UNEXPLAINED PEDIATRIC DEATHS:
Investigation, Certification & Family Needs

Procedural guidance and key considerations
developed by the
National Association of Medical Examiner's Panel on Sudden Unexpected Death In Pediatrics

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DISCLOSURES

- No financial disclosures for speaker (B. McCleskey)
- NAME panel work funded by SUDC Foundation.
- Reference to book published by AFP.

Vivienne, 3 years old *Keegan, 8 months old* *Adeline, 14 months old* *Bryson, 10 weeks old* *Tayjon, 2 ½ years old,*

THE MOTIVATION

With parent permission

NATIONAL ASSOCIATION OF MEDICAL EXAMINER'S PANEL ON SUDDEN UNEXPECTED DEATH IN PEDIATRICS

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THE RESULT

- **Over three years of work – started in late 2016**
  - **Massive reference collection, organization and review**
  - **Numerous committee conference calls as well as separate subcommittee activities**
  - **Two in-person 2 day meetings; meeting at NAME Annual Meeting; editors retreat**
- **Support by SUDC Foundation:**
  - **Publication of book by AFP**
  - **Made available to NAME members and others**
  - **Publicly available for purchase on Amazon.**

Procedural Guidance/Key Considerations for:

Scene investigation

Autopsy and ancillary testing

Certification and Surveillance

Synoptic Reporting

Family and professional interactions

OBJECTIVES

At the conclusion of this presentation, participants should be able to:

- Understand what constitutes an unexplained pediatric death
- Apply investigative and certification guidelines to their medicolegal death investigation practice
- Recognize value in standardized certification practices and the impact of such on vital statistics and public health

TOPICS COVERED:

- Historical Perspectives
- Medicolegal Death Investigation
- Autopsy and Ancillary Testing
- Synoptic Reporting
- Death Certification and Surveillance
- Family Needs & Professional Relations

HISTORICAL OVERVIEW

- Ancient, Medieval, and Renaissance
  - Infant and child mortality was significant and multifactorial
  - Focused primarily on overlay
- 19th Century
  - Some children began being autopsied
  - 1830 (J.H. Kopp) described "thymic asthma" ascribing blame to an enlarged thymus for death
  - Despite being debunked 28 years later using autopsy data (Friedleben), was used in court in 1884
  - Continued battle between natural and unnatural means by authorities
    - Over 140 years of the "great divide"
    - Overlay and later child abuse
    - 1892 (Dr. Templeman) described 258 cases with accidental overlay and factors common among them
      - Earliest description of associated risk factors

HISTORICAL OVERVIEW

- 20th Century
  - Dr. Bruce Beckwith adamantly opposed to "blaming the parents"
    - Named (along with Valdes-Dapena) Sudden Infant Death Syndrome
  - 1944: Dr. Harold Abramson identified another risk factor
    - Prone sleeping position
    - Advised parents on safe sleep
  - Natural means focused on respiratory illness and bacterial infections
    - 1956: Adelson and Kinney published results of 126 child deaths with most being due to respiratory infection
    - Disproved the concept of diagnostic findings of suffocation
  - Child abuse, "battered child syndrome," and "shaken baby" took years to take hold as a possibility for death (1960s and 1970s)

HISTORICAL OVERVIEW

- 1963: Conference in Seattle (10 panel members/30 guests)
  - Pediatric pathologists, pediatricians, forensic pathologists (minority)
  - Lacked consensus internationally
  - Concluded use of "sudden death syndrome"
- 1969: Follow-up Seattle conference where Beckwith proposed and the panel adopted "Sudden Infant Death Syndrome"
  - Unexpected by history and in which a thorough postmortem examination fails to demonstrate a cause of death
- Two peaks in "nontraumatic" childhood deaths
  - 1 – 4 years: undetermined or infectious
  - 14 – 21 years: heart and/or brain related findings

