Testimony for HR 669
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Laura Crandall
Program Director of The Sudden Unexplained Death in Childhood Program
*a program of the CJ Foundation for SIDS*

## Summary Page

- In 2010 alone, over 3,600 infants and nearly 200 toddlers died suddenly and without explanation and over 26,000 babies were lost to Stillbirth.
- SUID rates first decreased in the 1990's during the "Back to Sleep" campaign but have since remained unchanged since the late 1990's.
- Greatest Need Today to Address: Inconsistent data collection of fetal, infant and childhood deaths limits our ability to fully inform parents and address these public health issues.
- The medicolegal death investigation of these cases needs to be standardized, resourced, and the resultant data centralized and specifically studied as supported in HR669.
- Specifically, HR669 will improve the effectiveness of the current activities of the CDC by recognizing and addressing the current obstacles their projects face by:
    - Ensuring comprehensive autopsies
    - Improving Scene Investigations of infant/child deaths
    - Improving the Surveillance of Stillbirth
    - Improving the Surveillance of Infant/Child Deaths
    - Supporting Evidence Based Community Interventions
    - Supporting Evidence Based Public Awareness Campaigns
    - Supporting Bereaved Families

## Oral Testimony

### My Personal Story

Good afternoon. My name is Laura Crandall and I am grateful to have this opportunity to speak with you regarding HR669 – the Sudden Unexpected Death Data Enhancement and Awareness act. The problems that the bill seeks to address were first made known to me through a very personal experience.

July 30th 1997 was a gorgeous summer day- 80 degrees, sunny and completely blue skies- that is what I remember that morning sitting out on our front steps while waiting to awaken my daughter, Maria, from her nap. She had her 15 month pediatric well visit scheduled for later that morning. But when I went to wake her, I found Maria in her crib- not breathing and blue. I called 911, did CPR and even with the immediate efforts of Police, EMTs and those at the ER- Maria could not be revived. She had died- a thriving, happy, walking, talking beautiful little girl died.

We returned home from the hospital to find the police waiting for us with lots of questions and needing to investigate our home. A medical investigator from the ME's office called and came over the next morning to take pictures and ask many more questions, and asked me to replay the most horrific moment of my life- how I found Maria. Over the next few days, it was all we could do to plan her funeral and try to keep ourselves going on. I had no idea that during those same days, that the investigation of Maria's death was the most crucial. I did not know, that what **was,** and **was not** done at that time would have such a lasting impact on myself and the rest of my family.

It is not like TV- nothing happens quickly. Questions don't get answered in an hour- if they ever do at all. Two long years later, her investigation was concluded and- a cause for her death was never found. So I am left with the understanding that her true cause of death was buried with her, and that is a tragedy of missed opportunities. I do not want to see this happen for other families in the future.

Sadly, my story is not unique. There are many bereaved families who could sit in this chair and tell you the same story of tragedy, inexplicable loss and missed chances. In 2010 alone, over 3,600 infants and nearly 200 toddlers died suddenly and without explanation and over 26,000 babies were lost to Stillbirth. HR669 efficiently addresses the core problems present in our country today to allow us to improve the collection of comprehensive and standardized information to better understand these presently inexplicable deaths.

**Issues related to Stillbirth**

Of the 26,000 babies a year in the U.S. who are stillborn, nearly half go unexplained. Additionally, deaths due to Stillbirth represent almost half of all our country's perinatal deaths. This is a significant public health issue and one who's current surveillance is quite limited through fetal death records with studies showing that the data collected is often incomplete and insufficient.

The state of Iowa, Metropolitan Atlanta and, more recently, counties around Denver, parts of Hawaii and Western NY have joined in a CDC funded effort to gather comprehensive and standardized data through their existing birth defect surveillance programs. This includes more qualitative data like pregnancy related and post mortem information. Studies have shown the benefit of such a program structure far outweighs the information gathered from the fetal death record system alone.

Education of healthcare providers and expectant families is also needed to emphasize and teach the importance and potential benefit of known prenatal health initiatives that is not standardized today.

