December, 2007

Promises

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

Surviving the Holidays

My son died on New Year's Eve. I never thought I'd be able to celebrate another holiday, but somehow I've watched 17 holiday seasons come and go without him.

Holidays are never easy for families that have lost a child. For a grieving family, the holidays intensify the sadness and pain surrounding the loss. Celebrating feels disrespectful. For my family, the combination of the holidays and the anniversary of Mikey's death makes this time of year particularly challenging.

Memories of past holidays contrast dramatically with how you feel now. After your baby dies, the holidays are different just as life is different. In getting through the intensified grief of the holidays, you find yourself making new traditions. I never call my parents on New Year's Eve anymore. The holidays are less about parties and more about quiet time with my immediate family. My warmest holiday memories after Mikey involve sitting with my children in front of a fire, reading Christmas stories. We stopped longstanding holiday traditions, as they just seemed to intensify our grief.

Anticipating the holiday is sometimes as painful as the holiday itself. Was I ever going to be able to celebrate New Year's again? Should I put the ornaments that celebrated Mikey's new life on the tree? Each year, my husband and I talk about how we will celebrate. This can be challenging, as everyone grieves differently. It is important to be respectful of each other's needs. What you need to give yourself is time—which is often in short supply at this time of year. Be gentle with yourself and surround yourself with supportive, accepting people.

After Mikey died, we made new traditions. New Year's Eve with Mikey was at home, so the next year, we went out with close friends. Some years I joined in celebrations, others I could not. This year, I will carefully put the Mikey ornaments in a place of honor on the tree. I will light a candle at midnight mass, and embrace the memory of a little boy who holds a special place in my heart

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Medical news

The following articles highlight recently published reports on research being conducted on stillbirth, fetal demise, sudden unexpected death in children and sudden infant death syndrome.

Sudden Death in Toddlers Associated with Developmental Abnormalities of the Hippocampus. A Report of 5 Cases

Hannah C. Kinney, Dawna L. Amstrong, Amy E. Chadwick, Laura A. Crandall, Chelsea Hilbert, Richard A. Belliveau, William J Kupsky, and Henry F. Krous

Hannah Kinney, a neuropathologist at Children's Hospital and a long-time SIDS researcher, has recently published a report on a number of cases of sudden, unexplained death in childhood (SUDC). SUDC is the sudden death of a child older than one year of age that remains unexplained after thorough investigation. Although it occurs throughout childhood, most SUDC victims are toddlers between 1 and 4 years of age. SUDC differs from SIDS only by the age criteria.

While doing research on 50 cases of sudden unexplained childhood death, Dr. Kinney discovered five cases that showed essentially identical abnormalities characterized by asymmetry in a part of the brain called the hippocampus. During this study, the birth, medical office, hospital, scene investigator records, and autopsy reports including toxicology, vitreous electrolyte, microbiology, radiographic, and metabolic screening studies were reviewed. In addition, the parents completed a detailed questionnaire concerning the child's medical, neurodevelopmental, environmental, and family history. The age of death of the five cases ranged from 13 to 36 months.

The report proposes that these 5 cases define a potential subset of SUDC. All of the toddlers died unexpectedly during the night, apparently during sleep. Within 48 hours before death, 2 toddlers had fever, 3 had minor upper respiratory tract infection, and 3 experienced minor head trauma. Suggested risk factors include a history of febrile seizures and/or a family history of febrile seizures.

Dr. Kinney plans to conduct further studies to confirm these initial findings and to define the link between sudden death, hippocampal anomalies, and febrile seizures in toddlers.

This research addresses sudden unexplained death in toddlers.

These five cases all had similar abnormalities in the brain and had some history of fever, minor upper respiratory tract infections, or minor head trauma.

Deaths & Injuries Attributed to Infant Crib Bumper Pads

B.T. Thach, G.W. Rutherford Jr., K. Harris in J. of Pediatrics, Sept 2007.

The objective of this study is to document deaths attributed to bumper pads and injuries from their use that are potentially preventable.

