



# REFLECTIONS

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## A Note from the President

It seems fitting to be writing my final President's message on what would have been my son's 7<sup>th</sup> birthday. I have spent the last six years working with GISOC in honor of my son Ryan: Working to raise funds for SIDS research and making peer support a priority. I have met many amazing SIDS families along the way. We have shared all the ups and downs that come with this journey. I've even had the joy of watching our subsequent children grow-up together. One thing I can say for sure is that I am a better person because of these relationships.

My time serving on the board has been one of immense personal growth and I am grateful for every moment spent alongside so many amazing people through the years. GISOC is special because of the commitment and perseverance of its members. There's never been a time that I didn't have someone to call upon for support. This time it's *Colleen Ma*, a SIDS parent who will step into the role as president. Colleen has been working with the board for some time and was instrumental in our recent fundraiser at the beautiful Anaheim White House. She is passionate about peer support and has great vision for the organization.

My hope is that GISOC continues to thrive through the support of families that recognize its significance and importance. I will never forget how much it meant to be able to simply talk with other SIDS parents at a time I felt so alone. For this reason, my gratitude and commitment to the organization will always remain.

As mentioned before, it's Ryan's birthday today--- a time to celebrate! So I bid you farewell as I am off to Disneyland with the family, a tradition on this day each year.

All the best in 2013,

*Jordy Jahn*

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***GISOC Luncheon October 17<sup>th</sup>,  
2012--Anaheim White House***

*Bruno Serato, long time owner of the historical Anaheim White House awarded the Guild for Infant Survival Orange County with a very special Luncheon for over 50 attendees on October 17<sup>th</sup>, 2012 from 11:30 to 1:30 pm. The GISOC then turned the gift into a fundraising event and also honored three very special individuals who were so deserving of recognition. (see below). It was a wonderful luncheon, a great time to connect with friends and SIDS families, enjoy raffle prizes, listen to those who were honored, and just have a great and energized/relaxing time with wine and music.*

*Thank you Seghesio Family Vineyards for donating the wine and thank you Jordy Jahn, our GISOC President who presided over this event and made the wine donation possible. Thank You Jordy! Also a special "Thank You" for all of those on the luncheon committee who gave many hours to make this event possible ...Colleen Ma, Rachel Strickland, Barbara Estep, our Executive Director of GISOC, Liz Willett, Alpha Doo, Evie Clemente, Karen Jackson, OCHCA SIDS Coordinator, and myself.*

*The luncheon afforded a wonderful opportunity to give tribute and to honor three very special individuals, Ms. Lisa Biakanja, Dr. Thomas Keens and Dr. Henry Krous. **Lisa Biakanja**, a SIDS parent most importantly, who lost Kristy to SIDS over 30 years ago on September 18, 1982 was honored for her dedicated service to SIDS parents and families and the entire SIDS community. Lisa was given a gorgeous vase and beautiful spray of flowers. In addition*

*to all that she does, Lisa also continues to tirelessly produce our quarterly GISOC newsletter which is always "over the top". Thank you Lisa!*

***Dr. Thomas Keens and Dr. Henry Krous** were honored for 30+ years of SIDS research and education and their dedication to helping our GISOC. Dr. Keens was given a \$3,000 check to be used for SIDS research at Children's Hospital Los Angeles. Dr. Henry Krous who is retired was given a beautiful decorative plaque with inscriptions denoting his many years of service and dedication to GISOC.*

*It was a great honor for me to be able to introduce and to honor two doctors, two individuals who have made more differences from their contributions to the SIDS community here in Orange County, California, US and internationally than any two doctors I have had the privilege to work with. These two world renown professors, doctors, researchers, and educators have been our voices and our hearts as we plea to find a cause for this terrible disease, this tragedy, this devastating destructive thing called Sudden Infant Death Syndrome.*

*And if that isn't bad enough we now have to contend with other names for basically the same kind of death, namely, SUID or SUDI and even in some jurisdictions called an "undetermined". Whatever the label for SIDS, these 2 doctors have gone to battle for us for over 30+ years and we owe them much more than anything we can give them in the way of awards or honors that we could bestow*

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## Cleaning Out in the New Year

By Carlene Vester Eneroth, Spokane, WA

Hello! As we start a new year, we hear people talking about making resolutions or goals. I wonder if your goal might be to clean out a closet, room, study, den, office... wherever our special person used to keep their possessions? It's the same place that literally shouts to us, "They're gone" every time we go by it or glance in there or vacuum around it or whatever. Cleaning things out seems like one job we universally dread after death, don't you think?

I don't know about you, but I remember thinking, "If I open this closet door one more time and see that old, familiar coat hanging there or that shirt I gave Greg last year that became a favorite, I think my heart will burst right in two."

