

Angel of Hope Memorial Service

Please join us to celebrate the lives of our children at this annual candlelight memorial service.

Who: Parents who have lost a child, of any age, for any reason.

What: Candlelight Memorial service at the Angel of Hope Monument.

When: Wednesday, December 6, at 7 p.m.

*Where: El Toro Memorial Park
25751 Trabuco Rd.
Lake Forest, CA 92630*

Why: To come together to remember our children who have died.

The Angel of Hope monument is a place for grieving parents to gather who have lost a child of any age, for any reason. There are 63 angels throughout the country; the Lake Forest angel is the only monument in Southern California. The 4-foot-3-inch bronze statue of a child with her arms and wings outstretched stands on a granite pedestal inscribed "Angel of Hope," "Our children loved, missed and remembered." This monument is a place for parents to go to release their emotions and have a physical reminder that their child is not lost or forgotten.

Please bring a flashlight for use at the ceremony.

Flowers and candles are provided free of charge.

For more information on the Angel of Hope monument and memorial ceremony, please visit www.careandkindness.org/angelofhope/ or contact Lisa Biakanja at (714) 960-9897.



"To keep new lives living."

REFLECTIONS

VOLUME 76

FALL ISSUE

NOVEMBER 2006

President

Lisa Biakanja

Vice President

Mary Williams

Treasurer

Shari Morinishi

Recording Secretary

Mary Ann Garcia

Historian

Carole Guttilla

Parent Contacts

- Lisa Biakanja
(714)960-9897

lbiakanja@yahoo.com

- Lisa Billings
(909) 569-7416

Billingsfam@verizon.net

- Shari Morinishi
(714)952-1466

sharmori@ca.rr.com

- Rachel Strickland
(714) 630-0400

shawnrachelhuntr@aol.com

- Elizabeth Willett
(949) 861-1491

actionfigure1284@yahoo.com

Spanish Speaking Contact

- Liz Ramirez
(562) 233-7864

Grandparent Contact

Carole Guttilla
(714)524-7647

CGuttilla@maintech.com

Medical Advisors

- Thomas G. Keens, MD
Professor of Pediatrics
University of Southern
California School of
Medicine/Children's Hospital,
Los Angeles

- Henry Krous, MD, Vice-
Chair Director of Pathology
Children's Hospital, San Diego

Technical Consultant

Andrew Beale
Unisys Corporation

Executive Director

Barbara Estep
gisoc@compuall.net

The Angels Who Always Keep Singing ...From a Parent's Point of View

By: Debbie Gemmill

(reprinted from *Getting Through Grief: From a Parent's Point of View*)

"Do the angels sing even when we're not listening?" four-year-old Jennifer asked. *Not this year*, I thought, as I methodically placed another ornament on the tree. Since Tyler's death in May, I wasn't sure I even believed in angels anymore.

We had decided to "do" Christmas after all, mostly for Jen's sake and in a half-hearted effort to get things back to normal for all of us. And so we made our annual trek to the Christmas tree lot and went through all the motions, deciding finally on the Right Tree, tying it onto the roof of our car and singing Christmas carols on the way home. Just as we had done all the years we had been together. Just as we had done last year—except this year there was no baby next to Jen in the back seat.

Life had been pretty close to perfect for us before that day in May that brought our hopes and dreams to a crashing halt. Walking into the sunny nursery to find a baby who had died in his sleep changed everything. Tyler had died quickly and quietly, with no warning at all, and—as far as anyone knows—with no pain at all. The overwhelming, crippling pain we were drowning in was ours alone.

With Ty's scattered ashes, our own lives flew before us in pieces. Even with our remaining daughter reminding us that "life goes on," the effort to survive was like walking into a vacuum. Security, trust, faith—our very foundation crumpled beneath the weight of our grief.

(continued on page 3)

Inside this issue:

A Note From The President	3
Memorial Donations	5
The Holidays Are Coming	6
Guild's Annual Fundraiser	8
NEW SIDS Research Identifies Potential Biological Cause	9
2006 Meeting Calendar	11

Save The Date!