The US Consumer Product Safety Commission maintains files on cases voluntarily reported to them of deaths and injury related to commercial products. These cases represent an unknown fraction of total occurrences. The researchers searched this database for deaths related to crib bumpers for the years 1985 - 2005. They also searched other Consumer Product Safety Commission databases for crib-related injuries that potentially might have been prevented by bumpers. Additionally, we examined 22 retail crib bumpers and described features that could be hazardous.

Twenty-seven accidental deaths reported by medical examiners or coroners were attributed to bumper pads. The mechanism of death included suffocation and strangulation by bumper ties. Twenty-five nonfatal injuries were identified, and most consisted of minor contusions. All retail bumpers had hazardous properties.

These findings suggest that crib and bassinet bumpers are dangerous. Their use prevents only minor injuries. Because bumpers can cause death, the study concluded that they should not be used.

Workup of a Stillborn: A Review of the Evidence

R.M. Silver, M.W. Varner, U. Reddy, R. Goldenberg, H. Pinar, D. Conway, R. Bukowski, M. Carpenter, C. Hogue, M. Willinger, D. Dudley, Gr. Saade, B. Stoll in American Journal of Obstetrics and Gynecology, May 2007

Despite improvements in antenatal and intrapartum care, stillbirth, defined as in utero fetal death at 20 weeks of gestation or greater, remains an important, largely unstudied, and poignant problem in obstetrics. More than 26,000 stillbirths were reported in the United States in 2001. Although several conditions have been linked to stillbirth, it is difficult to define the precise etiology in many cases. This paper reviews known and suspected causes of stillbirth including genetic abnormalities, infection, fetal-maternal hemorrhage, and a variety of medical conditions in the mother. The proportion of stillbirths that have a diagnostic explanation is higher in centers that conduct a defined and systematic evaluation. The evidence for recommended diagnostic tests for stillbirth is discussed. The ongoing work of the National Institute of Child Health and Human Development Stillbirth Collaborative Research Network, a consortium of 5 academic centers in the United States that are studying the scope and causes of stillbirth, is presented.

Stillbirth remains an important, largely understudied, poignant problem in the US.

Medical news

SIDS and Parental Smoking

P. Fleming and P.S. Blair, Early Human Development, Sept. 2007

Prenatal exposure to tobacco smoke is a major risk factor associated with SIDS and the risk has increased despite continued advice against this practice.

Evidence from the UK suggests the prevalence of maternal smoking during pregnancy has risen amongst SIDS mothers (from 50% to 80%) when the rate amongst expectant mothers in the general population has fallen (from 30% to 20%) confirming pooled estimates from recent studies of a four-fold risk.

An additional risk from postnatal exposure has also been identified; increasing with the number of smokers in the household or the daily hours the infant is subjected to a smoke filled environment.

Exposure may lead to a complex range of effects upon normal physiological and anatomical development in fetal and postnatal life that places infants at greatly increased risk of SIDS.

Recent legislation prohibiting smoking in public places needs to emphasize the adverse effects of tobacco smoke exposure to infants and amongst pregnant women.

A Link Between Hearing and SIDS

Pediatric anesthesiologist Daniel Rubens of Children's Hospital Regional Medical Center in Seattle recently published a study in "Early Human Development" (July, 2007) that suggests that SIDS results from an injury to the inner ear and brain caused by a high pressure surge of blood from the placenta during delivery.

The inner ear contains tiny hairs involved with both hearing and balance. Dr. Rubens suggests these hair cells may play an important role in transmitting information to the brain about levels of carbon dioxide in the blood. Injury to vestibular hair cells may disrupt respiratory control and predispose infants to SIDS.

Using archived newborn hearing tests, Rubens compared the tests of 31 Rhode Island babies born between 1993 and 2006 who died of SIDS to others who survived. Researchers found that all the SIDS victims had lower hearing levels in the right inner ear.

The findings do not prove that hearing tests will identify babies at risk for SIDS, but they do give researchers a direction for future study. They need to more clearly define the link between inner ear damage and how an infant controls breathing.

