



September 13, 2010 – the day our first-born daughter, Hanna, turned 4 months old. What happened that day would forever alter our outlook on life.

At 1:30 a.m., I hear my wife Bre screaming my name. I ran to Hanna's room to find my wife holding our daughter who was nonresponsive and barely breathing. I remember the fear that overwhelmed me at that moment. When we arrived to the ER, they were able to get Hanna stable enough to life-flight her to Amarillo. At the hospital in Amarillo, they ran CT scans, chest x-rays, EKG's and EEG's, but no answers.

It was eventually suggested that we see a neurologist. But even after that visit, and more tests, there were still no medical answers and we weren't sure what to do or where to go next. But we did what we knew to do - and that's pray. Within hours of us praying that prayer, my father called me and said "Why don't you bring Hanna to Austin? We have a top-notch children's hospital and I'll pay for the moving expenses. Find a job when you get here, it's Austin. It's a big town, you'll find something." On November 11, 2010, Hanna's 6th month birthday, we packed up the family, and on faith moved to Austin.

At Hanna's six-month checkup, the pediatrician decided to give Hanna a partial set of vaccinations given the history around her 4 month checkup. We waited to see if Hanna would have a reaction. She did not, so we were released to go home. By 5 o'clock that evening, Hanna was still doing great so we decided to go out and get some groceries. We were almost done shopping when Bre saw Hanna's arm flinch. Then it happened again. We started making our way to the front of the store when.....I saw my daughter begin to seize. I picked her up out of the shopping cart and made my way outside. Holding Hanna in one arm and my phone in the other as I called 9-1-1. Bre was right beside me calling the pediatrician to inform her of what was going on. **Hanna seized for 45 minutes that day.**

The on-call neurologist diagnosed Hanna with idiopathic epilepsy – meaning seizures from an unidentified cause. She told us that most kids have seizures when they are little and grow out of them by the time they are in high school. Some of our questions from the September episode were being answered, and it was more than likely a seizure. This is when Hanna was prescribed her first anticonvulsant. But the medicine did not help, and her situation progressively worsened. A couple of weeks went by, and Hanna began to have more seizures and more often. She would have multiple seizures in a day. She spent five of the seven days before Christmas in the hospital. She had a seizure opening gifts Christmas morning. She would have another a couple of days later, and then again on New Year's Eve. After the New Year's seizure, her neurologist placed her on a new anticonvulsant.

Hanna would go a little over a month before her next seizure. We thought it was from the medication change, and so did her neurologist. He added a 2nd anticonvulsant to her daily medication plan and asked us "Do you want to do genetic testing?" Without hesitation, we both agreed.



Then came another very significant day in our journey - April 25, 2011 – the date we received Hanna’s genetic test results. Her neurologist began explaining about the genetic mutation that Hanna had been tested for, the SCN1A gene. His facial expression changed from non-expressive to concerned. That’s when I knew - Hanna tested positive for the genetic mutation. The neurologist began to tell us how he believes Hanna has Dravet Syndrome. He explained to us the devastating prognosis, and that a child with Dravet is expected between two and four years of age to have a seizure that could cause regression in speech, mobility, and fine motor skills. As any parent would be, we were heartbroken for our daughter, but she now needed us to be strong for her. Her neurologist agreed with us that being proactive with therapies could increase her chances of being "above the curve" in case the regression was to come.

Two weeks after receiving the diagnosis, Hanna turned one. She is now four and a half years old. She has been in and out of the hospital several times since her diagnosis. At one point, Hanna was on three anticonvulsants and still having multiple seizures a week. That’s when we started her on the Ketogenic Diet, and also around the same time we saw Dr. Sanjay Gupta's documentary "Weed" on CNN. We contemplated moving to Colorado just so Hanna could receive CBD oil for treatment of her seizures because Hanna has had serious reactions to the medications she has received. One drug increased her seizure activity. Another drug made her violent and aggressive. And another caused facial edema and hair loss. And the list goes on. She's had to take and currently taking meds and supplements to counter side effects of the anticonvulsant medications.

Lawmakers of Texas, I urge you to not just consider making CBD oil legal in Texas, but to actually make it legal in Texas to where those that need it can actually receive the treatment they so desperately deserve.

Please, do right by our children... you would if they were yours!