



REFLECTIONS

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When I had my first son Hunter, I would lay him down to sleep and worry about him not waking up— not ever really thinking he wouldn't wake up. Now, realizing that my second son was laid down and never woke up, I have lost my innocence in a sense. I lost what all moms should have—the feeling that it's going to be ok.

Since Hayden, most of you know I have had a subsequent daughter named Hope. It's rare that she sleeps without me or my husband not checking on her at night... in fact, it's rare that my 11 year old goes to bed at night without us checking on him. God forbid one of our kids sleeps too sound. I was thinking about this while flying home from the 2009 SIDS conference.

When my kids decide to have babies of their own, they will never have that innocence that we all deserve to have when we first hold our babies. How

sad that they forever have to hold on to this. This thought broke my heart.

My hope is that maybe—just maybe—by then there won't be a need for this newsletter or SIDS support groups. That the reason for SIDS will have been found and I can honestly say to my kids when they ask me, "Is my baby going to die like Hayden died?" I can look them in the eyes and say "NO!"



Rachel

The greatest gift is a portion of thyself.

Ralph Waldo Emerson

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Parent's Corner

My name is Melissa Child, and we lost our son, Luke Matthew Child, to AIDS on June 8th 2006. He was two months old, (74 days). We put Luke to bed that night, and found him in the morning, passed away. A tragedy you all know way too well, and the fear of an event in your life that will never subside.

Since Luke's passing we have had three subsequent children, a little girl who is two years old, and twin baby boys. That first year when you put your child to sleep, you can't help but think, will they still be breathing when I go in and check on them? Will my baby still be alive in the morning? It's not something you want to be thinking about but is always weighing on the back of your mind. With our two-year-old daughter it was a little easier for me. We still took every precaution but having two older daughters that were healthy and strong helped me believe that she was going to be okay.

When we had the twin boys, it felt like such a blessing. How exciting it has been to have the presence of these special little boys in our home. When I used to walk by the boy's clothing in a store, I longed to buy a little outfit, or when I walked the aisles at a toy store, I wanted to purchase a little train. Now we get to do that, and our boys have filled our home with so much joy. Behind that joy, there is still the fear. The fear of wondering

if they will be okay. All of the what ifs you have when you lose your baby to AIDS. If I do everything perfect, maybe they won't leave us, maybe they will be here in the morning, but it still doesn't take away the fears of checking on your sleeping baby.

We have made it past the first year! Beau and Brody Child turned one on January 14th 2010. I had no idea what a relief it would be. It feels so good to be at this stage. We got to plan a first birthday party, and celebrate their day, but deep down it was also a celebration for my husband and me. We had all made it! I truly had no idea how much it was weighing on my body and spirit. It felt like a huge weight had been lifted from me, and I was able to love with my whole heart...

I am so glad we decided to have more children no matter how scary it has been. The joy has definitely outweighed living in fear. I still grieve for the memories I should be having with my son Luke, and wish more than anything that I could bring him back to us. But now I look forward to the memories I will get to have with my other children and hope to teach them about their big brother.



If new parents want to meet with other AIDS parents for support, please feel free to call:

Rachel 714-305-0421
or
Jordy 714-501-6346

We will be more than happy to meet up with you.

Date: November 11, 2009

Good morning Lisa, All of you helped me so much after my son Ian died that I would like to find a way to help others that have lost their babies to AIDS. I now live in Moreno Valley (Riverside County) and I work in San Bernardino, so anywhere in those areas that you know of a support group would be wonderful.

I want you to know (and if you could pass this on to the others at GISOC) that the support group was instrumental to my well being, and I am so appreciative of the support I received. I don't live in your area any longer, but I sing your praises still in hopes that others can be helped by what you do.

