



Iowa SIDS Foundation

Support

Education

Hope

Volume 13, Issue 3

Fall 2004

From My Perspective

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As one of the Walk for the Future coordinators for the Iowa City location, a SIDS parent and co-captain of Joey's Team, I wanted to give my perspective on what the walk means to me.

For the last five years I have been amazed by the generosity that I've seen at the walk events in Iowa City. I've also been caught inexplicably mute when trying to express my gratitude. I have so many things I want to say to each member of Joey's Team and yet none of them come out. I give them a hug and the only thing I can think to say is, "Thank you," but thank you doesn't seem like enough! I hope that they can see deep into my heart to know that the "thank you" represents just how grateful I am that they are here supporting this walk, supporting me and most importantly, remembering and loving Joey.

Maybe it's that I have so many emotions that are competing to get out the day of the walk, that I can't find the right words. I feel gratitude and love towards all that have come out in the rain to remember our babies. I want to walk over hot coals or wash their car or do just about anything for them because they are doing so much for me. I want to cry for all that I have lost and all that I have missed out on over the years since we lost Joey. But, I also want to sing for the love that I still feel for Joey today and was so worried would dwindle. And unfortunately, I feel a little despair as I see parents who have just recently lost their child and I know the long road they have in front of them.

I wonder, "Are these people angels or saints that come to this walk when they could be doing something else on a Saturday morning? Do they have some special gift? Do they somehow know that the walk has turned into the day for Joey?" The walk for me and the other parents here is the celebration that takes the place of our child's birthday, first steps, or first day of school. It's the day that we can talk about our child that we still love and miss so much, without worrying that we are making someone uncomfortable. It's the day that when someone says, "I know how you feel," they really do!

The people who come to the walk seem so modest about their gift to us, so unselfish. They must know to come back year after year, rain or shine (there was one sunny year!), that they are helping. To some, the walk must look like a gathering of sadness, but the people who come know it is actually a celebration of life. For Joey's Team, we celebrate the dimpled little boy who was physically alive for just a short time, but will live forever in our hearts. To some, the mixture of tears and laughter may seem strange, but the people who come know it's through these emotions that we heal. I remember feeling so alone when we lost Joey, like my husband and I were

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From My Perspective

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on an island by ourselves. It's been through the walk that I have realized that we were not alone at all. These wonderful, amazing people were walking with us all along, and they come out every August to remind us.

At the end of the walk this year, a grandmother who recently lost her grandbaby asked me through tear-filled eyes how I did it. How did I survive losing my first child? It was her child who had lost their first child, and she needed to know how I did it. A million thoughts raced through my head, because there are a million components that go into it. After I let the revelation sink in that I had indeed survived, I finally pointed towards the shelter filled with rain-soaked people, and said, "Find someone who's wearing a Joey's Team button. That's how I did it."

And again, the only thing I can think to say is, "Thank you." Thank you Joey's Team and thank you to all of our walk participants!

-Submitted by Kori Cusick

How did I survive losing my first child?

Find someone who's wearing a "Joey's Team" button. That's how I did it.

Research Update

As a SIDS parent, I know I am one of many who are constantly searching for a cause so that someday we will know what we can do to prevent SIDS from happening. I am frustrated by the lack of answers, surrounded by multitudes of speculation.

I have come across a few good articles over the last few months that were very interesting and contained some good information and theories.

The first is an article by Steven Reinberg of *HealthDay News* summarizing a study performed by the University of Chicago. The study focuses on a portion of the brain thought to be responsible for gasping, a so-called "respiratory pacemaker." The researchers theorize that these cells are responsible for restoring breathing in hypoxic infants. They believe that in children who die of SIDS, these cells are not intact so their bodies are not able to compensate for hypoxic events. When hypoxia (lack of oxygen reaching body tissues) occurs, neurons begin to shutdown. Without these neurons, babies cannot sigh or gasp to restore their breathing. This study refers to others that have found decreased levels of serotonin in babies who have died of SIDS. Serotonin is an important neurotransmitter involved in many body

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New Arrivals:



Congratulations to the following family on their new addition:



Ambere Marie Kallsen was born September 12, 2003 to Patrick and Amy Kallsen.



