



REFLECTIONS

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GUILD FOR INFANT SURVIVAL ORANGE COUNTY

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Dear Friends of the Guild,

The Guild for Infant Survival Orange County (GISOC) would like to invite you to support our Fall Luncheon and Silent Auction to be held Wednesday, October 17, 2012. The event will be held at the Anaheim White House Restaurant, a 1909 Historical Landmark, known for their excellent food and service. The menu features a salad of contemporary greens, an entrée of chicken volaille supreme (vegetarian pasta is available upon request) and strawberry enchantment for dessert. You have your choice of soft drink. Wine will also be served. The cost of each ticket is \$50.00 and valet parking of \$5.00.

The occasion will be an opportunity to come together in memory of loved ones lost and to acknowledge those who have worked to build our organization while supporting a very worthwhile cause. We are honored to welcome Dr. Tom Keens of Children's Hospital Los Angeles and Dr. Henry Krous of Children's Hospital San Diego as our special guests for the luncheon. Both doctors are well known for their long-time dedication to Sudden Infant Death Syndrome (SIDS) research.

GISOC was established in 1975, and for 37 years has served Orange County and surrounding areas. We are here to support families and extended families that have lost a precious baby to Sudden Infant Death Syndrome, educate

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On "Picking Up the Pieces"

Had someone say to me not too long ago that she was glad to see that I was "picking up the pieces and going on." Well, I am picking up the pieces all right—but what she doesn't know is that they're almost a whole set of new pieces! I haven't been able to go on as though nothing about me has changed since my child died. I'm a different me, and I am still learning about how the new me reacts to old situations.

I am finding that this new set of pieces doesn't exactly fit together all nice and neat like a jigsaw puzzle. Some of the old pieces are still hanging in there, but they don't quite mesh with some of the new pieces. I am in the process of grinding off the rough edges now, hoping eventually for a better fit, one that I can live with more comfortably. Time, patience and hard work are helping me accomplish this.

How are the rough edges on your new pieces coming along?

~ Mary Cleckley

A Research Study on Mitochondrial Disorders and SIDS

Mitochondria are small structures present in every living cell. They are the energy factories of cells. The food we eat is digested and brought to mitochondria, where it is converted into the energy required for us to live. Like every other part of the body, mitochondria are built from proteins. This assembly is supervised or directed by genes. We now know that some people have mutations of these mitochondrial genes, which can cause abnormal mitochondria to be made. Abnormal mitochondria do not produce energy normally. Any cell that has no energy, or has decreased energy, will not function well. As a result, mitochondrial disorders can cause a wide variety of different disease conditions. In fact, a few percent of babies who died of SIDS were found to have mutations in mitochondrial proteins. Is it possible that other mitochondrial disorders can cause a substantial proportion of SIDS, or at least make some infants more likely to die from SIDS?

At Children's Hospital Los Angeles, we are fortunate to have one of the world's leading experts on mitochondrial disorders, *Doctor Richard Boles*. *Doctor Boles* has spent his life doing research on patients who have abnormalities in mitochondria. Because mitochondria are in every cell of the body, disorders or diseases of mitochondria can have a wide variety of symptoms. Some are serious, and even fatal. Others may not be life-threatening, but can include things like depression, migraine headaches, intestinal problems, muscle weakness, heart disease, etc. Because symptoms can be so broad, sometimes these disorders are not obvious, and it may take quite some time before a mitochondrial disorder is suspected and diagnosed.

In collaboration with *Doctor Boles* and his research team, we would like to conduct a pilot research study to see if babies who died from SIDS had evidence of abnormal mitochondrial genes. We would like to study genes (DNA) from the tissues stored in the Coroner's Office from a small number of babies who died from SIDS, and we would also like to study the DNA of the parents of these babies. Taking DNA from the parents involves only spitting some saliva into a special collection cup that is sent by mail (no

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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!

