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The Parent Corner

by Jordy Jahn



It's been three years since my son Ryan left my arms forever. I distinctly remember how well I had prepared and guarded myself from what I knew would continue to unravel me: the letter from the coroner's office, the death certificate, and the hospital bills. Even more clearly, I remember all the things I couldn't possibly prepare for, the unexpected: seeing the ambulance company pull up next to me at a street light, the sound of sirens, the letter from the insurance department at work that marked "remove" next to his name after losing him just a few weeks earlier, and the phone call from the coroner that confirmed it was SIDS.

Three years later, it is still the unexpected that takes my breath away. I wasn't prepared for my five year old son's question as I drove him to school just a few weeks ago. He was inquiring about death and for some reason I still didn't come to realize where his questioning was headed until he asked, "How did Ryan die?" Suddenly my heart sank and my mind started to race as tears filled my eyes. I thought if I tell him Ryan died in his sleep, he will be terrified. So I scrambled for the words as my heart grew heavier. Finally I said, "He stopped breathing." I could hear him hold his breath, as if to test the theory or try to understand how it was even possible. (*I didn't even know how it was possible.*) Then he continued, "I don't want Natalie to die!" His little sister's safety, our subsequent daughter, had quickly come to mind. Although I repeatedly confirmed that she would be fine, unfortunately I knew all too well that I couldn't promise. And as suddenly and unexpectedly as this had all begun, a new question surfaced, "How are cars made?"

If you would like to contribute to our "Parent's Corner", email your submission to lbiakanja@yahoo.com.

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A Note From The President

Happy New Year! Wow, another year has passed. As I was taking down another year of Christmas decorations, I was thinking about all the parents that are going through their first year of not having their baby for Christmas. It's hard to believe that it has been 5 years since all of my firsts. It's no wonder after going to sleep that night that I had a dream about Hayden. I could see him from a distance what he would look like now at 5 years old. He had straight sandy blond hair that went just passed his eyebrows. I strained my eyes to get a better look, but no matter what I did, I could not see his precious face. After a few seconds of straining my eyes, I saw my Grandma walk up next to him. I instantly started crying. My Grandma passed away 2 years ago and before she died, I told her to give Hayden a hug for me. I guess she is doing more than I asked. Needless to say, I woke up from my dream with real tears. How wonderful it is to know that my baby is being taken care of by a loved one! Whether you believe in heaven or not, I doubt there's one of you out there that wouldn't be overwhelmed with tears of joy that your baby is being taken care of by a loved one. I hope that 2009 brings all the families affected by SIDS or that will be affected by SIDS the overwhelming sense of comfort that their babies are being taken care.

TIP Fundraiser is All Heart

The Orange County Chapter of the Trauma Intervention Program (TIP) held its annual **Heroes with Heart** fundraiser at the Hilton in Costa Mesa on November 7, 2008. TIP is a volunteer based program where citizens are called upon to support people who are in distress due to a traumatic event. Many SIDS parents have been helped through the selfless dedication of these volunteers. Board members, Rachel Strickland and Jordy Jahn, attended on behalf of the organization and were deeply touched by their **Heroes with Heart** tribute for a select group of Orange County first responders who had been nominated by TIP volunteers. There were many TIP volunteers in attendance as well as founder of TIP, Wayne Fortin. He spoke of the program, its need for volunteers, and the dedication of the many people who continue to give their time and hearts so freely. There were several Orange County Fire and Sheriff representatives who shared stories where these volunteers were able to step in and be the support these victims so desperately needed. Sheriff

Sandra Hutchins also spoke about the importance of the program and its partnership with the Orange County Sheriff's Department. It truly was a heart-warming event!

Recruitment for this program is in process and their next training is set for February 2009. If you are interested in learning more about the program, or becoming a volunteer, please call Donna Quagliarini, Assistant Crisis Team Manager, at (714) 343-0738.



Some people give time, some money, some their skills and connections; some literally give their blood . . . but everyone has something to give.

Barbara Bush

Continued on column 2

THE HOLIDAYS ARE BEHIND US

Thanks to Marie Andres, TCF So. MD
Chapter, MD

It is the new year. The holidays are behind us. We did with them what we could. Whether they were a time of sorrow, a time of joy or a combination of both, they are now a part of our memories. In a strange way, as a memory in our hearts and in our minds, our child's place is there among all the other memories of the season. There is hurt along with the memory, but also a thankfulness for the memories.

Now we look out at the winter landscape. The earth is cold, the land sharply defined. Yet underneath the hard crust, the energy and warmth of our earth is guarding and providing life to all that grows. We may personally know the coldness and hardness of a grief so fresh that we feel numb - a grief so hurtful that our body feels physically hard, our throats tight from tears shed or unshed, our chests banded tight to our mourning heart.

