

SUDC Foundation Ambassador Training

Step 3: Ambassador Resource Discussion Guide

In this document you will find answers to questions regarding the foundation and our community, research on SUDC, and medical information. The Foundation's Ambassadors focus their efforts on sharing the latest, trusted research, spreading accurate awareness of our cause, and otherwise serving families who have experienced SUDC. There is a lot of information here, so do not feel the need to read all of it at one time, just know that answers can be found here if you need to refer back at another time.

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The Foundation and Our Community

★ How does the SUDC Foundation determine who is a part of its community?

The SUDC Foundation determines its community based on a shared mission of supporting those affected by SUDC and providing a nurturing space for healing, connection, and advocacy. The SUDC Foundation determines who is part of its community through a deliberate process focused on inclusivity, support, and shared values. Our community is open to individuals and families who have been affected by the unexpected death of a child, particularly Sudden Unexplained Death in Childhood (SUDC).

We strive to create a safe and supportive environment where everyone feels accepted, valued, and respected. Our guidelines, developed in collaboration with mental health professionals, promote diversity, equity, and inclusion. We welcome individuals from all backgrounds and walks of life, recognizing the unique challenges they may face in their grief journey.

Membership in our community is based on a commitment to our core values, including empathy, compassion, and mutual support. We encourage active participation and engagement, whether through online forums, support groups, educational events, or other initiatives.

★ Maintaining a Supportive Community:

To ensure our community remains a safe and supportive place for those grieving, our mental health professionals have helped us establish these guidelines. The guidelines are designed to ensure:

- **Respectful and Inclusive Interactions:** We embrace diversity and inclusion and strive to create a supportive environment where all members feel accepted and valued. Everyone can share their experiences and receive support without fear of discrimination or intolerance, and family choices are respected without pressure.
- **Supportive and Accurate Information:** Our family service programming is dedicated to supporting families who have experienced the unexpected death of a child. Our priority is to provide them with trusted, accurate information and ensure that they feel safe in both online and in-person settings. It is important to avoid spreading misinformation or unfounded conspiracy theories. Misinformation can cause additional stress and anxiety.
- **Collaborative Community Spirit:** We promote a spirit of collaboration and mutual respect among our members and our community partners. By working together and supporting each other, we create a larger community where everyone can feel safe and informed.

In instances where these guidelines are not followed, individuals will be reminded of the Community Guidelines. Members who consistently disregard these guidelines may be placed on probation and, ultimately, removed as an Ambassador.

We warmly welcome those who choose to adhere to these guidelines to continue being a part of our supportive group.

★ Do/can family members share their personal stories?

- Each parent or family member chooses whether to share information about their child. If they do share information about SUDC, we request consistent details on SUDC definitions, statistics, and research. This clarity is crucial for raising awareness and addressing SUDC effectively. Consistent information aids in interviews with reporters, aligning with our mission to provide accurate and consistent information to news organizations and the general public.

★ Why do we focus on community building?

- When we started the SUDC program 19 years ago, we were a handful of people isolated by grief and desperate for information and seeking comfort through connection and information. This led us to create a safe space with agreed-upon guidelines. These guidelines prioritize trusted scientific information, respect for each individual's unique lived experience, and a commitment to never retraumatize or contribute to the stress families are experiencing.

★ Is an additional group focused on SUDC helpful for our efforts?

- While the Foundation highly values collaboration across similar organizations, our overall hope is to sustain one centralized community able to speak with one shared voice. There are many and varied details associated with SUDC, which has no known single cause(s) or prevention tools. A centralized community facilitates clearer communication about SUDC – something that's vital to creating the awareness necessary to secure funding, advocating for policy and enabling important research on this relatively rare occurrence.
- This unified approach has yielded tangible results, including [groundbreaking research](#) that actually explained some deaths not previously understood and the [first national guidelines](#) on how to investigate SUDC – an achievement for our community and a symbol of hope of solutions to come. Additionally, the SUDC Foundation partners with other SUDC mission-based organizations that support awareness, advocacy and research work and recognize their strategic value in understanding SUDC.

