

January 11th, SUDC Foundation Follow-Up Webinar

1. Could birth-related factors, such as cord wrapping or dusky episodes, lead to brain damage and increased susceptibility to seizures in children?

If these factors were going to create issues for the child, you would expect them to occur early with signs such as increased tone, developmental delay or neonatal seizures (seizures in the first month of life).

2. If a child with no seizure history potentially experienced a seizure on the night of their death, how does this impact their living siblings, and should they undergo neurologist testing?

If a child with no seizure history potentially experienced a seizure on the night of their death, it can be a deeply distressing and concerning situation for the family. In such cases, the impact on living siblings and whether they should undergo neurologist testing depends on various factors, including the circumstances surrounding the incident, family medical history, and any specific symptoms or concerns observed in the siblings.

It's important for parents to communicate openly with healthcare professionals to express their concerns and receive appropriate guidance. The decision to undergo neurologist testing for living siblings should be based on a comprehensive assessment of the family's medical history and the specific circumstances surrounding the potential seizure.

Generally speaking, if the SUDC child had a known history of seizures and the surviving sibling has a seizure (simple or complex), it would be reasonable for the child to have a Pediatric Neurology consultation. Most children who have a complex seizure will receive a referral regardless of family history. However, a child with a simple febrile seizure would not typically undergo an evaluation. This would be a situation where knowing the history of the SUDC sibling could change the standard management.

For SUDC siblings without seizures, it is helpful for the family to monitor for developmental delays or any concerns for seizures.

Seeking the expertise of healthcare providers can help determine the most appropriate course of action tailored to the individual needs of the family and the well-being of the siblings.

3. Should surviving siblings, especially those with a history of febrile seizures, consider undergoing EEGs?

The decision for surviving siblings, particularly those with a history of febrile seizures, to undergo electroencephalograms (EEGs) should be made in consultation with healthcare professionals. Considerations include the family's medical history, the presence of symptoms, and any concerns about potential genetic predisposition. If a sibling exhibits unexplained changes in behavior, developmental issues, or other signs of neurological problems, it may warrant consideration for EEG testing.

It is important to note that there have been children affected by SUDC who had normal EEGs and MRIs, reflecting that these tests may not provide information that would identify a child at

risk for death. The differentiating factors between children who experience benign febrile seizures and those who are at risk for death remain to be seen and is an area for future research.

Pediatricians or neurologists can provide guidance based on a thorough evaluation of each sibling's individual circumstances, helping to determine if EEGs or other diagnostic measures would provide information that would be useful for the care of the child. Open communication with healthcare professionals is essential in ensuring your specific concerns are addressed.

4. Can you provide information on the time lapse between seizure activity and death in the reported cases? Were any deaths witnessed, and were life-saving measures attempted?

The study indicates that in the cases where continuous recordings were available, convulsions were observed shortly before death, lasting between 8 and 50 seconds. Importantly, four children survived for more than 2.5 minutes post-convulsion.

The paper does not explicitly provide information on whether the deaths were witnessed or if life-saving measures were attempted in the reported cases.

5. What is known about the nature of pain and duration in seizure-related deaths? Are they typically quick, and is there pain involved?

In clinical cases of reported seizures most individuals state they do not feel pain during the actual seizure events. In some cases, individuals will report residual pain felt in certain areas due to muscle contractions. Also, there may be associated pain if an injury was sustained during the seizure.

6. For families with previous testing through SUDC, can existing samples be duplicated for future advancements, and is there an option to forward parent findings?

If you have participated in DNA banking or stored samples and have undergone additional genetic testing, we recommend reaching out directly to the specific study or research team overseeing your involvement. While the SUDC Foundation is happy to provide support and guidance, the specific study or research team is best equipped to address inquiries regarding sample duplication, potential advancements, or any available opportunities for ongoing or future research initiatives. It is important to understand that samples submitted to research typically belong to the research study itself, and while withdrawal from most research studies is possible, returning or duplicating individual samples may not always be feasible due to the collaborative nature of genetic research.

