



2005-2006 PUBLIC POLICY EXECUTIVE SUMMARY

First Candle/ Sudden Infant Death Syndrome Alliance is a national non-profit voluntary health organization that unites families, caregivers, health professionals and scientists with government, business and community service groups nationwide to promote infant health and survival. Our mission includes advocacy, education, and research on behalf of important Stillbirth, Sudden Infant Death, Newborn Screening and other infant health and safety initiatives. First Candle requests congressional support for the following:

- **Support a six percent (6%) increase in funding for the National Institutes of Health (NIH) and a proportionate six percent (6%) increase for the National Institute of Child Health and Human Development (NICHD),** with priority consideration for Stillbirth and SIDS. Continue focus on SIDS research and Back to Sleep messages. Provide additional funding for Stillbirth Research.
- **Continue funding efforts to the Centers for Disease Control (CDC) for field-testing of the Sudden Unexplained Infant Death Scene Investigations Reporting Form,** which includes training for medical examiners, coroners, and death scenes investigations on how to sensitively administer the form to parents. **Support adequate funding through CDC for previously approved, critically needed pilot stillbirth registries in Iowa and Atlanta, with the ultimate goal being a national Stillbirth Registry.**
- **Support a National Campaign for Cribs,** providing funds for community based crib campaigns for needy children in communities with elevated incidence of SIDS, high rates of poverty and minority ethnicity. Specifically approve 2005 earmarked congressional funds for a 5 state First Candle Member Crib Campaign pilot effort.
- **Support Senate Bill 423, introduced by Senator Santorum to Cover Stillborn Infants Under Serviceman's Group Life Insurance, and S.B. 1235, the Increase Servicemembers' Group Life Insurance bill which includes the Senator 's provision allowing for death benefits for stillborns.** In addition, initiate national legislation guaranteeing mothers who experience Stillbirth a minimum mandated leave for physical and emotional healing, through an Amendment to the Family and Medical Leave Act of 1993... by inclusion of stillbirth as a covered disability.
- **Support recommendations prepared for Maternal and Child Health by the American College of Medical Genetics with regard to expansion of Newborn Screening.** Encourage Health Services and Resources Administration (HRSA) leadership to assist states in expanding newborn screening to include 29 listed disorders, including all 9 metabolic tests, as well as newborn hearing screening.

In addition, First Candle recognizes that infant health and survival is intricately related to maternal health and advocates for comprehensive healthcare coverage for every expectant mother and child. We also support efforts to create a national safety net of grief support for families who lose stillborn babies and infants. Funding should be provided for bereavement training of hospital and community nurses and first responders, such as law enforcement personnel and Emergency Medical Technicians.

BACKGROUND INFORMATION ON ADVOCACY AGENDA

RESEARCH

- **Support a six percent (6%) increase in funding for the National Institutes for Health (NIH) and a proportionate six percent (6%) increase for the National Institute for Child Health and Human Development (NICHD), with priority consideration for Stillbirth and SIDS. Continue focus on SIDS research and Back to Sleep messages. Provide additional funding for Stillbirth Research.**

It is imperative that NIH/NICHD assure continued focus on the physiology and environmental factors involved with SIDS deaths. In spite of tremendous progress to date, seven babies continue to die of SIDS each day. SIDS remains the leading cause of death for infants between one month and one year. Funding support must also be assured for the Back to Sleep Campaign and Safe Sleep public health messaging which is vital information for caregivers of every newborn infant. Just a decade ago, more than twice the number of SIDS deaths were occurring in the United States. Prioritization should be given to understanding and preventing disparities in numbers of SIDS deaths occurring in babies of certain racial and ethnic groups. African American infants face twice the risk of succumbing to SIDS. Native American and Alaska Native babies are almost three times as likely to die.

