# October is SIDS Awareness Month

Share what you know Inform your friends Reduce the risk

## Uniting to Make a Difference

Visit any of these sites to learn more about SIDS and what you can do to make a difference.

CJ Foundation for SIDS, www.cjsids.com First Candle/SIDS Alliance, www.firstcandle.org Tiny Handprints, www.tinyhandprints.org

American SIDS Institute, www.sids.org



**Tiny Handprints** PO Box 100153 Nashville, TN 37210

For more information visit us at: www.tinyhandprints.org

## TINY NEWS PRINT



Newsletter of The Jacob Hughes Williams Foundation

## The Journey Continues The end of our first year!

Stephanie Williams

It was early October, only one year ago when we officially launched Tiny Handprints – The Jacob Hughes Williams Foundation as a non-profit organization. We had finally completed all the paperwork to register with the state of Tennessee and the Internal Revenue Service and were ready to unveil our new ministry. We sent a letter out to everyone we knew announcing the formation of Tiny Handprints and our plans to "blaze a trail" in Tennessee. We had 3 families at that time and hoped to adopt 100 families by the end of our first year, and I remember thinking that we had probably set our goal entirely too high!

Here we are, one year later...how have we done? Tiny Handprints has adopted 110 families since last October from cities all over the United States (and a few in Canada) and have logged over 275,000 hits to our website. We've helped several families start their own non-profit organizations and have provided numerous families with funeral expense assistance. Isn't it amazing what a year can bring?

We're sure that this next year will prove to be even more exciting than the first! We hope to reach 500 families by the end of our second year. Additionally, Tiny Handprints has been awarded a grant from CJ Foundation for SIDS to take on an exciting project in Tennessee in the coming year! This grant will enable us to produce and print brochures to be distributed to physicians' offices, hospitals and bereavement facilitators in every county across the state of Tennessee. These brochures will contain SIDS facts and grief information, along with a listing of local and national resources, to ensure that no family who experiences a sudden, unexpected loss of an infant will leave the hospital empty-handed.

Tiny Handprints is making a real difference in the SIDS/SUID community! Thank you, family and friends, for your continued confidence in our ministry and for your continued support of our organization. We couldn't do it without you! We can't wait to see what blessings and opportunities this next year holds for Tiny Handprints. We hope you'll continue on this journey with us, and keep us in your prayers as we seek to continue to offer comfort and support to families who have lost an infant to SIDS/SUID!

#### **Upcoming Editions of the Tiny News Print**

The next edition of our newsletter is coming soon! To submit your stories, poems and other items for possible inclusion in the newsletter, or to subscribe to the newsletter, please e-mail us: contact@tinyhandprints.org.

October, 2009 . Volume 1 . Issue 3

## In This Issue

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## 29TH ANNUAL SIDS CONFERENCE October 19th & 20th, 2009

Stephanie and Traci will travel to Sacramento, CA to participate in this year's national conference. Look for a full report in our next issue.



Coming soon to a city near you.

Strides for SIDS Across America *Uniting to Make a Difference* 

October 24, 2009

Josephine DeMello SIDS Foundation 5k Run

### One Mom's Experience

## Should your new baby be on an apnea monitor?

#### Jennifer Thomas

When we found out we were pregnant with a new baby girl, we were overtaken with fear and anxiety that SIDS could strike again. We spent so many hours researching preventative tests, safe baby supplies, and home monitors. The question of whether or not to use an apnea monitor was difficult to answer.

In the 1990's the National Institute of Health conducted the C.H.I.M.E. study\* to evaluate the effectiveness of home monitors in high risk infants. Their studies found that SIDS siblings had no more apnea or low heart rate episodes than normal, healthy babies and that monitoring would not provide any help to the baby or parents. I read this study over and over again and I still believed that the monitor was the right answer for us.



We started with our pediatrician. He wrote a letter of medical necessity to our insurance company. They agreed to cover the monitor for the first six months of our baby's life. The day we got home from the hospital with her, a respiratory therapist brought the monitor to our home and showed us how

to operate the machine and apply the leads to the baby. We were pleasantly surprised by its small size and ease of use.