7. If seizures can be identified, what interventions could potentially save children's lives? Are position changes sufficient, or should more involved measures like CPR be considered?

While most seizures are self-limiting, being prepared for emergencies is important. For children with known seizure disorders, individualized seizure management plans should be discussed with healthcare providers. If there are specific concerns or questions about seizures and potential interventions, consulting with a healthcare professional is essential for personalized advice based on the child's medical history.

Basic seizure management includes creating a safe environment by moving objects and placing the child on a soft surface to minimize injury risk. If the child is prone, gently turning them onto

their side helps to maintain an open airway. Avoid restraining movements; note the seizure's duration and seek emergency medical assistance if it lasts longer than a few minutes or if there are repeated seizures without recovery. After the seizure, provide comfort and reassurance. If the child becomes unresponsive and stops breathing, those trained in CPR should initiate it.

8. How common is vomiting during seizures, and does it often lead to aspiration/blockage and subsequent death? How relevant is vomiting in understanding the cause of death?

Vomiting occurs in ~ 5% of all seizures.

9. Considering the potential link between SUDC and seizures, are there anticipated changes in medical recommendations for febrile seizures?

Ongoing research in this field holds the potential to influence medical recommendations and guidelines concerning febrile seizures, particularly if a discernible association with an elevated risk of sudden unexplained deaths is established. It is important to acknowledge that any specific recommendations or alterations in medical practices would be contingent upon continued investigations and the accumulation of conclusive evidence definitively establishing a clear link between febrile seizures and SUDC. Furthermore, in order to change management we would need to have a clear evidence base to suggest that the management change would change the outcome. At this point, there is no known intervention to prevent these deaths.

10. In future research, will the focus be on identifying seizures as a potential cause, or will there be exploration of genetic factors and other avenues?

Currently, SUDCRRRC is exploring other factors such as genetic links. [For example, in 2021 a study was published looking at the genetic trios \(parents and SUDC child\), showing in 9% of the deaths there were de novo \(present in child but not parents\) mutations in genes associated with cardiac and seizure disorders.](#) The way that the data is collected is one in which trends will become apparent and that is what helps us with directions for future research.

We know that it is likely that SUDC represents multiple underlying diagnoses rather than a single unified diagnosis. The research will continue to look at all potential pathways. The SUDCRRRC has a multidisciplinary approach that includes experts in Pediatrics, Neurology, Infectious Disease, Genetics, Cardiology, Radiology and Pathology.

11. How can one determine if a seizure is the cause of death without genetic or coroner report findings? What distinguishes these seizures from others leading to death?

Determining if a seizure is the cause of death without genetic or coroner report findings poses challenges. Seizures, in isolation, are typically not fatal, but complications during or after a seizure may lead to life-threatening situations. In the absence of genetic or coroner report details, assessing the cause of death often relies on considering circumstances, witness accounts, and the individual's medical history, especially if they have a known seizure disorder. However, definitively attributing the cause of death to a seizure without more detailed examination can be challenging.

12. Is SUDC preventable, and are any of its sub-categories linked to causes that might be preventable?

Sudden Unexplained Death in Childhood (SUDC) is a tragic and complex phenomenon, and the underlying causes are not fully understood. SUDC refers to the sudden and unexpected death of a child over the age of 1 that remains unexplained even after a thorough investigation.

There are no known prevention strategies for SUDC. It is important to note that SUDC is not a single, identifiable condition but rather a category used when a thorough investigation does not reveal a cause of death. Understanding the various sub-categories and potential contributing factors is an ongoing area of research.

The factors leading to SUDC are likely multifactorial and can involve a combination of genetic, environmental, and unknown elements. The lack of a clear cause makes it challenging to identify specific preventive measures.

Research into SUDC and its sub-categories continues, and advancements may shed light on potential preventive strategies in the future. If you have specific concerns or questions about SUDC prevention or its sub-categories, consulting with healthcare professionals or researchers specializing in this area would be beneficial for the most up-to-date information.

