



Iowa SIDS Foundation

Support

Education

Hope

Volume 13, Issue 2

Summer 2004

From My Perspective

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My name is Jenny Atzen. I have worked as a labor and delivery nurse for 6 years. I spent the first 4 of those 6 years educating patients about Back to Sleep recommendations, not ever truly believing them or practicing them myself.

In 2002, I was one of 13 nurses that worked together all expecting babies. We had many discussions throughout our pregnancy, questioning this thing that is called "SIDS." There were many times that we all said, "There has to be some other explanation... It would never happen to any of us." There is something in the brain of a nurse that requires proof, evidence or some sort of pathophysiology surrounding diagnoses. Perhaps because SIDS is a "catch-all" for unknown cause of death, we all had a hard time believing that it is a real thing. We all knew about the correlation between stomach sleeping and SIDS, but because there had not yet been an identified cause, many of us ignored the recommendations. All we knew was that our babies slept better on their tummies and as new parents we were able to get some much needed sleep.

On November 4, 2002, my belief system was shattered. I was at work just getting back from lunch when I received a phone call from my babysitter. My oldest daughter, Olivia, had not been feeling well the night before and I thought that the babysitter was calling me to tell me Olivia was not feeling well again, and could I come pick her up. I knew immediately when I heard the tone of my baby sitter's voice that something was terribly wrong. I will always be able to hear her in my head, "Jenny, I found your baby not breathing." I remember not saying a word, just hanging up the phone, grabbing my things and heading straight for the door. Thankfully, my boss could tell something was wrong and followed me out the door. She drove me to the hospital without any questions. The drive there was full of phone calls to my husband, my mom and my babysitter. In between calls I prayed. This could not be happening to our family? How was I going to explain it to Olivia? How was I going to be able to face a day without Elizabeth? Most of all, how could I be so ignorant?

The days following Elizabeth's death are now a blur. I remember bits and pieces. Most of all, I remember being surrounded by people who cared about our family. At the time I felt as though I was in a fog, just floating through. I could not imagine how her death could affect so many people. As word of her death spread through my co-workers, we were all haunted by our past discussions. How could we be so naïve? How could we think we were so invincible? There is a tremendous amount of guilt surrounding her death. I think we can all relate to the what-ifs that surround SIDS, but I have never been able to get past how I blatantly ignored all the education I had.

(Continued on page 2)

From My Perspective

(Continued from page 1)

Since Elizabeth has died, I have tried to focus all of my energy into educating others. Many of my co-workers have gone on to have other children, and I have become the “resident expert” on SIDS. I can tell that it is still hard for many of the nurses I work with to comprehend the recommendations. Although I cannot explain to them why SIDS happens and what exactly causes it, I constantly reinforce the recommendations on how to reduce the risks. I also spend a great deal of time speaking at prenatal classes, and providing conferences for fellow healthcare workers. Getting out there and telling my story has helped me to begin to heal from this awful tragedy. If I can keep one family from having to experience this, then my time has been well spent.

I recently was elected to the board of directors of the Iowa SIDS Foundation. Although the circumstances surrounding my involvement with this group are none I would have ever wished for, I am honored to be part of it. I will spend the rest of my life educating and trying to “get into the heads” of healthcare providers to change their line of thinking regarding SIDS and sleep position. I hope that my story helps to change their minds—that the way it has always been done is not necessarily the right way.

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A Call for Children’s Grief Resources

Children who experience the death of someone close to them grieve differently from adults. It is difficult to locate resources to help children understand death and cope with their grief. Finding materials for very young children is especially difficult.

If you can recommend any books, articles, Web sites, videos and other resources that you have found particularly helpful in explaining death to children, helping children in their grief or helping parents support their children, we’d like to hear from you.

Please send all pertinent information such as the title, author, web address, a brief description of the resource and the age group you feel it best fits.

From your recommendations, we plan to build a list of these resources on our Web site and for a future newsletter article.

Send recommendations to ingrid@iowasids.org, or mail them to the Iowa SIDS Foundation.

New Arrivals:



Congratulations to the following family on their new addition:

Maxwell VanDerSchaaf was born July 1 to Steve and Betsy VanDerSchaaf. Max weighed 7lbs., 13 oz.



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.

Walk for the Future 2004 is This Month!

It is not too late to participate in the fifth annual Walk for the Future. If you are reading this before Saturday, August 28, 2004 and have not yet registered for the walk, come join us at one of the following locations. Registration begins at 8:30 a.m., the walk begins at 9:00 a.m.