Fragmenting the community would complicate the centralization of information necessary for research and the consistency needed for effective policy advocacy, such as developing national guidelines. To enhance our collaborative strategy, we advocate for pooling resources and expertise within a unified community. This approach allows for a more coherent strategy, maximizing the impact of our advocacy and research efforts while ensuring efficient use of limited funds.



SUDC Research

★ How can families encourage or participate in SUDC research?

- Researchers need case studies – stories, details and autopsy findings from victims of SUDC – to analyze hypotheses, spot trends, and identify potential causes and possible solutions. The Foundation was instrumental in the creation of and continued financial support for the world's largest database of SUDC case studies that lives at the [SUDC Registry and Research Collaborative](#) (SUDCRRC), which is located at New York University Langone Health and works in collaboration with Columbia University and the Mayo Clinic. The SUDC Foundation invites families worldwide to participate in the SUDCRRC and manages referrals to ensure we are gathering a diverse set of case studies.
- Researchers are able to be most effective when this information lives in one central location for them to study, and more effective research is more likely to quickly yield insights that can prevent loss and suffering. Researchers respect this approach to referrals, because the SUDCRRC is approved by what's called an IRB. IRB stands for Institutional Review Board and refers to the federal mandated committees at all academic institutions that protect the rights and welfare of humans involved in research projects. Research that's not IRB approved cannot be published in reputable scientific journals, and publishing is vital to the wide dissemination of findings and the demonstration of scientifically valid information that can lead to solutions.

★ What results have come from research? How will it help?

- Research insights have actually explained some deaths not previously understood, and those explanations bring comfort and clear knowledge to families as well as guide clinicians in working towards reducing the risk associated with those now explained deaths. In 2019, the Foundation collaborated with the [National Association of Medical Examiners](#) and [American Academy of Pediatrics](#) to create the first [national guidelines](#) on how to investigate SUDC – an achievement for our community and a symbol of hope that we can better understand SUDC and prevent other families from suffering what we have all experienced.

★ How often does SUDC occur and why don't we know exactly how often it occurs?

- SUDC is believed to be rare; with our most conservative estimates being about one in every 100,000 children.

- **We do not know exactly how widespread SUDC is.** [The Vital Statistics Cooperative Program](#), the system that tracks death in the U.S., codes deaths based on what is written on the death certificate. Only those deaths described as unexplained, unexplained sudden death or undetermined will be captured by the R96-99 codes, and those codes are the best way to currently estimate the occurrences of SUDC. Additionally, if the death certificate reads “unexplained with a history of X,” then the death will not be included in SUDC estimates and instead coded as “X.” For example, a death certificate listing “Unexplained death with history of remote febrile seizure” would not be included in SUDC estimates.
- Variations in the comprehensiveness of death investigations are widespread in the U.S., unlike the U.K. where a national protocol is followed at predetermined centers for pediatric cases. These inconsistencies further complicate the interpretation of death certificates. This also makes identifying deaths by death certificates alone that have been determined to be unexplained only after a thorough investigation impossible at present. Measuring SUDC by R96-R99 is most likely an underestimation of the true incidence of SUDC.
- **Every year, at least 500+ children are lost to undetermined causes in the U.S. It is most common in young children and is the fourth leading category of death among children ages 1 to 4 years.**
- In order to better understand the true incidence of SUDC, we need population-based studies where we examine cases that reflect the gender and ethnic diversity of the general population. [The Center for Disease and Control Sudden Death in the Young Case Registry](#) (CDC SDY) was created to increase the understanding of the prevalence, causes and risk factors for infants and children through age 19 years who die suddenly and unexpectedly. Currently, 14 U.S. jurisdictions participate in the registry ([CDC Registry](#)). The SUDCRRRC of NYU Langone Health has the largest database of SUDC victims to date. It is available to accept new cases for enrollment and has partnered with more than 20 medical examiner and coroner offices, representing over 40 million people in the U.S. population to better understand the true incidence of SUDC.

★ Why haven't I heard of SUDC before?

