



Art by Barbara Gould, Grandmother of  
Maria Crandall (4/21/96—7/30/97)

*Grief, like a wave, has a rhythm of its own. At first, it comes sweeping in, then it recedes, leaving us in a quiet peace with the treasures of memory, love, and strength that is carries to our shore.*

*\* author unknown*



**SUDC  
PROGRAM**

*sudden unexplained death in childhood*

The SUDC Program  
c/o The CJ Foundation for SIDS  
The Don Imus WFAN Pediatric Center  
30 Prospect Avenue  
Hackensack, NJ 07601

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A PROGRAM OF THE CJ FOUNDATION FOR SIDS

THE SUDC PROGRAM: AN ANSWER WHEN THERE'S NO EXPLANATION



# SUDC PROGRAM

*sudden unexplained death in childhood*

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## Dear Reader:

Welcome to the fourth annual newsletter of the SUDC program! With each newsletter we seem to have more to write about and this year is no different. We hope you find the information provided to be useful.

**Research:** The SUDC Research Project continues with more participants and several recent publications which are outlined in this newsletter.

**Support:** With an increase in support services, awareness and research, we continue to be ever grateful for the commitment the CJ Foundation for SIDS has made to the SUDC cause. And thank you to all the researchers who tirelessly continue their efforts to learning more about SUDC so we can prevent this from happening to others. And finally, thank you to our SUDC families who continue to support the program in countless ways.

**Advocacy and Information:** We have continued our presence at medical conferences to get the word out that we are here to help families who suffer the tragic unexplained loss of their child. According to the CDC, SUDC type deaths occur about 200 times annually to children between the ages of 1 and 4 years of age, with a lower incidence in older children. Typically, we receive about 35 to 40 referrals of new families each year. So, where are the rest of these bereaved families? We imagine most are grieving alone, thinking they are the only ones who have experienced such an unexplained loss. They are wrong, and we are here to help. Please contact us if you know of a family whom we could help.

Sincerely,  
 Laura Crandall  
 Program Director  
 SUDC Parent

## NJ Legislation Allows for SIDS/SUDC Research

By LAURA CRANDALL • *Mother of Maria (4/21/96 – 7/30/97)*

Legislation recently passed the NJ Senate and Assembly that will allow for research into SIDS and SUDC. The bill, originally sponsored by Senator Richard Codey (now NJ's Acting Governor) was introduced last year and has finally landed on the Governor's desk for enacting into law.

NJ already had important statutes that mandated investigations on all sudden and unexpected deaths and the referral of families (who have lost a child under the age of the 3) to the SIDS Center of NJ for free bereavement support services. In 2000, a new law was created that established the NJ Sudden Child Death Autopsy Protocol Committee which was charged with creating standardized autopsy and investigation protocols to be used throughout the state whenever a child died suddenly and unexpectedly.

But still, SIDS and SUDC research could not be performed in NJ. Another statute existed in NJ. It prevented Medical Examiners from participating in research all together. This hurts families who are struggling to understand their immense loss and limits the medical field and public health in their ability to find a way to prevent these deaths from happening to anyone else. Senator Codey's bill — S1684 — will change all that.

S1684 charges the NJ Sudden Death Autopsy Protocol Committee to create a protocol to allow Medical Examiners who wish to participate in the crucial research needed to end SIDS and SUDC, and allows families more options in their pursuit of understanding why their precious child died. The system does not pose a financial burden to the State or the participating Medical Examiner. And, research is only performed with parental consent.

With the passage of this important piece of legislation, NJ families who suffer one of life's greatest tragedies- the loss of their beloved child - will have access to more research options when to trying to uncover the mystery of their child's death. It will help Medical Examiner's be part of the process that will lead to a greater understanding of these death's, with the ultimate goal being their prevention for all. Hopefully, it will serve as model for other states, because living without answers is a most difficult journey that never ends for those touched by such a devastating tragedy.



RICHARD J. CODEY  
Acting Governor of New Jersey

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# Update from the San Diego SUDC Research Project

- Currently, more than 70 families have entered the study for participation.
- The study is still accepting new cases for inclusion of children who have succumbed to SUDC.
- There has been an addition of the following Pediatric Forensic Pathology Fellows for SIDS/SUDC research
  - Chris Wixom, M.D., 2004-2005
  - Anna Mboyan, M.D., 2005-2006
  - Homeyra Masoumi, M.D., 2005-2006)
- Recent Publications:
  - Krous HF, Chadwick AE, Crandall L, Nadeau-Manning JM  
**Sudden Unexpected Death in Childhood: A Report of 50 Cases.** *Pediatr Dev Pathol.* 2005 July 14
  - Wixom C, Krous HF, Chadwick AE  
**Sudden, Unexpected Death Associated with Meningioangiomas.** *Pediatr Dev Pathol.* 8, 240-244, 2005
  - Kinney H, Armstrong DL, Chadwick AE, Crandall L, Hilbert C, Krous H.  
**Seizures, Cerebral Edema and Hippocampal Anomalies in Sudden Unexplained Death in Childhood (SUDC): Report of a Series.** *J Neuropathol Exp Neurol.* 2004;63(5):556

## Sudden Unexpected Death in Childhood: A Report of 50 Cases

*Pediatr Dev Pathol.* 2005 Jul 14

**KROUS HF, CHADWICK AE CRANDALL L, NADEAU-MANNING JM.**

Departments of Pathology and Pediatrics, Children's Hospital and Health Center, 3020 Children's Way, MC5007, San Diego, CA, 92123, USA.

**ABSTRACT:** Sudden unexplained death in childhood (SUDC) is rare, with a reported incidence in the United States of 1.5 deaths per 100,000 live births compared with 56 deaths per 100,000 live births for sudden infant death syndrome in 2001. The objectives of this study include a proposal for a general definition for SUDC and presentation of 36 cases of SUDC and 14 cases of sudden unexpected death in childhood. Cases were accrued through referrals or unsolicited via our Web page (<http://www.sudc.org>). Our analyses tentatively suggest a SUDC profile characterized by cases being 1 to 3 years in age, predominantly male, and frequently having a personal and family history of seizures that are often

associated with a fever. A history of recent minor head trauma is not uncommon. They are usually born at term as singletons and occasionally have a family history of sudden infant death syndrome or SUDC. Most are found prone, often with their face straight down into the sleep surface. Minor findings are commonly seen at postmortem examination but do not explain their deaths. Comprehensive review of the medical history and circumstances of death and performance of a complete postmortem examination including ancillary studies and extensive histologic sampling of the brain are critical in determining the cause of death in these cases of sudden unexpected childhood death. Legislation enabling research and formation of a multicenter research team is recommended to unravel the mystery of SUDC.

## Sudden, Unexpected Death Associated with Meningioangiomas.

*Pediatr Dev Pathol.* 8, 240-244, 2005

**WIXOM C, KROUS HF, CHADWICK AE**

Departments of Pathology and Pediatrics, Children's Hospital and Health Center, 3020 Children's Way, MC5007, San Diego, CA, 92123, USA.

**ABSTRACT:** We report a case of sudden, unexpected death associated with meningioangiomas in a 13 year old previously healthy male without a history of seizures, neurological deficits, or clinical stigmata of neurofibromatosis. There was no family history of neurofibromatosis. The postmortem examination showed a 5-cm mass involving the right posterior frontal and orbital frontal cortex that had microscopic features diagnostic of meningioangiomas. Because no other cause of death was found, we postulate that he likely died as a result of a seizure secondary to meningioangiomas.