SIDS: Another Year of Hope but No Cure

DA Loghmanee and DE Weese-Mayer in "Current Op. in Pulmonary Med.", Nov. 2007

SIDS has inspired increasingly sophisticated studies at a time when rates are declining because of the "Back to Sleep" campaign, but ethnic disparities are widening. This review evaluates and discusses original, recent research in this area.

The epidemiology of SIDS was evaluated, corroborating known risk factors and identifying new risk factors such as socioeconomic depression and air pollution. Deficits in our understanding of risk factors for this syndrome persist, suggesting a need for ethnicity-specific education, especially among the underserved. Both autopsy and genetic testing were found to improve diagnostic accuracy or identify other causes of death (e.g. long Q-T syndrome). Debate persists over counseling regarding pacifiers and co-sleeping within the context of breastfeeding. Support was found for a relationship between SIDS and autonomic dysregulation via the serotonergic pathway, but more research is needed.

The cause of SIDS remains elusive. Recent studies suggest that improved culturally sensitive education programs, increased diagnostic specificity, and further clarification of the link between genetics and developmental stage might decrease the number of infants lost to this devastating disease and elucidate the mechanism(s) responsible.

The SIDS Center works with health professionals who come from various racial & ethnic backgrounds including African-American, Haitian, Latino, Portuguese, West Indian and Cape Verdean. They are fluent in Spanish, Haitian, French Creole, Portuguese and French. These health professionals provide culturally sensitive bereavement counseling, as they are trained in cultural beliefs regarding death, dying, and bereavement. Appropriate bereavement follow-up is enhanced with the assistance of qualified interpreters

Springfield Fetal and Infant Mortality Review

By Andrew Balder, MD, Co-Principal Investigator.

The SIDS Center and the Springfield Fetal Infant Mortality Review (FIMR) committee have continued their collaborative effort to provide bereavement services and understand the problem of fetal and infant mortality in Springfield. A representative of the Center sits on the FIMR committee, providing timely insight into the challenges faced by parents who have recently lost infant children and late pregnancies and engaging in FIMR planning efforts.

Infant and fetal losses are identified by death certificate review, Baystate Medical Center death records, referrals from emergency room and inpatient social workers, and newspaper obituaries. The SIDS Center is then notified to initiate outreach to the parent while at the same time a process of medical record review is initiated. As the grieving process resolves, bereavement counselors (nurses, social workers and licensed mental health professionals) trained by the SIDS Center then inquire whether the parent(s) would be willing to participate in a structured interview designed to ascertain the multiple factors present around the death of a fetus or infant – whether cause or effect.

As information is gathered through case review, it is collated and presented to Springfield community members for analysis and action. While the FIMR process is still young in Springfield, it could not move forward without the participation of the SIDS Center and its ability to work sensitively with grieving parents in a real time fashion.

Effort to Stop SIDS Gains Steam

Reprinted with Permission. By Kyle Alspach, Brockton Enterprise Staff Writer, October 15, 2007.

Brockton – Although Massachusetts has one of the lowest rates of sudden infant death syndrome, local doctors say communicating a national campaign's message to non-English-speaking parents in the area can be a challenge.

"We have a very diverse population, and we have been trying to reach out to the community over the last few years," said Dr. Shah Hossain, chief of newborn services at Caritas Good Samaritan Medical Center in Brockton.

The national "Back to Sleep" campaign, which encourages parents to put their babies to sleep on their backs, is credited with helping to lessen the problem, a leading cause of death for babies in the United States. The campaign launched in the mid-1990s.

Of great concern right now is the death of infants in unsafe sleep environments

Hossain said the hospital began giving out a DVD, which contains information in four different languages, to all parents of newborn children who come through the hospital.

Part of the DVD addresses how to safely put a child to sleep: On its back, on a firm mattress and in a crib that isn't crowded with heavy blankets or toys. Babies also should never be sharing a bed or a sofa with a parent or other person, Hossain said.

