

CHD Awareness - A Mom's Perspective



My son Trey was prenatally diagnosed with Transposition of the Great Arteries. He was born in July 2008. I am sharing his story to help other parents who have been or will be thrown into the “battlefield” of Congenital Heart Defects. I call it a battlefield because you as a parent have to fight for the best care for your child, and you should be prepared. We were totally unprepared. Yes, we knew prior to birth, but we were told not to look up information on the internet, “...you do not want to freak yourself out,” etc.

We consulted with our OB and met the cardiothoracic surgeon. We were told that he was one of the best in the country, and we clicked with him - we trusted him. We were told that while this was one of the most severe heart defects, it was a “one-time fix,” and besides not being able to play contact sports, our baby would live a very healthy, productive, normal life.

Trey had his surgery at 5 days old, and his chest had to remain open after surgery, due to swelling. It was extremely difficult to see his little heart beating below the medical wrap over his chest. They were able to close his chest after two days, and he started to recover like a warrior, a “heart warrior.” After three weeks in the hospital, he came home with an NG, or nasal gastric, feeding tube, and several heart medications. To say we were nervous is an understatement. When you are in the hospital, you have the nurses and doctors who we were in awe of, they miraculously performed open heart surgery and saved our baby. We were so grateful to have our son at home with his big sister.

After only a week, Trey started making these strange noises. At first, we thought he was choking. The doctors said he had “stridor,” which is noisy breathing caused by the breathing tube. We were told not to worry, that all cardiac babies have that. Then he started having these breathing episodes and the noise was getting more noticeable. We rushed him to the doctor, and they consulted with cardiology and he was diagnosed with breath holding. We were told to blow into his face when he did this and he would start breathing. On a Sunday night, only one month after being home, my husband had to perform CPR on Trey. He seemed lifeless - I thought we were going to lose him. In the ER, he had another one of these episodes - we were told this was called a “cyanotic episode” and he had to be “bagged” to breathe. Again it was mentioned about the breath holding. Two days later, they scheduled a bronchoscopy, a camera placed down the airway, and then a heart catheter to assess his episodes. The bronchoscopy revealed “mild pulsatile compression” and mild tracheomalacia (floppy airway) on the trachea. The pulmonologist told us that “convincing cardiology” would be the issue just before they were about to start the catheter lab. Trey’s cardiologist gave us wonderful news and told us that it was NOT his heart causing the issues. We were thrilled with this news but there still was no explanation for the cyanotic episodes. That very night, he was difficult to bag and they intubated him, placing a breathing tube down his throat.

We consulted with the doctors, and they said they needed to insert a tracheotomy tube because traditional CPR might not work the next time. That Friday, Trey had surgery and a trach was placed in his neck. He would now breathe through his neck until the Tracheomalacia healed. We were told it would probably be about 3 months with the trach.

We were in PICU for over a week because Trey kept having episodes and they could not get him off the CPAP, Continued Positive Airway Pressure supplied by a ventilator. The ventilator was not breathing for him, but pushing air into his trach tube to keep his airway open. We learned trach care and learned to “bag” Trey because of the repeated episodes. We were told to stop worrying why he was having the episodes, and learn how to save his life when he did, which was daily. We were learning to take our baby home with medical supplies and machines to keep him alive, including a trach, ventilator, pulse ox machine, apnea monitor, suction machine, and oxygen. Back when we were told that our baby would need heart surgery, I never in a million years could have been prepared for this scenario.

We took Trey home on October 23rd and began a horrible week of bagging and suctioning. Trey was getting worse and was taking longer to bag. We rushed him back to the ER on Halloween morning. My mother-in-law drove, I changed the oxygen from the ventilator to the Ambu bag, a hand-held device used to provide positive pressure ventilation, and my husband bagged Trey the entire way, about 20 minutes.

We were told in the ER that he had over a pound of extra fluid on his heart and lungs, and that his diuretics needed to be tweaked. We never left the PICU after that day. He continued to have cyanotic episodes which we learned later were also known as “dying spells.” It is hard to believe, though, that in-between these episodes Trey was the happiest, cutest baby ever. They kept saying he was holding his breath, but now he was on a ventilator... how do you hold your breath when a machine is breathing for you?



I started doing my own research on the internet because the trach wasn't working. I searched using terms like “heart pressing on airway” and “tracheostomy,” and found a journal article about a procedure called an aortopexy, where the heart is pulled away from the trachea. I mentioned it to the doctors during rounds on November 5th, 2008, and asked for another bronchoscopy. They said it wouldn't tell them more than they already know. After another agonizing week, I called a “Care Conference” on Thursday, November 13th. They scheduled it, surprisingly, for the next day. Before the conference, they said that they had decided to run a CT scan on his chest and that we would have the conference pending the results. The CT scan was done on the 15th and the pulmonologist told us that Trey had a Right Aortic Arch, and that a

normal branching pattern is a Left Aortic Arch. He had a second heart defect, called a vascular ring. One of the arteries had formed a circle around his trachea and esophagus, and it was essentially choking him. The reason it was taking longer and longer to “bag” or resuscitate Trey, every single day, was because his right lung was now 80% collapsed. They told us the heart defect was very rare and they needed to do surgery right away.



If we had not pressed for answers and demanded a Care Conference, this story would have a very different ending. Trey is a sweet, gentle soul with a contagious smile. He is now 4 ½ and enjoying pre-k with his friends. He is a puzzle aficionado and loves to play outside with his sister. We are so proud of him and continue to be in awe of this boy that has changed our family forever!

I want to urge parents to get as much information as possible beforehand, do research, be your child’s biggest advocate and **find support from other heart parents**. I beg you to be informed and present in your child’s care. You need to be prepared for battle and have every option possible before you send your baby into the battlefield.

Carrol Mayer
Proud Heart Mom to Heart Warrior, Trey