



Iowa SIDS Foundation

Support

Education

Hope

Volume 14, Issue 2

Summer 2005

From My Perspective

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Many of those in the “SIDS circle” in Iowa may wonder about how the Iowa SIDS Foundation works and what is being planned by the foundation board of directors. As a member of the board of directors and current president, I wanted to take the opportunity to share a little bit about our organization.

The Iowa SIDS Foundation is a nonprofit organization comprised of twelve or more volunteer board members and one paid part-time employee, the executive director. The board oversees the general activities and business of the organization and the executive director helps carry out and oversee the day-to-day activities and operations. Together we work to stay focused on our mission which has three basic prongs: support, education, and hope. Each of the goals of the Iowa SIDS Foundation are closely tied to one or more prongs of our mission.

In this article, I have tried to answer some of the questions we have been asked by various people we come in contact with in Iowa.

How does the Iowa SIDS Foundation operate?

We are able to provide support and education mostly through donations (general donations, funds raised during the Walk for the Future, and memorials) and grants. The State of Iowa thankfully helps offset some costs, but cutbacks have been difficult on our organization and state funding has decreased dramatically.

Where do the donation dollars go?

The funds we receive from donations go to support each part of our mission.

Support: A portion of the money from donations is spent for grief materials for families who have lost a baby to SIDS. Bereavement support is vital and the board of directors is continually trying to find new ways to reach out throughout this vast state. This year, we trained new and refreshed current peer contacts in a one-day Peer Contact Training session. The peer contacts help support bereaved families and some help run support groups.

An Iowa SIDS Foundation memorial event has been planned for October 2, 2005 at the Reiman Gardens at Iowa State University in Ames.

Education: Last year, foundation dollars went toward a “Train the Trainer” conference where we provided training materials and educated health care, day care, first responder and law enforcement professionals about SIDS and best practices so they could train other professionals in their field.

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From My Perspective

(Continued from page 1)

Educating through baby fairs, seminars, and specifically requested training and speaking engagements occurs year-round throughout the state of Iowa.

Hope: In the past, foundation dollars for research went only to the national SIDS Alliance to support general research of SIDS. This year the board of directors evaluated specific SIDS-related research projects being conducted throughout the country. The Iowa SIDS Foundation directors then chose one program to which it will provide a donation to help fund their project. The board is excited to take this direct approach to funding research.

The funds we receive from donations go to support each part of our mission.

Another exciting development this year is our new advisory council that includes professionals from law enforcement, emergency medical services, infant and child care, infant health, grief support and mental health. The board of directors and the advisory council collaborate when necessary to improve communication, educate, and gain expert advice regarding infant safety, health, emergency services and/or grief support.

What are the Foundation's plans and goals for the future?

Just a few...

Newborn Onesie Program- We are in the beginning phase of expanding on a pilot program giving newborn babies in participating hospitals across the state a one-piece t-shirt promoting safe sleep and "back to sleep."

Rural Support Program- We are working on improving grief and support materials for those in rural areas or areas that do not have access to a support group. This should be ready by the first part of 2006.

State-wide SIDS Conference- We are in the beginning stages of planning a state-wide conference for parents and professionals in the spring of 2007. More details will be announced as planning continues.

If you are interested in becoming more involved with the Iowa SIDS Foundation as a peer contact, board member or as a volunteer for one of our many events, please email info@iowasids.org or call Ingrid at 515-279-6928.

Submitted by
Karen Swanson
Iowa SIDS Foundation board president

New Arrivals:

Congratulations to the following families on their new additions:



Joseph Ray Varner was born February 7, 2005 to Christine and Mark Varner.

Gavin Andrew White was born January 1, 2004 to Barbara and Tony White.



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.

A Kid with Passion



Hunter Ohrt prepares donation buckets in memory of sister Hope.

Hunter Ohrt may be an average ten year-old boy in many ways, but he has a passion that makes him more unique.

Hunter lost his sister, Hope ElizaRae Ohrt, to SIDS in September 2003. In honor of Hope, he is helping his family fundraise for the Iowa SIDS Foundation Walk for the Future.

Hunter's family set a goal last year to raise \$1000 for the walk. Their efforts brought \$3000.

Hunter is helping out by selling raffle tickets and setting out collection buckets which

he helped decorate with Hope's photograph.

This year Hunter got a new "fast" bike so he figures he will be able to sell more raffle tickets this way. That's proving true.

Hunter set for himself a \$100 goal for selling raffle tickets. In less than an hour he exceeded the first goal and continued to raise the bar for himself. In less than two days he had already sold \$375 worth of tickets.

Hunter's stepmother, Janaé, is so impressed by Hunter's dedication to this cause, "He is so into helping this organization and I am so proud of him. For a ten year-old to have such a passion about anything but themselves is great."

Hunter lives in Jesup, Iowa with his father Jeremy, stepmother Janaé, and family.

Way to go, Hunter! Thank you for being such a caring kid!

Borrowed Hope

Lend me your hope for awhile, I seem to have mislaid mine.

Lost and hopeless feelings accompany me daily.
Pain and confusions are my companions.
I know not where to turn.
Looking ahead to future times
Does not bring forth images of renewed hope.
I see mirthless times, pain filled days,
and more tragedy.

Hold my hand and hug me.
Listen to all my ramblings.
I need to unleash the pain and let it tumble out.
Recovery seems so far distant,
The road to healing a long and lonely one.
Stand by me. Offer your presence.
Your ears and your love.
Acknowledge my pain, it is so real and ever present.
I am overwhelmed with sad and conflicting thoughts.

