

with serotonergic brainstem abnormalities. They have discovered evidence that the arcuate nucleus of the ventral surface of the medulla oblongata portion of the human infant brain is chemosensitive. They have hypothesized that serotonin receptors could be blocked, like other present medical interventions used for health concerns involving vital chemical and electrical production sites and their receptors. This new research had not been published at the time of the conference.

Dr Robert Darnall, MD (Department of Physiology, Dartmouth Medical School, Lebanon, New Hampshire) reviewed his recent research on young piglets. He and **Dr William Fifer, PhD** (Columbia University) reviewed their assessments of the autonomic function in the fetus and infant. Dr Darnall's team chose to experiment with piglets that match the age of children who die of SIDS most frequently, to utilize a living organism that would have similarly immature respiratory, circulatory and neurological systems. This work reviewed the inhibition of serotonergic neurons in the nucleus paragigantocellularis lateralis and how it fragments sleep by decreasing rapid eye movement, effecting muscular shivering, decreasing body temperature and heart rate, and impacting arousal levels during sleep in the piglet.

Researchers were able to intervene in synapse activity at the neuron in the brainstem of the piglets, using dialysis to change the chemical environment and resulting electrical impulse response to prove that serotonin levels did impact sleep levels. They conclude that neurons expressing 5-HT_{1A} autoreceptors in the juxtafacial PGCL are involved in regulating or modulating sleep and that abnormalities in the function of these neurons may alter sleep homeostasis and contribute to the etiology of SIDS.

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American Academy of Pediatrics Sleep Recommendations

The American Academy of Pediatrics (AAP) task force on Sudden Infant Death Syndrome recently released revised sleep and SIDS risk reduction recommendations:

[excerpted from:

The Changing Concept of Sudden Infant Death Syndrome: Diagnostic Coding Shifts, Controversies Regarding the Sleep Environment and New Variables to Consider in Reducing the Risk of SIDS]

1. Back to sleep. Infants should be placed for sleep in a supine position (wholly on the back) for every sleep. Side sleeping is not as safe as supine sleeping and is not advised.

2. Use a firm sleep surface. Soft materials or objects, such as pillows, quilts, comforters, or sheepskins, should not be placed under a sleeping infant. A firm crib mattress, covered by a sheet, is the recommended sleeping surface.

3. Keep soft objects and loose bedding out of the crib. Soft objects such as pillows, quilts, comforters, sheepskins, stuffed toys, and other soft objects should be kept out of an infant's sleeping environment. If bumper pads are used in cribs, they should be thin, firm, well secured, and not "pillow-like." In addition, loose bedding, such as blankets and sheets, may be hazardous. If blankets are to be used, they should be tucked in around the crib mattress so the infant's face is less likely to become covered by bedding. One strategy is to

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Walk for the Future 2005 Wrap-Up

The sixth annual Walk For The Future was held on Saturday, August 27 in Albia, Boone, Cedar Rapids, Keswick, the Quad Cities, Spirit Lake and West Des Moines. There were over 800 participants at the various locations. The event raised nearly \$54,000 of which over \$12,000 was from generous corporate donations. The following amounts were raised at the various locations the day of the walk:

Boone:	\$ 1,283	Quad Cities:	\$ 8,194
Cedar Rapids:	\$10,634	Spirit Lake:	\$ 1,929
Keswick:	\$ 4,664	West Des Moines:	\$ 7,907

Thanks to all of the participants and volunteers for making this event so successful.

Special thanks to the following walk organizers for their hard work:

Dawn Maughan in Albia, Tami Hartwig in Boone, Tricia Borelli and Jodi Greene in Cedar Rapids, Ann Danner in Keswick, Betsy VanDerSchaaf and Jenny Atzen in the Quad Cities, April Mueller in Spirit Lake, and Delaine and Gary Marker in West Des Moines...And to the many volunteers who faithfully gave their time, whether this was their first year or their sixth!

