



REFLECTIONS

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The Measure of His Days... From a Parent's Point of View

By: Debbie Gemmill c2004

(reprinted from Getting Through Grief: From a Parent's Point of View)

The holidays are behind us. As I vacuum up pine needles and repack ornaments, I find myself looking forward to the New Year. It doesn't look much different from the old year—it's still in the 70's outside; the only real sign of a seasonal change is the blanket of leaves on the front yard and the mental list of resolutions I find myself reluctantly creating.

It's only the taking down of the old calendar that really marks the start of a New Year. The children gave me a beautiful new calendar filled with photographs of exotic orchids, and I am eager to hang it on the kitchen wall by the phone. The old calendar is dog-eared and water-spotted; its daily squares filled with color-coded notations of how we've spent the last year. I'm eager to replace its tattered pages with this gorgeous new one, but I won't throw away the old one just yet. I want to take some quiet time to flip through its pages and make notes about birthdays and special events to transfer to the new clean pages of this year. **(continued on page 3)**

A Note From The

It's becoming painfully apparent that our group needs new blood. We need young parents to come forward to facilitate as peer support contacts, people with new ideas to chair committees for fundraising, speaking forums, public awareness, and other areas that support and communicate the GISOC's mission. The individuals that have worked tirelessly for years on behalf of our group are now ready to step aside and hand over the reins to the new generation of parents. Our problem – very few people are coming forward to assume the roles left vacant by others.

It seems that the advent of the computer and online support have superceded the need for newly grieving parents to be present at peer support meetings.

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A Note From The

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Our in-home meetings that once overflowed in our living rooms are now poorly attended with fathers rarely participating. If you attended a peer support meeting in a SIDS parent home in the past, you know that nothing can take the place of it. Being able to look into the eyes of a mother that has gone through the same horrific experience that you have is a powerful experience. She can reassure you that reading the obituaries doesn't equate to craziness or that feeling uncomfortable around your sister's baby is a common experience. Having her number in your purse or pocket to call at any time is a lifeline that helps many young parents put one foot in front of the other in the hours, days, weeks, and months following the death of their baby. Only another SIDS parent can tell you that she knows how you feel and you believe her because she has walked in your shoes.

The new research studies conducted on SIDS promises us hope that the rate of SIDS will be further reduced. Future parents may be saved from the excruciating pain that the death of a baby brings. One day . . . Until then, however, we continue to need the support and encouragement of other parents that have walked in our shoes. Parents that feel the human touch is more powerful than a computer screen.

Won't you consider stepping up to the task? I can assure you that helping others on this journey can be a rewarding, influential experience – one that benefits the newly grieving parent but also you as the legacy of your child lives on in your works.

Newsletter

The cost to print and mail the *Reflections* newsletter is steadily rising. Therefore, it is important that we have your latest contact information. If the address shown on your newsletter is not correct, please e-mail Laura Kirchner at gisoc@compuall.net or call her at (714) 973-8417 with your current information.

Newsletter donations of \$20 covers the cost of printing and mailing quarterly newsletters. Mail your donations in today.

REFLECTIONS

P.O. Box 17432
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Editor: Cory Morinishi

Reflections is a quarterly 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.

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Newsletter Deadlines

If you would like to contribute an article or poem to an upcoming issue of *Reflections*, please contact: Cory Morinishi at (714) 952-1466 or e-mail him at shar-mori@ca.rr.com. The next Newsletter deadline is 6/15/07. We encourage your participation!

The Measure of His Days ...From a Parent's Point of View

(Continued from Page 1)

It was a couple of years ago, about this time of year, when filled with enthusiasm and dedication to begin the New Year in an "Organized Manner", we tackled the first of our many projects: the garage. John, legs dangling from the rafters, handed box after box to me with instructions to go through them, toss what we no longer needed or wanted, then label the outside of each one with its contents. We dove into our project with determination. Out with the old, in with the new. Who needs all this stuff anyway?

