



"To keep new lives living."

REFLECTIONS

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A Note From The President

President

Jordy Jahn

Vice President

Penny Stastny

Treasurer

Evelyn Clemente

Recording Secretary

Liz Willett

Historian

Carole Guttilla

Parent Contacts

- Jordy Jahn
(949) 501-6346
- Arlene Barela
(520) 252-7660
- Colleen Ma
(714) 315-4605

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

Every day, there are many reminders of my son Ryan who passed away from SIDS five years ago. Sometimes it's hearing an ambulance siren or seeing the hospital where I saw him last in the distance each morning on my drive to work. I've become almost numb to them, and I am usually able to quickly recover from any thoughts that might keep me from continuing on with my day. But there are also the reminders that still take my breath away or cause me to cease anything else I may have been doing. And occasionally, I even feel sorry for myself again. For example, the other morning my daughter Natalie pulled out a necklace from my jewelry drawer. It's a heart with exactly one-third carved out of it. I haven't worn it in a few years so it's badly tarnished. I remember buying it and the significance of its

warped shape. The rust now symbolizes the time that's passed.

For me, time will never replace the piece of my heart missing since Ryan passed away. The necklace, innocently placed before me, was a painful reminder of the little boy I can no longer embrace. Instead of making memories with him, I have moments or objects that symbolize his absence.

Although the exact details may be different, I know I am not alone in these moments. I wouldn't characterize them as good or bad, they simply are just part of our lives. If you'd ever like to share your story please join us at one of our support meetings each month. Sometimes I experience enormous relief just being able to talk about Ryan. Won't you join us?

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Poem written in memory of
Genesis Cash Emerson
8/18/10—11/20/10



Dear Mama,

Mama, I'm so sorry to
hear you cry.

I know you still can't un-
derstand how or
why.

God allowed me to come down to experi-
ence love,

I'm so sorry me being gone made it so
tough.

I deeply regret I didn't get to say goodbye.
Our time was short, and only God knows
why.

I hope you can find it in your heart to forgive
yourself and try,

To understand why I'm up here and you're
not the reason why.

I am needed because little angels are high
in demand.

Heaven's little helper, I'm important,
And God has me holding His hand.

With my new little wings, I am breaking
them in

Mama, please no more tears of sadness
No more what could have been.

I miss you all and I wish I could have stayed
longer

But Mama, each day you and Dad will grow
a little bit stronger.

Every now and then you will be filled with
warmth and love

Just know it was sent from your angel above.

Spoiled by your hugs and kisses that I will
cherish forever

Don't worry, Mama, one day we will be
together.

Community Outreach

On May 24, 2011, a conference on "Safe Sleep for Infants: New Data on Bedsharing and Increased Infant Deaths" was presented by the Southern California Public Health Association (Nursing Section), Guild for Infant Survival, Orange County, and Long Beach Memorial Medical Center. The event was attended by 117 healthcare professionals who were privileged to hear presentations by Thomas G. Keens, MD (Professor of Pediatrics, Physiology and Biophysics, Keck School of Medicine USC, Division of Pediatric Pulmonology Children's Hospital Los Angeles), Penny F. Stastny (Sr. P.H.N., R.N., B.S.N., Retired SIDS Coordinator, Los Angeles County Department of Public Health, Orange County Health Care Agency), and Daniele Sees (R.N., P.H.N., C.L.E., SIDS Coordinator, Department of Health and Human Services City of Long Beach).

The conference included an update on SIDS research, reducing the risk of sudden unexpected infant deaths (SUID), bedsharing and the risk of SUID, infant safe sleep education by health care professionals and concluded with a wrap-up of questions and answers. Three continuing education units were available for RN's. Each presentation was excellent in content and very well received by the listening audience. Thank you to all who were part of this timely outreach.

