

Holiday 2011

A Newsletter from the Massachusetts Center for Sudden Infant Death Syndrome/
The Massachusetts Center for Infant and Child Death Bereavement Program

Promises

SIDS & Other Sleep-Related Infant Deaths: Creating a Safe Environment for Infant Sleep

From Pediatrics Online, 10/17/11

The American Academy of Pediatrics (AAP) has released two new resources to help pediatricians, health professionals, parents and others reduce the risk of sudden infant death syndrome (SIDS) and sleep-related suffocation, asphyxia and entrapment among infants in the general population.

The American Academy of Pediatrics (AAP) recently published a new policy statement and technical report expanding the recommendations on how to create a safe environment for infant sleep. The report is titled *SIDS and Other Sleep-Related Infant Deaths: Expansion of Recommendations for a Safe Infant Sleep Environment*.

There has been a major decrease in the incidence of SIDS since the AAP recommended in 1992 that caregivers put infants to sleep on their backs. This decline has leveled off in recent years, while

other causes of sudden unexpected infant death that occur during sleep have increased, particularly since 2005. Other causes of death that occur during sleep include suffocation, asphyxia and entrapment and ill-defined causes of death. The AAP is expanding its recommendations from focusing on SIDS to focusing on a safe sleep environment that can reduce the risk of all sleep-related infant deaths, including SIDS.

The first set of recommendations (Level A) are based on good and consistent scientific evidence. These recommendations come from consistent findings from at least two well-designed, well-conducted case-control studies, a systematic review or a meta-analysis. Experts are highly certain that the net benefits of these recommendations are substantial and that future studies will probably not change these conclusions.

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New Recommendations on a Safe Sleep Environment

Level A Recommendations

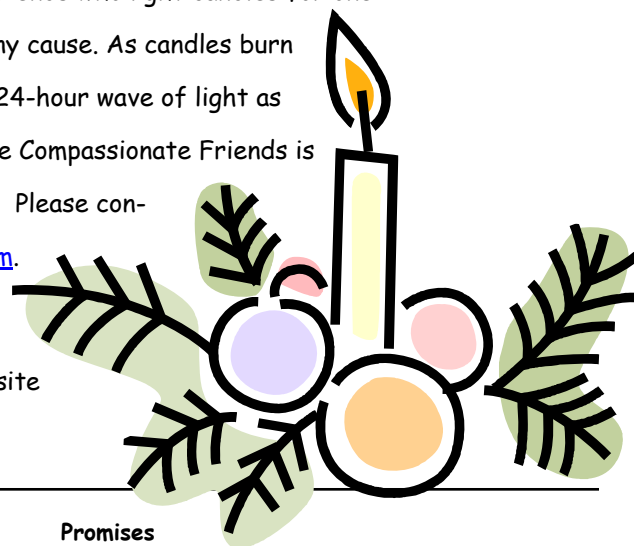
(based on scientific evidence.)

1. **Back to sleep** for every sleep.
2. **Use a firm sleep surface.** A firm crib mattress covered by a tight fitting sheet is the recommended sleeping surface.
3. **Room-sharing without bed-sharing** is recommended. Baby's crib should in parents' bedroom close to parents' bed.
4. **Keep soft objects and loose bedding out of the crib.** This includes pillows, quilts, comforters, sheepskins, stuffed toys, bumper pads and other soft objects.
5. **Pregnant women should receive regular prenatal care.**
6. **Avoid smoke exposure** during pregnancy and after birth
7. **Avoid alcohol and illicit drug use** during pregnancy and after birth
8. **Breastfeed your baby.**
9. **Consider offering a pacifier** at nap time and bedtime.
10. **Avoid overheating** your baby.
11. **Do not use home cardio-respiratory monitors** as a strategy for reducing the risk of SIDS.
12. **Expand the national campaign to reduce the risks of SIDS** to include a major focus on the safe sleep environment and ways to reduce the risks of all sleep-related infant deaths, including SIDS, suffocation and other accidental deaths; pediatricians, family physicians and other primary care providers should actively participate in this campaign.

Join a Worldwide Candle Lighting Ceremony, Sun. Dec. 11

The 15th Compassionate Friends Worldwide Candle Lighting December 11, 2011. Held annually the second Sunday in December the worldwide Candle Lighting unites family and friends who light candles for one hour to honor and remember children who have died at any age from any cause. As candles burn down in one time zone, they are then lit in the next, creating a virtual 24-hour wave of light as the observance continues around the world. The Boston Chapter of the Compassionate Friends is holding its first Candle Lighting service event at Forest Hill Cemetery. Please contact Linda Strother at the compassionatefriendsofboston@hotmail.com.