So, I tried to clean out *some* things very soon. Of course, way back in the recesses of my befogged mind I know I was hoping that by doing this little bit of "exorcism" somehow I'd instantly start to feel better. If *you* are thinking the same thing and are tempted to quickly rush through that job, let me caution you: A project of this emotional magnitude doesn't produce instant good feelings. But don't get too discouraged, either. I think it's just another example of how we sometimes have to just muddle through grief instead of trying to dig a tunnel and work our way around it.

Obviously, each of us must go at our own pace; and since grief saps so much of our energy, that pace is usually close to a snail's! Maybe your children want to come help and you want to postpone the job until that time. Maybe a special friend or neighbor has volunteered to help you sort through the baby's toys and drawers. You're very blessed to have that kind of help at this incredibly difficult time.

Be sure to save some things and not send them *all* away. To this day, I have my "Greg Box" downstairs. I'm remarried,

and yet I have stored away wedding pictures, special cards, family vacation albums and other mementos that seemed too hard to just toss. When I did start sorting things, I wasn't thinking too clearly about what to save or how to save anything at all. Thank goodness, someone else suggested the idea of keeping a box and having it around to refer to from time

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## Trauma and Grief: The Dynamic Duo in Sudden Loss

Written by Lisa Marain, MSW, LCSW,  
SUDC Support Services Coordinator

Grief is a natural process of emotions that occurs when someone dies. It integrates itself into normal routines with variable timeframes for each person. Complicated grief occurs when the initial grief emotions continue and significantly impact functioning over the long term. Professional support should be sought around the six month mark if symptoms of complicated grief are present. Trauma can be a component of grief. The purpose of this articles is to describe:

- ◆ Trauma related to grief
- ◆ When professional services should be pursued, and
- ◆ The possible forms of treatment and resources to pursue

One form of trauma a person can experience is when someone they love dies suddenly and unexpectedly especially a child. This can leave survivors feeling helpless and vulnerable. Symptoms vary among individuals, but gradually face as the trauma is processed. However, painful memories can resurface symptoms of trauma months and even years after the loss. Time and processing of the even are crucial to the recovery process and acceptance of the loss.

### Emotional and Psychological Symptoms of Trauma Can Include:

- ◆ Shock, denial, or disbelief
- ◆ Anger, irritability, mood swings
- ◆ Guilt, shame, self-blame
- ◆ Feeling sad or hopeless
- ◆ Confusion, difficulty concentrating
- ◆ Anxiety and fear
- ◆ Withdrawing from others
- ◆ Feeling disconnected or numb

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## Newsletter Deadline

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 10/1/12.** We encourage your participation!

Dear Members of the Guild for Infant Survival, Orange County,

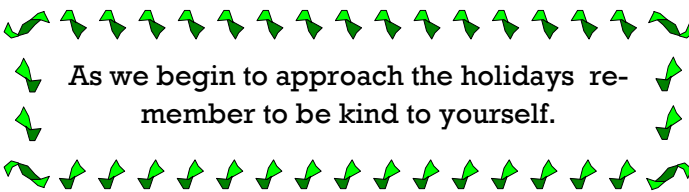
I would like to thank you so very much for the wonderful luncheon you hosted on October 17, 2012, at The White House Restaurant. I was thrilled to be honored by the Guild at this festive and enjoyable event. Thank you so much for honoring me in this way.

Thank you also for your very generous \$3,000 donation to our SIDS Research Program at Children’s Hospital Los Angeles. As you know, at Children’s Hospital Los Angeles, we have been involved in SIDS research since 1979, and we believe we have made some important contributions toward a better understanding of SIDS. However, the costs of maintaining such a research program remain high, and funding is increasingly difficult to obtain. Therefore, your generous donation is greatly appreciated.

For the past three decades, we have enjoyed the support of the Guild, for which we consider ourselves very fortunate. If there is anything that I, or other members of our *SIDS Research Program* at Children’s Hospital Los Angeles, can do for you now, or in the future, please do not hesitate to contact me. Thank you so much for the wonderful luncheon and your generous research donation.

Sincerely,

Thomas G. Keens, M.D.  
Professor of Pediatrics, Physiology and Biophysics  
Keck School of Medicine of the University of Southern California



As we begin to approach the holidays remember to be kind to yourself.

**Hazardous Cosleeping Environments and Risk Factors Amenable to Change: Case-Control Study of SIDS in South West England**

Peter S. Blair, Sr. Research Fellow, Peter Sidebotham, Assoc. Professor in Child Health, Carol Evason-Coombe, Research Health Visitor, Margaret Edmonds, Research Health Visitor, Ellen M A Heckstall-Smith, Research Assistant, Peter Fleming, Professor of Infant Health and Development Physiology

**Objectives:** To investigate the factors associated with Sudden Infant Death Syndrome (SIDS) from birth to age 2 years, whether recent advice has been followed, whether any new risk factors have emerged, and the specific circumstances in which SIDS occurs while cosleeping (infant sharing the same bed or sofa with an adult or child).