OC Walk to Remember

Registration is now open for the 2012 OC Walk to Remember Memorial Service, 5K Walk and Celebration of Angels

When: October 6

Where: The District at Tustin Legacy

Schedule of Events:

6:00 am—8 am: Registration check-in, support information available

8:15 am Remembrance Ceremony: Each baby's name will be read and parents receive a white rose

9:00 am 5K Walk (half-route available): We walk the steps our babies will never take

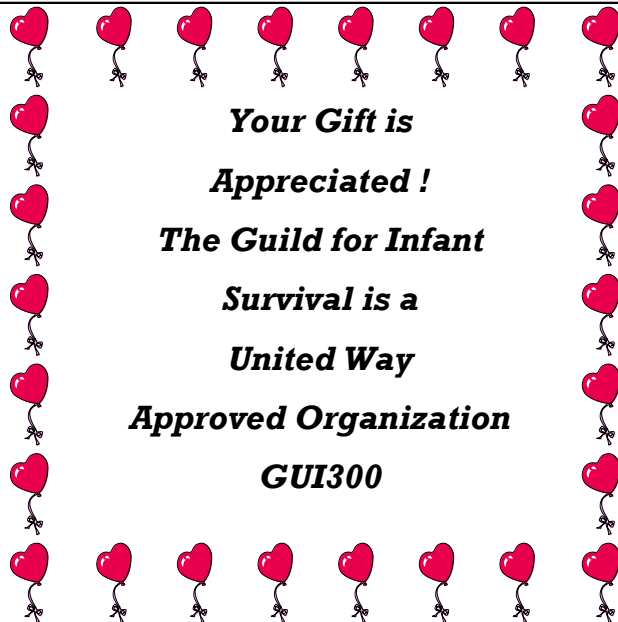
9:30 Celebration of Angels: A time to celebrate the babies we love and miss.

CA State Senator Daniel E. Boatwright (January 30, 1930 – April 27, 2012)

We are saddened to inform the California SIDS Community that California State Senator Daniel E. Boatwright died on April 27, 2012, at the age of 82. He was an effective and influential California legislator, serving 8-years in the Assembly and 16-years in the Senate.

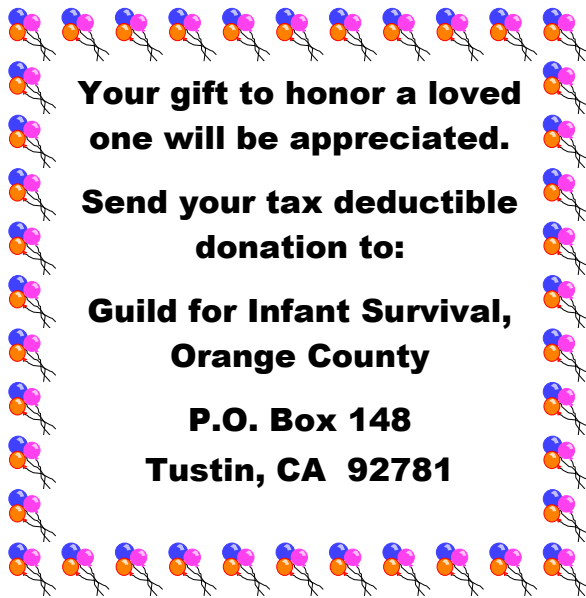


However, he will be forever known and beloved by the California SIDS Community for his visionary *Boatwright Bills of 1989*, which transformed SIDS services, education, and research in California.

