Wilson has an extremely rare DNM1 genetic mutation. Because of this, he has epileptic encephalopathy, global developmental delays, hypotonia, and CVI (cortical visual impairment). Like most parents of children with disabilities, this has been a difficult journey so far and of course Covid has not made it any easier for us, as most doctor's visits only allow one caretaker to attend.

When he was first born, no red flags popped up. My pregnancy had been extremely normal, I exercised and took my vitamins, we were even told he was head down at 35 weeks. He came a little early at 37 weeks and was surprised to hear he was in breech position. Following his birth, he struggled to pass hearing tests (they blamed it on his breech presentation) and seemed "floppy" to his experienced grandparents... but as first time parents nothing seemed out of the ordinary. He started showing, what we thought, looked like seizure-like episodes. We took videos and showed them to his pediatrician. We were told it didn't seem too concerning, but we pushed to see neurology. Neurology said something about "babies do weird things" and it would likely go away. We pushed for an EEG (he was about a month old at this point). Once it came back abnormal, we started to get attention from doctors. For months, we watched Wilson fall more behind in development, started PT and OT (around 3 or 4 months old), and waited for answers from genetics (tested at 4 months, received answers at 7 months). Even now with a diagnosis, our plan doesn't change, we just have an answer to what is causing this. I'm not able to ask Dr. Google about his disease because the only information out there are medical documents that I can't actually comprehend. We were fortunate to have a wonderful support system behind us pushing for answers and interventions, and I often wonder how long his issues would have gone with addressing had we not advocated for Wilson in those very early months.

Since we were in private PT & OT, at first I didn't understand what set Early Intervention services apart from our initial private physical and occupational therapies. Once we got set up, I realized EI offered more than just PT & OT, but taught us how to work with Wilson more at home and allowed us to find more emotional support. As we struggled to find out what was happening with our sweet baby, I found myself struggling with my own identity (I had to cut back from the job I loved), we were grieving with the loss of the life we thought we would have with our child (we're still dealing with this one!), and I was craving to find a community that understood the struggles we have gone through. Our service coordinator passed along information about the Momma's and Poppa's Connection - a weekly support group via Zoom for families with children in early intervention- and it is something I've started looking forward to weekly. I love having the opportunity to connect with other families going through similar struggles in the area and the parents with more experience have already passed along information that I probably would have missed out on had I not been a part of this group. It gives me an outlet to release my frustrations and we keep each other accountable by checking in on our weekly "self care" goals... something that is often forgotten when dealing with a disabled little one! The Momma's and Poppa's Connection has given me more knowledge of the complex system and the confidence to advocate for my little Warrior!

Also these are our social media pages sharing his journey if anyone wants to follow 😊 It's sort of my therapeutic way of getting information to our families and friends as well as spreading the word about his super rare genetic mutation to anyone who wants to listen!

facebook.com/wilsonthewarrior

https://www.instagram.com/wilson_the_warrior/