



The SUDC Program c/o The CJ Foundation for SIDS
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- The collection of accurate healthcare statistics regarding SUDC.

To advocate for issues relative to SUDC.

These include, but are not limited to:

- The fair and sensitive treatment of families.
- Comprehensive and standardized death investigations and autopsy protocols.

To improve public awareness.

To share accurate and current information about SUDC.

To develop peer support among families. Trained peer

support is available to families, including ongoing support, provided by the Outreach Services Coordinator. Support through email, live chats and conference calls are also available to SUDC family members.

To raise charitable funds to meet the many needs of SUDC

including crucial research to discover the underlying cause(s) of SUDC.



sudden unexplained death in childhood



FREQUENTLY ASKED QUESTIONS ABOUT SUDC

ANSWERED BY DR. HENRY KROUS

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WHAT IS SUDC?

Sudden Unexplained Death in Childhood (SUDC) occurs in children beyond the age of twelve months. The cause of death remains unexplained after thorough case investigation including: examination of the death scene, performance of a complete autopsy, and a review of the child's and family's medical history. SUDC is a diagnosis of exclusion, in other words, a diagnosis of SUDC is made when other causes of death are not identified after a thorough evaluation.

WE HAVE NEVER HEARD OF SUDC.

IS THIS SOMETHING NEW?

SUDC is not new, but it is very rare. Its incidence is approximately 1 death per 100,000 children. In comparison, the incidence of sudden infant death syndrome (SIDS) is 45 times more common, being approximately 1 death per 2000 liveborn infants. It is not surprising therefore that there is very little in the medical literature about SUDC.

WHAT CAUSES SUDC?

By definition, the cause of death in these children is unknown. The diagnosis of SUDC can be made only after thorough review of the medical history of the child and its family, evaluation of the scene where the child was found lifeless, and the postmortem examination. The latter includes microscopic tissues examination, toxicology, vitreous electrolyte measurements, and metabolic screening. Microbiologic testing may be necessary in some cases.

In some cases of children dying suddenly and unexpectedly, comprehensive postmortem evaluations lead to identification of a known cause of death, in which case, the diagnosis is not SUDC.

CAN SUDC BE PREDICTED?

No. At the present time, there is not enough known about the underlying mechanisms of death in SUDC to allow predication of which children might die suddenly and unexpectedly. Since these children appear healthy,

health care professionals would not know what kind of testing should be done. And even if a particular test were abnormal, it would not predict which child would die given the very low incidence of SUDC.

CAN SUDC BE PREVENTED?

Presently, there is no way to prevent SUDC since its cause is unknown. It is hoped that research will identify means by which the risk of SUDC can be reduced, or even prevented. For example, research showed that prone (tummy) sleep position was an important risk factor for SIDS, and its avoidance has been followed by a 50% reduction in its incidence in the general population. It is our hope that similar factors will be identified for SUDC. In the meantime, optimal pediatric care recommendations, including attending well child visits, maintaining current vaccinations, and obtaining appropriate health care when clinically indicated, should be followed.

IS SUDC INHERITED?

There is no current evidence to suggest that SUDC is inherited. However, until more is known, this question is difficult, if not impossible question to answer. To date, research has not shown examples of recurrence in the same family. And, the medical literature does not suggest an increased risk of recurrence in the family if a thorough evaluation of child who died does not identify a cause of death. More research needs to be done before this question can be answered.

It should be remembered though that there are inherited or genetic disorders that will recur in families and cause sudden death. This is why comprehensive postmortem examination is very important. If such a disorder is identified, then appropriate pregnancy counseling can be obtained and proper medical management of subsequently born children can be undertaken.

ARE THERE STATE OR NATIONAL GUIDELINES FOR INVESTIGATING SUDC?

Death investigations vary widely throughout the United States and abroad. Virtually all states in the United States mandate autopsy examination in cases of sudden death in infancy. Although cases of SUDC would legally fall under the jurisdiction of the medical examiner or coroner, autopsy examination may not be performed in some jurisdictions. This is especially true if the attending physician is willing to sign a death certificate. The postmortem evaluation of a case of SUDC may not be

affected by the tragedy of SUDC, and promotes awareness of SUDC in communities.

OUR MISSION IS:

To provide a centralized resource for SUDC.

THE SUDC PROGRAM WELCOMES FAMILY, PROFESSIONAL AND COMMUNITY INVOLVEMENT.

COLLABORATION WITH MEDICAL PROFESSIONALS AND BEREAVEMENT PROFESSIONALS IS ESSENTIAL TO OUR MISSION. PLEASE CONTACT US FOR MORE INFORMATION.

HOW THE SUDC PROGRAM CAN HELP:

The SUDC Program was created in September 2001 as part of the CJ Foundation for SIDS. It was developed to provide a centralized resource for information, support,

as comprehensive or systematic as in cases of sudden unexplained death in infancy. For example, even though an autopsy is performed, important ancillary studies, such as metabolic analysis, may have been omitted.

There are standardized protocols for death scene investigation and postmortem examination in sudden unexplained infant deaths that have been endorsed by the National Association of Medical Examiners and the Society for Pediatric Pathology. Unfortunately, there are no published protocols mandated for cases of sudden death after the first birthday. However, the existent protocols for infants could serve as an important, but imperfect diagnostic aid for children over age one year.

HOW DOES AN SUDC CHILD AFFECT THE FAMILY?

The family and caregivers of SUDC children are devastated by their loss and the sudden and unexpected nature in which it occurred. At one moment a family has a happy, healthy child. Then, without warning, the child is found dead. Even after a thorough investigation, medical professionals cannot explain to the family why their child did not wake up. This lack of understanding complicates their grief.

Families are further burdened with the commonly held belief that once a child reaches their first birthday, that sudden and unexplained deaths cannot and do not occur. Limited awareness and understanding of SUDC exists among both the scientific and bereavement support communities. Families often grieve in isolation, without information, resources or knowing that other families exist with their similar loss. Until now, there has not been a centralized entity that has addressed the many issues specific to SUDC tragedies.

Contact with other SUDC families can help. The newly bereaved can find understanding, hope, insight and objectivity through peer support of those who have had a similar loss.

WHAT ARE THE GOALS OF RESEARCH INTO SUDC?

The goals are to identify the cause or causes of SUDC, identify factors (the avoidance of which can reduce the risk or prevent SUDC), improve the postmortem evaluation of these children, aid in the creation of state and national legislation that will facilitate research into SUDC, stimulate increased research into SUDC, improve the quality and quantity of support services for relatives of SUDC, improve vital statistics regarding SUDC, and educate health professionals and the public about SUDC. (For complete information on the SUDC Research Project, go to www.sudc.org)