Autonomic Nervous System Dysfunction and SIDS

SIDS is not as simple as babies stopping breathing during sleep. Research by *Professor Hannah Kinney* and her colleagues at Harvard suggests significant abnormalities in brainstem serotonin in babies who died from SIDS compared to controls. This finding implies abnormalities in



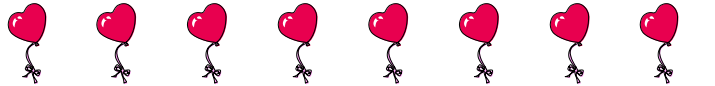
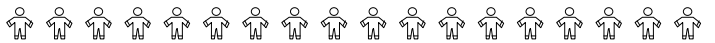
Always place your baby on his or her Back to Sleep.

cardio respiratory control and control of sleep-wakefulness. We believe that autonomic nervous system dysfunction, perhaps precipitated by hypoxia which occurs in infants during sleep, causes abnormalities in the cardiovascular system precipitating arrhythmias, blood pressure changes, or a shock-like state, which causes death. Our current work, in collaboration with the Department of Biomedical Engineering at the Viterbi School of Engineering at the University of Southern California, explores how abnormalities in children with obstructive sleep apnea syndrome alter the autonomic nervous system control of cardio respiratory and metabolic physiology. We are completing one study funded by the National Institutes of Health, and we were recently awarded another study. This exciting study will measure upper airway function and obstruction in real time using MRI, and correlate these abnormalities with computer modeling of cardio respiratory control. The question is, how much of obstructive apnea is due to structural or anatomic abnormalities, and how much is due to abnormal cardio respiratory control? In the future, it is hoped that we can translate these findings to infants, but research must first be performed on subjects who can cooperate with these sophisticated physiologic studies.



Peer Contacts and Support Group Facilitators Needed

Are you a parent, grandparent, family member, childcare provider or foster parent, affected by a SIDS death? Are you interested in learning how to help newly bereaved SIDS families? Then, consider being trained as a peer contact. We ask that interested individuals have experienced their loss at least one year before volunteering. Peer contacts who are interested in managing a SIDS support group are encouraged to be trained as facilitators. Please contact Jordy Jahn at (949) 501-6346 if you are interested in helping support SIDS families.



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

GUI300



Newsletter Deadlines

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 9/1/11.** We encourage your participation!

What can I do to lower my baby's risk of SIDS?

Here are 10 ways that you and others who care for your baby can reduce the risk of SIDS.

Safe Sleep Top 10

1. **Always place your baby on his or her back to sleep, for naps and at night.** The back sleep position is the safest, and every sleep time counts.
2. **Place your baby on a firm sleep surface, such as on a safety-approved* crib mattress, covered by a fitted sheet.** Never place your baby to sleep on pillows, quilts, sheepskins, or other soft surfaces.
3. **Keep soft objects, toys, and loose bedding out of your baby's sleep area.** Don't use pillows, blankets, quilts, sheepskins, and pillow-like crib bumpers in your baby's sleep area, and keep any other items away from your baby's face.
4. **Do not allow smoking around your baby.** Don't smoke before or after the birth of your baby, and don't let others smoke around your baby.
5. **Keep your baby's sleep area close to, but separate from, where you and others sleep.** Your baby should not sleep in a bed or on a couch or armchair with adults or other children, but he or she can sleep in the same room as you. If you bring the baby into bed with you to breastfeed, put him or her back in a separate sleep area, such as a bassinet, crib, cradle, or a bedside co sleeper (infant bed that attaches to an adult bed) when finished.
6. **Think about using a clean, dry pacifier when placing the infant down to sleep,** but don't force the baby to take it. (If you are breastfeeding your baby, wait until your child is 1 month old or is used to breastfeeding before using a pacifier.)
7. **Do not let your baby overheat during sleep.** Dress your baby in light sleep clothing, and keep the room at a temperature that is comfortable for an adult.
8. **Avoid products that claim to reduce the risk of SIDS** because most have not been tested for effectiveness or safety.
9. **Do not use home monitors to reduce the risk of SIDS.** If you have questions about using monitors for other conditions talk to your health care provider.
10. **Reduce the chance that flat spots will develop on your baby's head:** provide "Tummy Time" when your baby is awake and someone is watching; change the direction that your baby lies in the crib from one week to the next; and avoid too much time in car seats, carriers, and bouncers.

