

**S.1130 116**

**th**

**Congress**

**Introducing Senate**

**Sponsor**

**s**

**:**

Bob Casey (D

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PA)

, Johnny Isakson

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GA), Sherrod Brown (D

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OH)

Doug Jones (D

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AL)

**H.R. 2271 116**

**th**

**Congress**

**Introducing**

**House Sponsor**

**s**

**:**

Rep.

Gwen Moore (WI

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Rep. Tom Cole (OK

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Rep. Jaime Herrera Beutler (WA

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**We urge you to cosponsor Scarlett’s Sunshine for Sudden Unexpected Death Act (S1130, HR2271.)** This bill will improve our understanding of the causes of sudden unexpected death of infants and children by facilitating and standardizing data collection and analysis. It will also improve prevention by enhancing safe sleep education to address a major factor contributing to sudden infant death. It is named after Scarlett Pauley who was lost to Sudden Unexplained Death in Childhood (SUDC) in January 2017 when she was just 16 months old. Scarlett was happy, healthy and thriving when she went to sleep one night and never woke up. Her death was tragic, as are the deaths of too many children across the United States.

**According to statistics from the Centers for Disease Control and Prevention (CDC), we have lost approximately 80,000 children since the mid-1990s in the U.S., equating to approximately two busloads of children every week from Sudden Unexpected Infant Death and SUDC.**

The U.S. ranks 32nd of 35 developed countries in infant mortality. **Sudden Unexpected Infant Death (SUID**), which accounts for more than 3,600 infant deaths annually, is the leading cause of infant death. SUID includes infant deaths that are later explained, such as accidental suffocation or strangulation in bed (ASSB), as well as deaths that remain unexplained after a thorough investigation, review of clinical history, and autopsy, which are known as “Sudden Infant Death Syndrome” (SIDS).   **Sudden Unexplained Death in Childhood (SUDC)** is defined as death in children between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy. SUDC is the 5th leading category of death in children ages 1 to 4. We have seen no measurable reduction in the overall rate of SUID or SUDC since the late 1990s**.** Currently we do not know what causes SIDS or SUDC or how to predict or prevent these deaths.

We need to enable researchers to study ways to reduce the incidence of SUID and SUDC. To inform that research we need to develop a system of consistent data collection on these deaths that includes data on children and their parents. Scarlett’s Sunshine Act will enable us to be a world leader in saving children’s lives by:

**Improving data quality and availability:**

* Supporting and strengthening fatality case reporting systems, including increasing the number of states participating in these registries; improving the utility of data collected in registries by making it available to researchers in a timely manner; and encouraging the use of CDC reporting forms to improve the quality of data submitted to registries
* Improving and standardizing data collection on SUID and SUDC deaths, including improving the completion of death scene investigations; training of medical personnel and others who conduct death scene investigations; and voluntary inclusion of genetic materials in registries

**Sharing information on known risk factor**s:

* Identifying, developing and implementing best practices to reduce the incidence of SUID and SUDC, including safe sleep practices; and disseminating information on risk factors to health care professionals and the public

**Establishes new monitoring measures:**

* Requiring biennial reports to Congress to include the absolute number and incidence of SUID/SUDC, actions undertaken, and any new recommendations