**Conclusions:** Although socioeconomic markers were more prevalent among the families of SIDS infants, the major influences on risk were from factors amenable to change within the infant’s sleeping environment. Some of the risk reduction messages seem to be getting across and may have contributed to the continued fall in the SIDS rate. Identifying emerging dangers and re-emphasizing ones already observed within the infant sleeping environment may further reduce the number of deaths from SIDS. This is clearly illustrated in the current polarized debate surrounding cosleeping.

The safest place for an infant to sleep is in a cot beside the parents’ bed. Based on evidence from research into SIDS it is questionable whether advice to avoid bed sharing is generalizable and whether such a simplistic approach would do no harm. Parents of young infants need to feed them during the night, sometimes several times, and if we demonize the parents’ bed we may be in danger of the sofa being chosen. A better approach may be to warn parents of the specific circumstances that put infants at risk. Parents need to be advised never to put themselves in a situation where they might fall asleep with a young infant on a sofa. Parents also need to be reminded that they should never cosleep with an infant in any environment if they have consumed alcohol or drugs.

### The Grief of a Parent Who Has Lost an Infant

To experience the loss of an infant is to grieve for what never was. After all the months of anticipation and preparation, the actual birth of a child brings the feeling of hope and fulfillment. Should that child be stillborn, or die hours, days or even months later, the unrealized dreams become a source of pain for the parents. No parent expects to outlive his child; the death of an infant is often the loss of a child unknown even to the parents.

The expected stage of grief, (guilt, disbelief, anger, etc.) can have new directions for the parents who have lost an infant.

1. **Shame and guilt.** Especially if the infant was stillborn or had a birth defect, the mother may feel she has failed as a woman. "Other women have live, normal babies, why can't I?" Should an infant die months after birth, parents find it hard to resolve feelings that it was their fault.
2. **No memories.** Parents may only have "souvenirs of an occasion" (birth certificate, ID bracelet) by which to remember their child. If the infant is older, they may have pictures and a few belongings, but they still feel they hadn't really gotten to know their child.
3. **Loneliness in grief.** It is hard for friends and relatives to share your grief for a child they never knew. If the child is a newborn they may give the impression that you are grieving unnecessarily over a non-person. They hope that you can "forget this baby" and "have another one."
4. **Neglected father.** Too often the sympathies of professionals and friends are directed mainly to the mother. It is important to remember that the father had made plans for this baby too.
5. **Mothers vs. fathers.** Since the mother has bonded with her child all during pregnancy, her grief may be much deeper than the father who only came to know this child after birth. It may be difficult for a father to understand why his wife's grief is so profound and so prolonged.

Claire McGauhey and Sue Shelley, TCF, St. Louis, MI

*Your Gift is  
Appreciated !  
The Guild for Infant  
Survival is a  
United Way  
Approved Organization  
GUI300*

### The Worldwide Candle Lighting

Held annually the second Sunday in December, this year December 9th. The Compassionate Friends Candle Lighting unites family and friends around the globe in lighting candles for one hour in each time zone, allowing all to join together in unity to remember and honor the memories of all children who are no longer with us so they may never be forgotten. This year the OC Chapter Candle Lighting Ceremony will be held at Grace Bible Chapel in Fullerton. We ask that you plan on arriving at 6:30 pm to allow time to place a photo of your child on our memory table. The Candle Lighting will begin promptly at 7 pm so that the wave of light around the world will not be broken.



We do this...that their light may always shine.



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### Physical Symptoms of Trauma Can Include:

- ◆ Insomnia or nightmares
- ◆ Being startled easily
- ◆ Racing heartbeat
- ◆ Aches and pains
- ◆ Fatigue
- ◆ Difficulty concentrating
- ◆ Edginess and agitation
- ◆ Muscle tension

### Consider Professional Support When You Have:

- ◆ Trouble functioning at home or work after an extended period of time
- ◆ Suffering from severe fear, anxiety, or depression
- ◆ Unable to form close, satisfying relationships
- ◆ Experiencing terrifying memories, nightmares, or flashbacks
- ◆ Avoiding more and more things that are related to the trauma
- ◆ Emotionally numb and disconnected from others
- ◆ Using alcohol or drugs to feel better

### Therapeutic Approaches

Trauma disrupts the body's natural equilibrium, putting one in a state of hyperarousal and fear. The purpose of specific therapeutic approaches is to address this imbalance and reestablish a sense of safety. Trauma treatment and healing involve:

- ◆ Processing trauma-related memories and feelings
- ◆ Discharging pent-up "fight-or-flight" energy

- ◆ Learning how to regulate strong emotions
- ◆ Building or rebuilding the ability to trust other people

*Types of approaches include:*

**Somatic experiencing** takes advantage of the body's unique ability to heal itself. The focus of therapy is on bodily sensations, rather than thoughts and memories about the traumatic event. By concentrating on what's happening in the body, natural survival instincts take over, safely releasing this pent-up energy through shaking, crying, and other forms of physical release.