## Issues related to Infant and Childhood Deaths

One of the great barriers to understanding infant and child deaths is the recognition that death investigation systems in our country vary greatly. Coroner and medical examiner offices are charged and have the authority to conduct medicolegal death investigation of all unexplained, unexpected, and suspicious deaths in the United States. Consequently, all of the unexpected infant and child deaths we speak of today will/should undergo a medicolegal death investigation.

It is clear, however, that the medicolegal death investigation system in our nation is poorly-funded and without consistency and standardization from state to state, and often from county to county. The investigation that parents encounter, is directly tied to where they live and the resources and policies which their local Medical Examiner or Coroner's office utilizes.  I also know, from working with the National Association of Medical Examiners, specifically Dr Victor Weedn, as well as the Scientific Working Group for Medicolegal Death Investigation, that the federal government has little influence on coroner and medical examiner systems with only the Armed Forces Medical Examiner System under its purview.  Additionally, the only federal assistance that coroner and medical examiner offices receive is through the Paul Coverdell grants.

It is also clear that the investigations of unexpected infant or child deaths are some of the most difficult cases for the medicolegal death investigation system. They require a thorough investigation of the scene where the child was found, comprehensive interviews of the caregivers, a review of the child's medical history, and a "complete" autopsy. Guidelines for scene investigation created by the CDC are not universally adopted and there are no national guidelines or standards for what constitutes a complete autopsy of a sudden infant or child death. This results not only in incomplete information for the family struggling to understand their loss, but drastically limits the ability of public health to address problem.

Currently, little medical headway has been made with regard to understanding the nature of unexpected and unexplained deaths of fetuses, infants, and young children, because they occur sporadically and because an overarching structure is not in place to study these cases, and thus the information about each case lays fallow. This is yet another source of long term distress to the family - that their child's death will not assist in the prevention of another.

The tracking of sudden unexpected infant death rates showed a significant drop in the early 1990's with the initiation of NICHD's successful "Back to Sleep" campaign- unfortunately, we have not seen any additional progress in lowering the rates further. As shown in the CDC graph I submitted in my written testimony (page 8), our progress as a country has seen a plateau for more than the last decade. If we are committed to **see** a change and prevent more of these deaths in the future, we must **make** a change in our process. The medicolegal death investigation of these cases needs to be standardized, resourced, and the resultant data centralized and specifically studied as described in HR669. The Sudden Unexpected Death Data Enhancement and Awareness Act addresses these critical limitations in order to provide answers to families and our nation overall.

Specifically, the bill will improve the effectiveness of the current activities of the CDC by addressing the current obstacles that impede their success by:

- <u>Ensuring comprehensive autopsies:</u> Creating and supporting national guidelines for the standardization of autopsies for infants and children who die unexpectedly.

- Improving Scene Investigations: Supporting the specialized infant/child death investigation training needed for death investigators.
- Improving the Surveillance of Infant/Child Deaths: Enhancing the national case reporting system to better track infant and childhood deaths and identify risk factors to prevent them in the future.
- Supporting Evidence Based Community Interventions: Expanding successful child death review programs to track and analyze the circumstances surrounding infant's and children's deaths in their community to create/implement evidence based initiatives to prevent them.
- Improving the Surveillance of Stillbirth: Expand current data collection activities to additional states to identify the causes of stillbirth and ways to prevent it in the future.
- Supporting Evidence Based Public Awareness Campaigns: Create a national public awareness and education campaign to educate parents and caregivers about known risk factors for stillbirth, and sudden unexpected death in infancy and childhood.
- Supporting Bereaved Families: Expand support services, such as grief counseling, for families who have experienced stillbirth, or sudden unexpected infant or child death.

Our country is in dire need of standardized protocols for death scene investigations and comprehensive autopsies. This will ensure that our public health and research efforts are driven by data that is complete and consistent. Each individual family expects and deserves this as well.