## Update on SUDC Support Services

By CHELSEA HILBERT, LCSW • *Director of Outreach Services*

The SUDC Program's Outreach Services continue to be developed to meet the needs of our families. The program offers support services to any new family with whom we make contact. Currently the program serves 145 families around the globe. Families may access the SUDC program via our toll-free number 1-800-620-SUDC or our website [www.sudc.org](http://www.sudc.org)

### Outreach Services:

#### Peer Contact Program:

The Outreach Services program offers a Peer Contact Support Program to each new parent or grandparent. The volunteers are SUDC parents and grandparents who have passed the first anniversary of their child's death and have been assessed as compassionate and competent to assist newly bereaved families. Currently the program has 30 Peer Contact Volunteers. The program welcomes any family who would like to participate in providing these support services.

#### Online Support Group:

We continue to offer the Online Support Group and have 46 active members. The Online Support Group provides connection to other families all over the globe at anytime of day.

The Group is offered through Yahoo! And also enables members to post photos and family stories. Through the group, families receive extra support on their child's anniversary and birthday.

#### Subsequent Child Support Group:

Many SUDC families experience the birth of another child following the loss of a child. We offer a monthly conference call specifically for these families in order to discuss hopes, fears and coping with a new baby after the loss of their child due to unknown causes.

#### Birthday and Anniversary Cards:

The program sends Birthday and Anniversary cards to all families, parents and grandparents registered with the program. The artwork on the cards is designed by SUDC family members. This year the program is privileged to have 4 beautiful cards that were designed by two siblings, a parent and a grandparent.

#### Pen Pal Program:

Last year we added a sibling Pen Pal program and have 14 siblings participating. Each pen pal pair was matched by age and other similarities. They communicate via mail and email. This year, we will provide supportive follow-up to each matched pair.

#### New Jersey Support Group:

The SUDC program feels very

privileged to be able to offer a Monthly Grief Support Group in New Jersey. The facilitators are staff from the SIDS Center of New Jersey and we are grateful to their commitment to SUDC families.

We continue to update our grief materials for the program. These include those that are offered on the SUDC website and in the SUDC information binders that are sent to families and professionals on first contact. Several of our SUDC families have contributed ideas and materials to further improve this service.

As always, we are interested in any of your comments and feedback. Thank you to everyone who has volunteered his or her time, ideas and emotional support. We truly appreciate your efforts!

#### We would like to recognize some of our wonderful SUDC volunteers:

Tricia and Jim Adams	Parent Peer Contact
Lori Caffrey	Parent Peer Contact
William Carrington	Parent Peer Contact
Alexandra Costa	Artwork for Family Cards
Christina Costa	Parent Peer contact, Anniversary and Birthday Cards
Rita Frisher	Grandparent Peer Contact
Barbara Gould	Grandparent Peer Contact, Artwork for Family Cards
Marge and Dick Griffin	Grandparent Peer Contacts
Allison Joucovsky	Parent Peer Contact
Julie Kennedy	Parent Peer Contact
Scott Kopen	Parent Peer Contact
Susan Lavelle-Kopen	Parent Peer Contact
Phil and Donna Lively	Grandparent Peer Contact
Lunden MacDonald	Parent Peer Contact
Cindy Marin	Parent Peer Contact
Michelle McGarry	Parent Peer Contact
Jane Redmond	Parent Peer Contact
Margie Torres	Parent Peer Contact
Javier Rivera	Parent Peer Contact
Dawn Sandoval	Parent Peer Contact, Online Anniversary and Birthday Reminders
Jacob Sandoval	Artwork for Family Cards
Suzanne Tom	Parent Peer Contact, Moderator for Subsequent Family Support Group

# Update on Research Concerning the Neuropathology of SUDC

By LAURA CRANDALL

As part of the San Diego SUDC Research Project, all children entered into the study are first evaluated by Pediatric Pathologist, Dr Henry Krous. Upon completion of that evaluation, a neuropathology exam (when info is available for study) is sent to Dr. Hannah Kinney, pediatric neuropathologist, at the Children's Hospital of Boston for evaluation. Dr Dawna Armstrong, pediatric neuropathologist, also consulted on the case reviews.

In 2004, the data from this neuropathology review was described in the May 2004 issue of the Journal of Neuropathology and Experimental Neurology, through the following abstract. The printed abstract was followed by the annual meeting of the American Association of Neuropathologists held in Cleveland on June 25-28, 2004 where Dr Kinney presented her data on SUDC.

Kinney H, Armstrong DL, Chadwick AE, Crandall L, Hilbert C, Krous H. Seizures, Cerebral Edema and Hippocampal Anomalies in Sudden Unexplained Death in Childhood (Sudc): Report of a Series. J Neuropathol Exp Neurology 2004;63(5):556

## ABSTRACT 185:

In the practice of forensic pathology, there is an increasing awareness of the phenomena of SUDC. These deaths fulfill the criteria for the sudden infant death syndrome (SIDS), but they occur beyond the age of one year. They occur in apparently healthy children during a sleep period, for whom site visits and complete autopsy examinations fail to reveal a cause of death.

Neuropathology studies are in progress and have identified 6 cases between 1-3 years with hippocampal anomalies, some of which could be classified as

microdysgenesis (e.g., asymmetry between the right and left sides, hyperconvoluted dentate gyrus, subicular defects, granule cell heterotopia, hamartia and ectopic neurons). In this SUDC subgroup, there is a history at the time of death of upper respiratory tract infection or fever in 67%, definite or probable history of febrile seizures in 50%, history of trivial head trauma in 33% and evidence of cerebral edema at autopsy in 50%. We hypothesize that these "risk factors" in this small group of toddlers who have hippocampal anomalies define a common brain defect that is responsible for fatal seizures, brain edema, and sudden death during a sleep period.

The data was also presented as a poster at the SIDS International Meeting in Alberta Canada, July 2004, and at the National Association of

Medical Examiner's Annual Scientific meeting in Nashville, TN Sept 2005.

It is important to note, that the above findings in SUDC have not been described in the literature before. The fact that these findings were not revealed by the original pathologists are not surprising, due to the absence of this information in the literature, the degree of abnormality that has been found (very subtle), and that saving and studying this area of the brain has not been part of the standard of practice when investigating SUDC.

The degree of which this may or may not present a genetic predisposition in some families cannot be answered at this time.

The manuscript of this work is in its final stages and we anticipate publication very soon.

## What is the Hippocampus

- The name derives from its curved shape, which supposedly resembles that of a seahorse.
- The hippocampus is a horseshoe shaped sheet of neurons located within the temporal lobes and adjacent to the amygdala. It is part of the limbic system.
- The hippocampus is a part of the brain that is located in the temporal lobe, which is on the side of the brain, above the region of the ear.
- Humans have two hippocampi, one in each side of the brain.
- It aids in learning and memory and is also a center for which temporal lobes seizures are known to originate.
- It has input into the brainstem that directly controls breathing and blood pressure.



[http://en.wikipedia.org/wiki/Hippocampus#Related\\_topics](http://en.wikipedia.org/wiki/Hippocampus#Related_topics)

## “Run for a Reason” Events Continue to Grow

The SUDC Program is proud to announce the creation of Six “Run for a Reason” events held across the nation in 2005 to raise awareness and funds for SUDC research and support services! The first event of this kind- Max’s Run for a Reason- was held in Nov 2003 and was founded by Jen and Mitchell Best in honor of their son, Max who succumbed to SUDC at the age of 13 months. Details on all events can be found at [www.sudc.org](http://www.sudc.org).

