# *Procedural Guidance and Key Considerations*

## SCENE INVESTIGATION (SEE CHAPTER 4)

1. Any child death falling under the jurisdiction of a medical examiner/coroner should be investigated by a certified medicolegal death investigator, independent from law enforcement.

2. Individual death scene investigation requirements will vary based on the circumstances surrounding the death, and the age and the developmental capabilities of the child.

3. Use of an infant/child death reporting form is recommended to ensure requisite information is gathered uniformly, including housing and living environment, developmental milestones passed, caregiver arrangements, and school information (when applicable).

4. Scene investigation should be performed within 24 hours, even when the child has been transported to the hospital, to include evaluation of any potential hazards or exposures.

5. In cases of death during apparent sleep, the sleeping environment should be documented to include softness, such as the presence of a pillow top mattress and excessive bedding materials.

6. Doll reenactment is recommended for death during apparent sleep of 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.

7. Documentation of the scene should include the condition of the residence, lighting, power and heat sources, and ambient temperature and humidity, where applicable. The clothing of any adults or siblings should be viewed and photographed for infants/children found dead while sharing sleep surfaces, either by law enforcement or the medicolegal death investigator, depending on the jurisdiction.

8. Documentation of the body should include the type and amount of clothing and blankets on the child, rigor mortis and lividity, evidence of medical intervention, and any injuries.

9. Photographic documentation of the scene and the body at the scene (when applicable) is required, including overall views of the environment, availability of food and necessary care items (e.g., diapers, formula, baby bottles), focused views of the sleeping environment and the presence of any body fluids near the child. Use of a ruler/scale is recommended for injuries and sleeping environment (demonstrating the thickness of the bedding/dimensions of the crib/bassinet) for all cases in which the child apparently dies during sleep.

10. Video surveillance (e.g., crib monitors, home security systems, law enforcement body cameras) should be inquired about and viewed when available.

11. Cell phone and social media photographs and videos of the child prior to death may be obtained from the parents/caregivers.

12. Removal of the child from the residence should be performed with care and compassion. It is recommended that the child be wrapped in a sheet or blanket and carried to the transport vehicle, to be placed inside a body bag and/or transport box.

13. Medical records (i.e., birth, pediatrician, any hospital/emergency department visits) should be obtained. School records may be requested for those children of school age. The medical examiner/coroner should work with local hospitals and other agencies to obtain and store records and/or gain electronic off-site access. Case management software must be secure, access-controlled, and have the capability to store third party records.

14. The death investigator should be familiar with current social media platforms and work with parents/law enforcement agencies to gain access to electronic devices when necessary.

## THE AUTOPSY (SEE CHAPTER 5)

1. 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).

2. The autopsy should be performed promptly and as soon as practical following death, to preserve the quality of diagnostic specimens including those for microbiological, genetic, and metabolic studies.

3. A radiologic skeletal survey should be performed in all infants and young children. Consultation with a pediatric radiologist, if available, may be considered. Memoranda of understanding may be established with local hospitals to obtain postmortem skeletal surveys in cases in which the infant or child is transported to the hospital.

4. Histology must be performed in all sudden unexpected deaths in infants and children.

5. Comprehensive toxicology must be performed in all cases, and that testing should include illicit and prescription drugs, over-the-counter medications, and alcohols. Investigative findings and pathologist discretion should guide the scope of testing.

6. Microbiological cultures and other related studies should be performed at the time of autopsy in deaths that remain unexplained after gross autopsy examination, directed by the case history and autopsy findings. Molecular testing may be performed in conjunction with cultures, and specimens should be preserved for additional infectious disease-related molecular testing methods if later. See **Chapter 6** Evaluation for Infectious Diseases for details.

7. Chemical analysis of vitreous fluid for electrolytes and glucose should be performed in deaths that remain unexplained after gross autopsy examination.

