



"To keep new lives living."

REFLECTIONS

VOLUME 72

FALL ISSUE

November 2005

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

- Debbie Gemmill
(760)747-4429

mom2127@aol.com

- Irene Holguin
(909)783-2944 (Spanish)

gisie01@yahoo.com

- Shari Morinishi
(714)952-1466

sharmori@comcast.net

- Mary Williams
(714)846-0229

zach4596@aol.com

- Mary Ann Garcia
(714)403-1814

mriversgarcia@yahoo.com

Grandparent Contact

Carole Guttilla

(714)524-7647

gutticarole@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

Public Health Advisor

Penny Stastny, Public Health
Nurse/Medical Professional

Technical Consultant

Andrew Beale

Unisys Corporation

Executive Director

Barbara Estep

gisoc@compull.net

Unseen Scars

...From a Parent's Point of View

Debbie Gemmill c 2005

John and I took the train up the coast to spend a long weekend in Santa Barbara to celebrate our birthdays. It's been a tough few months dealing with my mother's illness and death, and then the subsequent loss of a job I love, due to cuts in our district's education budget. During the midst of it all, I had an unfortunate and painful encounter with a tidal wave of hot cooking oil, resulting in second degree burns covering much of my arm, hand, neck and collar bone. A trip to the emergency room, some removal of skin and something that felt like plastic wrap encasing my arm and I was assured I'd be fine. Ugly for sure, but I'd survive.

The doctor told me it would be best, after a couple of days, to leave the wounds uncovered to aid healing. I stayed home for a day, not wanting to be out in public. My arm was badly blistered. It was unpleasant to look at, and it made me very uncomfortable. Vain? You bet. But life goes on, and back out to the Real World I went. It took about 5 minutes to realize that I wasn't the only one uncomfortable. People

(continued on page 6)

Inside this issue:

President's Note	2
Angel of Hope Memorial Service	2-3
Help Someone Grieve This Holiday Season	4
"Happy Birthday Jason!" and "Remembering"	9
SIDS Prevention Recommendations	10
2006 Meeting Calendar	11

SAVE THE DATE!



*Angel of
Hope
Memorial
Service*

December 6, 2005



A Note From The President



I had a miserable weekend. I couldn't quite put my finger on what was wrong, but I was definitely out of sorts. My mood was edgy and my tongue was sharp. Nothing was good enough and no matter how hard my family tried, nothing was going to get me out of this mood. Everyone attributed it to the events of the past year – going through a nasty divorce, finishing my credential program to be an elementary teacher and then not being able to find a job, caring for two special needs teenage boys, worrying about my sister's bout with breast cancer, and taking care of my elderly mother that lives alone 45 minutes away. But it was more than that . . .

I later realized it was that thing we call "anticipation anxiety". My daughter, Kristy, died 23 years ago September 18. Subconsciously for days I had been anticipating this date. I became more and more agitated and I didn't attribute this edginess to this anniversary. When the day came, it finally dawned on me why I had been acting so unusual.

Why this year hit me so hard, I'm not sure. Perhaps it is because of all the superfluous things that have happened to me and what I will undoubtedly face in the coming months – perhaps it's just the unknown that has me so boggled.

I spent the morning at the Angel of Hope Monument. It helped to see Kristy's name engraved on her brick at the angel's base. I finally had a place to mourn. When I reached the angel, I found dozens of flowers, notes, cards, stuffed animals, and pictures – more than I had ever seen before at one time. It was comforting to know that others felt as connected to the angel as I continue to feel. Just knowing that another parent sat at her base as I now was, somehow helped lessen my grief.

I guess I'm writing this to assure you that you won't ever forget your baby. Years will pass. Some will do so swiftly but others will hit you like it was yesterday and that's OK. This signifies to me that my love for my baby will never die no matter how many years pass. I take solace in this knowledge. It helps me to sleep at night and to dream of better days to come.

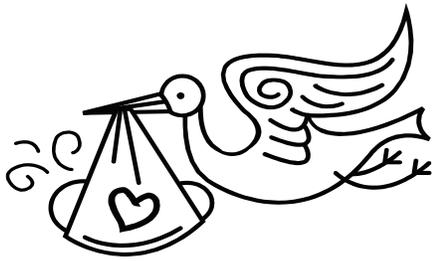
Angel of Hope Memorial Service

Every year, on December 6th, a candlelight ceremony is held at the angel status in memory of those children we have lost. It is an evening of healing and remembrance. This ceremony takes place at 7:00 pm around the country.

