

## **The Changing Landscape of SIDS**

**by Lorraine Lee, PHN, San Mateo County Health Services**

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Hello, my name is Lorraine Lee. I am a Public Health Nurse and SIDS Coordinator for San Mateo County. I began my Public Health Nursing career in 1978, so I have witnessed first hand the changing landscape of Sudden Infant Death Syndrome.

The core of a Public Health Nursing Program is to support the family in the home – particularly providing guidance to new parents. Earlier in my practice, SIDS would register in the back of my mind but I dared not discuss it with new parents. What could I have offered? We weren't aware of risk factors. By saying SIDS could occur I would only add to new parents' anxiety. I avoided the subject unless asked. It was my little secret. I would leave the homes of these new parents and hope that they would not be one of the tragic statistics where I would have to return and provide SIDS bereavement support.

Beginning in 1992, with the recognition of placing an infant on his/her back to sleep and subsequent other risk factors, I was able to address the subject of SIDS. Now, I had some concrete advice to give to reduce the risk of SIDS. In the earlier years, the number of issues addressing SIDS and the missions were relatively small, the message clear and seemingly easy to communicate. Today the landscape is different, fraught with bumps and pitfalls.

Risk reduction recognition and education has dramatically cut the rate of SIDS. However, ongoing research regarding risk factors and the institution of death scene investigations have led to a far more complex set of diagnostic issues that broaden the discussion from one diagnosis – SIDS – to a more differentiated approach to diagnosis of the sudden unexpected death of infants (SUID) and frequently with the name “undetermined” attached. Medical Examiners and Coroners began struggling with the final diagnostic determination of infants who died so suddenly, with death scenes fraught with risk factor issues.

We hope this workshop will put a face to the “undetermined” diagnosis and we in the SIDS community (the experts, the messengers, the parents and family) begin to address and have a dialogue in order that no family falls through the cracks – that all the support and services available to the classic SIDS family be extended to any family whose child has died suddenly and unexpectedly.

The word “undetermined” is a powerful word. It's a detrimental word to a parent. SIDS parents hang onto every word we say, note every word we print. I want to share with you an incident in my SIDS follow up that exemplified the power of words, of semantics, of language and of names.

There was a SIDS case for which I needed to make an initial phone call. As those of you in the audience who do SIDS follow up know, these cases are most emotionally difficult and challenging. I wanted to be prepared. I read the report, highlighted the parents' names as well as the baby's. I proceeded to make the call. A person answered. I asked to speak to the mother – instead of stating the mother's name, I had mistakenly asked to speak to the baby who had died. The person at the other end was just livid – stating, “You call yourself a Public Health Nurse? What kind of a professional are you?” My mouth was not big enough for my foot or for both feet and my body put together. In fact, I wanted my whole body to be swallowed to the center of the Earth. Nothing I said, nor did my apology appease her. She asked for my supervisor's name and number. I gave her what she requested. In fact, I was ready to give her the number of the Mayor, the Governor and the President of the United States and have the President order a whole firing squad to do away with me. That's how bad I felt at that moment. I had just negated everything that I had been taught. Instead of relieving pain, I had inflicted more. I ran to the SIDS Coordinator at that time. I will be forever grateful to her. She reassured and calmed me and she said she would take care of it. She did. She saw the family and never uttered nor repeated anything that the family may have said about me. That was a lesson learned: that SIDS families are so vulnerable and so much in pain. Words can make or break their journey to heal and recover.

Now I would like to segue to the next presenter's encounter with the word “undetermined”. My path crossed with her one very beautiful sunny spring day in May 2005. At the door, I found myself looking at a face filled with vulnerability, pain, sadness and hopelessness. That day, I had to break the news that her son Kai (nicknamed Bean) had died of presumptive SIDS. I remembered the visit well. I was accompanied by a PHN new to the SIDS team. I thought the visit went well considering the circumstances. Later -- a month, six weeks, I don't remember -- the Coroner's report made its way to my desk. Gone was the initial finding of presumptive SIDS. In its place now the cause of death was given the name “undetermined”. I believed I called her and talked about it. She remembered. I did not. You see, I still struggle with how best to support parents with “undetermined” attached to their child's death because it robs the parents of the certainty of a SIDS diagnosis.

Now I would like to introduce you to the mother whose face I saw on that beautiful, sunny, spring day. Once a client, now a colleague – a radiant face filled now with determination, intelligence, compassion and hope. I know that her path is journeyed with the love and support of her husband, Mark. May I present the mother or Kai “Bean” Leialoha – Magali Leialoha.



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