

Representative Kennedy,

My wife and I are writing in support of Scarlett's Sunshine Act. We request that you submit the following to the Subcommittee on Health of the Committee on Energy and Commerce hearing on "Legislation to Improve Americans' Health Care Coverage and Outcomes" on January 8, 2020. We are grateful to you for co-sponsoring Scarlett's Sunshine Act and for elevating this bi-partisan, bi-cameral bill.

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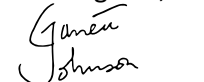
Our son Luke was a healthy, fully-vaccinated, walking, playful, and carefree 18-month-old toddler. Luke stood out for his serenity and joy; he was an old soul who loved to smile, eat berries, and laugh. In March 2019, we put our apparently healthy son to bed. We never thought that our son would not wake up, yet our worst nightmare unfolded the next morning. Tragically, we are not alone: hundreds of healthy children over the age of one die suddenly and unexpectedly every year.

Scarlett's Sunshine Act will work to improve investigations into and statistical reporting of unexplained death in children under 5 years. Unexplained death is the 5th leading category of toddler (age 1-5) death in the U.S.. However, medical examiners are ill-prepared to handle these cases, resulting in the full scope of the problem being unclear. Our own son's cause of death was not classified as Sudden Unexpected or Unexplained Death in Childhood (SUDC), even though he is a classic case, because of local medical examiner autopsy reporting norms. Many parents have waited many months or even years for autopsy results all the while living with the anxiety and guilt provoked by the sudden and unexplained nature of their loss.

We are exceptionally fortunate to have stumbled into the Robert's Program at Boston Children's Hospital, a Boston-based research program conducting leading-edge research in SIDS and SUDC. Having a clearer sense of our son's cause of death—and that there was no way we could have predicted or prevented it—ameliorated the considerable guilt we feel as bereaved parents. The guilt and stigma that follows these deaths is a burden no parent should bear. Guilt and stigma are especially acute for parents of SIDS (age <1) victims, who face the public misconception that sleep position causes SIDS when unsafe sleeping efforts is only a risk factor, not a cause. Low-income bereaved parents face even greater legal suspicion and are much less likely to find community resources.

More than anything, we hope that greater attention and research in sudden and unexplained death in children will one day help us identify and treat children who are at risk. We hope future parents will be spared the greatest pain they can know.

Best regards,



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*More information*

SUDC Foundation: <https://sudc.org/>

Robert's Program at Boston Children's Hospital: <http://www.childrenshospital.org/robertsprogram>