



Barth Syndrome
Foundation

Quote of the Day:

"...I was fortunate enough to attend the 2010 BSF conference where some of the most amazing children you will ever meet were. ... I wish Lattigo could have met all of these wonderful children. The Barth Syndrome Foundation does a wonderful job at keeping families informed on new research and support. The daily support these families give each other is outstanding." ~ Cherie, Aunt to Lattigo, Illinois

Featured Story: A Personal Message from Cherie

(The following story was submitted by Cherie Schrader, Aunt to Lattigo who passed away due to complications from Barth syndrome in January 2002. Cherie has continued to be active in supporting the Foundation.)



Lattigo and his dog, Boo
(05/01/2000 – 01/25/2002)

Lattigo is my nephew, a beautiful blonde baby with the most gentle touch. He loved Elmo, Shrek, Pickles, and his dog Boo. My sister, Carol (Lattigo's mom), knew from the beginning that Lattigo had struggles but no one would listen, brushing her off as an anxious mom. But she is the eldest of seven and has two older daughters of her own. Carol was not new to motherhood and she had that natural mother's instinct.

She put every ounce of energy and then some to the diagnosis of our little Lattigo. Carol had a huge binder of papers she put together with her own research coupled with Lattigo's medical information.

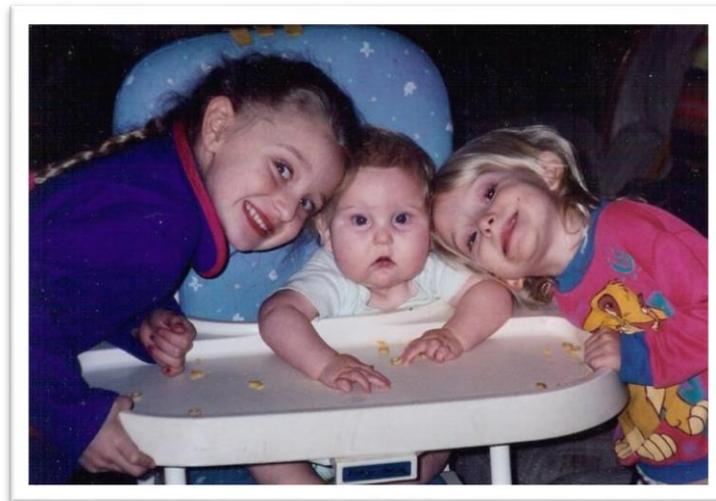
My Mom started her own research on the computer as well and together they found the Barth Syndrome Foundation website. The contacts they made there were wonderful people. The geneticist involved with the Foundation was so concerned about getting our diagnosis to us she even worked from her own hospital bed where she had her own medical issues at the time to get the results so Carol could report to her local doctors and get the right meds going.



(L-R) Cherie & Lattigo

The diagnosis of Barth syndrome is very time sensitive. Lattigo went through over a year of struggling and heart-damaging time before we found BSF. As an Aunt, I rode to the ER with my sister and nephew and took care of Lattigo's sisters when he and his parents had to go out of town for special medical attention. I have raised money for Barth syndrome while marathoning, and I am currently planning some sort of photography fundraiser (I am a photographer). Just as it "takes a village to raise a child," it takes the whole support system - moms, dads, grandmas, grandpas, aunts, uncles, neighbors, and friends - to get through this.

I was fortunate enough to attend the 2010 BSF conference where some of the most amazing children you will ever meet were. The natural brotherhood and sisterhood that was present between all of the affected boys and siblings was beautiful to see. During clinics I watched a little boy from California run over to tenderly console a toddler from England that was getting pricked by a needle for blood work. They didn't really know each other but there was a beautiful bond that existed without prompting. I wish Lattigo could have met all of these wonderful children. The Barth Syndrome Foundation does a wonderful job at keeping families informed on new research and support. The daily support these families give each other is outstanding.



(L-R) Dakota, Lattigo & Bailee