

What an amazing year it's been!

In one year all of our lives have changed in so many ways. It's been a year full of ups and downs but more importantly; it's been a year of making nonstop memories. On July 3rd, 2014, I woke up and went to work just like any other day. I knew that I had a scheduled weekly check up with my doctor to check on Raxton. When I got there, things were just as normal as any other appointment. I felt great even though my feet were swollen like balloons. As I sat in the chair listening to my sweet baby's heartbeat and listening for any movements or kicks that I might be able to hear, I noticed that his heart rate dropped for a little bit longer than I had ever heard or seen before. Shortly after, the doctor sent me to the hospital to be monitored a few hours longer to make sure everything was ok. As I laid in the hospital bed, talking to my best friend, they came in and told me that as soon as my husband could get there, they were going to take me back for an emergency c-section. I freaked out, but I was also over the top excited that this was the day we would finally meet our sweet baby Raxton! When Raxton was born I remember anxiously waiting to hear his sweet cry, but it never came. I also remember that there was a bit of panic on everyone's face since he wasn't moving like a newborn baby normally would. But with my husband being right there to comfort me, I knew that everything would be ok. The next morning, the doctor came in and told my husband and I that Raxton was going to be flown to Cook Children's in Ft. Worth, TX to see a few specialists. In that moment so many things ran through my mind, "What's going on? Is there something really wrong with my baby? Are they taking him without taking me too??" So Ryan and I talked and cried together then decided that it was best that he went ahead and drove to Ft. Worth to be with Raxton so he wasn't alone with a lot of strangers. Finally, 3 days after I had Raxton, I was out of the hospital and physically as ready as I could be to fly to Ft. Worth to see my babies. That turned out to be the first day that I got to hold Raxton. My heart was so full!

We had no idea what kind of journey we would go through in 1 year.

Raxton was in the NICU until early September and came home with no diagnosis. In late November we got a call letting us know that Raxton's diagnosis is X-linked Myotubular Myopathy. Immediately we started researching and trying to find other families with kids that have MTM and we were fortunate to find the Joshua Frase Foundation. We were devastated but at the same time, relieved to know exactly what we were dealing with so that we could help Raxton in any way possible. In early December, we went to Dallas to meet a new team of doctors. They admitted him into the PICU for his second hospital visit to try to get him the breathing support that he needed and to help him gain weight. That hospital stay lasted until early January. We got to be home for a little over a month until Raxton seemed to be getting sick. We had no idea the severity of what was going on until they flew him to Dallas Children's for his third hospital visit. As soon as he got there, they took him downstairs for a CT scan and that's when we were told that he had a severe brain bleed and he wouldn't make it through the next 30 minutes to an hour. We had never felt so sad, scared and helpless in our lives. 3 weeks after being in the PICU, Raxton was able to be extubated and put back on BiPAP, which is what he was on before he was in the hospital. He was stable for a few days until they mentioned possibly having to re-intubate due to the amount of thick secretions. That day we scheduled Raxton's trach surgery for March 23, 2015. After his surgery he did so great! He did so well that about a week later, he was able to move out of the PICU into a regular room. As he continued to recover and get used to his new normal, I noticed that he seemed to be in pain when I would move his arms and legs. After a couple of x-rays and a skeletal survey we found out that he had a few fractures due to him also having osteopenia. We hoped and prayed that this wouldn't be something that would keep him in the hospital even longer. Fortunately, his fractures were so small when they were found that they were already healing.

After being away from home for almost 3 months, we finally got to come home the first week of May. Since then, Raxton has grown a ton and become a little bit stronger everyday. We look so forward to seeing all of the amazing accomplishments he will make. He has affected so many lives in such a positive way with how hard he has fought in his, now 11 months of life. We know that he will do many more amazing things in his lifetime and he will always be #RaxtonStrong.