Tristan F. Williams
(Age 9)

Tristan is your normal looking 9 year old. If you are able to meet this sports loving kid you would never know he was born with a congenital heart condition. It would be hard to know the extent of his situation until he lifts his shirt and shows the chest scar from his surgery.

Right after birth Tristan was diagnosed with congenital heart disease known as Truncus Arteriosus. (TRUN'kus ar-te"re-O'sis) This is a complex malformation where only one artery arises from the heart and forms the aorta and pulmonary artery.

Within hours of his birth a pediatric cardiologist was called in to perform an echo-cardiogram and the extent of the condition was diagnosed. Once his condition was confirmed he was rushed to a Pediatric Hospital to monitor the severity of his condition with the appropriate staff and equipment.

After a week in the hospital we were able to bring our baby home but with a bitter-sweet circumstance. Our home environment became very sterile; no one could visit us or our new baby and when it was required that we had to leave the home it was mandatory for a complete wardrobe change and scrub down. Our routine was very hectic with several doctors' visits a week; close monitoring, extensive medications to keep him alive; to regulate his blood flow and oxygen levels, and an alarm going off every 3 hours for feedings. This was difficult to do to a child who was going through severer congestive heart failure and all he wanted to do is sleep. Tristan's condition was so extreme that open heart surgery would be needed to reconstruct his deformed heart.

At 6 weeks and just over 7 lbs, Tristan's cardiologist told us that his tiny heart had endured maximum distress and heart failure. It was time for the team of specialists to intervene with life saving open heart surgery. The intensive repair and reconstruction lasted over 8 hours. Tristan had to be on a heart-lung by-pass machine so that blood would be routed away from his heart to the machine. To complete the surgery, the Doctors had to stop his heart from beating for almost an hour. Tristan was clinically dead for that entire time. Thankfully he pulled through!

After surgery Tristan spent a week in the Pediatric ICU and then spent a few extra days in his own private room before going home. Again, our release from the hospital came with an extensive long list of instructions on his care. We were told that due to the strenuous surgery, and type of condition Tristan would face many challenges; he could be blind, partially to fully retarded and he would most likely not experience a "normal" life. It was expected for him to have permanent, marked or severe functional limitations. Only time and testing would let us know for certain.

Tristan was only home for 2 weeks and about to make his first post operation check up and the hospital and Doctor bills came pouring in. Each bill was higher and higher than the next. It was costing so much money to just afford the special medications he needed to survive. Although insurance has helped pay, the non-covered expenses, fees, deductibles, specialists and hospital bills have really added up over the years. We have tried to pay on these but it has become impossible to even imagine how to pay them down. While trying our best to pay what little we can and giving Tristan as much of a childhood as possible, we have had to continue our 3-6 month check-ups. For the past 9 years Tristan is required to visit his cardiologist, Dr. Susan Denfield at Texas Children's

Hospital every 3 to 6 months for what is described as lifelong cardiology visits for monitoring of his condition and medication. Each visit tracks his condition with a variety of tests. Every visit has multiples tests and exams which can include Electrocardiograms, Halter Monitors, Exercise Stress tests, Echocardiograms and x-rays. These tests help determine what kinds and amounts of medication is needed and also helps assist in the explaining of when the next procedure is needed.

In July 2006 Dr. Denfield felt that Tristan's condition was showing signs that the pulmonary artery conduit was becoming narrowed and that he had to undergo a heart catheterization so that a full and detailed inspection of his condition could be seen. The procedure was performed by specialized doctors in TXCH Cath Labs. During the procedure they were able to dilate Tristan's conduit and take internal pictures and measurements. In many ways, this procedure was a blessing. It allowed Tristan to not have to undergo any surgeries or procedures for a year.

After a year of monitoring and testing, Tristan's cardiologist stated that instead of open heart surgery, Tristan would need yet another catheterization to put in a stent to allow better blood flow through his pulmonary arteries. In early August 2007 we met with Dr. Nugent, the catheter specialist at TXCH, so he could better explain the procedure, results and outcome of the stent. Within the same week, we were back at TXCH so Tristan could undergo his second heart catheterization. Dr. Nugent stated that the placement of the stent is so close to his pulmonary valve, he has little to no valve function. This requires close monitoring and testing to determine when his heart has endured enough trauma to require his next open heart surgery to replace a deformed aortic valve, donor pulmonary valve and conduit.

Tristan looks great for a child who has had a major reconstructive surgery and 2 cardiac catheterizations. While his hospital days and future surgeries have not come to an end we are very hopeful that with future technological advances, Tristan will have a long life of playing, jumping and breathing. While we (Mom, Dad and little brother) face the challenges of Tristan's congenital heart condition we continue to live, love and play like a typical family. Life is truly short and we are on borrowed time…..