- The term SUDC was first published in 2005. It has received very little focus from public health officials, has not received targeted public research funding and there have been no major awareness campaigns devoted to addressing it. Currently,
- awareness efforts are limited to the vital work of the SUDC Foundation and its Ambassador community. Unfortunately, most people first learn of SUDC after a

tragedy in their own child, their patient or someone they know. Raising awareness of SUDC is at the core of the work of the SUDC Foundation.

★ Why has SUDC not received public funding for research?

- It is difficult to know for sure. SUDC-related deaths are rare, and a lack of consistency in reporting them makes it difficult to recognize trends on a national or international level. As with the study of any rare medical phenomenon, it is vital to collect information to study enough children lost to SUDC to evaluate trends, identify risk factors, and gain insight into its causes and eventual prevention. The SUDCRRC is a centralized registry to collect this vital information for the access of multiple researchers who would otherwise not be able to identify enough cases to study.

★ What are we doing to understand SUDC?

The SUDC Foundation works tirelessly to identify the most accurate answers for sudden, unexpected and/or unexplained child deaths, whatever they may be. Through funding the most highly-qualified research to date on SUDC, we endeavor to not just find “an” answer for our children’s deaths, but “the” answers to ensure a brighter future for all children. This includes, but is not limited to:

1. **[The Sudden Unexplained Death in Childhood Registry and Research](#)**
Collaborative: The SUDCRRC is multi-site research collaborative 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.
2. **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.
3. **Federal legislative advocacy** such as the [Scarlett’s Sunshine Act. Scarlett’s Sunshine Act](#) (H.R. 2271/ S. 1130) would strengthen existing efforts to better understand SUID and SUDC, facilitate data collection and analysis to improve prevention efforts and support children and families.

Other organizations such as the [National Heart, Lung, and Blood Institute \(NHLBI\)](#) are also involved with research efforts including the [Sudden Death in the Young \(SDY\) Case Registry](#). This is a joint project with the CDC-based at [Michigan Public Health Institute](#).

The SUDC Foundation is listed on the CDC's [SUID and SIDS page](#).



Medical Information

★ Is SUDC like SIDS (Sudden Infant Death Syndrome)?

- Terminology by acronym alone can be confusing dependent on location. Sudden Unexpected Infant Death (SUID), as used commonly by public health officials in the United States, refers to the combined rate of the three most frequent types of sudden unexpected deaths in infancy: sudden infant death syndrome (SIDS), accidental suffocation in a sleeping environment and other deaths from unknown causes.
- **SUID** may also be used by medical examiners and coroners as a final death certification: sudden unexplained infant death. **SIDS** is “the sudden, unexplained death of an infant younger than 1 year old,” (Eunice Kennedy Shriver National Institute of Child Health and Human Development.)
- In the United Kingdom, where the term “infant” can refer to children under 24 months, the definition of SIDS differs by age, and describes it as the sudden, unexpected and unexplained death of an apparently healthy baby under 24 months of age [(NHS, Department of Health and Social Care (DHSC)).]
- SUDC is similar to SUID in that it occurs in otherwise healthy children most often occurs during sleep and has no known explanation. There may be other similarities, but research into SUDC is in its early stages and more is needed to better understand how similar or different the underlying causes are. **The biggest difference we know is that a child’s death may be certified as SIDS or SUID in the U.S. if the child is less than 12 months of age. A child’s death may be certified as SUDC if they are over 1 year old, but under the age of 18.**
- A death is “certified” based on how the cause and manner of death is described on the death certificate. In most areas, this is performed by a medical examiner or coroner, although some exceptions do exist. One challenge to answering this question, and to research on this subject in general, is the lack of standardized autopsies on infants and children who die suddenly, resulting in data that is inconsistent and incomplete.

Consistent and complete data is essential for sound research. The Sudden Unexplained Death in Childhood Registry and Research Collaborative (SUDCRRC) is collecting the largest registry of SUDC victims and is poised to better explain the similarities and differences of sudden infant versus child death in the future.

★ Do vaccines cause SUDC?

