



## ***Transplant Mom Ly Tells Their Story***

While Axel's journey is over, we hope that by sharing our story, we can raise awareness about the immense financial burden families endure when a child is facing a life-threatening condition. The costs are often unseen and unsung, but they are real, and they matter.

The night was cold, windy, and the rain poured down as we followed the ambulance, carrying our 15-month-old Axel, on a two-and-a-half-hour journey to Stanford Hospital. Axel was in heart failure, diagnosed with idiopathic dilated cardiomyopathy, and his only chance of survival was to get him on ECMO (Extracorporeal Membrane Oxygenation) to give his heart and lungs a chance to rest. Five days later, he was implanted with a BIVAD (biventricular assist device) as we anxiously waited for him to be placed on the heart transplant list. He waited for over a year.

During that time, Axel endured two strokes, numerous infections, septic shock, and severe nosebleeds, leading to significant blood loss. When we finally received the call that a donor heart was available, we allowed ourselves to feel a flicker of hope. We were heartbroken for the family who had just suffered an immeasurable loss, but we knew we would give this heart—and Axel—the best life we could. Our goal was to get him home and give both lives a second chance. Axel had two older brothers and a dog waiting anxiously for him.

Sadly, just weeks after his transplant, Axel's donor heart began to reject. Despite aggressive anti-rejection therapies, we learned Axel had immune dysregulation, which caused his body to resist treatment. By this time, so much damage had been done to his heart that during his next procedure, Axel had to be resuscitated and placed on ECMO once again. The hope now was to give his heart a rest and consult with specialists on how to help him. Thanks to the support of world-renowned stem cell specialists, we were able to halt the progression of the rejection.

Over the next six months, Axel underwent a tracheostomy for respiratory support and was placed on dialysis for kidney disease. He coded two more times and was resuscitated both times, but despite everything, Axel wasn't getting better. After many more infections, viruses, and periods of instability, Axel spent 600 days at Lucile Packard Children's Hospital. Sadly, the very next day, Axel passed away, leaving behind not just our grief but also the pain and struggles he had endured.

Until the loss of our baby boy, Axel's hospitalization was the most difficult time we had ever faced. Our household was torn in half, with one parent staying with Axel's brothers at home to offer them stability, while the other stayed bedside with Axel. Axel's mother was unable to work and ultimately lost her job, while his father continued to work from home to care for his



brothers but would travel to be with Axel during major procedures and events. With a single income and the constant need to take time off to be present for Axel, our financial situation became strained.

Throughout this journey, our priority was always Axel—his care, his treatments, and his unpredictable medical plan. However, the financial toll became overwhelming. The cost of hospital stays, procedures, medications, and ongoing care adds up quickly, and as we focused on Axel's well-being, we also faced the looming risk of losing our home due to lost wages. The emotional strain of caring for Axel while navigating financial uncertainty weighed heavily on us.

In times of crisis like this, financial support is a lifeline for families. It allows us to focus on our child's care, to be present with them without the added stress of wondering how we will keep the roof over our heads. It is through this support that families like ours can weather the storm, ensuring that their loved ones are given the best chance at survival, while also protecting the stability of their household. Without the financial help we received, we would not have been able to provide Axel's brothers with the normalcy they needed during such a challenging time.