Sudden infant death syndrome, or SIDS, is defined as the unexplainable death of a child less than one year old.

It is the leading cause of death for infants between one and 12 months of age in the United States, killing more than 4,500 babies a year, according to the Centers for Disease Control and Prevention.

Massachusetts has the third lowest rate of SIDS of any state, according to federal CDC figures. Between 2000 and 2004, the rate was 1.95 per 100,000 births. Only New York and Rhode Island had lower rates.

Mary McClain, project nurse coordinator for the SIDS Center at Boston Medical Center, called the "Back to Sleep" campaign "one of the most successful public health campaigns in history."

Now, advocates are turning their attention to an effort to get parents to make sure their babies sleep only in the crib.

"What we're seeing right now is a population of infants who are dying while in the adult bed with parents or siblings," McClain said. "Of great concern right now is the death of infants in these unsafe sleep environments.

Advocates hope this new campaign, combined with research into the genetic factors that may be involved with SIDS, will help reduce the instances of SIDS even further.

By definition, SIDS is a mysterious occurrence. It happens to babies that are "healthy, doing well, growing well," McClain said. "They give no sign of being ill, and are found unexpectedly by parents and caregivers.

But researchers at Children's Hospital in Boston have reported that infants who die from SIDS often have an abnormality in the part of the brain that produces serotonin. The scientists believe these findings could be used to help predict which babies are at a high risk for SIDS.

Between 2000 and 2004, two dozen babies died from SIDS in the region, 13 in Plymouth county and 11 in Bristol county.

The number of babies who died form SIDS in Massachusetts actually rose between 2000 and 2004.

*In 2000 there were 19 deaths from SIDS, while in 2001 there were 24 and in 2002 there were 18 deaths.

*The figure rose in 2003, when there were 30 deaths from SIDS, and continued rising in 2004, when there were 33 deaths.

Legislators Work on the Paige Victoria Perry Act

Jeffrey Davis Perry, a Massachusetts State Representative serving the 5th Barnstable District, is sponsoring a bill to establish a Sudden Infant Death Syndrome (SIDS) Advisory Committee. The Committee's main goal is to adopt regulations for reporting and handling SIDS cases, as well as promulgate regulations for the training of first responders. Mr. Perry's granddaughter, Paige, was born on March 11, 2006 and died 48 short days later, on April 28, 2006.

The Act currently under consideration by the House, establishes an advisory council under the Chief Medical Examiners Office. The council will research and develop appropriate training on sudden unexplained child death including medical information, sensitivity in dealing with families, and community resources. This council will work closely with the Massachusetts Center for Sudden Infant Death Syndrome. In addition, the council will oversee training for death scene investigators and will develop guidelines for each coroner, medical examiner, law enforcement officer, and other emergency medical personnel involved in investigating sudden unexplained deaths for children under 3 years of age. This includes protocols for autopsies.

Members of the council, who will serve two years, will include a professional member of the Mass. Center for SIDS, the commissioner of the Department of Public Health or his designee, The Chief Medical Examiner or his designee, A Mass. State Police CPAC unit member, a representative from emergency medical services, and two members of the general public who have lost a family member to SIDS.

Paige Victoria Perry

New Arrivals

Isabella Hope was born on Sept. 19, 2007 to Robert & Diane Lowe. She is the sister of Chelsea who died suddenly and unexpectedly 5/12/07.

Shane Brady was born on Sept. 27, to Tom & Suzette Vermilya and their siblings Jacob Ryan (12/3/97- 3/3/98), Paige Ryanne (4/24/99), Jordan Rylie (1/18/2001), and Kyle Thomas (5/13/2003)

Faith Angelina was born on July 31, 2007 to Chris & Tiffany Perry. She is the sister of Paige Victoria Perry.

Bereaved Parent Meeting Notice

The Massachusetts SIDS Center has scheduled two support group meetings every month for parents, grandparents and care providers whose infants and young children have died of sudden infant death syndrome, heart disease, infection, 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 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 800-641-7437 before 4:30 PM on the day of the meeting.