If we are not now experiencing this, our memories recollect so easily those early days. Yet, as we live these days, like the earth from which we receive our sustenance, we too, in our searchings find places of warmth and change and love and growth deep within. Let our hearts and minds dwell in these places and be armed and renewed by them, and let us have the courage and love to share them with our loved ones, to talk about even that first dim shape of new hope or of new acceptance or of new understanding or of new love.

These are the new roots, born of our love for our child, that are forming and stirring within, gathering strength so that our lives, at the right time, can blossom once again and be fruitful in a new and deep way.



28th ANNUAL CALIFORNIA SIDS PROGRAM FALL CONFERENCE

“LESSONS OF LOVE AND HOPE”

by Rachel Strickland

My husband Shawn and I recently attended the Southern California SIDS conference at The Endowment Center in the city of Los Angeles. It was held on October 23rd and the 24th.

The conference started Thursday night with a memorial service in honor of babies lost to SIDS.

Two SIDS parents from the San Diego area named Drew and Angela put on a wonderful service that made many parents feel at peace. The parents were given a paper cut out of a heart and were asked to write their baby's name on it. At the end of the service each parent came forward and said their baby's name out loud and hung the heart on a Christmas tree. There is something very intense about a parent walking to the front of the room and saying their baby's name out loud. It makes all these beautiful babies “real” instead of just a SIDS statistic.

The next morning started out with a parent panel consisting of me, my husband and another SIDS parent. This time always seems very close to parents' hearts. New SIDS parents see that other SIDS parents' years beyond them can smile and be happy again. I myself remember seeing these parent panels 5 years ago at my first conference and longed to be where they were.

The panel was followed by a SIDS researcher named Dr. Harper that explained what we have learned from SIDS to date. It was then followed by a panel of experts ready to answer any questions parents or nurses had.

We broke for lunch and then separated into 3 groups. One group consisted of new SIDS families, the second was for SIDS parents years beyond and the last was for the nurses. I found this time to be very warming. It felt like the old parent support groups, the kind of support groups I wish we could get parents to come to in Orange County. I feel at home with these parents. They have an understanding of life that few know.

The conference ended with a Sudden Love program put on by Drew and Angela. I personally enjoy going to these conferences and wish more SIDS parents would go. The conference alternates from Northern to Southern California each year. If you are interested in attending next year the dates are October 19th and 20th in Sacramento. I would love to see some of you there. If you can't make it, be sure the conference will be back here in Southern California in 2010.



Preventing SIDS Advice from Dr. Nora Davis:

Babies lose and gain heat primarily from their head, so in cold weather it's important they wear a hat when they go outside. Inside they need to lose heat to keep from overheating. Contrary to what you may have been taught, babies cannot tolerate excessive HEAT. During sleep, their room should be the same temperature as yours, 65-70 degrees. They should wear the same number of layers as you find comfortable. For babies under six months, we encourage use of a sleep sack and no blankets. For older babies, sleepers with feet can be a safe substitute.

For preemies, just home, I would suggest a sleep sack and a thin receiving blanket when they sleep. Arms and head should always be uncovered. If the baby's head or forehead is hot and sweaty, then your baby is dressed too warmly.

At all times, the baby should be placed flat on the back to sleep with no blankets, pillows, bumper pads or stuffed toys in the crib or bassinette. I do not recommend babies sleep in car seats, strollers or bouncy seats unless for a medical reason.

Babies are safest sleeping in the same room as their parents but NOT bedsharing.

Many grandmothers and other people who may care for your baby were taught the opposite so you should share this new information with them.



Death leaves a
Heartache no one can
Heal, love leaves a
Memory no one
Can steal

From a headstone in Ireland
Via Orange County TCF

The Language of Tears
By Yvonne Williams, M.S.
Muncie, Indiana

When someone you love dies, many different feelings flood into your heart, many thoughts and unanswered questions fill your head. These thoughts and feelings are hard, if not impossible, to express in words. But there is a wordless language that can pour out all these things that are so hard to speak about. This special language flows naturally when you need it—it is your tears.

Continued on column 3

The language of tears is a gift we all have that can communicate deep feelings we might not even understand, much less be able to describe with words. When we cry, our tears are like a river to carry us closer to what we need to understand about ourselves.

What do your tears seem to be telling you? Do they want you to pay attention to your painful sadness? Your loneliness? Your anger? Your fear? Your disappointment? Do your tears ever help you feel better? Can you think of some blessing that your tears have given you?