Please read our Memorials and Donations section on page 9 to recognize our kind corporate contributors.



Scholarships Available for February SIDS Conference

The CJ Foundation for SIDS will host *The Caring Connection: Caring Today with Hope for Tomorrow*, a 2006 national conference dedicated to bringing together professionals and families to address SIDS, SUDC and SUDI on February 23 through February 26, 2006 in Philadelphia, PA.

Limited scholarships toward the conference fee are available through the CJ Foundation for SIDS by contacting Jean Marie Bellotti, Program Coordinator at 888-8CJ-SIDS ext. 4 or jeanmarie@cjsids.com as soon as possible.

Limited additional scholarships are also available through the Iowa SIDS Foundation by contacting Ingrid at 866-480-4741 or email info@iowasids.org before January 15.

For more information about the conference, visit www.cjsids.com/2005_caring_connection_conference/2005_conference.htm, or call CJ Foundation for SIDS at 888-8CJ-SIDS.

Register and make hotel reservations by January 19 for reduced rates.

We hope you can join us in Philadelphia.

Gear Up for United Way



United Way

Many work places recently held their annual United Way campaign. The Iowa SIDS Foundation can be designated as the recipient of your United Way donation. If you participate in this campaign at your workplace, please consider designating the Iowa SIDS Foundation as an organization to receive your donation by writing in the organization name and address on your form.

We appreciate those of you who have chosen to donate to the fight against SIDS in the past, and we thank those of you who have already designated the Iowa SIDS Foundation to receive your 2006 United Way gift.

AAP Sleep and SIDS Risk Reduction Recommendations Revised

(Continued from page 3)

The Iowa SIDS Foundation strongly urges parents to not place a blanket in the crib with an infant. Instead, consider the baby's clothing, adjust the room temperature or use a wearable blanket to provide an appropriate thermal environment for the infant. Never allow an infant to become overheated.

make up the bedding so that the infant's feet are able to reach the foot of the crib (feet to foot), with the blankets tucked in around the crib mattress and reaching only to the level of the infant's chest. Another strategy is to use sleep clothing with no other covering over the infant or infant sleep sacks that are designed to keep the baby warm without the possible hazard of head covering.

4. Do not smoke during pregnancy. Maternal smoking during pregnancy has emerged

as a major risk factor in almost every epidemiologic study of SIDS. Smoke in the infant's environment after birth has emerged as a separate risk factor in a few studies, although separating this variable from maternal smoking before birth is problematic. Avoiding an infant's exposure to second-hand smoke is advisable for numerous reasons in addition to SIDS risk.

5. A separate but proximate sleeping environment is recommended. The risk of SIDS has been shown to be reduced when the infant sleeps in the same room as the mother. A crib, bassinet, or cradle that conforms to the safety standards of the Consumer Product Safety Commission and ASTM (formerly the American Society for Testing and Materials) is recommended. "Co-sleepers" (infant beds that attach to the mother's bed) provide easy access for the mother to the infant, especially for breastfeeding, but safety standards for these devices have not yet been established by the Consumer Product Safety Commission.

Although bed sharing rates are increasing in the United States for a number of reasons, including facilitation of breastfeeding, the task force concludes that the evidence is growing that bed sharing, as practiced in the United States and other western countries, is more hazardous than the infant sleeping on a separate

sleep surface and, therefore, recommends that infants not bed share during sleep. Infants may be brought into bed for nursing or comforting but should be returned to their own crib or bassinet when the parent is ready to return to sleep. The baby should not be brought into bed when the parent is excessively tired or using medications or substances that could impair his or her alertness. The task force recommends that the baby's crib or bassinet be placed in the parents' bedroom, which when placed close to their bed, will allow for more convenient breastfeeding and contact. Infants should not bed share with other children. Because it is very dangerous to sleep with an infant on a couch or armchair, no one should sleep with an infant on these surfaces.