Stillbirth is the death of an infant in-utero past twenty completed gestational weeks. Majority of these deaths occur at or near full term; therefore, otherwise healthy babies die shortly before or during birth. There are more than 27,000 parents in the United States alone that experience a stillbirth annually, and it is estimated that the majority of stillbirth deaths remained unexplained. *This translates into more than 70 stillborn babies being delivered each day in our country. More than half of the deaths are at 28 or more weeks' gestation. One in every five stillborn infants is full term.* In 2003, NICHD committed the first \$3 million to establish the Stillbirth Collaborative Network of researchers at centers in four states to focus on central data collection and research protocols for stillbirth deaths. This amount is highly inadequate. It is barely enough per child to send a sympathy card with postage to every families devastated by such a loss, as one stillbirth father who tracks spending notes...but is still woefully inadequate. **First Candle urges Congress to support increased funding and focus on Stillbirth at NICHD, with the goal of reducing the incidence of stillbirth in our country by 50% during the decade ahead. This percentage improvement was accomplished through NICHD efforts for SIDS and should similarly be a goal for stillbirth.**

PROTOCOLS and REGISTRIES

- **Continue funding efforts to the Centers for Disease Control (CDC) for field-testing of the Sudden Unexplained Infant Death Scene Investigations Reporting Form, which includes training for medical examiners, coroners, and death scenes investigations on how to sensitively administer the form to parents. Support adequate funding through CDC for previously approved, critically needed pilot stillbirth registries in Iowa and Atlanta, with the ultimate goal being a national Stillbirth Registry.**

Prevention of sudden, unexplained infant deaths including SIDS depends on thorough collection of information at the death scene investigation, and accurate and consistent reporting of cause-of-death on the death certificate. In order to do this, CDC and a national Work Group are creating an improved standard protocol for collecting information at infant death scenes and training individuals involved in infant death scene investigation how to use the protocol and fill out a death certificate. This process is integral to avoiding awkward, emotionally charged misunderstandings at the scene of an unexplained infant death and to help differentiate cases of SIDS from cases of child abuse. Furthermore these protocols will increase the epidemiological information available about SIDS deaths. A Work Group at CDC has been diligently revising and field-testing revisions to 1996 Protocols that were determined to be lengthy, cumbersome and not being used. A congressional appropriation of \$300,000 for implementation of this project was made in Fiscal-Year 2004. **First Candle urges Congress to provide continued funding to CDC for field- testing of the Sudden Unexplained Infant Death Protocols, which includes training for medical examiners, coroners, and death scene investigators on how to sensitively administer the form to parents.**

In addition, we advocate for adequate funding for pilot Stillbirth Registries in Iowa and Atlanta, and ultimately for creation of a National Central Repository for Autopsies and a National Stillbirth Registry. At issue is the fact that unless there is a comprehensive post-mortem protocol and a central repository, all of the information gleaned from autopsies of stillborn infants is lost to medical science,

making the search for causes and prevention of future stillbirth deaths impossible. Presently most of these autopsy records are filed in hospital file cabinets. First Candle believes that autopsies should be offered at no charge to all parents in the third trimester. We cannot begin to gain critical national information regarding the epidemiology of stillbirths and possible commonalities in such pregnant mothers and babies in-utero unless there is a national stillbirth registry to document the occurrence.

In 2004 congressional funding under the leadership of Senator Harkin of Iowa allowed the creation of pilot Stillbirth Registries in the state of Iowa and in Atlanta, Georgia. These projects, under the auspices of CDC, are presently in the initial stages of implementation. First Candle calls for ongoing funding of the two pilot efforts, adequate evaluation, and expansion of these pilot efforts to other states in the near future.

CAMPAIGN FOR CRIBS

- **Support a National Campaign for Cribs. Provide funds to support community based crib campaigns for children in need, particularly in those communities with elevated incidence of SIDS and high rates of poverty and minority ethnicity. Provide support specifically for 2005 earmarked congressional funds for a five state First Candle Member Crib Campaign pilot effort.**

Recent research by Dr. James Kemp, pediatric pulmonologist from the St. Louis University School of Medicine indicates that infants who sleep in adult beds face multiple times the risk of deaths as those who sleep in cribs. Dr. Kemp found that the risk of suffocation is up to 40 times higher, and that risk remains high even when overlying deaths are discounted. Part of the problem may relate to loose bedding and pillows. Another aspect of unsafe sleep is the increased risk associated with couches, bean-bag chairs and other inappropriate sleep surfaces. **A baby is safest alone, on his or her back, in a safe crib.** An essential element to preventing such deaths is creating a nationally effective, culturally sensitive public education campaign. *Another issue that needs to be addressed, however, is the inability for many single mothers and families with inadequate income to afford a crib for their baby.*

In response to the cost dilemma, many community based organizations, often in partnership with local and state health departments have developed an array of programs to provide free cribs and safe sleep education to new and expectant parents. This national "patchwork" of programs needs to be evaluated and expanded, with "Best Practice Models" identified and coordination of such campaigns campaign into a national initiative. First Candle believes that just as every child in our country is expected to have a car seat when they leave the hospital, so too should every child have a crib. In doing so we can save the lives of thousands of babies, especially those from lower income families.

