

S. 1130, the Scarlett's Sunshine on Sudden Unexpected Death Act

Introduced by Senators Casey, Isakson, Brown, and Jones

Background

Sudden Unexpected Infant Death is any sudden and unexpected death that occurs during infancy (from birth to age one), including Sudden Infant Death Syndrome (SIDS) and other ill-defined deaths. In 2016, about 3,600 infant deaths were sudden and unexpected. SIDS is the fourth leading cause of infant deaths.

Sudden Unexpected Death in Childhood is any sudden and unexpected death of a child who is 1 year of age or older that, when first discovered, did not have an obvious cause. Even after thorough investigation, 236 children between 1–4 years of age died without clear explanation in 2016. These unexplained deaths are the fifth leading cause of death in young children.

- Achieving lower rates of death in these categories is problematic. Over the past five years, rates of sudden unexpected deaths in infants and children remained relatively flat.
- Inconsistent death reporting has hindered progress. Sleep-related factors remain a leading factor in unexpected infant deaths. However, despite thorough investigations, it remains challenging to identify root causes for other deaths, especially in children ages 1–4. Inconsistent death case reporting, coupled with inconsistent findings, make it challenging for public health officials and clinicians to change practice and advise parents accordingly.
- Children and families benefit from outreach services. Local and national groups, including non-profit organizations and public-private partnerships, have developed evidence-based outreach programs for parents and families to promote safe sleep. Improved capacity to support families, especially those in underserved communities, can help reduce infant and young child mortality.

Legislation

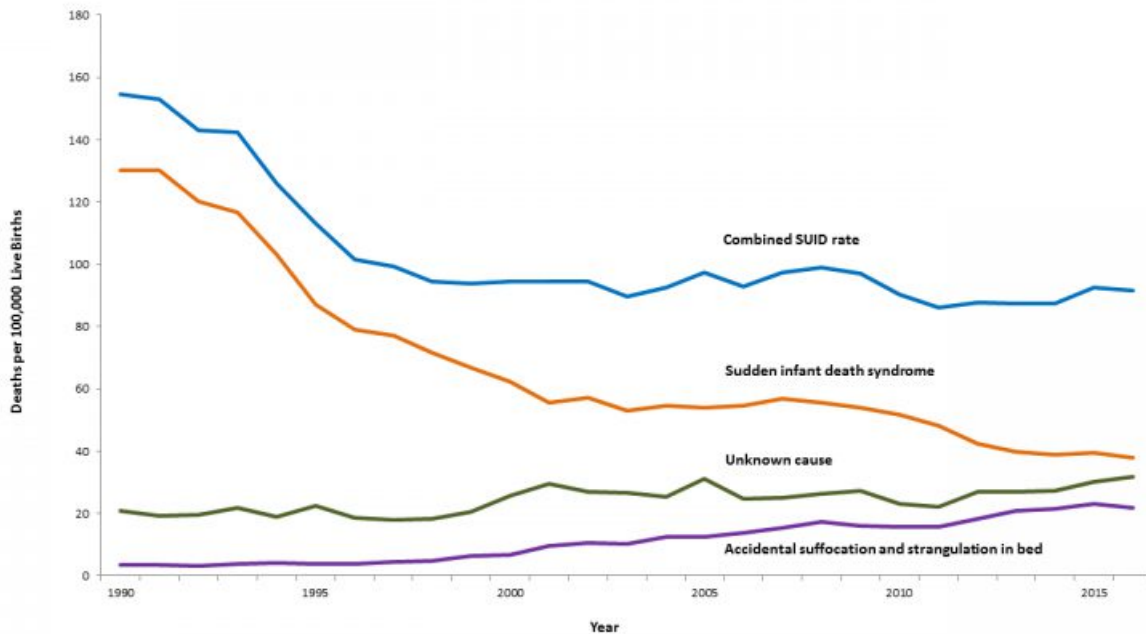
Scarlett's Sunshine Act would strengthen existing efforts to better understand sudden unexpected deaths in infants and children, facilitate data collection and analysis to improve prevention efforts, and support children and families.

- Establishes a grant program for states to engage in activities to address sudden unexpected infant death and sudden unexpected death in childhood, including:
 - Supporting state fetal and infant mortality and child death review programs.
 - Improving data collection related to unexpected infant and child deaths, including by improving the completion of comprehensive death scene investigations and autopsies and training death scene investigators.
 - Identifying, developing and implementing best practices to reduce or prevent these unexpected deaths.
 - Increasing participation in registries for the purposes of conducting research into sudden unexpected infant and child deaths.
 - Disseminating information and materials to health care professionals and the public on risk factors for unexpected death, including sleep-related risk factors.

- Directs the Secretary to encourage the use of the Sudden Unexplained Infant Death Investigation Reporting Form (which is used to ensure consistency of data collected on infant deaths) and assess whether it needs to be updated; it also directs the Secretary to encourage the use of a new form recently developed in collaboration with CDC to report sudden unexpected death in childhood.
- Requires annual reports to the Senate HELP and House E&C Committees to include the absolute number and incidence of sudden unexpected deaths in infants and children, actions undertaken, and any new recommendations.

Scarlett’s Sunshine Act will support existing efforts to understand sudden unexpected deaths in infants and children, support communities in their response to infant and child death cases, and support parents and children with education and support.

U.S. Rates of Sudden Unexpected Infant Death, 1990-2016



Source: <https://www.cdc.gov/sids/data.htm>

This legislation has been endorsed by the following groups:

- American Academy of Pediatrics
- March of Dimes
- Children’s Hospital Association
- Cribs for Kids
- First Candle
- SUDC Foundation
- KID: Fighting for Product Safety
- Aaron Matthew SIDS Research Guild of Seattle Children’s Hospital
- Child Care Aware

For more information or to become a cosponsor, please contact Sara Maskornick (Sara_Maskornick@help.senate.gov) in Senator Casey’s office, or Will Dent (William_Dent@isakson.senate.gov) in Senator Isakson’s office.