#### **EMDR (Eye Movement Desensitization and Reprocessing)**

Incorporates elements of cognitive-behavioral therapy with eye movements or other forms of rhythmic, left-right stimulation. These back-and-forth eye movements are thought to work by "unfreezing" traumatic memories, allowing resolution.

**Cognitive-behavioral therapy** processes and evaluates thoughts and feelings that surround a trauma. While cognitive-behavioral therapy doesn't treat the physiological effects of trauma, it can be helpful when used in addition to a body-based therapy such as somatic experiencing or EMDR.

Additionally, self-help strategies for coping can include:

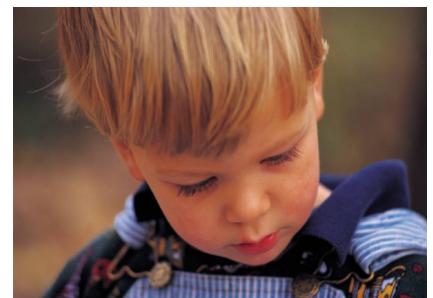
- ◆ Staying connected (i.e. volunteer, social activities)
- ◆ Support groups
- ◆ Exercise
- ◆ Patience
- ◆ Practical support-accepting support with concrete tasks (i.e. grocery shopping, laundry)

### Don't Forget the Kids!

Like adults, children can feel intense sadness and loss when a person close to them dies. And like adults, children express their grief in how they behave, what they think and say, and how they feel emotionally and physically. Each child grieves differently, and there is no right or wrong way or length of time to grieve.

Grief reactions vary among developmental levels, and children may show their grief in many different ways. Bereaved children may also act in ways that those around them may not recognize as reactions to grief. Whatever a child's age, they may feel guilt regarding the death. Sometimes bereaved children take on adult responsibilities: worrying about surviving family members as well as their own wellbeing.

Professional involvement is warranted if grief reactions continue without any relief and significantly impact the ability to function.



*A good exercise for the heart is to bend down and help another up...*

**Your gift to honor a loved one will be appreciated.**

**Send your tax deductible donation to:**

**Guild for Infant Survival, Orange County**

**P.O. Box 148  
Tustin, CA 92781**

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to time. I can't count the number of occasions when I've gone down to look in the box for a specific date or to find an old photo or just to look — and remember.

I'm sure many of you have done lots of special things with some of the possessions you are keeping. (It seems to me that grieving people all have so much more creativity than I could ever muster! Many of you put me to shame.)

Darryl, my friend, Deanna's husband died in a trucking accident three years ago. Because he was involved in so many community sporting events and played on several teams, she didn't want to throw away all of his things or put them in a yard sale. With two little boys at home, she was smart enough to realize how proud each of them would be some day to have some of Daddy's special sports things. So she bought two of those huge, *Rubbermaid*, under-the-bed boxes and put the boy's

Names on them. Then she divided up the jerseys, referee shirts, autographed balls, catcher's mitts, etc. She also thought to include a special album that had pictures of each boy by himself with Daddy.

As she was telling me about this project, the boys heard us and ran out of the room. Around the corner they returned, huffing and puffing as they dragged the boxes behind them. They almost came to blows over who was going to be first to show me "MY dad's box." even at such young ages, those were already very special boxes.

Sheila, from Sault Te. Marie, Michigan, wrote to mention something she did as she donated some of her husband's clothing. Thinking that somehow his clothes would be lonesome by themselves, she sent along an item from her own closet for each of his. She thought they could still be a twosome! I liked that sweet idea.

Whatever you decide to do, don't let anyone rush you. Only you can know when you're ready to tackle this project. It won't be easy, but then that's a pretty common grief ingredient, isn't it?

Everything, (including breathing itself) takes a lot of energy and just plain hard work.



Good luck in this New Year!

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*upon them on October 17<sup>th</sup>, 2012 or any day. Please know, Dr. Tom and Dr. Henry, how much we appreciate and love the work you do and continue to advocate for all of us within the SIDS Community.*

*Penny Statsny*

**The 32nd Annual California SIDS Conference at The California Endowment Center**

The Conference this year was truly remarkable. The Conference began with a 'Meet n Mingle' for bereaved parents and family members at The Doubletree Grand Kyoto Hotel. Parents were treated to a quiet time to decorate a picture frame and share their stories. An encouraging message was delivered by Rev Ritter reminding us that grief is a process and an extra challenge when someone you helped create leaves this world. He encouraged us to not let our grief be the end, but to use our pain to bring more good into the world. The memorial celebration concluded with breathtaking music, a slide show of our sweet babies, and a fantastic offering of desserts.

