

Brody



My son Brody Tucker was born prematurely at 34 weeks gestation on April 25th, 2007. It was after a six day stretch of being on bed rest in constant labor. So when he was born looking relatively healthy and normal, everybody was ecstatic. We were discharged after just a few days, with his weight at only 4.3 pounds. One week later, he was shipped to Children's Mercy Hospital in Kansas City, MO for dehydration, apnea, and bradycardia. That was the scariest day for my family, but the flight team nurses and the NICU nurses literally saved my son's life. He stayed in the NICU for three and a half weeks.

During this hospitalization, we found that he had a congenital heart defect called "hypertrophic cardiomyopathy". This causes the heart to thicken and become enlarged. The doctors did not know the cause of his condition and began numerous genetic testings. However, we were still all hoping it was due to stress, dehydration, and infection. After being discharged, we came back to cardiology after two weeks for a follow up. Brody's heart had continued to thicken and we now knew this was serious. About two weeks later, Brody was hospitalized again for spitting up, due to so called "GI issues". After repeated requests for an echo, the doctors finally gave in. This was when our lives changed forever. The cardiologist informed me that my son's heart was three times the size of a normal infant's heart and that he had a pericardial effusion. He suspected my son had "Noonan's syndrome" and that he would probably die in two months. He said that there is no medication, no procedure, and no treatment available for my son, except a heart transplant. I was told to "go home, breastfeed him and spend quality time with him". Immediately my husband and I said "no!" to the idea of giving up, and requested medication and to be shipped somewhere for a second opinion. Brody was air-lifted



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to St. Louis Children's Hospital and was listed for a heart transplant after two weeks of evaluation for candidacy. He was on numerous IV medications, intubated for oxygenation and had a nasogastric tube for nutrition. Within 48 hours of being intubated and ordering the Berlin Heart (life support), Brody had received his new heart on August 1st, 2007! He recovered well and was discharged one week after his transplant. It was amazing. We were so excited, scared, nervous and happy; all rolled into one!

Brody will have to take immunosuppressants life long to prevent rejection. He follows up with his cardiologist frequently to complete cardiac clinic visits, echocardiograms, EKGs, chest X-rays, and lab work. Brody will also have to undergo heart catherizations/biopsies life long as well. Everything went well except in the feeding area. Brody still depended on the NG tube for most of his nutrition. He just seemed orally averted to food. Then in late January 2008, he had his first so called mild "rejection" episode. It hit us like a brick because it was totally unexpected. But we pulled up our bootstraps and said, "No big deal, we'll treat this." So he got three days of IV steroids and started the weaning process with oral steroids again. We have since found out that the "rejection" may not have been a true rejection, which is great. Things went pretty smoothly until late February, when he had his gastrointestinal tube put in. That was when everything went down hill. He started vomiting like crazy and began to lose weight. He was hospitalized again in April. The doctors put him on continuous feeds (by g-tube) and that created diarrhea, which hastened his weight loss. We were in the hospital for a month, when we finally got a request granted to be transferred back to the transplant center. Once there, he was diagnosed with "hyperammonemia" (high ammonia levels in his blood). Apparently his liver cannot break down protein necessary for ammonia excretion. This was the beginning to our new saga.

The doctors are continuing to search for a diagnosis so we can effectively treat our son. The doctors are very inclined to say that he has a mitochondrial disorder, which entails no cure. To tell you the truth, this medical revelation has been harder on us and more shocking than his cardiomyopathy. We are still trying to take in and register this new situation. Actually, we just got home this Monday (August 11th), after a very bad episode. Brody got very sick. His ammonia levels suddenly went through the roof and he became comatose. He required hemodialysis to clear out his blood. He was in acute liver and kidney failure out of the blue. Just the day before, he had completed a new feat; he traveled 108 inches backwards in his walker! This new “situation” has taught us that life can change literally in minutes.

It’s funny. All I kept saying to myself last summer was that Brody just had to hang on until the heart came. Once the heart came, everything would be fine. We just need the heart, we just need the heart. Then once the heart came, I started questioning how long this was gonna work. How much time would this heart give my son? I started gauging my son’s life in quantity, not quality. Ten, fifteen years was not enough for me. But now, I just want whatever time I can get with him. Just give me another 15 good months like we had. Not only that, but I truly realized that I have another daughter who deserves a mother, too. I have truly realized that we need to all be a family, together. I am slowly learning to let go of my anxiety-ridden thoughts and behaviors so that we can all spend quality time together. Now, I will always be a germaphobe, but I’ve realized it is okay for sissy to kiss him on the head and hold him! I will still always protect my kids and harbor my son from germs, but I won’t sacrifice his life to live in his ‘sterile’ room. I want to make memories! I don’t want to live in regret.

So, I have learned a lot during Brody’s journey. I am not angry



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at God. I'm not envious of other healthy babies. But I did ask why. Why is this happening? And my outlook was changed when my father gave me a token of advice while we were waiting for a heart match. My dad said, "Be glad this is happening to you." I was dumbfounded. I asked why I would be happy for this. He said, "Be glad that you are Brody's parents. Could you imagine Brody going through this without having you as his parents?" And I couldn't. Gary and I are the best parents possible for Brody. We would do anything and everything for our kids. Maybe this was destined to happen. Maybe Brody was born to travel this journey. So maybe this is happening because we were chosen to be Brody's parents because God knew we would care for him like we do.

So every day, I thank God for getting another day to spend with my family. I thank the donors for giving Brody a second chance of life. Without them, we wouldn't have Brody here today.

Sometimes it takes a horrible situation to realize something so wonderful: Family. It is time for the Tucker family to live life to its fullest together!

Editor's Note:

Sadly, Brody became an Angel on March 7th, 2009.

*He went very peacefully in his Mommy's arms,
surrounded by his family.*