* For information on crib safety guidelines, contact the Consumer Product Safety Commission at 1-800-638-2772 or <http://www.cpsc.gov>

Men Do Cry

by Ken Falk

I heard quite often "men don't cry"
though no one ever told me why.
So when I fell and skinned a knee,
no one came by to comfort me.

And when some bully-boy at
school
would pull a prank so mean and
cruel,
I'd quickly learn to turn and quip,
"It doesn't hurt," and bite my lip.

So as I grew to reasoned years,
I learned to stifle any tears.
Though "Be a big boy" it began,
quite soon I learned to "Be a man."

And I could play that stoic role
while storm and tempest wracked
my
soul.
No pain or setback could there be
could wrest one single tear from
me.
Then one long night I stood nearby
and helplessly watched my son die.
And quickly found, to my surprise,
that all that tearless talk was lies.

And still I cry, and have no shame.
I cannot play that "big boy" game.
And openly, without remorse,
I let my sorrow takes its course.

So those of you who can't abide
a man you've seen who's often
cried,
reach out to him with all your heart
as one whose life's been torn apart.

For men DO cry when they can see
their loss of immortality.
And tears will come in endless
streams
when mindless fate destroys their
dreams.

*Ken is a member of the
Northwest Connecticut Chapter of
The Compassionate Friends*

Can You Be a Parent When Your Baby's Not With You?

Anonymous from SIDS Resources of Oregon

I thought of you and closed my eyes
And prayed to God today
I asked what makes a Parent
And I know I heard Him say

A Parent has a baby
This we know is true.
But, God, can you be a parent
When your baby's not with you?

Yes, you can. He replied
With confidence in His voice.
I give many parents babies
When they leave is not your choice.

Some I send for a lifetime.
And others for a day.
And some I send to feel your womb
But there's no need to stay.

I just don't understand this, God,
I want my baby here.
He took a breath and cleared His throat
And then I saw a tear.

I wish that I could show you
What your child is doing today.
If you could see your child smile
With other children and say:

"We go to Earth to learn our lessons
of love and life and fear.
My parents loved me o so much
I got to come straight here.

I feel so lucky to have parents
Who had so much love for me
I learned my lessons very quickly
My parents set me free.

I miss my parents o so much
But I visit them each day
When they go to sleep
On their pillows where I lay.

I stroke their hair and kiss their cheek
And whisper in their ear,
"Don't be sad today,
I'm your baby and I'm here."

So, you see my dear sweet one
Your children are okay
Your babies are here in My home
They'll be at the gates for you one day.

So now you know what makes a parent
It's the feeling in your heart,
It's the love you had so much of,
Right from the very start.

Though some on Earth
May not realize you are a parent
Until their time is done.
They'll be up here with Me one day
And you'll know that you're
The best one!

Tips for Fathers who are Grieving Their Children

1. Be kind to yourself. Many fathers may feel anger, sadness, guilt and a host of other emotions because their child died before them. These emotions may seem foreign but are very common with grief—don't try to avoid them.
2. Reach out for support; it is not a sign of weakness but a sign of courage. Boys are taught to "shake it off" and "take it like a man." It is unrealistic and mistaken that grief can be "shaken off" or avoided.
3. Allow time to grieve and express your emotions in a healthy way. Finding balance is key to healing.
4. Be patient with yourself. Talk openly with family and friends about your child and encourage them to talk openly with you too—hearing your child's name mentioned can be helpful.
5. Create your own memorial. Whether it involves planting, writing, building or painting, be creative and put your energy into doing something in memory of your child.

Letting Go

Compliments of
Hospice of Saddleback Valley

Letting go is a slow process which is a difficult and emotional task. Grief and mourning allow you to heal, to reconcile and invest in your future life. In letting go you validate your feelings and leave behind some of your old self... you're not the same person. You begin to create the new you and build a new and different life for yourself. It's a time for you to develop and grow. It's a turning point.

Letting go does NOT mean that you forget about your loved one or block the memories of your life with them. The loss becomes part of who you are and what you've experienced. Now you need to move on without guilt or remorse in beginning your new life.