***Walk for the Future:
In memory of the
children who have
died from SIDS...
With hope for all
new life***

☞ # Iowa City - City Park. Additional information 319-358-0778

☞ # Keswick - Iron Street* Additional information 319-738-3588

*Walk begins at 8:00 a.m. in front of the fire station.

☞ # Quad Cities - Scott County Park. Additional information 563-332-6265

☞ # Sioux City - Chris Larsen Park. Additional information 712-279-6119

☞ # West Des Moines - Raccoon River Park. Additional information 515-285-2605

If you are reading this after the walk, and were unable to join us, your donations are still welcome. Proceeds from the walk go to educate healthcare and childcare providers, parents and the community about the risks for SIDS, to provide grief support for parents and others touched by SIDS, and to support research into the causes of SIDS.

Donations of \$25 or more will receive a walk t-shirt; donations of \$100 or more will receive a walk sweatshirt, while supplies last. Please note Walk for the Future and a shirt size in the memo of your check or in your online donation to receive a shirt.

Have Researchers Found a Genetic Cause for SIDS?

Recently, the media has mistakenly reported that a new study identifies a gene for a primary form of SIDS. The study these reports are referring to is *Mapping of sudden infant death with dysgenesis of the testes syndrome (SIDDT) by a SNP genome scan and identification of TSPYL loss of function.*

The study found a genetic defect in a very small, isolated Amish order in Pennsylvania in which people rarely move in or out. This group tends to marry within their community. The infants they studied were all males that had other known defects before their deaths. They were able to find the genetic link in their deaths. These infant deaths, however, were not SIDS.

It may be possible that SIDS researchers will be able to learn something from this research, however the research did not actually find something directly related to SIDS.

International Committee Determines New SIDS Definition

The definition of Sudden Infant Death Syndrome (SIDS) was recently redefined during a January 2004 meeting hosted by CJ Foundation for SIDS. An international panel of experts, including pediatric pathologists, forensic pathologists and pediatricians, all with extensive experience with SIDS, worked to update the definition of SIDS as well as to categorize types of SIDS deaths based on several factors. This meeting and its outcome is described in a special article in *Pediatrics* Vol. 114 No. 1 July 2004.

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Be the Eyes and Ears for Family Support

A primary part of the mission of the Iowa SIDS Foundation is to provide grief support to families as soon as possible. Our support comes in many ways including sending grief packets and the *SIDS Survival Guide* book, providing volunteer peer contacts, and sponsoring support groups in several locations across the state.

We learn of new SIDS deaths through many channels of communication. However, some of this information is often delayed.

The Iowa SIDS Foundation could use your help. If you learn about a SIDS death in your community, please contact us as soon as you hear about it. It is helpful for us to know as much of the following information as possible:

- ..# parents' names and baby's name
- ..# names and ages of any siblings
- ..# baby's birth date and death date
- ..# parents' address and telephone number
- ..# any additional information that would help us provide compassionate support.

Please call our toll free number at 866-480-4741 or email info@iowasids.org. Thank you for helping us provide support to families as early in their grief process as possible.

Strike Out SIDS—Softball Tournament

Craig and Jenny Atzen will host a co-ed slow pitch softball tournament, Strike Out SIDS, on Saturday, October 9, 2004 at the Dugout Sports Complex in Davenport, Iowa in memory of Elizabeth Atzen.

The entry fee is \$150, or \$170 for non-sanctioned teams. All proceeds go to benefit the Iowa SIDS Foundation. The Atzens hope the tournament is successful enough to make it an annual event.

If you have questions, to enter a team or to volunteer to help, call Craig or Jenny at 563-285-4046 or email atzen37@msn.com. For specific questions about the tournament or entering a team you may also contact Jim Muhs at the Dugout Sports Complex at 563-391-4211.

Gear Up for United Way



United Way

Many work places are gearing up for 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 designated the Iowa SIDS Foundation to receive your 2004 United Way gift. Thank you to the following individuals who have committed to the Iowa SIDS Foundation through their workplace campaign:

Julianne Aye
Kori Cusick
Robert Gonzales

Jennifer McKenna
Lisa Steinkamp
Stacey Twedt

Steven VanDerSchaaf

New SIDS Definition

(Continued from page 3)

New Definition: SIDS is the sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.

