



REFLECTIONS

VOLUME 85

FALL/WINTER ISSUE

NOVEMBER 2009

A Note From The President

President

Rachel Strickland

Vice President

Jordy Jahn

Treasurer

Carol Jahn

Recording Secretary

Lisa Billings and Liz Willett

Historian

Carole Guttilla

Parent Contacts

- Rachel Strickland
shawnrachelhuntr@aol.com

- Lisa Billings
(909) 597-6391

Billingsfam@verizon.net

- Jordy Jahn
(949) 347-8583

Spanish Speaking

Contact

- Liz Ramirez
(562) 233-7864

Grandparent Contact

Carole Guttilla
(714)524-7647

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

Being involved with the Guild for Infant Survival Orange County has not only given me the satisfaction of feeling like I'm giving back to my son Hayden, but it has also opened the door for so many new relationships with my "normal SIDS moms" as I call them. Really I consider them more to be like me. They get me . . . they understand me without words. We have an understanding for each other that so few will ever understand. With saying that, one of my SIDS moms made me a CD of songs that I have always cherished. One song in particular has always stuck out in my mind. It makes me and my 10 year old son cry each time we hear it. It's called "Fly" by Celine Dion. When I was sitting down thinking about what to write about in this president's letter, this song popped in my head. So I thought I would share it with the rest of you. For all my "normal SIDS moms" and friends that understand me . . .

Fly lyrics

Fly, fly little wing
Fly beyond imagining
The softest cloud, the whitest dove
Upon the wind of heaven's love
Past the planets and the stars
Leave this lonely world of ours
Escape the sorrow and the pain
And fly again

Fly, fly precious one
Your endless journey has begun
Take your gentle happiness
Far too beautiful for this
Cross over to the other shore
There is peace forevermore
But hold this memory bittersweet
Until we meet

Fly, fly do not fear
Don't waste a breath, don't shed a tear
Your heart is pure, your soul is free
Be on your way, don't wait for me
Above the universe you'll climb
On beyond the hands of time
The moon will rise, the sun will set
But I won't forget

Fly, fly little wing
Fly where only angels sing
Fly away, the time is right
Go now, find the light

I know we all wish that are babies were still here cuddled in our arms. Especially reading the last two lines of that song . . . man those two lines get me every time. If you need the support of a "normal SIDS mom" to talk to, we are here for you at the Guild.

Blessings on your Holidays.....Rachel

Inside This Issue:

Parent's Corner	2
Apnea, Sudden Infant Death Syndrome and Home Monitoring	3
Good Grief, It's the Holidays	4
Recommendation to Include Breastfeeding in California SIDS Risk Reduction Education	5
Meeting Schedule	11

Parent's Corner

I will never forget you
 My precious little baby
 I will always cherish memories
 The love we shared, your smile
 And you will be remembered
 Each day, right from the start
 As my special little angel
 Who lives in my heart

My handsome son
 Adriel Isaac
*My love goes with you,
 My soul waits to join you.*

Arlene Barela
Word of Life Orange
County
Reaching People,
Touching Lives

Seasoned Parents

- ◆ My life was turned upside down within four short hours three years ago. My precious Nicholas could never smile or laugh with me again. There is a rainbow out there, you will love again, laugh again and live again. My nephew's life continues to go on with respect and honor. I am a SIDS aunt and also a social worker who helps others with the loss of their child. I may not ever have the answers to my nephew's death, but instead I have chosen to channel my love for my nephew into helping others.



- ◆ I remember wondering when I could smile, have fun and be "normal" again. As time passed and I gave more of myself to people and decided to live life, the smile slowly came back.
- ◆ I am the sister of a SIDS baby. I was two when my sister died at four months. I still remember her. I have memories of day to day activities; they only mean a lot more to me now. I am 29 now and not a day goes by that I do not remember her. Your children will remember more than you think.
- ◆ When I was pregnant with my first subsequent child, I was so terrified that I would not be able to love this baby and that I would wish he was my first. But when Kyle was born, I just loved him and he started a whole new *healing* for me.

