

“My Child, My Story”

Delainey’s Story

The most life changing moments begin with such simple words - “Will you marry me?”, “I do,” “You’re pregnant,” “You’re having a girl.” And then, out of nowhere, come the words that no parent ever wants to hear, “We see an abnormality.”

And so it began.

My husband and I were thrilled to learn that we were expecting our first child. With great anticipation, we waited for the 20 week ultrasound to catch the first glimpse of our baby. When she appeared on the monitor, we were in awe. We had no idea that our world was about to be turned upside down. During that ultrasound, our doctor noticed something unusual on our baby’s head, a choroid plexis cyst; a growth that does no damage but sometimes indicates other problems.

We were sent to see a specialist for a level II ultrasound with the doctor’s words still ringing in our ears, “Don’t worry. Many times these cysts mean nothing.” Something told me that this wasn’t one of those times. I knew in my heart that something was wrong. By the next week, the cyst had already dissolved, but that concern was quickly replaced when the doctor informed us that he noticed several additional abnormalities including a two-vessel umbilical cord rather than the typical three-vessel cord, the appearance of fluid on the right kidney, a cystic hygroma on her neck and then the news that sent chills down my body. It appeared that our daughter had a severe heart defect.

During that appointment, the doctor mentioned that many of the abnormalities seen in our child are common in a variety of genetic conditions. Based on the presence of so many of these indicators, an amniocentesis was performed. We soon learned that our daughter had Turner Syndrome, a genetic condition that affects only females. This condition occurs when one of the XX sex chromosomes found in females is either missing or incomplete. Affecting nearly 1 in 2,500 births, Turner Syndrome is most dangerous in utero, with approximately 98 percent of Turner Syndrome pregnancies ending in miscarriage, typically within the first trimester.

Within a week, Children’s Mercy pediatric cardiologist, Dr. Gowdamarajan (Dr. Rajan) conducted a heart echo and diagnosed our daughter with Hypoplastic Left Heart Syndrome (HLHS). This would require a series of three surgeries, with the possibility of a heart transplant.

On September 13, 2004, Delainey Alexis Barcus was born. Within an hour, the Children’s Mercy transport team arrived. As my newborn daughter was wheeled away, followed by my husband and our families, I found myself alone with my thoughts. This was the moment when I realized the depth of a mother’s love and at the same time, the unbearable fear of losing your child.

I remember so vividly the first time I entered Children’s Mercy and scrubbed in to see her in the NICU - things that soon became so familiar. In what seemed like only seconds after our arrival, the cardiology team walked toward us with smiles on their faces. We were told that a heart echo that morning revealed that our daughter did not have HLHS after all. She did however, have another heart condition, aortic coarctation. Although this condition still required surgery, it was a single surgery and to our relief, it would not require an open heart procedure.

How this change in her condition occurred despite the numerous high quality heart echos that were conducted during pregnancy was a mystery which left all of us confused, yet overjoyed. We didn't need an explanation for why this happened; we were just thrilled that it had. To us, what happened that day was a miracle.

One week later, surgery day was upon us. There is NOTHING more terrifying than handing your child to the nurse on surgery day, nothing that makes you feel so small or helpless than watching the door close between you and your child, nothing that can calm your heart and mind until you hear the surgeon's voice telling you that everything went well.

When Delainey was 7 days old, Dr. O'Brien and his team saved her life. Children's Mercy was our home for five weeks. During this time, we watched our daughter struggle with unexpected hurdles in her recovery and we experienced our share of bad days when we felt helpless in our parental instinct to protect, nurture and heal our child. But, each day, we felt blessed that we had Children's Mercy.

The Children's Mercy team nurtures the children and families who are going through the most extraordinary of life experiences. They fight to save the lives of countless children. They go to the greatest lengths and regardless of the prognosis or outcome, they offer more than medical attention - they provide hope.

Today, at nearly 4 years old, Delainey remains the joy of our lives. You would never know the challenges she has overcome in her short life by looking at her big blue eyes and watching her blonde curls bounce as she dances and twirls across the room. She is a gift. I continue to be amazed by her strength and spirit, I'm sure that I always will be.

Delainey still visits Children's Mercy often, to be seen by doctors in cardiology, urology, ENT and endocrinology - it is because of their expertise that she is thriving. When asked what she wants to be when she grows up, she has no hesitation in her answer. "I want to be a doctor and fix special babies like me. I think I will be a doctor, teacher, librarian and a mommy."

While the words, "Thank you" don't even come close to what we feel in our hearts, please know just how much we appreciate what Children's Mercy did for Delainey and for what they do for thousands of other children each year. Miracles happen there every day. One just danced by me wearing a tiara and tutu.

Kyla Barcus - Kansas City, MO

