

News, Information, & Events from A Place To Remember

From A Place To Remember

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A Place To Remember offers this space to share information that we feel might be helpful to grieving families and their caregivers. By posting this news, we do not endorse any opinions expressed or research results.

BREAKTHROUGH IN SIDS RESEARCH ANNOUNCED

Low production of serotonin in the brainstem a likely cause for SIDS

Doctors closing in on mysterious cause of death in infants

Boston, Mass. – Taking the next step in more than 20 years of research, researchers at Children's Hospital Boston have linked sudden infant death syndrome (SIDS) with low production of serotonin in the brainstem, based on a comparison of brainstem samples from infants dying of SIDS compared to brainstems of infants dying from other, known causes.

The findings, published in the Feb. 3 issue of *The Journal of the American Medical Association*, may give a concrete approach to identifying babies at risk for SIDS, the leading cause of death for infants between 1 and 12 months old in the United States.

In the brainstem, serotonin helps regulate some of the body's involuntary actions, such as breathing, heart rate and blood pressure during sleep. The researchers, led by Children's neuropathologist Hannah Kinney, MD, believe that a low serotonin level impairs the function of the brainstem circuits that regulate these activities, putting a baby at risk for sudden death from stresses such as rebreathing carbon dioxide when sleeping in the face down position.

The future goal of this work is to devise a test to identify infants with a serotonin brainstem defect early, and to develop preventive treatments that would correct the serotonin deficiency.

In 2006, Kinney and colleagues showed that SIDS is associated with abnormalities in the number of cells and receptors related to serotonin in the brainstem, but it wasn't clear whether SIDS may be caused by overproduction or underproduction of the chemical.

In the new study, the team measured the levels of serotonin and tryptophan hydroxylase, the enzyme that helps make serotonin, in 36 infants dying from SIDS and two control groups (5 infants dying acutely from other causes, and 5 hospitalized infants with chronic hypoxia-

ischemia (insufficient oxygen supply to tissues). Tissue samples from the brainstem were obtained from autopsies and provided by research partners at the San Diego County Medical Examiner's Office in California.

Compared with controls, the serotonin levels in the lower brainstem were 26 percent lower in the SIDS cases compared to controls, while the tryptophan hydroxylase levels were 22 percent lower. Levels of binding to serotonin receptors were also lower by more than 50 percent. The consistency and correlation of these findings with each other reinforce the idea that SIDS in the majority of cases is a disorder of serotonin in the brainstem, the researchers say.

"The baby looks normal during the day; there's nothing that would tell you that baby is going to die of SIDS that night," says Kinney, who has studied SIDS for more than 20 years.

"There's something about sleep that unmasks the defect, which we believe is in serotonin circuits: the baby experiences some kind of stress during sleep, such as rebreathing carbon dioxide in the face-down position or increased temperature from over-bundling, that cannot be compensated for by the defective brainstem circuits, and the baby then goes on to die."

In a normal baby rebreathing carbon dioxide, serotonin pathways in the brainstem would stir the baby awake long enough to turn its head, allowing it to breathe fresh air, Kinney adds. A baby with low serotonin levels in the brainstem may never stir.

SIDS has puzzled doctors and families for decades, but once the medical community recognized that a baby's position while sleeping affects the risk for SIDS, national awareness campaigns sprouted to persuade parents to place babies to sleep on their backs. However, such campaigns haven't completely solved the problem, prompting ongoing research to find a biological component to SIDS.

While this study provides strong evidence for a biological cause of SIDS, it also shows that other risk factors, such as sleeping on one's stomach, can aggravate the risk. Of the SIDS infants in the current study, 95 percent died with at least one risk factor, and 88 percent died with at least two.

The next step in this research is to find out what causes abnormally low serotonin levels in the first place. Genetic variations may be partly responsible, says neuroscientist David Paterson, PhD, in Kinney's lab, a contributing author of the paper. Kinney's lab is searching for such variations.

In the meantime, parents should remove unnecessary SIDS risk factors, Kinney says. During pregnancy, there is no safe level of alcohol a mother can drink and no safe level of smoking, both firsthand and secondhand. Until 12 months of age, babies should sleep on their backs in a crib with a firm mattress, and without toys, soft pillows, excessive blanketing or excessive clothing.

This study was supported by funds from the First Candle/SIDS Alliance, CJ Martin Overseas Fellowship, the CJ Murphy Foundation, the National Institute of Child Health and

Development, and the Developmental Disabilities Research Center at Children's Hospital Boston.