Dedication to Milo

I love you, Milo, my grandson. I was struck when we truly connected at great-grandma, Rosalie's, while I was gently massaging your muscles as a pre-lesson in crawling. You looked at me in thanks and smiled; your eyes held mine, never

wavering, full of clarity. I felt as if you knew everything about me in that moment. I felt as if I had received darshan or enlightenment – a master's blessing with pure, radiant unconditional love.

You transformed your parents. I saw my son's heart open and a gentleness unfold towards you together with a powerful protectiveness. I saw your mom's confidence bloom and was in awe of her commitment to your well being.

You paced your rhythm to many who held you, delighting and calming them, and bringing out nurturing, loving qualities that I was able to see for the first time. I saw your 100-year old great grandma glowing and beaming in your presence, reaching into her memory to entertain you with affectionate sounds like "Barn Barn Boochie" and with the song, "Baby Bye," and bouncing you on her knee to "horsey riding." You truly opened my eyes and taught me how people respond to pure love.

Now that you are with G-d, or in some beautiful iridescent star, I hope that whatever you brought that opened me to give my gifts even when I was not sure how, that I can continue to give these gifts in honor of your life. I love you so much, Milo.

Blessing Grace Kobey

Grandmother of Milo Henry Salomonis

Who lived from September 17, 2009 to

January 20, 2009

Apnea, Sudden Infant Death Syndrome, and Home Monitoring

Committee on Fetus and Newborn *Pediatrics* 2003;111;914-917

ABSTRACT. More than 25 years have elapsed since continuous cardio respiratory monitoring at home was suggested to decrease the risk of sudden infant death syndrome (SIDS). In the ensuing interval, multiple studies have been unable to establish the alleged efficacy of its use. In this statement, the most recent research information, concerning extreme limits for a prolonged course of apnea of prematurity is reviewed. Recommendations regarding the appropriate use of home cardio respiratory monitoring after hospital discharge emphasize limiting use to specific clinical indications for a predetermined period, using only monitors equipped with an event recorder, and counseling parents that monitor use does not prevent sudden, unexpected death in all circumstances. The continued implementation of proven SIDS prevention measures is encouraged.

Recommendations

1. Home cardio respiratory monitoring should not be prescribed to prevent SIDS.
2. Home cardio respiratory monitoring may be warranted for premature infants who are at high risk of recurrent episodes of apnea, bradycardia, and hypoxemia after hospital discharge. The use of home cardio respiratory monitoring in this population should be limited to approximately 43 weeks' postmenstrual age or after the cessation of extreme episodes, whichever comes last.
3. Home cardio respiratory monitoring may be warranted for infants who are technology dependent (tracheotomy, continuous positive airway pressure), have unstable airways, have rare medical conditions affecting regulation of breathing, or have symptomatic chronic lung disease.
4. If home cardio respiratory monitoring is prescribed, the monitor should be equipped with an event recorder.
5. Parents should be advised that home cardio respiratory monitoring has not been proven to prevent sudden unexpected deaths in infants.
6. Pediatricians should continue to promote proven practices that decrease the risk of SIDS—supine sleep position, safe sleeping environments, and elimination of prenatal and postnatal exposure to tobacco smoke.

The Gift of Someone Who Listens

by Nancy Myerholts,
TCF, Waterville, Toledo, OH

Those of us who have traveled a while
Along this path called grief
Need to stop and remember that mile,
That first mile of no relief.

It wasn't the person with answers
Who told us of ways to deal
It wasn't the one who talked and talked
That helped us to start to heal

Think of the friends who quietly sat
And held our hands in theirs
The ones who let us talk and talk
And hugged away our tears.

We need to always remember
That more than the words we speak
It's the gift of someone who listens
That most of desperately seek.

IMPORTANT

This could be your last newsletter!
Contact lbiakanja@yahoo.com to
confirm your desire to receive
Reflections by email or email
gisoc@att.net to remain on the
mailing list.