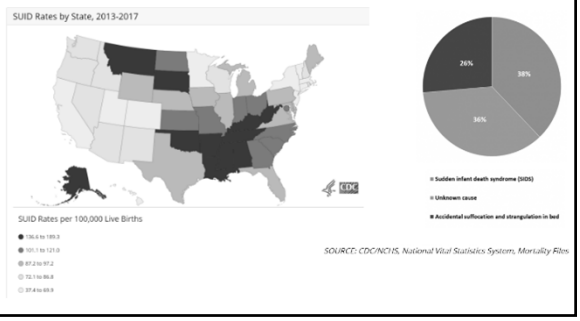
HISTORICAL OVERVIEW

- Mechanistic shifts: Infectious, hypoxemia, apnea
  - History and scene investigations required
- 1985: SIDS finally defined as "heterogeneous group of pathogenetic phenomena rather than single entity" (Valdes-Dapena)
- Shift to scene investigation, medicolegal death investigators, forensic pathology involvement
  - 1989: US National Institute of Child Health and Human Development
    - Defined criteria for diagnosis of SIDS (including "only during sleep")
  - Early 90s: "Back to Sleep" campaign

HISTORICAL OVERVIEW

- Triple Risk Model (1994)
- 1996: Guidelines for investigation and reporting (CDC)
- 2004: Expert panel refined SIDS into categories
- Shift to "Sudden Unexplained Infant Death" among some experts
- 2005: Krous published "sudden unexplained death in childhood" paper
- 2007: NAME provided SUID position paper
- 2020: …..

HISTORICAL OVERVIEW



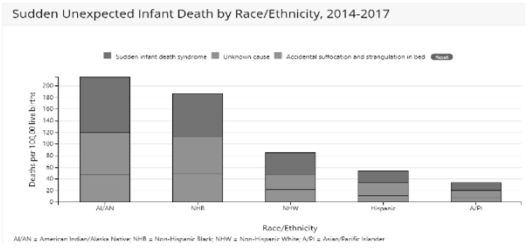
HISTORICAL OVERVIEW

- Shift away from SIDS on death certificate crippled ability to look at vital statistics
- No consensus among certifiers
- More recently these cases are lost as "undetermined"

RISK FACTORS

Case-control studies demonstrate ASSOCIATION between exposure and risk (or protective) factor NOT CAUSATION

Established before shift away from SIDS



RISK FACTORS

- Non-Hispanic black and American Indian/Alaska Native
- Low maternal socioeconomic and educational status
- Young maternal age
- Prone positioning (on stomach)
- Bed-sharing
- Parental smoking
- Prematurity and low birth weight

HISTORICAL OVERVIEW

- Prone positioning increases risk of
  - Hypercapnia and hypoxia
  - Overheating
  - Changes in autonomic control of cardiovascular system
  - Increased arousal thresholds
- Tobacco exposure (dose-dependent)
  - Estimated that 1/3 could be prevented if all exposure eliminated
- Bed sharing and soft bedding
  - Particularly dangerous when adult bed-sharers have consumed alcohol or arousal-altering medications/drugs
  - Never on couches or cushioned surfaces
  - Use caution in sitting devices for those less than 4 months of age

HISTORICAL OVERVIEW

- Room sharing
  - Tight-fitting mattress in a crib
- Feeding of breast milk
- Pacifier use

HISTORICAL OVERVIEW

- Sudden Unexpected Deaths in Athletes
  - Rarely reported in the prepubertal age group
  - Typically of a cardiac etiology (hereditary or acquired)
- Children with history of epilepsy and/or febrile seizure
  - Most events occur during sleep
  - Apnea may be only symptom in infancy
- Siblings
  - Modifiable sleep-environment risk factors
  - Potential genetic associations

HISTORICAL OVERVIEW

- Ability to study is limited based on current certification practices
- Ability to study genetic predisposition has expanded
  - Neuropathological
  - Cardiovascular
  - Metabolic
- Sophisticated testing platforms for infectious agents

MEDICOLEGAL DEATH INVESTIGATION

MEDICOLEGAL DEATH INVESTIGATION

- Children are not small adults
  - All age groups have different concerns, developmental abilities and milestones
- 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
- Information obtained relies on parents, caregivers, and other relatives
  - Often distraught at the scene/hospital
  - May or may not have played a role in the death
  - Delicate balance: obtaining information needed for investigation while being sensitive to the family's grief

