

Olivia was born in January, 2006 at Lakewood Ranch Women's Center. She weighed in at an unsuspecting 3lbs 9oz. She was transferred to All Children's Hospital in St. Pete, FL the same day for precautionary testing to see if a reason for her lack of size could be determined. Two days later on Friday, an Echocardiogram (heart ultrasound) revealed that Olivia had a Congenital Heart Defect called Truncus Arteriosus. That afternoon as Dr. Martinez and Nurse Practitioner Pat Mullen explained the situation, our world was slowly crashing down on us. We definitely were not ready for such news and I really don't know if we knew what we had just been told. After a couple of days of processing the numerous emotions and getting hundreds of questions answered, I think that we finally realized that we had a tough but beatable road ahead of us and that our life was now changed forever.

Truncus Arteriosus is a result of the pulmonary artery and aorta artery not splitting during the gestation period around week eight. This lack of splitting makes one great trunk, thus Truncus Arteriosus. At the aortic arch, the pulmonary then splits off and goes to the lungs, as it should. With this defect, blood that should be headed to the body goes to the lungs and vice versa. We were also told that due to Olivia's CHD diagnosis that genetic testing should be done to determine if Olivia also had DiGeorge Syndrome/VCFS/22q Deletion Syndrome (the syndrome has many names, all meaning the same thing). Simply put DiGeorge Syndrome is when one is missing a piece of the 22 chromosome. The blood work was done and a week later we were told that Olivia did in fact have DiGeorge as well. DiGeorge Syndrome is the 2nd most common genetic defect, 1st being Downs Syndrome.

Because of Olivia's lack of size, the doctors and surgeons decided to give her an opportunity to gain as much weight as possible to increase her chances of a successful surgery. This was also possible because she was not showing serious signs of distress.

On March 7th, my wife and I took the longest and shortest walk in our lives. We were led from the NICU to the operating room holding area and into an operating holding room, where we met with the anesthesiologist and an operating room nurse, from whom we would get the periodic updates during surgery. After a few minutes, we both had to walk out of the room and leave Olivia so they could prep her for open heart surgery. This has to be the hardest thing that either one of us have had to do. To leave your six week old lying on a bed looking up at you like she just wants to be held, having no idea what is about to happen is something that no parent should have to go through. Along with many family members, we waited in the waiting room for each update. We received word that everything was going fine and on schedule with no surprises. Roughly six hours after we left Olivia in that room, we received the update that the surgeon was done and we would be able to see her in a couple of hours in the cardiovascular ICU. We saw Olivia in CVICU as soon as they would let us and honestly, she looked wonderful. I am not sure if that is because we expected the worse, or what, but we both thought that Olivia looked awesome. The next day, the breathing tube was removed and slowly, day by day, one at a time, each tube, wire and IV was removed. She had done remarkably well during her recovery and was getting stronger every day.

On March 30th, 64 days after being admitted, we headed home with Olivia for the first time. She weighed just under 6lbs and was getting bigger by the minute. A few days previous, she was

given a feeding tube to assist in making sure she is getting enough nutrients so she can continue to gain weight.

Olivia is now a happy “healthy” 1 year. We are quickly approaching her 2nd birthday and we thank God everyday for her life and what she has given to us. Olivia does still require a feeding tube for her nutrition, but this is due to her DiGeorge Syndrome, not her heart.

A week after her heart diagnosis, we were told about a support group called, Mended Little Hearts. We were not sure if we were ready to “go public” with our new found way of life. We really didn’t know what our own emotions were, so how were we going to talk to strangers about it. We finally decided that we would attend the meeting. We are extremely glad that we did. It was the perfect thing at the perfect time. We saw other ‘heart’ kids running around being kids, we talked to other heart parents that had been exactly where we were and we were able to ask questions about what was in front of us. Everyone in the group provided us support and for that we will forever be grateful. Without the Mended Little Hearts support group, I am not sure where we would have ended up.

Olivia’s prognosis is good. She will need additional heart surgeries in the future, we just do not know when. We live life one day at a time and cherish each and every moment that we are afforded. We know that we have a very special little girl.

Heart Hugs <3