Good Grief, It's the Holidays
by Father Tom Johnson-Medland
Mt. Laurel, New Jersey

When I had to co-officiate the funeral for my grandfather, I was a wreck. Aside from blubbering my way through one of the readings and a piece of the homily, I nearly fell into the grave prior to the interment. I hit that astro turf they place around the grave with all my nerves and new pair of slick leather wing tips. Zoom! The Abbot who had been officiating with me, grabbed me by the arm, breaking my fall and averting a scene. As he steadied me, pulling me up, he leaned into my ear. "One at a time please, Tom. It's not your turn."

I shared that memory at a local pastoral care workshop on death and dying. All of the clergy present were interested in the workshop because of the continual work with dying and grief they experience in their ministries. Recognizing the approach of the holidays can send Shivers up many peoples' spines—not just clergy—as they anticipate having to celebrate amid the mending process of grief. Stories like this are central to everyone's experience of a loved one.

The holidays are a time we gather together as family, friends, and a society as a whole. They are times we gain a sense of connection to the various communities we belong to. And, depending on the holiday and its meaning, they can be times of deep awe or gleeful abandon. Holidays always carry emotion. It is because they carry emotion that we connect deeply with the people around us who celebrate these festivities at any level. Consequently, when they are absent, we miss them deeply around the holidays. It takes many years to be able to integrate the loss of a loved one into the holiday celebrations and all of life. That integration comes as we learn to live in the absence of our loved ones and still hold them present in our memories.

Another story that I told at the workshop was about my learning to celebrate my grandfather at Thanksgiving and Christmas. Pop-pop made the family eggnog at all of the major holidays. Several years in a row, he included me in the preparations. I was eighteen and nineteen when I was invited into the inner circle of family lore and allowed to co-celebrate the sacred Levitical task of making the nog. Of course, at that age, I had no eye to the future and did not care to write down the recipe.

All of you know where is headed. Pop-pop died with the family recipe in his head and nowhere else. Over the past six years, I have memorialized Pop-pop at the holidays by spending time alone in my kitchen with all of the ingredients I can recall. I dive into his memorialized presence and pray I'll call forth some mystic recipe that will come close. I have not come close, but I drag the attempts to the grave site,

raise my cup, have a drink and pour some out for Pop-pop and Mom-mom every year—sometimes twice a year. I share a few stories, chuckle at some memories and pray for a better batch next year. It's silly, but it is my little integration. It's my little ritual.

What tends to get us the most in preparing for the holidays is the anticipation. Our fear tends to grow and mount as we anticipate having to face family, friends and traditional customs without our loved ones. Will we say and do the "right" things, or will we fall apart? (As if falling apart is not the right thing!) Will somebody say something that will make everyone upset? How will we get through? All of this builds and mounts and forces us into a corner from which we would just as soon forget the whole mess and hide out. "Why bother?"

Although the holidays will be different and some changes may occur (like a new eggnog recipe or a new turkey carver or cook), it is not the healthiest choice to forego them altogether. There are a few steps you can take to help gain back a little of the control you will need to integrate your loss. You don't want to squish the feelings, just provide a healthy space for them to happen within. You want to feel, but not be overwhelmed by the feeling.

Talking with friends and family about memories you have of your loved one

Continued on Page 6

**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@att.net
Website Address:
www.gisoc.org

Newsletter

If you would like to contribute an article or poem to an upcoming issue of **Reflections**, please contact: Lisa Biakanja at (714) 960-9897 or email her at lbiakanja@yahoo.com. **The next newsletter deadline is 2/1/10.** We encourage your participation!

Recommendation to Include Breastfeeding in California SIDS Risk Reduction Education. California SIDS Advisory Council

The *California SIDS Advisory Council* is empowered to make recommendations about SIDS services, education, and research to the *California Department of Health Services*, when the *Council* believes that such action is warranted. Currently, the State of California, through its Maternal, Child, and Adolescent Health Section and the *California SIDS Program*, conducts SIDS education campaigns to reduce the risk of SIDS. Such education is based on scientific studies showing that the risk of an infant dying can be decreased if parents practice specific behaviors. Currently, the California recommendations coincide with the *American Academy of Pediatrics* recommendations published in 2005 ¹.

