

# Steven

Written by his Mother, Berenice

I would like to share Baby Steven's story and give you a glimpse of how Steven's life was for the 6 months he was on this earth. Steven was born March 10, 2018, with a birth defect called congenital diaphragmatic hernia (CDH). My husband and I found out about this birth defect too far along into the pregnancy that nothing could be done until he was born. We were told by doctors from the start he had 50/50 survival rate. As you can imagine our family was devastated to hear of this, especially my husband and I, since he was our first child.

The moment Steven was born he was put on a ventilator to help him breath and then put on ECMO. Being put on EMCO was a critical surgery for him; there was a strong chance that he wouldn't make it through that. But miraculously he did! ECMO provides temporary support for lung failure by circulating the baby's blood through a heart-lung type machine. It can be life-saving, but can be used for only limited time. As days passed and we saw no improvement of lung function things really started to sink in that there was a strong possibility that he won't make it. Tests only showed Steven only having the left lung which was not supporting his body. We were told he only needs one good healthy lung, so we were all betting on this one little lung. A few days of being on ECMO and he was stable it was time to perform another big surgery, which we all held our breath for again. Rearranging of his organs and repairing his diaphragm. With him being on ECMO and his blood completely thin there was so many odds against him. Again, we were told he could possibly not make it out of surgery. But to our surprise this wonder of boy and by the grace of GOD made it through.

A week passed and he was stable but his left lung still wasn't showing enough improvement and he needed to come off ECMO and just be on the ventilator. They tried a few times to wean him off and his oxygen just dropped to a point where he wouldn't survive without it. We were told that they would try weaning him of a few more times and if there were no improvements in his numbers there was nothing more they could do. Our family was devastated and completely broken at the news. On March 23rd, our family was prepared to say good bye to little Steven as the doctors told us the day before "we'll give it one more try but I don't think there will be improvement based on his condition." That last try came and as his numbers began to drop. Within in minutes a Miracle literally happened right before everyone's eyes. Baby Steven's numbers began to rise and was holding. Hours went by and we prayed that his lung would hold up with the vent and it did. Steven was stable and was moved to smaller ventilator since that left lung was functional and healthy. Day by day it continued to get stronger. After the 2nd surgery they did find the right lung but is was very small. Baby Steven was still on a lot of medications and sedation but they were slowly weaning him off of everything. The days went by and he kept on improving. The doctors were positive but some had their opinions on how well Steven was improving to the worst.

The months passed by and the doctors came together and decided that Steven was in a need of a Trach. On May 13, 2018, he was transferred to Banner Deserts NICU. In this hospital they specialize on tracheotomies and G-tubes. A couple of days passed and doctors came in to see who our baby boy was and doctors and nurses immediately fell in love with him. The days passed by and his doctor came in and asked us if we had tried to take his breathing tube out. We never did. On May 21st, the doctor decided to take his breathing tube out. Everything was going great thank goodness, until he got the rhinovirus. He was sick for a while and he wasn't getting any antibiotics because the doctors said that it had to go away on its own.

On July 3rd, 2018, the surgery's happened. Our baby boy got his tracheotomy and G-Tube. Everything was going good with both of his surgeries. He was tolerating his feed and was gaining weight the way doctors wanted him too. The doctors tried twice to switch him to home ventilators but unfortunately every time they would do it he would end in getting sick or he wouldn't tolerate it. On July 23rd 2018, he was moved to the PICU side of Desert Banner. Baby Steven was having really good days and some bad days. The doctors he had always tried their best to make him feel better and get better. The RT's began doing CPT (Chest physiotherapy) to try to open up his lungs. Little by Little that started working and it kept on opening up his lungs. At this moment Baby Steven started getting X-rays and cultures. Cultures because he kept getting fevers but every time the doctors had the cultures done they all came back negative. Until one night me and my husband went home to get some rest. We got home around 10 and we received a phone call around 12, the doctor had told us that we needed to go back to the hospital.

They were bagging baby Steven for about 3 hrs and his numbers were staying the same. The doctors decided to paralyze him to make his numbers better. He was paralyzed for 3 days. The doctors came to the conclusion that our son developed pulmonary hypertension. The days were getting a little better. He was smiling and being his little self once again. Then again the pulmonary hypertension decided to come back and made things worse. Our baby boy was maxed out on his oxygen and medication. Unfortunately September 24, 2018 at 4:45 am our baby boy lost his battle to pulmonary hypertension due to CDH. We miss you so much our baby boy. Mommy and Daddy are so proud of you and always will be. We love you baby boy!

