

Working Together to Support Families and Solve SUDC

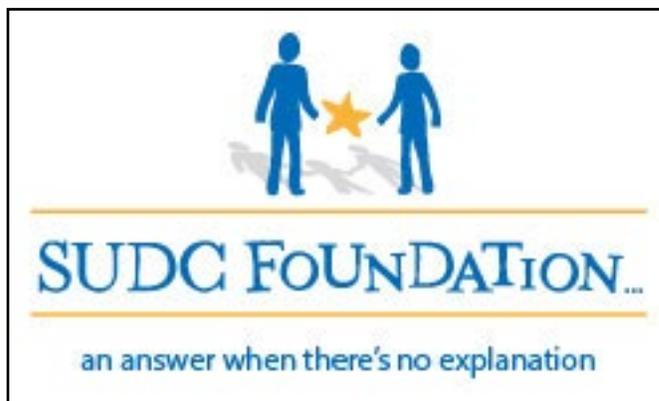
Caring for the family who has suffered the sudden and unexpected death of a child has always been central to the mission of the SUDC Foundation. That care takes many forms.

The SUDC Foundation was founded in 2014 (previously a program since 2001), to be the central resource for families and professionals affected by these tragedies. We remain the only organization worldwide focused on sudden deaths of children older than 12 months of age. Our services are free, funded by private donations, largely from families holding fundraising events to support other families and eradicate SUDC.

Although it seems rare, due to lack of awareness, sudden unexplained deaths in children is more common than most believe. The U.S. Centers for Disease Control and Prevention identifies about 400 sudden childhood deaths between the ages of 12 months and 19 years of age for whom no cause is identified. Most are toddlers, aged 12 months to 4 years, which represents the 5th leading category of death of toddler aged children.

Family support is a core service at the SUDC Foundation that takes many forms. Our services for families include: Individualized case advocacy to assist families with navigating the death investigation process, personalized support by licensed clinical social workers, private web-based support groups, peer support programs matching trained family volunteers with newly bereaved, resources for siblings and grandparents, memorial and event planning websites, DNA Banking Services, SUDC research opportunities, private access to a Family Directory, and support to host events supporting SUDC.

Our support for MDI professionals currently includes: help with the care and communication of families experiencing



such a death, the ability to create a personalized “Help For Families” brochure for your office, assistance completing DNA banking services for the family, information services, access to our SUDC Scientific Advisory board, research opportunities, publications on SUDC, and advocacy for optimal public policy and legislation for MDI issues. Our most effective collaborations to benefit investigation and care of the family relies on clear communication as early in the investigation as possible.

Living without answers and an unspoken anxiety and uncertainty regarding the possible recurrence of SUDC in another sibling, are some of the lasting consequences of these inexplicable deaths. In 2014, we collaborated with NYU Langone Medical Center to create the SUDC Registry and Research Collaborative (SUDCRRC). This is a collaborative partnership involving NYU, Columbia University, the Mayo Clinic (MN), Forensic Pathologists, and partnering Medical Examiner and Coroner offices around the country. SUDC is too rare for any one office to be able to study comprehensively. By bringing cases together into the registry, we can identify trends and create a large database for researchers.

The study design of the SUDCRRC is three-fold: 1) Assist families with access to additional testing commonly not available in most death investigations, 2) Assist Medical Examiner and Coroner offices' investigation of these cases by providing access to study resources, such as whole brain neuroimaging, comprehensive neuropathology and genetic analysis, and 3) enhance our limited understanding of this deaths and communicate that to the medical community through published works. The vast majority of families want to pursue additional research if the death investigation is inconclusive. Their reasons often include the hope of more information about their child's death, as well as helping medical research in general who to prevent this in others.

The SUDCRRC handles all consent procedures with the family and reimburse MDI offices for all study incurred expenses including shipping supplies, shipping costs, slide recuts etc. The study will review the child's death, medical and family history, neuroimaging/neuropathology evaluations, and genetic analysis (whole exome sequencing) on the child who died, both parents and

some family members. The SUDCRRC will study the risks that lead to sudden death, identify at-risk individuals with the hopes of gaining knowledge to develop prevention strategies.

The SUDC Foundation and the SUDCRRC collaborate with families and referring MDI offices throughout the investigation process and study participation. Our open and ongoing communication helps to reduce confusion for families, conveys unified compassion in a deeply traumatic situation, and our combined commitment to help support them and uncover the true explanation of their child's unexpected death. To learn more about the SUDC Foundation or SUDCRRC, go to www.sudc.org

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