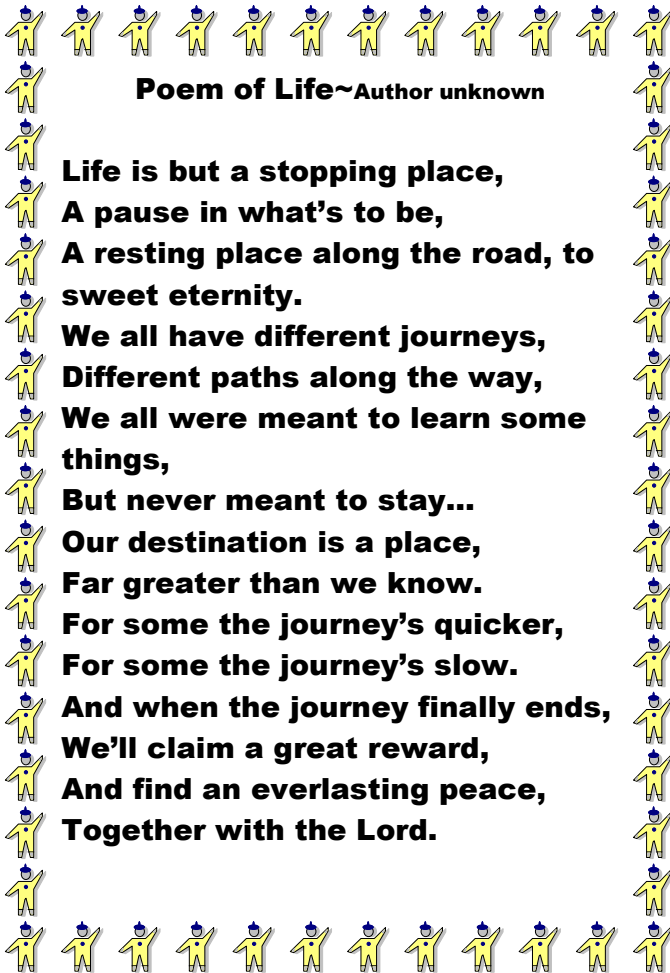


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Email Address:
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Website Address:
www.gisoc.org



**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**



Poem of Life~Author unknown

Life is but a stopping place,
 A pause in what's to be,
 A resting place along the road, to
 sweet eternity.
 We all have different journeys,
 Different paths along the way,
 We all were meant to learn some
 things,
 But never meant to stay...
 Our destination is a place,
 Far greater than we know.
 For some the journey's quicker,
 For some the journey's slow.
 And when the journey finally ends,
 We'll claim a great reward,
 And find an everlasting peace,
 Together with the Lord.

Be Kind to Your Self

Many things keep you stuck in a place I like to call "self-bashing". While you're grieving the feelings of guilt and anger are especially powerful – they can send you into a tail-spin of blame and self-criticism. The physical effects of grief, such as sleeplessness, lack of hunger, and depression can bring you into that dark place too, where you feel it's appropriate to be less than kind to your Self.

HOPE isn't a place or a thing.
 HOPE is not the absence of pain,
 or fear, or sadness.

HOPE is the possibility of renewed JOY.
 It's the memory of love given and received.

HOPE is here, within the magic and the memories of your heart.

~Darcie Sims

To the California SIDS
 Community:

The 2012 International Conference on Stillbirth, SIDS, and Infant Survival, sponsored by First Candle and by ISPID (International Society for the Study and Prevention of Infant Deaths) will be held in Baltimore, Maryland (Baltimore Marriott Waterfront Hotel), October 5-7, 2012. More information will be forthcoming. However, these international conferences combine the latest in biomedical and epidemiological research with support for parents and SIDS and infant death program professionals.

— Tom Keens

Rooms and Things

By Mary Cleckley, Atlanta Chapters

How many people have suggested to you in subtle and not so subtle ways that you'd be better off if you'd only go ahead and get rid of your child's things and redo the room? You see, they think that the holding on to these things is morbid. These people, who have never suffered the loss of one of their children, really do not understand that you have to do your grief work, and whether you do this sad task now or later really doesn't affect the length nor depth of your pain.

Some parents need to make the changes and decisions about personal belongings as soon as possible after the death. Having the chore ahead of them is more painful than the doing. These parents are advised, however, to go slowly when disposing of belongings. It may seem to you, also, that not seeing or having anything around to remind you of your dead child will somehow make your pain less. Later, though, when your grief has softened, you may find you need that special something, but by then it's too late.

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Children and Funerals

William G. Hoy

When contacted by a family with children in the immediate aftermath of a death, the most frequent question I hear is some form of, "What about the kids and the funeral—should they go, should they not, and why or why not?" Over the years, I have developed a fairly straightforward response—neither force attendance nor forbid it, but strongly encourage it with complete, factual information.

At the outset, I believe it is important to strongly encourage *any* child of *any* age to attend and participate in the funeral of a person to whom they are "connected." Let me explain. Once upon a time, I thought young children were best excluded from the funeral service—their presence might be too distracting for the "grown up mourners." As I studied the role of death-related rituals around the world and in history, however, I've changed my mind.