8. Appropriate specimens must be preserved to allow for later genetic testing (a purple top EDTA tube of blood at minimum). Ideally, genetic screening tests for cardiac channelopathies and cardiomyopathies should be performed in all sudden unexplained infant and child deaths that remain unexplained after autopsy and all other ancillary testing, prior to finalizing cause of death as undetermined or equivalent. Other genetic studies (for metabolic and neurologic disorders) may be appropriate based on medical history, circumstances of death, and autopsy findings. It is understood that the yield of genetic testing is low in sudden unexplained infant deaths, but somewhat higher in sudden unexplained deaths in childhood. DNA banking may be offered to families (at their cost) when a cause of death is not identified through autopsy and other ancillary testing including genetic screening. See **Chapter 9** Evaluation for Genetic and Metabolic Disorders for details.

9. Metabolic testing must be performed in any death in which the clinical history or autopsy findings suggest a diagnosis of inborn error of metabolism; clinical consultation may be useful in appropriately targeting the testing. Routine metabolic screening on all sudden unexplained infant and child deaths is extremely low-yield, and a negative result from the limited testing typically performed postmortem may provide false reassurance. A metabolic blood/bile spot card should be prepared at the time of autopsy and held (to be later sent if indicated by unexpected findings). See **Chapter 9** Evaluation for Genetic and Metabolic Disorders for details.

10. The pediatric brain and spinal cord should be preserved in formalin prior to sectioning, photography, and histologic sampling if organ retention is not precluded by statute and the autopsy has not revealed a definitive cause of death. The intracranial dura may be examined with or without fixation. See **Chapter 8** Evaluation for Central Nervous System Dis orders for further details.

11. The orientation of the heart and great vessels must be examined *in situ* in all pediatric cases. When abnormalities are already apparent, the heart, lungs, and thoracic aorta should be removed *en bloc* for further examination. Otherwise, the method of removal is at the discretion of the pathologist. In infants, the heart should be opened along lines of blood inflow and outflow. In older children, the adult method (transverse apical sections, followed by dissection of the heart base by blood inflow and outflow method) may be used. See **Chapter 7** Evaluation for Cardiac Diseases for further details.

12. Communication should be considered a "step" in the autopsy. Preliminary results should be communicated to the family of the deceased and other important stakeholders within 48 hours of autopsy, with clear communication of anticipated scope of testing and turn around times, and who they should contact for updates or questions. Final results and the cause of death should be communicated to the family and other stakeholders. The family should receive this information verbally (by scheduled appointment, either via tele phone or in-person) and in writing, if desired, and the family should have the opportunity to ask questions of the pathologist of record in order to best understand the findings in the report. A written request from the family for this information may be required in some states.

13. The autopsy report should include a synoptic report (See **Chapter 11**) and detailed opinion section that explains the rationale for the cause and manner of death determination; this should be written in a manner accessible to the lay reader, and questions about un usual results or circumstances should be anticipated and explained proactively, when possible. The opinion section may include a recommendation that surviving family members be clinically evaluated when a genetic condition has been diagnosed or remains in the differential diagnosis. Such recommendations may also be addressed in a separate letter rather than in the autopsy report, if a letter is sent to the family.

14. Greater financial support must be provided to death investigation systems (medical examiners and coroners) to provide adequate training, forensic pathologist staffing, support staffing, and needed facilities, equipment, laboratory supplies, and budget for testing. This funding is needed to ensure thorough death scene investigation, complete autopsies (including the recommended levels of associated ancillary testing, procedures, and consultations), timeliness of results, and the appropriate care and counseling of the next of kin. Financial incentives to encourage more medical trainees to enter the field of forensic pathology should be pursued to combat a critical workforce shortage that threatens the capacity to perform necessary autopsies and associated advanced procedures recommended here. Forensic pathologists who seek and/or attain dual training, especially in areas of pediatric pathology, cardiac pathology, and neuropathology, should be supported and encouraged.

