



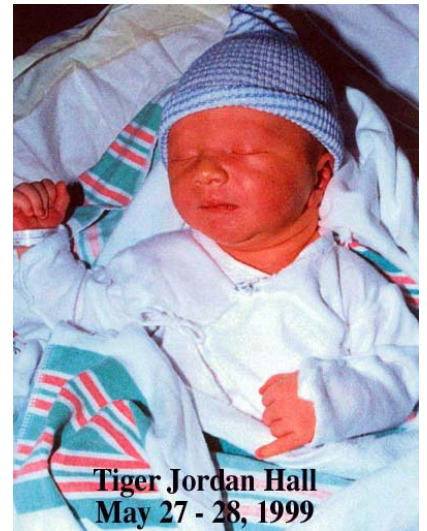
Newborn Screening
Saves Babies
One Foot
at a Time

Storm & Tiger

THIS IS A PERSONAL STORY SHARED BY A FAMILY LOST TWO CHILDREN TO
VERY-LONG-CHAIN ACYL-COA DEHYDROGENASE DEFICIENCY (VLCADD)

Storm Tyler, was born on September 23, 1996. He was 7 pounds 9 ounces and 21 1/2 inches, with an APGAR of 8 & 9. He had a head full of hair and looked like a little man. I stayed the required 24 hours and a few hours after coming home from the hospital he suddenly stopped breathing. In spite of my CPR and the EMT's efforts Storm was pronounced dead on our living room floor. I lay there with him for two hours while the officials did their crime scene scenario. Photos taken of his unused crib and nursery. Finally, we were given just 5 minutes to hold him and say goodbye before our son was taken away into the night. We buried him in his coming home outfit in the cemetery's Babyland. Tragically for us, his cause of death was misdiagnosed as "coarctation of the aorta".

Three years later we tried again. During pregnancy we had this baby's heart tested by ultrasound, everything was normal. Our second son, Tiger Jordan, was born May 27, 1999. He was 8 pounds 1 ounce and 21 3/4 inches, also with an APGAR of 8 & 9. Tiger had these huge "paws"! He was such a big boy, you could tell he loved to stretch and arch his back. We requested his heart be re-tested by a pediatric cardiologist for peace of mind. The results were normal yet five hours later while still in the hospital he was pronounced dead. I remember looking at him in PICU, and seeing his little chest rising and falling. I looked at my husband and said, "Wait! He's still breathing." The nurse said the ventilator was breathing for him. It was too, too much for me, and Clint literally caught me as I fell backward. We buried him next to his brother.



Tiger Jordan Hall
May 27 - 28, 1999



We were told that our sons' deaths were clearly not related since Tiger's heart had no defect. Tiger's cause of death was "unknown". But I was convinced after watching them both die that the signs were identical including them both living just 28 hours.

The Pediatric Cardiologist thought it sounded metabolic when we met with him days after Tiger's death. He gave us key words to help with my search. I was spending hours on the web looking in medical journals for similar signs and symptoms. Just one week after Tiger's death, I found VLCAD, Very Long Chain Acyl-CoA Dehydrogenase Deficiency. Call it luck or call it mother's intuition, but I was sure I was onto something! I faxed every Dr. in NM with the medical journal article and my request to look into this disorder. All responses were that Tiger did not fit the profile for metabolic disorders. Months went by while they exhausted every other avenue before FINALLY screening for metabolic.

After the results came back as VLCAD for Tiger, I went down to the Office of Medical Investigators and had Storm's post-mortem blood spot sent for analysis. The test confirmed what I already knew; he too had died from VLCAD.

Storm would now be turning four this month on the 23rd. And Tiger would be a little over a year. The nursery still intact, clothes still in drawers. I still need a place in my home for my boys.

The Tyler for Life Foundation (now Save Babies Through Screening) has been the greatest opportunity for me to help save others from the pain we have suffered. I can't thank Tera enough for her strength in starting the foundation and giving me the opportunity to use the vehicle she created to be able to make a difference.

Thank you for letting me share my story. Please feel free to contact me at any time.

Sincerely,

Kileen Hall
Written September 2000 by Kileen Hall
Mom to Storm & Tiger
New Mexico