

**Testimony of John Kahan**  
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**House Energy and Commerce Subcommittee on Health Hearing**  
**Legislation to improve Americans' health care coverage and outcomes**

**January 8, 2020**

Chairman Eshoo, Ranking Member Burgess and members of the Health Subcommittee, thank you for giving me the opportunity to submit testimony in support of H.R. 2271, Scarlett's Sunshine on Sudden Unexpected Death Act.

On October 6, 2003, the lives of my wife and I were turned upside down when we lost our only son, Aaron Matthew to Sudden Infant Death Syndrome (SIDS). As we started to learn more about SIDS, we were frustrated by what we discovered: it is the leading cause of death in infants, one month to one year of age, in all developed nations. In the United States alone, more than two busloads of children a week – 3,500 a year -- die of SIDS related causes. That's why we have dedicated our lives to ensuring no parent experiences a similar loss or worries their child will be next.

The Aaron Matthew SIDS Research Guild was founded with an innovative approach to solving the medical mystery of SIDS. We bring some of the world's leading data scientists, led by Microsoft, together with some of the world's best medical researchers at the Center for Integrative Brain Research Institute at Seattle Children's. Together they are discovering exciting new avenues of research that are now enable researchers in the field to test their theories using large data sets that were previously unavailable.

The Aaron Matthew SIDS Research Guild is also embarking on its most promising research effort to date – building the first cloud-based genetic database specifically dedicated to SIDS and ultimately infant mortality. This effort, a collaboration between Microsoft and Seattle Children's, promises to bring genetic data from around the world to researchers so they can analyze the genome sequences of babies lost to SIDS for anomalies and clues.

Despite all this promise, we still do not know what causes SIDS nor do we know how to predict or prevent them. All up, SIDS related deaths known as Sudden Unexpected Infant Deaths (SUID) have remained flat since the mid 90s. As medical researchers, data scientists, and business professionals we know what it takes to get us on a path to solve this terrible mystery, and the Scarlett Sunshine on Sudden Unexpected Death Act will help us get there.

H.R. 2271 would strengthen existing efforts to better understand the causes of SIDS by facilitating data collection and analysis to improve prevention efforts. We need to enable researchers to study and find better ways to reduce the incidence of Sudden Unexpected Infant Death (SUID; defined as sudden unexpected deaths in infants between one month and one year) and Sudden Unexplained Death in Childhood (SUDC; defined as death in children between 1 and 18 years that remains unexplained after a thorough investigation, including an autopsy). We need to develop an ongoing system of consistent data collection on all births/deaths that includes data on infants (or children) and both parents. We need to enable our top medical researchers and world class data scientists to succeed. Many of us are parents who have lost children to SUID or SUDC, and we know firsthand the impact on us and on parents everywhere. We have an obligation to turn our technological advances into medical advances that will save many lives.

Scarlett's Sunshine on Sudden Unexpected Death Act takes the following critical steps:

- **Strengthen data consistency and completion** by directing the CDC to authorize grants to state and local agencies to revise standardized case reporting forms for SUID and SUDC.
- **Enables updated data collection guidelines by** authorizing a CDC-commissioned study to advise on the appropriateness of genetic analyses and best practices for testing in these cases.
- **Authorizes funding for essential grants** to support, among other things:
  - Training grants and materials for death scene investigators
  - Grants to states to review of all SUID and SUDC cases; and to support data infrastructure that will enable the leveraging of data to inform prevention experts and clinical care.
  - New HRSA grants for outreach to educate families on safer-sleep practices for infants, to provide low- or reduced-cost products conducive to safer sleep recommendations from national organizations, and for new local grants to support grieving families.
- **Establishes new monitoring measures** by requiring annual reports to the appropriate Senate committees to include the absolute number and incidence of SUID/SUDC, actions undertaken, and any new recommendations.
- **Improve training** to address unsafe sleep practices, a major factor contributing to SIDS.