We Westerners (western Europeans, Canadians, and Americans) were apparently the first people to think up the notion of excluding children from community death-related rituals. People groups who have recently immigrated to our shores seem to rarely consider excluding children, even though the services may last many hours, or even days, with great complexity. When living in southern California, I frequently observed the customs of Cambodian Buddhist families in Long Beach, and saw that children were always included, even if they had no connection to the deceased other than that they were all Cambodian, perhaps lived or worked nearby, or possibly attended the same temple.

The notion of keeping children away from funerals is of relatively recent evolution, even among westerners. When I was a child in 1960's Louisiana, kids were expected to attend funerals of neighbors, church people, and certainly of family members. You will be hard-pressed to find a person born after World War II who did not attend many funerals as a child, and many of those services would have been for people the child barely knew.

So is the idea that we should protect kids by excluding them from rituals a more "evolved" per-

spective, demonstrating our great depth of understanding in how children are emotionally wired? I don't think so, and there is quite a bit of research to support my perspective. Nearly ten years ago, a National Institutes of Mental Health-funded research study with broad application followed 318 parent-bereaved children age 5-17 for more than two years. Perhaps the most significant finding for the purpose of this discussion was a conclusion reached by the researchers, told be in their own words:

Parents frequently request guidance, particularly for younger children, on whether attending a funeral home (or other type of) visitation will negatively affect the child. Interestingly, in our study, 11 percent of children's families did not have a visitation. By one year post-parental death, these children had twice as many behavior, anxiety, mood, and other symptoms, and they experienced more severe depressive symptoms than children who had attended a visitation. At two years post-parental death, they had more PTSD symptoms than children who had attended a visitation (Fristad, et. Al, 2000/2001).

Of course there could be other confounding variables in the study. Perhaps the same family-systems issues, for example, that caused a family to depart from the community's "traditional norms" might have been causative for the higher incidence of psychological symptomatology. The visitation/funeral-positive findings of the Fristad study, however, were also confirmed in a much smaller British research project. The researcher found children had no negative effects from attending funeral rituals and tended to regret not attending or having been excluded (Holland, 2004).

The Harvard Child Bereavement Study conducted by Phyllis Silverman and my mentor, J. William Worden, reached similar conclusions. Reporting that 95% of children attended their parent's funeral, Worden (1996) writes,

Children were included in funeral planning and in the funeral itself in various ways.

Continued on Page 2

needles and no travel needed). Although the DNA sequences of the approximately 1,100 mitochondrial genes will be studied in particular detail, we intend to sequence essentially every gene in the DNA (about 20,000) from the babies and both parents. The technology to do this has only recently become available.

Your family is eligible for this study if there is adequate tissue stored at the Coroner's Office, and if both parents are willing to participate and sign informed consent forms.

Funding for this pilot study has been obtained from the CureMito! Foundation (www.curemito.org), which supports research into mitochondrial disorders. If this study suggests that some or all of the SIDS babies have a possible abnormality in mitochondria, we would then be able to perform a larger study to confirm the earlier findings. If mitochondrial dysfunction does indeed seem to be common in babies who die from SIDS, these could potentially be detected at birth, and special interventions made in these babies identified with these abnormalities in hopes of preventing some SIDS deaths.

This study is not quite ready to begin. *Doctor Boles* is finishing preparations for how to do the actual science, and also going through regulatory requirements. However, once everything is approved, we are hoping to do this study in Orange County, because of our long history of support for SIDS research from the Orange County Guild for Infant Survival. More information about this study will be forthcoming when we are ready to begin.

Thomas G. Keens, M.D.
Children's Hospital Los Angeles

It has been said that time heals all wounds. I do not agree. The wounds remain. In time the mind, protecting its sanity, covers them with scar tissue and the pain lessens, but it is never gone. ~ Rose Kennedy

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On the other hand, you may try to keep everything, and it may take many months and several acts of sorting through the belongings at intervals before you're able to decide on just the special things you want as mementoes. As time goes by, you will be able to let go of the less important things without it ripping you to pieces. Not everything will forever have the same value to you. You may change in how you feel and find that it comforts instead of hurts to see your subsequent child wearing some of the baby's clothes.

