

## If you have lost a child to a sudden unexpected death:

The SUDCRRC partners with the SUDC Foundation to provide grief support services throughout enrollment and beyond. The family incurs no costs for study enrollment or service participation. They are connected to a parent peer support community that is available worldwide. For more information:

**Phone:** Calling SUDC at 800-620-SUDC (7832)

**Email:** [info@sudc.org](mailto:info@sudc.org)

**Web:** Go to [SUDC.org](http://SUDC.org) and click on the orange "Bereaved Families" button

## If you are a professional...

and would like to refer a family or learn more about the SUDC Registry and Research Collaborative, please contact the SUDCRRC Research Scientist, Laura Gould Crandall, by:

**Telephone** at 646-754-2230

**Email** to [laura.crandall@nyulangone.org](mailto:laura.crandall@nyulangone.org)

## The SUDCRRC Members

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# Striving to Understand and Prevent Sudden Unexplained Death in Childhood



**SUDCRRC**  
*SUDC Registry and Research Collaborative*

SUDC is defined as the sudden death of a child greater than 1 year of age that remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the child's medical history. (Krous et al. 2005)

#### **How often does SUDC occur?**

According to the Center for Disease Control (CDC), approximately 243 children between the ages of 1 and 4 years, 33 children between the ages of 5 and 9 years, 39 children between the ages of 10 and 14 years, and 74 children between the ages of 15 and 18 were affected by sudden unexplained death in 2017. The incidence of SUDC in toddlers is about 1.5 per 100,000 children. This rarity makes research difficult.\*

*\*Based on Codes R95-99 of CDC Wonder Database, 2017*

#### **About the Registry**

The SUDC Registry and Research Collaborative is now available to assist families and the medicolegal death investigation community when these tragedies occur.

Before you make your decision to participate in the SUDC Registry and Research Collaborative, you will need to know what the study is about, the possible risks and benefits, and what your participation would involve. You may also decide to discuss the study with your family, friends or doctor before making a decision. Please take your time to make your decision and please be sure to ask the study investigators any questions that you may have.

#### **The Purpose of the SUDC Registry and Research Collaborative is...**

The purpose is to increase the understanding of the characteristics, circumstances surrounding death, medical histories and pathologies of children from ages 11 months through 18 years who have died suddenly and unexpectedly, and in some instances, without explanation.

The SUDC Registry and Research Collaborative will analyze cases of sudden unexpected deaths in children to understand risk factors and causes, and develop preventative measures. By bringing together these rare cases, we hope to support grieving families with a greater understanding of their child's death and support medical research efforts into all causes of Sudden Unexplained Death in Childhood.

#### **The SUDC Registry and Research Collaborative will...**

- Review the child's death, medical and family history by our study pathologists (including forensic, pediatric, cardiac and neuropathologists) to determine whether a possible, probable or definite cause of death can be identified and whether additional studies would be helpful in determining a specific cause of death
- For case investigations that are open/active, the registry offers neuroimaging and neuropathology consultation
- For those cases confirmed to be unexplained after review - access to genetic analysis (whole exome sequencing) when viable samples are available. Additional genetic analysis opportunities for biological parents and some family members.
- Study the risks that lead to sudden unexplained death in childhood (SUDC)
- Provide families with a review of their child's death through a study report
- Identify at-risk individuals with the hopes of gaining knowledge to establish prevention strategies to reduce the chances of sudden unexplained death in the future.

#### **Participation Requirements include...**

Participants must be a parent or guardian of a child from 11 months through 18 years of age who has died suddenly and unexpectedly where the cause is unknown or unclear, and where an investigation has occurred.