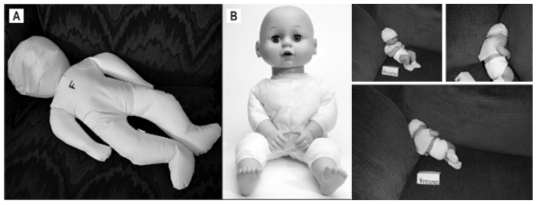
MEDICOLEGAL DEATH INVESTIGATION

- Scene investigation is **critical**
  - 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
  - The **child's environment plays a much larger role** in death investigation than most adults
- 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

MEDICOLEGAL DEATH INVESTIGATION

- Must visit and photograph the environment where the child was **initially found**
  - Many infants/children are transported to the hospital with attempts at resuscitation
- **Doll reenactment is recommended** to document the position of the child **when placed to sleep and when found**
- Best to use a doll brought with you; **avoid** using something in the residence if possible
  - Use placards denoting "found" and "placed"

DOLL REENACTMENT MEDICOLEGAL DEATH INVESTIGATION



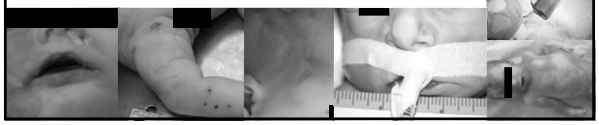
MEDICOLEGAL DEATH INVESTIGATION

- Photographic documentation of the scene is required
  - Overall views of the environment
  - Availability of food and necessary care items
  - Use of a ruler/scale is recommended for injuries and sleeping environment for all cases in which the child apparently dies during sleep
  - The condition of the residence should be documented
  - The clothing of any adults or siblings should be viewed and photographed for infants/children found dead while sharing sleep surfaces

MEDICOLEGAL DEATH INVESTIGATION

DOCUMENTATION OF THE BODY

- The type and amount of clothing and blankets on and around the child
- Focused views of the sleeping environment and the presence of any body fluids near the child
- Lividity pattern and rigor mortis
- Visible injuries
- Evidence of medical intervention



MEDICOLEGAL DEATH INVESTIGATION

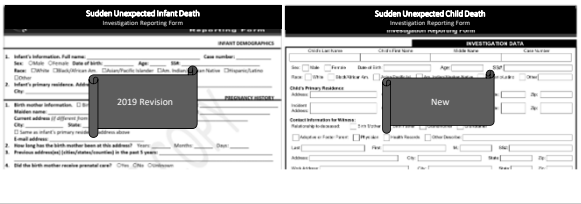
- If the child wasn't transported initially, removal of the child from the residence should be performed with care and compassion
  - Recommended that the child be wrapped in a sheet or blanket and carried to the transport vehicle, to be placed inside a body bag and/or transport box
- Some states/jurisdictions have laws allow for viewing of a deceased child
  - Usually requires supervision
  - Be as accommodating as possible without jeopardizing the investigation

MEDICOLEGAL DEATH INVESTIGATION

- Use of an infant/child death reporting form is recommended
  - Ensures required information is gathered uniformly
  - As a standard practice, may help the family feel less interrogated
  - Provides background information for obtaining necessary records
- BEST PRACTICE: ask all the questions, all the time, as soon as possible

MEDICOLEGAL DEATH INVESTIGATION

- Sudden unexplained infant and child death reporting forms
  - Checklist with all information needed for pediatric death investigation
  - Infant form recently revised by CDC
  - Childhood form developed by Panel
  - Both available in the appendices of the reference text



AUTOPSY AND ANCILLARY TESTING

AUTOPSY AND ANCILLARY TESTING

- **An autopsy must be performed in all sudden unexpected deaths in infants and children**
- **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.
- **Histology and comprehensive toxicology must be performed** in all sudden unexpected deaths in infants and children.
  - When unexplained after gross examination:
    - **Microbiological cultures** (and other related studies), directed by the case history and autopsy findings.
    - **Molecular testing** may be performed in conjunction with cultures
    - **Chemical analysis of vitreous fluid** for electrolytes and glucose should be performed.