The 2005 American Academy of Pediatrics recommendations did not include breastfeeding as a behavior to reduce the risk of SIDS. Although several research studies suggest that breastfed babies have a lower SIDS risk than those babies who were not breastfed, more sophisticated statistical analyses suggested at that time that breastfeeding mothers are also more likely to adhere to other risk reduction behaviors

REFLECTIONS

P.O. Box 148

Tustin, CA 92781

Editor: Lisa Biakanja

Reflections is a tri-annual 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.

(supine sleeping, no cigarette smoking, safe bedding, etc.). Therefore, breastfeeding was not thought to be an independent risk factor, and it was not included in the recommendations. Obviously, the American Academy of Pediatrics does support breastfeeding because of its many benefits for infants.

Research from Germany has re-examined this issue ². Using multiple regression statistical analyses, they found the breastfeeding does have a protective effect at all ages in the first year of life. The SIDS rate in breastfed babies is ~half the SIDS rate in babies who were never breastfed and/or who were not exclusively breastfed. The *California SIDS Advisory Council* finds this research to be compelling.

The Council further recommends that existing materials on SIDS Risk Reduction should not be discarded or destroyed. They should continue to be used. But, any newly developed materials or presentations should include breastfeeding as one of the SIDS Risk Reduction recommendations.

This recommendation was officially made on August 18, 2009.



¹ A.A.P. Task Force on Sudden Infant Death Syndrome. The changing concept of sudden infant death syndrome: diagnostic coding shifts, controversies regarding the sleep environment, and new variables to consider in reducing risk. *Pediatrics*, 116: 1245-1255, 2005.

² Vennemann, M.M., T. Bajanowski, B. Brinkmann, G. Jorch, K. Yucesan, C. Sauerland, E.A. Mitchell, and the GeSIDS Study Group. Does breastfeeding reduce the risk of sudden infant death syndrome? *Pediatrics*, 123: e406-e410, 2009.

Legislative Action Alert
Your help is needed!

Newly introduced Legislation will Support Education and Prevention Efforts for Stillbirth, SIDS and other Sudden, Unexpected Infant Deaths (SUID)

First Candle is pleased to announce that the Stillbirth and SUID Prevention, Education and Awareness Act of 2009 was filed July 14 by Senator Frank Lautenberg, D-NJ. A companion bill was filed in the House by Frank Pallone, Jr., D-NJ-6. This bill would improve the collection of critical data to determine the causes of stillbirth, SIDS and SUID, increase education and awareness about how to prevent these tragedies in the future and expand support services for families who have experienced a stillbirth, SIDS or SUID loss.

Every year there are more than 25,000 stillbirths in the United States. For more than half these deaths there is no known cause, leaving parents with more questions than answers as to why the baby died. The bill would expand activities to identify the causes of stillbirth, identify ways to prevent it in the future and increase education and awareness about the issue among healthcare providers and parents.

In addition, there are more than 4,600 sudden unexpected infant deaths each

WHEN ADVICE IS UNSOLICITED

by Patricia Kolstad, O'Connor Mortuary

One of the most frequently heard complaints bereaved people share with their counselors and in support groups relates to the amount of unsolicited advice they receive from well meaning family members and friends. The "Helpful Hannahs" in the lives of bereaved people offer suggestions about everything from how long grief ought to last ("You should be moving on by now. . .") to how they should experience bereavement ("John wouldn't want you carrying on like this. . .")

How do we help the people who look to us for support when they are receiving such unhelpful comments from their friends? First, I encourage clients to consider the source of the comments. Often, these comments do not come from one's very best friends or closest family members, but rather, from those who are superficially related to them—a friend they see periodically, perhaps, or a family member who never has a positive word to offer about anything. Sometimes, taking stock of where the advice is coming from is a huge piece of helping our clients move past it.