Thank you and have a wonderful day :-)

Kendra Lakkees

Yogman MW, and S.H. Zeisel. Diet and sleep patterns in newborn infants. *N. Eng. J. Med.*, 309: 1147-1149, 1983

Sleep behavior is modulated by serotonergic neurons within the brain, and the synthesis and release of serotonin by such neurons is thought to be influenced by the availability of tryptophan, the amino acid precursor of serotonin. We investigated the effects on the sleep patterns of newborn infants of variations in diet designed to affect tryptophan availability. Twenty healthy newborns (two to three days of age) were randomly assigned to receive a feeding consisting either of tryptophan in 10 per cent glucose or valine in 5 percent glucose (valine competes with tryptophan for entry into the brain). Sleep patterns during the three hours after this feeding were compared with those after a feeding of routine formula (Similac). The infants fed tryptophan entered active sleep 14.1 minutes sooner than they did after Similac, and entered quiet sleep 20 minutes sooner. Those fed valine entered active sleep 15.8 minutes later than they did after Similac, and entered quiet sleep 39 minutes later. The differences between the tryptophan and valine groups were significant (P less than 0.01 for active sleep and P less than 0.005 for quiet sleep). We conclude that variations in the composition of the diet may influence sleep behavior in newborns.

Coping with Your Emotional Reactions to Loss

by Robert Bougher and Marc Calija

The road of working through a loss is long and painful and the journey filled with many emotional reactions. Responses to grief do not occur in any particular order but rather, they recycle again, as time goes by. Regardless where you are in your journey of grief, others who have experienced the death of a child, sibling, spouse, partner, friend or other relative, can provide helpful insight and suggestions. As you read this article with recommendations from other "grief survivors," choose the suggestions that will help you in coping with your own loss. Although you may experience all, some or none of these same reactions, remember that grieving takes time. Be patient. The road to healing and grief resolution is traveled one day at a time, one step at a time.

It may seem that everywhere you look there are things that suddenly bring back memories of

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From the Desk of Dr. Thomas Keens

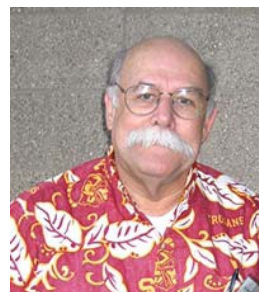
To the California SIDS Community:

As most of you know, last week, *Professor Hannah Kinney's* research group at Harvard University published a research study showing that the brainstems of babies who died from SIDS had decreased amounts of the neurotransmitter, serotonin, compared to babies who died from other causes. Serotonin is a neurotransmitter, which is important in the life-support activities of the brainstem (breathing, heart rate response to environmental challenges, temperature regulation, etc.). This recent study is an extension of her work from a few years ago, which showed decreased serotonin receptor binding activity in SIDS brainstems. This important research continues to provide a biological basis for SIDS, and it suggests that the problem with SIDS babies lies in brainstem dysfunction, or suboptimal function, in response to environmental challenges.

An excellent commentary by *Professor Henry F. Krous*, from the Rady Children's Hospital in San Diego and UCSD School of Medicine, can be found on Page 4. *Professor Krous* is a coauthor on this paper.

As *Professor Krous* notes in his commentary, we can all be proud, as Californians working to put an end to SIDS, that this research would not have been possible without passage of the Boatwright Bills in 1989, one of which permits Coroners to remove tissues for research purposes so long as the removal is not disfiguring. The brainstems used in *Professor Kinney's* studies were from San Diego and from the Medical Examiners from the Los Angeles Coroner's office, and were able to be used because of this law.

If you have any comments or questions, please do not hesitate to contact me through this *Reflections* newsletter. Thank you for all you do to improve SIDS services, education, and research in California.



---Dr. Thomas Keens

Brainstem Serotonergic Deficiency in Sudden Infant Death Syndrome

Henry F. Krous, MD

San Diego SIDS/SUDC Research Project

SIDS is defined as the sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.¹ Our current working "triple-risk" hypothesis posits that SIDS results from the simultaneous occurrence of an underlying vulnerability in the infant, a critical developmental period during infancy, and exposure of an infant to an exogenous stressor.² An underlying vulnerability is a pathologic abnormality that in itself is not necessarily fatal, but when interacting with other factors can act as the tipping point leading to a lethal event. In the case of SIDS, the critical developmental period is the first half of infancy when physiologic and anatomic growth and development are very rapid and thus inherently unstable, especially during sleep. Exogenous stressors are risk factors for SIDS, especially those that pose a risk of asphyxia to the sleeping infant. Prone sleep position, sleeping on a soft surface, having the head covered, and/or exposure to cigarette smoke are particularly important risk factors. Exogenous risk factors have been identified and confirmed through numerous epidemiologic studies of large numbers of infants.

