

# Ending Discrimination in the Organ Transplantation Process: Zion's Legacy

*Written by Bobbi Sarmiento,  
mother of Zion Sarmiento*

My husband, Josh, and I are the proud parents of two sons, Josiah and Zion. When I was 10 weeks pregnant with Zion, we found out he would be born with Down syndrome, and at the 20 week anatomy scan, we learned he had a congenital heart defect (CHD) called a complete AV canal heart defect, a common CHD for individuals with Down syndrome. After years of Josiah praying for a sibling and doctors telling Josh and I that I couldn't have another child, Zion was born on June 15, 2021. He was the perfect addition to our family.

We spent 40 days in the NICU navigating Zion's heart condition and learning how to manage his care at home before his heart surgery, which was scheduled for September 20, 2021. We asked all the questions, even the worst-case scenarios, to be prepared for the big day. We had the best weeks at home together before his open heart surgery.

On September 20th, we had no idea that Zion would have the worst-case scenario story. After five open heart surgeries in 12 days, the surgeons had exhausted all options to repair his heart, and it was determined that Zion needed a heart transplant. The hospital we were at did not have a transplant program, but we were told to qualify for a transplant, all of Zion's other organs needed to be healthy, which they were, and he had to successfully come off life support, which he did.

We had three options in Florida for a pediatric heart transplant. The first option told us they had never done a successful heart transplant for someone with Down syndrome — I have since learned they have never tried one. Our second option said they felt incapable of performing a successful heart transplant on Zion. Our third option, who kept us sitting on pins and needles, finally came back and said, after much debate, **they just couldn't waste a heart.**



On October 8, 2021, with no options left, we made the difficult decision to remove the machines that were keeping our son alive. I held Zion in my arms one last time as he took his last breath.

Individuals with Down syndrome and other disabilities deserve the same chance at life as everyone else. A human should never be determined to be a "waste" just because of a disability diagnosis, especially when the other qualifications for a transplant have been met. While many believe this type of discrimination doesn't happen, our story is a real and heartbreaking example that it still does. We pray that no other families will ever have to live this nightmare. **Please help make this change happen. Please support the Charlotte Woodward Organ Transplant Discrimination Act.**



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