January 16,
2007

PUMP IT UP!!
IN IRVINE AT 16871 NOYES

Contact the Guild Office at (714) 973-8417
for additional information.





A Note From The



On behalf of the Guild for Infant Survival, Orange County, I want to personally extend an invitation to each of you to attend the Angel of Hope Memorial Service Wednesday, December 6, at 7:00 pm. If you have not attended in the past, you can expect to gather with hundreds of parents that have lost a child for one reason or another. One parent may carry a picture of their son that died in the Vietnam War, another lost their entire family in a house fire, other individuals, like us, remember a baby that died too soon. We gather together to remember our children.

During the course of the evening we light a candle to commemorate our child's life, we place a flower at the base of the angel, and we announce our baby's name. For many it is the only time during the year that we are encouraged to remember our sons and daughters. We do so with others that can appreciate just how meaningful this night is.

Please consider beginning your holiday season with us at the El Toro Memorial Park. Feel free to bring a picture of your baby to share with other participants or quietly reflect on your baby's memory, the choice is yours. We understand. . .

REFLECTIONS

P.O. Box 17432
Irvine, CA 92623-7432
Editor: Cory Morinishi

Reflections is a quarterly publication of the Guild for Infant Survival, Orange County—a non-profit organization. *Reflections* is committed to the collection and dissemination of accurate, up-to-date, scientific and lay information and the correction of misinformation related to SIDS. The Guild is dedicated to the support of families and friends suffering the death of an infant to SIDS.

The Guild For Infant Survival, Orange County Information:

2130 E. Fourth Street #125
Santa Ana, CA 92705
Ph: (714) 973-8417
Fax: (714) 973-8429
(800) 474-SIDS (7437)
Email Address:
gisoc@compuall.net
Website Address:
www.gisoc.org

Newsletter Deadlines

If you would like to contribute an article or poem to an upcoming issue of *Reflections*, please contact: Cory Morinishi at (714) 952-1466 or e-mail him at sharmori@ca.rr.com. The next Newsletter deadline is 1/1/07. We encourage your participation!

The Angels Who Always Keep Singing ...From a Parent's Point of View (Continued from Page 1)

Yet, here we were, face to face with a season that shouted all the things we knew we'd never feel again—happiness, joy, frivolity. We were pretending so hard.

Our Christmas tree was heavy with decoration when Jen asked me for the hundredth time about Heaven, God, and the angels. As hard as it was for us to understand Ty's death, how much harder for this little girl to realize that her baby brother was not coming back. Once again, "And do the angels sing even when we're not listening, Mommy?"

When will this get easier, I wondered.

Leaning over the sides of the big cardboard box that held our decorations, Jen reached for one of the last remaining ornaments. "What about this one, Mommy?" she asked, as she surfaced with a treasure of green velvet and wood, a small rocking horse. Ty's ornament. His only one.

Pain born of sweet memories of a child's first Christmas and the undeniable knowledge that there would be no more Christmases for him swept over me. It was too much.

"Put that back," I shouted, immediately ashamed of my reaction, yet not knowing what else to do.

I gathered her into my arms and we both cried, her tears of confusion rolling together with mine of sadness, grief and resolution.

"I'm sorry, I'm sorry," I apologized, holding her close and breathing in her sweet smell of pine needles and baby shampoo.

Recovering quickly, Jen asked, "Can I hang it on the tree?" She slid off my lap and dove for the cardboard box. Before I could object, she had placed the little wooden horse in the center of the tree. Standing back to admire her work, she turned to me with four-year-old wisdom and said, "Now it's Christmas."

That was five Christmases ago and Jen, now nine, is helped by her four-year-old brother, Jordan, as we decorate this year's tree. Jordan places the green velvet-and-wood little horse on the branches. He knows about Tyler, the brother who died before he was born.