We were really concerned about "false" alarms and if the machine was going to "keep us up all night." The therapist explained that as long as everything was properly placed, that we would have nothing to worry about. The machine has different warning beeps too. If it can't get a proper reading or something is disconnected, the sound is different than if something is wrong with the baby. While any of the sounds will definitely make you jump, it helps to know what is wrong before you get to the baby.

The respiratory therapist comes back to our home about once a month to download information from the machine. That information is sent to a SIDS institute to evaluate the data. A report is then sent to our pediatrician. The detailed process gives us a feeling that we are really doing all we can do to protect our baby girl.

While the CHIME study found that the monitors don't decrease anxiety in parents, I can't imagine going through this period without it. I can wake up at any point in the night and see a light blink every time her heart beats and every time she takes a breath. I know that the machine will wake me if anything is wrong with her.

Do monitors really help to save lives? I can't say if the monitor is life saving. We have had some low heart rate alarms. We have found her every time in a deep sleep and slow to respond. She is able to be aroused though. I don't know how you could ever prove that a monitor saved a life, but I like knowing that if she does not take a breath after 20 seconds. I will know about it!

It is important to note that apnea monitors do not guarantee that your child will not die of SIDS or some other specific illness. The

monitor will, however, alert you to the possibility of a life-threatening occurrence. Because of the monitor, we sleep a little better at night. We can also let our baby sleep without constant poking and prodding. Our new baby is now four months old and we have no regrets about using the apnea monitor. We plan to use it for a few more months and I know it will be hard to let go of it when the time comes.

I would encourage any parent struggling with this decision to talk to your pediatrician and consider trying it out. If you find that the monitor is not bringing you more peace or better sleep, then you can always return it.

\* Study Raises Questions About Relationship Between SIDS And Events Detected By Home Monitors, May 1, 2001, National Institute of Child Health and Human Development, http://www.nichd.nih.gov/news/releases/home monitors.cfm.



#### October is SIDS Awareness Month!

In honor of SIDS Awareness Month, we'd like to revisit what we know about SIDS (Sudden Infant Death Syndrome) and what steps can be taken to reduce the risk in infants.



- **SIDS** claims the lives of almost 2,500 infants in the US each year; that's nearly 7 babies every day.
- **SIDS** is not caused by immunizations.
- SIDS deaths occur unexpectedly and quickly to apparently healthy infants, usually during periods of sleep.
- SIDS is not caused by suffocation, choking, or smothering.
- SIDS is not caused by child abuse or neglect.
- **SIDS** is not contagious.
- SIDS occurs in families of all races and socioeconomic levels.
- SIDS cannot be predicted or prevented and can claim any baby, in spite of parents doing everything right.

#### Reducing the Risk

- Put your healthy baby on its back to sleep.
- No smoking near the baby.
- Do not let your baby get too hot dress your baby in as much or as little as you would wear.
- Put your baby to sleep on a firm mattress do not let the baby sleep on soft things like cushions, pillows, blankets, the couch, sheepskins, foam pads, or waterbeds.
- Take good care of yourself and your
- baby, both during pregnancy and after.
- When your baby is awake, put your baby on his or her tummy to play.
- Offer your baby a pacifier.
- If possible, breast feed your baby.

It's important to share this information with everyone who takes care of your baby. **Spread the word!** 

#### In The News

#### SUID AND STILLBIRTH PREVENTION, EDUCATION, AND AWARENESS ACT OF 2009

On July 14, 2009, Senator Frank Lautenberg (D-NJ) introduced S. 1445, the SUID and Still Birth Prevention, Education, and Awareness Act of 2009. The proposed bill would improve the collection of critical data to determine the causes of stillbirth and Sudden Unexpected Infant Death (SUID), increase education and awareness about how to prevent these tragedies in the future, and expand support services for families who have experienced a stillbirth or SUID loss.