For more information, about the national event, go to the national website at www.compassionatefriends.org.



Level B Recommendations

are based on limited or inconsistent scientific evidence. The available evidence is sufficient to determine the effects of the recommendations on health outcomes, but confidence in the estimate is constrained by such factors as the number, size or quality of individual studies or inconsistent findings across individual studies. As more information becomes available, the magnitude or directions of the observed effect could change and this change may be large enough to alter the conclusion.

1. **Infants should be immunized** in accordance with recommendations of the AAP and Centers for Disease Control and Prevention.
2. **Do not use bumper pads in cribs.** There is no evidence that bumper pads prevent injuries, and there is a potential risk of suffocation, strangulation or entrapment.
3. **Avoid commercial devices marketed to reduce the risk of SIDS.**
4. **Supervise awake tummy time** to facilitate development and to minimize development of positional plagiocephaly.

Level C recommendations

are based primarily on consensus and expert opinion.

1. **Health care professionals, staff in newborn nurseries and NICU's and child care providers should endorse the SIDS risk-reduction recommendations from birth.**
 2. **Media and manufacturers should follow safe-sleep guidelines in their messaging and advertising.**
 3. **Continue research and surveillance on the risk factors, causes and patho-physiological mechanisms of SIDS** and other sleep-related deaths with the ultimate goal of eliminating these deaths entirely.
- Pediatrics* Volume 128, Number 5, November 2011. Go to www.aap.org for additional information.

The U.S. Food and Drug Administration issued a statement regarding baby products with SIDS prevention claims on October 31, 2011. Some baby products are being marketed over the counter with claims to cure, treat or prevent a disease or condition. Because of these claims, these baby products are considered medical devices, subject to FDA regulation. A common medical claim being made is the prevention of sudden infant death syndrome (SIDS). The FDA states it has never cleared or approved a baby product to prevent or reduce the risk of SIDS and is not aware of any scientific studies showing that a medical device prevents or reduces the risk of SIDS. Examples of over the counter baby products with unproven claims to prevent or reduce the risk of SIDS include: baby monitors, mattresses, crib tents, pillows, crib bedding (bumpers and blankets), infant positioners. The best way to reduce the risk of SIDS is to follow the recommendations of the American Academy of Pediatrics to create a safe sleep environment for a baby.

Thank you

Donations to the Mass. Center for SIDS and the SIDS Outreach Foundation, Inc.



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In memory of

Elaine Assaf by Norma Browinski
Eric W. Barry by his mother Annette
Barry
Suzanne Begley by Mary Ellen
McCarthy
Karl Edward Bombaugh by Keith &
Maryanne Bombaugh
Geoffrey Buzzell by Anne & Greg
Buzzell
Jeff Caron by Brian and Patty O'Dell
James "Larry" Cavanaugh by Brian and
Cynthia Burns
John O'Connell
Jeffrey Granski & Susan Crowell

Knights of Columbus Holyoke #90
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 Tom and Cathy Philpott
 Jeanie Elizabeth Couture by her
 parents Karen and Richard Couture,
 and by her grandparents John &
 Jean Cunniffe on what would have
 been her 16th Christmas Day
 Caleb Croto by Ann M. Albert
 Brigitte & John Crocker
 Stephen & Martha Donohue
 Michael & Patricia Doyle
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 Gerard & Donna Hevern
 Paul & Jacqueline Kramer
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John & Maureen Skorupski
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 McLaughlin
 John Michna, Jr. by parents Jack &
 Judy Michna on his 38th birthday
 Ryan Sulloway O'Connell by Jeanne
 O'Connell
 Katelyn Patricia O'Dell by Brian and
 Patricia O'Dell
 Michael Owen O'Loughlin by William
 Maley
 William and Jean Griffin
 Ryan David Parsons by Kenneth &
 Robin Parsons
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 Patricia Locarni
 Jenna Ann Rumsey by Traci Lepore
 David Jacques Sasson by Doris Sas-
 son
 John Michael Sikora by The Sikora
 Family
 Raymond St. Onge by Leo & Pat
 Turner
 Victoire, Frances & Arnold Schutz-
 berg by Daniel & Frederique
 Schutzberg
 Amy Lynn Suprenant by Rosies Café/
 Rosmarie Surprenant
 Devin Jeffrey Thiffault by Judith
 and Henry Thiffault Jr.
 Mikey Whelan by Judith Allard
 Brian Patrick Wyse with Love from
 Mommy and Daddy on the occasion
 of his 12th birthday