Boston

Dates: December 4, 2007, Jan. 8, Feb. 5, March 4, April 8, May 6, June 10, July 1, Aug 5, 2008

Meetings are held on the first Tuesday of the month at 7:30 PM, at Children's Hospital, 300 Longwood Ave., Boston, MA, Fegan 7 Conference Room. Mary McClain, RN, MS leads the group.

Western MA

Dates: December 3, 2007, Jan. 7, Feb. 4, March 3, April 7, May 5, June 2, July 7, Aug. 4, 2008
Time: Meetings are held on the first Monday of the month at 7:30 PM at Shriner's Hospital, Volunteer Conference Room, 516 Carew Street, Springfield, MA. Marcia Kelly, RN, MA leads the group.

Donations to the Mass. Center for SIDS, Mass. Infant and Child Death Bereavement Program

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Jacqueline&Dennis Wood

In Memory of:
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Griffin Michael Cardwell
John Corson
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Scott George
Jesse Holmes
Jonathan Kerins
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SIDS Fundraiser in Memory of Kayla M. Rozzi

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 & you were sitting right next to me, I would sign it
xoxo, Rose

Rose today

If I were writing this poem to you the day after 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

Fundraisers Throughout Massachusetts

Thank you to all who organized and supported fundraisers held throughout Massachusetts.

The LPM Charitable Foundation Golf Tournament was held at Sandy Burr Country Club in Wayland on August 8, 2007. For more information and photos go to www. lpmcharity.org.

Friends and family of **Kayla M. Rozzi** attended the second SIDS fundraiser at the Georgetown Country Club, on Thursday, Nov. 8, 2007. The evening included hors d/oeuvres, desserts, raffles, and a silent auction. The proceeds support the SIDS Outreach Foundation. Special thanks to Kayla's parents, Colleen and Chris.

Saturday, Sept. 8, 2007 marked the **17th running of the SIDS Race for Life** which has become a very popular road race in Western Massachusetts. They raised over $200,000.00 for the SIDS Center. This 5-mile road race and fun walk is held in Springfield's Forest Park and includes a post-race dinner and live entertainment. For more information, go to www.sidsrace4life.org.

The **Paige Victoria Perry Trust Fund** conducted a raffle for a 7-day cruise to Bermuda. To announce the winner, the Perry's will hold a cocktail and dessert reception at the Sandwich Hollows Golf Course in Sandwich on Wed., Dec. 12. The evening also includes a silent auction. For more information, please visit paigevictoriafund.org.

The 26th Annual Road Race for SIDS was held on Sun., Sept 16 at Wampanoag State Park in Hingham. Over 400 participants enjoyed the fall weather, raising over $18,000 for the SIDS Center. Thanks to all the participants and sponsors! Special thanks go to Kathy Mahoney & Nicole Nelson, and to the Orshak family for their guidance and mentoring. The SIDS Road Race is a sizeable undertaking which requires a team effort. If you want to help, please visit www.sidsroadrace.org or call Meghan and George Sikora at 617-842-9517. Please consider becoming a committee member so this event can continue to support the fine work of the SIDS Center.

Mass. SID Center/Infant & Child Death Bereavement Program Report Calendar Year 2006

The Center received 80 infant death referrals in calendar year 2006 from medical examiners, hospitals, pediatricians and family members and friends.

Causes of death included:

Fetal demise. 19

Congenital anomalies 6

Conditions of pre-maturity 9;

Sudden infant death syndrome 9

Sudden unexpected infant death associated with unsafe sleep position or environment or co-sleeping in adult bed or on a couch 20

Positional asphyxia 4

Undetermined 3

Other causes such as accidents or medical conditions 9

Pending .....1.

There were 41 male and 38 female children who died; 6 were multiple birth babies. 48 children were found unresponsive in their homes, 4 in day care and shelter settings and 28 infants died in hospitals. Seven children were over one year of age.