## EVALUATION FOR INFECTIOUS DISEASES (SEE CHAPTER 6)

1. Forensic pathologists should consider consulting with a clinical microbiologist in cases in which there are unexpected or equivocal culture results, or if the results are challenging to interpret in the context of the clinical symptoms and/or autopsy results.

2. Forensic pathologists may consider consulting with the microbiology laboratories at the Centers for Disease Control and Prevention or their state health laboratory when an infectious cause of death is identified but not the etiology of that infection.

3. If there is a clinical suspicion of infectious disease based on the history, presentation, and/or the autopsy findings, sample collection at the time of autopsy examination for molecular testing conducted by local/state laboratories and/or the Centers for Disease Control and Prevention may be beneficial.

4. Application of routine protocols for which samples are collected and which studies are performed are recommended as follows:

    a. For cases without clinical symptoms and the absence of gross autopsy findings, the following specimens and indicated studies are recommended:

        i. Blood in a sodium citrate sterile tube or sulfite polymyxin sulfadiazine agar for bacterial culture for aerobic organisms.

        ii. Nasopharyngeal swabs for viral culture placed in viral transport medium.

iii. Lung tissue in sterile containers for bacterial or viral culture and consider frozen tissue for molecular studies.

iv. Heart tissue in sterile containers for viral culture and consider frozen heart tissue for molecular tests.

v. Feces, 2-3 mL in a sterile container for ELISA or PCR testing for viral pathogens or toxins.

vi. Cerebrospinal fluid in a sterile tube for bacterial and viral cultures; if available, consider a sample in a sterile tube for molecular studies.

vii. Consider spleen for bacterial culture and molecular studies.

viii. Consider serum (from centrifugation of peripheral blood in a serum separator tube) for serology and antigenic analysis*.

b. For all cases with clinical symptoms and/or the presence of gross autopsy findings of an infectious process, the following specimens may be collected, according to symptoms or findings*:

i. For neurological symptoms, meningitis/encephalitis: submit cerebrospinal fluid and brain tissue (including meninges) for bacterial and viral cultures, consider freezing portions for potential molecular studies.

ii. For sepsis, submit tissue from any grossly abnormal organ plus cerebrospinal fluid for bacterial and fungal cultures as indicated; plus consider freezing portions of abnormal organs for potential molecular studies.

iii. For respiratory symptoms and/or pneumonia: submit a nasopharyngeal swab for viral studies; submit a sample of affected lung tissue and a bronchial swab for bacterial cultures (and fungal culture if indicated); and consider freezing tissue for potential molecular studies as a backup.

iv. For suspected congenital/perinatal infections (including meningitis or septic shock) in those younger than 3 months old, collect cerebrospinal fluid, brain, urine, and saliva and consider testing based on symptoms/findings, vaccination status, and available resources: cerebrospinal fluid and brain for PCR/ELISA for measles, mumps, rubella, varicella, and erythema infectiosum; PCR for entero virus; PCR for *Streptococcus agalactiae* and *Listeria*; cerebrospinal fluid for non-treponemal assays; and PCR plus ELISA for toxoplasmosis; urine and saliva for ELISA, PCR, and viral cultures for congenital cytomegalovirus.

v. For pericarditis, submit both pericardial fluid and heart tissue for bacterial culture and consider freezing portions for potential molecular studies as a backup.

vi. For all infectious cases, an ideal practice would include collection and freezing a portion of the spleen for potential molecular studies. Additionally, if peripheral blood is still available following routine collections, consider freezing an aliquot for potential molecular studies. Should there be remaining peripheral blood after these collections, separate serum and freeze it for potential molecular testing.