- There is no scientific evidence that vaccinations increase the risk for SUDC.
- As a matter of fact, the American Academy of Pediatrics recommends routine immunization to help reduce the risk of SIDS.
- “There is no evidence that there is a causal relationship between immunizations and SIDS. Indeed, recent evidence suggests that vaccination may have a protective effect against SIDS.” -AAP Task Force on Sudden Infant Death Syndrome
- Although this research focuses on children under 1 year, **vaccines are not shown to cause any increase in SUDC for children over 1 year.** Vaccines work with a child’s natural defenses by arming him or her with ingredients called antigens. These antigens cause the body to develop immunity for the particular disease of that vaccine. That way, when the child is exposed to the actual disease, his or her body will know how to fight the infection. Immune responses do vary from individual to individual.
- Before approved for use, vaccines are tested extensively by scientists and are continually being monitored for safety and efficacy. To further address public health concerns and provide a legal outlet to address potential concerns regarding vaccinations recommended by the U.S. government, Congress passed the National Childhood Vaccine Injury Act (NCVIA) in 1986 which created the Vaccine Adverse Event Reporting System (VAERS) and National Vaccine Injury Compensation Program (NVICP). The NCVIA requires reporting adverse events (possible side effects) to VAERS, a national vaccine safety surveillance program used by the Federal Drug Administration (FDA) and the Centers for Disease Control and Prevention (CDC). NVICP addresses petitions filed regarding a potential vaccine injury. It is a program that does not require either party to be found “at fault” developed to resolve vaccine injury petitions and reduce the risk that potential lawsuits would contribute to a decline in vaccination rates.⁵

The data collected from VAERS and NVICP has not shown to SUDC. In a review of over 1,000 deaths reported to VAERS from 1990-1997, there was a decline in infant deaths after the “Back to Sleep” campaign was implemented and a decline in

deaths from other causes during the time when the number of vaccines administered significantly increased.⁶

- “Multiple other published reviews of VAERS data for specific vaccines and vaccine types have found no concerning patterns that would suggest a causal relationship between vaccination and deaths.”⁶ The SUDC Foundation recommends all families work with their primary care physicians to best follow guidelines provided by the American Academy of Pediatrics in regard to maintaining current vaccinations. These vaccinations protect children from significant diseases that are dangerous or even deadly and have a higher incidence of death than SUDC.

★ Is SUDC caused by brain abnormalities that have been reported in some cases of SIDS/SUID?

- We do not yet know if there is a correlation between brain abnormalities and SUDC, although research is currently being conducted.
- Research into the possible causes of SIDS/SUID has received over \$500 million in public funding to date. SUDC has received no targeted public funding in the U.S. for research, so it has been far less extensive. The SUDCRRC is currently performing comprehensive brain analyses of children affected by SUDC to better understand potential brain mechanisms that may exist (SUDCRRC). Data is also collected and tracked for the CDC’s Sudden Death in the Young (SDY) Case Registry. The SDY component of the Case Registry was created to increase the understanding of the prevalence, causes and risk factors for infants and children through age 19 years who die suddenly and unexpectedly ([CDC](#)).
- Research involving brain abnormalities in some cases of infants who have passed from SIDS/SUID studied abnormalities in the autonomic nervous system (brainstem) which may have affected an infant’s ability to react to some life-threatening situations, such as increasing levels of carbon dioxide. Similar studies have not yet occurred in SUDC cases due to several issues, including, but not limited to, difficulties accessing appropriate biospecimen from suspected SUDC victims. Published findings also exist concerning abnormalities in the area of the brain called the hippocampus in SIDS/SUID and SUDC, but their significance is unclear as they may be a cause of seizure activity, the result of past seizure activity or variants in the normal population.²⁻⁴

★ Is SUDC genetic? Can it happen more than once in the same family?

- Although rare, we know that there are some genetic causes of sudden death that are not discovered by standard autopsy investigations. This is one of the many reasons that we advocate for comprehensive investigations, including genetic testing, for all

sudden unexplained deaths, as well as screening of family members and DNA banking. Research will improve our understanding of the specific genetic variations that may contribute to some cases of sudden death that currently fall under SUDC. This could lead to the ability to screen at-risk children and help them receive appropriate medical care.

