S. 3521, the Scarlett’s Sunshine on Sudden Unexpected Death Act
Introduced by Senators Casey, Isakson and Brown

**Background**

**Sudden Unexpected Infant Death (SUID)** refers to 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 infants died in the United States and were classified as SUID. SIDS is the third leading cause of infant deaths.

**Sudden Unexplained Death in Childhood (SUDC)** refers to the death of a child 12 months and older, which remains unexplained after a thorough case review is conducted. In 2016, 236 children between 1–4 years of age died without clear explanation. SUDC is the fifth leading cause of death in young children.

- Achieving lower rates of SUID and SUDC has been elusive. Over the past five years, SUID and SUDC rates 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 SUID and SUDC, 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 SUID and SUDC, and authorizes grants to states and local agencies to improve SUID/SUDC case reporting form completion and autopsies. It also authorizes a CDC-commissioned study to advise on the appropriateness of genetic analyses and best practices for testing in these cases. The bill also provides training grants and materials for death scene investigators, and authorizes the National Infant and Child Death Case Reporting System. Authorizes $111 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 recommendations from national organizations. Authorizes $33 million over 5 years for these activities.

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 (will_dent@isakson.senate.gov) in Senator Isakson’s office.
Finally, the bill would require annual reports to the Senate HELP and House E&C Committees to include the absolute number and incidence of SUID/SUDC, actions undertaken, and any new recommendations.

**Scarlett’s Sunshine Act will support existing efforts to understand SUID and SUDC, 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](https://www.cdc.gov/sids/data.htm)

This legislation has been endorsed by the following groups:

- American Academy of Pediatrics
- Children’s Hospital Association
- Cribs for Kids
- First Candle
- John Kahan, President Aaron Matthew SIDS Research Guild of Seattle Children’s Hospital and Chief Data Analytics Officer, Microsoft, CELA
- Kids in Danger
- March of Dimes
- SUDC Foundation
- Within Our Reach

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