I also like to encourage bereaved people, if they have emotional energy for it, to turn the tables on "Helpful Harry" a bit by asking something like, "Oh, now that's an interesting thought. What have you seen that makes you conclude *that*?" Perhaps it is my wicked sense of humor but I enjoy watching people who always have a word of advice for everybody else when they themselves are "on the spot." Some possible responses that work, almost regardless of what the friend says: "I'll have to ponder that further. Thank you." works well as a response.

Third, I encourage my client to consider what "kernel of truth" might lurk in the advice. Is she bothered because she herself thinks deep inside that she *should have* moved on by now? Giving further thought to the advice you are given and processing that with others is a very helpful technique, sometimes allowing your-

self to go deeper in your own understanding of the bereavement experience. Sometimes the criticism or advice is perceived by the bereaved person to be partially true, and that's what makes it so difficult to dismiss.

My fourth strategy for helping bereaved people who are given unhelpful advice is to help them gain some perspective. There are excellent books to help them realize what grief is like for others. Some of the really good books that help grieving people find normalization in their experience are Therese Rando's *How to Go On Living When Someone You Love Dies* (Bantam, 1991), Joyce Brothers' little paperback, *Widowed* (Ballantine, 1992, but available in many editions including cassette tape), and Helen Fitzgerald's *The Mourning Handbook* (Fireside, 1995). I also like the question-and-answer format of Harold Ivan Smith's book, *Grievers Ask* (Augsburg Fortress, 2004), and though written for friends of the bereaved, I especially like Lynne Kelley's little book, *Don't Ask for the Dead Man's Golf Clubs* (Workman, 2000)—a book whose title alone makes it worth the purchase price!

One last strategy I find helpful is to lead bereaved people in placing this advice (or lack of response when that is the case) from this individual in the context of the whole relationship. I think it is helpful for bereaved people to hear us say that most people don't say hurtful things because they want to be hurtful; they say them because they think it will help. When we talk together about what the relationship was like with this friend or family member before the loved one died, together we get some perspective on whether this unsolicited advice is coming because that's what he or she always does or whether it has been said in a desire to stop their friend's hurt. Misguided and hopeless as this latter goal is for a friend, sometimes it helps the bereaved person just to realize that the friend or family member has offered this advice because they don't want their friend to keep hurting.

Both in individual sessions with clients and in groups, one of the questions I like to ask is, "Of all the really dumb things people have said to you, which comment or advice 'wins the prize' for the absolute worst?" In group, people inevitably laugh—not only at what others have been told but at what they have been told, as well. We help our clients enhance their own self-efficacy when we teach them skills for laughing at what they can, applying truth when appropriate, and dismissing poorly-thought advice whenever possible.



Continued from Page 4

will help. You can share stories that come from celebrating the holidays with them—the foods they liked or the special decorations they insisted on (or how they hated Thanksgiving.)

Share ways in which the holidays will be different without them. Perhaps someone else will have to make the pumpkin pie or carve the turkey. You can decide this together. Maybe you can even invest this person with the new sacred task of doing this thing in memory of your loved one or in honor of them. "Sally, we would like you to be the one who bakes Mom's pumpkin pie for Thanksgiving. I think she would want it that way, and I know we'd be proud." maybe you will have to go out for dinner since Mom always cooked it all and everyone feels it would be too much this first year to try it without her. Then plan to have a go at it next year.

You could give a special gift to someone, donate money to a worthy cause, plant a tree or send flowers in



Continued on Page 8

Continued from page 4

year (including SIDS) and 200 sudden unexpected deaths of children between the ages of one and four. This bill encourages states to complete scene investigations to better understand why these children died, establishes a national database to track these deaths and identify risk factors to prevent them in the future, supports more comprehensive reviews and creates a national public awareness campaign to educate parents and caregivers.

Participating in First Candle's letter-writing campaign is easy!

Visit 222.house.gov to get contact information for the Congressman in your District. You will need your 9-digit zip code. If you do not know your 4-digit extension, you can get it at <http://zip4.usps.com/zip4/welcome.jsp>. You will then be able to link directly to your Representative's website.

Visit www.senate.gov to get contact information for your state's two Senators. Simply select your state from the drop down menu to connect to your Senators' websites.