6. Consider offering a pacifier at nap time and bed time. Although the mechanism is not known, the reduced risk of SIDS associated with pacifier use during sleep is compelling, and the evidence that pacifier use inhibits breastfeeding or causes later dental complications is not. Until further evidence dictates otherwise, the task force recommends use of a pacifier throughout the first year of life according to the following procedures:

- The pacifier should be used when placing the infant down for sleep and not be reinserted once the baby falls asleep. If the baby refuses the pacifier, he or she should not be forced to take it.
- Pacifiers should not be coated in any sweet solution.
- Pacifiers should be cleaned often and replaced regularly.
- For breastfed infants, delay pacifier introduction until 1 month of age to ensure that breastfeeding is firmly established.

7. Avoid overheating. The infant should be lightly clothed for sleep, and the bedroom temperature should be kept comfortable for a lightly clothed adult. Over bundling should be avoided, and the infant should not feel hot to the touch.

8. Avoid commercial devices marketed to

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AAP Sleep and SIDS Risk Reduction Recommendations Revised

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reduce the risk of SIDS. Although various devices have been developed to maintain sleep position or to reduce the risk of rebreathing, none have been tested sufficiently to show efficacy or safety.

9. Do not use home monitors as a strategy to reduce the risk of SIDS.

Electronic respiratory and cardiac monitors are available to detect cardiorespiratory arrest and may be of value for home monitoring of selected infants who are deemed to have extreme cardiorespiratory instability. However, there is no evidence that use of such home monitors decreases the incidence of SIDS. Furthermore, there is no evidence that infants at increased risk of SIDS can be identified by in-hospital respiratory or cardiac monitoring.

10. Avoid development of positional plagiocephaly (flat head).

- Encourage “tummy time” when the infant is awake and observed. This will also enhance motor development.
- Avoid having the infant spend excessive time in car seat carriers and “bouncers,” in which pressure is applied to the occiput. Upright “cuddle time” should be encouraged.
- Alter the supine head position during sleep. Techniques for accomplishing this include placing the infant to sleep with the head to one side for a week and then changing to the other and periodically changing the orientation of the infant to outside activity (e.g., the door of the room).
- Particular care should be taken to implement the aforementioned recommendations for infants with neurologic injury or suspected developmental delay.
- Consideration should be given to early referral of infants with plagiocephaly when it is evident that conservative measures have been ineffective. In some cases, orthotic devices may help avoid the need for surgery.

11. Continue the “Back to Sleep” campaign. Public education should be intensified for secondary caregivers (child care providers, grandparents, foster parents, and babysitters). The campaign should continue to have a special focus on the black and American Indian/Alaska Native populations. Health care professionals in intensive care nurseries, as well as those in well-baby nurseries, should implement these recommendations well before an anticipated discharge.

The AAP recommends that breastfeeding be firmly established before offering an infant a pacifier.

In addition, the pacifier should not be reinserted in an infant’s mouth after he has fallen asleep.

Quick Takes

Babies Remembered at Tree Festival

Jodi Greene designed and decorated a tree at the 2005 St. Luke’s Festival of Trees in Cedar Rapids. The theme of the tree was, “A Little Light from Heaven.” Festival proceeds went to purchase equipment for the newborn intensive care nursery and Children’s Specialty Services at St. Luke’s Hospital. Thank you Jodi!

Elizabeth, raised more than \$1,200 for the Iowa SIDS Foundation. Seven softball teams competed in the double-elimination tournament on October 8.

Proceeds will go toward a statewide program to distribute baby onesie t-shirts with a “This Side Up” message to babies delivered at participating hospitals throughout the state.

Tournament Aids SIDS Education

Strike Out SIDS, organized by Craig and Jenny Atzen in memory of their daughter,

Strike Out SIDS is an annual event. Mark your calendars for the fall of 2006 and get your co-ed softball teams together for next year.

