

DAY ON THE  
*Hill*  
2009

wednesday, march 25, 2009

**OUR CHILDREN, OUR FUTURE**

*Working Together, Supporting  
Families, Saving Lives*



# PUBLIC POLICY AGENDA

**First Candle calls upon Congress and the President to pass and authorize appropriations for these landmark bills addressing stillbirth, Sudden Infant Death Syndrome (SIDS), Sudden Unexpected Infant Death (SUID) and Sudden Unexplained Death in Childhood (SUDC).**

## **The Stillbirth and SUID Prevention, Education and Awareness Act of 2009**

*This bill is expected to be introduced by Senator Frank R. Lautenberg and Congressman Frank Pallone, Jr.*

In regard to Sudden Infant Death Syndrome (SIDS), Sudden Unexpected Infant Death (SUID) and Sudden Unexplained Death in Childhood (SUDC), this bill calls for comprehensive death scene investigations and training of investigators, increased use of comprehensive standardized autopsies, partial funding of autopsies for families who cannot afford them, building capacity for state and local Child Death Review programs and prevention strategies, a national registry for all sudden unexpected deaths of infants and children, implementation of a public health campaign to reduce the risks, and grants to provide grief support for families.

With regard to stillbirth, this bill calls for the development and dissemination of a standard protocol for data collection and surveillance, guidelines to encourage and increase the use of comprehensive autopsies, evidence-based public education and awareness programs to reduce the occurrence and increased education for pregnant women and health professionals about risk factors and the importance of regular prenatal care. The bill also recommends the creation of a task force to develop a national research plan that focuses on causes and preventive strategies and directs grant awards for grief support services for families, including counseling, home visits and hotlines.

**Stillbirth Awareness and Research Act of 2009 House Bill (H.R. 521) Introduced by Congressman Peter King and Congressman Charles Gonzalez** With regard to stillbirth, this bill calls for the establishment of a national stillbirth registry, creation of a standard definition of stillbirth and standardized protocols for data collection and surveillance. The bill also establishes public education and general awareness campaigns and educates pregnant women and health professionals about early warning signs and the importance of monitoring fetal movements.

**In addition, First Candle advocates for increased funding for the following programs:**

## **Title V Maternal and Child Health Services Block Grant**

Recommend increasing funding to \$850 million to allow states to provide essential services that reduce infant mortality, promote the prenatal health of mothers and infants and fund delivery and postpartum care for low income at-risk pregnant women. Funding would also be provided for the national centers providing SIDS and Infant Death resource and support services, *including the Program Support Center at First Candle.*

## **National Institute of Child Health and Human Development**

Recommend an increase of at least 7 percent for FY2010. It is imperative that research into both SIDS and stillbirth be strengthened and outreach campaigns continue to reduce the risk of SIDS.

## **Centers for Disease Control and Prevention**

In particular, the National Center for Chronic Disease Prevention and Health Promotion, Maternal and Infant Health Branch and the National Center for Birth Defects and Developmental Disabilities.

**For more information, please contact Dr. Marian Sokol, First Candle President, at 800.221.7437 or [marian.sokol@firstcandle.org](mailto:marian.sokol@firstcandle.org).**

# SIDS FACTS

**Sudden Infant Death Syndrome** is the sudden, unexpected death of an apparently healthy infant under one year of age that remains unexplained after the performance of a complete postmortem investigation, including an autopsy, an examination of the scene of death and a review of the medical history.

As a result of the national Back To Sleep Campaign, launched in 1994 as a joint effort between First Candle/SIDS Alliance, the American Academy of Pediatrics and National Institute of Child Health and Human Development, SIDS rates have declined by more than 50 percent. Despite this success, SIDS remains the leading cause of death for infants one month to one year of age, continuing to claim the lives of more than 2,100 babies each year.

- While SIDS occurs in all socio-economic, racial and ethnic groups, African American and Native American babies are 2-3 times more likely to die of SIDS than Caucasian babies.
- Most SIDS deaths occur when a baby is between 2 and 4 months old; 90 percent of all SIDS deaths occur before 6 months of age.
- Most babies that die of SIDS appear to be healthy prior to death.
- 60 percent of SIDS victims are male; 40 percent are female.

At this time there is no known way to prevent SIDS in all cases, but there are steps parents and caregivers can take to reduce the risk of sudden infant death:

- Always place babies on their **BACK** at nap and nighttime. Side and tummy sleep positions are not safe choices.
- Do not fall asleep with a baby in an adult bed or on a sofa. Bring them in bed to breastfeed and bond, but when it's time to fall asleep, place them alongside your bed in a separate, safe sleep area.
- You should not smoke while you are pregnant and babies should not be exposed to secondhand smoke after they are born.
- For sleep, use a safety-approved crib with a firm, tight-fitting mattress, covered by only a sheet. Place your baby's safe sleep area alongside your bed for at least the first six months to reduce the risk of SIDS.
- Do not place babies to sleep on soft surfaces (adult beds, waterbeds, sofas, chairs, quilts, sheepskins).
- Use a wearable blanket or other type sleeper instead of loose blankets to keep your baby warm and safe.
- Remove all soft bedding and other soft items from the crib (including soft or pillow-like bumpers) before placing the baby to sleep.
- Take care not to overheat babies with too much clothing. Keep room temperature at what would be comfortable for a lightly clothed adult.
- Use a pacifier at nap and nighttime for the first year.
- Educate everyone you know who cares for babies about these important safety tips.

For more information, please contact First Candle at 800.221.7437 or visit us on the web at [www.firstcandle.org](http://www.firstcandle.org).

# STILLBIRTH FACTS

**Stillbirth is the death of an infant in-utero** at 20 or more completed gestational weeks. More than 25,000 babies are stillborn in the United States each year.

- Almost 50 percent of these deaths occur at or near full term and often seem to be otherwise healthy babies. The majority of stillbirths (85%) occur before delivery with 15 percent occurring during labor and delivery.
- It is estimated that nearly two-thirds of all stillbirth deaths remain unexplained. Researchers feel that this is more likely due to a failure to investigate the deaths, rather than a medical mystery.
- Stillbirth deaths cut across all socio-economic classes, races, religions and maternal age groups. No woman is immune.
- Some of the more common diagnosable causes for stillbirth are: placental abruption and other placental problems, birth defects and chromosomal abnormalities, uncontrolled diabetes, preeclampsia, cord accidents and infections.
- The risk factors for stillbirth include: advanced maternal age, maternal obesity, maternal smoking, prior stillbirth, neonatal death or other fetal losses, uncontrolled maternal diabetes and maternal hypertension.
- After a stillbirth, few hospitals offer an autopsy, placental exam or clinical testing to the parents to determine the cause of death.
- Mothers who suffer a stillbirth do not receive recognition in 25 out of 50 states. There is no certificate of birth — making these babies' births "invisible."

While studies into potential prevention strategies for stillbirth are ongoing, following are some helpful strategies for pregnant women to help reduce the risk of stillbirth:

- Begin to monitor your baby's activity beginning at 28 weeks and report any drastic or prolonged changes to your doctor (see [www.firstcandle.org/kickscout](http://www.firstcandle.org/kickscout)).
- Do not smoke, drink alcohol or use drugs (unless prescribed by your doctor).
- Report any vaginal bleeding, leakage or sharp pain.
- If you are post-term, discuss options with your doctor. Pregnancies longer than 42 weeks may be at increased risk for stillbirth.
- Do not hesitate to request a second or third opinion anytime during your pregnancy if needed to put your mind at ease.

*This is for informational purposes only and is not intended to replace your doctor's advice.*

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