It went pretty well at first. We really didn't need two crockpots or an electric frying pan with no cord. It was pretty easy to casually toss the hamster cage and the fondue pot into the Give Away pile, and although the To Keep pile was much larger than the Give Away pile, we were still making progress and feeling fairly smug about our efforts. Down came another box which I opened with a certain amount of excitement. What would be in this one?

It was a mishmash of objects: half-burned candles, some winter mittens the moths had feasted upon, some carefully folded Christmas wrapping paper. I must have tossed all these items in this box some end-of-the-holiday season. Maybe each item had some special significance at the time, or maybe I was just impatient with the post-Christmas clutter in the house and filled up this box just to clear away some of the mess. *Well*, I thought confidently, *this box is easy. Everything goes!*

I quickly ruffled through it to the bottom just to make sure I'd found everything. There was one more item flat on the bottom. A calendar.

"What a lot of junk we've managed to save," I laughed as I added the calendar to the Throw Away pile. Why in the world would I have saved an old calendar?

The day went well. Exhausted and dusty, we congratulated one another on our new ability to be organized. The New Year was off to a wonderful start.

It wasn't until later that night that I remembered why I had saved that old calendar. It was from 1982. The year Tyler had died. I don't know why it wasn't in the chest that holds his other things. But there it was, in the pile of Things to Be Thrown Away. I rescued it, of course, and spent some time alone with the past.

There on its dog-eared, water-spotted pages was the life we had spent with our son. Some of the daily squares were filled with notes about well-baby checks, and playdates at the park or the beach. Jen's gymnastic lessons and preschool events were carefully noted. Most touching of all was the writing on the 22nd of each month, indicating Tyler's age by month. The last of those entries was on May 22. *Jennifer's fourth birthday. Ty's seven-month birthday.* Little did we know that just three days later he would be dead.

The Measure of His Days ...From a Parent's Point of View

(Continued from Page 3)

There were few entries on the squares that followed. A lot of things happened, I know, but somehow memorial services and relatives' visits did not need to be written down. I remember turning the calendar page from May to June, unbelieving that we could start a new month without our baby.

There were a lot of things that didn't get written down. When, for instance, was I able to get dressed before noon? When was the first day I didn't cry? What day was it that John and I realized we were going to survive?

The calendar marked many things that year. It told a lot about who we were, what we did, what we planned to do. Everything changed for us on that day in May: you could tell just by looking at the calendar. I was as if New Year's had come in late spring: we were now facing an entirely new life, with changes we'd had no time to prepare for, and certainly nothing to celebrate.

It was almost like looking at a calendar switched mid-year, belonging to two different families. The first happy, busy...the second empty, heavy with sadness.

Looking back, I think those unmarked days, those blank squares which followed Ty's death, told even more about what was really happening to us. While it looked like nothing, those bold lines surrounding the empty squares were like thick walls that held pain and sadness, but also healing. Impossible to measure, impossible to gauge, slow and awful.

I looked through that old calendar for a long time. It seemed hard to believe that Ty's life was so short that it could be contained in a half of a calendar. Somehow it seems as if he was with us for much, much longer. There was so much *life* in him. He was, it seems, much more than the measure of his days.

Yes, I know. It's just an old calendar, I convinced myself, but it won't take up much room. I'll just stick it in this box.

It's still up in the rafters, a small record of a small life in a small family. Some other New Year we'll climb back up there, go through the box, and decide just how organized we need to be. In the meantime, I'll hang my new beautiful orchid calendar and enjoy its shiny, unmarked (for now) pages, and then I'll sit down with the old marked-up one and try to remember that it's more than just a measure of days.

COMMUNITY OUTREACH

Thank you to SIDS mom, Mary Ann Garcia, for joining our Executive Director, Barbara Estep, in presenting an educational outreach to case workers from the Bridges for Newborns program. Our special thanks to Jodie Reddingius Tintorer, MSW, Bridges for Newborns, Supervisor, for inviting us to participate in this important program for babies at risk.

