Sudden Unexplained Death in Childhood

Sudden Unexplained Death in Childhood (SUDC) is a category of death in children between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy. Most often, a seemingly healthy child goes to sleep and never wakes up.

At this time, we do not know what causes SUDC, how to predict it or how to prevent it.

A medical examiner or coroner could rule a child’s death SUDC when s/he completes a thorough evaluation and finds no other cause of death.

SUDC Facts

SUDC is believed to be rare; occurring in about one in every 100,000 children.

Every year, at least 400 children are lost to SUDC. It is most common in young children and is the 5th leading category of death among children between the ages of 1 and 4.

According to the Centers for Disease Control and Prevention (CDC), in 2016, SUDC affected:

- 236 children ages of 1-4 years;
- 30 children ages of 5-9 years;
- 37 children ages of 10-14 years; and
- 142 teens ages of 15-19 years.

We do not know exactly how often SUDC occurs. Because the World Health Organization (WHO) lacks a specific way to record sudden and unexplained deaths in children that have been thoroughly investigated, it is impossible to know how widespread the problem is.
The SUDC Foundation

The SUDC Foundation envisions a world where no more children are lost to Sudden Unexplained Death in Childhood. The SUDC Foundation is the only organization worldwide whose purpose is to promote awareness, advocate for research and support those affected by SUDC.

The SUDC Foundation:

• **Funds and Promotes Research.** The SUDC Foundation provides grants for and conducts research that will further our understanding of the cause(s) and ways to prevent SUDC.

• **Supports Families.** The SUDC Foundation currently supports over 800 families in 18 countries. It provides personalized, comprehensive care from licensed clinical social workers and cultivates a community of support for bereaved families so no one grieves alone. The Foundation also helps families navigate the difficult and often confusing investigation into their child’s death by being a liaison between families and the medical examiner or coroner. It also assists families in accessing research and DNA banking services which could lead to answers on what may have happened to their child.

• **Assists Medical Professionals.** The Foundation provides resources to help medical examiners and coroners, pediatricians and other doctors care for and communicate with families experiencing the sudden, unexpected and unexplained loss of a child.

• **Advocates for the SUDC community.** The Foundation supports efforts, including legislative, to ensure comprehensive and standardized death investigations. It also advocates for fair treatment of and appropriate medical care for families and thorough data collection to improve our understanding of SUDC.

The SUDC Foundation provides all services at no cost to the people it serves.

The Latest at the SUDC Foundation

**SUDC Registry & Research Collaborative:** The Sudden Unexplained Death in Childhood Registry and Research Collaborative (SUDCRRRC) is a five-year study on SUDC conducted at New York University. Its purpose is to further our understanding of the cause(s) and ways to prevent sudden death in children. The SUDCRRRC provides families with a thorough case review of a child’s medical history and death, as well as additional testing to examine possible contributing factors and potential causes of death of the child they lost.

**Investing in National Guidelines for the Investigation of Sudden Deaths of Children:** The SUDC Foundation awarded nearly $100,000 to the National Association of Medical Examiners (NAME) to work collaboratively with the American Academy of Pediatrics (AAP) to investigate and establish national practice guidelines surrounding the investigations of sudden unexpected deaths in infants and young children. The “Sudden Death in Pediatrics: Consensus for Investigation, Certification, Research Direction and Family Needs” project will also make recommendations to determine future research needs and the sensitive care of families affected.

**SUDC Banner Project:** The SUDC Foundation Banner Project is a moving tribute to children lost to SUDC created to raise awareness of Sudden Unexplained Death in Childhood. The SUDC Banner has traveled to 33 U.S. states and six countries.

**Events Benefitting the SUDC Foundation:** Please visit the website to view upcoming events benefitting the SUDC Foundation all over the world.

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Facebook: @SUDCProgram  Twitter: @SUDC  YouTube: TheSUDCProgram

Media Contact: Elizabeth Milliken, Director of Development 973.459.1092 elizabeth@sudc.org
Press Releases: Read our latest press releases on our website.

Other Resources on SUDC

Explaining the Unexplained: A short and poignant video that captures facts on SUDC and its raw, emotional cost.

The Faces of SUDC: A video featuring children taken far too soon from SUDC.

Love Beyond Reason: An 8-minute documentary depicting the challenges the medical community faces as it tries to understand this classification of death and the heartache of parents and families who have experienced the sudden loss of a thriving child with no medical cause or explanation.

Frequently Asked Questions about SUDC: Find answers to frequently asked questions about SUDC on our website.

SUDC Literature: Read additional literature on SUDC on our website.

