

01/30/2006

Sammy's legacy: How an infant's death from heart disease touched so many

By KATHLEEN E. CAREY , kcarey@delcotimes.com

Danielle and Dan Kennedy knew something was wrong when the doctor whisked away their newborn son moments after birth five years ago. Nothing could have prepared them for what occurred next, although they have spent the time since trying to help those who find themselves in the same circumstance.

Samuel Nicholas Kennedy was born in 2000 with a heart defect. He died two days after he was born. Two Saturdays ago, some 150 people gathered at Church Road Field in Springfield for the fourth Sammy Bowl, a two-hand touch football tournament in his honor to raise funds for the group that helped the Kennedys cope with his loss.



After his death, the Kennedys didn't know where to turn. Through a grief counselor, they were able to find UNITE Inc. and through it, the kinship with others grappling with the same, or similar, experience.

UNITE Inc. is a non-profit Delaware Valley organization that provides support for families who have experienced a loss due to stillborn, miscarriage or infant death.

"It's such a unique grief experience," Danielle Kennedy said.

According to St. Louis, Mo.-based Share Pregnancy & Infant Loss Support Inc., there are 900,000 miscarriages a year amid the 4.5 million pregnancies.

Also, in 2002, there were 25,943 stillborn deaths, or 6.4 per 1,000 births, and 18,791 deaths of infants 28 days or younger, or 4.7 per 1,000 births.

There was nothing in Danielle Kennedy's pregnancy to warn them of Sam's condition.

A photo album at her Willistown home shows pictures of Danielle beaming with her hands holding an extended belly.

It also holds several ultrasound pictures, one with a miniature thumb's up, baby shower pictures and one of Danielle packing her bag complete with the "What to Expect When You're Expecting" book to go to the hospital.

"It's kind of weird," she said recently, "because there's no way to expect what took place."

The July before he was born, Danielle would play Christmas songs in anticipation. "Oh I can't wait for Christmas this year," she thought. "It's going to be great."

A sense of something wrong

At 2 a.m. Nov. 6, 2000, the Kennedys arrived at Lankenau Hospital. As the labor pains ensued, Danielle fondly remembers watching football on the television.

At 4:44 p.m., Samuel Nicholas Kennedy was born, weighing 7 pounds, 10 ounces.

Immediately, the medical staff sensed something was wrong -- Sam had a hard time breathing, and the doctor took him to the neonatal intensive-care unit.

"They didn't know if it was a heart issue or a lung issue," Danielle said. "I was hoping it was a heart issue because I knew that was repairable."

Before he was transported to the Alfred I. DuPont Hospital for Children, she was allowed to see him one last time.

"I was just grateful that I could see his face," she said. "He had big eyes and black hair, just gorgeous."

Sam was diagnosed with transposition of the great arteries.

Perinatal cardiologist Dr. Sharon R. Weil-Chalker described the condition as a reversal of the pulmonary artery and the aorta.

In a normal heart, the Havertown doctor said, blue blood is pumped through the right ventricle and the pulmonary artery carries it to the lungs, where it receives oxygen.

The red, oxygen-rich blood is then pumped through the left atrium, and the aorta carries it from the left ventricle through the rest of the body.

In transposition of the great arteries, Weil-Chalker explained, there are two separate circulations, prohibiting the blood from properly receiving oxygen.

There are surgical options available, she said, some of which have been performed at area hospitals since the early 1980s. But, she added, the long-term impacts of surgical corrections are unknown.

After getting some advised sleep, Dan Kennedy went to duPont Nov. 7 as Danielle remained at Lankenau, recovering from some bleeding during delivery.

"I wish I had been able to be there," she said.

That morning, Sam was stabilized through medication and surgery was scheduled for the following day.

On the 8th, Danielle was getting telephone updates every 15 minutes to a half-hour. After surgery, Sam was taken off the ventilator and she was told he was stable.

Dan was told to get something to eat. As he prepared to go, he was called back.

"He's going to pass," the medical staff told him. "Do you want to hold him?"

Danielle said Dan cradled the infant in his arms. "They baptized him as he was passing," she said.

He then drove to Lankenau, where his wife was waiting, unaware of what had transpired.

He walked through her hospital room door, clutching a keepsake box.

"I was so glad to see him," she said. "Then, I thought, 'What the hell is he doing here? He would not have left Sam.' And, then, I just looked at his face and I started screaming, 'No, no, no.' I didn't want him to say it to me."

But, it was inevitable.

"Sam's dead," Dan told her and she turned to her mother and asked, "What do I do now?"

Still in the maternity ward, Kennedy said, "I asked them to discharge me. They were bringing babies up and down the floor."