He can't know the pain, the long road to recovery our family has traveled. He'll never know how it felt that first Christmas without Ty—the emptiness of our house, the loudness of a quiet nursery, the struggle of our little family as we hobbled through the holiday on three legs where once there were four. I hope he'll never know the futility of trying to pretend things are the same when they can never be.

It is enough for him to know that, in his sister's wise words, "Now it is Christmas."

MEMORIAL DONATIONS

Donations have been made in the loving memory of the following babies by those who loved them:

In Memory Of Scott Francis Hogan

John & Anne B. Hogan

In Memory Of Ashley Gutilla

David McKee

In Memory Of Paul Humas-Marton

Sharmayne Rasberry

In Memory Of Kristy Kirchner

Carol Suits

In Memory Of Ian Watson

Toni & Russell Hudson

In Memory Of Jill Suzanne

Mildred Sparks

In Memory Of Hayden Strickland

Jennifer Obermoeller

Michael & Lisa Tittle

In Memory Of Mathew A. Gaalswijk

Cornelis & Maria Gaalswijk

Pete & Liz Gaalswijk

In Memory Of Jacob Tyler Williams

“Baby Jake”

Steve & Mary Williams

Phyllis Edwards

In Memory Of Kaylee Billings

Dale & Judy Dunbar

Lori & Lance Blake

Andrew & Lisa Billings

In Memory Of Ryan Joseph Jahn

Orlando & Brenda Rodriguez

Michael & Mary Karr

Carl Joseph Adelhardt

David Dauncey

Gary Soto

Michelle Schmitt

Emmett & Laura Black

Lila Jenkins

Ian & Tiphany Ruppert

Irene Takushi

Dennis Dockstader

Michael & Gloria Spelber

Mary Free

Brooke Wright

Thomas Copenhaver

Lisa & Terry Jeffers

Charles Connelly

COMMUNITY OUTREACH

A great many thanks to our volunteers Lisa Billings, Carole Guttilla, Rachel Strickland, Liz Willett, Shari Morinishi, Cory Morinishi, and Teri Green. September 9, 2006, these dedicated volunteers gave hours of their free time to appear at Babies "R" Us stores in Cerritos, Westminster, Irvine and Brea to hand out literature on how to reduce the risk of Sudden Infant Death Syndrome and to take the opportunity to speak with parents and parents to be. This is a very important educational outreach and we are proud to be invited to participate in this Babies "R" Us event.

The Holidays are Coming!

By Marge Frankenberg/TCF, Arlington Heights, IL
Compassionate Friends December 2003

“The Holidays are coming! The Holidays are coming!” Most bereaved parents make that observation with the same sense of fear and dread that Chicken Little had when he announced, “The sky is falling! The sky is falling!” We view Christmas or Hanukkah differently than the rest of the world. In our minds they become great trials to be endured.

In my opinion, this trial is tougher than birthdays or death anniversaries. This is the time when love abounds. The family (and extended family) all gather together, coming from near and far, to share in this love. The only trouble with this happy scene is that our child is missing. He or she has traveled too far from us to come for the holidays! We can't buy gifts for a photograph or hug and kiss a memory. The emptiness that this creates in us cannot be filled, no matter how many relatives gather by our hearth. To add to the pain, most well-meaning friends and relatives feel that the best way to handle the problem is to pretend that it doesn't exist. They never mention the one person that is on the minds and in the hearts of everyone. We found out early on that it is not possible to keep the “presence” of our child out of a family gathering. Trying to do so makes everyone uncomfortable and causes us as parents to feel disloyal.

The first Christmas after our son died, we did it “their” way. Never again! Now we make sure that he is very much a part of our holiday. For starters, we decided to hang all three stockings. We don't fill them, but just seeing them all hanging together is right for us. We have a very special tree, about 3 feet tall, that we weigh heavily at the bottom. We decorate it with weather-proof ornaments and place it at his grave. We leave the tree there until spring so it can mark the gravesite when the snows are deep. We also have a lovely candle that we burn on special days. This is our way of including our missing son in the family circle. But most important, we talk about him. We don't do it obsessively; but we don't hesitate to recall memories of him as often as we recall those of other children in the family. Because we talk of him in an easy and natural manner, the rest of the family has taken our cue. They now bring up his name naturally. It is all so much more comfortable than the way we tried to handle it that first year.