Parents, relatives, and friends gather around the base of the angel monument and appreciate a moment of silence. They then lay white flowers and mementos at the base of their angel, as a sign that their loved ones are not forgotten.

(continued to Page 3)





The STORK REPORT

Makenna Kaylee Billings

Born August 29, 2005

6 pounds 12 ounces

Congratulations to
Lisa and A.J. and big brother Jared

Is there a new little one at your house?
If so, we would love to share your happiness. Please send all pertinent information to the Guild office for publication in our next newsletter.



Angel of Hope Memorial

(continued from Page 2)

People will come from all over the state to find solace in the statue's presence and to rest their grief in the outspread arms of an angel . . . a stone angel . . . an angel with hope in its wings.

We invite you to attend this annual ceremony in remembrance of your baby on Tuesday, December 6.

Community Outreach

In July, Glenn Morinishi, MD spoke to the Trauma Intervention Program (TIP) volunteers at Western Medical Hospital in Santa Ana. In attendance, there were about 25 volunteer trainees, who are dispatched to hospital and trauma sites in order to provide emotional support. He presented the perspective of a SIDS parent and the effect that first responders have on the grief process.

.....
On September 29, Mary Ann Garcia, a SIDS mom and Guild volunteer, along with Barbara Estep, our Executive Director, made a presentation to the MOM's club of East Fullerton. Mary Ann spoke about October 23, being the fifth anniversary of her daughter Kayla's death and how they, as a family, honor her. She also spoke about SIDS and its effect on the family and why she actively participates as a volunteer. Barbara responded to questions regarding who the Guild is and what we do for families and the community. A sincere thank you was given to Alyce Finch, President of the East Fullerton's MOM's Club, for their generous donation and invitation to the Guild to share information.

Community Support Campaign Donations:

- Gail Cady
- Nancy LaRuffa
- Kim M. Young
- Michele Phillips and a matching gift from SAFECO
- Jennifer L. St.John

Beatitudes for those who comfort

Reprinted from Life-Line,
No. 37, Winter 1998

- ◆ **Blessed** are those who do not use tears to measure the true feelings of the bereaved.
- ◆ **Blessed** are those who do not always have a quick “comforting” answer.
- ◆ **Blessed** are those who do not make judgments on the bereaved’s closeness to God by their reaction to the loss of their loved one.
- ◆ **Blessed** are those who hear with their hearts and not with their minds.
- ◆ **Blessed** are those who allow the bereaved enough time to heal.
- ◆ **Blessed** are those who admit their uncomfortableness and put it aside to help the bereaved.
- ◆ **Blessed** are those who do not give unwanted advice.
- ◆ **Blessed** are those who continue to call, visit, and reach out when the crowd has dwindled and the wounded are left standing alone.
- ◆ **Blessed** are those who know the worth of each person as a unique individual and do not pretend that they can be replaced or forgotten.
- ◆ **Blessed** are those who realize the fragility of bereavement and handle it with an understanding shoulder and a loving heart.

MEMORIAL DONATIONS

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

In Memory of Kari Lorraine Anderson

Terry & Kristie Anderson

In Memory of Mitchell Alan Bennett

Karen & Alan Bennett

In Memory of Kaylee Rene Billings

Dale & Judy Dunbar

Lisa & A.J. Billings

In Memory of Jason Doo

David & Alpha Doo

In Memory of Jamie Lynn Dow

Melinda Dow

In Memory of Bailey Downs

Devin & Tiffany Downs

In Memory of Madelyn Frowine

Pam Borchard & Nancy Maruyama

In Memory of Mathew A. Gaalswijk

Pete & Liz Gaalswijk

Cornelis & Maria Gaalswijk

In Memory of Kayla Garcia

Stuart & Jennifer Barada

In Memory of Lauren Elizabeth Gehrke

Lorie & Werner Gehrke

In Memory of Scott Francis Hogan

Mr. & Mrs. Richard R. Hogan

In Memory of Amy Michelle Kopic

Bonnie & William Merrill

In Memory of Daniel Kevin Nichols

Donald & Mary Nichols

In Memory of Sarah Ashley Robbins

Leslee Milch

Denise & Thomas Robbins

In Memory of Kurt Andrew Rosenquist

Robert & Connie Rosenquist

In Memory of Anne Frances Schmidt

The Schmidt Family

In Memory of Hayden Raye Strickland

Daddy & Mommy

Big Brother Hunter

Little Sister Hope

In Memory of Ian Russell A. Watson

Russell & Toni Hudson

Thank you to

Tracy A. Ruddy

Help Someone Grieve This Holiday Season

By Kris Wurm, Northeastern Satellite Coordinator

Reprinted by the California SIDS Program

Many people are wary of reaching out to a grieving person. Some are fearful of saying the wrong thing and causing further pain. Others think talking about the child will prevent parents from being able to move on. Still others are uncomfortable with death and intense feelings of sadness.

