

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

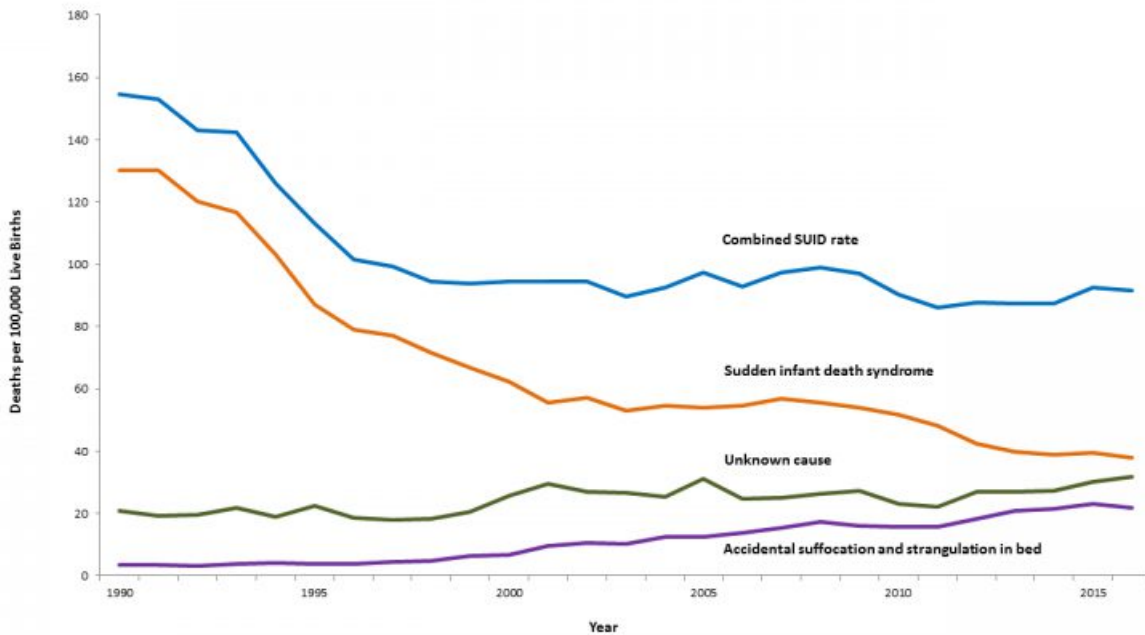
Scarlett's Sunshine Act would strengthen existing efforts to better understand sudden unexpected deaths in infants and children, facilitate data collection and analysis to improve prevention efforts, and support children and families.

- The bill directs CDC to revise standardized case reporting forms for sudden unexpected deaths in infants and children, and align the forms with the National Fatality Review Case Reporting System. It also authorizes grants to states and local agencies to increase the completion of comprehensive death scene investigations for sudden unexpected deaths in infants and children, cases using standardized protocols and comprehensive autopsies. It also authorizes the CDC director to work with experts to develop recommendations for a standard protocol for determining when to utilize genetic analyses along with standards and protocols for the collection and storage of specimens suitable for genetic analysis. The bill also provides training grants and materials for death scene investigators, and authorizes the National Infant and Child Death Case Reporting System. Authorizes \$11 million per year in new federal funding for these activities.
- The bill provides HRSA grants to states to enable 100 percent review of all infant and child deaths, and support data infrastructure so the data can inform prevention experts and clinical care. Authorizes \$15 million per year for these activities.

- The bill creates new HRSA grants for outreach efforts to educate families on safer-sleep practices for infants and provide low- or reduced-cost products conducive to safer sleep consistent with recommendations from national organizations. Authorizes \$33 million over 5 years for these activities.
- Finally, the bill would require 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

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