

Peanut's Story

by Tera Young-Clark

Nolan, aka "Peanut" was born at thirty-eight weeks gestation via emergency cesarian. An ultrasound had shown that not only had he stopped gaining weight, but that his head circumference had stopped growing for a few weeks. He weighed just 5 lbs 3 oz, due to late term placenta insufficiency, in which the placenta stops functioning well. This causes the baby to receive a lack of nutrients in the womb and can halt development. He had good APGAR scores and was able to stay out of the PICU. It was noted that his white blood cell count was abnormally low. All I knew at the time was that he had a gorgeous head of dark hair, large, trusting eyes that looked even more round because his face was so tiny, hollow and pale. He also had the longest, thinnest fingers that wrapped tightly around mine when I fed him a bottle. I was smitten!

Peanut, along with his one year old sister, Rose, and his mother, lived with us at the time. My husband is his maternal grandpa, so that would make me his step grandma, although we don't use the word "step" in our family. So, we brought this tiny, little Peanut, with a low white blood cell count home and we all tried to continue our lives to some degree. Until he wouldn't gain any weight, that is. Then, as a household, we were setting alarms to wake up and feed the baby every hour and a half. Two people at a time, one to keep the other awake. Except that it took him an hour to eat the two ounces that the doctor wanted him to eat, and he could barely stay awake to eat that much. Then we were just falling back to sleep before another alarm was going off to feed Peanut. He still wasn't gaining weight. Before we knew it, he was running fevers, vomiting, had two hospital admissions, all within his first three weeks of life.

Over the next few months, it seemed as though Peanut and I were part time residents at Children's Mercy. He had admissions for viral infections, bronchial infections, failure to thrive and feeding studies, low blood counts. I was told that we weren't feeding enough, so he got an NG tube and we had to push more formula above what he would eat by bottle still. As frustrating as it was, Peanut still could not gain enough weight to maintain any kind of a growth curve. Hematology did a bone marrow biopsy, with the idea that he might have leukemia. They had no other good ideas as to why his white blood cell counts and hemoglobin would be low one day and then bounce back the next, even without a transfusion. None of it made sense, nobody had answers, and our sweet, tiny boy was never home more than a week out of each month. They finally sent genetic testing, which would take weeks to months to get back.

After seven months of this roller coaster, we had a memorable weekend at home. Rosie came home with a stomach bug from daycare. She was over it in 24 hours. The next day, Peanut got sick. He had 24 hours of diarrhea and stopped eating well. He became listless, pale and began running a low-grade fever. I took him to the pediatrician's office. All color had drained from his face and he was so sleepy that he could barely stay awake. They checked his hemoglobin and it was 6. By the time he got to Children's Mercy an hour later it was at 5. His diarrhea was constant and his belly was distended. He spent a few hours in a room before being transferred to the PICU where he began the fight of his life.

They took him to surgery to insert drain tubes in his abdomen, as infection was ravaging his tiny, fluid filled belly. It wasn't enough. His bowels were getting destroyed by bacteria that the antibiotics were unable to attack and his body clearly wasn't able to fight off. He was taken to surgery to repair his bowel and other places in his tiny abdomen that had been destroyed by bacteria. While that surgery was successful, Peanut's breathing was too shallow to come off of the ventilator. A couple of days passed and he was still on that vent. Respiratory therapy was doing treatments, but he could not get off that vent. Then, on a night when his platelets were borderline low, respiratory therapy, did some suction on his lungs. It seems that RT suctioned too deep, as Peanut stopped breathing, his heart stopped, and he suffered a pulmonary embolism. I was sleeping in a recliner in his room that night and was suddenly surrounded by doctors and nurses who were trying to revive him. Pushed out of his room, panicking, praying, I watched helplessly as they barely managed to get back a thready pulse. We were told that he might need ECHMO, a last resort that could save him, a procedure that we were told he was truly unlikely to survive. A hail Mary. They would have to remove the blood from his body, oxygenate it, then pump it back into his body. He had to fight and hang on without it. It was his best chance. As several teams waited to see what Peanut needed through the night, my head was spinning. We waited. Amazingly, Peanut made it through the night with doctors being able to revive him as he coded over and over again.

Peanut made it through the days that followed as well, although he was unstable and continued to stop breathing, his heart stopped multiple times. He fought on. He was sedated, on an oscillator, a shell of a baby. Still, he was in there, fighting. The bacteria in his belly continued to cause problems. There were multiple surgeries to clear bacteria from his intestines. He was yellow from jaundice as his liver was shutting down. The Palliative Care Team and Chaplains were speaking with us frequently. I was terrified.

When Peanut came off the vent, after months of laying paralyzed in the PICU, he could no longer lift his head, roll over or sit up assisted. The poor little thing was swollen with fluid, yellow and had no muscle tone. He would need to work for months to gain weight and muscle to even get back to baseline. Still, the first thing he did was lock eyes with me and smile. I knew right then and there that he would be just fine. He worked with OT and PT

daily and eventually rolled over, got up on his knees and was able to sit up assisted again. His muscle tone wasn't what it had been, but Peanut worked and played hard to get it back, smiling the entire time. He won the hearts of every nurse and therapist he encountered.

