My family’s journey with congenital heart disease (CHD) began almost 34 years ago, when my husband was born with pulmonary valve stenosis. He had open-heart surgery at the age of 10, and his defect was able to be repaired. Congenital heart disease is heart disease that is present at birth, rather than acquired later in life through lifestyle choices or the aging process. It also goes by the names congenital heart defects and congenital heart anomalies, and is often abbreviated CHD.

Because of my husband’s history of congenital heart disease, I was scheduled for a routine fetal echocardiogram during my pregnancy with our son. It is strange to say that I am thankful that my husband has a CHD, because if it weren’t for his history, I never would have had the fetal echo that saved my son’s life.

Doug’s Birth and Early Surgeries

My son, Doug, was diagnosed with congenital heart disease when I was 22 weeks pregnant. I was very lucky that he was prenatally diagnosed so we could be prepared for his birth. During my pregnancy, I had three fetal echocardiograms, five level II ultrasounds, and 13 non-stress tests to monitor the condition of my son’s heart. Despite all of the intense monitoring I went through, my son was born with multiple other birth defects that were not detected by ultrasound. But because we knew about his heart condition, we were prepared for a complicated birth, which ultimately saved his life.
My son was born via C-section to a waiting throng of neonatologists. At eight minutes old, he was intubated because he had difficulty breathing. He was stabilized, and at six hours old he was transported by ambulance to our children’s hospital. I only got to see him for three minutes on his birthday, as he was wheeled in his transport incubator past my bed in recovery. I did not see him again for four days.

Doug had open-heart surgery to correct a condition called coarctation of the aorta when he was just six days old. The aorta is the blood vessel by which blood is pumped from the heart to the rest of the body. Coarctation of the aorta is a condition in which the aorta is narrowed and blood cannot adequately be pumped from the left ventricle out to the body, causing increased pressure in the left side of the heart and differences in blood pressure between the upper and lower parts of the body. My son also had two small holes in his heart repaired at the same time. For me, the hardest part of my son’s surgery was that I did not get a chance to hold him before he was taken to surgery.

Nothing can prepare you to see your child after heart surgery. There are more tubes, wires, IVs, and machines than you would ever want to see. My son was lucky, because he recovered very well from his first heart surgery. His other birth defects caused him complications that caused him to need three more surgeries. He spent 57 days in the NICU recovering before he could come home from the hospital. He came home on one heart medication and one reflux medication. I thought we were very lucky.

**More Defects and Surgeries**

The next year of Doug’s life was dominated by regular visits to his cardiologist and his other specialists. As the year progressed, we saw symptoms in him that showed that his heart was still not functioning as well as it could. These symptoms included increases in blood pressure, heart rate, and his breathing rate, as well as extreme fatigue, and frequent vomiting. Exactly one year and two days after his first open heart surgery, Doug had a second open-heart surgery to correct other defects in his heart. This second surgery addressed structural defects in the left side of his heart, including both his mitral valve and aortic valve. Because of the different left-sided heart defects he suffers from, Doug was diagnosed with a condition called Shone’s complex. Doug was only in the hospital for four days after this second surgery. His recovery was truly miraculous.

Now, about four months after this second surgery, Doug is doing much better. He now naps like a normal 16-month-old child. His gross motor development has skyrocketed. Before the surgery he could barely roll over, but now he can roll, creep, crawl, and even cruise around the furniture. He only vomits once a day, instead of the four or five times a day he used to. Although he still doesn’t eat by mouth, he now shows more interest in food than he ever has. He breathes better, sleeps better, and he’s happier. Plus, he’s off his heart medicine.
The Journey Continues

Approximately one child of every 100 births is affected by congenital heart disease. Nearly twice as many children die from congenital heart defects each year as die from all forms of pediatric cancer combined, yet childhood cancer receives five times as much funding. There is no equivalent of St. Jude’s research hospital for children with CHD, even though it is the most common birth defect.

Like many families dealing with CHD, our family’s journey is nowhere near over. My husband’s heart condition is stable now, and he only requires yearly monitoring by a cardiologist who specializes in treating adults with congenital heart disease. Doug faces visits to the cardiologist four times a year for frequent monitoring. As he grows, he will need more open-heart surgery to replace his defective mitral valve and potentially his aortic valve as well.

Doug’s medical problems are caused by a genetic disorder called Noonan Syndrome, and he will face a lifetime of challenges. But if he faces these challenges with as much heart and courage as he has shown during these first months of his life, then he will succeed in whatever he chooses to do with his life. Every day I pray that he turns out just like his daddy.

Resources:

http://www.itsmyheart.org/chd-information/chd-facts/

Chrissy Spayde is Doug’s mom. She has a master's degree in Library Science and currently works as a children's librarian in Columbus, Ohio.