Research Update and Report from SIDS Conference

(Continued from page 3)

Jennifer and I wish to thank the Iowa SIDS Foundation for this inspiring global education experience. As a result of our experiences, we bring hope to the SIDS Foundation Board and to the reading audience of this newsletter that a global focus on infant deaths will one day unveil

the actual cause of SIDS and reduce prenatal and infant deaths for all of us.

-Submitted by
Karen Doughan, RN, BS, CCNC,
Regional Child Care Nurse Consultant and
Iowa SIDS Foundation board member

Remembering Our Babies

Happy Birthday

January

Justice Marie Ruthann Newsom

February

Grant Philip Evans
Kenneth Edward Giffin

March

Benjamin James Swanson

April

Tianna J'Nae Purk

In Memoriam

January

Cody James Beck
Hailey Erin Lincoln

February

Ross "Rosco" Jacob McGlothlen

March

Robby Matthew Miller
Nathaniel Charles Seymour

April

Kenneth Edward Giffin

To include your baby, please send the following information via email (info@iowasids.org), phone (515-279-6928), or mail:

- Your name(s)
- Your baby's name as you would like it listed
- Your baby's birthday, including year
- Your baby's death anniversary, including year
- Please indicate if you would like us to recognize your baby's birthday, death anniversary, or both.

We will continue to recognize your baby each year after unless you contact us.



Will I Survive the Holidays?

Whether this is your first or your twentieth year without your baby, holidays are often a difficult time. You may have chosen to change how you celebrate holidays, and that is your right.

Often bereaved parents say that the days leading up to a holiday are the most challenging. You are anxious about how you'll handle seeing the newest baby in the family or how you'll feel when your mother-in-law avoids your baby's name. These are natural concerns.

So, how do you prepare? First, decide how you would like to celebrate (or not) the holiday. Next, communicate your plans with family or friends who may have certain expectations of you. Do not feel you need to apologize for your choices. Finally, find a special way to include your baby in your holiday—whether you light a candle in his memory, donate a toy to a child in need or hang her stocking. Starting a new ritual of remembrance will help you feel your baby has a special place in your holiday celebration.

SIDS Support Group Meetings

Des Moines group meets the second Tuesday of every month from 7-9 p.m. in the Kelley Room at Iowa Methodist Medical Center, 1200 Pleasant St. (basement level, past the cafeteria). For information call Carol at 515-223-1600.

Quad Cities group meets every month, second or third week Wednesday or Thursday at 7:00 p.m. For information call Betsy 563-332-6265.

Cedar Falls group meets as requested by appointment. Call Roxanne Novak at 319-277-3476 for information.

Knoxville group meets as request by appointment. Call Lori Howard 641-828-6515 for information.

Cedar Rapids/Iowa City group meets as requested by appointment. Call Tricia Borelli at 319-398-6795 for information.

Washington group meets the first Tuesday of each month from 7-8:30 p.m. at St. James Catholic Church basement. When a holiday falls in that week, the meeting will be the second Tuesday of the month. For information call Karen Swanson at 641-472-0898.

Clarion group meets as requested by appointment. Call 1-800-944-1713 and ask for Cheryl.

PEER CONTACT SUPPORT

If you are a bereaved parent, grandparent or family member and would like additional peer contact individuals who are willing to listen, feel free to call:

Karen Swanson (641) 472-0898
Gary Marker (Grandparent) (515)285-2605

Other Resources

Serving all of Iowa

Amanda The Panda Support Groups (ages 6-17) – Children and families meet in a group with a therapist for 6-8 weeks periodically during winter, spring and summer months. Weekend camps. Family “Fun Days.” Pen Pal Program. No charge. Chat line and bulletin board on website. www.amandathepanda.org 1000 73rd Suite 12, Des Moines, IA 50311-1321. 515-223-4847.

Camp Amanda (for grieving children, teens, young adults and families) – Children’s grief camp held 3 times a year for 40 kids ages 6-17. Adult camps also held 3 times a year. College-age camp held once a year. No charge. 1000 73rd St. Suite 12, Des Moines, IA 50311-1321. 515-223-4847.