Lend me your hope for awhile. A time will come
When I will heal, and I will lend my renewed hope to others.

By Eloise Cole

Mark your Calendar: Important 2005 Dates

Saturday, August 27

Iowa SIDS Foundation 6th annual **Walk for the Future**
Albia, Boone, Cedar Rapids, Keswick, Quad Cities, Spirit Lake, West
Des Moines
Registration at 8:30am except in Albia and Keswick (Albia:
Registration at 7am; Keswick at 7:30am)
The Albia event also includes a 5K run.
Visit www.iowasids.org for more information.

*Join us August 27 for
the Walk for the Future
in one of these
locations:
Albia, Boone,
Cedar Rapids,
Keswick, Quad Cities,
Spirit Lake or
West Des Moines*

Sunday, October 2

Iowa SIDS Foundation **Memorial Event**
Reiman Gardens, Iowa State University, Ames
1:00pm
Watch your mailbox and www.iowasids.org for more information.

Saturday, October 8

Strike Out SIDS softball tournament
Davenport, IA
Register Now!
All-day Co-ed softball tournament to raise funds to fight SIDS
For more information email atzen37@msn.com or call 515-279-6928.

CJ Foundation for SIDS Conference Date Change

An announcement regarding the CJ Foundation for SIDS conference was printed in our last newsletter giving an October 2005 date. The date for this exciting conference has been changed.

Philadelphia, PA. The conference will address SIDS as well as SUDC (Sudden Unexpected Death in Childhood) and is targeted to meet the needs of health care professionals, researchers and bereaved family members.

On February 23-26, 2006, CJ Foundation for SIDS presents its first national conference at the Wyndham Franklin Plaza Hotel in

For more information watch www.cjsids.com or call 888-825-7437 x4 to be added to the mailing list.

Designate Iowa SIDS Foundation in United Way Campaign



United Way

Many work places are preparing to hold their annual United Way campaign. Did you know that you can designate the Iowa SIDS

Foundation as the recipient of all or part 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 our 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.

Newsletter Memorials to Begin this Fall

Would you like for us to join you in remembering your baby's birthday and/or death anniversary?

We need your help!

Beginning with our Fall newsletter, we would like to remember babies in a Happy Birthday and In Memoriam section by listing their names under the appropriate month. Four months will be listed in each newsletter.

In Memoriam

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.

Iowa SIDS Foundation Funds Hope...

Each year, ten percent of Iowa SIDS Foundation revenues go to fund SIDS research. In the past this money was given to the national SIDS Alliance to fund general research.

Beginning this year, the Iowa SIDS Foundation board of directors has elected to choose research that the foundation will directly fund.

This year, the Iowa SIDS Foundation will help support the SIDS Center of Excellence for

Brainstem Research lead by Dr. Hannah Kinney. Dr. Kinney and her colleagues at Boston Children's Hospital and Harvard University continue to research the idea that SIDS is due to the abnormal development in the brainstem or a defect in autonomic and/or respiratory control of an infant during sleep.

The goals of this research are to hopefully define related abnormalities in living infants and to define ways of preventing the abnormalities from leading to sudden infant death.

First State-wide SIDS Memorial Event October 2

A special state-wide SIDS memorial event is planned for October 2 at Reiman Gardens at Iowa State University in Ames at 1:00pm. This event will include keynote speaker Carole Harder and a special memorial reflection.

Invitations for this event will be mailed shortly. Read carefully for information about how to recognize your baby during the memorial reflection.

Contact the Iowa SIDS Foundation if you will need child care during the memorial.

This event is free of charge and those attending will be admitted into the Reiman Gardens as well as the Christina Reiman Butterfly Wing.

We have negotiated a price on a block of hotel rooms for Saturday night at Quality Inn and Suites Starlite Village at 2601 E. 13th St. in Ames for \$74.00+tax per room with two queen beds. You may call 515-232-9260 to reserve a room. Website: www.amesqualityinn.com.

We look forward to remembering our babies together.

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 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 August 1, 2005.

In Memory Of

Nathaniel Seymour

2005 2nd grade class of St. Malachy Religious Education, in honor of Nathaniel's grandmother Judy Friederes' 30 years of teaching

Benjamin Swanson

Jean Spanko
Dennis Storbeck

General Donations

Camryn Stuckwisch
Diana Rojahn

Scott and Robin Ehredt
Susan Holder
Tim and Jodi Hoskins
Dr. Ronald and Jill Kolegraff



CJ Foundation for SIDS Awards Grant

The CJ Foundation for SIDS, a national non-profit organization dedicated to recognizing the special needs of the SIDS community through funding SIDS research and support services, has announced its award of a program services grant to the Iowa SIDS Foundation.

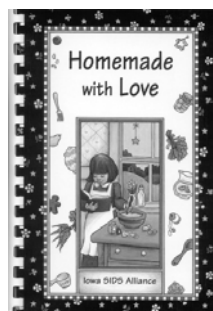
The CJ Foundation for SIDS was founded in 1994 by Joel and Susan Hollander after losing

their daughter Carly Jenna to SIDS.

The CJ Foundation for SIDS has supported multiple programs and projects of the Iowa SIDS Foundation over the past several years. We appreciate their support of our programs in Iowa!

For more information about the CJ Foundation for SIDS, visit www.cjsids.com.

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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.