Our team of investigators, led by Dr. Hannah Kinney, has been pursuing for many years what makes an infant vulnerable to SIDS by concentrating on the medullary serotonergic system. This system plays a crucial role in the control and homeostasis of the respiratory, cardiovascular, and autonomic systems.

Our recent report that brainstem serotonin (5-HT) and tryptophan hydroxylase (TPH2) levels were lower in SIDS cases than in age-adjusted controls provides further evidence that defects in the medullary serotonergic system are important in SIDS.³ 5-HT and TPH2 levels critical to respiration were 26% and 22% lower, respectively, in brainstems from SIDS cases compared to controls. This finding indicates that 5-HT levels were low as a result of decreased synthesis rather than increased degradation. Serotonin receptor (5-HT1A) binding was also reduced, thus confirming earlier observations.

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U.S. Department of Health and Human Services

NIH News
National Institutes of Health

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
Embargoed for Release
Tuesday, February 2, 2010
4 p.m. EST

Contact:
Robert Bock or Marianne Glass Miller
301-496-5133

SIDS Linked to Low Levels of Serotonin

NIH-Funded Study Finds Abnormalities in Brain Region That Regulates Breathing, Sleep

The brains of infants who die of sudden infant death syndrome (SIDS) produce low levels of serotonin, a brain chemical that conveys messages between cells and plays a vital role in regulating breathing, heart rate, and sleep, reported researchers funded by the National Institutes of Health.

SIDS is the death of an infant before his or her first birthday that cannot be explained after a complete autopsy, an investigation of the scene and circumstances of the death, and a review of the medical history of the infant and of his or her family. According to the National Center for Health Statistics, SIDS is the third leading cause of infant death (http://www.cdc.gov/NCHS/data/nvsr/nvsr57/nvsr57_14.pdf), claiming more than 2,300 lives in 2006.

The researchers theorize that this newly discovered serotonin abnormality may reduce infants' capacity to respond to breathing challenges, such as low oxygen levels or high levels of carbon dioxide. These high levels may result from re-breathing exhaled carbon dioxide that accumulates in bedding while sleeping face down. The findings appear in the Feb. 3 issue of *The Journal of the American Medical Association*.

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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



On the sea of grief,
Becalmed ships wait patiently
For the winds of hope.

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 6/1/10.** We encourage your participation!

Brainstem continued from Page 4

How do our reported abnormalities in the serotonin metabolism relate to our “triple risk” hypothesis for SIDS? Remember that the typical case of SIDS usually involves an apparently healthy infant between one and six months of age who has been sleeping and is later discovered lifeless. Even though one or more of the above-mentioned SIDS risk factors that threatens the sleeping infant with asphyxia, hypercarbia, and/or hypoxia are usually present, evaluation of both the circumstances of death after death scene investigation as well as the postmortem examination does not reveal a definitive cause of death. Therefore, the diagnosis defaults to SIDS. In this scenario, the developmental period and the exogenous SIDS risk factors are present, but according to our hypothesis, infant vulnerability must also be present for death to occur. We have found that a high percentage of infants we studied have abnormalities in the medullary serotonergic system that unmasks or exposes the danger posed by the combination of sleep during the critical developmental period while sleeping in a potentially asphyxial environment. Thus, when medullary serotonergic system abnormalities are present, the infant may not be able to rescue itself from an asphyxial environment, i.e., compared to an infant without these abnormalities, an affected infant may not raise or turn its head to remove its nose and mouth from a face down position on a soft sleep surface.

Much work remains to be done to expand our understanding of the interaction of infant development, exogenous risk factors, and the medullary serotonergic system. But it is hoped through this understanding that it will be possible to predict which infants are at risk of SIDS and thereby intervene somehow before death occurs. This is several years away, however.