5. A protocol for sample collection and submission is recommended as follows:

   a. Disinfect the skin with chlorhexidine 0.05% with cetrimonium bromide 0.5% in water for any percutaneous specimen collections.

   b. Sear the surface of organs with a red-hot spatula, scalpel blade, or soldering iron before sampling with sterile scalpel blades or other instruments.

   c. Use flocked swabs (i.e., a plastic shaft with tufted polyester at one end).

   d. Use sterile containers.

   e. In general, the following sample sizes are recommended (as available): 3-5 mL of blood for cultures, 2-3 mL of other fluids/materials (e.g., cerebrospinal fluid, feces), and greater than 1-2 $cm^3$ of tissue.

   f. Samples should be delivered to the microbiology laboratory within 2 hours if stored at room temperature; delivery to the laboratory should be made within 48 hours if the samples are refrigerated at 2-8° C.

*Some autopsy facilities will not have adequate frozen storage to accommodate this practice.

## EVALUATION FOR CARDIAC DISEASES (SEE CHAPTER 7)

1. The orientation of the heart and great vessels must be examined *in situ* in all pediatric cases. When abnormalities are already apparent, the heart, lungs, and thoracic aorta should be removed *en bloc* for further examination. Otherwise, the method of removal is at the discretion of the pathologist. In infants, the heart should be opened along lines of blood inflow and outflow. In older children, the adult method (transverse apical sections, followed by dissection of the heart base by blood inflow and outflow method) should be used.

2. In deaths that remain unexplained after autopsy, portions of heart containing the conduction system should be retained in formalin. Depending on the circumstances of the case and at the discretion of the pathologist, the conduction system can be submitted for microscopic examination or referred to a cardiac pathologist for evaluation.

3. In all pediatric deaths that remain unexplained after autopsy, microscopic examination of the left and right ventricles, interventricular septum and grossly apparent lesions must be performed. Examination of atria and conduction system are at the pathologist's discretion.

4. Examination by a cardiac pathologist is recommended when the heart is externally abnormal or there is a history of congenital heart defect, and retention of organs is not restricted by statute.

## EVALUATION FOR CENTRAL NERVOUS SYSTEM DISEASES (SEE CHAPTER 8)

1. The pediatric brain and spinal cord should be preserved in formalin prior to sectioning, photography, and histologic sampling if organ retention is not precluded by statute and the autopsy has not revealed a definitive cause of death. The intracranial dura may be examined with or without fixation.

2. Examination of the formalin-fixed specimens by a neuropathologist experienced in forensic cases is recommended but at the discretion of the autopsy pathologist if resources are limited or retention of organs is restricted.

3. For pediatric deaths that remain unexplained after autopsy, microscopic examination of at least the following brain regions is performed: 1) cortex and white matter at frontal watershed (with leptomeninges), 2) hippocampi (bilateral) at level of lateral geniculate nucleus, 3) rostral medulla, 4) cerebellum, 5) grossly apparent lesions. Examination of additional regions (basal ganglia with insula, thalamus, midbrain, pons, cervical cord) is encouraged.

4. In anticipation that findings in routine sections or additional case information prompt further examination, representative formalin-fixed sections of cortex from each lobe, both hippocampi, basal ganglia with adjacent insular cortex, thalamus, midbrain, pons, medulla, cerebellum, and cervical cord should be available until the case is complete or office policy for specimen disposal is satisfied, whichever is later.

## EVALUATION FOR GENETIC AND METABOLIC DISORDERS (SEE CHAPTER 9)

1. Sample(s) for possible genetic testing should be collected in all pediatric cases of sudden unexpected death. Genetic screening tests for cardiac channelopathies and cardiomyopathies should be performed in all sudden unexplained infant and child deaths that remain unexplained after autopsy and all other ancillary testing, prior to finalizing cause of death as undetermined or equivalent. Other genetic studies may be indicated.

2. Blood or heart tissue are the preferred samples for genetic testing, with highest-quality material being (in order of preference): 1) extracted soon after collection from fresh sample (e.g., sent immediately to testing laboratory or for DNA banking), 2) stabilized in an intermediary preservative and stored, or 3) snap-frozen and stored frozen. Blood stored in EDTA usually yields good results and is therefore the recommended minimum. Storage of frozen tissue in addition to blood is ideal. Blood spot cards may be accepted by a few laboratories.

