



"To keep new lives living."

REFLECTIONS

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"A Father's Grief"

...From a Parent's Point of View

As I write this, Jennifer and Jordan are arguing--hmmmm...discussing their choices for a Father's Day gift for their dad. Shall it be an ice cream maker or a dozen golf balls? As each side presents its case, I find myself remembering back to another, less happy Father's Day.

Jennifer was in preschool then, and her gift to her dad was her handprint, done in brightly colored tempera paint. Her chubby fingers were immortalized forever, to remind us always of those little hands, usually sticky, clinging to ours. I had known about the project ahead of time and I remember thinking what a wonderful idea it was--and that I should make a handprint of Tyler's, our then 7-month-old son, to give to John along with Jen's.

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Save The Date!

October 26th and 27th 2006



Riverside Community College

For additional information, call
Barbra Estep at the Guild Office

(714) 973-8417



A Note From The



I recently sat across the table from a newly bereaved mother at a board meeting. Jordy had lost her baby less than 2 ½ months earlier, yet here she sat. This woman was “consumed” with doing something, anything to help raise funds for research. She felt compelled to use her grief in a useful, productive manner not only for her own sanity but for other SIDS parents. I marveled at her courage and strength. Jordy had already spoken with Dr. Keens, Dr. Krous, the coroner – anyone and everyone that could help explain what happened. She had even attended her first parent meeting – unfortunately, poorly attended. Jordy wondered where all the bereaved mothers and fathers were, why they didn’t attend peer support meetings, and how we could get them into our homes and be proactive.

She desperately wants to connect with parents that are nearer to her age, nearer to the date of her loss. We looked around the table – 5 years, 10 years, even 25 years have passed since our babies have died. Our organization needs new blood – new volunteers to carry on the cause, new parents to support each other. Won’t you help?

Please consider attending our next peer support meeting Tuesday, July 11th, at 7 pm. This meeting will take place at my home, located at 20732 Alicante Lane, Huntington Beach. RSVP to 714/960-9897. We need to carry on the legacy of our babies by reaching out to others. Help us help you. . .

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@comcast.net. The next Newsletter deadline is 7/1/06. We encourage your participation!

"A Father's Grief"

...From a Parent's Point of View

(Continued from Page 1)

I never got around to it. Tyler died two weeks before Father's Day, leaving not a handprint, but a father consumed by grief and a helplessness he had never felt before.

We celebrated Father's Day—how could we not—but it was an incredibly sad celebration. It made no sense. How could a father outlive his son?

Grief was new and intense and we were struggling to keep from drowning. We'd heard and read a lot about the differences in grieving which often occurs between couples, but the words did little to comfort us. It was a scary time for a couple who had, up till then, leaned heavily on one another. In looking back, it's a little easier to understand. I was wrapped up in my own loss; it was hard for me to understand why John wasn't reacting in the same way. Why wasn't he crying?

How could he want to make love? Why didn't he want another baby? It's been eight years since our son's death, and I've had a lot of time to think this over. I'd never really looked at what John had lost that sunny afternoon when he got the call at work to "come home right away." He'd lost his first son, a loss that would cripple the strongest man. But he'd also lost more than that. Along with the ballgames and fishing trips, he'd lost the hopes and dreams that all of us have for our children. All of them, wiped out as soon as he walked into the emergency room and saw the faces of a doctor, a nurse, and a mother who could make no sense of what happened.

And on top of that, he'd lost the wife he had before. Instead of the mostly-happy woman he left in the morning, he returned to find a grief-wracked, frightened, angry person, a woman who would never, it appeared, be happy again.

But perhaps the most staggering part of all this was that he had lost whatever control he felt he had over his life. He couldn't bring back his son, he couldn't make his wife stop crying, he couldn't make his own aching pain go away. The thought of the future held no comfort. How could he trust tomorrow when today had taken away the sweet, wide-eyed, bald bundle of love in a totally unexpected, awful surprise.

Only time has helped. It was important for us to know that our differences and difficulties were normal in the face of a very abnormal situation. We slowly digested that, but it was very, very hard. The simple, overwhelming truth is that people grieve differently. A father's grief is his own.