Walk. Run. Laugh. Remember.

### MINNEAPOLIS, MN

SATURDAY NOV 13, 10AM AT LAKE HARRIET BAND SHELTER

Walk. Run. Laugh. Remember.

## MAX'S RUN FOR A REASON

A 5K Run and 2K Family Fitness Walk

Benefiting the Sudden Unexplained Death  
in Childhood (SUDC) Program



Fun Family Games • Great Drawings • Refreshments • Silent Auction • Live Music



[www.maxwellbest.com](http://www.maxwellbest.com) for more information  
and to register or call 612.922.8100.

### DENVER, CO

Walk. Run. Laugh. Remember.

2nd  
Annual

## JOSH & GUS'S RUN FOR A REASON

A 5K Run\* and 2K Family Fitness Walk  
Benefiting the Sudden Unexplained Death in Childhood (SUDC) Program

Saturday, November 5, 2005

Clement Park - Littleton, Colorado

\*USATF certified course

[www.joshandgus.com](http://www.joshandgus.com) for more information and registration

### VANCOUVER, WA

Walk, Run, Laugh, Remember

## ALEX'S RUN FOR A REASON



A 2.5 Mile Family Fitness Walk

Benefiting the Sudden Unexplained Death in Childhood Program

Saturday, October 15, 2005 Vancouver, WA Marine Park

### ST. LOUIS, MO

Walk. Run. Laugh. Remember.

## RILEY'S RUN FOR A REASON



A 5K Run/Walk and 1 Mile Family Fitness Walk

October 16, 2005 Saint Louis, MO

[www.rileyborisenko.com](http://www.rileyborisenko.com)

**KANSAS CITY, MO**

SUNDAY Oct 30, 8AM at 75th and Wornall

**MAGNOLIA'S  
RUN FOR  
A REASON**

A 5K Run and 2K Family Fitness Walk

Benefiting the Sudden Unexplained Death in Childhood (SUDC) Program



Family Fun

Great Drawings

Live

Hosted by  
**Maggie's Shoes** 

[www.maggieshoes.org](http://www.maggieshoes.org) for more information and registration

**ORINDA, CA**

Walk. Run. Laugh. Remember.

**HALEY'S  
4<sup>TH</sup> OF JULY  
RUN FOR  
A REASON**

A 5-Mile Run and 2-Mile Family Walk

Benefiting the Sudden Unexplained Death in Childhood (SUDC) Program

On May 15, it marked Haley's 5 year angel date. A big milestone we really didn't want to reach. But this year we did something that made this day a little easier to handle — we held our 1st annual Haley's 4th of July Run for a Reason. It was a part of our city's 4th of July celebration that includes a pancake breakfast, parade, run/walk and park activities.

It was a good family project. Our other two children, Megan (5) and Ashton (3), who have no connection with Haley other than pictures and videos were now our little "helpers." They handed out flyers at our concerts-in-the-park along with their other little friends and hung banners and flyers around town. They would get so excited to see them around town! For Donovan and myself, we loved the fact that we were saying Haley's name about 30 times a day once again.

We are happy that we raised \$14,000 our first year and can't wait for next year's event!

**By Suzanne and Donovan Tom**



## A Peer Contact Interview

By CHELSEA HILBERT, LCSW

Through the Peer Contact program, the SUDC program is able to connect newly bereaved parents with other parents who have had children die of unknown causes. Since its inception, peer contact volunteers have provided support to approximately 45 families. The Director of Outreach services interviewed two parents who were recently paired for support.

Rebecca Butt, mom to Jameson, who died in January 2005 of unknown causes receives peer contact support from Lunden MacDonald. Lunden is mom to Gus, who died June 2003, also, of unknown causes. Lunden has two subsequent children, Murphy and Maeve with her husband, Patrick. Rebecca is single and hoping for a future with children.

### How did you both meet?

**Rebecca:** “Lunden and I met, initially, through mutual acquaintances and it just happened that we live in the same city. My friend who made the introduction knew that I would benefit from talking with someone in the same situation as me. Lunden called me about two weeks after Jameson died.”



Lunden and Gus

**Lunden:** “I remember the first day that I met with Rebecca. The disbelief, distress, and terrified look on her face were very overwhelming. The horror of losing a child was

something I knew so well that it hit me hard. I also could tell that when Rebecca looked at me and spoke with me, she could see that my life had returned to almost normal. I knew she saw the hope of that healing in her future. The idea of being normal, again, is very powerful.”

### Why did you get involved with the Peer Contact Program?

**Lunden:** “When I looked back at my own experience, the only thing that got me through the pain was talking about it, crying about it and sharing stories of Gus. I wanted to be able to give that healing experience back to someone else.

**Rebecca:** “I knew that I needed to find someone who could relate to what I was going through. Lunden acknowledged how huge my loss was. People who haven’t been through it said things like: “have another baby” and “time heals all wounds.” Lunden didn’t say that. She didn’t try and sugar-coat the loss. She simply said “This really sucks. I am so sorry” Lunden did not say everything would be great one day. Instead, she said “your life will be very different and the pain will certainly ease.” She was so affirming when she said that it was nothing I did that caused Jameson’s death. Then she said “I say that a million times (it was nothing you did) because maybe it will sink in for me, too, and I will believe it for myself!”

### What have you gained from your Peer Contact Volunteer?

**Rebecca:** “It is unfortunate to talk with someone who has had a child die, but I have found that communication is vital. I don’t know how people cope without someone to talk with. It is helpful from the very beginning to see that life goes on. Also knowing that our feelings of loss are similar. I don’t relate as easily to parents who’ve lost their kids to

different circumstances. It is just not the same.

I see that Lunden does experience happiness and I know that I will feel happiness and joy again, too. It certainly doesn’t take away from my loss but it gives me hope. I can be totally honest with someone who has been there. In the beginning, you feel



Rebecca and Jameson

like the thoughts you are having are crazy. Then, Lunden says “I’ve had that thought a thousand times.” I am a social worker and I know this stuff but it is different when you’re the one experiencing it. It is nice to have someone to say, “I’ve been there and what you are feeling is normal.”

### What have you gained from being a Peer Contact Volunteer?

**Lunden:** “I have also gained perspective. We all seem to compare ourselves to others. They have a nice house, great kids, good job, etc. When you lose a child, life is at the very worst it can get for that time. Now, things are better compared to a year ago. A terrible thing has happened in our lives, but life does go on and happiness comes. You realize that you make the choice to be happy. Now I am glad to wake up everyday.

### What have you offered to your Peer Contact Partner?

**Rebecca:** I imagine that it must be very therapeutic for Lunden to extend

*continued on page 23*

# Questions and Answers About Long QT Syndrome

With MICHAEL J. ACKERMAN, M.D., Ph.D.

Director, Long QT Syndrome Clinic and Sudden Death Genomics Laboratory  
Mayo Clinic College of Medicine • Mayo Clinic, Rochester, MN

## What is Long QT Syndrome?

Long QT Syndrome (LQTS) is a disorder of the electrical system of the lower chambers of the heart (ventricles). The mechanical or pumping function of the heart is normal. However, the recharging (repolarization) system of the heart is either slow, taking longer than normal to recharge, or inefficient (disorganized). LQTS can be divided into two broad categories: congenital and acquired. In acquired LQTS, the electrical recharging abnormality is secondary to medications, abnormalities in electrolytes, or other illnesses (like anorexia nervosa for example) that prolong the QT interval. In contrast, congenital LQTS is known as a primary cardiac ion channel disease due mostly to mutations in the genes encoding the proteins (ion channels) responsible for this electrical recharging process. It is estimated that 1 in 5000 persons may have congenital LQTS.