13. Based on the SUDCRRC findings, what recommendations exist for creating a safe sleep environment for toddlers?

There are no findings from the study to suggest that a different sleep environment would have made a difference in the outcome. Even in SUDEP (Sudden Unexpected Death in Epilepsy) research, there is no research to suggest that a different mattress or a monitoring device would prevent the deaths. The American Academy of Pediatrics (AAP) continues to recommend specific safe sleep recommendations for infants.

<https://publications.aap.org/pediatrics/article/150/1/e2022057990/188304/Sleep-Related-Infant-Deaths-Updated-2022?autologincheck=redirected>

14. What are the ongoing plans for future information gathering and research on SUDC?

<https://vimeo.com/430014733>

15. Did the children in the study exhibit markers for epilepsy, and what criteria might be developed to determine when a seizure could be potentially deadly?

The children in the study did not exhibit clear markers for epilepsy. At this point, there are no specific risk factors to identify which children with seizures are at higher risk for death.

16. Have there been documented cases where witnessed febrile seizures in sleep were successfully intervened, and similarly for non-sleep-related febrile seizures?

It is recognized in medical literature and practice that interventions for febrile seizures can be successful in both sleep-related and non-sleep-related situations. Prompt and appropriate actions, such as placing the child in a safe position, removing potential hazards, and closely monitoring their breathing, can contribute to managing the episode. If the febrile seizure lasts longer than a few minutes or is recurrent, seeking immediate medical attention is recommended.

17. Among the seven children with recorded videos, how many were found face down, were there genetic abnormalities noted, and what are the next steps in the research?

Among the seven children with recorded videos, all were found in a prone position with their faces down. While the study did not report specific genetic abnormalities for these cases, it mentioned that whole-exome sequencing failed to identify likely or definite pathogenic, inherited or de novo, variations in any case.

Moving forward, our focus remains on supporting and facilitating further exploration and research into the causes of sudden unexplained deaths in childhood (SUDC). We are dedicated to fostering collaboration and helping researchers in their efforts to unravel the complexities surrounding SUDC.

18. Can the study team compile a resource list of neurologists and pediatricians with advanced education in SUDC/epilepsy for families seeking medical support?

Reach out to the SUDRRC Directly.

To access our [Caring for the SUDC Family: Medical and Bereavement Information for the Clinicians' Consideration](https://sudc.org/caring-for-the-sudc-family-medical-and-bereavement-information-for-the-clinicians-consideration/), offering crucial medical and bereavement information for clinicians' consideration, please follow this link: <https://sudc.org/caring-for-the-sudc-family-medical-and-bereavement-information-for-the-clinicians-consideration/>.

19. Is acute myocarditis a commonly observed cause of SUDC in toddlers, and what strategies can be employed to mitigate this risk?

No, myocarditis is not a commonly observed cause of death in SUDC cases.

20. How long do parents typically keep video cameras on their children, and are there existing bed monitors that record seizure activity during sleep?

The duration parents keep video cameras on their children can vary widely and depends on individual preferences and circumstances. Some parents may use video cameras for monitoring their children during sleep or other activities for a limited period, such as during infancy or when specific concerns arise, while others may choose to use them for an extended duration.

As for bed monitors recording seizure activity during sleep, there are devices available that can track movement, heart rate, and other physiological indicators, potentially detecting seizures. However, the effectiveness of such devices can vary, and they may not be able to capture all types of seizures or provide a definitive diagnosis. One of the limitations of these devices are they are less likely to detect a non-convulsive seizure. It is crucial for parents to consult with healthcare professionals, such as neurologists or epileptologists, for guidance on the most appropriate monitoring tools based on their child's specific medical needs.

The decision to use video cameras or monitoring devices is a personal one, influenced by the child's health conditions, parental concerns, and medical recommendations. It is recommended that parents discuss their specific needs and concerns with healthcare providers to determine the most suitable monitoring approach for their child.

The Epilepsy Foundation and the Danny Did Foundation both provide resources regarding monitoring devices. The SUDC Foundation does not recommend or endorse any of these

products. We encourage families to have a discussion with their health care provider to help guide them in making an informed decision on whether a monitoring device would be helpful based on their individual history and needs.

