

Austin: A Family's Story



From Karla Cox, an Arizona mom

Our precious son, Austin was born 4 ½ years ago, and our first 24 hours were just as I had always imagined. We had no idea of the amazing and scary turn our lives were about to take as a family with a congenital heart defect.

Austin was delivered at 39 weeks after a healthy pregnancy and was beautiful. At 1-day-old, during Austin's routine visit with the pediatrician on rounds, they noticed that he was slightly bluish and took him out of the room to do some tests. Within the next 20

minutes we learned that he had a serious congenital heart defect and within an hour he was helicoptered to Phoenix Children's Hospital to await his first surgery. We now had a lot to learn in a very short amount of time with a very sick little boy. The only thing worse was the thought that if they had not noticed his symptoms in the hospital we might have taken him home and lost him.

We learned some very important facts very quickly. One in every 100 babies is born with a congenital heart defect and CHDs are the leading cause of all infant deaths.

His diagnosis is Hypoplastic Left Heart Syndrome which basically means that the left side of his heart did not develop. Austin's first open heart surgery was at 4-days-old and his second was at 4-months-old. These first surgeries were so emotional and stressful, but so were taking home an infant on oxygen, pulse oximeter (monitoring oxygen levels and heart rate) and a feeding tube. Thankfully, there are groups out there to help new parents of babies with heart problems, and we had a great surgeon and cardiologist who offered their shoulders to cry on more than once. Our Austin is a fighter, and he came through the surgeries far better than we expected. He made great strides by first coming off the oxygen and then learning how to drink and eventually eat on his own. We arrived at 2½-years-old and it was time for his third open heart surgery, hopefully his last for a while. Austin did very well; he was out of the hospital in eight days, and trick-or-treating only 11 days post-surgery. The series of three surgeries allowed his heart to function as well as possible with only a single ventricle.

Today Austin is 4 ½ and although he still has a long road ahead of him and probably more surgeries, he is so much more than his diagnosis or congenital heart defect. He is a beloved son. He is a preschooler. He is a big brother. He is a swimmer. He is a member of Mended Little Hearts of Phoenix. He is a member of Hopekids. He has so much more to accomplish in his life. Austin lives each day to the fullest, and thanks to him, so do we.