3. A metabolic blood/bile spot card should be prepared at the time of autopsy and held. When history, signs and symptoms, and/or pathologic findings suggest the potential for an inborn error of metabolism, sending the metabolic blood/bile spot card for screening is an appropriate first step but may be insufficient for final diagnosis. Therefore, storage of fresh frozen tissues at -80°C (brain, heart, liver, kidney, skeletal muscle), glutaraldehyde-fixed tissues (brain, kidney, skeletal muscle), and skin for fibroblast culture should be considered in such cases. Given the rarity of such cases, complexity of specimen storage, and likely need for consultation to determine appropriate testing, establishing collaboration in advance with local academic or clinical institutions that have such storage resources is recommended.

4. If a genetic or metabolic condition is suspected, the medical examiner/coroner should inform the family, and the primary care physician/pediatrician if next of kin consent is obtained, as soon as possible after the death.

5. Early involvement of a medical geneticist, pediatric pathologist, and genetic counselor is recommended if a genetic condition is suspected.

6. Relationships between the medical examiner/coroner, medical geneticists, genetic counselors, physicians, academic hospitals and testing laboratories should be well established in advance, to simplify the process for involved professionals and to assist families with decision making and testing of survivors if the results or clinical concern indicate.

## CERTIFICATION AND SURVEILLANCE (SEE CHAPTER 10)

1. When cause can be determined, Part 1 of the death certificate must indicate the specific underlying etiology.

2. The following criteria for certification of an infant death as being caused by an asphyxia etiology are recommended:

    a. The case must have a complete/full autopsy.

    b. Toxicology, histology, vitreous electrolytes, cultures, and review of medical history are to be performed, as necessary as determined by investigation and autopsy.

    c. The infant must have obstruction of both nose and mouth or compression of the neck or chest, that is reliably witnessed or demonstrated by doll reenactment, or other reliable evidence of overlay or entrapment.

    d. Asphyxiation must be probable given infant's age and stage of development.

    e. There cannot be a reasonable competing cause of death.

3. When cause of death cannot be determined, one of the following cause statements are recommended as applicable (See **Chapter 10** for definitions and criteria):

    a. Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors).

    b. Unexplained Sudden Death (Intrinsic Factors Identified).

    c. Unexplained Sudden Death (Extrinsic Factors Identified).

    d. Unexplained Sudden Death (Intrinsic and Extrinsic Factors Identified).

    e. Undetermined (Not further specified).

    f. Undetermined (Insufficient Data).

## SYNOPTIC REPORTING (SEE CHAPTER 11)

1. For deaths in which the cause of death cannot be determined, the autopsy report should contain:

    a. At minimum, a synoptic report, including the following elements: cause of death, manner of death, investigation, medical history, sleep environment concerns, other environmental concerns, other objective concerns, autopsy, toxicology, ancillary studies, and radiologic studies, and;

    b. Ideally, an organized, well-written summary section that details a rationale for the chosen cause of death statement, highlighting influential aspects of the history, investigation, or autopsy.

## FAMILY INTERACTIONS FOR MEDICAL EXAMINER, CORONERS, AND DEATH INVESTIGATORS (SEE CHAPTER 12)

1. Medicolegal death investigation professionals should maintain an unbiased, nonaccusatory approach to parents during the investigation and should provide services or referrals to address grief and stresses for surviving family members.

2. Irrespective of whether there are concerns about intentional or criminal intent, there should be a respect for privacy, dignity, and comfort for families of deceased infants and children, referrals for bereavement support, follow-up, and meaningful communication with families by hospital staff and primary care providers. Timely communication is indicated irrespective of potential culpability because it is associated with positive long-term bereavement outcomes.