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

(Continued from page 2)

I am one of many who are constantly searching for a cause so that someday we will know what we can do to prevent SIDS from happening.

functions including breathing. The researchers state that when there is a decrease in serotonin, there is a decrease in activation of these cells. They believe this is the missing link in previous studies involving serotonin levels. The researchers believe if this finding proves to be true, we may be able to detect which infants are at risk for SIDS. Dr. Warren Guntheroth, a SIDS expert at University of Washington feels the study is of no clinical value. He states that disorders involving serotonin levels and sodium channels are inherited disorders and because SIDS has been proven not to be an inherited syndrome, the two cannot be linked.

The second article, by Kwanza Griffin, was published in the *Milwaukee Journal Sentinel*. It outlines the well-known triple risk model. This theory involves three key elements that, when they come together, make an infant more at risk for SIDS. First, there is an underlying brainstem abnormality. Second, the infant is in a critical development period. Between the ages of two and four months is when the nervous system is developing. Third are modifiable external stressors such as stomach sleeping, exposure to second hand smoke and overheating. When these three factors are all present, an infant is at greatest risk for SIDS.

Recently, a couple of articles have been published giving false hope for many SIDS parents. One article published in Wisconsin reported a virus found in two sudden deaths among infants. The discovery of this virus is interesting, but has not been linked to SIDS or any other sudden death cases.

There is still much to be learned about SIDS. A lot of research still needs to be conducted in order to find a cause. We can only hope that this happens in our lifetime.

-Submitted by Jenny Atzen

Peer Contact Training Scheduled for February 26, 2005

The Iowa SIDS Foundation will host a day-long training in Des Moines for all current and new peer contacts on Saturday, February 26, 2005, to prepare peer contacts to effectively assist new families who experience the death of an infant from SIDS in their bereavement.

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. To facilitate those traveling a long distance, hotel rooms will be provided on Friday to those traveling over 150 miles. Contact Ingrid regarding your needs.

New SIDS Definition—Continued from Summer Newsletter

An article in the Summer 2004 newsletter described the recently reworked definition of Sudden Infant Death Syndrome (SIDS) as a result of a January 2004 international panel meeting hosted by CJ Foundation for SIDS. This international panel of experts, 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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Walk for the Future 2004 Wrap-Up

The fifth annual Walk For The Future was held on Saturday, August 28 in Keswick, Iowa City, the Quad Cities, Sioux City and West Des Moines. There were over 600 participants at the various locations. The event raised nearly \$43,000, of which over \$9,000 was from generous corporate donations. The following amounts were raised at the various locations the day of the walk:

Keswick:	\$1,400	Sioux City:	\$1,302
Iowa City:	\$8,504	West Des Moines:	\$7,083
Quad Cities:	\$8,323		

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:

Ann Danner in Keswick
Denise Mougins and Kori Cusick in Iowa City
Mona Scaletta in Sioux City
Betsy VanDerSchaaf and Jenny Atzen in the Quad Cities
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 fifth!

Please read our Memorials and Donations section on page 7 to recognize our kind corporate contributors.



August 28 was a soggy day in Iowa City but that didn't stop about 250 walkers of all ages.

Softball Tournament helps to Strike Out SIDS

Strike Out SIDS, a co-ed softball tournament organized by Craig and Jenny Atzen in memory of their daughter, Elizabeth, raised more than \$1,600 for the Iowa SIDS Foundation. Nine teams competed in the double-elimination tournament held on October 9.

The tournament, which included a raffle and silent auction funded an education program at the Genesis Medical Center in Davenport, Iowa. SIDS education packets and baby onesie t-shirts with a "This Side Up" message were given to over 200 families who delivered a baby at Genesis this October.

The Atzens will make the Strike Out SIDS tournament an annual event, so mark your calendars for late September 2005 and get your co-ed softball teams together for next year.

