

Aaron's Story

Aaron was born in 2002 with Hypoplastic Left Heart Syndrome, a fatal heart defect. It was diagnosed within 4 hours of his birth and he settled into the NICU at Children's Hospital of Pittsburgh 3 hours later. We were given 3 choices: let him go, try a surgery that had had some success or list him for a heart transplant. We chose the surgery and Aaron entered the OR for a 7 hour open heart surgery at 5 days old. In two days' time he was very near cardiac arrest and was placed on ECMO. After being on complete life support for 3 days, it was obvious to his team of doctors that Aaron could not survive. We were again faced with a choice. Now we were down to only two. After seeking the Lord's guidance, as He continued to sustain us, we chose to list Aaron for a transplant. However, we were not given much hope from his doctors. Aaron could only be kept alive for a week before complications would begin that would leave us with no choices. We were told it was highly unlikely that a heart would become available to "fit" a newborn in only a week's time. To everyone's complete shock, within 26 hours of being listed, Aaron was offered his 2nd chance at life.

He finally arrived home near Grove City, PA at 3 months old. His first 2 1/2 years were full of an overwhelming number of crises but he, his parents and brothers faced them with courage, persistence and determination through the grace of God. God had blessed us with a supportive group of friends and family that filled in the gaps when we were stretched too thin.

Our life has taken on a new normal; one that contains clinic visits, EKGs, ECHOs, heart biopsies and the dreaded labwork; one that expects about one admit to the hospital per year, for one thing or another; one that grieves with friends from the hospital who have lost their child to the fight. Life will never be the same, but we will certainly take it without complaint.

Another child's heart beats within my son's chest. It allowed his life to go on, it allowed us to keep and love our 3rd son, it allowed us to experience the transplant world that has forever changed all of us. Even though it has been 10 years since another family gave us the Gift of Life, I continue to feel a deep, deep love and gratefulness for the choice they made. Aaron would not be here without them. Our previous choices had only bought Aaron time, but it was their choice that has given Aaron the past 10 years. Without them he would not have competed in the U.S. Transplant Olympics and won silver in the 25m swim, he would never have rode calves in the PA Youth Rodeo, he would never have visited and encouraged other heart kids in the hospital. I would never have celebrated all of his "firsts" or watched with pride as he hit a runner in at a Little League game or sat quietly with him gazing into a campfire, listening to the peepers.

We, the Amons, are so very, very blessed through the struggles and the joys!