Some of the things you can do in your "letting go" process could include reviewing your life with the person who died. Look at old photos and family movies. Remember the good and bad times and especially the fun times.

Write a letter to your loved one including what I wish I had said to you, I could ask you, I had done, and what I would like to tell you. Pour out your feelings. Say goodbye. You can express your feelings by keeping a journal or diary, writing stories or poems, playing music, or using art to express your feelings. Choose a special place to let out your feelings where you feel peace or renewal such as the beach, mountains, woods, or a park. For feelings of anger engage in a physical activity such as running or exercise.

Remember that letting go occurs when you're able to accept whatever your feelings are (anger, fear, guilt, sadness, etc). Letting go occurs when you can tolerate those feelings, to wait, hope and trust again.

Take time to make decisions (be patient with yourself and make them gradually),

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and the present. The songs of the birds invite us to join them in a celebration of new life. In the springtime of our grief, there can be a new song for us to sing. It will be a song we composed through the heartaches of loss.

Optimism for a better day may awaken us one morning. Hearing laughter and discovering it is coming from within ourselves gives us promise for today. Dreams and hopes for a better tomorrow shine brightly with the morning sun.

Surviving the winter of our grief with the openness to embrace change is a decision to embrace loss and integrate its impact into the fabric of our lives. It can be a willingness to explore new possibilities that create a different landscape to behold. We can make a decision that we will begin to appreciate what we still have, not just focus on what is missing.

We will know when we have made that decision. Something buds; something opens. The harshness of winter is softened with new life and new growth. It is not something we can force, it is something that unfolds when the time is right. The springtime of grief arrives with no dramatic entrance, no flashing lights. The stillness of the beauty unfolds and captures our attention. It is happening around us, but it is also happening to us.

If spring has already crossed the path of your personal journey of grief, rejoice! But if the chill of winter remains in your heart, be encouraged, spring is on its way. Look for it, expect it, and it will be yours to experience around you and in you!



Babies sleep safest on their backs

One of the easiest ways to lower your baby's risk of SIDS is to put him or her on the back to sleep, for naps and at night. Health care providers used to think that babies should sleep on their stomachs, but research now shows that babies are less likely to die of SIDS when they sleep on their backs. Placing your baby on his or her back to sleep is the number one way to reduce the risk of SIDS.

Q. But won't my baby choke if he or she sleeps on his or her back?

A. No. Healthy babies automatically swallow or cough up fluids. There has been no increase in choking or other problems for babies who sleep on their backs.

Enjoy your baby!

Spread the word!

Make sure everyone who cares for your baby knows the Safe Sleep Top 10 (Page 5)! Tell grandparents, babysitters, childcare providers, and other caregivers to always place your baby on his or her back to sleep to reduce the risk of SIDS. Babies who usually sleep on their backs but who are then placed on their stomachs, even for a nap, are at very high risk for SIDS—so every sleep time counts!



If you use a blanket, place the baby with feet at the end of the crib. The blanket should reach no higher than the baby's chest. Tuck the ends of the blanket under the crib mattress to ensure safety.

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share (have someone share your pain, memories and sadness), believe (have faith in yourself to make a future, perhaps you might find comfort in religion) forgive (accept your imperfections), feel good about yourself (explore new interests, hobbies), pursue new opportunities (re-invest your energies), meet new friends (leave your safe boundaries), and laugh as laughter helps us to survive.

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.

**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

2011 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

Tuesday, July 5th

Monday, August 1st

Monday, September 5th

Monday, October 3rd,

Business Meetings— held at the Guild for Infant Survival, Orange County office located at 2130 E. 4th Street, Suite 125, in Santa Ana. 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 9, 2011

November 8, 2011

Save the Date!

“Orange County Walk to Remember” Pregnancy and Infant Loss Support and Awareness to be held **October 15, 2011**, at The District at Tustin Legacy in Tustin. There will be a 5K Walk and Memorial Ceremony with table displays by non-profit organizations throughout Orange County. Participants will “Walk For The Steps Our Babies Will Never Take”.



Sponsorship opportunities are available and you can register at www.ocwalktoremember.org.

We hope to see you there!