Another couple in our chapter had a wonderful idea for the first holiday after their daughter died. Their greatest fear was that no one would mention her, so they compiled an album of her pictures and casually left it out on the coffee table. It wasn't long before people were looking through it, recalling favorite memories of her, and the ice was broken. There must be so many other ways that you can make your child a part of your holiday – ways that seem right and comfortable for you. You may choose to keep your thoughts private rather than share them with others. But the most important thing to remember is that choice is yours. Do what makes you comfortable, not what others think should make you comfortable. If you follow the dictates of your heart and that which gives you comfort, those around you will see it also and follow your lead.

"Candles in the Night"

Candles flame in darkness,
 Flicker, steadily glow,
 Bringing light from shadows
 And help to soothe me so.

My daughter, like the candles,
 Gave my life true light,
 I use the candle's beacon
 To connect us in the night.

As I light the candles,
 My wish and my request
 Is that she'll see my signal
 And know my love's expressed.

As her light joins my lights,
 Our worlds touch and flame.
 As I snuff out the candles,
 I softly say her name.



~Anonymous

YOUR GIFT IS APPRECIATED

This Gift Is In Memory Of:

This Gift Is In Honor Of:

Acknowledge To: _____

Address: _____

Donor: _____

Address: _____

Please print. Make checks payable to:
 Guild for Infant Survival (GIS)
 P.O. Box 17432, Irvine, CA 92623-7432

Thank you Fundraising Committee

If you didn't come to our annual fundraiser, *Billiards for Babies*, you missed out on an exciting evening. We had one of the most profitable events and it is due in no small part to the wonderful people on our committee. Jordy Jahn and Rachel Strickland chaired the event this year and did a phenomenal job coordinating every detail. Jordy and Rachel along with Denise Royal and Laura Kirchner were instrumental in attaining fabulous silent auction and raffle prizes. Their efforts paid off as we raised in excess of \$15,000 this year. Expert basket makers included Nancy Eckert, Carole Guttilla, Liz Willet, and Shari Yamamoto while Barbara Estep completed numerous tasks required to make this evening extra special. Events like these take so much time and effort. If it weren't for individuals like these volunteers, our group would not be able to support the researchers and families that we do. On behalf of the Guild, thank you, thank you, thank you!

GUILD'S ANNUAL FUNDRAISER A

Over 130 people attended this year's "8th Annual Billiard's For Babies". Co-chair Jordy Jahn commented, "That's the best attendance the Guild has ever had and we raised the most money ever, thanks to our great sponsors, donors and attendees. We really live in a wonderful, supportive community."

Held on October 21st at Danny K's Billiards & Sports Bar in Orange, some attendees chose to participate in the spirited billiards tournaments, where both the winners and losers took home prizes.

However, the main attraction was the silent auction, which had close to 100 items to choose from, such as: magnificent baskets filled with gourmet foods and premium estate wines, to a digital camera and an i-pod with all the accessories, donated by Circuit City.

There were also items and events for children, from swimming lessons, to parties, to surfing lessons, which covered a whole table. Gardeners were not forgotten for there was also a wheelbarrow filled with garden tools and fun things for the entire family. Infant baskets and an Amby swing were also among the great items in the auction. There were fitness classes for men and women, kick-boxing, yoga, and rock climbing classes. The men vigorously competed for the deep sea fishing and golf packages.

Bids soared for Lakers, Ducks, Angels, and other sports event tickets and sports memorabilia. Theater tickets also increased the wide variety of items available. Mystery envelopes, with values guaranteed above the sales price disappeared rapidly. There were also dozens of raffle boxes, where the participants could "stuff" the box to increase their chances of winning some magnificent prizes, such as "High End" restaurant certificates.