To move forward in accomplishing this goal, First Candle has applied for 2005 Congressional earmark funds to provide funding for expansion of seven First Candle Member crib programs operating in five states: Maryland, Georgia, Indiana, Missouri and Texas. The appeal for such funds is at a \$60,000 per site request, with funding provided directly to that state. All programs serve high-risk families and assure that follow-up and related parental education is provided. First Candle advocates for the approval of these earmark allocations.

INSURANCE AND RECOGNITION OF STILLBIRTH IMPACT

- **Support Senate Bill 423, Legislation introduced by Senator Santorum to Cover Stillborn Infants Under Serviceman's Group Life Insurance, And S.B. 1235 the Increase Servicemen's Group Life Insurance bill which includes the Senator's provision for allowing death benefits for stillborn babies. In addition, initiate legislation at the national level that guarantees mothers who suffer a Stillbirth a minimum mandated leave for physical and emotional healing from the loss of their baby. This can be best accomplished through an Amendment to the Family and Medical Leave Act of 1993, by inclusion of stillbirth as a covered disability.**

An Indiana court case involving a stillborn baby of 38 weeks gestation, whose family had Serviceman's Group Life Insurance has brought to the forefront inequities in life insurance coverage for military families as well as those in the civilian community. While this family and others must provide a burial for the child and have obvious expenses related to the pregnancy, the families are usually denied death benefit claims. While the outcome of the court case is pending, **Senator Rick Santorum (PA) has introduced Senate Bill 423 that will amend title 38, United States Code, to make a stillborn child an insurable**

dependent for purposes of the Serviceman's Group Life Insurance program. It is the position of First Candle that similar changes should occur in all life insurance programs.

Similar inequities occur in the provision of time off from work for mothers whose babies are stillborn. "A birth is a birth," ... said one mother who recently faced this situation. Most corporate Human Resource policies cover time off (some with pay) after the birth of healthy baby. Yet in this situation, where a mother especially needs emotional healing and to regain her physical strength there are no family focused policies to guarantee minimum mandated medical leave. Beginning next year, in South Korea the government will guarantee time off from work for up to 45 days in the event of a stillbirth or miscarriage. **We must begin with mandating minimal standards for time off from work for mothers of stillborn babies here in the United States.** Addition of up to 27,000 stillbirth mothers, which would mean the world to them, would be a potentially statistically significant change to the base of 3.5 million mothers of living babies who if employed would most likely be eligible for this benefit.

NEWBORN SCREENING

- **Support recommendations prepared for Maternal and Child Health by the American College of Medical Genetics with regard to expansion of Newborn Screening. Encourage Health Services and Resources Administration (HRSA) leadership to assist states in expanding newborn screening to include 29 listed disorders, including all 9 metabolic tests, as well as newborn hearing screening.**

Many babies are placed at risk of death or devastating health conditions because they do not receive adequate newborn screening. For majority of the conditions there are also lifesaving and life-changing treatments available. Simple, safe and efficient tests exist, but it is up to each state to designate which tests will be authorized. **It is imperative that governors and legislators in every state be urged to sign bills that require the 29 recommended newborn screening tests and the resources to carry them out.** The cost of screening per child is \$100 or less, and is far more acceptable than watching a baby die or providing for a lifetime of medical care and special education costs.

Leadership from HRSA to assist in the adoption of expanded state policies is encouraged. In the interim, every new parent should be informed that such screening tests exist and they have the option of having such testing done through private pay at the time of birth.

For additional information regarding the 2005-2006 First Candle Public Policy Agenda contact Dr. Marian Sokol, President at 800-221-7437 or Marianne Adezio at Golin Harris International at 703-741-7500.