Overall, in congenital LQTS, approximately 50% of patients experience a long life with no symptoms. However, 5-10% encounter sudden death the first time the heart “spins electrically out of control”. Symptoms depend entirely on whether or not the long QT heart remains in normal rhythm albeit with abnormal recharging or degenerates into a potentially lethal rhythm like ventricular tachycardia or ventricular fibrillation. If the dangerous rhythm is ever so brief before the heart “catches itself”, the person may not even notice it or sense a brief rapid heart heart (palpitations). The most common symptom is a fainting spell usually in the setting of the “fight-flight-fright” response, such as fainting during an athletic/recreational activity like baseball, the 100-yard dash, while swimming, or fainting following a sudden startle like the doorbell, alarm clock, or telephone ring that catches you by surprise. Again, the person wakes back up rather than dies because

the heart “snaps back” into a normal rhythm on its own. Occasionally, LQTS can be misdiagnosed as seizures or epilepsy.

It is unclear at the present time how much of sudden infant death syndrome (SIDS) may be due to a channel problem in the heart. Previously, Ackerman and colleagues demonstrated (JAMA paper, November 2001 and Cardiovascular Research paper, August 2005) that approximately 3-5% of a population-based cohort of SIDS was found to possess LQTS-causing channel mutations. Much more work needs to be done in this area.

## How is it diagnosed?

During life, LQTS is suspected in the setting of an exertional or auditory-triggered faint, a family history of suspicious fainting and unexpected sudden death. The 12-lead electrocardiogram remains the central test in the evaluation of LQTS. In LQTS, the ECG often but not always provides evidence for the presence of the abnormal recharging process with a so-called prolonged QT interval. In older children (> 10 years) and adults, newer tests using epinephrine to unmask the presence of LQTS are being developed. Since congenital LQTS is usually inherited, the parents and all relatives on the appropriate side of the family should have a screening ECG. In addition, LQTS genetic testing is now a commercially available, clinical diagnostic test rather than a research test. The current clinical genetic test captures approximately 75% of LQTS and takes approximately 4-6 weeks. This genetic test has been available since May 2004 ([www.familion.com](http://www.familion.com)). Research laboratories continue to search for novel genetic mechanisms that explain the rest (25%) of LQTS.

If a sudden, unexpected death has tragically occurred already and the standard autopsy has not identified a



Michael J. Ackerman  
M.D., Ph.D.

probable cause of death, a “molecular autopsy” could be conducted from properly preserved tissue material (i.e. blood placed in EDTA preservative or quickly frozen tissue from heart, liver,

spleen). However, this is extremely labor intensive. Prior to seeking out such an examination, an exquisitely careful and thorough family history should be conducted, particularly of the parents and siblings – any fainters in the family, if so what circumstances, etc. It is critical to remember that fainting is extremely common — approximately 15-25% of all people will experience at least one fainting episode. Thus, in a case of SUDC, there is a good chance that a relative has fainted. However, it is the kind of faint that is key and this should be evaluated by your doctor. In general, a family history of one or more relatives with a fainting spell characterized by feeling lightheaded and whoozy and about to collapse is NOT a worrisome faint. In contrast, if a careful evaluation by the physician reveals that the mother fainted during cheerleading in high school and a distant relative on the mother’s side of the family had an unexplained drowning, NOW the red flag should be raised and the presence of LQTS or a related cardiac channelopathy should be intensely sought.

## If my child died a sudden unexplained death- do I have to worry about Long QT Syndrome in my family?

At the present time, an estimated 5-10% of SUDC is due to LQTS. Thus, its presence should be carefully sought as outlined above. Unfortunately, most of SUDC remains painfully unknown and unexplained.

## Ryan's Second Anniversary

By JOHN PHUA • *(In memory of my son, Ryan Phua 12/15/00 – 7/8/03)*

*Excerpt: from a letter to a friend describing how we felt on Ryan's anniversary*

**T**hanks for remembering. You can feel it in the family the days leading up to the anniversary date. If a person from the outside was able to look into our soul, he or she would sense that something was astray and out of sync.

Everyone at home felt the anticipation of what had happened that day, unfortunately this day will be forever marked as a reminder of Ryan who we love so dearly as the day he moved on. We still have his memories and his presence in our hearts, but the pain of his loss is always just below the surface. Ironically this pain keeps us "feeling" every moment of life. Our heart is tender and can wound at a moments notice. We learn to protect and shield it so that we can continue to "live".

I know Ryan wants us to live and live this life to the fullest. He wouldn't have it any other way. His twin brother, Matthew needs us to live that way too. Embracing every special moment together as a family, we enjoy that simple laugh, the giggle, the little battles, the many new things one experiences living in this world. It is by fully living in this world that we escape the regret of never having lived at all.

We went up to the mountains, a place of healing where one could feel things bigger than oneself and sense a connection with nature. ....The ocean, the mountains, the sky, the stars, the ground. We visited the Empire mining site, which is owned by the same folks that own Filoli Gardens by our house. It gave me another sense of connection.

Anyway, Mr. Bourne (the owner of the mining company) had this motto he lived by (being an

Irishman).... "Fight, Love, Live". I found that fitting given my fight for emotional healing, love of Ryan, and my desire to live my life.

The "fight": We struggle with many things that we face on our journey. We come upon these challenges that sometimes are insurmountable and unbeatable without any resolution, but yet with belief in the human spirit and hope we find the "strength and courage" to fight for our life and the life we want to live.

Love: Without "love" we cannot survive. When we were watching the blacksmith make Matthew a spoon out of cold dark steel, it had no life, no shape, no presence. The blacksmith needed fire to give shape to this steel. No fire can be a fire with out three things: oxygen, fuel and heat. Without any one of these, it does not exist. Love is the fire of life and life cannot exist without "love". Love is the core of our hope through which we can heal. Love from friends like you and from all

that know and remember Ryan and our family. This is our fuel.

And to "Live"... To live, can mean so much. To live doesn't mean just waking up and doing our jobs, having a family, playing with our children, riding a bike or any number of things we do... To live is to live in a way we know we can make a difference with our lives... to "give". Give each day your best attitude, give your best in your job, give your best in riding your bike, and give your best to your children by being present in mind and soul when you are with them.

I came across a quote that I think of often: "You only have what you give. By spending yourself you become rich". Through Ryan's Ride we were able to feel Ryan's gift. His gift was to give to others the joy and memories that they can have with each other and to give hope to those that face life challenges.

Ryan Phua Memorial Kids' Ride  
www.ryansride.org



*Matthew is on the left and Ryan is on the right. (May, 2003)*

## Home Apnea-Bradycardia Monitoring for Siblings of SUDC

By THOMAS G. KEENS, M.D.

*Professor of Pediatrics, Physiology and Biophysics*

*Keck School of Medicine of the University of Southern California • Childrens Hospital Los Angeles*

**H**ow can you best protect your new child from dying, when you do not know what caused your previous child's death? This is a difficult question to answer. Clearly, if we knew the cause of SUDC, we could determine whether it was likely to happen again in your new baby/child, and we could make interventions to prevent your new child from dying. However, since we do not know the cause of SUDC and do not know which children are particularly vulnerable, we don't have specific scientific information that assures us of preventing SUDC in any given child.

