



My name is Kevin Clark. I have 3 daughters. My middle daughter Mackenzie Clark contracted viral encephalitis in 2003 when she was 9 years old. Up to this point in Mackenzie's life was that of a normal child physically and intellectually. She was physically fit. She was my tomboy. I had coached her for 5 years in soccer, she played on a basketball team, t-ball, rock climbed. She was in great shape. Kenzie had been tested at school that year for advance classes, and had been accepted. In late spring of 2003 going into the last week of school Kenzie came down with a fever. We took her to the doctor 3 times that week. The doctor tested Kenzie for Strep and it was negative. She said it was a virus and would have to run its course, and it did.

On May, 23rd 2003 I received a call at work stating that Kenzie was headed towards Cook Children's hospital. She had a seizure and an ambulance was called. When I arrived at the ER the doctors quickly ran multiple tests, ruling out most common causes. Kenzie was finally diagnosed with Viral Encephalitis. Kenzie was hospitalized for 105 days. She was placed in a medicated coma for 40 days. Finally, Kenzie was given high doses of phenobarbital to get her out of a coma. She also had a Vagal Nerve Stimulator implanted in hopes it would help to control the seizures the medications did not. The medications and the VNS together controlled her seizures enough for her to be discharged. This was after 2 months of rehabilitation. However, she wasn't seizure free.

For the last 10 years Kenzie has been on just about every anti-seizure medication. Those medications have caused all different types of side effects. Behavior problems, hair loss, weight gain, nausea, insomnia, extreme exhaustion. When she entered middle school, bad behavior really started to cause problems. Eventually, Kenzie was also seen by a psychiatrist, and so, we started down a different road dealing with psychiatric medications and their side effects. Today Kenzie is 20 years old. Her seizures are still not fully under control. She has on average 50 to 150 a month. She is on three seizures medications (lamictal, Keppra, Onfi) and one psych med (Geodon). The level of seizure control has been up and down over the last 10 years. We believe that the behavior is a side effect from the seizure medications. Our hope is to one day wean Kenzie from all of the medications, so that we can see who she really is.

Kenzie has many risks with refractory epilepsy. Here is a list of ones she has experienced; severely burned hand due to hot food (had a seizure while we wasn't watching. It only took a few seconds for her hand to drop in hot soup. This was early on after the 2003 hospital stay. We learned not to put hot food around her). She has had many drop seizures (no broken bones yet), going into status from missing one single medication (she takes 16 pills a day), had thousands of seizures in her sleep (possibly suffocate if the seizure was long enough, and turned her face into the pillow). The side effects of behavior has created other problems; Kenzie was not allowed in public school because of angry outbursts, she has attempted to run away more times than I can count, she has jumped in our swimming pool multiple times in the dead of winter, police have been called and have restrained her because of violent hitting and kicking, she spent a week in JPS psychiatric floor.

What has epilepsy cost Kenzie. Friends, she has one her age that knew her before she got sick. Future, she is fully dependent on us for food, shelter, protection. She will most likely never have a job, get married, or have children. Her biggest love before getting sick was sports. It still is, however, any physical activity triggers a seizure.

In February of this year (2014) Kenzie was hospitalized for 13 days with uncontrolled seizures at Cook Children's of Fort Worth. In April she was in the hospital again as a result of stomach ulcers that were caused by the blood thinner she was on. When Kenzie left the hospital in February the seizures were under better control, but like the last 11 years, never full control (average 50 to 150 per month). She came home with a blood clot in her left leg, which required shots for 3 months. The medications just aren't working for Kenzie. As a parent I'm simply looking for the best non-invasive treatment for my child.

We have watched Kenzie live this nightmare for 10 years, and for 10 years we have heard our daughter make statements that she just wants to die and go to heaven. Cannabidiol (CBD) is Kenzie's best hope for a future.