MEMORIAL DONATIONS

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

In Memory Of Bailey Annmarie Downs

Mom's Club of La Habra

In Memory Of 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

In Memory Of Scott Francis Hogan

In Honor Of His 16th Birthday

John & Becky Hogan

In Memory Of Christopher B. Phillips

Marie T. Bowen

In Memory Of Sarah Ashley Robbins

Iain & Margo McCormick

In Memory Of Jason Doo

David & Alpha Doo

In Memory Of Kaylee Billings

Lance and Lori Blake

**"THOSE WE LOVE DON'T GO AWAY
THEY WALK BESIDE US EVERY DAY
UNSEEN, UNHEARD, BUT ALWAYS THERE
STILL LOVED, STILL MISSED AND VERY DEAR"**

-ANONYMOUS

Why is a Post Mortem Examination Important When a Child Dies Suddenly?

By Henry F. Krous, MD

Director of Pathology, Children's Hospital – San Diego

Professor of Pathology & Pediatrics, University of California, San Diego School of Medicine

Director, San Diego SIDS/SUDC Research Project

Stricken with grief, parents experiencing the sudden death of their child are often and understandably reluctant to have a postmortem examination performed on their son or daughter. And yet, sudden deaths of individuals of any age and without apparent explanation are under the legal jurisdiction of the medical examiner who must determine the cause and manner of death. In order to do this, the medical examiner must perform a postmortem examination as well as be knowledgeable of the medical history and circumstances of death.

Perhaps it will help to begin with a basic description of the postmortem examination. It begins with a review of the medical history of the infant or child who has died. Secondly, it also involves a careful evaluation of the circumstances of death, including a reconstruction of the site where the infant or child was found apparently lifeless. The postmortem examination itself is the evaluation of the external appearance of the body and internal organs. It is undertaken much like an operation, but by a pathologist rather than a surgeon. In addition to the anatomic studies, ancillary studies are typically done as well. They may include postmortem radiographs (X-rays), microbiology, toxicology, metabolic screening, and chemistry evaluations. The dignity of the body is always maintained and disfigurement does not occur, therefore, funerals of choice can be performed.

With this background, what advantages accrue to the parents and other survivors of these children when a postmortem examination is performed? There are many and they have long term implications. First, when supplemented by the medical history and circumstances of death, the postmortem examination is the best way of determining the cause of death. Without the examination, the medical examiner does not have enough information to make this determination unless there is something lethal about the scene, such as a toxic environment, where the child died.

Secondly, some of these parents may experience unwarranted guilt as they wonder if they may have caused the sudden unexpected death of their infants and children especially when they lack an understanding of the cause of death. Therefore, knowing why one's child died as the result of the postmortem examination can facilitate healthier grieving over their loss by allowing parents to focus on the wonderful memories of his or her life rather than agonizing over the unknown. When parents do not know what caused their child's death, they may imagine terrible, but unrealistic scenarios, such as "did my child suffer great pain before dying?"

Third, the knowledge gained from postmortem examinations of every infant and child is vitally important for every pathologist who performs them. It is only through experience, as well as continuous study that we as physicians and pathologists improve our personal knowledge and expertise in complex areas of medicine, and that includes especially the topic of sudden unexpected death in childhood and infancy.

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Why is a Post Mortem Examination Important When a Child Dies Suddenly?

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Aside from the valuable experience and expertise accruing to pathologists and other physicians, diagnoses derived by postmortem examinations are critical to the accuracy of vital statistics. Vital statistics are the basis for the allocation of health care resources by governmental agencies, such as the National Institutes of Health, and private sources, such as the CJ Foundation for SIDS. In this regard, the CJ Foundation is the only organization that funds research directed towards sudden unexplained death in childhood (SUDC).

Fourth, scene investigations and postmortem examinations are critical to research into sudden unexplained death in childhood (SUDC). In comparison, for example, risk factors for sudden infant death syndrome (SIDS) were identified long before the underlying mechanisms involved in the cause of death have been clarified. Public education campaigns using epidemiologic data about these risk factors have led to dramatic reductions in SIDS rates with many fewer infants dying today compared to just a few years ago. We have no reason to doubt that the same thing will not happen with respect to SUDC.

With this in mind, the value of communication between families of SIDS infants and SUDC children and the medical examiners and coroners who investigate these children's deaths can not be overestimated. Face to face meetings are encouraged for several reasons. The autopsy report will never answer every question that a family will inevitably have. And, these reports will nearly always include medical terminology that may not be understood by the families. In contrast to telephone conversations, face to face conversations allow the medical examiner to "read" the nonverbal conversation of the families, thus providing the opportunity for clarification of confusing issues. The medical examiner's concerns for the family as they grieve the loss of their children are better expressed as well. In this regard, the medical examiners are fulfilling a role similar to clinical physicians in their interactions with their patients and their families.