MEMORIAL DONATIONS

Donations have been made in the loving memory of the following babies by those who loved them:

Bailey Annmarie Downs
Mom's Club of La Habra

Ryan Joseph Jahn
Keith and Renae Boyum
Roger and Mary Free
Raymond E. Alburger

Linda Birtler

Robert & Christine Perkins
Family Friends of Ryan

John & Barbara Steinberger
Bob Newgard & Betty Smith
John & L. Beatrice Shamlin

Scott Francis Hogan
in honor of his 16th Birthday

John & Becky Hogan
Christopher B. Phillips
Marie T. Bowen

Sarah Ashley Robbins
Iain & Margo McCormick

Jason Doo
David & Alpha Doo
Kaylee Billings
Lance and Lori Blake

Community Support Campaign

Elaine L. Nelson
Kim M. Young
Oscar Gaitan
Peter Irvin
Roxanne Raftery
Arlene Solis
Chad M. Franks
Douglas Hand
Jennifer L. St. John
Debra J. Jimenez

**Thank you to
United Way Donor**

Q Liu

*Newsletter Thoughts
And Opinions*

Once again the Guild is asking our readers to communicate their thoughts and ideas regarding our newsletter. What do you like about "Reflections"? What would you like to see changed or included? We strive to meet YOUR needs and any suggestions or comments will be appreciated. Please send your written responses to GISOC, P. O. Box 17432, Irvine, CA 92623.

Dear GISOC Friends...

(Update from the Oishi Family)

Dear GISOC Friends,

I enjoy reading each newsletter and am thankful that I can keep in touch with all of the wonderful things you are doing to fight SIDS. I miss all of my dear friends in the Guild and am so encouraged to see the progress that you are making in helping SIDS families survive their loss. The help I received from the Guild when we lost our son, Reece to SIDS in 1995, made all the difference in our journey through grief and helping us to become the strong family that we are today.

It's hard to believe that we moved from Los Alamitos to central Pennsylvania almost four years ago and overall are very happy that we came. As SIDS parents, we of all people understand that change happens beyond our control and that we have learned we can survive almost anything. Having a support network to get you through the trying times is the most important factor. The rural community we live in doesn't have a SIDS group and the closest affiliate group is a four hour drive away. I have tried to reach out to SIDS parents through our pastor and local hospital but haven't been called to help anyone yet.

Once again we have been facing some significant changes in our lives. At the beginning of this year, I lost my job with Avery, which was the reason we were transferred to Pennsylvania in 2003. We were very blessed with Gary finding a great job locally as a Technical Service Chemist, giving me the flexibility to start my own consulting business. I have gotten off to a great start and love working for other businesses helping them develop their occupational health and safety compliance and management systems. The best part is that I have a much better work-life balance and get to spend more time with our children, Bryce (13) and Hope (9).

So, it looks like we're here to stay awhile longer to enjoy the beauty of the woods and wildlife right out our back door. I have even adjusted to the 45 minute drive to the closest Target, but find now that I have to plan the "big" trip well in advance! It is amazing how our minds adapt to new situations, good or bad. The important thing is to focus on doing what truly brings you happiness and fulfillment. I miss you and want you to know that you'll always hold a special place in my heart.

Love, Emilie



The Vines

**By: Bill Pridham
Ridge, New York**



Picture if you will, a large forest. Somewhere in this forest there is a small clearing. In the center of the clearing, there are two young vines, side by side, growing together. In time, their branches and tendrils intertwine. Together, they face the icy blasts of winter, the welcome warmth of spring, and they bask in the golden glow of summer.

Then one day, someone comes along and decides that one of the vines would be better in another place. Upon digging it up, he finds that the only way the vines can be separated is to cut them down the middle – thus they are parted.

We have been told that all wounds are healed by time. That remains to be seen. But, we are also assured that wherever the vine was taken, a part of the remaining vine went with it, and the remaining vine holds near and dear a part of the vine that was taken away.

THINGS A FIREFIGHTER/MEDIC WANTS YOU TO KNOW

By Aaron Espy, Firefighter/Paramedic
Port Orchard, Washington

As an EMT trainer, one of the things I instruct fire fighters on is how to be sensitive to the needs of bereaved moms and dads. Bereaved parents have patiently and graciously taught me, so that I might teach my fellow firefighters. As I share what I've learned, I continue to see my peers reveal misconceptions about what it means to lose a child.

