

SUDC FOUNDATION DIFFICULT QUESTIONS AND THEIR ANSWERS

Messaging Guidance

Question: What is the cause of SUDC?

Answer: *At this time, we do not know what causes SUDC. Sudden Unexplained Death in Childhood (SUDC) is a category of death, **not a cause of death**, in children between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy. It is likely that SUDC does not have a single cause, but many causes, and is an umbrella term to describe these deaths that have not been specifically determined.*

Question: Is SUDC like SIDS (Sudden Infant Death Syndrome) and/or SUID (Sudden Unexplained Infant Death)?

Answer:

*SUDC is **similar** to SIDS/SUID in that it occurs in otherwise healthy children most often during sleep and has no known explanation. There may be other similarities, but research on 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 SIDS/SUID only before he or she is 12 months old. A child's death may be certified as SUDC if he or she is over 1 year old, but under the age of 18.*

More background information: *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 SUDCRRRC 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.*

To learn more about the differences between SUDC and SIDS/SUID, please refer to the SIDS/SUDC message guidance on the Ambassador website. Of note, there are two meanings to the acronym SUID. Sudden Unexpected Infant Death (SUID) is used to describe the death rate of the three most frequent types of sudden unexpected deaths, which are SIDS, undetermined deaths and accidental asphyxia. Sudden Unexplained Infant Death, SUID, as used in this document refers to the terminology used for a final cause of death sometimes used by pathologists.



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

Answer: *Research into the possible causes of SIDS/SUID and sudden unexpected infant deaths has received over \$500 million in public funding to date. SUDC has received no public funding for research, so SUDC research has been far less extensive. We do not yet know if there is a correlation between brain abnormalities and SUDC.*

More background information: *Research involving brain abnormalities in some cases of infants who have passed from SIDS/SUID studied abnormalities in the autonomic nervous system 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 to date in SUDC cases due to lack of funding, as well as difficulties accessing appropriate biospecimens from suspected SUDC victims. The SUDC Registry and Research Collaborative (SUDCRRC) is currently performing comprehensive brain analyses of children affected by SUDC to better understand potential brain mechanisms that may exist.*

Question: Do vaccines cause SUDC?

Answer: *There is no scientific evidence that vaccinations increase the risk for SUDC. However, it is important to understand that the purpose of a vaccine is to cause an immune response to build immunity for that disease if/when exposed in the future. Immune responses vary from individual to individual, whether that response is from an exposure to a virus, bacteria or vaccine.*

Significant research in this area has occurred. A study published in 2015 examined over 2,000 deaths reported to the U.S. Vaccine Adverse Event Reporting System (VAERS) database between 1997-2003. This study found no relationship between vaccinations and death despite an estimated 2 billion doses of vaccines administered during the same time period.

The SUDC Foundation recommends all families follow guidelines provided by the American Academy of Pediatrics in regards to maintaining current vaccinations. These vaccinations protect children from significant diseases that have a higher incidence of death than SUDC and lead to disability and mortality.

The SUDC Foundation works tirelessly to find 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" irrefutable answers to ensure a brighter future for all children.

You can read more at:

<https://academic.oup.com/cid/article/61/6/980/451431>

<https://www.cdc.gov/vaccinesafety/concerns/febrile-seizures.html>



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

Answer: *SUDC is believed to be rare; occurring in about one in every 100,000 children. We do not know exactly how widespread SUDC is. Unlike with SIDS/SUID and known causes of death, the World Health Organization (WHO) does not have a specific classification code for sudden, unexplained deaths in children over 364 days old when a comprehensive investigation has taken place. This makes tracking deaths determined to be unexplained after a thorough investigation impossible at present. We are only able to estimate SUDC deaths by examining the statistics of deaths with "undetermined" causes (R99), which is most likely an underestimation of the true incidence of SUDC.*

Every year, at least 400 children are lost to undetermined causes. It is most common in young children and is the fifth leading category of death among children ages 1 to 4 years.

Question: Why haven't I heard of SUDC before?

Answer: *The term SUDC was first used in 2005. It has received no focus from public health officials, no public research funding and no major awareness campaigns devoted to it. Currently, awareness efforts are limited to the vital work of the SUDC Foundation and its community. Unfortunately, most people first learn of it after a tragedy in their own child or someone they know. Raising awareness of SUDC is at the core of the work of the SUDC Foundation.*

Question: Why has SUDC not received public funding for research?

Answer: *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 SUDCRRRC 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.*

Question: Do febrile seizures cause SUDC?

Answer: *At this time, we do not know. Febrile seizures are seizures provoked by fever and/or illness. They are believed to be harmless, and more than 95 percent occur in around two to four percent of all children 6 months to 6 years. They commonly run in families. In some patients, prolonged febrile seizures can cause scar tissue in the brain and predispose the child to subsequent epilepsy. Among families registered with the SUDC Foundation, more than 25 percent report a history of at least one febrile seizure in their child who died. We know the incidence of febrile seizures among families registered with the SUDC Foundation, but we do not know how this relates to all families affected by SUDC in the general population. The data collected by the SUDC Foundation is based on families registered with us. It does not represent all families affected by SUDC and it is not population-based. This could lead to biased data. The SUDC Registry and Research Collaborative is examining the potential link between febrile seizures and some instances of SUDC.*



Additionally, 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 are not diagnosed with epilepsy, however SUDEP research may also aid SUDC research in better understanding possible causes of death.

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

Answer: *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. 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.*