There were some spectacular items highlighted. Barjon, Custom Jewelry Designers of Santa Barbara, created a one of a kind "LOVE ANGEL" Necklace for the annual event that was designed by the brother of a SIDS mom.

Another highlight of the evening was several get-away packages: The historic Saddleback Inn at Lake Arrowhead, a Central Coast Package and a Palm Springs Package. A generous donation from the "Montage" in Laguna Beach had the most exciting bidding and brought in the most money for a single item that evening.

"My husband brought in the second highest amount of money for a single item," said Rachel Strickland, fundraiser co-chair, laughing. Her husband Shawn, who was a contractor, was auctioned off as a "Hire-A-Hunk." He not only came with eight hours of professional work, but also with \$200 in gift cards from Home Depot!

"There was something for everyone," said Rachel Strickland. "It was a great event."

Then Jordy Jahn mused, "But now that researchers have identified a potential biological cause of SIDS, maybe next year our fundraising focus will be helping fund the development of a diagnostic test to identify newborns at risk. At last prevention! Can you imagine a world where no infant will ever again be lost to SIDS?"

SIDS No Longer a Mystery – New Research Identifies a Potential Biological Cause

Researchers hope to develop a diagnostic test to identify newborns at risk

[Baltimore, MD – October 31, 2006] First Candle/SIDS Alliance, the nation's leading organization dedicated to infant health and survival, is pleased to announce that researchers at Children's Hospital in Boston have new autopsy data that provides the strongest evidence yet that sudden infant death syndrome (SIDS) is not a "mystery" disease, but has a concrete biological basis. Based on their findings, the researchers hope to develop a diagnostic test to identify newborns at risk and envision treatments to protect them during the vulnerable period. First Candle is available as a resource, with experts and parents for interviews, for anyone interested in reporting on this important topic!

Despite tremendous success at reducing SIDS rates since inception of the Back to Sleep campaign in 1994, SIDS remains the leading cause of death for infants one month to one year of age. The Back to Sleep campaign warns parents about the dangers of tummy sleeping, soft bedding, bed sharing and tobacco exposure both during pregnancy and after birth as leading risk factors for SIDS. The study results strongly underscore the importance of avoiding these practices in order to save as many lives as possible.

The current study, which appeared in the November 1, 2006 Journal of the American Medical Association, is important because it provides more conclusive evidence that a significant number of SIDS babies have a brain disorder. The abnormalities identified in this study suggest that there is a problem in the development of the brain that occurs in utero and after birth as well. According to Dr. Hannah Kinney, senior author of the paper, this opens the window of time available for identifying infants at high risk and provides the opportunity to use drugs and other interventions as the baby passes through the critical first six months of life where the risk for SIDS is the greatest. "My hope is that this research will in some way ease the pain for parents of SIDS victims, helping them understand that their baby's death was part of a disease process rather than a mystery," says Kinney.

The abnormalities identified as part of this study appear to affect the brainstem's ability to use and recycle serotonin, a brain chemical which plays a role in communications between brain cells. Serotonin is most well known for its role in regulating mood, but it also plays a role in regulating vital functions like breathing, heart rate, temperature, blood pressure and arousal. While the SIDS cases contained more serotonin using neurons, they appeared to contain fewer receptors for serotonin than did the control cases. The researchers also found that male SIDS infants had fewer serotonin receptors than did either female SIDS infants or control infants. The finding may provide insight into why SIDS affects roughly twice as many males as females.

"This finding lends credence to the view that SIDS risk may greatly increase when an underlying predisposition combines with an environmental risk—such as sleeping face down—at a developmentally sensitive time in early life," said Duane Alexander, M.D., Director of the NIH's National Institute of Child Health and Human Development.

The majority (65 percent) of the SIDS cases in the data set were sleeping prone or on their side and 23 percent were sharing a bed at the time of death, indicating the need for continued public health messages on safe sleep practices.