The group agreed that the current definition of SIDS needed to be updated because the term SIDS has been misused or underused by pathologists and others. A more inclusive SIDS definition would facilitate more consistency in diagnosing SIDS, which would also provide more consistent data for studies.

The former definition defined SIDS as, “the sudden death of an infant under one 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 new definition of SIDS includes the fact that the infant must be sleeping at the apparent time of death. In addition, the term “death scene investigation” has been replaced by “review of the circumstances of death.” The committee hoped that this change would encourage “more comprehensive assessments of the events surrounding death. For example, although an infant’s death may occur in a hospital after an attempted resuscitation and thus the scene is technically an emergency department, the circumstances involve the crib, room, and house where the infant was found.”

More information about new SIDS categories will follow in the fall newsletter.

Quick Takes

Peer Contact Training Coming in February

On Saturday, February 26, 2005, the Iowa SIDS Foundation will host a training session in Des Moines for all current and new peer contacts. Peer contacts are the backbone of the grief support we provide to families. If you are interested in becoming a peer contact, please contact Ingrid at 515-279-6928 or ingrid@iowasids.org.

Iowa City SHARE Group Disbands

Mercy Hospital of Iowa City has decided to end the Iowa City SHARE support group. The hospital will continue to support families in need through individual counseling and care in its obstetrics unit as well as offering a lending library of resource materials. The hospital will also continue the SHARE newsletter.

Jewelry for a Cause

Jewelry designer Michelle Blunk has found a unique way to support the Iowa SIDS Foundation and SIDS awareness through her beadbuzz.com jewelry. Michelle’s cousin and his wife lost their daughter to SIDS in November 2002. To raise awareness about SIDS, Michelle designed two styles of Sudden Infant Death Syndrome Awareness bracelets and donates a portion of her proceeds to the Iowa SIDS Foundation. Thank you, Michelle!

Please Report Speaking Engagements

If you present to others about SIDS for your job, or as a volunteer in your community, in your church or elsewhere, we want to hear about it. On an annual basis, we track how many people we reach about SIDS. Drop us a note, e-mail, or give us a call at 515-279-6928. Let us know how many people you spoke to and the type of audience (expectant parents, nurses, community group, etc.). Or complete our Speaker Evaluation form online at www.iowasids.org/SpeakerEvaluation.htm.

Newsletter Help Wanted

The Iowa SIDS Foundation is looking for a volunteer with a writing background to assist with writing and compiling our newsletter. We publish three times a year. If you are interested, please contact Ingrid at ingrid@iowasids.org.

Web Site is Growing

The Iowa SIDS Foundation Web site is continuously evolving. You can now make donations, order our products and register for the Walk for the Future online. We continue to add more resources for SIDS information and grief support as well. Keep checking www.iowasids.org for new additions.

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 City 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.

Sioux City group meets the second Tuesday of each month from 7:30-9 p.m. at the Siouxland

Public Health Dept. 205 Fifth St. For information call Mona Scaletta at 712-279-6119.

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

Iowa City group meets as requested by appointment. Call Kori Cusick at 319-358-0778 for information.

Clarion group meets as requested by appointment. Call Tiffini Mericle at 515-825-3893.

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
Jackie VanMeighem (309) 755-5523
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 New Hope United Methodist Church, 4525 Beaver 7:30-9:00 p.m. 515-965-1922.

Empty Arms - Meets along with Compassionate Friends, the first Tuesday of each month at New Hope United Methodist Church, 4525 Beaver, 7:30-9:00 p.m. 515-253-9739 or 515-270-8766.

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 July 25, 2004.

In Memory Of

Sydney Leigh Aschenbrenner

The employees of
McLeodUSA

Elizabeth Grace Atzen

Michelle Blunk

Ryan Burris

Rich and Rose Anderson
Craig and Kathy Bartlet
Jason and Mindy Benson
Brent and Jodi Bowles
Nadean Buch and Brad Litt
Mike and Janice Burris
Brian Burton
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Roxanne Ruden, Robert Kelly
and the boys

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Judy and Dwight Frideres

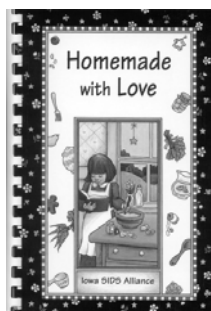
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www.iowasids.org/products/products.htm



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Research Update... Grief resources for children... New SIDS definition...

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Iowa SIDS Foundation

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.