

SUDC Foundation: An Answer When There's No Explanation

As a death investigator of 10 years, I often find myself being asked the same question repeatedly: "What is the worst thing you have ever seen?". It is interesting to me that even after the multitude of deaths I have been involved in investigating, my answer is always as consistent as the question... a death that occurs that is unexplainable despite countless hours of investigation by multiple professionals. "Goodbyes hurt the most when the story was not finished...". The death of a child is heart breaking... the unexplained death of a child is unimaginable; yet, each year 400 families are faced with their worst nightmare, sudden unexplained death in childhood (SUDC). SUDC is the sudden and unexpected death of a child 12 months or older which remains unexplained after a thorough case investigation. This must include examination of the death scene, a complete autopsy, and a review of the child and family's medical history. SUDC is most common among toddlers aged 1-4 years, and is a category of deaths that currently eludes our scientific understanding. Perhaps what makes SUDC so devastating to those affected is that it is unpredictable and unpreventable, with no known method of risk reduction.

A little over a year ago, I was requested to respond to a local children's emergency department to conduct the death investigation of a 4-year-old child. Our routine, as death investigators, is often the same: view and examine the body, interview medical professionals, interview family members of the deceased, discuss the case and circumstances with the supervising pathologist, and come to a conclusion regarding the cause and manner of death, or determine the need for further forensic examination. Upon my arrival, I viewed the body of the deceased. According to the nurse, the child that had died was Levi (first name used with parent permission), a previously

healthy and vibrant 4-year-old little boy. Levi was supine on a hospital cart covered with a blanket and dressed in a white t-shirt. All the elaborate medical equipment was in place demonstrating how diligently medical professionals worked to revive Levi. Levi's height and weight indicated that he was well-nourished and well-developed for his age. There was no evidence of traumatic injury: no bruises, no lacerations, no abrasions. Body temperature, livor mortis, and rigor mortis were all consistent with the leading events as described by the nurse.

I remember asking the nurse if Levi's parents were present on scene, and if they were, may I speak with them. I was escorted to the family waiting room where I first met Levi's parents. They were appropriately tearful but calm and willing to talk to me. I cannot imagine the distress a parent feels when their child dies unexpectedly. I have been told that being separated from that child after their death for extended periods of time is even worse. Our office policy allows family interviews in the presence of the deceased's body. I asked Levi's parents if they would like to be with Levi while I asked them questions to gather as much information as possible to assist in providing them answers as to what happened to Levi. I had no idea how much this simple gesture meant to Levi's parents until a year later. Levi's parents answered every question I asked of them, no matter how personal, in search of answers. Levi had a remote history of febrile seizures and a very minor surgery shortly after birth. Vaccinations were up to date and he routinely visited his pediatrician for well child checks. His mother's pregnancy was uneventful (no smoking, alcohol, or drugs), and his birth was uncomplicated. Levi had not been recently exposed to illness. According to his parents, Levi's only recent complaints were malaise, excessive thirst, and head and abdominal pain. A detailed discussion regarding family

history only revealed a sister with a heart murmur; all other family members were healthy and without chronic medical conditions. Levi's parents explained that he was last known alive resting in bed. When his mother checked on him, she found him prone in bed (airway unobstructed) and unresponsive. Emergency medical services were immediately summoned and Levi was transported to the hospital while cardiopulmonary resuscitation was in progress.

After a discussion with my supervising pathologist, we decided to proceed with complete forensic examination, including autopsy. Child life was allowed to proceed with hand molds for Levi's parents as it was determined they would not compromise forensic information/evidence. I explained to Levi's parents that my office would proceed with a full autopsy, in hopes of providing them with answers. I then left the hospital with Levi in my care.

Autopsy, microscopic slides, viral cultures, bacterial cultures, and full toxicology panels failed to help us determine what happened to Levi. I then made the most dreaded phone call of my career... the call to Levi's parents to explain we simply do not know why their son died.

It was a short time later I learned of the SUDC foundation, an organization dedicated to increasing the awareness of sudden unexpected deaths in childhood, and funding crucial research to better understand and prevent such tragedies. With Levi's parent's permission, I provided their contact information and details of Levi's death to the Foundation. Over a year after Levi's death, my office received a letter from his mother thanking us for our efforts in attempting to determine what happened to Levi and also for our kindness during such a devastating time. In this letter, I learned that Levi's parents connected with the SUDC Foundation and have become active members in support groups for other families affected by SUDC. The Foundation pursued other testing, including genetic analysis, in hopes of supplementing our investigation with the ultimate goal of determining a cause of death. Levi's mother wrote to us commending us for our compassion and empathy; the hand molds became a comforting "piece of Levi" during such a difficult time. She continued to explain that not every parent's experience with a medical examiner's office is as gentle.

As medicolegal death investigators, we investigate death daily. The worst moment in someone's life seems to become routine for us. We may even become cynical or callous in an attempt to protect ourselves and ensure we are able to complete the task at hand. It is our calling to "listen to" and "speak for" the deceased. To ensure that, if wrong-doing occurred, it does not go unnoticed. It is our calling to search for answers and to collaborate with other agencies and groups such as the SUDC Foundation. We must also remember that we serve the families of the deceased. We are allowed into the lives of grieving individuals and ask a multitude of personal and potentially hurtful questions, which are endured for the potential answer to "why?". This time we spend with the families of the deceased is so intimate.

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