<https://epilepsyfoundation.org.au/understanding-epilepsy/epilepsy-and-seizure-management-tools/seizure-monitors-devices/>

<https://www.dannydid.org/devices-technology/>

21. What steps is The SUDC Foundation taking to understand the connection between febrile seizures and sudden death, and what future research endeavors are planned in this regard?

The SUDC Foundation is actively engaged in understanding the connection between febrile seizures and sudden death, and they are dedicated to advancing research into all of the possible causes of Sudden Unexplained Death in Childhood (SUDC). The Foundation takes several steps in this regard:

The SUDC Foundation provides financial support for research initiatives through grants, both independent and external. This funding is directed towards investigations aimed at unraveling the underlying causes of SUDC, which may include exploring potential connections with febrile seizures.

The Foundation endorses research performed by other organizations and entities that contributes to the understanding of SUDC. This collaborative approach fosters a broader research community working towards the common goal of unraveling the mysteries surrounding sudden unexplained deaths in childhood.

The SUDC Foundation actively participates in organizational and public advocacy efforts related to SUDC research. This involvement includes supporting and advocating for research initiatives that aim to shed light on the factors, including febrile seizures, that may contribute to sudden death in children.

Chat Questions:

1. Most of these kids had low fevers not high fevers. Do we know why low-grade fevers cause febrile seizures?

Febrile seizures in children are typically associated with rapid rises in body temperature, often caused by infections or illnesses. While the majority of febrile seizures are linked to high fevers, it is not uncommon for some children to experience seizures with lower-grade fevers. The exact reasons why febrile seizures occur are not fully understood, but it's believed that the rapid increase in body temperature may trigger an abnormal electrical discharge in the brain, leading to a seizure.

2. Did any of the video FS passings have any preventive meds before going to sleep? (Tylenol, ibuprofen)

There is no information suggesting the administration of preventive medications such as Tylenol or ibuprofen before going to sleep. Contact the SUDCRRC for specific answers to this question.

3. Do we know if any of these children had elevated WBC at the time of autopsy that would indicate something which might cause a fever?

The information available from the provided study does not specify whether the children in the recorded cases had elevated white blood cell (WBC) counts at the time of autopsy indicating a potential source of fever. Contact the SUDCRRC for a specific answer to this question.

4. Will future studies include non-convulsive seizures?

It is important to note that not all seizures result in convulsions. For example, absence seizures are a type of seizures typically characterized by staring spells. The direction of future studies and research endeavors would depend on evolving scientific inquiries, emerging evidence, and the goals of researchers investigating sudden unexplained deaths in childhood (SUDC).

5. Were any of these seizures not while the child was asleep? Were any of these experienced during regular daytime?

All of the recorded convulsive activity occurred during the child's last sleep period. There were no instances of seizures experienced during regular daytime activities in this study.

6. Is it the hypoxia during the postictal period that then likely leads to death after the seizure? Since the kids are usually found prone and face down.

The postictal period, which follows a seizure, is characterized by a recovery phase during which individuals may experience confusion, fatigue, and in some cases, temporary weakness. While hypoxia (low oxygen levels) can occur during a seizure, it is typically brief and self-resolving. The risk of death after a seizure is generally low, but it is crucial to consider individual circumstances. If a child is found prone and face down after a seizure, there may be a risk of airway obstruction, potentially leading to decreased oxygen levels.

7. Did any of these children have a history of periodic fever syndrome?

The study made no mention of this. Contact the SUDCRRC for specific answers to this question.

8. Were they able to locate what area of the brain the seizures are going through? Eg locations that affect their stimulus to breathe by CO2.

The study did not provide detailed information on the specific areas of the brain involved in the observed seizures or whether there was an exploration of regions related to the stimulus to breathe by CO2. Contact the SUDCRRRC for specific answers to this question.