We encourage you to call your representatives directly, or set up an appointment to meet with them face-to-face. Writing a letter or sending an email can be effective as well. Emails can be sent directly through your representative's websites.

A fact sheet about the bill, as well as a sample letter to help guide you can be found on <http://www.sidsalliance.org/>.

Whether you are writing a letter or speaking with your representatives directly, be sure to include your personal story.

First Candle would love to receive a copy of your letter or an email detailing your conversation with your representatives for our files.

Members of Congress rely on input from their constituents to help them better understand what issues are important to those they serve. Help give our babies a voice!

OC Walk to Remember

by Liz Willet

I, along with eleven of my friends and family members, attended The OC Walk to Remember this year. The OC Walk to Remember is a 5K walk, done in remembrance of all the babies lost to miscarriage and pregnancy and infant loss of any kind. The walk was preceded

Continued on column 3



Angel of Hope
Candlelight Memorial
Service
Sunday, December 6
@ 7 pm
El Toro Memorial Park
25751 Trabuco Road
Lake Forest
Join other parents
honoring their children

Grief, A Bitter Cup

by John Barry
Cromwell, Connecticut

Grief, a bitter cup that grows no sweeter with the passing days,

So grasp it up and drink it in with deep and measured draughts

Tasting all the while from the first to the dregs,

But remember, always, a few drops remain,

Bittersweet reminders of solemn victory,

Love has passed through death and yet remains.



by a memorial service, where each baby's name was read. No baby should ever be forgotten. The ceremony was touching as usual. There were more people this year than ever. It always brings me joy to see families and friends coming together to support those of us who have lost our babies. I lost

Continued on page 9

IMPORTANT

This could be your last newsletter! Contact lbiakanja@yahoo.com to confirm your desire to receive *Reflections* by email or send an email gisoc@att.net to remain on the mailing list.

Continued from page 6

in memory of your loved one. Many times, the holidays are filled with gift giving and presents. Including your loved one in this can help integrate the loss by celebrating his or her life.

Looking at pictures and videos is always a part of good healthy family development. It is a way of marking our days together and seeing how we have grown. Make sure to include some photos or footage of your loved one who died. Sure, people will cry a bit, but allowing ourselves to feel the loss will keep us from sublimating the loss and being eaten alive by the overwhelming attack of buried emotion.

Be gentle with yourself. Sit down and decide which of the tasks that are coming up for the holidays will be tough and which ones easy. Write out a list of the tasks you need to do: buy gifts, get a tree, candles, send cards, etc. Then, next to the task, list some of the emotions that you feel while thinking about the task: sadness, joy, fear, warmth. This will help you identify the different ways you were connected to the person and will help give you a piece of control via self-awareness.

Get plenty of rest. Eat healthy foods stay away from excessive use of alcohol (and other drugs). The wrong amount of any of these things is a form of trying to medicate yourself by obsessing on one thing (food, sleep, etc.) and avoid the feelings of loss. Spend a balance of time with people and alone, with large groups and small. go for walks and exercise breathe deeply. Cry. Laugh.

Above all else, remember that it will be very different. It will be tough. You have lost someone

you love. Take your time and don't load yourself with anywhere near the normal amount of work you would have done before.

After each day or event is over, make sure to check on yourself and on each other. Think about the event and identify things you thought or felt or said. Then ask how you did with that and how you coped. Talk about this with others who know you or who have experienced the same loss. It might be a good idea to speak with a grief therapist or go to a grief/bereavement group. You could check with your family doctor or local hospital or church for referral information. Bringing these things to light will not remove the pain of loss, but it will give you some control over your reactions.

If you, or someone you love, is not eating or is sleeping all the time, skipping work or social events regularly or without notice, abusing alcohol or drugs, or threatening to do harm, these are serious and alarming problems. Grieving is not going well, and while grieving is very different for everyone, some people will come dangerously close to the edge. Contact a doctor, clergy or therapist if you suspect that these symptoms apply to you or someone you care about.