She thought it would be better if she just got home. But, when she arrived, she realized, "it's just changing locations."

Kennedy walked into her bedroom and saw the bassinet next to her bed. "Just get it out of here," she screamed as Dan ripped it apart to remove it.

Blurry funeral memories

Kennedy has a blurry memory of the funeral but remembers going into Sam's nursery after the service and curling up on his floor with a blanket, tears streaming down her face.

A week later, she tried to regain her life. She went out to breakfast, and as her food arrived, a lady sat down at the table next to her, plopping an infant carrier with a 2-week-old baby on the floor.

After that, Kennedy didn't go out for another month. There were reminders of Sam all over the place.

She remembered feeling his gentle movements in the shower. In bed, "I felt him kick for the first time," she said.

In the supermarket, she used her hands to shield her from the baby items aisle.

"I went everywhere with him for nine months," she said.

All she could think was, "I should be nursing. I should be diapering. I should know his cries."

She would see a baby and all the pain would flood back.

Then, one of the UNITE support group facilitators, Gerri Wismer, called and started counseling her, one on one.

Continued from PAGE XX

"When I first lost Sam, the status of mother had been ripped from me," Kennedy said. "I was ready to be a stay-at-home mom."

She eventually began attending meetings.

"It gave me a forum to tell his story," she said. "We're there to support everybody and no loss is minimized. It's a place you can go and not feel like an outsider."

Sam's loss used to cripple her, bring her to her knees. And, although it's still painful, she's learned to use it to help others.

Now, she works with nurses and hospital professionals to share what it's like to be a parent who's experienced an infant loss.

"I really grappled with --- still do --- that I never got to hold him," she said.

After she was discharged, she went to duPont and was asked if she wanted to hold him one last time, but she said no, unable to think that she'd have to leave him in a cold, sterile morgue.

What she didn't know then is that she would have been able to embrace her son in a hospital room.

"And that was my last opportunity to hold him," she said as her voice trembled. "I have deeply regretted that decision."

Loss takes many forms

UNITE Inc. administrator Joanne Porreca of the Drexel Hill section of Upper Darby can relate to the Kennedys' pain.

Eleven years ago, she had a miscarriage during her 10th week of pregnancy.

"I felt shock, numb," Porreca said. "I couldn't believe this was happening to me. I was just totally lost."

Unable to sleep for eight months, she remembers becoming disoriented when walking to her hairdresser around the block.

"I completely forgot where I was going," Porreca said.

Some parents also experience empty arms syndrome, where their arms actually hurt. Some hear phantom cries coming from the nursery.

"It's very, very real," Kennedy said.

Porreca said she considers herself a strong person and planned on dealing with it herself. However, she eventually realized, "this is not something you can handle yourself."

After attending a few UNITE meetings, she began sleeping again.

"It was such a relief to find other people who felt like I felt," Porreca said, adding she recognized that "I can get through this. I can survive this. But you're never the same person again."

In her backyard, she planted an Alberta dwarf spruce tree that she can see from her kitchen. She released some balloons by it on what would have been the baby's second birthday.

"It's really raw and painful," Porreca said. "As time goes on, the rawness goes away, the really hurtful pain goes away, but you never forget."

The Kennedys treasure their memories as well.

Pictures of Sam dot their entrance foyer and living room. A keepsake box holds his footprints and a lock of his hair.

A memory book outlines a family tree, their dreams for him and the stories of how they learned they were losing him.

The first two Sammy Bowls raised enough funds so the Kennedys could provide keepsake boxes and memory books for parents of lost babies at local hospitals. This year, they raised \$4,000 for UNITE.

The holidays, Kennedy said, can be especially sensitive.

At Christmas, they hang a stocking for Sam and then they take what Santa brings to SS. Peter and Paul Cemetery in Marple.

Sam is buried in the little Angels section underneath a tree holding rosaries, wind chimes and rattles.

It's not an easy place for Danielle to visit.

Now the parent of 22-month-old Owen and 4-year-old Abby, Danielle said it's hard for their daughter to understand why they visit the cemetery when Sam is in heaven.

"Sometimes I look at his stone and I think, 'Am I just still waiting?'" Kennedy said. "I can't believe he's gone. It doesn't make any sense. It upsets me his name is on that stone and his name just shouldn't be there.

"I always think there's a piece of my heart that is missing," she said.

On Saturday, after the football games had finished, Dan Kennedy drove over to SS. Peter and Paul Cemetery and stopped by his son's grave.

He unraveled a red, child-sized "Sammy Bowl" T-shirt - testament to the baby's legacy that is helping countless other families --- and laid it on the ground in front of the gray stone that read "Our Peanut, We Love You."