Meet Bly & Ty

Bly, Tracy & DW

Our story begins over 11 years ago when we welcomed our first child, Bly, into our lives. As new parents, things seemed relatively normal with our beautiful boy, but before too long he wasn't nursing as well and began vomiting regularly. Things worsened as the weeks carried on, but no doctor could give us the right answer as to why. Bly showed signs of acid reflux, so an upper GI was performed when he was three months old. That's when life as we knew it, was no longer going to be the same… That's when we saw his heart greatly enlarged. Our thin, pale-faced boy was in heart failure.

Over the next several months, there was only slight improvement with his heart. A transplant was considered by his doctors, but by nearly a year later, our blonde, fuzzy haired boy with the longest eyelashes, improved significantly. By two and a half years old, his heart function was within normal ranges. He has remained stable in low normal function for over nine years now. Bly is in 6th grade homeschool and loves trains, animals, 4-wheeling, metal detecting, fishing, racing, and video games.

Our cardiologist at Mayo Clinic suspected Barth syndrome when he noticed lower than normal neutrophils, in addition to Bly's dilated cardiomyopathy. Genetic testing was done right away, and Bly received the Barth syndrome (BTHS) diagnosis just before his second birthday. Since Bly was showing signs of neutropenia at this point, he began taking GCSF daily and responded beautifully. Bly is very responsible and attentive when it comes to his heart medications/GCSF and will often have to help remind his parents when they forget his leg poke.

Bly

Once Bly was a climbing, walking, and talking toddler who seemed to be stable and healthy, my heart deeply desired to have another child, but tests had confirmed that I'm a carrier of BTHS. I always dreamt of having a few kids, but my husband and I felt trapped in our decision to have more. We were left immobilized as we feared all of the "what ifs". Years went by with this struggle. Although I rejoiced over having Bly and his good health, no matter how hard I tried, my heart ached for another child. I always thought it would be wonderful to have enough faith to try for another child, even welcoming another little Barth boy, if that was what God had planned for us. However, knowing all the possible things that could happen with BTHS scared us.

Over time, our hearts softened and became more receptive to receive the Lord's direction and we were able to surrender our fears as we trusted in Him. Our fears were slowly turning into faith, trusting that God would do what's best for us, regardless the number of children.

When Bly was nearly 8 years old, he became a BIG brother to a little sister. We were thrilled. As much as they enjoy fighting sometimes, they'd be lost without each other. Willow adores her big brother.

Ty

Nearly two years following, our freckle-faced, green-eyed Bly and our brown-eyed Willow, with beautiful long blonde hair, became siblings to a tiny little brother named Ty. Ty did beautifully his first year. He nursed well and grew some of the sweetest and chubbiest cheeks; however, his growth suddenly plateaued around a year old, and then he began losing weight. He seemed stuck in reaching his developmental milestones, not making progress for quite some time, especially gross motor skills. Ty had failure to thrive. It was found that a G-tube was necessary for Ty to get the nutrition he needs in order to gain weight and grow. He's only had the tube for a few days so far, but he's never slept better and is gaining weight like a champ already. What a blessing to have peace of mind knowing he's getting adequate nutrition and for giving his meds as well!

Ty's heart remains stable in the moderate function range and his neutropenia is well controlled by giving GCSF bi-weekly. His muscle tone has been weaker than his big brother's, but we think the feeding tube and continued therapies will really help him along developmentally as time goes on.

Ty is currently a small, brown-eyed 20 month old boy sporting the same beautifully long eye lashes as his big brother, and he has the sweetest smile you've ever seen. He is a happy, content child who adores his siblings. He has filled our lives with smiles. It would have been terribly sad if we didn't try having another child. He keeps us busy, but it's completely worth it.

Ty

I find the difference between the two boys' diagnoses remarkable. We found out, after those very difficult times of Bly having heart failure, not understanding why it was happening. We often felt, alone without other families relating to us. We suspected Ty to have BTHS when I was pregnant with him, after an echo revealed the same type of weaker heart muscle as his older brother. Ty was diagnosed at just a couple months old, but because of his symptoms, we knew beforehand.

The difference in the timing of the diagnosis: SUPPORT - and an unbelievable wealth of knowledge through the Listserv, the Barth syndrome website, and the many contacts available through the Barth Syndrome Foundation. We are no longer walking blindly down the road before us. We have each other. Likely, someone has already traveled this same road. We are not alone. There are families all over the world who understand, who support us, who encourage us.

(L-R) Bly & Ty