The purpose of "good grief" is to integrate loss into the rest of life and to find appropriate ways to change the life of the survivor that will honor both the absence and the memory of the absent loved one.



Congratulations!

Please join us in congratulating **Susan Moore** as the 2009 Daniel E. Boatwright Award recipient from the California Sudden Infant Death Syndrome (SIDS) community. The Daniel E. Boatwright Award is given for "extraordinary public service on behalf of Californians touched by SIDS". She was honored for her work with the California SIDS Program as a grief counselor and educator of extraordinary talent, ability, and dedication. She is only the 19th person to be so honored by the California SIDS Community. Dr. Tom Keens presented her with this award on October 20, 2009, at the California SIDS Conference in Sacramento. Please join us in congratulating Susie on this richly deserved honor.



.....
: There is love in our pain :
: Memories in our Grief :
: Hope in our sharing :
.....
Dallas TCF

California SIDS Advisory Council: October, 2009, Update.

To Members of the California SIDS Community:

The *California SIDS Advisory Council* was established by California legislation in 1990 to advise the California Department of Public Health on SIDS issues. By law, the *Council* is a nine-member volunteer and interdisciplinary group consisting of SIDS parents, public health nurses, physicians, coroners, and first responders. The goal of the *California SIDS Advisory Council* is to improve SIDS services, education, and research in California.

This nine-member *Council* is only the tip of the iceberg in terms of the hundreds of people who work to improve SIDS services, education, and research in California. Therefore, we need your help, as we are here to help you. In order for the California SIDS community to have access to the activities and actions of the *California SIDS Advisory Council*, we have established a website, which is part of the California SIDS Program website. The purpose of the website is to inform the public about our activities. An important goal of the Council is complete transparency of

Continued from page 7

my son, Kaulin, on October 1st, 2003. I do the walk every year for the same reason their motto so eloquently explains:

- ◆ We walk for the steps they will never take.

Continued on page 10

New Year's Resolutions

Lovingly lifted from Sunlight & Shadows
Volume 32, Number 2, 1996.

I will try not to expect so much understanding from others who have not walked the same path.

I will be kind to myself in health, appearance, and take time to be alone.

I will remember that I owe it to myself to try to enjoy life. I will be considerate of my spouse, children, and parents. They, too, are coping and deserve my help.

I resolve in memory of my child to do something to help someone else. For I know, that in doing this, my child will live on through me.



END OF THE YEAR DONATIONS

Don't forget to make your charitable donations for 2009 prior to December 31. Checks can be made payable to GISOC.

BOOK REVIEW

Zunin, L.M. & Zunin, H.S. (1992). *The art of condolence: What to write, what to say, what to do at a time of loss*. San Francisco: Harper Paperbacks.

In seminars and workshops, one of the most often-heard concerns from would-be caregivers, friends of the bereaved, is, "I just never know what to say or do." Though now more than 15 years old, *The Art of Condolence* is still one of the very best books around to help these people learn how to help in ways that really are meaningful to grieving family members and friends.

The Zunins provide a plethora of practical advice. They begin the book talking about the ancient art of condolence itself and why it is so important that we give the gift of presence to grieving people—whether through visits, written or spoken words, story sharing, or practical actions of helping. In our fast-paced world, these simple things are often overlooked.

Their section on writing to the bereaved is especially helpful and this is one of the few books that thoroughly addresses this issue. Receiving notes and letters of condolence is a welcome respite for bereaved people—not in place of personal visits and phone calls but in addition to them. The advantage, of course, to written correspondence is that it can be cherished to be read over and over again. In the book, the Zunins provide seven essential points to consider when writing to the bereaved.

All in all, this book has stood the test of time. In large measure, its "staying power" might be in part because it is and continues to be one of the most practical books to help the friends of the bereaved to take better care of the folks they love.



MEMORIAL DONATIONS

Special Thanks

Donations have been made in loving memory by those who loved them:

In Memory of Bailey Downs

Mom's Club of La Habra

In Memory of Michael Andrew Elliott

Matthew R. Elliott

In Memory of Jason Alexander Robar

Richard E. Council

In Memory of Sarah Ashley Robbins

Margaret & Iain McCormick

This newsletter is being published thanks to a grant from the Pacific Life Foundation.