A Poem for Victoire

By Rose Schutzberg, her big sister



"Dear Victoire,

If I were writing this poem to you, and you had not died I would sign it

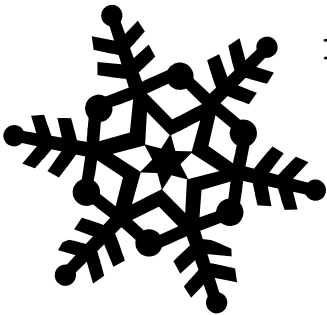
- With love, Rose

If I were writing this poem to you, before you were born, I would sign it

- Your new big sister, Rose

If I were writing this poem to you and you were sitting right next to me, I would sign it

- xoxo, Rose



If I were writing this poem to you the day of your death I would sign it

- Grieving for you, Rose

If I were writing this poem tomorrow I would sign it

- Looking into the past, Rose

But as I write this poem to you, I think of how to sign it and I remember what your birth,

life, and death have done to me and I sign it

- A stronger human being, Rose

Life Changes

By Mary McClain, RN, MS

How does the sudden and unexpected death of a child change a parent, a family? We speak of the enduring nature of grief- the pain, the dull heartache at times, a deep and in-

tense longing for the baby at other times, sadness which seems to never end.

Parents ask, can you tell me when this pain will stop? Will I ever feel better; will I ever be the same, will I

always be angry; will I go crazy? We always hold out hope things will be better; that the pain will become tolerable. You will be able to live with it, we say, understanding its intensity comes and goes. How does one learn to live without a child's physical pres-

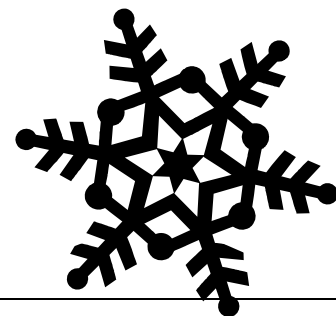
ence; to believe in oneself and the ability to survive, to grieve in one's own way without judgment, to speak of the regrets, the guilt, the insensitivity of others. How does one deal with the surviving children and the ones born after?

The death of a child forever

changes the family, how they view themselves, their families, the world, the everyday things, and even the meaning of life. For some the care and concern for others who suffer in similar ways becomes a new mission.

For those of you who are newly grieved, know that most people do

survive the death of their children. They find a way to live with the drastic change that death brings.



Time to Heal

By Kathy Whelan for Mikey's Eighth Birthday

People said only time will heal this gaping wound.
I wonder how much time.

You lived ten weeks. Such a short time,
But you changed my life more than anyone
before or since.

When you first died, every minute
seemed like a year without you.
I was surprised the sun rose the next day,
surprised I took one more breath.

I watched the hours pass and counted the days.

One day since you died.

One week since you died.

One month since you died.

One year since you died.

Tears flush the wound, their waters life-giving.

Eight years since you died.

Plenty of time to heal.
Slowly I build a life without you.
Even as my arms ache for your warm body,
as I long for the small of your clean skin,
I begin to hope and smile again.

People were right.
Time does heal the wound,
but no one told me about the scar.

A scar that, even with the passing of time,
tears open now and then.
It opens at a glance of a sensationalized headline:
"Suspicious Surface in Cases Termed Sudden Infant Death"
Sobbing shakes my shoulders;
tears salt my coffee.

Really, I cry for Mikey:
I cry for what is lost,
for a little boy who in my head,
grows with my family.

I cry remembering a gray body laid out like a cross
I cry and my face drags itself down,
Quivering into its familiar frown.

2012 Bereaved Parent Meeting Notice

The Massachusetts SIDS Center recommends the following support group meetings for parents, grandparents and care providers whose infants and young children have died of sudden infant death syndrome, medical illness, conditions of prematurity, stillbirth and accidental injury. Topics discussed include dealing with grief, information about cause of death, changing relationships with family and friends, helping parents help children to comprehend the death of a sibling, and feelings about subsequent children. Please RSVP to (617) 414-7437 or (800) 641-7437.