There are more than 4,600 sudden unexpected infant deaths each year, and another 200 children between the ages of 1 and 4 die without any obvious cause of their death. Many such tragedies could be prevented if there were a better understanding of the reasons why these infants and children died. The Act encourages states to complete death scene investigations and establishes a national database to track these deaths and identify risk factors to prevent them in the future. Specifically, it would:

- Encourage states to complete death scene investigations and autopsies to help determine causes of death and collect uniform data by establishing standard protocols.
- Provide funding to train state and local personnel on completing death scene investigations.
- Expand successful child death review programs to review the circumstances surrounding infant's and children's deaths in their community.
- Establish a national database to track these deaths and identify risk factors to prevent them in the future.
- Perform a study on the benefits of genetic testing.
- Create a national public awareness and education campaign to
  educate parents and caregivers by providing information that is
  focused on decreasing the risk factors for sudden unexplained
  infant death, including educating individuals about safe sleep
  environments, sleep positions, and reducing exposure to smoking during pregnancy and after birth.
- Expand support services, such as grief counseling and support groups, for families who have experienced the loss of a child.

This is the first step in improving the health of our children and hopefully eliminating the occurrence of Sudden Unexpected Infant Death. The current status of this bill is that it has been referred to the Committee on Health, Education, Labor, and Pensions.

To follow Bill S 1445, please follow this link http://thomas.loc.gov and search by the bill number. Tiny Handprints encourages you to contact your local senator and let him/her know that you are in support of this bill. To find the contact information for your local senator, go to http://www.senate.gov.

### Baby, Baby!

upcoming arrival of two new addition to our Tiny Handprints family! Ladd & Stephanie are expecting their third child, baby boy, in mid-January 2010. Scott & Traci are expecting their second child, als a baby boy, in early February 2010! Pleas keep us in your prayers as we anticipate th arrival of our newest blessings!



## The Tiny Handprints Team

The key to our success at Tiny Handprints is that the sum of our parts is much greater than each individual – that is, we have an amazing team whose unique talents combine to allow us to better serve our families. Our Tiny Handprints family is made up of the combination of two families: The Tennessee Williams', Ladd, Stephanie and Abby Grace, and the Texas Williams', Scott, Traci and Beckham. Although we share the same last name, the two families are not actually related. Scott and Ladd were roommates in college, and their wives later became the best of friends. We've been sharing vacations, blessings as tragedies together as a "family" for several years, and came together last year as a team with a new purpose: to reach out to other families who have experienced a loss to SIDS/SUID.

#### Stephanie Williams, President

Stephanie is a native of West Virginia who has made her home in middle Tennessee for over 15 years. She is a graduate of Middle Tennessee State University where she earned her Bachelor of Business Administration in Accounting. She works part-time



as an operations manager for a financial planning firm. As President of Tiny Handprints, Stephanie leads the planning efforts for the organization and is responsible for initiating and maintaining contact with our families through mailing of our Survival Kits.

#### Ladd Williams, Vice President

Ladd was born and raised in Nashville, Tennessee. He is a graduate of The Art Institute of Dallas where he earned his degree in Visual Communications. He is a salesman for a national plumbing and lighting supply company. As VP, Ladd supports the efforts of the President, participates in the planning efforts of the organization, and aids in the development of advertising and marketing ideas.

Stephanie & Ladd lost their first son, Jacob, to SIDS in January 2007. They live in Murfreesboro with their daughter Abigail, age 2, and their dog Petie.

## Traci Williams, Secretary/Treasurer

Traci is a Texas native. She works as COO and operations manager of a dental practice. As Secretary/Treasurer, Traci leads in the planning efforts of the organization and maintains the important business and financial records of the organization.



#### **Scott Williams, Chief Marketing Officer**

Scott is also a native Texan. He is a graduate of UT Arlington where he earned his Bachelor of Arts in Communication. He is owner/operator of a graphic design company in Dallas. As Chief Marketing Officer, Scott designs the artwork for Tiny Handprints, from our logo and website, to our newsletters and event t-shirts. He also participates in the planning efforts of the organization.

Scott & Traci experienced a SIDS loss through Stephanie & Ladd. They live in Dallas with their son Beckham and their dog Lamont.