Whether you've made changes or haven't been able to make changes, it's okay. There's no rule about when you do it, and don't let well-meaning friends or relatives make you feel guilty because your needs don't meet their timetables. What we would like to suggest to you is, though there are no rules about when you do it, that you do have as a goal eventually making the changes; otherwise, the room and things become a shrine, and if you have surviving children, or a spouse, they may find it very difficult to live in this atmosphere forevermore. If they could be honest with you, many would tell you they don't want their dead sibling punished; instead, bring the record player and records into the den, or use the backpack and tent, or whatever, because it comforts them to feel that their sibling has once again become a part of the family and not relegated to "the room."

I don't think I know of anyone who hasn't kept some belongings of their dead child, so that must be normal. What we learn after the death is that life is tenuous at best, and rather than hanging on to an unchanged room, try to value the important people who are left in this life, be they family or friends, and savor them, along with the memories of your dead child. For when all is said and done, those memories are truly the important part of what you have left of your child. That's truth that doesn't need changing.

2012 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

July 2

August 6

September 10

October 8

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.

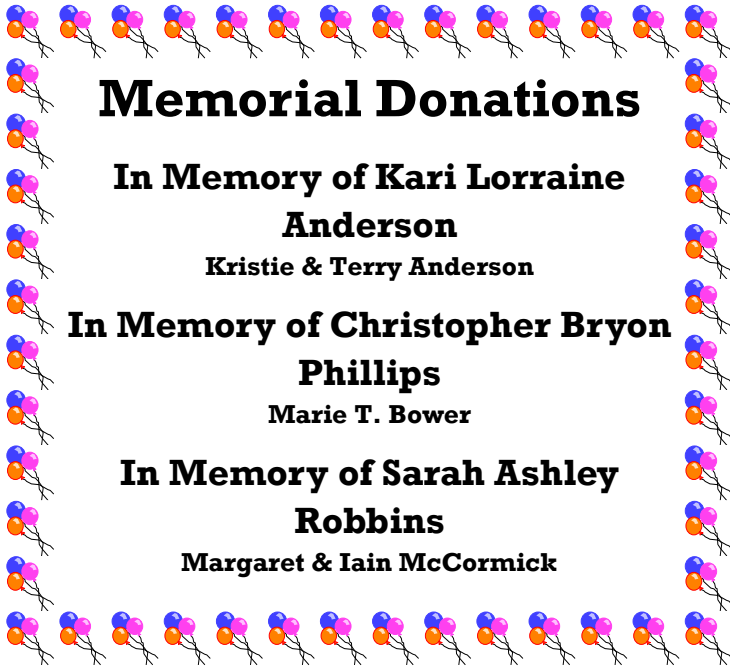
August 14

October 4

Save the Date!

October 17, 2012
Guild luncheon to be held at
Anaheim White House Restaurant
887 South Anaheim Blvd.
Anaheim, CA
For more information please call
Barbara Estep (714) 973-8417





Memorial Donations

In Memory of Kari Lorraine Anderson

Kristie & Terry Anderson

In Memory of Christopher Bryon Phillips

Marie T. Bower

In Memory of Sarah Ashley Robbins

Margaret & Iain McCormick



Community Campaign Donations

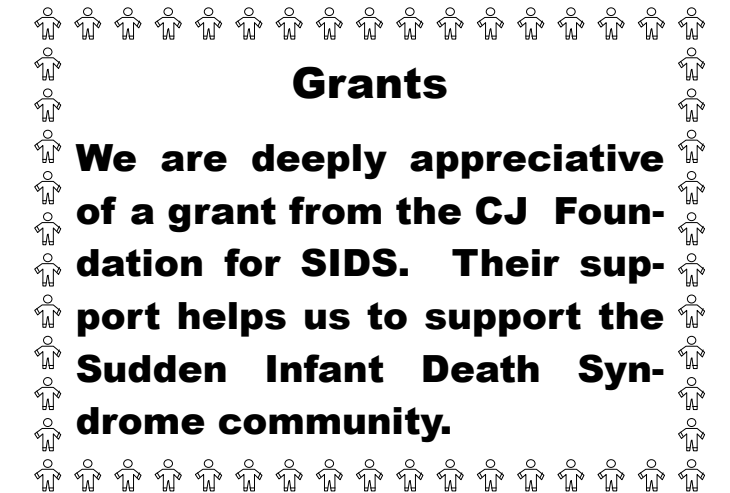
Thanks to:

Orange County Walk to

Remember

Wells Fargo Community

Support Team



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
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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.