This work was undertaken by investigators from Harvard, UCSD/Rady Children’s Hospital-San Diego (Dr. Henry Krous, Elisabeth Haas), the San Diego Medical Examiner’s Office (Dr. Christina Stanley), University of New England College of Osteopathic Medicine, Dartmouth, and the New England Research Institutes. The study cases were obtained from the San Diego SIDS/SUDC Research Project after undergoing postmortem examination at the San Diego Medical Examiner’s Office and Children’s Hospital Boston. This work could not have been carried out without California law and the generous support of many parent and family survivors of infants dying of SIDS.

1. Krous HF, Beckwith JB, Byard RW, et al. Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach. *Pediatrics*. 2004;114:234-238.
2. Kinney HC, Richerson GB, Dymecki SM, Darnall RA, Nattie EE. The brainstem and serotonin in the sudden infant death syndrome. *Annu Rev Pathol*. 2009;4:517-550.
3. Duncan JR, Paterson DS, Hoffman JM, et al. Brainstem serotonergic deficiency in sudden infant death syndrome. *JAMA*. 2010;303:430-437.

The Other Side of Now by Frances A. Kraft

The sales girl shot a bewildered look at my mother. How does one respond to the terse statement, “My son just died?” My mother felt compelled to announce this fact to a perfect stranger. I was horrified. How long would it take to get to the other side of now? I hated now; it was too painful.

My brother, Arthur, had been dead only three weeks when this incident took place. In an attempt to establish a normal

daughter relationship, my mother suggested a shopping spree. I was ecstatic with the prospect of having my mother to myself, even if only for a few hours. She has been an emotionally absentee mother the past five years while she dedicated her life to the care of my ailing brother. During that time, my life was on automatic pilot. Unattended by parents, I blundered my way through acne, getting my period, developing breasts and my first

2010 OC Walk to Remember Saturday, October 23

New Location

There’s been many exciting things happening with the OC Walk to Remember organization.

This year the walk will take place at The District in Tustin. This allows us to provide you with free parking, many opportunities to shop and eat after the walk, a full 5K route (a half-route will also be available), and so much more.

Fundraising will begin shortly, and registration will open in the coming months.

Contact information is below:

OC Walk to Remember

800-714-9320

www.ocwalktoremember.org



kiss. They were there—but not really. By thirteen I’d experienced enough sadness to last a lifetime, and I desperately wanted to be happy-go-lucky, like the rest of my friends. The effect of losing my brother was profound. Naïvely, I expected to sever the hurts of the past and move on. Worse yet, I couldn’t understand why my mother didn’t just snap out of it. She would never be the same again, always blaming herself for Arthur’s death.

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Serotonin continued from Page 4

"We have known for many years that placing infants to sleep on their backs is the single most effective way to reduce the risk of SIDS," said Alan E. Guttmacher, M.D., acting director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the NIH institute that funded the research. "The current findings provide important clues to the biological basis of SIDS and may ultimately lead to ways to identify infants most at risk as well as additional strategies for reducing the risk of SIDS for all infants."

NICHD's Back to Sleep (<http://nichd.nih.gov/sids/>) campaign urges parents and caregivers to place infants to sleep on their backs. Following the campaign's launch in 1994, the rate of SIDS dropped by more than 50 percent. Widespread adoption of back sleeping appears to have reduced the occurrence of SIDS, but has not eliminated it.

For this study, senior author Hannah C. Kinney, M.D., of Harvard Medical School and Children's Hospital Boston, and her colleagues examined small samples of tissue from the medulla, a region at the base of the brain that regulates basic functions such as body temperature, breathing, blood pressure, and heart rate. The researchers analyzed brain tissue from infants who died from SIDS and controls who died of other causes. Included in the analysis were 35 infants who died of SIDS, 5 infants who died unexpectedly of other causes, and 5 infants who were hospitalized and died for reasons associated with a lack of oxygen.

The researchers found that serotonin levels were 26 percent lower in tissue from infants who died of SIDS than in tissue from the group of infants who had otherwise died unexpectedly. Measurements of tryptophan hydroxylase, an enzyme needed to make serotonin, also were 22 percent lower.

