C.A.F.E. TEXAS Compassionate Access for Epilepsy

Marley

Marley entered the world on December 15, 2010. The first 6 months were full of joy as we watched our little one grow and develop. She was our perfect, awaited blessing! June 15, 2011, hours after Marley's 6 month immunizations, is the day our world changed inevitably. Marley awoke from a nap with a cry we had never heard before. We went to her crib and her left arm and leg were jerking in a rhythmic motion. This continued for 40 minutes and stopped with medication after an ambulance ride to our local emergency room. The following day we were discharged. Although Marley's temperature only reached 99.5, we were told it was most likely a febrile seizure. We held on to hopes this was true and life would return to normal.

Things were mostly normal until Marley seized again 3 months later with the onset of a virus, again no real fever, but we were told it was most likely a febrile seizure and sent home. The months that followed were a blur. They were filled with multiple generalized tonic clonic seizures- many involving ear infections and never any answers. We endured countless ambulance rides, ER visits and hospital stays. We requested a 2nd opinion and when Marley was 13 months old, we drove 5 hours to see a new neurologist. We felt encouraged at this visit, the word "epilepsy" was finally used, but we were told that Marley would most likely outgrow the seizures related to how well she was doing developmentally. She continued right on track with her peers, even more active than most. At 15 months old, while playing outside with her cousins, Marley froze in place and stared off, followed by eye/facial twitching. These focal seizures continued over the next few months triggered while playing from overstimulation. Life continued this way with frequent seizures. We sought answers, but all labs, EEG's, and scans were always normal.

When Marley was 22 months old, we relocated after my husband and I both felt the urge that something big was ahead for us. We had no idea that something BIG would be Dravet syndrome. After meeting a 3rd neurologist, we finally had hope for answers and possible treatment. In April 2013, when Marley was 2 years old, we received confirmation of the diagnosis of Dravet syndrome. With changes in medication, once diagnosed, we were able to gain control of the focal and partial complex seizures. Marley is now 4 years old and we continue to face tonic clonic seizures and have seen myoclonic seizures. Marley's seizures are triggered by any sudden change in temperature (increase or decrease), overexcitement, and illness/fever. Birthday parties, family gatherings, parks- these are all things that trigger seizures for Marley. In her 4 years of life, Marley has tried 5 different daily anti-seizure medications. She is currently on 2 medications daily- Onfi and Depakote. Dravet syndrome is an intractable form of epilepsy, and unfortunately our options are extremely limited. Marley and other children like her deserve the opportunity to live. She has taught us so much about hope and joy despite the adversities she faces.

We will continue to do all we can to ensure the best life possible for our little girl!