I have learned from many bereaved parents that being avoided, or the lack of conversation with friends about their baby, is far worse than having someone say something that doesn't help. It is more important to talk to people with good intentions. Avoidance results in greater feelings of isolation and loneliness.

The holidays are a time many bereaving parents need companionship most. Unfortunately, it also is a time people are less likely to give it. Therefore, remember to make a special effort to include a grieving person in a conversation or activity.

Some people believe talking about the baby will prevent the parents from being able to move on. This is not true. The majority of parents will be pleased you remember their child and need for support. Talking about their feelings enables them to work through their grief. By sharing thoughts and feelings, you are showing them you care and that it is OK to talk about it.

Another reason people do not reach out to bereaving parents is their own discomfort with death. The rude reality is tragedies like this can happen. Realize there are many things in life we cannot control. Also, set realistic goals. Do not expect to make the person happy. You cannot make it better, but you can make the grief process easier by being there and allowing them to grieve as they wish.

The following suggestions may help you reach out to someone grieving this holiday season:

- Remember their child – purchase a memorial in the child's name (a memorial brick at the Angel of Hope Monument, a tree, park bench, piece of playground equipment). Make a donation to an organization the parents endorse in memory of their baby (such as GISOC). Place a holiday decoration on the baby's grave. Give them a memento of their baby (an angel). Collect memories from those who knew their baby and compile them in a book. Give them a book on grief and mourning or a subscription to a bereavement magazine.
- Provide opportunities for social interaction – call the parents just to talk. Invite them to join you in an activity, such as a meal, shopping, or ice skating. Offer to attend a support group meeting with them or watch their other children so they might attend. Go with them to their child's gravesite.
- Assist them with their activities – offer to do the parent's grocery shopping. Send a plant or a care package of holiday treats, scented soaps or a casserole. Invite them over to make cookies and candies or offer to do these things with their other children for them. Help them wrap holiday gifts; prepare a holiday meal for them. Help them put up or take down decorations.
- Respect their feelings – the parents may want to observe the holidays in a way that is different from before. Remember incorporating their child's death into their holiday rituals is important and may change over time. Though the holidays will be difficult and different this year, they still can be a time of comfort, hope, and love.

Unseen Scars

...From a Parent's Point of View

(Continued from Page 1)

looked at me, then my arm, and then they looked away. I found myself wishing they would ask, so that I could tell them that I was still the same person as I had been the week before. I was more than my wounds. But they didn't ask, and I didn't offer.

The doctor and nurses were right of course; I am healing. They were optimistic that eventually my scars will fade and only I will know that they are there. In the big picture, it was a blip on the screen.

By the time we left for our train trip, three months later, I was back to wearing sleeveless tops without hesitation. The scars are still there. I've just mostly forgotten about them.

We had a wonderful time away. Lots of walking around, lots of beautiful things to explore, lots of great food. We spent as much time as we could on the wharf, breathing in the salt air, and feeling the coolness of ocean breezes on our faces. We'd lived at the beach when Tyler died from SIDS; his ashes were scattered there. I always forgot how transformed I feel when I am back at the ocean; it's like a rerun of time remembering how the children and I (Ty in his stroller) would walk down to the beach every afternoon during that time between naps and dinner. It restored me then, and it restored me again, all these years later.

We packed up on Sunday morning, walked down to the train station and headed home; feeling refreshed and ready to face whatever awaits us back in the Real World. We weren't settled in long before a couple of women and a young man sat in the seats across the aisle. The older woman was 80, she proudly told us, and was traveling with her daughter and grandson from a family wedding. A big family wedding, and she was happy to tell me all about it, and all about her family...children, grandchildren and great grandchildren. During the conversation she mentioned her son, Kevin, who as a child, had died from leukemia. She looked out at the ocean as she mentioned his name. "It was years ago," she said softly. "But you never forget."

