

The SUDC Foundation 2024 Media Kit

Sudden Unexplained Death in Childhood

[March is Sudden Unexplained Death in Childhood \(SUDC\) Awareness Month](#). From March 1st - March 31st, communities across the globe will show their support to help raise SUDC awareness, honor those children who are gone too soon and help families affected by SUDC, feel seen, and supported by Shining a Light on SUDC.

[Landmarks](#) throughout the world will be illuminated in the colors of the Sudden Unexpected Death in Childhood (SUDC) Foundation: Blue and Yellow from March 1st - March 31st.

Each year, the SUDC Foundation spearheads a nationwide effort for each U.S. state and local municipalities to declare March as SUDC Awareness Month. These [proclamations](#) call attention to the medical mystery that claims the lives of approximately 400 children in the United States each year and helps bereaved families know they are not alone.

A devastating occurrence across the globe, 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. We hope that future research will identify means by which SUDC can be prevented.

A medical examiner or coroner could rule a child's death SUDC when they complete 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 four hundred children are lost to SUDC in the United States. It is most common in young children and is the fifth leading category of death among children between the ages of 1 and 4.

According to the Centers for Disease Control and Prevention (CDC), in 2021, SUDC affected:

- 249 children ages of 1-4 years
- 50 children ages of 5-9 years
- 44 children ages of 10-14 years
- 107 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.

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 raise awareness, fund research, and serve those affected by SUDC. The SUDC Foundation is 501(3) not for profit organization located in Roseland, New Jersey. (www.sudc.org)

The SUDC Foundation:

- ★ **Funds Research.** The SUDC Foundation provides grants for [research](#) that will further our understanding of the cause(s) and ways to prevent SUDC.
- ★ **Serves Families.** The SUDC Foundation offers personalized, trauma-informed care to over 1,900+ families across 23 countries, ensuring no one grieves alone. With [support](#) from licensed social workers, it fosters a supportive community for bereaved families. Acting as a liaison between families and medical examiners and coroners, the Foundation assists families navigate the difficult and often confusing investigation into their child's death. Additionally, the Foundation assists families in accessing research and genetic testing opportunities 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 medical professionals in caring for and communicating with families experiencing the sudden, unexpected and unexplained loss of a child.
- ★ **Advocates for the SUDC community.** The Foundation supports efforts, including [legislative initiatives](#), to ensure comprehensive and standardized death investigations, advocates for equitable, accessible, and appropriate medical treatment and care for families and promotes 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 (SUDCRRC) is a multi-site research collaborative at NYU Langone Health under the direction of Orrin Devinsky, MD and Laura Gould, MSc. The SUDCRRC studies sudden unexplained deaths in childhood (SUDC) with a team of experts from pediatrics, neurology, cardiology, radiology, pathology, and infectious disease to better understand and learn to prevent these tragedies. Global participation and support bolster the SUDCRRC's efforts, advancing international scientific knowledge on sudden death. The SUDC Foundation is a significant grantor of the SUDCRRC, with a financial grant commitment of 2.5 million dollars over the next 5 years. With 16 publications to date, their recent groundbreaking study published in **Neurology**, January 2024 analyzed crib videos of 7 children and revealed convulsive movements preceding their deaths, providing evidence that children may experience seizures and muscle convulsions before their untimely deaths. Although the study analyzed only a small group of children, it highlights the need for further research to understand the prevalence of convulsions among SUDC victims. (<https://www.neurology.org/doi/10.1212/WNL.000000000208038>)

■ 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.

[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 and activities benefitting the SUDC Foundation all over the world.
- [The Microscope](#): The Microscope is the official blog of the SUDC Foundation, offering valuable insights and fostering conversations relevant to the SUDC Community. Through articles, discussions, and shared experiences, it provides diverse perspectives on navigating the challenges of SUDC, fostering a sense of community and support while contributing to a deeper understanding of the SUDC.
- [In the News](#): Read our latest press releases and media coverage on our website.

Other Resources on 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.