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 2005 United Way gift.

New SIDS Definition and Categories

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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 new definition (see box at left) also included sub-categories of SIDS. These subcategories were defined to aid in studying the effects of changes in infant care and public health recommendations.

The subcategories are:

Category IA SIDS: Classic Features of SIDS Present and Completely Documented:

- More than 21 days and less than 9 months of age.
- Normal clinical history including a full-term pregnancy.
- Normal growth and development.

- No similar deaths among close genetic relatives or other infants in custody of same caregiver.

- Investigations of scenes where something may have caused the death reveal nothing to explain the death; found in safe sleep environment; no evidence of an accident.
- Autopsy reveals no fatal pathologic findings, evidence of unexplained trauma, injury or

neglect, and negative results on other tests.

Category IB SIDS: Classic Features of SIDS

Present but Incompletely Documented: death meets the requirements of the general definition and all of the criteria for category IA except that either a death scene investigation or one or more screenings or tests were not performed.

Category II SIDS: Meets criteria of category I except one or more of the following:

- Age range outside of category IA or IB.
- Similar deaths among close relatives or in care of same caregiver that are not suspect.
- Neonatal or perinatal conditions have resolved by time of death.
- Suffocation caused by overlaying cannot be determined with certainty.
- Abnormal growth and development not thought to have contributed to death.

Unclassified Sudden Infant Death: deaths that do not meet the criteria for category I or II SIDS but other diagnosis are inconclusive, or autopsies were not performed.

Postresuscitation Cases: Infants who are resuscitated and later die may be included in the other categories depending on how they fit the category criteria.

Quick Takes

Memorial Event Planned for Fall 2005

A special state-wide SIDS memorial event is being planned for late September or early October in Central Iowa. This event will include keynote speaker Carole Harder and a special memorial reflection. Watch for future information about the location and time.

Employees Support Iowa SIDS Foundation

Several employee groups have chosen to support the Iowa SIDS Foundation this year through Jeans Days and other unique ways. Employees at Aegon and McLeod USA, both in Cedar Rapids, held jeans days as did Genesis Medical Center of Davenport and Orthopaedic & Rheumatology Associates of Bettendorf.

Employees at O'Reilly Automotive, Inc. in

Ankeny chose to donate proceeds from their can and paper recycling program.

Thanks to the employees of these organizations who help organize and support these programs.

Iowa SIDS Foundation represented at Cedar Rapids Festival of Trees

Jodi Greene and Jill Dowe purchased decorations, designed and decorated a tree at the St. Luke's Festival of Trees in Cedar Rapids this November. The tree's theme was Our Shining Stars. The Surgery Center Cedar Rapids sponsored the tree. All trees are auctioned at the end of the event and this year the proceeds go to help update the rehabilitation facilities at St. Luke's Hospital in Cedar Rapids. Thank you Jodi and Jill!

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.

Cedar Rapids/Iowa City

group meets as requested by appointment. Call Tricia Borelli at 319-398-6795 for information.

Special Holiday Support

Group meeting scheduled for Tuesday, December 14 from 7-8:30pm at Mercy Health Plaza on Park Place in Cedar Rapids (not the Mercy Medical Center downtown). For more information, contact Tricia Borelli at 319-398-6795.

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
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 November 17, 2004.

In Memory Of

Ryan Burris

Ashley, Doug and Jack Olson
Terry and Gwen Luloff

Ryan Mougín

Curt and Amy Bowman
Richard and Jane Gent
Frank and Vivian Mougín

Kayla Petalver

Marie Umbower

Benjamin James Swanson

Jim and Dianne Swanson

AJ VanDerSchaaf

Michael Littmann

General Donations

Shannon and Kevin Tanner
Wendy Thatcher
Kyle Woitel

Erika Zito

Employees of Genesis Medical Center
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Employees of Orthopaedic & Rheumatology Associates, P.C.
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Walk for the Future Corporate Contributors

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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.