3. Open communication with the medical examiner/coroner's office is essential. The first 72 hours is chaos for surviving families and follow-up throughout the entirety of the investigation should be provided as needed by the family, preferably through a single point of

contact. It is important that information be shared through more than one avenue (e.g., verbal and written, etc.) due to the decreased capacity of families to process information. Death investigation systems should seek guidance and training in grief communication and develop policies and procedures for communication of cause of death determinations and genetic testing recommendations/results to facilitate appropriate follow-up for survivors.

4. The medical examiner/coroner should be available to participate in a post-autopsy conference with family members, as time and geography permit and as desired by the family, after the investigation is complete. A meeting or telephone call with medical providers before this meeting may help those who know the family to evaluate and understand the family reactions and assist in responding to surviving children's needs in age and developmentally appropriate ways. Upon request, the medical examiner should provide information to surviving family regarding options for obtaining an independent autopsy or a review of the medical examiner's findings and conclusions.

5. As permitted by local regulation, state statute, and specifics of an individual case, the medical examiner/coroner should be available to hospital personnel such as the deceased's attending and/or personal physician(s). If desired by the family, pediatricians and family physicians should have a face-to-face meeting with family after the autopsy report is finalized, to review findings, and to facilitate referrals for further assessment if potential inheritable conditions are identified.

6. Death investigators and forensic pathologists should be trained and skilled in the recognition of potentially important family reactions and should be knowledgeable about local and national support services for referral. Consultations with primary care pediatricians, family physicians and other physical and mental providers, as allowed by regulation and statute, are invaluable.

## FAMILY INTERACTIONS FOR FIRST RESPONDERS, HOSPITALS, AND COMMUNITIES (SEE CHAPTER 12)

1. Hospitals should establish protocols and a single point of contact/liaison to coordinate communication with families. The same point of contact should coordinate communication with medical personnel with an interest in the case (primary care providers, attending physicians, hospital pathologists risk managers, etc.) and the investigating agencies. The hospital's point of contact should be identified in all communications.

2. Hospital and professional staff should use age appropriate, educationally appropriate, and culturally sensitive guidance for families in their native language while being alert for normal and complicated grief responses.

3. Depending on local protocols and statutes, and at the discretion of the medical examiner/coroner, the family should be given an opportunity to see and hold the infant/child in supervised conditions once death has been pronounced and before transport. It is suggested that an unrelated observer remain with the family throughout this period to serve as a witness should issues regarding postmortem artifacts arise.

4. Personnel on first-response teams should be trained to make observations at the scene, including the reaction of grieving family members. Medics and emergency department personnel should be trained to recognize normal reactions in family members in addition to acute decompensation, the need for immediate crisis intervention, and referrals to long-term support services.

5. Hospitals should educate members of their medical staffs and other relevant hospital personnel about the locality's medicolegal death investigation system, state statutes and local regulations regarding notification of deaths, and the hospital's related policies and procedures.

6. Home-visits should be considered for selected families to facilitate grief support, sudden infant death education, and to offer resources and referrals to parents and siblings.

7. Pediatricians, family physicians, first responders, and hospital personnel should participate on child death review committees to facilitate the development of procedures in the community that reflect trauma-informed care and supportive practices.

## PROFESSIONAL RELATIONS (SEE CHAPTER 13)

1. Establishment of subcommittees of child fatality review teams to provide annual review of formal agreements between hospitals, death investigation system offices, and law enforcement agencies, and checklists of these agencies, in order to update or troubleshoot any gaps or flaws in the system. Such subcommittees would be comprised of stakeholders; namely, families of decedents, hospitals, medical examiners, and law enforcement. The subcommittee may also be charged with oversight of the annual education and training sessions described in the above section.

2. Revision of undergraduate and graduate medical curricula to place greater emphasis on meaningful and dedicated multidisciplinary education and training, specifically amongst the specialties of pediatrics, pediatric pathology, and forensic pathology. Teams of representatives of each specialty should conduct such training.