Oddly enough, as I talk to bereaved parents, I find many of them also have misunderstandings – particularly about what a firefighter feels as he does his job. One such assumption I've heard is that rescue personnel must develop an immunity to sorrow. A woman once commented to me, "You must get used to it." But believe me, the death of a child is never routine in the 911 world!

When an especially tragic circumstance is shared by firefighters, the firehouse is not unlike any other home during a stressful time. The hall is unusually quiet, the laughter is gone, and some of us are angry without knowing who we should be angry at. The loss of a child knocks the wind out of a firefighter like an unexpected punch in the stomach. While we know it is inevitable in our field, exposure to this pain is a purposeful, deliberate, open-eyed risk we take when we are sworn to protect life and property. Yet it hurts just the same.

No, we don't forget. And no, we never, ever "get used to it."

Moms and Dads, can I talk to you for a minute? I was too busy during the emergency and afterward, and you had more important matters to attend to. It doesn't matter whether you live in the Pacific Northwest or Florida, Maine or Kansas City. If your child was taken from you suddenly, there was probably someone like me in attendance that fights fire and delivers medical aid for a living. Chances are they've struggled with the same feelings I struggle with. Here are five things I'd like to tell you; because it's my hope that something I say will make your struggle through grief a little easier to manage.

Your child was not "just another patient."

Perhaps you assume that because I've seen thousands of patients in my career, I wouldn't remember your child. Not true! Only the loss of a fellow firefighter affects us more profoundly than a child's death. When I lose a child in the line of duty, I don't leave the experience at the station. Your child's face comes home with me. I see him when I'm fishing, working in my garage or just drifting off to sleep.

It's the inability to come to terms with these memories that drives many a firefighter from his or her career. Those of us who are old timers in emergency medicine have learned to deal with the tragic cruelties of life that we must face. Some exercise vigorously, others (like me) write about our experiences. Sadly, there are some who are unable to cope with the pain and turn to drugs or alcohol.

I do more than provide medical care.

When I am fighting to save a child, I talk to them. It doesn't make any difference whether they're responding or not. I reassure and attempt to comfort them. If they're awake and very young, I give them a stuffed animal to hold. And I do one other thing: I tell them that their mom and dad love them very much. I do this because several years ago a mother told me, "I would have given anything to tell my son I loved him just one last time." Since then, I try to tell every child that you, their parents, love them very much.

I struggle with feelings of failure and inadequacy.

When a firefighter/paramedic loses a child, he or she may struggle with personal feelings of failure. So often we repeatedly ask ourselves "what if" questions. "What if I'd been at a closer station? What if I'd arrived five minutes sooner? What if I'd tried another course of treatment?"

It's these feelings of inadequacy that often keeps a medic from approaching the parents of his patient. If a firefighter

THINGS A FIREFIGHTER/MEDIC WANTS YOU TO KNOW

(Continued From Page 7)

seems to be avoiding eye contact, it's likely he is not only struggling with his emotions, but possibly struggling with the feeling that he has failed. It's a common occurrence, despite the fact that the medic may have performed flawlessly.

I grieve with you.

Macho as we'd like to portray ourselves, we are by nature a group of men and women sincerely touched by the sorrow and suffering of others. That's one of the reasons we are drawn to the fire service in the first place. We have a deep and passionate drive to make a difference, to alter tragedy in the making if we possibly can. Maybe it's because we feel we have an image to uphold. Whatever the reason, we firefighters tend to be good at holding our grief in check until we are alone. We present a tough-as-steel façade and inevitably do our crying in the station's hose tower of the compressor room where no one can hear us.

I'm available to answer questions.

Often there are procedures or treatments you may not understand. They are almost always done for a very good reason, and they are done with your child's best interest in mind. Almost without exception, the firefighters and medics who fought to save your child would be happy to answer any questions you may have. We also need to be informed when we unknowingly make comments that hurt or offend.

