

Samual

Written by his Mother, Jennifer

We found out about royalty entering our family in the summer of 2016. Biologically this was my second baby, Samual's dad's third. I had a history of preeclampsia I was diagnosed on the day my first was born at 26 weeks and 2 days. A NICU superstar, along with Samual.

The boys spent almost the same amount of time in the hospital, I often said that Franklin was my training for Samual. Little did I know, nothing compared to what CDH had in store for us.

Like many, the first time they could see that there was a problem was the day we found out we were having a boy at our 18-20 week anatomy ultrasound. When I was pregnant with Samual, Franklin called him his superhero, our Super-Sam.

Samual was born at 34 weeks and 1 day gestation due to absent blood flow through the umbilical cord, we had intermittent blood flow issues before that but seemed to resolve with bedrest. I had three ultrasounds a week, so that day, as soon as we started, I literally said, let's go. After begging them to hold off. Samual was ECHMO weight eligible, which he ended up not needing.

He got a clot early in his 1st PICC, it caused a blood staph infection. The doctors said he may lose a leg later in life because the clot stopped blood flow at the groin. Because of the staph infection we had to go on an Oscillator. I describe it like an oscillating fan in his lungs that pushed the air through the room to get better flow. He did amazing with that. After a month, he got his dual surgery 2 weeks earlier than expected because of the need of a Broviak port for blood draws as he had to start heparin therapy (replaced with Lovenox shots instead, do not regret the port still for blood draws). He got referred to a hematologist because they couldn't figure out why he clotted every line.



His surgery was long, they thought 4 hours. It was the longest 6 hours of my life at that point, they discovered more of his liver was up than anticipated. But they successfully repaired him with a muscle flap. The outside of him was healed before my cesarean incision. We had one more surgery to take the Broviak out, after they broke up the many clots his body had created.

After surgery they felt he had been on antibiotics for long enough. I had mixed feelings about it. I had worked in the hospital so I was aware of MRSA, a super-bug created by the overuse of antibiotics. I was worried, however, about infection lurking in his many clots. My fear was if it started breaking loose, it would reignite the staph infection he had been fighting for over a month now. I voiced my concerns during rounds when the discontinuing of the antibiotics was brought up. I am glad I did. Later a few doctors in the hospital came to confirm my fears about how the infection would have indeed spread. It really made me feel good, like I was actually helping in all of this. The most important thing was that I had saved my son from an infection, which was the most rewarding part of all of it.

The fighting to survive started diminishing as the healing began. I was amazed to see that his little cut on his lower left abdomen was healed up before my cesarean incision did. He was doing well with the Lovenox therapy. The doctors decided it was time for the Broviak to be removed, as any external line needs to be removed before it, itself starts clotting off.

He was off of oxygen in no time and took over 1/2 of his feeds by mouth. That's when they taught us how to place the ng and made sure I could give his Lovenox shots (which I was on throughout pregnancy to prevent preeclampsia). We were sent home 4 months before we anticipated according to everything we read and planned for. It was amazing, we were finally living life as a family.

We decided to take him to meet Papa Bear, his grandpa and the rest of my family and friends in WI for 2 nights. He was a little tired but we had been traveling. We were on our way home and he started crying a different cry. I thought he needed a rest as we had been driving for a few hours so we pulled over to eat and stretch. I called the doctor because of the crying we decided to go to the hospital instead of directly home for an appointment the next day as we still had an apartment there to make it easier for follow up appointments. I went to the bathroom and came out and Olivia, one of the 7 said Kay (my mom) says Samuel's not breathing. I ran to where we were seated and immediately took out his ng and started CPR. My mom even found a doctor that took over, it was like the ems was already there but the drive...the traffic was so bad I kept asking to be taken to a hospital with a NICU, we were too far from them. The hospital continued cpr and did everything they could for hours. ...months, and months went by and we did not have any answers until the autopsy came back. Natural Causes from complications of CDH and rhinovirus (the common cold)

It's been devastating. It was a very hard 1st year. I became a shut in. We got pregnant very shortly after his death with Quinn our rainbow baby. Hand-picked by Samuel and sent here from heaven. She even has a birthmark on her nose, I looked it up...an angel kiss. It is hard, every day is hard but we find ways to honor him in our house. One of his brother's prays to become a doctor to go to heaven to fix him and bring him home. The kids going through it all, witnessing it all really has been hard. We have started his non-profit foundation to honor him and help spread awareness, as we had no idea what congenital diaphragmatic hernia was pre-diagnosis and we are trying to find meaningful ways to help CDH families and patients to get tools to better their quality of life. His life was 110 days, he survived and overcame more in those days than most people ever have to face in life. He did it with the sweetest little smile and those big brown Peepers. He taught me lessons on everything from perseverance, love, heartache, courage, and so much more. He is an amazing person; his story isn't over.

His parents created a local foundation in his name to support CDH awareness, Samuel Zion Foundation. (SamualZionFoundation.org)