The morning was opened by Orange County's own Karen Jackson who did an excellent job as Conference chair. Our keynote speaker, Dr. Hannah Kinney, actually spoke by live computer webinar due to the hurricane on the East Coast.

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## Guild for Infant Survival, Orange County October 17, 2012

John Lennon said, "Life is what happens to you while you're busy are making other plans". Our lives are marked by events that happen to us --- some planned, but most unplanned and unexpected. I don't have to tell this audience that some of these events are profound, and they impact our lives forever --- like the death of an infant who was cherished and loved. Many of you have experienced this, and the rest of us have been profoundly moved and inspired by observing your courage in the face of great tragedy.

But, most life events are not so profound, are not so compelling, but they offer us an opportunity to pursue them or not. Our lives can be defined by the decisions we make --- which events we pursue, and which ones we let pass us by. I am here with you today because I chose to pursue some of these opportunities, but not others.

35-years, 2-months, and 2-days ago, I returned to Children's Hospital Los Angeles, as a young faculty member, eager to change the world. I had just completed my Pediatric Pulmonary Fellowship, at the Hospital for Sick Children in Toronto, Canada. At that time, I had no thought or desire to be involved with SIDS. I had trained, I thought, to be a cystic fibrosis researcher. But, institutional politics can be powerful, so it quickly became clear to me that this was not to be. Then, a perfect storm of four events occurred, which changed the course of my life, for the better.

First, I went to my boss, depressed about the apparent blockade in my cystic fibrosis research career. He said, "I think you should get involved in SIDS. Not too many people are doing that."

Second, we had a patient in the hospital with a rare disorder where he did not breathe whenever he went to sleep. I made the diagnosis, and he was the first child that we sent home from our hospital on a ventilator. Therefore, I became to "go to" doc for patients with respiratory control disorders.

Third, in the late 1970's, many scientists believed that SIDS occurred when babies stopped breathing during sleep. This was the era when many babies were sent home on apnea monitors. I was intrigued by this technology, and we established a large program at Children's Hospital Los Angeles to evaluate and manage infants thought to be at high risk for SIDS.

Finally, the *California SIDS Information and Counseling Project*, as it was called then, sent out a newsletter to all California pediatricians, describing SIDS and their program. In a small paragraph on the last page was a brief announcement that the physician member of the Southern California Regional SIDS Council had resigned, and they were seeking a replacement. Thinking I would be competing against hundreds for the position, I sent in a letter saying I was interested. Only a few days later, I received a phone call from the program, saying I was appointed. It is still true that few physicians and scientists choose the opportunity to be involved in SIDS.

When I attended my first Council meeting, I was not exactly a hit. The SIDS parents on the Council, including *Chris Elliott* from your Guild, were not at all impressed with me as a scientist, and my welcome was chilly, to say the least. But, fortunately, I did persevere. Since 1979, I have enjoyed unwavering support from the Orange County Guild for our SIDS research. You have donated research funding to us for over three decades, and you unselfishly shared your precious babies with us as research subjects.

I will not bore you with the details of all the research we were privileged to perform. But let me focus on a few highlights. Although we started using infant apnea monitoring to manage infants at high risk for SIDS, we were one of the first to show that pneumograms did not predict SIDS. We participated in the CHIME Study in the 1990's. This was a multi-center, NIH funded study which ended the use of home apnea monitoring.

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## What Happens After Christmas!!

By Mauryeen O'Brien, O.P.  
Hamden, Connecticut

"I spent a lot of energy anticipating and dreading the holidays." Chris told me over the phone one evening last week. "I pushed myself to be with people, even though I didn't want to be. I even shopped for presents and decorated the house as I had always done before Jim died. I guess it wasn't as bad as I thought it would be —though I have to tell you it wasn't great. But now I'm wondering, what happens after Christmas? What happens to me now that there aren't a lot of people visiting me, there are fewer distractions and there is much less running around? What happens now that I've worn myself out physically and emotionally trying to cope with the pain of my first Christmas without Jim? How can I get through these next few months?"

Chris's questions are very familiar to those going through "separation pain" due to the death of a loved one. There are many "Chris's" who have kept themselves overly busy, running from store-to-store or house-to-house, stuffing down old memories, traditions and expectations. They find that once the holidays are over, they are tired, nervous, distraught and fearful of the long winter months ahead of them.

We certainly can't change the nature of the winter that is upon us. No matter what we do there will be days with fewer hours of sunlight. It will be cold and snow and ice may well keep us inside more than we would like. Though none of that can be changed, what we can have complete control over is "slowing down" in mind and in body and giving ourselves some time to heal from the pain of loss.