However, there are general things that every parent should do to reduce the risks of death or illness in any baby or young child. These include attending well child care visits, obtaining healthcare when clinically indicated, maintaining current vaccinations and the Back to Sleep recommendations to reduce the risk of Sudden Infant Death Syndrome (SIDS) as



Riley Borisenko

below.

- Be sure to get good prenatal care and start it early in pregnancy. Do not smoke cigarettes during pregnancy. Do not drink alcohol or use

any drugs or medications (including street drugs) which are not prescribed by and discussed with your physician.

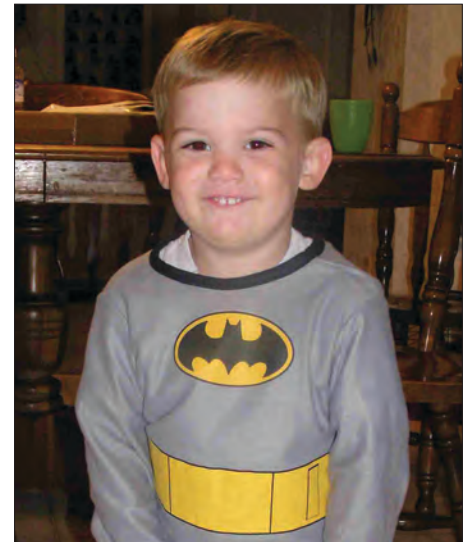
- Once your baby is born, be sure that your baby sleeps flat on his/her back for their first year of life. Although sleeping on the stomach is the highest risk for SIDS, side sleeping also has an increased risk. Do not use propping devices to keep your baby on the side. Sleeping on the back is the safest position. Back sleeping has not been associated with an increased risk of aspiration (inhaled material that was spit up).
- Do not smoke cigarettes around your baby/child. Do not let your baby/child be exposed to any cigarette smoke. Never allow anyone to smoke in the room where your baby/child sleeps.
- Use safe bedding for your baby/child to sleep on. This is a firm mattress without fluffy materials in the crib. Keep all quilts, beanbags, soft mattresses, pillows, stuffed animals, etc. out of the crib. Your baby can play with these when he/she is awake, but they should not be around your baby when he/she is sleeping. Do not cover your baby's head with a blanket. It is best to use a one piece suit for them to sleep in, or place your baby's feet to the foot of the crib and only bring a blanket to the mid-chest level.
- Do not let your baby get too hot. Temperatures that are comfortable for you are best for your baby. Dress your baby like you dress yourself. If it is hot outside, and you are wearing cool clothing, dress your baby in cool clothing as well.
- Breastfeed your baby if possible. Human milk has a number of health benefits for your baby.



Thomas G. Keens, M.D.

These recommendations have been shown to reduce the risk of SIDS in all infants. Therefore, we recommend them for siblings of SUDC children as well.

Many SUDC parents ask about the use of a home apnea-bradycardia monitor to prevent their new child from dying. A home monitor is a device which is connected to your baby by taping two electrodes to your baby's chest. The electrodes monitor



Riley Borisenko (11/18/02–2/20/05)  
[www.rileyborisenko.com](http://www.rileyborisenko.com)

your baby's heartbeat and movement of the chest (breathing). The monitor sounds an alarm if the heart rate goes below a set rate or if the baby's chest does not move for 20-seconds (apnea or period of not breathing). However, these monitors are not perfect. They monitor movement of the chest, not air going in and out of a baby's lungs. A baby can have an obstructive apnea (tongue falling back against the throat

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## We Remember Them

FROM THE JEWISH BOOK OF PRAYER

In the rising of the sun and its going down,  
We Remember Them.

In the blowing of the wind and in the chill of winter  
We Remember Them.

In the opening of the buds and in the rebirth of spring,  
We Remember Them.

In the blueness of the skies and in the warmth of summer,  
We Remember Them.

In the rustling of the leaves and in the beauty of Autumn,  
We Remember Them.

In the beginning of the year and when it ends,  
We Remember Them.

When we are weary and in need of strength,  
We Remember Them.

When we are lost and sick of heart.  
We Remember Them.

When we have joys and special celebrations we yearn to share,  
We Remember Them.

So long as we live, they too shall live, for they are part of us.  
We Remember Them.

# 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 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.

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



Henry F. Krous, M.D.

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

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## The SUDC Awareness Posters

(seen on the following pages) is made possible by the talent and generosity of the Della Femina Rothschild Jeary Ad Agency in NYC and a grant from the Maxwell Best Memorial Fund. To obtain copies of these posters, please contact The SUDC Program.



**“I read him his favorite bedtime story, tucked him in and kissed him goodnight. He never woke up.”**

**-Evelyn Gentile, Mother**



**The Sudden Unexplained Death in Childhood Program.**

**An answer when there's no explanation.**

**For more information call 1800.620.SUDC | [www.SUDC.org](http://www.SUDC.org) | [info@SUDC.org](mailto:info@SUDC.org)**

## How on Earth Can I Memorialize My Child in Heaven?

By CHELSEA HILBERT, LCSW • *Director of Outreach Services*

It was about three days after my son died when someone had the nerve to ask me how I planned to memorialize him. How can anyone ask this of a parent whose toddler has just died? Even my family had moved into high gear with brainstorming ways to make certain that Zach was never forgotten. In the mean time, my mom's group found a memorial path where they could purchase a brick and tree in his honor. Their suggestions were not comforting me. Why couldn't people just let me cry and leave it at that?!

Now, with almost six years gone by, I feel very differently about what these people did for us. I am so grateful that they were able to think about the long-term picture and do something special for us that we could not do for ourselves. Now, we have some very special places and projects to honor Zach's life. Those same people also encouraged me to start a family support project that with the help of Laura Crandall's advocacy skills and research knowledge has become The SUDC Program.

Would I recommend that a family new to grief delve into a huge project? No. Would I discourage it, if a family felt that was their pathway to deal with their grief? No! I think that each family has specific coping skills, support systems and means to dealing with their pain.

So many times, families ask Laura and I what they can do to raise SUDC awareness,

advocate for the cause, raise funds or most importantly honor their child. I would like to offer ideas that have come from the families in the SUDC program and present them as a collective list. Some of the more complex projects are listed on the SUDC website while many are more personal ideas that families have developed to address their own grief.

- Create "A Run for A Reason" in your child's name
- Silent auction to raise funds for SUDC awareness and research
- Website to honor your child's memory
- Teddy bears and quilts made from the child's clothing
- Book drive for a local library with donations made in your child's name
- Dedicate a bench, garden, and/or statue in a community park
- Create a playground for a church or neighborhood
- Memorial fund for grief counseling, burial funds or medical research for SUDC
- Scholarship to a local preschool
- Children's bike ride to raise funds for a national charity
- Group project to paint a mural in a pediatric unit on the day of the child's birthday
- Maintenance of the children's area of a local cemetery
- Memorial notice in local paper on birthday or anniversary date

- Family gathering on birthday or anniversary
- Seed packets sent to family and friends with a letter about the child
- Balloon release on the child's birthday or anniversary
- Letter writing campaign about SUDC to local and state politicians, Pediatricians and Medical Examiners
- Campaign to change a state's diagnostic codes to include SUDC
- \*• Donating toys/gifts at holiday times to Toys for Tots, a Giving tree or local organization that provides to disadvantaged children in the name of your child
- Book for children about SUDC loss and grief
- Candle lighting on child's anniversary, birthday or national day of remembrance in December
- A memory book or video of the child
- Plant a tree, bulbs or flowers in your yard that will bloom around your child's birthday or anniversary
- Poem, story or song written for the child
- Help someone, in the name of your child.