Let me conclude with my personal experience regarding the attitudes of families whose infants and children have died during the past 30 years. During the time frame surrounding the infant or child's death, some parents have been very reluctant to have a postmortem examination performed on their child. This is understandable. At times, these objections may center on religious or cultural beliefs. Other parents may simply object to having the procedure performed for aesthetic reasons. Many of these objections can be mitigated by a careful explanation of what an autopsy is and what is to be gained will hopefully mitigate some of these objections. It is particularly important for parents to understand that a cause of death cannot be reached without performance of a postmortem examination, which in some cases may involve only ancillary studies.

Parental attitudes and healthy, successful grieving six months or more after the child's death have always favored performance of the postmortem examination. That is to say, I have never met a parent whose child died some months before my conversation with them that regretted having the autopsy performed. Conversely, in those cases where the examination was not undertaken, the parents are left with an irresolvable uncertainty regarding the cause of their child's death and have invariably regretted that the postmortem examination was not performed.

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Why is a Post Mortem Examination Important When a Child Dies Suddenly?

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Those parents, whom I have met throughout my professional career whose child was examined were extremely grateful and rewarded that it had been undertaken. They have been able to reach closure in a more satisfactory fashion with knowing why their child died.

In selected cases genetic disorders were discovered only during the postmortem examination. This information is vital to families planning future pregnancies and better protects surviving family members.

It should be noted that a postmortem examination does not always identify a cause of death. Nevertheless, the parents can be comforted to know that the effort was made. But it also must be remembered that these cases also provide information and materials that are important to vital statistics, education, and research. There are many examples of this, perhaps the most obvious being the identification of risk factors for SIDS. Even though the exact cause of SIDS remains unknown even today, education of the public about what infant care practices should be avoided has resulted in dramatically lower SIDS rates throughout all developed countries of the world. Parents can share in this success by knowing that the postmortem examination of their children facilitated this progress.

Ask The Doctor

NEWSLETTER DONATIONS

This column offers our readers the unique opportunity to ask questions of a medical nature which will be answered by **Thomas G. Keens, MD**, Professor Pediatrics, University of Southern California School of Medicine/Children's Hospital Los Angeles and **Henry F. Krous, MD**, Professor of Pathology & Pediatrics, UCSD School of Medicine, Director, San Diego SIDS/SUDC Research Project, Children's Hospital San Diego. Please address your question in writing to either of our experts and mail to:

GISOC, P.O. Box 17432
Irvine, CA., 92623-7432
or e-mail to gisoc@compuall.net.

We thank Dr. Keens and Dr. Krous for being willing to volunteer their time and expertise in this way.

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 Barbara Estep 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.

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.

You Will Always Be My Baby

Written by: Jordy Jahn

In Memory of Ryan

11/5/05 – 1/27/06

I lost a child, my youngest son-
it is incomprehensible to even me.

There is no sense of normalcy, no familiar routine,
just the need to make it through the next longest day.
People are kind, some are even attentive. I ramble
on about how I'm doing, as if I'm a third person looking in.
I have conversations with people and wonder should I be
honest and tell them that I'm not hearing a word,
or maybe I could concentrate harder.
But all the while I'm thinking... would his eyes have stayed blue,
is he somehow going to be there when I go to daycare after work,
am I really having these pains in my chest from a broken heart?

I'm terrified to grieve, as if giving in to the pain would
somehow make me a little too human, the experience too real.
I might cry in the arms of a perfect stranger, and as often as people
reach out to me, I can't imagine making them feel so awkward.
Then there's the overwhelming fear that somehow to grieve is to accept my fate.
Or God forbid, that I could become trapped in a life of tragedy.

There's the sense of disconnectedness, to people I know, to work, to even family.
I often feel closer to the Mother I see in the near distance, the Mother who also
grasps at blades of grass for a moment to hold again what is so clearly out of our reach.
And I see hundreds of kids everyday. I think of the lost years, the memories never to be
had, that every child before me is somebody's baby.
I miss my baby.

It's not that I'm not grateful for the short time we had, with a heavy heart I'd
walk this path willingly...to love him is far greater than regrets or a broken heart.
But for now, there's no comfort in these thoughts because each day is one step further
away from his scent, the sound of his voice, the details of his delicate body.
These are the gifts that pictures can't provide and time will steal mercilessly.

I guess there's truly no way to convey in words the reality of the unthinkable, that
somehow I could not protect my child. The idea that perhaps there is a greater
force or presence in the driver's seat of my life. And yes, I do realize that my
life will never be the same. I won't even pretend to imagine all the pruning
and shaping that will inevitably take place.