First Candle supports a broad portfolio of research, but has been a primary funder for Dr. Kinney's research since its inception in 1985. This important extension of her ongoing brainstem research gives us renewed hope that we are on the right path to eliminating SIDS as a cause of death for our children . . . our future.

A FUZZY LOGIC BASED APNEA MONITOR FOR SIDS RISK INFANTS.

Burke M.J., Downes R.

J Med Eng Technol. 2006 Nov-Dec; 30(6):397-411.

A unit has been designed which monitors newborn infants at risk of Sudden Infant Death Syndrome (SIDS) in a home environment. The unit monitors respiration, electrocardiogram (ECG) and hemoglobin oxygen saturation (SpO₂) in combination, in order to detect any potentially life threatening event at an early stage. Provision is made for the generation of both audible and silent alarms and for the storage of signals and other information before, during and after an alarm episode for diagnostic purposes. An intelligent fuzzy logic algorithm is used to process the signals monitored and to implement several propositions concerning their status in order to determine the probability of an apnea event and initiate the appropriate action. This has substantially reduced the number of false alarms and of undetected dangerous situations compared with previous units, which greatly improves the reliability and usefulness of such a monitor.

Full-text available at:

<http://www.ingentaconnect.com/content/03091902/>

Ask The Doctor

This column offers our readers the unique opportunity to ask questions of a medical nature which will be answered by **Thomas G. Keens, MD**, Professor Pediatrics, University of Southern California School of Medicine/Children's Hospital Los Angeles and **Henry F. Krous, MD**, Professor of Pathology & Pediatrics, UCSD School of Medicine, Director, San Diego SIDS/SUDC Research Project, Children's Hospital San Diego. Please address your question in writing to either of our experts and mail to:

GISOC, P.O. Box 17432
Irvine, CA., 92623-7432
or e-mail to gisoc@compuall.net.

We thank Dr. Keens and Dr. Krous for being willing to volunteer their time and expertise in this way.

NEWSLETTER DONATIONS

The cost to print and mail the *Reflections* newsletter is steadily rising. Therefore, it is important that we have your latest contact information. If the address shown on your newsletter is not correct, please e-mail Barbara Estep at gisoc@compuall.net or call her at (714) 973-8417 with your current information.

Newsletter donations of \$20 covers the cost of printing and mailing quarterly newsletters. Mail your donations in today.



2006 MEETING CALENDAR

Parent Support Meetings– All meetings are from 7:00—8:30 PM.

*** Please RSVP to the parent host prior to the meeting**

January 16, 2007 PUMP IT UP! (6:30-8:30 P.M.)
16871 Noyes Ave., Irvine
RSVP to Lisa Billings at (909) 569-7416 or GISOC Office

March 13, 2007 Home of Chris and Nancy Eckert
26501 Valpariso, Mission Viejo
RSVP to (949) 768-1863

Business Meetings– Business meetings are held at the home of Lisa Biakanja located at 20732 Alicante Lane, Huntington Beach, (714) 960-9897. Meetings begin at 7:00 PM. If you would like to have an item added to the agenda, please contact Lisa at (714) 960-9897 or lbiakanja@yahoo.com.

February 7, 2007



**GUILD FOR INFANT SURVIVAL, ORANGE COUNTY
P.O. BOX 17432
IRVINE, CA 92623-7432**

**NON-PROFIT
U.S. Postage PAID
Tustin, CA
Permit No. 309**

This newsletter is made possible, in part, by a grant from The CJ Foundation for SIDS

WE NEED YOUR HELP

Stamp

We are updating our mailing list. Please help us by completing this form. To mail: Cut this page in half and fold it so the address on the opposite side is showing. Staple, add a stamp and mail.

Name _____

Address _____

City _____

State _____ Zip _____

**GUILD FOR INFANT SURVIVAL,
ORANGE COUNTY
P.O. BOX 17432
IRVINE, CA 92623-7432**

Please check all that apply:

_____ Please add me to the mailing list

_____ Please discontinue sending the newsletter

_____ The above address is new

_____ I receive more than one copy of the newsletter