Peanut also now had a genetically confirmed case of Shwachman-Diamond Syndrome, his doctors told me that he would need a bone marrow transplant. They wanted him to gain strength and to have his transplant in Kansas City. After additional research, guidance from the SDSF support group and talking to other SDS caregivers, we decided that I would take Peanut to Cincinnati, OH for his transplant. This was important to us, so he could be treated by a doctor and a team that specialized in SDS and BMT. That meant my husband would stay in KC to work and care for Rosie. Splitting our family in half, ten hours apart for several months. Peanut kept getting infection after infection, so as soon as insurance was approved, he was life flighted to Cincinnati. My husband put him on a plane with EMT's on December 23, 2019, while I drove all night, racing to get there before he did. I imagined he would be terrified when he got off the plane, having to fly without anybody that he knew. I can't recall many hugs that I have loved as much as the one I got from my little Peanut when he got off the gurney that morning.

Peanut's pre-transplant protocol, where the doctor's do a series of tests to make sure that he is healthy enough to go through the transplant process, should have taken a few weeks. His took two months, as he was continuously getting infections and viruses, despite being inpatient in Cincinnati Children's. His white blood cells just wouldn't fight anything for him, even with GCSF injections. He would have a good ANC, but his cells wouldn't go to the site of the infection to fight. Finally, Dr. Myers, his transplant doctor, chose a time when the risk was lowest for him and began his chemotherapy. As he had been sick going into chemo, he was sicker than many patients are during and after chemo, and throughout transplant. Peanut seemed to catch everything during BMT. Rhinovirus, adenovirus, staph infections, G-tube infections, a central line infection. This child's intestines were pushing horribly painful abscesses through his little bottom because he couldn't fight his own bacteria. There were days that I would beg that the meds would just put him to sleep and silence his tears so that I could let mine flow as I held his little body close. Then he came down with Epstein Barr virus. He would need a T-cell transplant to fight Epstein Barr, as he was losing the battle and was so very sick. I was so thankful that we were at Children's, as the virus specific, T-cell transplant is something that only they do. He was on a pain pump for what must have been months due to chemo, infections, surgeries, until finally, he turned the corner. The pain subsided, no more transfusions were necessary, and his activity level increased more and more.

When it was all over, Peanut was inpatient at Cincinnati Children's for six months for his BMT and had spent all but a few weeks of his life at Children's Mercy before going to

Cincinnati. He was eighteen months old when we brought him home from the hospital, released, and it was a bit of a shock to him to break out of the hospital!

Now, he is two and a half years old, hasn't spent another night in the hospital since his release, and is loving life! He is an active, happy, engaged, toddler who keeps us all on our toes! He would rather run than walk, he fights back when his sister gives him a hard time and he doesn't miss a thing. Peanut now eats three meals of both pureed and finger foods, as well as G-tube feeds, weighs 30 lbs., is in the 50th percentile for weight and the 37th percentile for height. We couldn't even get him on a growth curve before! He goes to OT, PT and SLP weekly, loves taking walks, playing with Legos, and dancing to his favorite music.

If I'm being honest, a lot of Peanut's stays in the hospital are a blur of scary moments. I felt panicked and ill equipped so much of the time. A couple of things helped me to know that it was all going to be ok. I met another grandma at Children's Mercy and became friends with her. Her name is Nancy and her grandson was fighting a battle against leukemia that he would ultimately lose in June 2021. Nancy's daughter had lived in Cincinnati, so when they found out that Peanut and I would be heading there for BMT, they made a call to some friends. Next thing you know, I was getting messages from some lady who was insisting that I should come have Christmas dinner at their house with their family, telling me about her whole life. There were more of them. It turns out, before Peanut and I ever arrived in Cincinnati, we had a family there. There would end up being a group of people that would come to be called Peanut's People: Paige, Doug, Bonnie, Kim, Laura, and Paul. They would come up to the hospital to stay with Peanut so I could get away, have me over for dinner, send me leftovers to the hospital, have me over to put my feet up and be part of a family, feel normal, call and check on us, you name it. They were the ones that I messaged when something was wrong with Peanut. The ones that I still do. This group of people taught me that it's ok to believe in the kindness of strangers, something that I had never actually done before.

Finally, a word about my little Peanut! Through all the trauma that he has been through, all the procedures, all the pain, this innocent baby that could not possibly understand, never stopped fighting. More than that, he never stopped smiling! He was always having fun in the little moments whenever he could. He's made his medical teams laugh day after day. Once Peanut was released from the hospital, he never looked back! He is truly the happiest little guy that I have ever known and all he wants to do is have fun! Peanut has taught me so much along this journey. My biggest take away is that if he can get through all that he has, there's not much that I can't handle in any given day, right? At least that's what I think he's saying when he grins at me.