There are reasons for seeking strength in the days ahead;
the laughter of my oldest son and the opportunity to honor my youngest son,
the boy who will always be my baby.

Mother's Day

Judy A. Sittner

(borrowed from HOPE LINE, a newsletter published by HOPE FOR BEREAVED, Syra-

Another Mother's Day!
But a different one this year.
For you see, I am a mother,
But my child isn't here.

I am a mother who is hurting
For this child who was so dear,
As I face this and other occasions,
Each and every year.

I am a mother who feels an emptiness
Over and over again,
Because I miss THIS child
And all that could have been.

I am a mother who cared
As I watched my child grow,
And truly loved her more
Than anyone will ever know.

I am a mother who has memories
And many tears to cry
Over regrets I'll have to live with
Until the day I die.

I am a mother who is thankful
For the miracle of birth,
And all my child has taught me
About life and my own self-worth.

I just can't stop being a mother
Just because my child isn't here,
Because the love we had for each other
Will continue for years and years.

And so . . .
On this special "Mother's" day,
I will feel within my heart,
All the pride, love and joy
Which are the parts
That make me who I am
And what I'll always be –

My Dad is a Survivor

By Kaye Des'Ormeaux

My Dad is a survivor too. . .
Which is no surprise to me.
He's always been like a lighthouse
That helps you cross a stormy sea.

But, I walk with my dad each day
To lift him when he's down.
I wipe the tears he hides from others
He cries when no one is around.

I watch him sit up late at night
With my picture in his hand.
He cries as he tries to grieve alone.
And wishes he could understand.

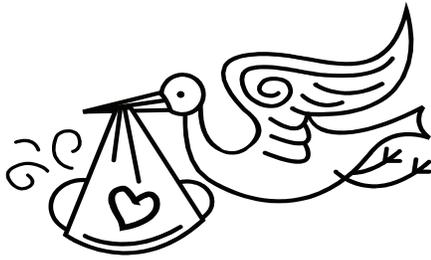
My Dad is like a tower of strength
He's the greatest of them all!
There are times when he needs to cry
Please be there when he falls.

Hold his hand or pat his shoulder. . .
And tell him it's okay.
Be his strength when he's sad
Help him mourn in his own way.

Now, as I watch my precious dad
From the Heavens up above. . .
I'm so proud that he's a survivor. . .
And I can still feel his love!

Community Support Campaign Donations:

Elaine L. Nelson
Kim M. Young



THE STORK REPORT

Jonathan Edward Thompson

Born March 30, 2006

7 pounds

Congratulations to

Marion and James Thompson

Is there a new little one at your house? If so, we would love to share your happiness. Please send all pertinent information to the Guild office for publication in our next newsletter.

YOUR GIFT IS APPRECIATED

This Gift Is In Memory Of:

This Gift Is In Honor Of:

Acknowledge To: _____

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Please print. Make checks payable to:
 Guild for Infant Survival (GIS)
 P.O. Box 17432, Irvine, CA 92623-7432

For Just A Moment

*For just a moment
 I'm sure I saw
 a flicker of light ahead.
 Perhaps it was your smile.
 Though past now, remembered,
 in my heart
 like the small sound of
 a butterfly passing by.
 No night
 is so dark
 that can not be brightened
 with memories of you.
 Raindrops carry along
 your blessings from heaven
 to wash away my tears*



I LOVED THE BOY WITH
 THE UTMOST LOVE OF
 WHICH MY SOUL IS
 CAPABLE; AND HE IS
 TAKEN FROM ME-YET IN
 THE AGONY OF MY SPIRIT
 IN SURRENDERING SUCH A
 TREASURE I FEEL A
 THOUSAND TIMES RICHER
 THAN IF I HAD NEVER
 POSSESSED IT.

~William Wordsworth,
 After the death of his
 son Thomas in 1812



2006 MEETING CALENDAR

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

* Please RSVP to the parent host prior to the meeting

July 11, 2006 Home of Lisa Biakanja
20732 Alicante Lane, Huntington Beach
RSVP to (714) 960-9897

September 12, 2006 GISOC Office
2130 East 4th Street, Suite 125, Santa Ana
RSVP to Shari Morinishi at (714) 952-1466

Business Meetings– Business meetings are held at the home of Lisa Biakanja located at 20732 Alicante Lane in Huntington Beach. 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.

July 5, 2006



**GUILD FOR INFANT SURVIVAL, ORANGE COUNTY
P.O. BOX 17432
IRVINE, CA 92623-7432**

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Stamp

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_____ I receive more than one copy of the newsletter