- Specific autopsy practices outlined in reference text
- **Preserve specimen to allow for later genetic testing** (lavender top EDTA tube of blood at minimum)
  - Considered critical in cases of SUDC to evaluate cardiomyopathies/channelopathies

AUTOPSY AND ANCILLARY TESTING

PROCEDURAL GUIDANCE

- **Communication should be considered a step in the autopsy.**
- Preliminary results to family, law enforcement, other stakeholders within 48 hours
- Final results and the cause of death to the family
  - verbally (by scheduled appointment, either via telephone or in-person)
  - and in writing (i.e., report if desired)
- **The autopsy report should include a detailed opinion section that explains the rationale** for the cause and manner of death determination
  - written in a manner accessible to the lay reader,
  - questions about unusual results or circumstances should be anticipated and explained proactively
  - may include recommendation for clinical evaluation and genetic testing for surviving family members

SYNOPTIC REPORTING

SYNOPTIC REPORTING

WHY A SYNOPTIC REPORT?

Challenges with Death Certificate

- Rich and detailed investigation cannot be conveyed
- Data elements for public health / research not readily gathered
- Poor surveillance tool for interventions, trends
- Wording on DC may totally change intent of certifier

Goals of Death Certificate

- Wanted to convey some major scene / investigation points
- Wanted clarity in diagnosis and certification

Desired Solution

- Certification terminology that CANNOT be incorrectly coded
- Certification that permits identification of areas for surveillance
- Report details of scene and autopsy findings
- Include level of investigation and testing
- Standardized certification choices
- Synoptic reporting of pediatric sudden deaths

SYNOPTIC REPORT BASIC ELEMENTS

I. Cause	VII. Other objective concerns
II. Manner	VIII. Autopsy
III. Investigation	IX. Toxicology
IV. Medical History	X. Ancillary Studies
V. Sleep environment	XI. Radiologic Studies
VI. Other environment	XII. Comments

Deaths should be certified in consistent way to reflect accuracy and intent of certifier while maximizing surveillance opportunities

DEATH CERTIFICATION AND SURVEILLANCE

S UnexpectedD I

Explained Natural

Explained Unnatural
- **Accidents**
- **Homicides**

Unexplained despite thorough investigation (SUnexplainedID or SIDS)

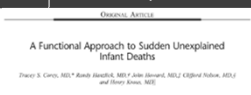
Undetermined for other reasons (e.g. insufficient investigation)

"Sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history."*

* Willinger M, James LS, Catz C. Pediatr Pathol 1991; 11(5):677-684

ICD-10 CODES FOR UNEXPLAINED DEATHS

ICD-10 Code	Title	Applies when
R95	Sudden Infant Death Syndrome	Age <365 days, COD is unexplained and includes the words "sudden" and "death"
R96	Other sudden death, cause unknown	Age ≥ 365 days, COD is unexplained and includes the word "sudden"; excludes sudden cardiac death
R99	Other ill-defined and unspecified causes of mortality	Any age, COD is unexplained but does not specifically indicate "sudden"


ORIGINAL ARTICLE

A Functional Approach to Sudden Unexplained Infant Deaths


A Systematic Training Program for the Professional Infant Death Investigation Specialist

Sudden Unexplained Infant Death Investigation

INCLUSION OF RISK FACTORS ON DC

CAUSE OF DEATH (See instructions and examples)

32. **PART I.** Enter the chain of events--diseases, injuries, or complications--that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.

Approximate interval: Onset to death

IMMEDIATE CAUSE (Final disease or condition resulting in death) → a. Sudden Unexplained Infant Death ← R95
Due to (or as a consequence of):

Sequentially list conditions, if any, leading to the cause listed on line a. Enter the **UNDERLYING CAUSE** (disease or injury that initiated the events resulting in death) **LAST**
b.
Due to (or as a consequence of):
c.
Due to (or as a consequence of):
d.