Families may be ready to develop a plan within weeks of a child's death. Others may never actively choose to do so. It is never too late to memorialize your child. The SUDC staff is available to discuss and support your ideas. Even though our children may not be present, their memory always can be.

### CJ Foundation for SIDS 2006 Conference

The CJ Foundation for SIDS National Conference will take place February 23 – 26, 2006 at the Wyndham Franklin Plaza Hotel in Philadelphia. The conference, which is a joint effort amongst the Foundation, its Partners and other organizations, will address Sudden Infant Death Syndrome (SIDS), Sudden Unexplained Death in Childhood (SUDC) and Sudden Unexpected Death in Infancy (SUDI).



While we are still in the planning phase, our goal is for this conference to meet the needs of health care professionals and researchers involved with SIDS, SUDC and SUDI and also

address the needs of bereaved families. You will continue to receive updates as they become available. Please contact Jean Marie Bellotti, Program Coordinator at [jeanmarie@cjsids.com](mailto:jeanmarie@cjsids.com) or 888-825-7437 x4 with any questions. Additional information, as it becomes available, can also be found at [www.cjsids.com](http://www.cjsids.com)

## HOME APNEA-BRADYCARDIA MONITORING FOR SIBLINGS OF SUDC

*continued from page 11*

blocking the airway) in which the baby's chest is still moving. The monitor will think the baby is breathing, and it will not sound an alarm. In addition, there are a number of "false alarms", where the monitor sounds an alarm, but nothing is actually wrong with the baby. The monitor does not do anything to save your baby. The monitor sounds an alarm, and the parent needs to come to the baby, observe to determine if the alarm is real, and then intervene by shaking the baby or performing CPR if necessary.

The truth is that there are no studies which show that home monitors do or do not prevent death in SIDS siblings. Similarly, there are no studies which show that monitors do or do not prevent death in SUDC siblings. However, we do know that some babies have died while using home monitors, and their use did not prevent a SIDS death. Research studies have shown that babies have apneas (periods where the baby stops breathing) earlier than the peak age (2-4 months) when SIDS occurs. Therefore, these apneas do not seem to be related to SIDS. Because these monitors are made for infants, they do not work well for toddlers and older children. They have frequent false alarms, and they do not accurately detect apneas in older children. Therefore, we do not think, based on the current evidence available from published research that home monitors will prevent death in infants or in older children that succumb to SIDS or SUDC.

Understanding that there is no scientific evidence to show that home monitors prevent these deaths, some SIDS and SUDC parents still request home monitors for emotional reassurance. If the use of a monitor will reduce the anxiety of parents so they

can be better parents, then the use of a home monitor may be helpful. If parents do choose to use a home monitor, we recommend that they be used no longer than until 6-months of age. If a baby has not had any serious events in the first 2-months of monitor use, he/she is unlikely to have any serious apneas after that (based on the CHIME research study). So, we would recommend stopping the use of a home monitor at that time. Note that this will be long before the age of a SUDC child.

In summary, the best thing you can do at this time is to obtain optimal pediatric care for your child and follow the Back to Sleep recommendations. These are recommended for all children- and therefore include siblings of SIDS and SUDC. There is no scientific evidence that home apnea-bradycardia monitoring prevents infant or child deaths, and it is therefore not recommended for prevention of SIDS or SUDC. However, some parents may wish to use home monitors for emotional reassurance, in which case they need not be used after 3-6 months of age. Individual insurance plans may or may not cover the cost of home monitors used in this way. For all these reasons, parents considering the use of home apnea monitors for their SUDC sibling should discuss all these issues with their pediatrician who can help them make a choice based on their specific situation and needs.

### REFERENCE FOR CHIME STUDY

DATA: Ramanathan, R., M.J. Corwin M.D., C.E. Hunt, G. Lister, L. Tinsley, T. Baird, J.M. Silvestri, D.H. Crowell, D. Hufford, R.J. Martin, M.R. Neuman, D.E. Weese-Mayer, L.A. Cupples, M. Peucker, M. Willinger, T.G. Keens, and The Collaborative Home Infant Monitoring Evaluation (CHIME) Study Group. Cardiorespiratory events recorded on home monitors: comparison of healthy infants with those at increased risk for SIDS. *Journal of the American Medical Association*, 285: 2199-2207, 2001.

## We Welcome With Love...

Congratulations to the Best/Adamek family: Mitch, Jen, Max (11/17/01-12/19/02), Sam and (Grandparents) Doug and Jackie Adamek announce the birth of their daughter/granddaughter Natalie Rebecca born on September 9, 2005.

Congratulations to the Orosz family: David, Ginny, Jordann (5/5/01-8/31/02), and Ty announce the birth of their daughter/sister Kallie Diane born on August 16th, 2005.

Congratulations to the White family: Neville, Janet, Kris, Matt, Tyler and beautiful Caleb in heaven (3/23/00-2/18/04) announce the birth of their son/brother Jayden Caleb born on January 3, 2005.

Congratulations to the MacDonald family: Patrick, Lunden, Murphy and Angus Dwyer "Gus" (12/6/01-6/1/03) announce the birth of their daughter/sister Beatriz Maeve Ruth on November 17, 2004.

Congratulations to the Mills family: Joe, Jeanie, Julia, Emily and Joseph (6/22/01-12/20/03) announce the birth of their daughter/sister Rachel Nathalie born on November 18, 2004.

Congratulations to the Callahan family: Kathy and Isabella (1/9/02-5/17/03) announce the birth of their daughter/sister Mia Isabella "Mia Bella" born on September 23, 2004.

Congratulations to the Cerrato family: Anthony, Renay, Justin, Alec and Jenna Nicole (6/4/02-8/25/03) announce the birth of their daughter/sister Victoria born on July 31, 2004.

Congratulations to the Caffrey family: Scott, Lorri and Jenna Morgan (8/17/01-1/11/03) announce the birth of their daughter/sister Kelley Hope born on April 15, 2004.




...that their  
light may  
always shine.

Light a candle for all children who have died.  
Second Sunday in December  
7 PM Around the Globe

THE COMPASSIONATE FRIENDS WORLDWIDE CANDLE LIGHTING

## Sudden Unexplained Death in Childhood (SUDC)

is the sudden unexpected death of a child over the age of twelve months, which remains unexplained after a thorough case investigation is conducted. This must include: examination of the death scene, performance of a complete autopsy, and a review of the child and family's medical history. SUDC is a diagnosis of exclusion—given when all known and possible causes of death have been ruled out.



### KAL'S AUCTION FOR AN ANSWER

On July 30th, 2005 The Kalahan K. Emery Memorial Fun hosted the 1st Annual "Kal's Auction For An Answer" to benefit the SUDC Program. The event was held in Concord, NH and was successful both financially and in raising awareness.

Plans are now being made for the 2nd Annual Kal's Auction For An Answer scheduled for autumn 2006.

Please visit [www.kalahansfund.org](http://www.kalahansfund.org) for more information and up to date happenings!