Winter is, in itself, a "slow" time. Life seems to come to a halt for a while; trees are bare and new life is dormant under snow-covered earth. There is a quiet that hangs on the air. It can be in the quietness, in this slow-paced expectancy of a spring that will eventually come, that we can begin to open ourselves to the gentle prodding of beginning a new life. But

in order to do that, we must indeed "slow down."

We can truly do something with these days after Christmas. They can be quiet times in which we can work at our healing and growth. The healing will never be perfect, and there will always be scars, because love has the capacity to leave scars. But the scars can produce a growth beyond just survival.

The growing may be difficult. Indeed, the grieving was and is. But as nature survives the winter and moves into the freshness of a new spring, we, too, can use this time before us to begin to nurture ourselves, listen to our inner yearnings, and realize that this time can be put to growth.

What happens after Christmas? We take the time to pay attention to ourselves and to the possibility of using the cold and dreary months, as nature does, to begin to heal and grow. Spring always follows winter no matter how harsh that winter has been. So, too, can strength follow suffering, if we try to work through the suffering to new life.

**I am past intense grief, but not  
loss.**

**Past questioning, but not wonder-  
ing**

**Past relentless sobbing,  
but not crying**

**Past guilt, but not regrets**

**I am simply years into my grief  
And life as it has been defined by  
the**

**Absence of my child.**

By Sally Silagy

### What to Expect as You Face the Special Times

The first year after your baby's death is very hard, and your baby's first birthday and the anniversary of his or her death may also be very difficult.

Even if you seem better, the sadness and pain may return. It will be hard to be around other children, especially babies. These are normal feelings.

It is OK to celebrate and enjoy these times. It is OK to laugh and cry at the same time. You can go from laughing to crying very quickly.

Other children in your family will need help during the holidays to celebrate as they have in the past or to understand why things are different.

Some parents...

- ◆ Choose to celebrate and participate in these occasions as they always have in the past, but find it is a struggle. Sometimes they even avoid talking about the baby who died.
- ◆ Choose to do completely different things during the holidays and special events. They may not participate in any of the usual activities or traditions.
- ◆ Try to balance their participation in holiday activities and cope with the pain and sadness of missing their baby.

These are difficult and personal choices.

Remember...

What you and your family decide to do for anniversaries, during the holidays, or for special events is your choice.

Your participation in these events may be very different during the first year or so. After a while, you may go back to normal activities or permanently change how you remember some holidays and special occasions.

**Guild For Infant Survival,  
Orange County  
Information:**

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Santa Ana, CA 92705  
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Fax: (714) 973-8429  
(800) 474-SIDS (7437)  
Email Address:  
gisoc@att.net  
Website Address:  
www.gisoc.org

Celebrating holidays and special events will reflect your cultural background and traditions. It is important for you to value these traditions because they are part of your life during happy and sad times.

**The Cord**

We are connected,  
My child and I,  
By an invisible cord  
Not seen by the eye.  
It's not like the cord  
That connects us 'til birth.  
This cord can't be seen  
By any on earth.  
This cord does its work  
Right from the start  
It binds us together  
Attached to my heart.  
I know that it's there  
Though no one can see  
The invisible cord  
From my child to me.  
The strength of this cord  
Is hard to describe.  
It can't be destroyed  
It can't be denied.  
It's stronger than any cord  
Man could create  
It withstands the test,  
Can hold any weight.  
And though you are gone  
Though you're not here with  
me,  
The cord is still there  
But no one can see.  
It pulls at my heart  
I am bruised...I am sore,  
But this cord is my lifeline  
As never before.  
I am thankful that God  
Connects us this way  
A mother and child

**Quotation of the Day**

***"Death leaves a heartache no one can heal, love leaves a memory no one can steal."***

***From a headstone in Ireland***

Continued from Page 8

Perhaps, we are best known for our studies of arousal or waking up to escape potentially dangerous situations during sleep. If a baby stops breathing, or is found in a dangerous situation, the best thing the baby can do is to wake up to move or deal with the situation. We showed that all infants, even those who will not die from SIDS, are born with a potentially protective arousal response to low oxygen, but they lose this at 3-months of age, when the incidence of SIDS increases. This is likely not the cause of SIDS in and of itself, but perhaps it is a contributor.

You have also given us valued critiques on our research. Several years ago, we studied arousal responses in babies to light and sound. Unexpectedly, we found that siblings of SIDS victims did not wake up as readily to a bright light as control infants did. I was asked to present our research to your Guild, and I did so with enthusiasm. But those present did not share my excitement. Finally, one SIDS parent said of her subsequent sibling, "You know we are always going in and turning on the light to see if our baby is still breathing. Maybe they are just used to bright lights." That woman was right, and our research was not as profound as we had thought.

