

101 Eisenhower Parkway  
Suite 300  
Roseland, NJ 07068



Ph: 973.795.1257  
Fax: 973.559.6191  
info@sudc.org

*Unexplained Pediatric Deaths: Investigation, Certification and Family Needs* is a groundbreaking new book just released.

### **Background**

Each year in the United States, more than 3,000 infants and children die suddenly, unexpectedly and without explanation, even after an investigation and autopsy. This includes deaths previously known as Sudden Infant Death Syndrome (SIDS), Sudden Unexpected Infant Death (SUID) and Sudden Unexplained Death in Childhood (SUDC)\*. While the number of deaths in children under the age of 1 declined in the 1990s, it has plateaued for the last two decades.

These unexplained pediatric deaths have profound effects on families, as well as serious implications for our medicolegal death investigation system, public health system and society at large.

Death investigation systems in the U.S. are governed by individual states and vary by jurisdiction. This not only handicaps our ability to accurately determine cause and manner of death for each child, but also renders us incapable of collecting consistent data nationally to empower research and public health efforts to understand and prevent these deaths.

### **Why is *Unexplained Pediatric Deaths* groundbreaking?**

*Unexplained Pediatric Deaths* offers the first national consensus guidelines to fill crucial needs to help identify why these deaths happen and support families after these tragedies. It is the product of an expert panel created in collaboration between the National Association of Medical Examiners (NAME) and the American Academy of Pediatrics (AAP) funded by the SUDC Foundation.

The guidelines are based on a thorough review of the literature, describing the changing perceptions, philosophies, medical theories and investigative and prevention initiatives through the centuries. It addresses the needs of the many professionals and agencies involved when an infant or child dies suddenly. It provides an innovative classification system to improve our surveillance of sudden pediatric deaths that has confounded our tracking efforts previously. Adoption of these guidelines is critical to achieve a better understanding these deaths, successful public health prevention strategies and appropriate care of the bereaved.

The *Unexplained Pediatric Deaths* project began in 2016, when the SUDC Foundation awarded a grant to NAME to work in collaboration with the AAP to convene an expert panel to identify and discuss these critical issues. The publication is a combined effort of more than thirty multidisciplinary contributors from across the country, including medical examiners, pediatricians, federal agency representatives in public health, clinical subspecialists (neurology, cardiology, child abuse, injury prevention, infectious diseases, genetics and metabolic diseases), researchers, epidemiologists and family advocates. The panel was chaired by forensic pathologists Elizabeth Bundock, M.D., Ph.D. and Tracey Corey, M.D.

101 Eisenhower Parkway  
Suite 300  
Roseland, NJ 07068



Ph: 973.795.1257  
Fax: 973.559.6191  
info@sudc.org

*Unexplained Pediatric Deaths* is published by Academic Forensic Pathology International. For a full list of contributors, to order or to learn more, please visit: <https://sudpeds.com/>

**The book's guidelines include:**

*Medicolegal Death Investigation:* Offers procedural guidance for the medicolegal death professional regarding scene investigation strategies, scene reenactments, collection of pertinent circumstance and historical data and proper documentation. It recommends:

- Any child death falling under the jurisdiction of a medical examiner/coroner should be investigated by a certified medicolegal death investigator who is independent from law enforcement.
- Investigation of the scene where the child died is critical and should be performed within 24 hours even when the child has been transported to the hospital.
- If the child died during apparent sleep, the sleeping environment should be documented and recreated with a doll for all children up to 24 months of age, developmentally delayed children, and children with a seizure history to document the position of the child when placed to sleep and when found.
- Photographic documentation of the scene should be required and include overall environment, sleeping environment and clothing of anyone who was sleeping with the child who passed.
- Parents and caregivers should be interviewed as soon as possible using a recommended death reporting form to ensure collection of uniform information. A form specific to infants is provided as well as a child form for those older than 12 months of age.
- Investigators should gather as much health history on the child as possible including records from his/her mother's obstetrician, birth hospital, pediatrician, other hospitals and emergency treatment, and school.
- Removal of the child from the residence should be performed with care and compassion and investigators should be as accommodating as possible when allowing family to view the child's body without jeopardizing the investigation.