Citation: Jhodie R. Duncan, PhD, David S. Paterson, PhD, Jill M. Hoffman, BS, David J. Mokler, PhD, Natalia S. Borenstein, MS, Richard A. Belliveau, BA, Henry F. Krous, MD, Elisabeth A. Haas, BA, Christina Stanley, MD, Eugene E. Nattie, MD, Felicia L. Trachtenberg, PhD, Hannah C. Kinney, MD. Brainstem serotonergic deficiency in Sudden Infant Death Syndrome. *JAMA* Feb. 3, 2010, Vol. 303, No. 5.

Children's Hospital Boston is home to the world's largest research enterprise based at a pediatric medical center, where its discoveries have benefited both children and adults since 1869. More than 500 scientists, including eight members of the National Academy of Sciences, 13 members of the Institute of Medicine and 12 members of the Howard Hughes Medical Institute comprise Children's research community. Founded as a 20-bed hospital for children, Children's Hospital Boston today is a 396-bed comprehensive center for pediatric and adolescent health care grounded in the values of excellence in patient care and sensitivity to the complex needs and diversity of children and families. Children's also is the primary pediatric teaching affiliate of Harvard Medical School. For more information about the hospital and its research visit: www.childrenshospital.org/newsroom.

17TH NATIONAL PERINATAL BEREAVEMENT CONFERENCE SCHEDULED FOR NOVEMBER 4-7, 2010 IN WASHINGTON DC

The Association of SIDS and Infant Death Mortality Programs and The Pregnancy Loss and Infant Death Alliance have scheduled their conference for November 4-7 in Washington D.C. More information will be available as the time draws near, so check their web sites at www.asip1.org and www.plida.org for updates. This is always an excellent conference.

SHARE AND MISSING GRACE OFFER SUPPORT GROUPS LOCAL, NATIONAL, AND INTERNATIONAL

For a list of support groups offered by SHARE or The Missing Grace Foundation, follow the links below.

<http://nationalshare.org/Groups.html>

<http://www.missinggrace.com/org/indexcalendar.html>

THE ANGEL OF ANGEL OF HOPE STATUES

The Angel of Hope was introduced to the world in the book ***The Christmas Box***, a worldwide bestseller and hit television movie by author Richard Paul Evans. In the book, a woman mourns the loss of her child at the base of an angel monument. Though the story is mostly fiction, the angel monument once existed but is speculated to have been destroyed. The new angel statue was commissioned by Richard Paul Evans, in response to reports that grieving parents were seeking out the angel as a place to grieve and heal. The monument was dedicated on December 6, 1994-corresponding with the date of the child's death in *The Christmas Box*.

At the request of Sexton Paul Byron and Salt Lake City, Utah Mayor Deedee Corradini, Salt Lake City donated the land on which the monument stands. The sculpture is the creation of a

father and son from Salt Lake City, Ortho and Jared Fairbanks, and modeled according to the description in Evans' book. The face of the angel is that of Evans' second daughter, Allyson-Danica. If you look closely you can find on the angel's right wing (west) the word "hope."

Flowers, sent from around the world, adorn the base of the monument year round, accompanying notes left by parents for their "little angels." On December 6th of each year (7 p.m. MST) a candlelight healing ceremony is held at the base of the Christmas Box Angel monument. After a few remarks, a moment of silence, and the lullaby of a children's choir, the attendees are invited to leave a white flower at the base of the angel statue.

In addition to the angel in the Salt Lake City cemetery, there are Christmas Box Angels in more than 25 other areas erected by great people just like you. Furthermore, there are nearly 100 in the works, and at least a dozen of these have dedication dates. To see a complete list of statue locations around the world, as well as direction as to how to visit, go to:

<http://richardpaulevans.com/angel-locations>

To see photos of the Salt Lake City statue and read more go to:

<http://richardpaulevans.com/angel-statues>

KICKS COUNT

Counting your baby's kicks is a great way for you and your partner to bond with your baby. By performing a kick count at the same time every day during your last trimester, you can also help your doctor monitor your baby's health. What your baby is telling you with its kicks is important!

Doctors recommend that parents start counting and keeping track of their baby's kicks beginning in the 28th week of pregnancy. By doing this every day, you will get to know within a week or two what your baby's normal pattern is. By using a kick count chart, you and your doctor will be able to tell if there are any changes in your baby's normal pattern. Studies show that a major decrease in your baby's normal pattern could be a signal that there's a problem.

Counting kicks is a simple, inexpensive and effective way to monitor your baby's health and may reduce the risk of stillbirth.