## Lisa's Rainbow Run.



A 5K Run & 2K Family Fitness Walk  
Benefiting the Lisa Marie Rainbow Foundation & Sudden Unexplained Death in Childhood Program

Saturday, November 5, 2005 Albuquerque Balloon Fiesta Park

## The Grief of Siblings

By ALISSA K. SANDLER, MSW, LCSW • *Social Work Supervisor*

*Pediatric Ambulatory Services and SIDS Center of New Jersey  
Joseph M. Sanzari Children's Hospital • Hackensack University Medical Center*

The sibling relationship is unique. The death of a sibling therefore, presents a unique experience that has been left virtually unexplored in the literature. While parents are grieving the death of their child they may not be available to attend to the grief of their living children. This can lead to a feeling of isolation, leaving a brother or sister to work through their grief alone.

More recently, parents of grieving siblings and grief counselors have begun to address this issue. The impact is immense. The legacy that a grieving sibling carries forward is immeasurable. If allowed to be explored, it may provide insight for future generations about family grieving. The living sibling also plays a role in educating society about the conditions that a brother or sister succumbed to.

Most of the information that is available regarding sibling bereavement is antidotal. Parental attitude determines how a deceased sibling is incorporated into the family. As parents and families have been allowed to openly grieve so to have siblings.

It is important to recognize that children grieve. The way they grieve is determined by their age. However, children, even infants and toddlers experience sadness especially if their caretaker is sad, distant or distraught. Therefore acknowledging siblings' feelings is vital. Allowing them to express an array of emotions will help them cope during a very stressful time. It is difficult to accept the expression of feelings such as crying, stubbornness, playfulness, and periods of withdrawal. However, like adults, it is unavoidable. Encouraging siblings to talk about their brother or sister, draw pictures, write poetry, attend memorial services is helpful. This process helps a child work through their grief and decreases isolation. Siblings want to be part of the grieving family.

Allowing children to talk and ask questions can be painful for adults. However, children learn and obtain

control through this process. When children ask about what happened to a brother or sister:

- Let the child direct the questions
- Keep it simple
- Explore and remove any issues of blame
- Listen
- Be honest

Help children honor their sibling:

- Create a memory book
- Plant a tree
- Light a candle

- Release a balloon
- Write a poem
- Draw a picture
- Acknowledge anniversaries of the siblings birth and death

The bereavement community is beginning to see the results of a decade of "open grieving" related to infant and child death. Sisters and brothers, including the subsequent sibling, seem to be well adjusted and consequently comfortable with issues of death and dying. They are loving and compassionate people. Parents and their children can grieve together and receive comfort and support from one another. A sibling allowed to integrate a deceased brother or sister into their lives seems to feel more complete. After all, the sibling relationship is unique and needs to be nurtured in life and death.



**The WindMill-NJM 3 Mile Breakfast Run held on April 16th in Longbranch, NJ once again raised over \$10,000 dollars for The SUDC Program! Supported by the NJ Lenders Corporation, it was a glorious fun-filled family day on the waterfront. Thank you to all those who participated and helped make the day such a success!**



## Quilting *Precious Moments*

By JANET CORUEIL • *Grandmother of Jenna Morgan Caffrey (8/17/01 – 1/11/03)*



As a quilter for many years, I've enjoyed visiting the Annual Quilters Heritage Celebration show in Lancaster, Pa. Quilters from all over the country come to this show and never would I have imagined that I would see my own handwork on display. This year, 2005, the theme was "quilts for a cause". Immediately I thought of Jenna, my granddaughter who passed away two years ago on January 11, 2003 and the photo quilt I made in her memory. Making this quilt was a comforting and almost peaceful experience for me. Every stitch was made with love. I named her quilt "Precious Moments" because all of

the photos depicted precious moments in the life of such a sweet angel. With tears and pride, her quilt hung bravely between all of the other quilts. Everyone seemed to gravitate toward Jenna's quilt because they wanted to know who this beautiful little girl was and what her quilt represented. I stood back and silently watched the viewers, waiting for reactions. As they read her story and the information about SUDC, some looked puzzled and some shook their heads in disbelief. Everyone, however, left with a raised awareness about SUDC and The SUDC Program.

## Planning Our Child's Run for a Reason

By TAMI GOVE • *Mother of Joshua Gove (10/31/01 – 2/16/03)*

Deciding to plan and implement Josh and Gus's Run For a Reason in 2004 was an important part of my grief journey. Our planning process began in July of 2004—almost a year and a half after losing our 15-month-old son Josh to SUDC in February of 2003. The horrible helplessness and hopelessness of early grief had given way to an energy fueled by anger and a desire to keep Josh's memory alive. I was looking for something that would allow me to channel my drive.

After a dinner with Jen and Mitch Best in the summer of 2004 (the founder's of Max's Run For A Reason), the venue for this energy became clear. We decided to bring their Run For a Reason concept to Denver

and take it to a national level. Shortly afterward, we decided to pair with Lunden and Patrick MacDonald, another Denver SUDC family who lost their 18-month-old son Gus in June of 2003. Together, we created Josh and Gus's Run For a Reason. The event was a fantastic success with almost \$60,000 raised and over 1000 participants. Josh and Gus's Run For a Reason gave purpose to my life, allowed me to spread Josh and Gus's legacy and educate the public on SUDC. The day itself was a whirlwind for me but what I remember most is being overwhelmed and awestruck by the fact that everyone at the event was there to honor and remember our two little boys, Josh and Gus.



Joshua Michael Gove  
(10/31/01 – 2/16/03)  
SUDC

### WHY IS A POST MORTEM EXAMINATION IMPORTANT WHEN A CHILD DIES SUDDENLY

*continued from page 13*

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 can not 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 post-mortem 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.

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 post-mortem examination. This information is vital to families planning future pregnancies and better protects surviving family members.

It should be noted that a post-mortem 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.



## Tragically, last year hundreds of children didn't wake.

It's a parent's worst nightmare. And what's worse, no one can give them a reason why it happened. Not the hospital. Not the doctors. Not the coroner. It's called Sudden Unexplained Death in Childhood. It happens in children over the age of 12 months. Fortunately, for these parents there is a resource called the SUDC Program. Where parents find solace and comfort in simply knowing they are not alone in their struggle. And where there are professionals who are dedicating their lives to looking for answers as to why these things happen.

**The SUDC Program. An answer when there's no explanation.**



A Program of the CJ Foundation for SIDS

For more info call 1.800.620.SUDC | [www.SUDC.org](http://www.SUDC.org) | [info@SUDC.org](mailto:info@SUDC.org)

## LOVE MESSAGES

TO: Our dear sweet Sugar Magnolia  
(10/18/02-9/23/04)

MESSAGE: Our first year without you has been so sad. We miss your squishy face and your goofy smiles. We miss your hugs and kisses and the way you made everything happy for us. We know you are happy and can enjoy the love of your Grandma and Great Papa Ted who you never got to know in this life. We can feel you around us always. Your joy and complete love for life inspires us and we can only hope that we can make you proud.

LOVE: Mommy, Daddy, "Emawee" and "Cowim"



TO: Lisa Marie Sandoval  
(6/28/94-11/4/99)

MESSAGE: Our "sweetie" angel, today like everyday, we remember your radiant smile, contagious giggle, and mischievous ways. We remember your loving heart, kind words and enormous faith. We remember your overflowing joy for life. We will always remember you!

LOVE: Mommy, Dada, Eric and Jacob



TO: Stephanie "Bubba" Bieniek  
(3/16/97-5/2/04)

MESSAGE: You are the light of our lives. We miss you and we will forever love you!