I won't make the mistake of telling you I know how you feel. I can try to imagine your pain, but I'm sure I could never know how it really feels unless I'd lost one of my children. I can tell you that I (and all my fellow fighters) do care. It is the chance that we will save the next victim of tragedy that keeps us doing what we're doing in the face of so much sorrow.

We wish for you strength and peace on your journey.

Recent national trends in sudden, unexpected infant deaths: More evidence supporting a change in classification or reporting.

Shapiro-Mendoza CK, Tomashek KM, Anderson RN, Wingo J.
Am J Epidemiol. 2006 Apr 15; 163(8):762-9.

The recent US decline in sudden infant death syndrome (SIDS) rates may be explained by a shift in how these deaths are classified or reported. To examine this hypothesis, the authors compared cause-specific mortality rates for SIDS, other sudden, unexpected infant deaths, and cause unknown/unspecified, and they evaluated trends in the age and month of death for these causes using 1989-2001 US linked birth/death certificate data. Reported deaths in state and national data were compared to assess underreporting or overreporting. SIDS rates declined significantly from 1989-1991 to 1995-1998, while deaths reported as cause unknown/unspecified and other sudden, unexpected infant deaths, such as accidental suffocation and strangulation in bed (ASSB), remained stable. From 1999-2001, the decline in SIDS rates was offset by increasing rates of cause unknown/unspecified and ASSB. Changes in the cause-specific age at death and month of death distributions suggest that cases once reported as SIDS are now being reported as ASSB and cause unknown/unspecified. Most of the decline in SIDS rates since 1999 is likely due to increased reporting of cause unknown/unspecified and ASSB. Standardizing data collection at death scenes and improving the reporting of cause of death on death certificates should improve national vital records data and enhance prevention efforts.

For Full-text: <http://aje.oxfordjournals.org/>

Risk reduction and sudden infant death syndrome.

Gurbutt D, Gurbutt R.

Community Pract. 2007 Jan; 80(1):24-7.

This article explores the concepts of 'risk' and 'risk reduction' in relation to sudden infant death syndrome (SIDS) and the implications for practice. Risk reduction is a term utilized in public health, which is usually linked to evidence-based outcomes. The Back to Sleep campaign is a high profile initiative which seeks to raise awareness of risk factors relating to SIDS and is largely credited with contributing to a significant reduction in the incidence of SIDS in the UK. Misunderstandings may occur between the terms 'risk reduction' and 'prevention' of health conditions and parents may feel that one equates to the other. There are also tensions which are inherent in defining risk in the context of SIDS. Certain measures may become 'shorthand' for a range of interventions and contributing factors. The practice of offering additional monitoring as support may reinforce a (mis)understanding about risk reduction and SIDS. There are implications for practice regarding how health professionals approach this issue, explain the guidelines and offer support. A clearer understanding of risk reduction would potentially enable bereaved parents to articulate their experiences without becoming too self critical in questioning their own consistent adherence to the accepted guidelines.

Benefits and Harms Associated With the Practice of Bed Sharing: A Systematic Review.

Horsley T, Clifford T, Barrowman N, Bennett S, Yazdi F, Sampson M, Moher D, Dingwall O, Schachter H, Cote A.

Objective: To examine evidence of benefits and harms to children associated with bed sharing, factors (eg, smoking) altering bed sharing risk, and effective strategies for reducing harms associated with bed sharing.

DATA SOURCES: MEDLINE, CINAHL, Healthstar, PsycINFO, the Cochrane Library, Turning Research Into Practice, and Allied and Alternative Medicine databases between January 1993 and January 2005. **Study Selection:** Published, English-language records investigating the practice of bed sharing (defined as a child sharing a sleep surface with another individual) and associated benefits and harms in children 0 to 2 years of age.

Data Extraction: Any reported benefits or harms (risk factors) associated with the practice of bed sharing.