*Autopsy and Ancillary Testing:* Offers procedural guidance for the forensic pathologist in completing the autopsy investigation and communicating with affected families, including:

- An autopsy must be performed in all sudden unexpected deaths in infants and children unless prohibited by law (such as in cases of religious objection in certain states).
- The autopsy should be performed promptly and as soon as practical following death to preserve the quality of diagnostic specimens.
- A radiologic skeletal survey should be performed in all infants and young children.
- The pediatric brain and spinal cord should be preserved in fixation for comprehensive examination. The heart and great vessels must be examined in situ, with fixation of the conduction system, and microscopic evaluation of the ventricles, interventricular septum and any lesions.
- Histology and comprehensive toxicology must be performed in all sudden, unexpected deaths in children and additional tests should be performed in deaths that remain unexplained after gross autopsy examination.
- Specimen should be preserved to allow for later genetic testing.

- Ideally, screening tests for cardiac channelopathies and cardiomyopathies should be performed when all other testing is negative and prior to finalizing cause of death as “undetermined.”
- DNA banking may be offered to families at their cost in “undetermined” cases with negative genetic screens.
- Metabolic testing must be performed whenever the clinical history or autopsy findings suggest a diagnosis of inborn error of metabolism.
- Communication with the family should be considered a step in the autopsy and the family should have the opportunity to ask questions of the pathologist to best understand the findings in the report.
- Greater financial support *must* be provided to death investigation systems to provide adequate training, staffing, facilities, equipment and supplies to perform recommended procedures, consultations and testing. This would include providing financial incentives to address the shortage of forensic pathologists in the work force.

*Death Certification and Surveillance:* Offers a crucial review of how specific text choices on death certificates may inadvertently cause the death to be recorded in a way that the certifier does not intend. The authors promote the use of a “synoptic” report to clarify key findings not included on the death certificate but that are essential to improve surveillance and research. It also limits the use of acronyms to improve accuracy, consistency in certification and reduce confusion.

Certification guidelines for unexplained pediatric deaths include the choice of one of the below:

- Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors)
- Unexplained Sudden Death (Intrinsic Factors Identified)
- Unexplained Sudden Death (Extrinsic Factors Identified)
- Unexplained Sudden Death (Intrinsic and Extrinsic Factors Identified)
- Undetermined (Not further specified)
- Undetermined (Insufficient Data)

*Family Needs and Professional Relations:* Offers strategies to help the professionals involved in unexplained pediatric deaths to recognize the complex needs of family members grieving during the death investigation and how to meet them with compassionate support. It also examines the roles of the professionals involved in pediatric death investigations and offers key considerations for successful interprofessional relations, including:

- Professionals should maintain an unbiased, non-accusatory approach to parents to prevent further trauma.
- Families should have the opportunity to see and hold the child in supervised conditions.
- Open and timely communication with a single point of contact helps to foster positive long-term bereavement outcomes.
- Professionals should be prepared to provide services or referrals for grief support for surviving family members.

101 Eisenhower Parkway  
Suite 300  
Roseland, NJ 07068



Ph: 973.795.1257  
Fax: 973.559.6191  
info@sudc.org

- Depending on the child's investigation findings and his/her family history, appropriate medical referrals should be provided for surviving family members.

*Risk Factors & Prevention:* Offers a thorough review of the latest evidence regarding risk factors and prevention strategies for sudden, unexpected pediatric deaths, including genetic, metabolic and cardiac evaluation for higher-risk children.

*Research Needs:* Provides an overview of the crucial research needs to improve our understanding and prevention of these currently unexplained pediatric deaths.

\*Sudden Unexpected Infant Death (SUID) is a category of death in children under the age of 1 that are later explained, such as accidental suffocation or strangulation, as well as deaths that remain unexplained after a thorough investigation, review of clinical history and autopsy, also known as Sudden Infant Death Syndrome (SIDS). Sudden Unexplained Death in Childhood (SUDC) is the sudden death of a child between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy.