



private pain behind a public struggle

BY LOUISE AHERN

Her name was Micaela. She was born March 28, 2003. She died four months and 30 days later. The cause of death: Sudden Infant Death Syndrome.

Eighteen months later Micaela's mother, Sharon Lang, professor of sociology and anthropology has turned her grief into a crusade to save other families from the same tragedy. With the help of some of her Redlands students, Sharon hosted a public event on campus last fall featuring two of the world's leading researchers on SIDS. And that's only the beginning. She also plans fund raisers for SIDS research and future awareness events.



This is a story of the private pain behind a public struggle.

The man across the street was a cop. Professor Sharon Lang knew that much about him but little else. She was new to the neighborhood and had only exchanged the kind of chance pleasantries with him that neighbors share when walking the dog or mowing the lawn.

But she knew he was a Redlands police officer, and that was enough, because Sharon was planning an event on campus that she hoped would attract first responders—police officers, paramedics, firefighters.

As the event drew closer, she finally worked up the courage to wander across the street and introduce herself. She told him she was a professor at the university and was hosting an event. Would he be willing to spread the word throughout the Redlands Police Department?

"It's about SIDS," she later recalled telling him. "Sudden Infant Death Syndrome."

Her neighbor nodded, somber. "I went out on a case of SIDS last year," he told her.

Sharon pressed him for details. As the new president of the Inland Empire Guild for Infant Survival, she felt like she knew every SIDS case in the region. Probably knew the baby's parents, too.

She realized instantly that she did know the case he was describing. She knew the house. The baby. The mother.

"That was me," she told him, the earth tilting beneath her feet. "That was my baby."

In her memory, the man appeared like a thundering ghost. One minute, she was crouched over her lifeless baby, screaming for help into the phone. The next, a man in a uniform crashed through her front door and seized her child from her arms. He ran to the living room, knocked over a coffee table, laid the baby on the floor and began CPR.

In her memory, he then said, "She has a faint pulse."

This matters to Sharon, this one small detail. It gnaws at the back of her mind where molecules of sanity battle to separate good days from bad. It haunts her at night when she lays in bed and remembers the way Micaela's eyes would dance when she smiled. It taunts her with the false promise that somehow knowing for sure whether Micaela still had a pulse will somehow answer all her lingering questions.

If Micaela's heart was still beating a slow, quiet fight, does that mean she could have been saved? Did the police officer really feel her pulse? Or did he confuse it with his own, pounding with the force of adrenaline in the thick pad of his thumb?

On the day she discovered who her neighbor really was, she asked him if he knew for sure whether he felt her baby's pulse. He wasn't. And so the question remains, along with a thousand others that terrorize all parents who have lost a child to SIDS.

The hardest one is this: If she had done something differently, would Micaela still be alive?

An invisible world

Sudden Infant Death Syndrome is, by definition, an unexplained death. An otherwise healthy child under a year old suddenly stops breathing and dies instantly without a sound, without a warning.

SIDS can only be ruled as a cause of death when everything else has been excluded following an autopsy, an investigation of the death scene, and a review of the medical history of the baby and the family.

SIDS can strike any family, regardless of socio-economic status, ethnicity or educational background, according to the California SIDS Program, which was developed under the California Department of Health Services to help families affected by the tragedy and to help collect data on SIDS.

While the cause of SIDS remains unknown, research is starting to reveal clues that could one day lead to real answers. Studies have found, for example, that parents can reduce the risk of SIDS by placing their babies to sleep on their backs, by using firm mattresses in empty cribs, by making sure their children are in a smoke-free environment, and by keeping their babies from getting too warm.

A recent study suggests that babies who die from SIDS might share a genetic tissue abnormality in the brain stem. If true, future research might lead to a way to test babies for their risk level and, hopefully, find a way to prevent it.

But even knowing the risk factors today can bring a false promise, Sharon said.

"There is no way to fully prevent SIDS," she said. "While it's good for people to understand the risks, this gives people a false sense of security. A parent could do everything right and still lose her child. I put Micaela to sleep on her back. I don't smoke. I put the blanket at her feet, not over her."

