Inexplicable Child Deaths: Medicolegal Death Investigation Resources From the SUDC Foundation and the SUDC Registry and Research Collaborative

Laura Gould Crandall

Acad Forensic Pathol. 2017 7(2): xxiv-xxvii

Every year in the US, about 400 children between one and 18 years of age die suddenly and unexpectedly without a known cause (1). Over 60% of these deaths are toddlers, aged one to four years, representing the fifth leading category of deaths for this age group (1). In 2005, the term SUDC—or sudden unexplained death in childhood—was first described. Defined as the sudden and unexpected death of a child 12 months and older that remains unexplained after a thorough case investigation is conducted, it must include examination of the death scene, performance of a complete autopsy, and a review of the child's and family's medical history (2). Sudden unexpected death in childhood is not a diagnosis, but a category of death that currently eludes our scientific understanding yet conveys a subcategory of undermined deaths that are comprehensive and not deemed suspicious.

Lacking public funding for family support services, public health campaigns or directed research funds, the barriers to an accurate understanding and prevention of these deaths are immense. Falling under the purview of the medicolegal death investigation (MDI) system, these cases can also be some of the most challenging, frustrating, and disheartening for all involved. However, the SUDC Foundation and the SUDC Registry and Research Collaborative (SUDCRRC) can

now support investigations of these deaths with no-cost access to neuroimaging, neuropathology, genetic analysis, clinical resources, and directed support services for families.

The SUDC Foundation is a national nonprofit organization dedicated to increasing the awareness of sudden

An Answer When
There's No Explanation

Page xxiv

Crandall • SUDC Foundation

ACADEMIC FORENSIC PATHOLOGY: THE OFFICIAL PUBLICATION OF THE NATIONAL ASSOCIATION OF MEDICAL EXAMINERS

©2017 Academic Forensic Pathology International

Downloaded from www.afpjournal.com by an AFP Journal subscriber

This article is for personal use only and may not be shared or distributed in any fashion

unexpected deaths in childhood, and funding research to understand and prevent these tragedies. The Foundation is devoted to the needs of professionals and families, funding crucial research, helping hundreds of families in over 16 countries, and leading advocacy efforts, including the passage of the Sudden Unexpected Death Data Enhancement and Awareness Act, which was signed into law by President Obama in December 2014. The Foundation is funded by private donations—primarily from families affected by SUDC.

The Foundation's comprehensive no-cost services are available to all professionals and families affected by the sudden unexpected and often unexplained death of a child.

Services for MDI Professionals

A sudden death of a child profoundly affects the professionals involved. The SUDC Foundation can assist the MDI community with services including:

- **Research:** The Foundation provides crucial funding of SUDC research and communicates new research publications and access to research opportunities, including the SUDC Registry and Research Collaborative (see below).
- **DNA Banking Services:** The SUDC Foundation advocates and supports DNA banking after the sudden death of a child to ensure opportunities for future genetic analyses. The Foundation provides logistical support for your office to attain DNA banking for families.
- **Information Services:** Through our newsletters,

website and social media updates, we provide you with up to date information about SUDC. If you would like to join our mailing list, you can sign up at www.sudc.org.

- **SUDC Scientific Advisory Board:** A multidisciplinary board of forensic pathologists, clinicians, and researchers to provide updated information to assist professionals. This includes guidance for classification, autopsy, and death scene investigations.
- **The care of and communication with families:** SUDC staff will assist with family communication and act as a liaison between them and your office during the investigation, provide them bereavement support with our social workers and peer community, and help them navigate the investigation process with realistic expectations.
- **Help for Families Brochure:** A brochure to assist medical examiners and coroners offices communicate with families during the investigation of sudden pediatric deaths. The brochure explains the death investigation process, the professionals involved, and bereavement services. It is personalized to the needs of the specific office. Printing is available upon request.
- **Advocacy in public policy and legislation:** The Foundation supports all efforts to ensure that MDI professionals have the resources and training needed to provide comprehensive and standardized investigations, as well as continued research.

LOVE BEYOND REASON

Supporting families when there is no answer. Find out more sudc.org

Services for Affected Families of Sudden Unexpected Deaths of Children

The SUDC Foundation provides no-cost bereavement and support services to affected families of any sudden unexpected childhood death, connecting them with our worldwide support community of over 800 families who have experienced similar losses. Services include, but are not limited to:

- Individualized case advocacy to help navigate the death investigation process.
- Personalized support by licensed clinical social workers.
- Private web-based peer support groups specific to sudden unexpected child deaths, that are moderated by mental health specialists.
- Peer support programs matching trained family volunteers with newly bereaved.
- Resources for siblings and grandparents.
- Personalized memorial websites.
- DNA banking services.
- SUDC research opportunities.
- Access to Foundation Family Directory.
- Support and resources for event planning and fundraising.

The SUDC Registry and Research Collaborative was created in 2014 with the recognition that in order for the MDI community to provide comprehensive investigations into sudden child deaths and support research, MDI must be supported with adequate re-

sources. The SUDCRRRC collaborative links researchers at the New York University Langone Medical Center, Columbia University, the Mayo Clinic, forensic pathologists, and crucial MDI partner offices.

Our goal is to increase the understanding of the characteristics, circumstances, medical histories, and pathologies of children from ages 11 months through 18 years of age who have died suddenly and unexpectedly, and sometimes, without explanation. The SUDCRRRC will:

- Contact the family and obtain informed consent.
- Provide proof of written consent to MDI office.
- Perform neuroimaging on whole, fixed brains, with standard fixation for two weeks at MDI office and provide full neuropathology evaluation.
- Provide referring office with full whole brain magnetic resonance imaging and neuropathology report (within 12 weeks) to sign out case, genetic, and case review reports upon completion.
- Review the child's death, medical, and family history by our study forensic, pediatric, cardiac, and neuropathologists to determine whether a possible, probable, or definite cause of death can be identified and whether additional studies might be helpful.
- Provide shipment kits for central nervous system specimens, genetic testing specimens, glass slides, and investigative reports.
- Cover all expenses incurred by the medical examiner or coroner (shipping supplies, shipment costs, slide recuts, etc.).
- Provide ongoing mental health support to next of kin throughout study.
- Perform genetic analysis (whole exome sequencing) on the child who died, both biological parents, and some family members.

SUDCRRRC
SUDC Registry and Research Collaborative

The SUDC Foundation and the SUDC Registry and Research Collaborative are dedicated to supporting professionals and families affected by sudden unexpected deaths of children. By partnering with affected family members and the MDI community, a collaborative effort to understand these tragedies and assist in their prevention is achievable.

For more information, to become a MDI study partner, and/or refer a family, go to:

Web: www.sudc.org

Email: info@sudc.org

Phone: 800.620.SUDC (direct dial 973.239.4849)

Fax: 973.559.6191

REFERENCES

- 1) CDC WONDER [Internet]. Atlanta: Centers for Disease Control and Prevention, National Center for Health Statistics, c2016. About multiple cause of death 1999-2015; [cited 2016 Dec 16]. Available from: <http://wonder.cdc.gov/mcd-icd10.html>.
- 2) Krous HF, Chadwick AE, Crandall L, Nadeau-Manning JM. Sudden unexpected death in childhood: a report of 50 cases. *Pediatr Dev Pathol*. 2005 May-Jun; 8(3):307-19. PMID: 16010494. <https://doi.org/10.1007/s10024-005-1155-8>.