Key Spokespeople

Please contact the SUDC Foundation to speak with any of our experts.

Laura Gould Crandall, M.A.: Laura is an expert on SUDC, offering insight both as the parent of a child lost to SUDC and as a medical professional. Laura is Executive Director, Co-Founder and Board President of the SUDC Foundation. Laura lost her first child, Maria, to SUDC in 1997 when she was 15 months old. Laura spearheaded advocacy efforts of 25 organizations that led to the passage of “The Sudden Unexpected Death Data Enhancement and Awareness Act.” The bill improves the quality and consistency of death scene investigations and autopsies to better understand infant and child deaths and was signed into law by President Obama in 2014. Laura also advocated for two pieces of statewide legislation passed in New Jersey that standardized death investigations for children ages birth to 3, created a multidisciplinary autopsy protocols committee and changed existing law to allow for medical examiners to participate in research to allow for further understanding of SUDC.

Laura was honored as Glamour magazine’s “Woman of Your Year” in 2007 and received the “Portrait of Courage” award from the National Organization of Rare Disorders (NORD) in 2015. Laura is a member of the National Association of Medical Examiners, an Executive Board Member of the North American SUDEP (Sudden Unexpected Death in Epilepsy) Registry (NASR) and Executive Officer of the (Federal) Organization for Scientific Area Committees (OSAC), subcommittee for medicolegal death investigation.

Laura is a research scientist in the Department of Neurology at the New York University Langone School of Medicine and a co-investigator and research scientist for the SUDC Registry and Research Collaborative (SUDCRRC). She is a licensed physical therapist in New Jersey and New York.

Orrin Devinsky, M.D.: Dr. Devinsky is an expert on SUDC, neurology, epilepsy, seizures and their possible correlation to SUDC. He is the Co-Founder of the SUDC Foundation and a member of the Foundation’s Scientific Advisory Board. Dr. Devinsky is the Director of the Comprehensive Epilepsy Center of the New York University Langone School of Medicine and the Principal Investigator of the SUDC Registry and Research Collaborative (SUDCRRC). He has been named one of New York Magazine’s Top Doctors for over 20 years. Dr. Devinsky is the Founder of Finding A Cure for Epilepsy and Seizures (FACES), Epilepsy.com and the Sudden Unexpected Death in Epilepsy (SUDEP) Registry. He is also a professor in the Departments of Neurology, Neurosurgery and Psychiatry at New York University’s Langone School of Medicine.
**Lorri Caffrey**: Lorri is Assistant Executive Director, Co-Founder and Board Secretary of the SUDC Foundation. She is the proud mother of Jenna, who Lorri lost to SUDC when Jenna was 16 months old. She holds leadership positions with the Girl Scouts USA, serves as a catechist at her church and is a member of the General Federation of Women’s Clubs. In 2017, she was invited to share her story on the Option B website which you can read here.

**Bobby Jenkins**: Bobby is a Board Member of the SUDC Foundation and the proud grandfather of Moss, who passed away from SUDC when he was 14 months old. Bobby is a leader in the business community of Austin, TX as owner of ABC Home & Commercial Services with offices throughout the state. Bobby currently serves as Vice-Chair of the Texas Higher Education Coordinating Board and board member of the Texas Better Business Bureau, Citizens Against Lawsuit Abuse, the Alzheimer's Association and the United Way Austin. He is on the Agricultural Development Council and Mays Business School Development Council at Texas A&M University. Bobby also serves as board chairs for the Austin chapter of the American Heart Association and Recognize Good, which he also co-founded.

**Matthew Polenzani**: Matthew is a Board Member of the SUDC Foundation and the proud father of Alessandra who he lost to SUDC in 2005. Matthew is a world-renowned opera singer and has appeared with the Metropolitan Opera, Seattle Opera, Royal Opera House, Bayerische Staatsoper, Lyric Opera of Chicago, Vienna State Opera and San Francisco Opera. He was the recipient of the 2004 Richard Tucker Award and Metropolitan Opera’s 2008 Beverly Sills Artist Award.

**Elizabeth Milliken**: Elizabeth is the Director of Development for the SUDC Foundation. Because the SUDC Foundation receives no public funding, it relies on private funding to serve its mission. Elizabeth leads all of the Foundation’s fundraising and event efforts.

For a full list of SUDC Board Members and its Scientific Advisory Board, please visit our [website](#).

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The SUDC Foundation provides all services at no cost to the over 800 families in 18 countries it serves.

To inquire about spokespeople in your area, please contact the SUDC Foundation.