Hero Heart: Our Family's Journey With Heart Transplant

Michael & Jesi Brandt,
parents of Myles Brandt



We are Michael and Jesi, the parents of Mighty Myles. Myles is 4 years old and was born with Down syndrome. Before Myles was born, we knew that he had Down syndrome, a complete AV Canal Defect, and valve regurgitation. We were told that Myles would have 2 two-week-long stays to repair his heart. We felt scared but ready for his arrival and the hospital stay that was to come with it. That was until our lives flipped upside down at four days old when we thought we were headed into a meeting to discuss Myles' upcoming heart surgery. **Instead, we were there to discuss the potential end of his life.**

We were informed that Myles' heart had severe valve regurgitation and that it did not look promising. As they discussed their plans and potential outcomes, I begged for a heart transplant. We were told he was not a candidate, and I fought back, thinking it was due to him having Down syndrome. In reality, it was because he was not expected to survive recovery from a heart surgery that was in a few days. As we approached his surgery date, the surgeon took a chance and took Myles off one of his heart medications. To everyone's surprise, Myles remained critically stable, and we were able to skip the risky surgery altogether. While this was a relief for us, we knew it was not over as Myles would still require additional intervention.

A few weeks later, a large team of doctors and surgeons walked into Myles' ICU room and asked if we were still interested in listing him for transplant. It turned out that the surgeon and one of his ICU doctors had advocated fiercely every week to list him for transplant. Shocked and excited at this chance at life, we made the quick decision to proceed with the listing process.

On December 14, 2022, Myles underwent open-heart surgery for AV Canal repair and biventricular assist device placement as part of a bridge-to-transplant strategy. On June 10th, 2023, the doctor walked into Myles' room to inform us that we had an organ offer, and it was time to prep Myles for transplant.

We felt numb. This was the moment that we had been waiting for, and now that it was here – it didn't feel real. We began labs, scans, tests, echos, and so much more, making sure that he was healthy enough for surgery and that this heart was going to be a good fit.

On June 11, 2023, Myles got his hero heart! As we handed him over to the surgeon, we were filled with emotions. We were excited, scared, and grieving. We were excited that his time was here. We were scared as we were sending our 8 1/2-month-old baby into his second open heart surgery with so many risks.

Finally, Myles came out of surgery and we were told he had done phenomenal! He had a smooth recovery in the hospital, and at last after 282 days, we brought our baby home for the first time in his life. We were informed that nobody expected Myles to survive, and because of his story our hospital has taken more chances on complex and risky cases. He was the first infant with Down syndrome in Utah to receive a heart transplant. Myles just celebrated three years with his hero heart, and he is doing great!

Children with disabilities deserve access to organ transplants free of discrimination because they deserve a chance at life. While we were so fortunate to have an amazing team of doctors that did not discriminate against Myles, that is not the case for most. The Charlotte Woodward Organ Transplant Discrimination Prevention Act is so incredibly important to our family because everyone deserves a chance at life. We went from potential tragedy to thriving because of a team that didn't discriminate against Myles. EVERY person deserves that opportunity.