We were quiet for a little while, I being unsure what to say. Did I jump in and say, "hey, me too," did I allow her moment of remembering a little boy lost too soon? Before I could decide what to say, she recovered quickly, turned to me and said "Dear, what happened to your arm?"

The conversation turned to funny recollections of bad kitchen experiences, birthday parties, the delicate balance of trying to raise a family and a career. As different as we were in age and generation, we had much in common. I felt connected to her somehow, and it no longer made

(continued on Page 7)

Unseen Scars

...From a Parent's Point of View

(Continued from Page 6)

sense to wait for a good time to tell her just how much we had in common. I blurted out "I lost a son too." Her face took on that knowing look of someone who can truly say "I know how you feel."

She wanted to know about Tyler, and what had claimed his life. She wanted to know how my life had changed ("because it does, dear, even if other people don't see it.") Putting one foot in front of the other. Pain you never forget. Unseen scars. Wanting to tell people about your pain, the incredible depth of the wounds to your heart and soul resulting from the death of a child. Knowing that we are more than our wounds; that we've chosen to be. Hoping they will ask. Hoping they won't.

I never asked her name. I will remember her as Kevin's mother. We shared something special... remembering when others have long forgotten. The experience of a train ride along the ocean where life exists in places deep below. The chance to say our sons' names out loud to someone. To someone who sees our scars.

Holiday Gift Giving

Need a special gift? Please visit our website, www.gisoc.org. Sales items are available that make perfect stocking stuffers! How about a cuddly lamb or stuffed bear or include a butterfly pen or heart pencil? Best of all your purchase is tax deductible! Order today for immediate delivery.

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@comcast.net. The next Newsletter deadline is 1/1/06. We encourage your participation!

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.

END OF THE YEAR DONATIONS

Don't forget to make your charitable donations for 2005 prior to December 31. An envelope is included for your convenience.

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

Don't Think I Do Not Grieve

By Brenda Penepent

Don't think I do not feel;
 Because you see no tears.
 A river rages deep inside
 Of grief, and loss, and fears.

Just because I do not cry now,
 Don't think my heart's not broken.

I keep inside the misery
 Of words not to be spoken.

Sometimes I smile, or crack a joke,
 So you won't see the pain;
 Or notice how my hands will shake,
 Or how I've gone insane.

Each time I chance to think of her,
 My heart is ripped asunder.
 The loss I feel is mine alone.
 You will not see my thunder.

ENTERTAINMENT BOOKS

The Guild is once again selling entertainment books for the year 2006. Local books are \$35.00 each. Non local books vary in price. They can make great gifts or make for a great family date night. Contact Barbara estep at (714) 973-8417.

Happy Birthday, Jason!

By: Susanna Shutz Robar

Thirty-five years! How could that possibly be true? We are still, my husband and I, in the same town, on the same street, and in the same house. Our cars are different, our other children are grown, and maybe we are a bit older. But, thirty-five years?

I never thought that I would ever be able to look back over such a long period of time toward our son's home-going. When Jason died on October 4th of 1970, it seemed as though time became one big black hole. It left me swirling in a deluge of mystery that did not want to be set free. There were no more days or weeks for me. The day he died evolved into one tremendously long night in which there was no rest and no understanding.

In those long-ago moments, I wondered how in the world life could be lived in my heart again. A great heaviness and emptiness swept over me. It felt so weighty that I could not comprehend any manifestation of its end.

However, as time, that wonderful blessing bestowed upon each one, moved into my life with various people and in innumerable ways, I slowly took passage on a new path toward wholeness. It was not a return to the same measure of life as I had experienced before. It was a new sort of fullness that has found sustainable under-girding, a secure support.

In the beginning of those dark days, I felt so weak and low. Though today, I read the words that came to me then as I tried to make sense of my tragedy. The sentiment ends with, "...and one day soon, we'll play again beyond the moon." Now I realize that even back then, there was evidence of a strength and courage displayed in me of which I was not aware.

Fittingly so, it seems, it is in our darkest hour that the capacity to endure which has lain dormant deep inside springs forth for such a moment. Even though it might not be immediately noticed, it is there, allowing us the grace to not only endure, but to eventually heal and to hope once again.