Those of us who have experienced the tragedy of SIDS personally understand the toll it takes. And no new parent, or their extended families, will rest easy until we have solved it. We believe that we are on the cusp of a breakthrough with researchers closer than ever to finding the answers to this confounding and devastating medical mystery. But we can't get to the finish line without your help. I urge all members of this subcommittee to support H.R. 2271 and for the Committee to favorably report the bill to the full House for consideration, doing so will help bring us all closer to a world without SIDS.

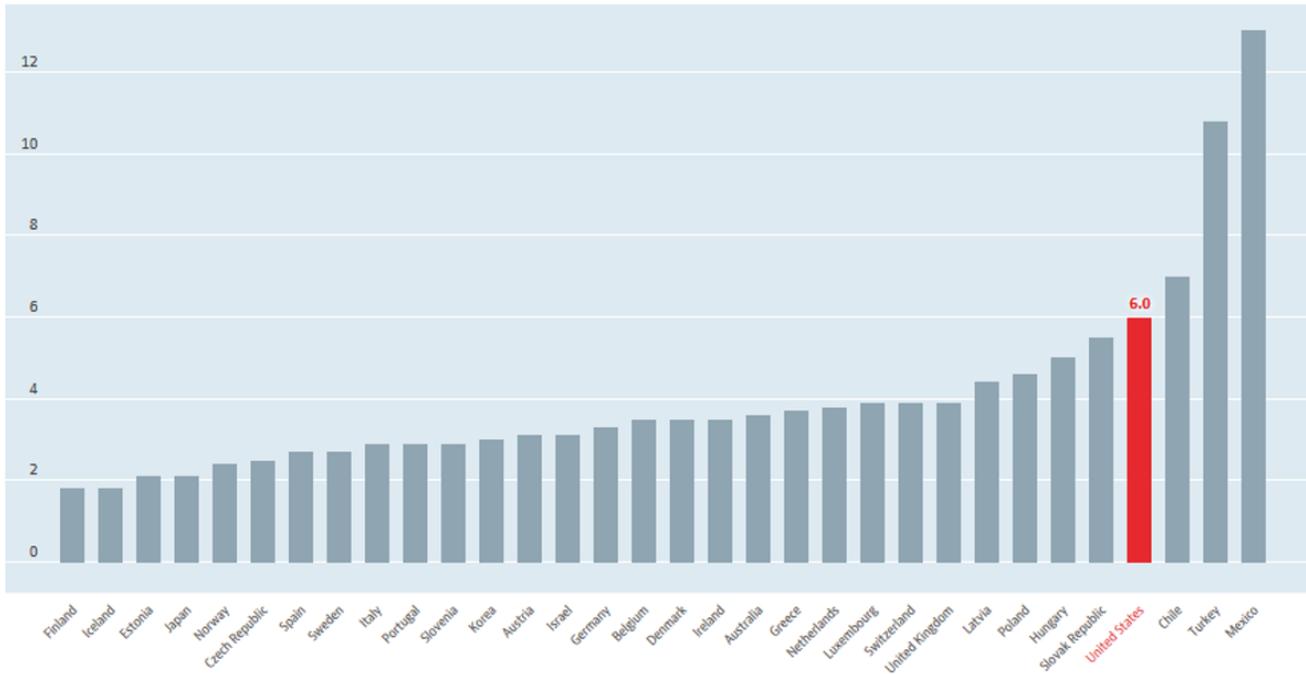
## Background

The CDC includes three categories in its definition of Sudden Unexpected Infant Death:

1. SIDS: Sudden Infant Death Syndrome: the sudden and unexplained death of an infant between one month and one year;
2. Accidental suffocation in a sleeping environment; and
3. Other deaths from unknown causes

### Infant mortality rates

deaths in the first year of life/1,000 live births, OECD countries, 2013



The following [data](#) from the Centers for Disease Control shows that while SIDS rates in the U.S. have come down, the overall SUID rate has not improved since the mid '90s. While we have seen great strides in prevention of death due to neonatal preterm birth complications (still the leading cause of death worldwide), there hasn't been a comparable improvement in preventing SUID or SUDC.

Trends in Sudden Unexpected Infant Death by Cause, 1990-2015