In earlier work comparing SIDS cases with other infant deaths (http://www.nichd.nih.gov/news/releases/sids_serotonin.cfm), Kinney and her coauthors showed that the brains of infants who died of SIDS had higher concentrations of cells that use serotonin in the medulla oblongata, a region of the brain stem. For the current study, the researchers set out to see if this meant the SIDS infants' brains in fact had altered levels of the brain chemical.

This abnormality appears to fit into the triple-risk model of SIDS, which holds that SIDS occurs only when three elements come together: an infant with an underlying vulnerability, a critical period of development, and an external stressor. The researchers speculate in this case that the low serotonin level would cause the underlying vulnerability. The first year of life is the critical period of development for stabilizing vital functions such as breathing. The

final element of the model, sleeping face down, might provide the external stressor.

"Our research suggests that sleep unmasks the brain defect," Dr. Kinney said. "When the infant is breathing in the face-down position, he or she may not get enough oxygen. An infant with a normal brainstem would turn his or her head and wake up in response. But a baby with an intrinsic abnormality is unable to respond to the stressor."

"It's no one single factor but a culmination of abnormalities that result in the death," Dr. Kinney said. In fact, in 88 percent of the SIDS cases they examined, the researchers found two or more risk factors, such as the infant's sleep position, an illness, or exposure to cigarette smoke.

Kinney hopes these findings will one day lead to a test that measures infants' serotonin levels in the blood or other tissues that reflect brain serotonin levels. Such a test might make it possible to identify those at the highest risk for SIDS so that additional steps could be taken to protect them. In the near term, the findings will provide the basis for the development of animal models with serotonin deficiencies, to mimic what occurs in SIDS in human beings.

Information on reducing the risk of Sudden Infant Death Syndrome is available on the NICHD Web site (http://www.nichd.nih.gov/health/topics/Sudden_Infant_Death_Syndrome.cfm).

The NICHD sponsors research on development, before and after birth; maternal, child, and family health; reproductive biology and population issues; and medical rehabilitation. For more information, visit the Institute's Web site at <http://www.nichd.nih.gov/>.

The National Institutes of Health (NIH) — *The Nation's Medical Research Agency* — includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

Other Side continued from Page 5

How long would it take to get to the other side of now? Years, I found out. It would take years. I thought I'd survived the tragedy of my brother's death relatively unscathed. But, not until I was married with children of my own, did the traumatic loss awaken feelings lying dormant for twenty years, like tentacles reaching out from a former life. Suddenly I became engulfed in fear over my children's well-being. It was my husband, a psychiatrist, who identified it as a normal

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SIDS Resource Websites

California SIDS Program - designed to serve the many individuals affected by a SIDS death, and to educate the public about SIDS. Provides a wide variety of information including grief and bereavement resources, SIDS facts, and infant care practices for reducing the risk of SIDS. <http://www.californiasids.com/Universal/MainPage.cfm?p=10>

Healthy Foster Care America - provides a pledge checklist for anyone providing care for a baby (foster, birth, or adoptive). http://www.aap.org/fostercare/PDFs/HFCA_SIDS.pdf

HealthyChildren.org - the only parenting Web site backed by 60,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.

Includes general information related to child health or specific guidance on parenting issues. Provides information regarding the American Academy of Pediatrics many programs and activities, policies and guidelines, publications and other child health resources. The information comes from the nation's leading child health experts and has scientific research supporting recommenda-

Some people come into our lives and quickly go. Some stay for a while and leave footprints on our hearts. And we are never, ever the same.



Source Unknown

Coping continued from Page 3

your loved one. Some are painful; some bring a smile. Some examples are: anniversaries, birthdays, holidays, another death, certain people, clothing, items that come in the mail, pictures, movies, smells, food, songs, special places, words and phrases. Some of these will surprise you. Tears may come to your eyes. You may even cry at something that may seem "insignificant." most bereaved people report a type of "searching" behavior in which they find themselves looking for their loved one. Sports events, graduation, plays. Dreams.