And despite reported declines in SIDS deaths thanks to the "Back to Sleep" campaign—a national public awareness initiative that encourages parents to put their babies to sleep on their backs—SIDS remains the leading cause of death for babies between the ages of one

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month and a year, according to a paper by Dr. Thomas Keens, a professor of pediatrics, physiology and biophysics at the University of Southern California. He is also one of the nation's leading experts on SIDS and was one of the featured speakers at the event Sharon hosted on campus last fall.

Sharon said our society cannot afford to ignore those facts. She calls it the invisible world of SIDS, a cruel club that no one asks to join and no one wants to talk about.

"Our society is not ready to accept that this is a real thing, but we have to talk about it. We have to stop it. If we can get funding, we can get the answers," she said.

"She was lifeless."

It sounds like a cliché, but the morning it happened was a just a normal morning in the Lang household. Except for one thing. It was the first time Sharon had gotten a full night of sleep since Micaela was born.

"I woke up a little later than normal," she recalled. "But I wasn't panicked. My first thought was to wonder where I would put her in daycare when I went back to work."

From her bed, she could hear her older daughter Maya, then four, playing with her Barbie Dolls in the room she shared with Micaela. Sharon had no reason to worry. She got up, brushed her teeth, and then wandered down the hallway.

"The minute I went into the room, I knew something was wrong," Sharon said. "There was this stillness in the room. The baby was in her crib, and she was on her back.

"I instantly knew something was wrong, and this wave of terror came over me. She was lifeless, like she was in a deep sleep. I started screaming her name. I flew downstairs with her and called 911."

The dispatcher who answered her call told Sharon to put Micaela on a table, to clear the baby's throat of any obstructions, and then to breathe into her mouth. Sharon did, and she heard a tiny gasp of breath from Micaela's throat. She realized that it was only her own air coming back out.

Micaela's face began to turn blue.

"I was having this out of body experience," Sharon later recalled. "I was out of my mind. The dispatcher told me to palpitate her heart. Nothing moved. My terror

overtook me. Then this figure flew through the door. I was screaming, 'Save my baby!'"

An ambulance arrived and took Micaela away. Sharon followed in another ambulance to the hospital. There, she was taken to a room where a chaplain sat waiting for her.

"Then a woman came in, and I asked her, 'Is my baby alive?' She said 'No.' And that was it. I just collapsed. I screamed and screamed. I wanted to see her. I kept asking to see her. It seemed like forever, but they finally took me to another room and they handed her to me. She was in a blanket. She was cold. And there was this piece of tape over her nose. I peeled it off because I thought, 'She can't breathe.'"

Then someone took Micaela from her arms. Sharon tried to hang on, but she couldn't. That's where her memory ceases. The hours, days and weeks following that moment are a hazy blur.

She remembers screaming and crying.

She remembers the moment of horror when she realized that a family member, in a well-intentioned effort to help out, had washed all of Micaela's things.

She couldn't eat. She lost 18 pounds from her already delicate frame.

She couldn't get out of bed.

But she can remember the funeral.

"They let me hold her for a couple of hours before the service," she said. "That was very healing and important to



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Professor Sharon Lang with daughter Maya.

me. I got to talk to her. At the service, I remember feeling the presence of the university community behind me.”

Yet the support of her friends, family and colleagues would not be enough.

“As much as everyone tried to be there for me, no one could help me,” she said. “I needed to talk to someone who knew what I was going through. I needed to look into the eyes of someone who understood my pain.”

Reaching out

It would be eight months before Sharon felt strong enough to reach out to other SIDS parents. Her uncle knew a man in New York who was active in SIDS awareness, and he directed her to groups in Southern California. Through them, she found the first ray of hope that her life could, and would, go on. And she found a new calling.

“I don’t know where I would be in the world if I hadn’t reached out to other SIDS parents,” she said. “I now look at my life as before and after. Working for the SIDS community is my way of honoring her life.”

Sharon immersed herself in learning as much as she could about SIDS. Her knowledge brought both pain and closure.

“I now know as much as a person can about SIDS, and I have a mix of feelings,” she said. “There were so many things I wasn’t aware of. I never really believed that a totally healthy baby could just instantly die.”

The more she learned, the more she wanted to spread the word. Before long, she was named president of the Inland Empire Guild for Infant Survival. Once a month, Sharon opens her home to other SIDS parents for support and conversation. They talk about their babies, their lives, their pain. But they also find ways to laugh.