In this study, we weren't able to locate the area of the brain where the seizures originated. Unfortunately, we are often unable to find epileptogenic foci (or "seizure producing" areas) at autopsy. Because a seizure is a transient electrical dysfunction there isn't always an anatomic correlation within the brain. This is more easily identified by EEGs (electroencephalographs) recorded when the patient was alive.

9. Will SUDC Foundation start relating this info to police, paramedics, fire...etc.? In our case, the detective would not let us see or say goodbye due to "death investigation." I know some families had CPS called on other living children.

The SUDC Foundation actively engages in professional outreach to enhance understanding and support for families affected by sudden unexplained death in childhood (SUDC). Initiatives include a comprehensive 5-part webinar series addressing sudden pediatric deaths, consensus guidelines developed by the National Association of Medical Examiners, and a referral system offering bereavement support and assistance in navigating investigations. The Foundation collaborates with multidisciplinary experts, advocates for research, and provides resources such as customized brochures for medical examiner and coroner offices. Educational videos, webinars, and medical press publications contribute to medical professionals' awareness and knowledge. The Foundation also supports legislative and regulatory advocacy for fair and compassionate treatment of families, comprehensive professional training, and research into sudden unexpected pediatric deaths.

In some jurisdictions CPS must be notified by law when a child dies suddenly or unexpectedly. They may become involved in certain situations not out of concern for foul play, or out of blame, but because they are legally required to investigate. Unfortunately, this often comes from tragic situations where CPS was not notified of a potentially concerning death, and the siblings were then exposed further to potentially harmful situations. While we recognize that CPS investigations can add distress to an already traumatic time for families, we advocate for training professionals on how to incorporate this investigation in a compassionate way that is trauma informed.

The national consensus guidelines that were created in collaboration with the National Association of Medical Examiners and the American Academy of Pediatrics, does recommend allowing the family time to "say goodbye" to their child and emphasizes that this can be done in a way that is sensitive to the families' needs, while also not compromising the need for a thorough investigation. We continue to engage in professional outreach to first responders as well as physicians to educate them regarding these important principles.

10. My daughter had staring episodes and also complained of her heart feeling funny. I'm wondering if the heart and brain can be connected in some cases.

In some cases, there may be a connection between the heart and brain, as certain conditions affecting these organs can potentially contribute to sudden unexplained deaths. The brain also innervates the heart, and the way that seizures may impact heart rhythms is an area of ongoing study.

13. The study is limited as only 7 videos were available. What further studies are planned? Will the focus remain on young children as febrile seizure more common to them, or will there be a way to look at older children too?

Contact the SUDCRRC for specific answers to this question.

14. Could the seizures cause heart arrhythmia?

Seizures and heart arrhythmias are distinct medical conditions, but in some cases, they may be linked.

15. Are there any estimates based on the neurology article what % of SUDC in this younger set of children might be seizure-related?

While the study highlights that convulsive seizures were implicated in the studied cases, it's important to note that the sample size is limited. Therefore, any estimates regarding the percentage of SUDC in this younger set of children being seizure-related should be approached with caution.

The findings from the seven cases with recorded videos suggest a significant association between convulsive seizures and sudden unexplained deaths in toddlers. However, generalizing these findings to the broader SUDC population requires further research with larger sample sizes and diverse cases.

In previous studies of SUDC children there has been a 30% history of febrile seizures. However, these studies did not show causation. While these children did have a history of febrile seizures, it is unknown if it was a seizure that led to their death. An example of this research is included with a link to a 2019 JAMA article is listed below but the limitations are that it is data collected at variable intervals after the child's death and that it is not population based. These are certainly areas for future research.

<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2731680>

16. Is it possible to have a child's case re-looked at after 15+ years? Wondering if my daughter's case could be looked at from the perspective of more recent research findings, etc.

You may consider contacting the SUDC Foundation Family Advocate to inquire about the possibility of reevaluating your daughter's case considering recent research. They can provide you with information on available resources, guidance, and information.

17. Could somebody provide the link to the epilepsy foundation's info on monitoring devices?

<https://www.epilepsy.com/complications-risks/early-death-sudep/role-seizure-alerts>