For more information, go to:

<http://www.firstcandle.org/kickscount/index.html>

CAREGIVER PRACTICE GUIDELINES AVAILABLE FROM PLIDA

The Pregnancy Loss and Infant Death Alliance (PLIDA) offers practice guidelines for caregivers on their web site. Go to www.PLIDA.org for more information.

SAFE SLEEPING TIPS FOR NEWBORNS

Providing a safe sleep environment is the single most important step you can take to reduce

your baby's risk of SIDS, suffocation and accidental infant deaths. Take time during your pregnancy to learn all you can about providing a safe sleep environment for your precious bundle!

#1 - Back is best! Placing your baby on his or her back is the only sleep position recommended for babies. Side and stomach positions are not safe alternatives.

#2 - Where should my baby sleep? For at least the first six months, your baby's crib or other separate sleep surface should be placed in your room, near where you sleep. Research shows that being in close proximity to your baby during sleep can greatly reduce the risk of SIDS.

#3 - The safest sleep area is a crib that meets current safety standards! The mattress should be firm and fit snugly in the crib. For parents looking for safe alternatives to a crib for their sleeping baby, such as a bassinet, cradle or co-sleeper, see the attached guidelines or visit www.cpsc.gov or www.jpma.org for crib safety standards.

#4 - What about sharing a sleep surface? Remember, adult beds, sofas and chairs are not safe for sleeping babies and can greatly increase the risk of SIDS, suffocation and accidental infant deaths. Bring baby into your bed to feed and bond, but when its time for sleep, place your baby alongside your bed in his or her own separate, safe sleep area.

#5 - Be wary of soft bedding and blankets! Anything loose, soft or fluffy in your baby's sleep area can be dangerous. Take care to remove pillows, blankets, bumpers, sheepskins, stuffed toys and other soft objects from your baby's sleep area when placing them down for nap and nighttime sleeps.

#6 - Keep your baby warm and safe during sleep! Loose blankets in your baby's sleep area can be dangerous. Consider using a wearable blanket or other type sleeper to keep your baby warm and safe.

#7 - Never put your baby to sleep on top of any soft surface! This includes adult beds, waterbeds, comforters, sheepskins, pillows or cushions.

#8 - Pacifiers can further reduce the risk of SIDS! Experts recommend giving your baby a pacifier every time you place them down to sleep. By following the First Candle Guidelines for Pacifier Use (www.firstcandle.org/research/pacifiers_guidelines.pdf), parents and caregivers can avoid concerns about breastfeeding and long-term dental problems.

#9 - Take care not to overheat your baby with too much clothing or too warm of room! Overheating is a leading risk factor for SIDS. Layer clothing as needed (no blankets!) and keep room temperature at a level that would be comfortable for a lightly clothed adult.

#10 - Educate everyone that cares for your baby about these safe sleep tips!

For more information please call 1-800-221-7437 or visit www.firstcandle.org

SHEROKEE ILSE AND TIM NELSON PUBLISH BOOK ON COUPLE COMMUNICATION FOLLOWING THE DEATH OF A BABY

A Place To Remember co-owner, Tim Nelson, and author/speaker, Sherokee Ilse, have released their book, ***Couple Communication After a Baby Dies – Differing Perspectives***. The book presents practical perspectives on the differences and similarities of men and women who grieve. The book's strength is the warm style it is written in and the fact that both Ilse and Nelson have lived through the respective deaths of their babies. Topics covered

range from hearing the news, intimacy, and grieving different dreams, to regrets and guilt, compromise, and spirituality. Use link below to find book on the A Place To Remember website. http://aplacetoremember.com/mall/prod_detail.asp?catID=1&prodID=1067

FAITH'S LODGE CONTINUES TO OFFER HOPE AND HEALING

Faith's Lodge is a tranquil get-away in northern Wisconsin where families facing the serious illness of a child, or the death of a child, can go to build hope for the future. Go to www.faithslodge.org to read more.

APTR CO-OWNER CALVIN DERUYTER A NATIONALLY RECOGNIZED WATERCOLOR ARTIST / INSTRUCTOR

In his "spare time," A Place To Remember co-owner, Calvin deRuyter, pursues his love of painting. In recent years he has become nationally recognized for his unique style and his work appears in galleries around the country. Recently, A Place To Remember created a line of cards from his paintings. Go to <http://aplacetoremember.com/mall/category.asp?cat=2> to view all of our cards. To see Cal's artwork, visit his website at: www.calsportfolio.net