“There’s an instant connection among people who have lost a baby,” she said.

Sharon recently became trained as a SIDS “first responder” through the California SIDS Program. Now, she can be called upon to visit parents who have recently lost a child to SIDS to help them through the painful process of investigation, answer their questions, and “just to be there.” (However, Sharon is angry to report that funding for the program was recently slashed, and that her class of trainees will be the last.)

Despite everything she has learned about SIDS, she can’t help but wonder sometimes if she could have done something differently that would have saved her daughter. The bedroom was warm that morning. Should she have turned on the air conditioner? She had used ant spray around the house. Did that contribute to Micaela’s death?

“Every one of us still has a sense that it’s our fault,” she said. “On a rational level, you know that the coroner and the researchers and everyone have told you that it was

nothing you did. But on an emotional level, you always have a feeling that you should have been able to protect your child. If only you’d done this or that...”

Back to Work

Coming back to work in January 2004 was daunting. She figured that most of her colleagues knew that Micaela had died, but she wasn’t sure if that would make her return easier or harder. When you lose a child, she said, people don’t know how to treat you. Is it better to acknowledge the loss with a hug? Or is it better to just ignore the issue?

She soon discovered that her students would help her heal. At the end of her first semester back, she admitted to her classes that she had recently lost her baby to SIDS. She told them she was working with a non-profit group called the Guild for Infant Survival, and she asked if any students would be interested in helping with efforts to raise awareness.

Several students came forward, all for different reasons, including one who had lost a sibling to SIDS.

Kristen Withers, a sophomore, said she felt compelled to help because of her own struggles with the affects of infant disabilities.

“I have a twin brother, and we were premature,” Kristen said. “We were literally the poster children for the March of Dimes.”

Kristen said she and other students find inspiration in Sharon’s struggle.

“She’s so brave,” Kristen said.

The relationship works both ways. The classroom was the one place Sharon found true solace. Her students gave her a reason to go in every day, to struggle through days when crying without warning was still a possibility. In them, she found the inspiration to not only organize the event on campus last fall, but to also open the meeting by sharing her own story.

Private pain

Many people later commented on how brave she was for getting up in front of a room full of people to talk about what she had been through. But for Sharon, staying quiet wasn’t an option.

“There is something in me that feels this needs to be public,” Sharon said. “I shouldn’t have to hide. This is my private pain, but people need to know that this is real. The one thing that is comforting to me is that I haven’t had to go through this alone.”

Perhaps her greatest comfort comes from her daughter Maya, now six.

“I have found a lot of strength in Maya,” Sharon said. “She is so open in talking about her sister. Sometimes I

feel guilty. This has robbed her of the happy mom she used to have. She has seen me cry. But she is the one person who remembers the most and I can talk about Micaela with.”

Sharon still has moments, though. Moments that other parents who have lost children understand.

Sometimes she’ll be driving and realize five miles too late that she missed her exit.

Sometimes she wants to hide in her house to avoid running into people she hasn’t seen for a while; she dreads the moment when they ask, “How’s your baby?”

Sometimes she wonders why she bothers with any of it.

“It’s a double-edged sword,” she said. “I do it because I have to do it. Because I need to be there for other people and because we have to stop this. But sometimes I think, ‘My daughter is dead and nothing is going to bring her back, so why am I doing this?’”

Then she sees Maya’s and Micaela’s faces and remembers why her struggle matters.

“When you lose your baby, you lose your future. It’s a lifetime of pain. But I would take it for the four months and 30 days I had with her. Her life meant everything to me. She was born into love and she died with love. And that’s a complete life.” **OT**

SIDS Resources

Back to Sleep Campaign
(800) 505-CRIB
www.nichd.nih.gov

First Candle/Sudden Infant Death Syndrome Alliance
(800) 221-SIDS
www.firstcandle.org

National Center for Education in Maternal and Child Health
(202) 784-9770
www.ncecmch.org

National SIDS & Infant Death Project IMPACT
(800) 930-SIDS
www.sidsprojectimpact.com

National SIDS/Infant Death Resource Center
(866) 866-SIDS
www.sidscenter.org

California SIDS Program
(800) 369-SIDS
www.californiasids.com

Guild for Infant Survival – Inland Empire
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