Data Synthesis: Forty observational studies met our inclusion criteria. Evidence consistently suggests that there may be an association between bed sharing and sudden infant death syndrome (SIDS) among smokers (however defined), but the evidence is not as consistent among nonsmokers. This does not mean that no association between bed sharing and SIDS exists among nonsmokers, but that existing data do not convincingly establish such an association. Data also suggest that bed sharing may be more strongly associated with SIDS in younger infants. A positive association between bed sharing and breastfeeding was identified. Current data could not establish causality. It is possible that women who are most likely to practice prolonged breastfeeding also prefer to bed share.

Conclusion: Well-designed, hypothesis-driven prospective cohort studies are warranted to improve our understanding of the mechanisms underlying the relationship between bed sharing, its benefits, and its harms.

Full-text available at: <http://archpedi.ama-assn.org>



I Try to Imagine

By Aaron Espy

I TRY TO IMAGINE WHAT YOUR GRIEF IS LIKE,
AND THEN YOU SHOW ME.

I IMAGINE A STORM,
YOU SHOW ME A HURRICANE.

I IMAGINE A RIVER OF TEARS,
YOU SHOW ME A FLOOD.

I IMAGINE EMPTINESS,
YOU SHOW ME ENDLESS EXPANSE OF THE UNIVERSE.

I TRIED TO IMAGINE, BUT COULD NOT UNDERSTAND -
UNTIL YOU SHOWED ME.

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P.O. Box 17432, Irvine, CA 92623-7432

Grant Update

The Guild acknowledges with sincere appreciation a recent grant from the CJ Foundation for SIDS. Proceeds will be used to print and mail our quarterly newsletter "Reflections" for one year. We could not publish our newsletter, educate the public and professionals through Guild projects if we did not have support from foundations, corporations, and donations from individuals who give us support during national campaigns. Donors who contribute to the Guild through United Way should use the designation GUI300. We encourage Guild donors to investigate opportunities that may be offered by their employers i.e., matching donations or corporate grants.

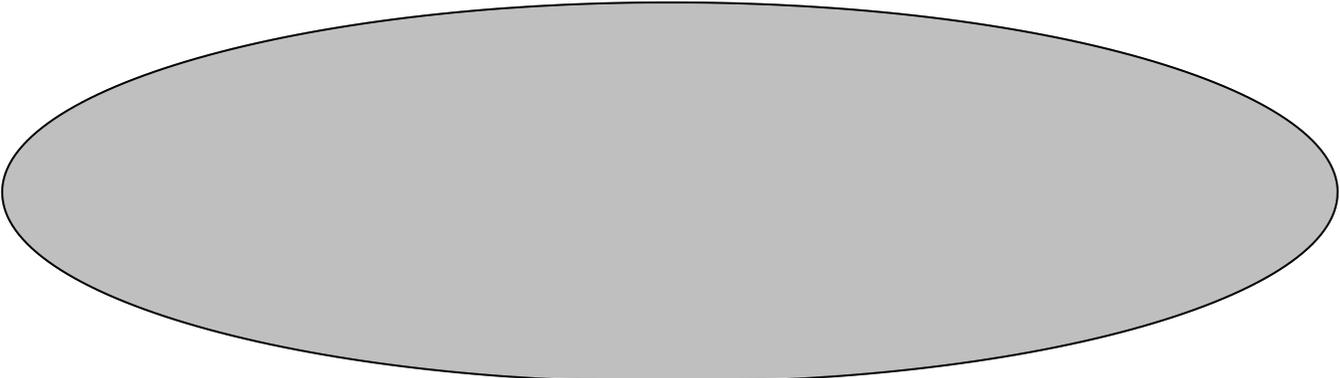
Any questions may be directed to Laura Kirchner, Interim Executive Director at the Guild office 714/973-8417.



2007 MEETING CALENDAR

Parent Support Meetings– All meetings are from 7:00—8:30 PM.

* Please RSVP to the parent host prior to the meeting



Business Meetings– Business meetings are held at the home of Lisa Biakanja located at 20732 Alicante Lane, Huntington Beach, (714) 960-9897. Meetings begin at 7:00 PM. If you would like to have an item added to the agenda, please contact Lisa at (714) 960-9897 or lbiakanja@yahoo.com.

May 2, 2007



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