Continued from page 9

- ◆ We walk for the babies that touched our hearts, taught us compassion, and made a difference.
- ◆ We walk for our friend, cousin, niece, nephew, sister, brother, child.

I want to especially thank Kristyn von Rotz and Lyndsey McLaughlan the Founders of OC Walk to Remember. Without them this wonderful walk would not take place each October. I, along with others, look forward to next year's walk. Hopefully each year the amount of supporters will continue to rise.

Impact of the Diagnosis on

Parents. California SIDS Advisory Council

One concern about the increasing use of the "undetermined" diagnosis is the impact of the specific determination of the cause of death on SIDS families, their grieving process, etc. There are a number of published studies on the impact of a SIDS death on parents, their psychological reactions to the death, etc. However, we are not aware of published studies, which address this specific issue. The Council believes that the specific diagnosis received *does* have an impact on parents' grief and road to recovery. SIDS is generally considered to be a biological disorder and a natural manner of death, which implies that parents did nothing to cause the death. According to the SIDS parents participating in Council discussions, this helped tremendously to reduce grief, as these parents could point to this diagnosis as evidence that they did not cause their baby's death. On the other hand, a diagnosis of "undetermined", or a similar non-SIDS diagnosis, tainted the baby's death. If the Coroner could not use the SIDS diagnosis, what did he or

she think the parents might have done to cause or contribute to the death? Many SIDS parents believe that the use of a non-SIDS diagnosis complicates grief and recovery.

In an attempt to identify any effect that the specific diagnosis may have on parent grief, the Council will launch a research study. *John Margetis*, a USC undergraduate working with *Doctor Thomas Keens*, and in collaboration with *Dawn Dailey*, *Kathleen Roche*, and *Gwen Edelstein*, is designing an anonymous questionnaire study (using validated instruments, demographic information, and open-ended questions), to attempt to assess if and/or how differing diagnoses affect parent grief.

If a non-SIDS diagnosis is found to complicate grief, this finding may dissuade Coroners from making such diagnoses when medical or scientific evidence is lacking to differentiate.



IMPORTANT

This could be your last newsletter! Contact lbiakanja@yahoo.com to confirm your desire to receive *Reflections* by email or email gisoc@att.net to remain on the mailing list.

2009/2010 MEETING CALENDAR

Parent Support Meetings– All meetings are from 6:00—7:30 PM
Dinner will not be served;

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

November 8, 2009
Sunday
Home of Jordy Jahn
26702 Las Tunas Dr.
Mission Viejo, CA 92692
RSVP to (949) 347-8583

December 13, 2009
Sunday
Home of Rachel Strickland
2828 East Puritan Place
Anaheim, CA 92806
RSVP to (714) 630-0400

January 10, 2010
Sunday
Home of Jordy Jahn
26702 Las Tunas Dr.
Mission Viejo, CA 92692
RSVP to (949) 347-8583

Business Meetings– Business meetings are held at the home of Rachel Strickland located at 2828 East Puritan Place in Anaheim (714) 630-0400. Meetings begin at 7:00 PM. If you would like to have an item added to the agenda, please contact Rachel at the number referenced or email her at shawnrachelhuntr@aol.com.

January 20, 2010

April 14, 2010



**GUILD FOR INFANT SURVIVAL, ORANGE COUNTY
P.O. BOX 148
TUSTIN, CA 92781**

**NON-PROFIT
U.S. Postage PAID
Santa Ana, CA
Permit No. 6086**

This newsletter is made possible, in part, by a grant from the Pacific Life Foundation

WE NEED YOUR HELP

For more information, email gisoc@att.net

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 _____

Email: _____

Please check all that apply:

Please add me to the mailing list

Please discontinue sending the newsletter

The above address is new

Stamp

**GUILD FOR INFANT SURVIVAL,
ORANGE COUNTY
P.O. BOX 148
TUSTIN, CA 92781**