

The SUDC Foundation Media Kit

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, approximately 400 children are lost to SUDC in the United States. 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 2018, SUDC affected:

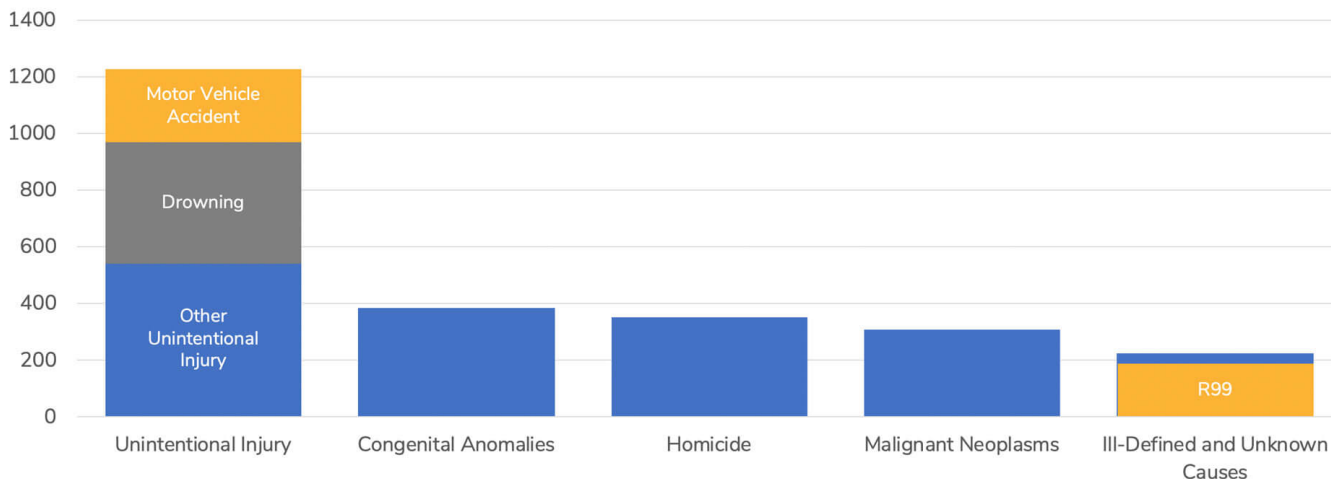
- 231 children ages of 1-4 years
- 46 children ages of 5-9 years
- 42 children ages of 10-14 years
- 73 teens ages of 15-18 years.



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.

Leading Causes of Death

Ages 1-4: US 2018



Source: CDC, National Vital Statistics System, 2018

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 1,000 families in 21 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.

Facebook: @SUDCFoundation Twitter: @SUDC YouTube: TheSUDCProgram Vimeo: SUDC
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The Latest at the SUDC Foundation

■ **[Unexplained Pediatric Deaths: Investigation, Certification and Family Needs:](#)** The SUDC Foundation provided a scientific grant award to the National Association of Medical Examiners (NAME) to create new U.S. national guidance to help determine why unexplained pediatric deaths happen and how to support families after these tragedies. NAME led an effort in coordination with the American Academy of Pediatrics (AAP) to create this first-of-its-kind book. The publication is a combined effort of a panel of over 30 medical examiners, pediatricians and federal agency representatives who represent the diverse interests of epidemiology, death investigation, autopsy performance, death certification, clinical subspecialties (neurology, cardiology, child abuse, injury prevention, infectious diseases, genetics and metabolic diseases), family needs, prevention and research.



■ **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 Registry & Research Collaborative:](#)** The Sudden Unexplained Death in Childhood Registry and Research Collaborative (SUDCRRC) 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 SUDCRRC 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.

[Research Advocacy:](#) Please visit our website for a comprehensive list of published SUDC-related research and to learn more about the ways the SUDC Foundation fulfills its mission to advocate for research by watching our enlightening video.

■ **[Events Benefitting the SUDC Foundation:](#)** Please visit the website to view upcoming events benefitting the SUDC Foundation all over the world.

■ **[The Microscope:](#)** The official blog of the SUDC Foundation which shares and discusses issues important to the understanding and the ultimate prevention of SUDC.

■ **[In the News:](#)** Read our latest press releases and media coverage 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.

★ [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.

★ [Memorial Sites](#)

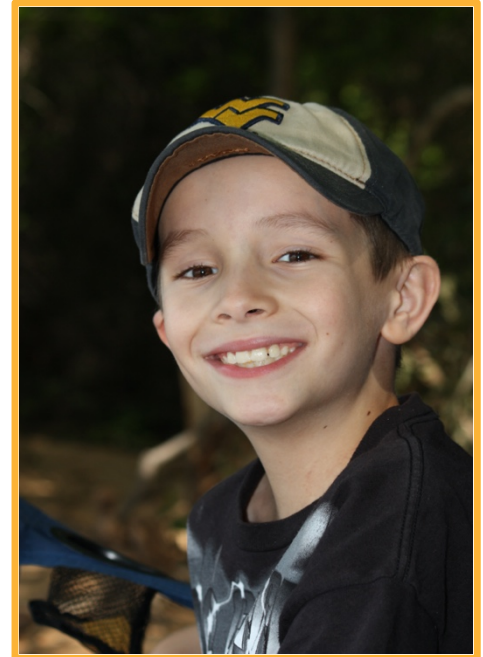
Memorial tribute sites and a video featuring children taken far too soon from SUDC.

★ [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 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 has authored several published research articles on SUDC. 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.

★ [Bobby Jenkins](#)

Bobby is the Chair of the Board of the SUDC Foundation and the proud grandfather of Moss, who was lost to 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.

★ Erin Bowen

Erin is Vice President of the SUDC Foundation, a pediatrician and the proud mother of Conor, who was lost to SUDC in 2016 when he was just 17 months old. Erin graduated from medical school at University College Cork in Cork, Ireland and received her bachelor's degree in English from Boston College. She is currently a pediatrician at Children's Medical Associates in Ansonia, CT and has over 10 years of experience in the medical field. Erin is a member of the American Academy of Pediatrics (AAP) where she is a member of the Section on Child Death Review and Prevention and previously served as an Assistant District Coordinator for medical students, residents and fellowship trainees. She was inducted into Alpha Omega Alpha Honor Medical society in recognition of teaching medical students. In addition to being an advocate on behalf of the SUDC community, Erin has dedicated herself to helping to improve the investigations of sudden unexpected deaths in infants and young children through the "Sudden Death in Pediatrics: Consensus for Investigation, Certification, Research Direction and Family Needs" project. This project, funded through a grant from the SUDC Foundation to the National Association of Medical Examiners (NAME) to work collaboratively with the AAP, established national practice guidelines, published in *Unexplained Pediatric Deaths: Investigation, Certification and Family Needs*, for investigations, research needs and the sensitive care of families affected by SUDC and sudden, unexpected deaths of infants and young children. Erin is the proud mom of Conor, as well as two daughters.

★ 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.

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