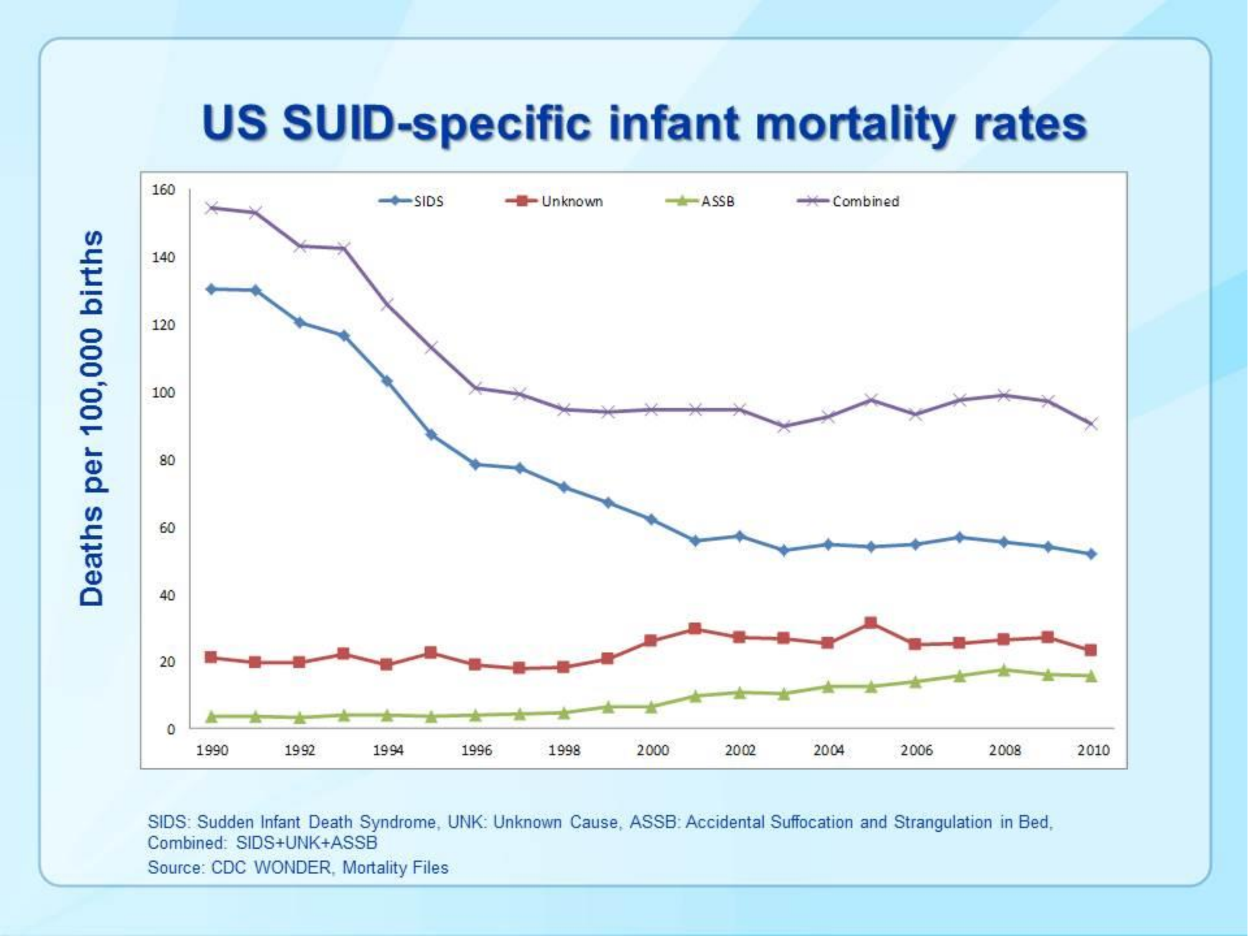
Thank you for allowing me to provide my views on this important legislation. And, on behalf of all the children gone to soon (my Maria, being one of so many) thank you for giving them a voice. I know they would want us to know what happened to them and help create a future free of these tragedies for others.