PART II. Enter other significant conditions contributing to death but not resulting in the underlying cause given in PART I
Sharing sleep surface with two adults ← LOST

33. WAS AN AUTOPSY PERFORMED? ☐ Yes ☐ No

EFFECT OF SEQUENCE AND PART II ON CODING WHEN COD INCLUDES "SUDDEN" AND "DEATH"

COD, Part I/Line A	Due to Part I/COD, Line B	Part II/CCOD	ICD-10 Underlying Cause Code	Code Title
Sudden infant death syndrome OR Sudden unexplained infant death			R95	Sudden Infant Death Syndrome
"		Risk factors: Bed sharing, prone sleep	R95	Sudden Infant Death Syndrome
"	Possible asphyxia due to bed sharing		R95	Sudden Infant Death Syndrome

EFFECT OF SEQUENCE AND PART II ON CODING WHEN COD INCLUDES "SUDDEN" AND "DEATH"

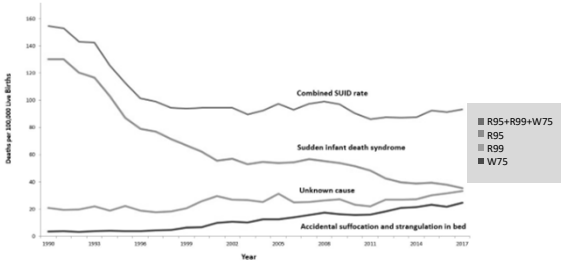
Part I/COD, Line A	Due to Part I/COD, Line B	Part II/CCOD	ICD-10 Underlying Cause Code	Code Title
Sudden infant death syndrome OR Sudden unexplained infant death	Possible overlay while bed sharing		W75	Accidental suffocation and strangulation in Bed
"		Possible overlay while bed sharing	R95	Sudden Infant Death Syndrome

Overlay will be used as the Underlying Cause when it appears in Part I, but not Part II.

EFFECT OF PART II ON CODING WHEN CAUSE OF DEATH IS "UNDETERMINED"

Part I/COD	Part II/CCOD	ICD-10 Code	Code Title
Undetermined		R99	Other ill-defined and unspecified causes of mortality
Undetermined	Risk factor: Bed sharing, Prone sleep	R99	Other ill-defined and unspecified causes of mortality
Undetermined	Risk factors: Bed sharing, Acute tracheitis	J041	Acute tracheitis

DIAGNOSTIC SHIFT

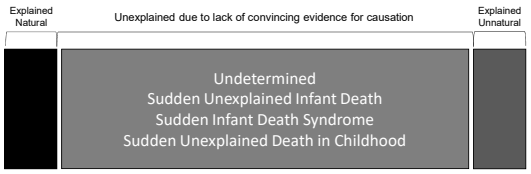


SOURCE: CDC/NCHS, National Vital Statistics System, Mortality Files https://www.cdc.gov/sids/data.htm

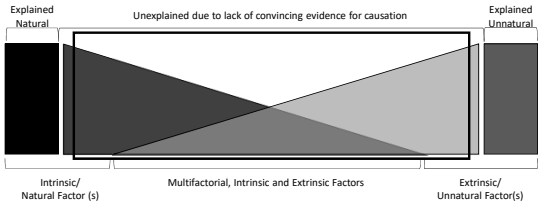
ONE STORY, THREE CODES

Part I/COD	Part II/CCOD	ICD-10 Underlying Cause Code	Code Title
Sudden infant death syndrome OR Sudden unexplained infant death	Possible asphyxia due to bed sharing	R95	Sudden Infant Death Syndrome
Undetermined	Risk factor: Bed sharing	R99	Other ill-defined and unspecified causes of mortality
Undetermined	Possible asphyxia due to bed sharing	W75	Accidental suffocation and strangulation in Bed

SUDDEN UNEXPECTED PEDIATRIC DEATHS



SUDDEN UNEXPECTED PEDIATRIC DEATHS



DEATH CERTIFICATION AND SURVEILLANCE

- When cause of death cannot be determined, one of the following cause statements are recommended as applicable :
  - 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).

****To better represent the current and future data captured by R95/MH11, it is recommended that the title of this code be changed to "Unexplained Sudden Death in Infancy or Sudden Infant Death Syndrome."**

DEATH CERTIFICATION AND SURVEILLANCE

- The following criteria for certification of an infant death as being caused by an **asphyxia etiology** are recommended:
  - The case must have a **complete/full autopsy**.
  - Toxicology, histology, vitreous electrolytes, cultures, and review of medical history **are to be performed**, as necessary as determined by investigation and autopsy.
  - 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.
  - **Asphyxiation must be probable** given infant's age and stage of development.
  - No reasonable competing cause of death.