More recently, we have been involved in research investigating the role of the autonomic nervous system, or life-support part of the brain, as a cause of SIDS. We are collaborating with Biomedical Engineers at USC, who are experts in cardiorespiratory control. It is my anticipation that this work will ultimately be directly applicable to babies and to SIDS.

Also, with the help of an internationally renowned expert on mitochondrial disorders at Children's Hospital, we hope to investigate whether mitochondrial dysfunction might predispose some infants to die from SIDS. We are planning to do this study right here in Orange County.

**Don't forget to make your 2012 charitable donation today. The Guild uses 100% of your memorial donations towards research to ultimately find a cure for Sudden Infant Death Syndrome.**

There are thousands of physician-scientists working on cystic fibrosis, but perhaps only a few hundred in the world working on SIDS. Robert Frost wrote:

I shall be telling this with a sigh  
Somewhere ages and ages hence:  
Two roads diverged in a wood, and I,  
I took the one less traveled by,  
And that has made all the difference.

Thank you for giving me a cause I could embrace and work for. Thank you for inspiring me with your courage in the face of tragedy. Thank you for enriching and changing my life for the better. Know that I have received very much more from being involved with you, and with SIDS, than I have given.

Thank you so much.

*Thomas G. Keens, M.D.*

Continued from Page 7

There was not even a hint of technical challenges; it was as though Dr. Kinney was really with us in Los Angeles. Her research in brain stem serotonin is remarkable and very encouraging. The laboratory work her team is doing in collaboration with labs all over the world brings me hope that medical understanding of SIDS will happen in my lifetime. It has been a long time since the chatter around the Conference was excitement about research.

A former colleague of Dr. Kinney and California SIDS champion Dr. Henry F. Krous was rightfully honored for his many years of research success and commitment to the SIDS community. Dr. Krous will enjoy his retirement, but we will certainly miss him. Other notable moments included the parent panel filled with parents who shared from their heart, Jeri Wilson receiving the Boatwright Award, breakout sessions for parents and professionals, and the drum ceremony conclusion.

The California SIDS program did a wonderful job planning and organizing this conference. I heard nothing but positive feedback as the day progressed. Please keep an eye on the Guild website for a link to the slide show and more information about Dr. Kinney's research.

Colleen Ma

# 2012/2013 MEETING CALENDAR

**Parent Support Meetings**— All meetings are from 7:00—8:30 PM.  
Meetings are hosted by Colleen Ma and Penny Stastny and take place at the Guild for Infant Survival, Orange County office located at 2130 E. 4th Street, Suite 125, in Santa Ana.

\* Please RSVP to Barbara Estep at (714) 973-8417 prior to the meeting

November 17

December 10

January 14

February 11

March 11

**Business Meetings**— held at a private home. Call for directions. Meetings begin at 7:00 PM. If you would like to have an item added to the agenda, please contact Jordy Jahn at (949) 347-8583.

\*Please RSVP to Barbara Estep at (714) 973-8417 prior to the meeting.