If weather conditions are bad, please call the SIDS Center at 800-641-7437 before 4:30 PM on the day of the meeting.

Boston Area Meeting

Meetings held on the first Tuesday of the month at 7:30 pm at Children's Hospital, 300 Longwood Avenue, Boston. In Fegan 7 Conference Room. Facilitator: Mary McClain, RN, MS.

January 3, February 7, March 6, April 3, May 1, June 5, July 3, August 7, September 4, October 2, November 6, December 4, 2012

Western Mass. Area Meeting

Meetings held on the first Monday of the month at 7:30 p.m. (except September) at Shriner's Hospital, Volunteer Conference Room, 516 Carew Street, Springfield, MA. Facilitator: Marcia Kelly, RN, MA, 413-210-2117.

January 2, February 6, March 5, April 2, May 7, June 4, July 2, August 6, October 1, November 5, December 3, 2012

Plymouth Area

Several grief programs and trainings are held during the year at Cranberry Hospice, 36 Cordage Park Circle, Suite 326, Plymouth, MA 02360. Please call Kathleen McAleer, LICSW at 508-746-0215 for additional information.

For more information about support groups go to

<http://www.bmc.org/pediatrics-MA-SIDS/services/bereavedparent-supportgroup.htm>

Massachusetts SIDS Center/ Infant & Child Death Bereavement Program Program Report, Jan. 1- Dec. 31, 2010

The SIDS Center received 111 infant and child death referrals in 2010.
 Causes of death included:

Fetal demise.....	19
Conditions of pre-maturity	11
Medical illness	4
Sudden unexpected infant death	69

The 69 sudden unexpected deaths included:

SIDS, SID, SUID, SUDC.....	13	Sudden cardiac arrest	2
Congenital syndrome	1	Medical illness	8
Asphyxia/suffocation	2	Undetermined	8
Injury (fall, drowning, other).....	8	Pending	2
Sudden unexpected infant death	25		

(in setting of unsafe sleep position or environment)

Age at death:

Fetal	19	6-12 months	9
Under 1 month	23	13-24 months	7
1-4 months	38	25-36 months	4
4-6 months	7	over 36 months	2

Gender:

Male	63
Female	46
Hospital	38
# of twins:	6

Site where found:

Residence	70
Day care	3

Bereavement services:

Hotline calls.....	399	Telephone calls	154
Home visits	54	Grief packets	111
Parent support groups	24/77 participants		
Parent to parent contacts	8		

Education and Outreach:

Educational programs were provided to 790 participants: hospital nurses, medical students, bereavement specialists, Head Start staff, first responders and police investigators. Center staff attended 30 child fatality and fetal and infant mortality meetings.

Literature Distribution:

A total of 5,530 grief and educational materials were distributed and included: bereavement packets (111), emergency department manuals (65), risk reduction/grief literature (2,154), newsletters (3,200).

Fundraising

SIDS Race for Life

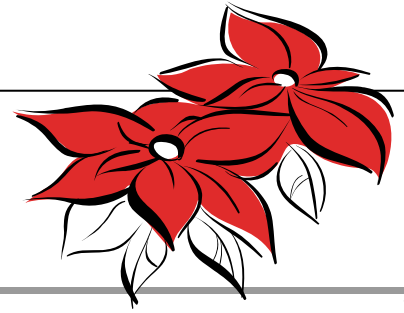
The 21st Annual Five Mile Road Race and 3.5 Mile Fun Walk in Loving Memory of Barry Metayer, Jr. was held on



Republican File Photo by Michael S. Gordon
From http://www.masslive.com/sports/index.ssf/2010/09/sids_race_for_life_finds_perma.html

Sunday, October 2, 2011 in Springfield, MA. Sponsored by Congressman Richard E. Neal, this year's event raised \$25,000 for the Massachusetts Center for SIDS. We extend

our heartfelt thanks to Congressman Neal, his staff and all of the volunteers and participants for giving their time and talents to ensure the outstanding success of this event. Over the years, this event has raised \$335,000.00 for the Center. We are most grateful.



New Arrivals

Scarlett Magnolia Stout

on March 11, 2011 to Ben and Deanna Stout

Angelina Falco

on November 3, 2011 to Chris Falco & Lorinda Champagne Falco

Madison Mancini

on November 3, 2011 to Amy and Kevin Mancini

Coco's Cookbook

Ben and Deanna Stout have put together a cookbook in honor of their daughter, Caroline Campbell Stout.