Teen Line – A statewide hotline that offers counseling and education 24 hours a day, seven days a week. 800-443-8336.

Des Moines Area

Compassionate Friends -Meets the first Tuesday of each month at Hamilton’s on Westown Parkway, 3601 Westown Parkway, West Des Moines, 7:00-9:00 p.m. Contact Anne at 515-276-7302.

Empty Arms - Meets along with Compassionate Friends, the first Tuesday of each month. See above. Contact 226-3143.

Cedar Rapids Area

Compassionate Friends – Meets at Mercy Medical Center, McKinley Room the second Monday of the month from 7:30-9 p.m. 319-626-6246.

Empty Arms – Meets the third Monday of the month at 7:30 p.m. in the formal lounge of St. Luke’s Hospital Resource Center. 319-369-7347.

Grieving and Growing Support Group – Mercy Medical Center Hospice. Open to youths up to age 14. Six sessions offered in the spring and fall. 319-398-6496.

Iowa City Area

Compassionate Friends – Meets on the first Monday of each month (in the case of a holiday – the second Monday) at 7:00 p.m. in the First Floor conference room at Mercy Hospital, 500 E. Market St. 319-351-2255.

Lake City Area

H.U.G.S. Support group for Children – For children 5-15 years old. One-on-one support for children who have experienced a death loss. For registration, contact Community Hospice, Stewart Memorial Community Hospital, 1301 West Main, Lake City, IA 51449. 800-262-2614.

Manchester Area

Regional Medical Center Grief Support Group – Support group for adults grieving the loss of a loved one. Meets the first Wednesday of each month at 4:00 p.m. at the Regional Medical Center of Northwest Iowa and Delaware County, conference Room B, 709 W. Main St. Please check in advance as time is subject to change. 319-927-7330.

Mason City Area

Understanding Grief & Loss Support Group – A six-session grief support group held periodically throughout the year to provide education and support for anyone affected by a death. Free of charge. Offered by Hospice of North Iowa. 232 2nd St. SE. 641-422-6208.

Nevada Area

Bereavement Support Group – For adults experiencing loss through death. Call St. Patrick’s Catholic Church for more information. Daytime-515-382-2974, Evenings-515-382-2539.

Pella Area

Empty Cradle Program – Sponsored by Hospice of Pella to provide emotional support and educational materials to families who have experienced the death of a baby due to miscarriage, ectopic pregnancy, stillbirth, SIDS and early infant loss. Services include support groups, individual counseling, keepsake box and newsletters. Empty Cradle educates the general public and medical professionals in the area of pregnancy loss and newborn death. Hospice of Pella, 414 Jefferson. 641-628-6644.

Memorials and Donations

The Iowa SIDS Foundation thanks the following individuals for their generous donations. These donations were received as of December 10, 2005.

In Memory Of

Ryan Burris
Mr. and Mrs. John Gentzkow

**Benjamin Person and
grandfather Don Fortner**
Kenneth and Rachael Seymour

Debby Duffy

Joey Cusick
Gloria and Joseph Burkle

General Donations
Matthew and Jerry Ann
Maughan

Employer Jeans Days

Aegon
Genesis Health System
Great River Medical Center

Ryan Mouglin
Pam and Bryan Mouglin
Richard and Jane Gent
Frank and Vivian Mouglin

Charlie and Barbara Hunt
Mary O'Brien
Pat Kelly

Walk for the Future Corporate Contributors

Thank you to our corporate sponsors:

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In This Issue...

Surviving the holidays... Walk for the Future Wrap-Up... Revised AAP Guidelines

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866-480-4741 (toll-free)

Email: info@iowasids.org
Web: www.iowasids.org

Our Mission

The Iowa Sudden Infant Death Syndrome Foundation is a statewide, non-profit, voluntary health organization dedicated to providing emotional support to SIDS families, educating professionals and the general public about SIDS, and funding medical research into the causes of SIDS.