DEATH CERTIFICATION CASE STUDIES

- Previously healthy, term born, 3mo boy was placed on side and found prone on adult bed; numerous pillows and blankets nearby (EXT)
  - Doll reenactment does not demonstrate obstruction of airway
- Medical record review showed no acute or chronic health problems
- Heart was enlarged at autopsy (INT)
- Toxicology, histology, vitreous electrolytes, cultures, radiographs, and genetic testing were all non-contributory

COD: UNEXPLAINED WITH INTRINSIC AND EXTRINSIC FACTORS IDENTIFIED
MOD: UNDETERMINED

DEATH CERTIFICATION CASE STUDIES

- 4mo infant placed supine on soft bedding between 2 adults in queen bed; found supine hours later
  - Doll reenactment does not reveal overlay
- Review of medical records, autopsy, toxicology, cultures, vitreous electrolytes, and radiographs were all noncontributory
- Cardiac channelopathy genetic testing revealed mutation for prolonged QT syndrome

COD: UNEXPLAINED WITH INTRINSIC AND EXTRINSIC FACTORS IDENTIFIED
MOD: UNDETERMINED

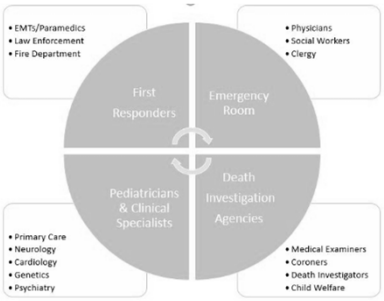
FAMILY NEEDS AND PROFESSIONAL RELATIONS

FAMILY NEEDS & PROFESSIONAL RELATIONSHIPS

Guidance for Professional Relations

- Establish trauma-informed inter-agency care protocols
- Training for first response teams
- Education for hospital teams about the local medicolegal death investigation system
- Medical Training
  - Multidisciplinary approach
  - Access for Debriefings/Panel Discussions
  - Develop Network of Suitable Consultants
- Role of child death review committees

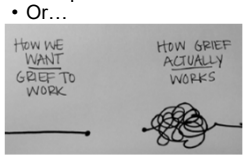
FAMILY NEEDS & PROFESSIONAL RELATIONSHIPS



FAMILY NEEDS & PROFESSIONAL RELATIONSHIPS

Grief

- Parental Bereavement
  - Hardest of Losses to Bear
  - In the Blink of an Eye
- First 72 Hours is Chaos for Families
  - Confusion, lack of control…
  - Multiple Agencies/Professionals Involved- none of their choosing
- What does it look like?
  - 5 Stages: Denial, Anger, Bargaining, Depression and Acceptance
  - Or…



PROCEDURAL GUIDELINES FOR FAMILY NEEDS

- To prevent further trauma, complete thorough investigations and foster positive outcomes
- Maintain an unbiased, non-accusatory approach to parents
- Respect for privacy, dignity, and comfort for families
- Opportunity to see and hold the infant in supervised conditions once death has been pronounced and before transport.
- Timely communication associated with positive long-term bereavement outcomes
- Open communication with MDI and single point of contact for families
  - Information in multiple formats - written (Help For Families Brochure), verbal, through clinicians, etc.

PROCEDURAL GUIDELINES FOR FAMILY NEEDS

- Provide services or referrals to address
  - Grief support for surviving family members
  - Medical follow-up (Cardiac/Genetic consults etc.) and related referrals (as clinically indicated by investigation)
  - Home Visits
- Opportunity for post-autopsy conference with family members and stakeholders/clinicians
- Investigation becomes part of each family's history

THANK YOU!

- All committee members who donated their time and expertise to see this project to completion
- SUDC Foundation for grant support for this project, the ability to publish the book and to provide complimentary copies to all NAME members
- NAME for administrative and organizational support
- American Academy of Pediatrics for organizational support
- Academic Forensic Pathology for the opportunity to publish this work in a volume adequate to address the complexity and depth of the issues