When you hold back feelings or try to hide or ignore our emotional discomfort, tears often burst forth. This is a sign that our feelings need to come out. Sometimes when we cry, it helps to talk to the person who died—like having a long distance phone call to heaven.

After a good cry we feel better. It is a relief to let out these emotions without having to talk about them if we don't want to. Our tears can say it all for us.

At times, we are embarrassed to let our tears show. However, our tears can tell others that we hurt and need comfort. Tears can be our fest fried—always there when needed. Tears understand us and

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**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.org
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 e-mail her at lbiakanja@yahoo.com. **The next Newsletter deadline is 4/1/09.** We encourage your participation!

Use of a Fan During Sleep and the Risk of Sudden Infant Death Syndrome

In October, 2008, Doctor De-Kun Li's epidemiological research group at Kaiser in Northern California published a study showing that the use of a fan in the room where a baby sleeps reduces the risk of dying from SIDS [1]. The study is a case-controlled study with 2 control infants for every SIDS baby. There were 185 SIDS babies enrolled, representing 47% of the SIDS babies. There were 312 controls. Of the SIDS victims, only 6 had a fan = 2 in their room (3.6%), compared to 36 controls (11.7%). Additionally, 26 SIDS victims had an open window where they slept (16.0%), compared to 77 controls (24.9%). Using adjusted odds ratios (AOR), the investigators found that having a fan in the room was associated with an odds ratio of 0.28 (meaning that babies with a fan in their room were only 28% as likely to die from SIDS as those without). Having an open window in the room was associated with an odds ratio of 0.64. The effect of a fan was greatest in infant sleeping environments thought to carry higher risk. That is, having a fan in the room reduced the risk of SIDS even more in: Prone sleeping position (AOR 0.14); Warm room (AOR 0.06); Bedsharing with parents (AOR 0.40); Bed-sharing with someone other than parents (AOR (0.15); Sleeping alone (AOR 0.23); and Did not use a pacifier (AOR 0.22). The investigators hypothesize that rebreathed air can accumulate and cause SIDS. A fan in the room, or an open window in the room, increases ventilation around the baby, and would tend to dissipate CO₂. The investigators found that use of a fan seemed to be more protective in

Continued on column 2

sleeping environments currently viewed as riskier, suggesting that the mechanisms of some of these deaths may be poorly circulated air. The study appears to be well conducted, and is based on a hypothesis which is reasonable. This study does support continued education about the traditional *Back to Sleep* recommendations, as use of a fan was not as protective in infants already sleeping in safe conditions. Professor Henry F. Krous, Rady Children's Hospital of San Diego and the University of California, San Diego, adds these comments: "The 72% reduction in SIDS is spectacular, to say the least. I would have emphasized the limitations in the paper to include things such as: Was the fan on? How close was it to the baby? How big was it? How fast was it running? (How much air did it move around the baby?) Was the sleep environment safe or unsafe? And if the latter, why was it unsafe? Were the SIDS diagnoses double-checked in the eleven counties that were evaluated? And, one could come up with other questions." As with other provocative studies, this issue warrants further research and investigation before these practices can be accepted or promulgated in the public.

However, based on these results, having babies sleep with a fan and/or open window may be a good idea. There is likely to be little harm from sleeping with a fan, and this study suggests that there may be benefit. It is too premature to make this a public health recommendation at present, but it will be interesting to see if other studies verify the results. - - - Tom Keens

[1] Coleman-Phox, K., R. Odouli, and D-K, Li. Use of a fan during sleep and the risk

of sudden infant death syndrome. *Arch. Pediatr. Adolesc. Med.*, 162: 963-968, .2008



Continued from page 4

know what we need. It is important to honor our tears and be thankful for them.

To help you understand better the purpose and value of your tears, make copies of the following questions so that you and every member of your family or grief group has a copy to fill out. After everyone has finished answering the questions, compare and discuss your answers with each other.

Questions about my Tears:

- ◆ I think my tears want me to know . . .
- ◆ I think my tears want me to think more about . . .
- ◆ My tears help me know that I need. . .
- ◆ My tears make me feel better when . . .
- ◆ I want my tears to help me. . .



Reducing the Risk of Sudden Infant Death Syndrome in Child Care and Changing Provider Practices; Lessons Learned From a Demonstration Project

Rachel Y. Mood, MD, Trisha Calabrese, BS, Laura Aird, MS

Abstract

OBJECTIVE: The goal was to evaluate, through an American Academy of Pediatrics demonstration project, the effectiveness of a curriculum and train-the-trainer model in changing child care providers' behaviors regarding safe infant sleep practices.

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We Walk to Remember

By: Debbie Gemmill

We walk to remember
The briefness of their lives
The brightness of their smiles
Both imagined and real.