## Additional Rationale for HR669

### Statistics of Sudden Unexpected Infant and Toddler Deaths

The most recent rates of Sudden Unexpected Infants Deaths from 2010 are reported by the CDC include: 2,063 SIDS, 918 Undetermined, and 629 to ASSB for a total of 3,610 sudden unexpected infant deaths.

Rates of Sudden Unexplained Death in Childhood are estimated from deaths ruled Undetermined (as SUDC does not have a specific diagnosis code). In 2010, there were 198 undetermined deaths of children ages 1- 4 years.


US SUID-specific infant mortality rates

SIDS: Sudden Infant Death Syndrome, UNK: Unknown Cause, ASSB: Accidental Suffocation and Strangulation in Bed, Combined: SIDS+UNK+ASSB
Source: CDC WONDER, Mortality Files

Data from the CDC’s tracking of death certificates from 1990 to 2010 shows an overall decrease in the total number of infants dying unexpectedly. This initial drop coincides with the initiation of the

"Back to Sleep" campaign initiated in 1994 by the NICHD. The lowest line (in green) for ASSB (accidental suffocation and strangulation in bed) shows a gradual increase in recognition of these preventable asphyxia related deaths and this uptrend correlates to the CDC's release and training of scene investigation guidelines for sudden unexpected infant death. While SIDS (in blue) and Undetermined (in red) may represent a shift in the way the deaths are being classified, it is more important to our discussions today that the overall rate of SUID (in purple) has seen a plateau in our country since the late 1990's. Therefore, the efforts we have pursued over the last 10 plus years have not materialized in continued progress to decrease the incidence of these deaths further.

The successful efforts of the National Institute of Child Health and Human Development (NICHD), in public awareness campaigns, and the CDC in scene investigative guidelines as well as tracking sudden infants deaths are apparent and have proven their success in the ultimate goal-the reduction of sudden infant death. However, we are here today discussing HR669 because of the stagnation in our further progress for more than a decade which causes us to look closely at our systems to remove the obstacles that may be contributing to this.

## Investigating Sudden Infant and Child Deaths

Over the last twelve years, I have worked with hundreds of families after the loss of a child, as well as worked with many dedicated professionals from all across our country who deal directly with the aftermath of a sudden child death. These include Medical Examiners, Coroners, Death Investigators, Law Enforcement, Pediatricians, Child Death Review team volunteers, Public Health professionals and Researchers.

All perform specific roles that are critical to our understanding of sudden deaths whether they be investigative, clinical care of the family, public health goals, and/or research.

Their success is strongly dependent on the consistent and thorough case information primarily collected in a critical window of opportunity- within 24 hours of the death. Families in crisis and shock have no idea that those initial hours after their child's death will be the most critical to the investigation- which either provide them comfort in the years ahead that every attempt was made to understand their child's death **or** provides them with a lifetime of regret of missed opportunities and unanswerable questions.

Death investigation systems vary throughout our country and so too do the specific investigations that exist. Resources, training and experience vary. There is no standardization for autopsies that exist similar to the scene investigation guidelines created by the CDC. And the difficulty of investigating these sudden deaths takes several weeks or many months before a case report is completed.

Simultaneously, there is an investigation by law enforcement to determine if a crime has been committed, all the while, young families are grappling with their loss, planning funerals and explaining to siblings why their brother or sister is not coming home.

We know that the creation and revision of the CDC’s Sudden Unexplained Infant Death Reporting Form (SUIDIRF) guidelines, training manual and curriculum coincide with improved data collection and have helped identify some causes of death that otherwise would have been left unexplained. However, the continued need for training is apparent. Death Investigators explain that these are some of the most difficult cases they work on. Not only are they extremely emotional and stressful environments but their investigation is heavily reliant on their ability to interview highly distraught parents and collect detailed and delicate information from them. Additionally, the scene is virtually always disturbed and chaotic due to rescue efforts at the home and frequent transportation to a hospital which results in them investigating the scene without the baby present after some time. These advanced skills require specialized training, covered in the CDC's training curriculum for SUID, to collect important information that the pathologist needs before they perform the autopsy.