Your mind has a multitude of memories of your loved one that will be stimulated by reminders in the course of your daily activities. You will find some reminders comforting, some neutral, and some very painful. As each painful reminder is confronted again and again, the intensity of the grief reaction tends to diminish. However, in the early part of the grief process some of the reminders will feel overwhelming and the intensity of the reactions will not decrease until several more exposures to the reminders. Because of the intense pain associated with death, there is a natural tendency to avoid reminders. This is our mind's way of protecting itself from additional pain. Keep in mind that an effective way to cope with grief is to try to balance this natural protective response with the necessary and healthy confrontation of reminders. Although confronting painful reminders is difficult, doing so appears to be one of the most constructive ways to work through the grief process.

Conversely, the continued avoidance of reminders such as places, situations and people may inhibit the resolution of grief. However, take your time and decide when it is the right time for you to confront a painful reminder. Continue to comfort yourself with positive memories. The searching behavior mentioned earlier continues for many people for a long period of time. Months, even years after death, you

may see someone that resembles your loved one and feel your heart skip a beat because, for a minute,

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Save The Date

3/13/10 - 2nd Annual Baby Joey SIDS Run for Life 5k Run/Walk; Constitution Park, 1287 Paseo Camarillo, Camarillo, CA www.joeydemellofoundation.org/events.html

10/4/10 & 10/5/10 - California SIDS Conference with Dr. Henry Krous as keynote speaker; Double Tree Hotel in Orange, CA www.californiasids.com

10/23/10 - 2010 OC 5k Walk to Remember; The District in Tustin; 800-714-9320 www.ocwalktoremember.org

IMPORTANT

This could be your last newsletter! Contact lbiakanja@yahoo.com to confirm your desire to receive *Reflections* by email or send an email gisoc@att.net to remain on the mailing

The Joey DeMello Foundation is proud to announce...

2nd Annual Baby Joey SIDS Run for Life 5k Run/Walk—**March 13, 2010** at Constitution Park, 1287 Paseo Camarillo, Camarillo, CA

On August 23, 2007, Baby Joey was born. A healthy baby girl full of love and a future ahead of her. She brought so much meaning in everyone's lives and many families and friends became close because of her. She taught her big sister Angelica the true meaning of LOVE.

On March 10, 2008, Baby Joey passed away from Sudden Infant Death Syndrome (SIDS) at the age of 6 months old. She was never given the chance to take her first step. We will never see her experience so many things in life. This is because of a tragedy that we do not know what caused it.

Sudden Infant Death Syndrome (SIDS) is the most common cause of death for babies between the ages of one month and one year. It is the sudden death of an infant under one year of age that remains unexplained after a thorough case investigation, including a complete autopsy, examination of death scene, and review of the clinical history. Although figures differ, at least 2,500 babies in the United States die from SIDS each year.

Please help us find the answers as to why our Baby Joey had gone too soon. We will never see her grow up and experience life... Her love and life have encouraged us to be better people and not to take anything or anyone for granted. Her story has taught us that love is amazing, loss is devastating and family and friends are everything.

I fancied that I heard them say, "Dear Lord, Thy will be done, for all the joy this child shall bring, the risk of grief we'll run. We'll love her while we may, and for the happiness we've known forever grateful stay. But should the angels call her much sooner than we planned, We'll brave the bitter grief that comes, and try to understand."

Please come and join the Josephine DeMello SIDS Foundation on its 2nd

annual Baby Joey SIDS Run for Life 5k Run/Walk!

Food, entertainment, prizes, meet new people! Most importantly...step up and make a difference.

Adults are \$25, Children 5 to 9 years old are \$15, and kids 5 and under are FREE!

To learn more and to register, visit www.joeydemellofoundation.org/events.html.

Pending Research Study

Impact of the Diagnosis on Parents' Grief Following the Sudden Unexpected Death of an Infant.

