

Sara and Hero

My story starts in October 2019. I figured out I was pregnant with my third child. We were not trying for a baby but we were not trying either. I was nervous but that quickly faded into pure excitement. I love being pregnant. Both my previous pregnancies were great without any complications which is exactly what I was expecting this third time. I intentionally waited to make my first appointment to be closer to what I thought would be around my 12-week mark. Fast forward to Thanksgiving, we told our family we were expecting but I hadn't had my first appointment yet so we weren't sure of the due date. I had my first appointment on December 10, 2019. My husband didn't come with me because I told him not to. We had been here twice before and I was not expecting any other news than the due date and to be told all looked well.



Come to find out I was 2 weeks off with my calculations and I was 14 weeks. It was undeniable to see we were going to have a boy! I was so excited and felt so bad for telling my husband not to come. They also found a marker for Down Syndrome, the nuchal fold, and so they started the screening testing they ask at the beginning of the pregnancy.

This was the whole reason I wanted to wait as long as possible before going in I didn't want any screenings done. Because the marker was there they told me about a simple blood test that could be pretty accurate. I said yes to the blood test and got a call from my doctor a week later. When you get a call from the actual doctor at a pretty big ob-gyn practice (especially after 2 easy and normal pregnancies) you know you should be concerned. She told me the bloodwork came back with a positive result for Down Syndrome. But again it was only screening so the only way to make sure is to do an amniocentesis. I talked to my husband and we decided to do the amniocentesis. He got tied up at work and missed the appointment. I laid on the table so incredibly still and so did the baby. He did exactly what the doctor wanted and stayed on the opposite side and didn't move until that needle was out of his space. He has always been a good boy. The test results came back positive for T21. We were heartbroken. All of the unknowns, all of the should haves, all of the grief of the lost perfect son we thought we would have. We had to tell our family that we had told with such excitement on thanksgiving and such utter disbelief of the gender reveal on December 10th that before the new year came our son was broken. I got so much advice and none of it was really wanted. I was feeling pressure to abort him. I really struggled with that. What would be best for the baby? What if there was a heart defect or lung issue or gi issue that would ultimately take his life before his first year? Would it be fair to him to suffer through that? What if he wasn't accepted by family, friends, or the world, would it be fair to him to make him go through that? Ultimately I figured out I couldn't live with myself if I made the decision to have my son killed. With a prenatal diagnosis, I had plenty of time to think and wonder and go through all the different scenarios. I thought we would give him up for adoption for a while. I contacted



an adoption agency specifically for children with DS. I really didn't think I would be able to care for him the way he would need to be cared for. We didn't have any money saved up for anything let alone medical bills that I was sure he was going to rack up. I really didn't think I was going to be able to teach him anything, my previous kids basically raised themselves and just learned what to do next without much intervention from me. Ultimately I couldn't just walk away from my son and let some strangers clean up my mess. Meanwhile, the world outside was going up in smoke. My husband got laid off from work in January 2020 and tried to start his own business. Obviously, he was going through a lot of stressors. Mid-March my 2 other kids were no longer allowed at school because of some nasty sickness going around the world. My husband snapped and ended up in a mental hospital and I was left trying to hold together our broken world. Fast forward to May 26, 2020. I was almost 39 weeks and they were going to induce me the following Monday. I had spotting and contractions so we went to the hospital that was 30 miles away because our second child came in about 2 hours of labor starting. They broke my water and Hero Isaac was born about 6 hours later. He was perfect. My beautiful baby boy. He was alert for a long time after he was born. There were no complications during or after delivery. All the scary things I kept waiting for never happened. We took him home and he was just like any other of our kids at his age. He ate, pooped, and slept. He did have some trouble latching but he was able to feed from a bottle so I just pumped and bottle-fed him. Eventually, he was able to get a hang of latching on (about 2 months in) and we were good to go. At 8 weeks old I got him evaluated with early intervention. Everyone was new to the virtual thing and everyone

was learning as they went. By October he had PT sessions virtually through EI.



I kept waiting for the DS to "kick in" when he was going to be delayed. As far as I could tell he was just like any other baby. He rolled over by 4 months. He started solid foods at 5 months. He could sit up by 6 months. He was able to scoot around by 8 months. Sure he was just starting to crawl by 1 but some typical kids are late walking. My sister had her first baby when Hero was 11 months. Now I had an easily comparable example to see how far behind Hero really is. I met Robin Church right before Hero's first birthday. Her and the Mama's and Papa's Connection saved me from myself. I figured out I wasn't alone through all of this. Yeah, I might not have a clue as to what I should be doing for Hero so he doesn't get too far behind but that's ok because I know people that can help me and Hero. I'm

figuring out what questions to ask. What services should Hero be utilizing? Before I knew it my nephew was doing the same things Hero was doing and more. Which is honestly all ok. Along my journey, I was able to gather a lot of great resources and partner with great people that have been with me through it all and will continue to be a great support for my family and me. We are just getting ready to transition into the school system and the world of IEPs but I know I will have my village right by my side to give good needed and wanted advice when I'm ready.

Thanks,
Sara

