

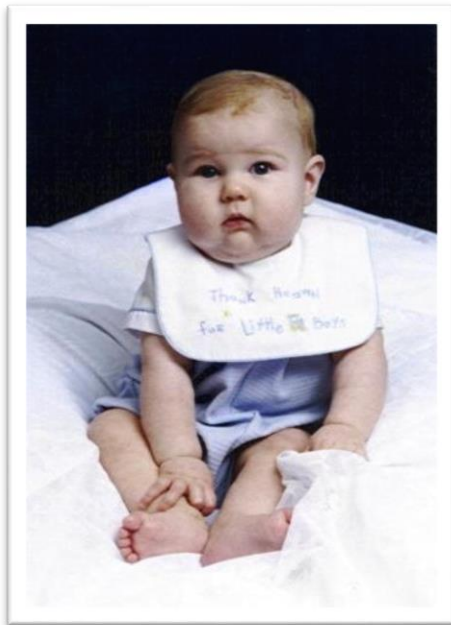


Barth Syndrome Foundation

Quote of the Day:

“We lost a son in 2003. It wasn’t until after his death when we learned he had Barth syndrome. During the timeframe of uncovering the cause of our son’s death I learned I was pregnant. Through prenatal testing the child I was carrying was determined to be a boy who had Barth syndrome. That information made it possible for us to closely monitor his heart function throughout the pregnancy and to assemble a team of well-prepared specialists in advance of his birth. This contributed immeasurably to our son’s care and progress during the first few months of his life.” ~ Keli, Mother of Affected Individual, Texas

Featured Story: A Personal Message from the Greg



Caleb
06/05/2002 – 08/08/2003

Keli and I always wanted a big family. We were high school sweet-hearts and, even then, spoke of wanting at least six children! That desire has never wavered.

As child bearing began, the Lord blessed us with twins and we never looked back. During a period of eight years, we received into our family six healthy children. Having babies seemed to go like clockwork. We never dreamed of a difficulty.

That naivety all changed with baby number seven. At birth, Caleb presented with a number of difficulties and was flown to Texas Children’s Hospital in Houston. He spent two weeks there, but came home without a diagnosis. The doctors could only say that he seemed to be “better”.

Though he had a variety of symptoms during his short life, no one was able to diagnose the root cause. His medical care always involved a lot of head scratching on the part of the doctors. At about fourteen months of age, it was discovered that Caleb’s heart had enlarged to the point of no return. He

was immediately flown to Lubbock, where he struggled for three days before going to be with the Lord. It was, to this point, the most difficult day of our lives.

Keli relentlessly set out to discover what the doctors had been unable to learn. She spent countless hours researching his condition. As a result of her persistence, she came to believe that he probably had Barth syndrome. Genetic testing of his tissue confirmed her belief.

We were at once relieved (to finally have a diagnosis), saddened (at not having known it sooner), and frightened (because we were, by then, expecting another child). We didn't yet know the sex of our unborn child, much less whether or not the mutation was present. We arranged for an amnio and then set out to learn what we could about Barth.

In July, we attended the BSF conference in Florida. At the time of the conference, we had not received the test results. We just knew that we needed to be there and learn all that we could. After returning home, we found out that Benjamin did indeed have the mutation.



Benjamin

Benjamin surprised us by arriving five weeks early, but presented well. His heart function was a bit low, but he was immediately started on the heart medications and responded well. He continues to grow and thrive, cared for by a loving family and a group of well-prepared doctors.

We're so thankful for having attended the BSF conference! It gave us the information we needed and also allowed us to meet a wonderful,