One concern about the increasing use of the "undetermined" diagnosis is the impact of the specific determination of the cause of death on SIDS families, their grieving process, etc. There are a number of published studies on the impact of a SIDS death on parents, their psychological reactions to the death, etc. However, we are not aware of published studies, which address this specific issue. The *California SIDS Advisory Council* believes that the specific diagnosis received *does* have an impact on parents' grief and road to recovery. SIDS is generally considered to be a biological disorder and a natural manner of death, which implies that parents did nothing to cause the death. According to the SIDS parents participating in *Council* discussions, the SIDS diagnosis helped tremendously to reduce guilt, as these parents could point to this diagnosis as evidence that they did not cause their baby's death. On the other hand, a diagnosis of "undetermined", or a similar non-SIDS diagnosis, tainted the baby's death. If the Coroner could not use the SIDS diagnosis, what did he or she think the parents might have done to cause or contribute to the death? Many SIDS parents believe that the use of a non-SIDS diagnosis complicates grief and recovery.

John Margetis, a USC undergraduate working with *Doctor Thomas Keens*, and in collaboration with *Dawn Dailey*, *Kathleen Roche*, *Susan Moore*, *Magali Leialoha*, and *Gwen Edelstein*, designed an anonymous questionnaire study (using validated instruments, demographic information and open-ended questions), to attempt to assess if and/or how differing diagnoses affect parent grief. The study received Institutional Review Board review and approval (to assure that the rights and welfare of human research subjects are protected). We have sent out over 500 questionnaires to SIDS parents from the *California SIDS Program* mailing list and from the *SIDS Alliance of Northern California* mailing list. We have already received some questionnaire, and are awaiting more. If a non-SIDS diagnosis is found to complicate grief, this finding may dissuade Coroners from making such diagnoses when medical or scientific evidence is lacking to differentiate.

Happy Mother's Day to Mothers Everywhere

**It's time again to celebrate
another Mother's Day,
A reminder that it's Spring
and the merry month of May.**

**But, oh, the sadness
this day imparts...
For the child that is missing
bringing an ache within our hearts.**

**But wouldn't it be sadder yet
had not the child been born...
Our life being unfulfilled
as a rose without a thorn.**

**So remember funny times
that bring a happy smile...
And be grateful that we had them
if only for awhile.**

**For if we had not had them,
Mothers, we'd not be...
So fill your hearts with gladness
and treasure each precious memory.**

Valerie Toth

MEMORIAL DONATIONS

Special Thanks

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

In Memory of Kaylee Rene Billings

Joan Baugh and Family

In Memory of Cory Eckert

Ms. Diane E. Gelormino

In Memory of Scotty Hogan

Anna H. Brown and Richard R. Hogan

John and Becky Hogan

Ms. Fran Hogan

In Memory of Ryan Jahn

Ms. Constance Hempel

In Memory of Kristy Louise Kirchner

Ryan Romero

In Memory of Jason Alexander Robar

Mrs. Elmer L. Robar

Mr. & Mrs. R. L. Aguilar

Mrs. Alexander Shutz

Mr. & Mrs. R. L. Robar

In Memory of Sarah Ashley Robbins

Margaret and Iain McCormick

In Memory of Justin David Stall

David, Linda and Traci Stall

In Memory of Hayden Strickland

Joseph L. Seitz

Mr. and Mrs. Curtis Bismeyer

Mr. and Mrs. Peter Kaufman

Mr. and Mrs. Howard T. Snyder

In Memory of Ian R.A. Watson

Russ and Toni Hudson

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Community Support Campaigns

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Gail Cady

Sinasan Mansouri

Dessirae Mayhue

Elaine L. Nelson

IMPORTANT

This could be your last newsletter!

Contact ibiakanja@yahoo.com to confirm your desire to receive *Reflections* by email or email gisoc@att.net to remain on the mailing list.

2009/2010 MEETING CALENDAR

NEW Infant Loss Grief Support Group

7:00 pm - 8:30 pm

Word of Life Church

Conference Room

902 N. Main St.

Santa Ana, CA, 92701

*Because the path through grief
is often a long and difficult journey,
New Hope would like to make that journey with you.*

Please call for information on the next 8 week class
to register & for more information.

(562) 429-0075

- ◆ Open to parents who are grieving the loss of an infant.
- ◆ Space is limited, so call soon to register
- ◆ Group is closed after 2nd session

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 21, 2010

July 21, 2010



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