Condolence letters and grief packets were sent to all referred families with information about parental, sibling and grandparent grief as well as information about bereavement home visits, parent groups and parent-to-parent contacts.

Center staff provided 58 bereavement home visits, 112 telephone counseling calls and 24 parent support groups. Fifty three educational programs on infant mortality, sudden unexpected infant death, risk reduction strategies and family bereavement were provided for hospital providers, first responders, police cadets, childcare providers and medical and nursing students. 3500 newsletters were distributed.

2007 Preliminary Report:

As of October 31, 2007 the Center received 78 infant and child death referrals. There were 43 male and 32 female children and 3 babies-gender unknown. Seven children were over 1 year of age. Causes of death include: fetal demise (29); congenital anomalies (5); pre-maturity related (1); SIDS (3); cardiac arrest (2); SUID in inappropriate sleep environment or co-sleeping (9); positional asphyxia (1); undetermined (4); infection (4); other medical conditions (2); pending (18).

Sincere thanks to Representative Jeffrey Davis Perry (Barnstable 5th District) who helped to ensure that the Massachusetts legislature increase state funding to the Massachusetts Center for SIDS. The increased funds will be used to provide bereavement support for families and risk reduction education for health professionals.

Parent Contact Training Program Volunteers Needed

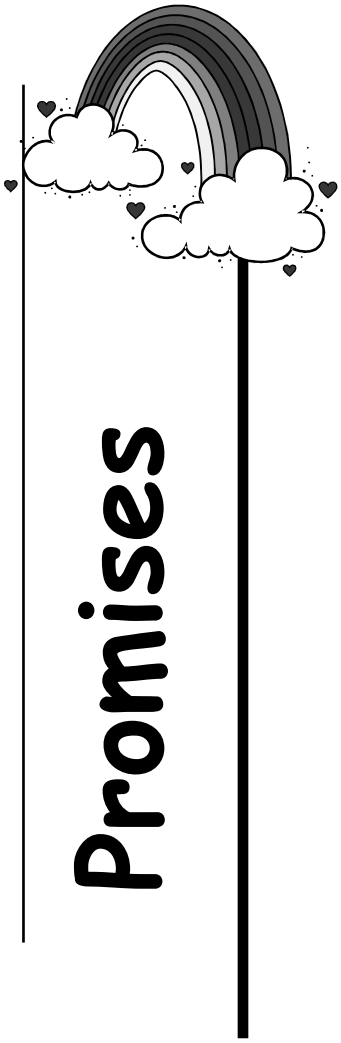
The Center will train parent volunteers who want to help newly bereaved parents cope with the deaths of their children. Parents of children who have died of all causes of death are invited to participate. Please respond by phone, fax or e-mail if you are interested. We will then schedule a training session and contact you to confirm your participation. Include your name, telephone and address and forward to:

Massachusetts SID Center/
Massachusetts Infant and Child
Death Bereavement Program
Telephone: 1-800-641-7437
Fax: 1-617-414-5555
E-mail: mary.mcclain@bmc.org

Consider a Donation to the Mass. Center for SIDS

Donations are an important source of our funding and allow us to reach out to newly bereaved parents, provide literature, print the newsletter, sponsor parent support groups, provide educational programs and participate in research. Please consider a gift to the SIDS Outreach Foundation (our 501C Charitable Foundation) in your annual charitable giving. The Outreach Foundation is a member charity of Community Health Charities of Massachusetts which allows federal (Combined Federal Campaign), state (COMECC-Commonwealth of Massachusetts Employees Charitable Campaign) and private sector employees to deduct gifts directly from their payroll. Some companies will also match gifts to the charity you choose.

Please consider supporting our work with a gift. We are most appreciative of your past, present and future donations. Thank you.



The Sudden Infant Death Syndrome Outreach Foundation, Inc.
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One Boston Medical Center Place
Boston, MA 02118

Phone: (617) 414-7437 or (800) 641-7437
Fax: (617) 414-5555 or e-mail: mary.mcclain@bmc.org
Web site: www.bmc.org/pediatrics/special/SIDS

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