For more information: http://www.cdc.gov/sids/SUIDAbout.htm

**Current efforts of the CDC regarding Sudden Unexplained Infant Deaths (SUID)**

In addition to the CDC's SUIDIRF, the SUID case registry project was created in 2010 by the CDC in partnership with the National Center for Child Death Review (NCCDR), and is funded by the Health Resources and Services Administration. Currently it includes 9 pilot states (Arizona, Colorado, Louisiana, Michigan, Minnesota, New Jersey, New Mexico, New Hampshire, and Wisconsin) who partner to collect and analyze comprehensive information on sudden infant deaths that occur in their state. Data is analyzed after the investigation is complete through the child death review process and utilized to create prevention strategies and enter the data into the web-based reporting system of NCCDR.

For more information: http://www.cdc.gov/sids/CaseRegistry.htm

The SUID case registry does not support or impact the training of death investigators, nor address the lack of standardization and quality of autopsies and therefore the data that is collected is often incomplete and weakens the strength of its analysis.

**Current efforts of CDC regarding Sudden Unexplained Deaths in Childhood (SUDC)**

There are no current efforts by the CDC to address SUDC specifically. Sudden Unexplained Death In Childhood of 1- 4 year olds is more rare that Sudden infant death. SIDS being 4O times more common than SUDC. Not surprisingly, there is little known about these deaths and due to their rarity, they are very difficult to study by any one jurisdiction, state or even region. There are also no scene investigative standards or autopsy guidelines for these deaths. Therefore the collection of comprehensive data on SUDC cases is extremely limited but its collection is vital to improving our understanding and pursuit of its prevention.

## Investigating Stillbirth and Current Efforts of the CDC

Approximately 26,000 babies a year in the US are stillborn (using the definition of 20 weeks gestation or more) which represent nearly half of all perinatal deaths. Additionally, there is not an identifiable causes for about half of all Stillbirths.

Current surveillance of Stillbirths occurs most commonly through fetal death records but studies show that the data collected is often incomplete and insufficient. (see references)

Post mortem investigations (autopsies) are also limited in Stillbirth, estimated as less than 40%. Postmortem findings often take weeks to finalize and therefore are often not included in fetal death records which are submitted within days of death. Although guidelines for Stillbirth investigation have been created by ACOG, it is clear they are not widely used.

The state of Iowa, Metropolitan Atlanta and, more recently, counties around Denver, parts of Hawaii and Western NY have joined in a CDC funded effort to gather comprehensive and standardized data through their birth defect surveillance program on Stillbirth which includes pregnancy related data and post mortem information. Studies have shown the benefit of such a program structure outweighs the information gathered from the fetal death record system alone.

Education of healthcare providers and expectant families is also needed to emphasize and teach the importance and potential benefit of prenatal health initiatives such as fetal movement awareness, G group B strep screening, obesity prevention/treatment, etc.

**HR669 seeks to address Stillbirth** by expanding state-based registries and standardized surveillance data to 8-9 states in order to provide a representative sample of Stillbirth deaths in the U.S. which will aid public health in creating evidence based strategic initiatives and fostering meaningful research to better understand the thousands of Stillbirths that occur each year each year.

## The Greatest Need Today: Improve Data Collection!!!

The lack of progress seen in the CDC SUID rates since the late 90's forces us to examine the complicated process when an infant or young child dies. This includes the medicolegal death investigation system as well as the efforts of those trying to understand and prevent these deaths through public health and research.

HR669 strategically addresses the single most important factor that effects our ability to inform families, arm public health with comprehensive and standardized information they can rely on to determine risk factors and create evidence based intervention measures, as well as, foster successful research by being able to ensure accurate and consistent data.

HR669 will improve the collection and analysis of standardized data that is only available in the first crucial hours of the investigation- and prevent it from being lost forever- and thereby maximize the ability to learn from every one of these tragic death.

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