We walk to remember
The plans for their futures
We remember instead
How our future has changed.

We walk to remember
The joy of anticipation
And now we remember
The sweetness of their memory.

With each step that we take
We carry our tears, our hopes
Our fears, our joy
Our dreams.

They are now a part of us
And they remain
In our faces, on our shoulders, in
our hearts.

The burden of sorrow
The weight of grief
The preciousness of their being
Making each footprint a little
deeper.

Reminding those who follow
behind us
That we have found a way to
Walk to remember
So that the rest will not forget.



The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing, not curing, not healing – and face with us the reality of our powerlessness – that is the friend who really cares.

Henri Nouwen

Get involved! Attend the Southern California Regional Meetings.

All parents are invited to attend these meetings. It is a good way to learn more about SIDS research and how you can help eradicate SIDS.

Below is a list of upcoming meeting dates:

- February 19
- May 14
- August 13
- November 12

All meetings are from 10:00 am to 1:00 pm and are held at:

Southern California Edison building
7300 Fenwick
Westminster, CA. 92683
Building 1 on first floor



*If I can stop one heart from breaking
I shall not live in vain.
If I can ease one life the aching,
Or cool one pain,
Or help one fainting robin unto his nest again,
I shall not live in vain.*

Emily Dickinson

Remembrance Brick Order

Bricks surrounding the base of the angel may be purchased for \$100.00 or more. Each brick includes up to 3 lines of engraving with as many as 20 characters, alpha or numeric, per line. Spaces, dashes, etc., count as a character. Your lines will automatically be spaced and centered by the engraver. Brick orders will be processed on a regular basis.



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Row #2: _____

Row #3: _____

Name _____

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Phone _____

E-Mail _____

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Angel of Hope Fund*

*Send to:
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Angel of Hope Fund
P.O. Box 17432
Irvine, CA 92623-7432*



**2009 SIDS
Conference
Friday, October 19,
in Sacramento by
capital building**

MEMORIAL DONATIONS

Special Thanks

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

In Memory of John Deakin Gough III

Love, Mom and Dad

John and Robin Gough

In Memory of Scott Francis Hogan

Ms. Fran Hogan

In Memory of Jason Alexander Robar

Mrs. Elmer L. Robar

Mr. & Mrs. R.L. Aguilar

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In Memory of Sarah Ashley Robbins

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In Memory of Roger Tourkow

David & Carol Tourkow

In Memory of Ian Watson

Toni & Russell Hudson

In Memory of Kaulin Riley Willett

Josh Johnson & Alicia Ashley

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



I expect to pass through life but once. If therefore, there can be any kindness I can show, or any good thing I can do to a fellow being, let me do it now, and do not defer or neglect it, as I shall not pass this way again.

William Penn

Continued from page 6

METHODS. Participating licensed child care centers and family child care homes were assigned randomly to intervention and control groups. Observers performed an initial unannounced visit to each site, to watch infants being placed for sleep, to inventory sleep policies, and to administer questionnaires to center staff members. Trainers then used the American Academy of Pediatrics curriculum in educational sessions at intervention sites. Three months later, observers conducted a follow-up observation at each site, and staff members completed a questionnaire about logistic barriers encountered in implementation of safe sleep recommendations.

RESULTS. A total of 264 programs and 1212 providers completed the study; the care of 1993 infants was observed. Provider awareness of the American Academy of Pediatrics infant supine sleep position recommendation increased from 59.7% (both groups) to 64.8% (control) and 80.5% (intervention). Exclusive

Continued on column 2

use of the supine position in programs increased from 65.0% to 70.4% (control) and 87.8% (intervention). Observed supine placement increased from 51.0% to 57.1% (control) and 62.1% (intervention).

CONCLUSIONS. A sudden infant death syndrome risk reduction curriculum using a train-the-trainer model is effective in improving the knowledge and practices of child care providers. Perceived parental objections, provider skepticism about the benefits of supine positioning, and lack of program policies and training opportunities are important barriers to implementation of safe sleep policies. Continued education of parents, expanded training efforts, and statewide regulations, mandates, and monitoring are critical to ongoing efforts to decrease further the risk of sudden infant death syndrome in child care. *Pediatrics* 2008; 122: 7888-798



2009 MEETING CALENDAR

Parent Support Meetings– All meetings are from 6:00—7:30 PM
Dinner will not be served;
no children please in deference to newly grieving parents

* Please RSVP to the parent host prior to the meeting

February 8, 2009
(Sunday)

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

March 8, 2009
(Sunday)

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

No April Meeting

May 10, 2009
(Sunday)

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

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.

April 22, 2009

July 15, 2009



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