Remembering

*A gift of joy for all who shared;
To hold the boy for whom we cared.*

*Carrot red hair and sky blue eyes;
Smile so rare and a look so wise.*

*Dimpled, soft marshmallow cheeks;
Nose aloft, with a laugh so sweet.*

*Baby Mine, Baby Dear;
One who gave us so much cheer.*

*Forever thankful we will be,
To remember you upon our knee.*

*Sleeping sound, sleeping fast,
Or laughing loud out of the past:*

*Be happy, my Dear, for one day soon,
We'll play again beyond the moon.*

©1970 Susanna Shutz Robar

SHOULD PARENTS OR CAREGIVERS USE PRODUCTS THAT ARE DESIGNED TO KEEP BABIES ON THEIR BACKS DURING SLEEP?

The American Academy of Pediatrics does not recommend the use of such products. Some of the devices are designed to keep babies on their sides, and there is good evidence that side sleeping is not as safe as supine (back) sleeping. Other devices are designed to keep a baby on his/her back or to prevent re-breathing. But none of the devices have been studied sufficiently to demonstrate a decrease risk in SIDS. Furthermore, no studies have been published that examine the safety of these products; in fact, there have been some anecdotal reports of babies being trapped against bedding while strapped into products that keep babies on their sides. Babies who sleep on their backs are very unlikely to roll onto their stomachs during the age range most associated with SIDS; therefore, the use of products to prevent babies who are sleeping on their backs from rolling onto their stomachs are unnecessary.

Adopted from Infant Sleep Position and SIDS - Questions and Answers for Health Care Professionals, National Institute of Child Health and Human Development, NIH Publication No. 02-7202, November 2003. Pages 10-11

California SIDS Program "Horizons", Volume 5, Number 6, July 2005.

AAP Revises SIDS Prevention Recommendations For Release: Monday October 10, 2005

"WASHINGTON, DC - Despite major decreases in the incidence of Sudden Infant Death Syndrome (SIDS) over the past decade, SIDS is still responsible for more infant deaths beyond the newborn period in the United States than any other cause of death during infancy. In an updated policy statement on "The Changing Concept of Sudden Infant Death Syndrome: Diagnostic Coding Shifts, Controversies Regarding the Sleeping Environment, and New Variables to Consider in Reducing Risk," the American Academy of Pediatrics (AAP) addresses several issues that have become relevant since they last published a statement in 2000.

The AAP no longer recognizes side sleeping as a reasonable alternative to fully supine (lying on back) sleeping. Studies have found that the side sleep position is unstable and increases the chances of the infant rolling onto his or her stomach. Every caregiver should use the back sleep position during every sleep period.

Bed sharing is not recommended 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. However, there is growing evidence that room sharing (infant sleeping in a crib in parent's bedroom) is associated with a reduced risk of SIDS. The AAP recommends a separate but proximate sleeping environment.

Research now indicates an association between pacifier use and a reduced risk of SIDS, which is why the revised statement recommends the use of pacifiers at nap time and bedtime throughout the first year of life. The evidence that pacifier use inhibits breastfeeding or causes later dental complications is not compelling enough to discredit the recommendation. However, it is recommended that pacifier introduction for breastfed infants be delayed until one month of age to ensure that breastfeeding is firmly established. In addition, if the infant refuses the pacifier, it should not be forced. There is a slight increased risk of ear infections associated with pacifier use, but the incidence of ear infection is generally lower in the first of life, especially the first six months, when the risk of SIDS is the highest."

This is a portion of a news release from the American Academy of Pediatrics (AAP). If you would like a copy of the entire release please send your request to GISOC, P.O. Box 17432, Irvine, CA 92623-7432.



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 10, 2006 | Home of Chris and Nancy Eckert
26501 Valpariso, Mission Viejo
RSVP to (949) 768-1813 |
| March 14, 2006 | Elizabeth Broderick's Home
17564 Santa Paula Circle, Fountain Valley
RSVP to Mary Ann at (714) 403-1814 or (714) 973-8417 |
| May 9, 2006 | Home of Chris and Nancy Eckert
26501 Valpariso, Mission Viejo
RSVP to (949) 768-1813 |
| July 11, 2006 | Home of Lisa and Krist Biakanja
20732 Alicante Lane, Huntington Beach
RSVP to (714) 960-9897 |
| September 12, 2006 | GISOC Office
2130 East 4th Street, Suite 125, Santa Ana
RSVP to Shari Morinishi at (714) 952-1466 |

Business Meetings– Business meetings are held at the home of Lisa Biakanja located at 20732 Alicante Lane in Huntington Beach. 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.

January 18, 2006

April 5, 2006



**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