3. Development of continuing medical education programs by multidisciplinary teams for practitioners in pediatrics, pediatric pathology, and forensic pathology for interdisciplinary education and training to be offered online and/or at state and local medical on an annual basis. Concomitantly, the respective national professional organizations should coordinate joint ancillary meetings or develop a joint annual meeting of the multiple disciplines.

4. Development of support structures for the various professionals at hospitals, for those in law enforcement and coroners, and for members of medical examiner's offices such that they may convene on a regular basis to participate in debriefings and/or panel discussions.

5. Creation by forensic pathologists of a network of suitable consultants, and with development of a protocol that facilitates the use of consultants. Such consultants may include, but are not limited to, neuropathologists, specialists in metabolic disorders, geneticists, pedi-

atric radiologists, and clinical pediatric microbiologists

## PREVENTION AND RESPONSE (SEE CHAPTER 14)

1. Reducing risk of sudden unexpected infant death includes avoidance of risk factors, as published by American Academy of Pediatrics. Therefore, the following are recommended:

   - Supine sleep position in safety-approved crib, without bedding, next to parents' bed, in smoke-free environment
   - Avoid smoking, alcohol, illicit drugs during pregnancy
   - Avoid second-hand smoke exposure
   - No sharing of sleep surfaces, especially if bed sharer is smoker or arousal impaired
   - No sleeping on cushioned surfaces, including sofas, couches, and armchairs

2. Factors associated with a protective effect on sudden unexpected infant death, which include breastfeeding, pacifier use, and room sharing without bed-sharing, are encouraged.

3. Measures to prevent sudden death in young athletes are not established. Pre-participation physical exam, particularly cardiovascular screening, is not standardized, but should include identification of symptoms associated with sudden death (e.g., syncope or seizure during exercise or excitement, consistent or unusual chest pain and/or shortness of breath during exercise, family history of an unexpected, unexplained sudden death in a young person) and further assessment when those are present.

4. If diagnosed with certain cardiac disorders (e.g., hypertrophic cardiomyopathy, long QT syndrome), limitation or modification of sports participation, adherence to prescribed medical therapy, and prophylactic lifestyle restrictions are recommended for athletes.

5. Knowledge about risk factors and prevention of sudden death due to epilepsy is limited. The following preventive measures may be considered:

   - Monitoring devices (oxygen saturation monitoring and seizure detection monitoring)
   - Room sharing while sleeping
   - Medication adherence
   - Measures to reduce hypoventilation (e.g., physical stimulation, serotonin selective reuptake inhibitors)

6. The mechanism and cause of unexplained death in children with a history of febrile seizures is poorly understood but usually occurs during sleep and shares some similar risk factors with sudden unexplained infant death (i.e., prone sleep, hyperthermia, infections, prematurity, exposure to tobacco smoke, and male gender). Further research is recommended.

7. Pediatrician offices and death investigation systems should develop policies and procedures for communication of cause of death determinations and genetic testing recommendations/results to facilitate appropriate follow-up for survivors.

## RESEARCH NEEDS (SEE CHAPTER 15)

1. More specific phenotypic and genotypic information should be identified to inform diagnosis, identification of other family members at risk, and actionable clinical information of value to the survivors. This will entail funding basic and translational research in sudden unexplained death in childhood (and furthering research in sudden unexplained death in infancy).

2. Consensus guidelines/recommendations are needed to define a comprehensive postmortem genetic investigation and appropriate genetic investigations for surviving first-degree relatives.

3. Additional research is needed to understand the etiology of febrile seizures and the mechanisms through which seizures cause death. There is also a need to develop markers (including genetic) to identify which patients with febrile seizures are at risk for sudden death and to provide guidance for physicians to counsel these families.

4. We need research to understand the potential role of systemic (e.g., mild pulmonary inflammation or infection) or neuropathological (e.g., abnormalities in the dentate gyrus of the hippocampus) findings as contributors to the cause of death, as markers or consequences for an independent process that led to death (e.g., systemic infection, seizure).