**Save the Date!**

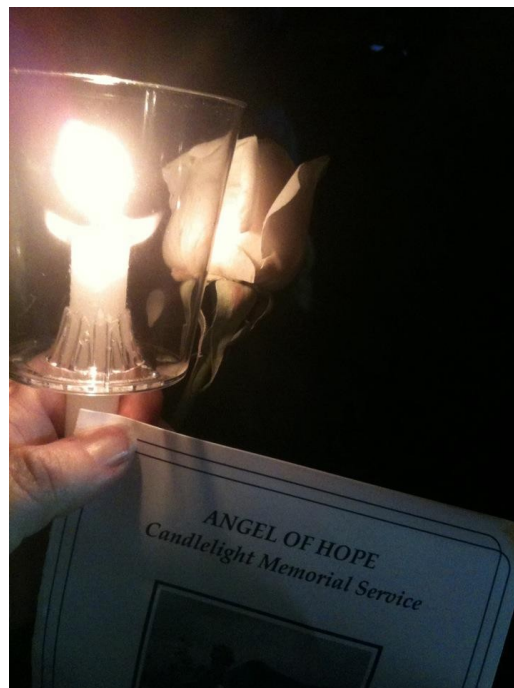
Angel of Hope Memorial Service

December 6, 2012 @ 7 pm

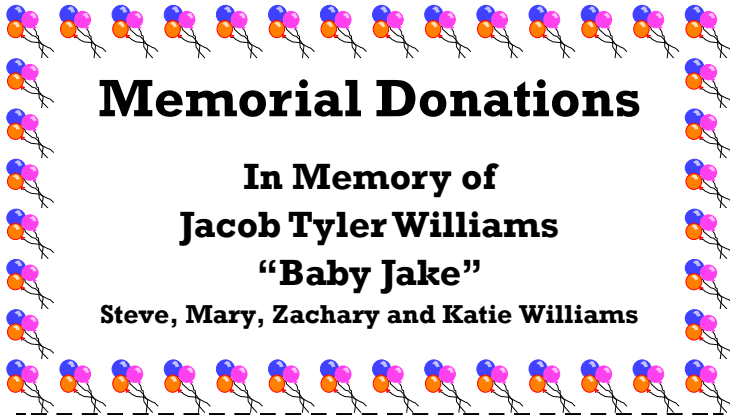
**El Toro Memorial Park**

**25751 Trabuco Rd.**

**Lake Forest, CA**







# Memorial Donations

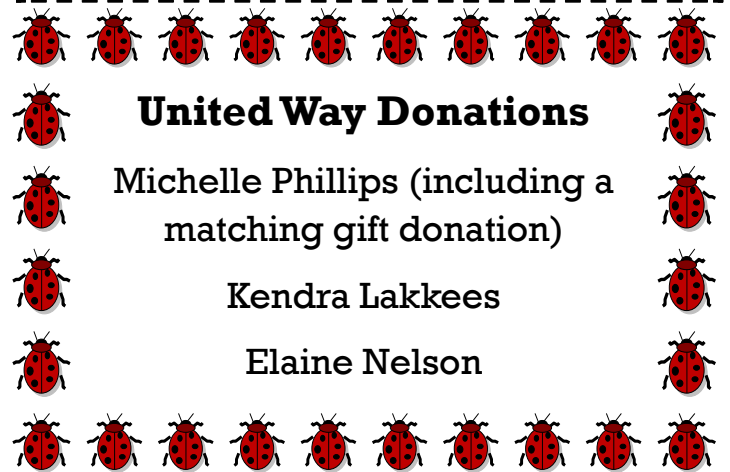
In Memory of  
**Jacob Tyler Williams**

**"Baby Jake"**

Steve, Mary, Zachary and Katie Williams

# Community Outreach

September 10, 2012—Penny Stastny, Vice President of the Guild, made a "Safe Sleep" presentation to over 100 childcare providers. Her presentation was very well received and we have been invited back in 2013.

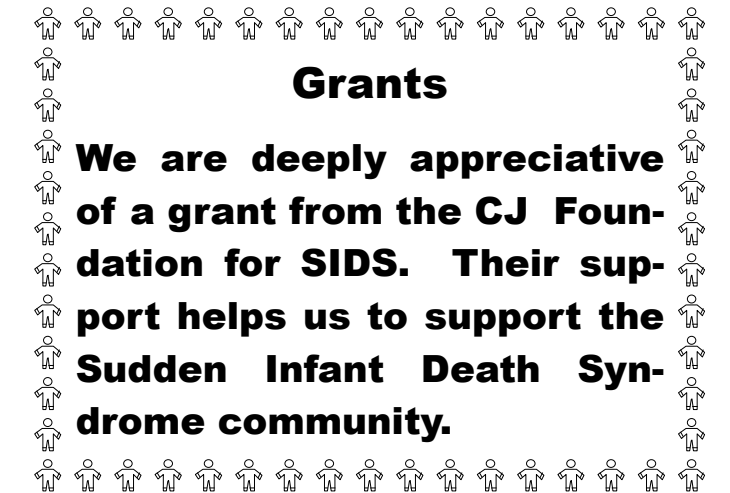


# United Way Donations

Michelle Phillips (including a matching gift donation)

Kendra Lakkees

Elaine Nelson



# Grants

**We are deeply appreciative of a grant from the CJ Foundation for SIDS. Their support helps us to support the Sudden Infant Death Syndrome community.**

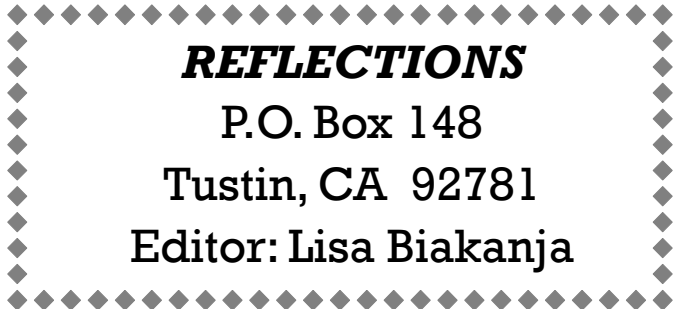


# Special Thanks

We appreciate the Employees Community Fund of Boeing California and thank them for their generous grant, helping the Guild to help others in our community.



This newsletter is being published thanks to a grant from Wells Fargo Foundation.



# REFLECTIONS

P.O. Box 148

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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.