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

Elliot

Shortly before Elliot's second birthday, he began having strange clusters of "jerks" where his arms popped up and head dropped. Early on epilepsy was confirmed by an EEG followed by our first trip (and certainly not last) to Dell Children's Medical Center in Austin for a full workup. We had so very much to learn about this devastating disease – we had no idea we had just embarked on a journey of adjusting our lives, minds, and expectations to having a child with a catastrophic form of epilepsy and special needs.

As the summer of 2012 went by Elliot's speech development halted, he stumbled and tripped, had behavioral outbursts, and the seizure clusters continued. When we returned from that vacation that summer, we went in for a 24 hour video EEG confirming epileptic encephalopathy and were put on Depakote. At this point, 2 drugs had already failed us. Shortly after this, Elliot was dismissed from his typical preschool and our days were filled with seizure tracking, research, and early intervention therapies. By the fall of 2012 we started the Ketogenic Diet and Onfi and seemed to get some early relief, which soon faded. Elliot was having 10-12 clusters a day often totaling 80 seizures. We continued to search for a diagnosis and answers.

Early in 2013 we saw a worldwide specialist who suggested Elliot may have Progressive Myoclonic Epilepsy; these forms of epilepsy result in progressive decline, losing all faculties including the ability to walk, talk, see … and end in early death. In order to confirm this, Elliot underwent an extensive genetic test called the Whole Exome Sequence. Thankfully this ruled out a Progressive Myoclonic Epilepsy, but left us with little to go on except that he had a marker that has been connected to Idiopathic Generalized Epilepsy. And the search for answers continued.

Eight months after the beginning of seizures, a Vagal Nerve Stimulator was placed in our little 2.5 year old, additional EEGs confirmed background slowing in his brain, and we continued with unending diet modifications. Continuing our search for a diagnosis and cure, we travelled across the country with our near catatonic child. At this point, he was wearing a helmet as protection from head drops and from the head banging that he used to express himself. Elliot was covered in bruises. He no longer said "Mama" or "Dada", touched toys, or made eye contact. The local school district assessed our nearly 3 year old child at a 5 month cognitive level. This specialist took one look at him and called his seizures 'spasms' as in Infantile Spasms. Though the time of onset did not match a typical Infantile Spasms case (they usually present between 4-8 months), Elliot's presentation seemed to correlate with Epileptic Spasms, an atypical version of IS. A month later she reviewed all 3 of his overnight EEG's and caught a signature pattern that correlates to spasms. We began appropriate treatment immediately and were able to gain control of his seizures with Sabril. His last spasm was on his 3rd birthday, at which point he began to regain speech, energy, life – and for the first time in over a year we began to see the Elliot Beall we knew had been arrested by seizures.

Sadly, during the careful wean of one of the 3 drugs he was on at the time, the spasms returned in November 2014. We had 16 months of progress and close monitoring, and now find ourselves back in the midst of searching for answers. We believe that one of those answers could be high CBD/low THC medication. With miracle cases coming out of Colorado and nationwide, it is impossible to deny that there is medicinal value and that children in Texas should have their chance at health and progress as well – without horrendous side effects. Pharmaceuticals that Elliot is or has been prescribed can incur cognitive delay, peripheral vision blindness, sleeplessness, adverse behavioral effects, gross motor impairment – the list goes on. Please consider Elliot and all of the other little Texans and their families dealing with this tyrant of a disease on a daily basis. We are always watching and waiting for the next seizure. Please give us the opportunity to hope.

Compassionate Access for Epilepsy (CAFE) is a project of the Epilepsy Foundation Texas affiliates. CAFE Texas brings together Texans and nonprofit organizations that support the therapeutic use of cannabidiol (CBD), a non-psychoactive component of cannabis, to treat epilepsy. For more information visit www.cafetx.org