- The SUDCRRC performs genetic analysis of the child who died and both biological parents who enroll in the study. Clinically-significant findings are provided to the participants by a genetic counselor at no cost. The more children studied; the more answers provided.

To learn more about genetic studies at the SUDCRRC, please watch Dr. Goldstein's presentation from the 2017 Understanding SUDC Conference, [Studying the Genetics of Sudden Death](#)

★ What are febrile seizures, and do they cause SUDC?

- Febrile seizures are seizures (abnormal electrical activity in the brain) or convulsions (tonic-clonic seizures) that are triggered by fever, typically over 101 degrees Fahrenheit, or illness.
- “Most febrile seizures happen in children between the ages of 6 months and 5 years. Two to five percent of young children will have at least one febrile seizure,” (Febrile Seizures Fact Sheet, National Institute of Neurological Disorders and Stroke.) Up to 1/3 of children have a recurrent febrile seizure, especially with earlier age of onset and when there is a family history. There are likely many causative genes, but the vast majority of febrile seizure genes remain unknown. Prophylactic anti-pyretics (fever reducing medications) do not reduce the risk of recurrence.
- The most common age range for children to have febrile seizures is 14–18 months. “Recent studies suggest that a prolonged febrile seizure more than 30 minutes in duration can injure the hippocampus, a brain structure involved with temporal lobe epilepsy (TLE,)” (Febrile Seizures Fact Sheet, National Institute of Neurological Disorders and Stroke.)
- A study published in 2015 utilizing SUDC Foundation data showed that nearly 32% of SUDC cases had a history of febrile seizures.⁷ The only published population-based study to date is from Ireland which described a 31% rate of among 44 cases of SUDC studied from 1994-2008. The SUDCRRC is continuing to examine the potential role febrile seizures and some instances of SUDC.⁸
- A recent paper published in the Journal of the American Medical Association (April 2019) examined family interviews from the SUDC Foundation from 2001- 2017 and

found, “In this case series of 391 children from 18 countries, febrile seizure rates were increased among both sudden explained and sudden unexplained deaths compared with the general population, suggesting that seizures contributed to some of these deaths. No sudden deaths occurred in more than 3100 life-years among siblings of children with sudden unexplained death.

- **Meaning:** patients with febrile seizures are at increased risk for sudden death, *but the risk is small* and identifying clinical features or biomarkers of high risk is essential to develop and assess preventive strategies.”⁸ (To read the paper in its entirety, please visit [JAMA](#))
- Of note, Sudden Unexpected Death in Epilepsy (SUDEP) refers to the sudden and unexpected death of a person with epilepsy that is unexplained after a thorough investigation. Children with febrile seizures alone are not diagnosed with epilepsy, as they are considered provoked seizures. Some types of epilepsy are initially symptomatic with febrile seizures (e.g., Dravet Syndrome), and therefore we don’t know if some SUDC children with febrile seizures may have gone on to develop epilepsy if they had lived longer. Risks factors of Pediatric SUDEP are not well understood.⁹ SUDEP research may aid SUDC research in better understanding possible causes of death.

SUDC families with a family history of febrile seizures are encouraged to consult with their primary care physician and a pediatric neurologist, as well as visit: [Medical Care after SUDC](#) and review [“Caring for the SUDC Sibling with Febrile Seizures”](#).

To learn more about febrile seizures, please watch Dr. Devinsky’s presentation [“Febrile Seizures and Sudden Unexplained Death in Childhood”](#) from [the 2017 Understanding SUDC Conference](#)

★ Is there a monitoring device that can prevent SUDC?

- SUDC is unpredictable, and no monitoring device protects against SUDC. Parents look for advances in technology that can protect their children, but SUDC is unpredictable and unpreventable at this time. A heart rate or breathing monitor may alert a parent to an emergency, however known cases of SUDC are witnessed, and swift action did not prevent these deaths. Pediatricians strongly recommend that parents pay attention to the child, not the device. Monitors may provide emotional support to parents, but there are no known prevention tools for SUDC. That’s why SUDC Foundation advocates for solutions and champion’s research.

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