LOVE: Daddy, Mommy, Aaron and Tyler



TO: Jenna Morgan  
(8/17/01-1/11/03)

MESSAGE: My precious little girl, what we wouldn't give to hold you in our arms. Not a day goes by that we don't think of you and miss you. You are an angel among angels. We love you with all our hearts.

LOVE: Daddy, Mommy and baby sister Kelley



TO: Micaela  
(10/30/98-2/27/03)

MESSAGE: We cherish all of our happy memories of the time we shared. We love you and miss you.

LOVE: Mom, Dad, Josh and Ben

TO: James  
(3/14/03-4/25/04)

MESSAGE: A whole year has passed and you are still first in our hearts and thoughts. We love and miss you little bubba-boo.

LOVE: Mommy and Sis-sis



TO: Alex Baker  
(10/7/00-7/15/02)

MESSAGE: We hope you join us for the walk and know that we miss you very much! Happy 5th Birthday!

LOVE: Mom, Dad and Tiffany



TO: Jessica Ashley Bixon  
(10/9/98-7/18/04)

MESSAGE: Everywhere I am there you'll be, I'll keep a part of you with me. Not a day goes by that you are not missed. Forever in our hearts, always by our side...We love you so much...

LOVE: Mom, Dad and Jason



TO: Matthew Shawn Ryan  
(5/22/02-1/31/04)

MESSAGE: To our little "sweet cheeks", we miss you so much! We love you!

LOVE: Mommy, Daddy and Alex



TO: Caleb Joshua White  
(3/23/00-2/18/04)

MESSAGE: We love and miss you just as much today as the day you were taken away. We will always love you to bits, Beautiful.

FROM: Daddy, Mummy, Kris, Matt, Tyler and your new brother Jayden Caleb.



TO: Isabella  
(1/9/02-5/17/03)

MESSAGE: Bella, there still is not a day that goes by that I don't think about you. I miss you more than words can say. Mia looks a lot like you and knows her big sissy. I'll never forget the time we spent together. It was the best days of my life.

LOVE: Mommy

TO: Jenna Nicole  
(6/4/02-8/25/03)

MESSAGE: As each day comes you are the first thing we think of. We miss you and love you dearly.

LOVE: Mommy, Daddy, Justin and Alec



TO: Daniel Greenbaum  
(7/11/00-1/13/02)

MESSAGE: You are always in our hearts, never far from our thoughts. We love you as much as ever and miss you more than words can say.

LOVE: Mommy, Daddy, Alexandra and Andrew



TO: Preston Jack Drummond  
(8/4/03-5/23/05)

MESSAGE: Our sweet baby boy. We love you and miss you so much. I hope you are getting all the kisses big brother sends up to you. We love you so much, our sweet angel.

LOVE: Mommy, Daddy, Big Brother Dakota and little sister Alivia.



TO: Madeline Chambers  
(7/22/01-11/27/02)

MESSAGE: Precious Maddie, words cannot express how much we miss your beautiful face, your precocious personality and your sweet voice. We love you and carry you in our hearts. Until we meet again.

LOVE: Mama, Da-da and baby Owen



TO: Eric Wyatt Marin  
(11/16/00-10/13/01)

MESSAGE: Missing you, our baby. Your memory remains always; and blessedly, it is steeped in a family that finds joy everyday.

LOVE: Your Mommy and Daddy



TO: Angus Dwyer MacDonald "Gus"  
(12/6/01-6/1/03)

MESSAGE: Our sweet Baby Gus, we watch you every night as you play on the moon. Murphy and Maeve know all about their big brother! We keep working hard to make you proud of us. We love you and miss you!

LOVE: Mommy, Daddy, Murphy and Maeve

**A PEER CONTACT INTERVIEW**

*continued from page 8*

herself to me. When my friend's nephew recently died, I felt like I had something to offer his parents, even though my loss was so recent. His mom said to me "I guess I have joined your club" and I knew that I could give them some comfort. Giving comfort somehow gives me comfort. I am sure that must be what it is like for Lunden.

**Lunden:** I guess we do this because we know that in the big picture, we are helping someone else. Nobody has a perfect life, perfect husband or perfect family, but Pat and I have managed to find some semblance of happiness. I know that you never let the pain of the death of your child go. It is always there to some degree, but you can find a new normal. I can give others hope through my experience

**Would you recommend the program?**

**Rebecca:** Yes, I think the program is vital for someone who has lost a child. Even though Lunden and I have our differences, we both are mothers. We both have been devastated.

The hardest thing for me is not feeling like I am intruding on her life. There are times when I know I should call someone but I feel like I have no one to call. I know that Lunden would tell me to pick up the phone and call anytime. I don't call and not because I feel intimidated, but because I know how busy she is. As a single mom, I have lots of time and any phone call I get, I appreciate. For Lunden, she is busy with two small kids, her husband, her jobs and I don't want to invade her family time.

"Not necessarily because it is so hard, emotionally. You get to a point where you can get through the day

without bawling your eyes out and then you talk to someone who has just had their child die. It brings you right back to the raw pain. Peer contact is not for everyone.

Before becoming a peer contact, you need to be secure in your own grief. You can't jump in and then say, oops, sorry, I can't help you. This is just too hard for me. You have to know yourself well enough to know whether or not you can handle it. You need to know whether you can give to someone in their time of pain and be able to manage your own grief.. The work of grief is constant and will always be there. It can take over your life if you allow it.

Then, I think about the first time I met Rebecca and realize the hope that I gave her with my "normal looking life". I remember that thought: will I ever look or feel normal again? It's nice to be able to see hope in someone's eyes.

PLEASE DETACH AND ENCLOSE ALONG WITH YOUR DONATION

**YOUR CONTRIBUTION MAKES A DIFFERENCE**

Enclosed is my tax deductible gift of \$ \_\_\_\_\_ to The SUDC Program of the CJ Foundation for SIDS.

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\*Secure online donations can also be made through [www.sudc.org](http://www.sudc.org)



# SUDC PROGRAM

*sudden unexplained death in childhood*

# NEWSLETTER

2008

A PROGRAM OF THE CJ FOUNDATION FOR SIDS

THE SUDC PROGRAM: AN ANSWER WHEN THERE'S NO EXPLANATION

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## Dear Reader:

Welcome to the fourth annual newsletter of the SUDC program! With each newsletter we seem to have more to write about and this year is no different. We hope you find the information provided to be useful.

**Research:** The SUDC Research Project continues with more participants and several recent publications which are outlined in this newsletter.

**Support:** With an increase in support services, awareness and research, we continue to be ever grateful for the commitment the CJ Foundation for SIDS has made to the SUDC cause. And thank you to all the researchers who tirelessly continue their efforts to learning more about SUDC so we can prevent this from happening to others. And finally, thank you to our SUDC families who continue to support the program in countless ways.

**Advocacy and Information:** We have continued our presence at medical conferences to get the word out that we are here to help families who suffer the tragic unexplained loss of their child. According to the CDC, SUDC type deaths occur about 200 times annually to children between the ages of 1 and 4 years of age, with a lower incidence in older children. Typically, we receive about 35 to 40 referrals of new families each year. So, where are the rest of these bereaved families? We imagine most are grieving alone, thinking they are the only ones who have experienced such an unexplained loss. They are wrong, and we are here to help. Please contact us if you know of a family whom we could help.

Sincerely,  
Laura Crandall  
Program Director  
SUDC Parent