★ [Memorial Tribute Pages](#):

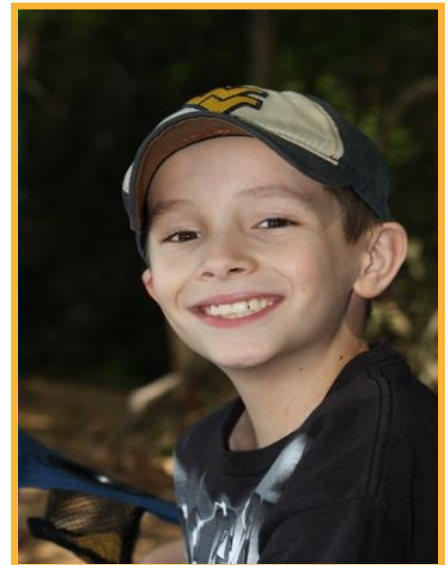
Memorial tribute pages and video featuring children taken far too soon from SUDC.

★ [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.

★ Bobby Jenkins

Bobby Jenkins is the Chair of the SUDC Foundation and is a graduate of Texas A&M University with a degree in business management. He is the owner of ABC Home & Commercial Services with offices in Austin, San Antonio, College Station, and Corpus Christi. ABC employs over 650 people and offers a wide variety of services including pest and termite control, lawn care and mowing, landscaping and irrigation, tree trimming, air conditioning and heating, plumbing and electrical, pool cleaning and repair, handyman services, appliance repair, and security system installation and monitoring.

Bobby is a past chair of the Austin Chamber of Commerce and current vice-chair of the Texas Higher Education Coordinating Board. He is a past president of both the Texas and National Pest Management Associations and a past chair and current board member of the Better Business Bureau, Citizens Against Lawsuit Abuse and the Alzheimer's Association. Bobby currently serves on the Agricultural Development Council and Mays Business School Development Council at Texas A&M University. He is a past chair for Caritas of Austin and has served as a trichair for the bond oversight committee with AISD. He has served as the co-chair for the Heart Walk for the American Heart Association and is the current Board Chair of the AHA. Bobby is a past co-chair for the United Way Annual Campaign and current United Way board member. He is the co-founder and board chairman of Recognize Good and past chair and board member of Austin Gives.

Bobby has been married to his wife Jan for 32 years and they have three children; Jessica Pieratt, Chelsea, and Bo. In 2014, Bobby's grandson Moss passed away suddenly and unexpectedly at the age of 14 months.

★ Julia Burgess

Julia is the President of the Board of the SUDC Foundation and the mother of Vivienne, who was lost to SUDC three days after her third birthday. Since that tragic loss, Julia has been deeply involved in the SUDC community, serving as an SUDC Ambassador and joining the board in 2019. Her focus is now on raising awareness of SUDC and providing support to other bereaved parents. Julia is the Founder and Executive Director of Vivienne's Joy Foundation. She resides in both Washington and Minnesota with her husband and Vivienne's older sister.

★ Erin Bowen, M.D.

Dr. Bowen 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.

★ Tina Yun Lee

Tina is the SUDC Foundation Executive Director. Tina is responsible for managing the daily operations of the foundation and works closely with the Board of Directors to implement strategic initiatives to achieve the foundation's mission. Tina believes in the power of effective advocacy and compassionate support particularly for human beings experiencing severe life stressors and trauma. Tina brings a wealth of knowledge in developing trauma informed, evidence-based grief programming. Her passion and dedication is the voice for SUDC families.

★ Elizabeth Milliken

Elizabeth is the Director of Development for the SUDC Foundation. Because the SUDC Foundation receives no public funding, it SUDC Foundation relies on private funding to serve its mission. Elizabeth joined the SUDC Foundation staff in 2016. She leads all of the Foundation's development initiatives to financially support the annual campaign.

Additional Experts:

★ Laura Gould, M.S.c.

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 former 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 a Co-founder of the SUDC Foundation. 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.

For a full list of SUDC Foundation Board Members, please visit our website: www.sudc.org.

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

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