All profits from this cookbook will be donated to the Massachusetts Center for Sudden Infant Death Syndrome & the Sudden Infant Death Syndrome Outreach Foundation Inc.

According to the Stouts, "The Massachusetts Center for Sudden Infant Death Syndrome (SIDS) is

near and dear to our hearts as it was this organization that contacted us and arranged for counseling services immediately after Caroline passed away. It was these services that were critical to our healing. This cookbook has been made not only to remember our dear Caroline but also to provide support to these organizations and to other families who are forced to endure the loss of a child.



For more information about the cookbook or to purchase a copy, go to www.cocoscookbook.com

Why we tell our stories...

By Kathy Whelan

"I had another child, my first, who died at 10 weeks to SIDS."

There comes a point in a new friendship where I feel like I must share this fact. Its utterance is usually painful for me and awkward, even shocking, for the person on the receiving end. Is there any way I can stop myself from sharing this fact? What does it bring but pain?

Many of my closest friends did not know me when Mikey died. We moved across the country and then across the state. For years we focused on raising three subsequent children: two of Mikey's siblings are grown and off to college, and his little brother is about to start driving.

Would be easier if I could keep my grief to myself? Maybe, but I've told his story many times in many different situations. If my life is a tapestry, then his is the brightest, thickest thread. Michael's death is so much a part of me that I wish I could have it branded on my head, "I survived my baby's death." Although you may not see my pain, it is there, ever-present, just under the surface.

When Mikey first died, I told everyone my story. I remember someone approaching me in the mall not a year after Mikey died. I was seven months pregnant, and the woman wanted to give me some advice: there is something about a pregnant belly that makes people want to impart wisdom. When she started talking, I stopped her, a stranger, mid-sentence to tell her that my baby died. I still feel bad for that poor woman!

I am happy to say that I no longer tell strangers my story. I've been lucky enough to find family and friends who will listen to my stories when I need to share them. These are people who remember Mikey's birthday. They are the ones who offer a hug when I get leaky-eyed, understanding that I will continue to grieve throughout my life, and that sharing my story is a healthy way to grieve.

Now when I tell the story of my son's life and death, I'm a bit more particular about who I tell. You must be someone I trust, someone who will care about me and my family. I've told this story enough times to know that if I find caring people, telling the story will help unburden some of

the grief I still carry. I preface the story with gentle words, so the person can be prepared for my inevitable tears.

However, every once in a while, the story surfaces, unplanned. This fall, just a day before what would have been Mikey's 22nd birthday, I was sitting in a college classroom with fellow students who are working to become secondary school English teachers. It was an introductory session: we were to talk about our background, and so I offered that I had written a book. When trying to describe Grief Songs, the book that chronicles the recovery of a community after a sudden infant death, I ended up telling the whole class my story, teary-eyed. I was shocked that I shared this information, and was a little embarrassed by my tears. Why did I share it? Because Mikey's story is part of my life, and if you are to know me, then you must know my son.

We tell you our stories to remember our babies and to unburden our grief.

Thank you for listening.

Activism—A father's perspective

By Steve Whelan

As a parent of a baby who died to SIDS, I know how hard it is to be active, vocal, and visible on behalf of Sudden Infant Death Syndrome programs.

Because I lost my first son, the time that we have with our subsequent children is much more important—the thought that they too could be taken at any time is very real to

Kathy and me.

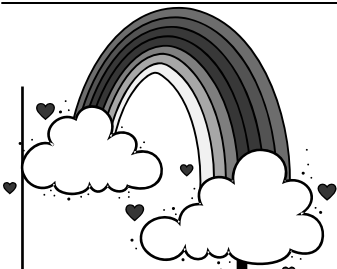
How do we find the time and the mental energy to promote more actively with in the public realm. How do we find the courage to stand up for our children with government officials? I truly understand how many, many parents, grandparents, and relatives cannot become active. It is too painful, or the time with other children is too precious.

However because our children can-

not advocate for themselves, it is important that we do spend some time letting our legislators know that we care about SIDS research and support services.

For more information about helping with legislative advocacy, see the link on our website, www.bmc.org/pediatrics/special/SIDS

The SIDS Outreach Foundation is a member of
Community Health Charities of New England Federation.



Promises

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Web site: www.bmc.org/pediatrics/special/SIDS

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