

Haley Smith

White

Stone, VA 22578

"She has gone from just existing to really living!"

My name is Haley Smith and I am 17 years old, my favorite things are firefighters, the Wiggles, the color purple, and Barney...and my daddy. I had my first seizure at 5 months of age. It lasted over 25 minutes. My second seizure was over 45 minutes. Both required IV rescue with Ativan to stop the seizures. My mommy and daddy were very scared.

My first neurologist, Dr. Ralph Northam (Now Governor of Virginia) diagnosed me with "idiopathic epilepsy". He said jokingly that was because "they were idiots and did not know what I had". He did not want to prescribe daily pharmaceuticals to me as a infant/toddler because he thought ***it would impede my brain development and ability to learn.*** He even thought I would outgrow my epilepsy. I continued to develop normally, if not ahead of my peers. By the time I was two I knew all my colors and shapes and could sing my ABC's. I could even write my name. However, when I turned two my seizures picked up in frequency and my mom was pregnant with twins. She requested at that time to put me on something to stop the seizures.

Since I did not have a diagnosis the doctors guessed at what might work. Some medicines made me lose my ability to talk, some made me fall down and I was covered in bruises, one even caused me to have more seizures and sent me to the ER or to be hospitalized every week from January to April in 2005. By the time I turned 5, I had tried and failed 13 different pharmaceuticals and combinations of them. Mommy read that **once you fail three epilepsy drugs the likelihood of the next one working is less than 1%**. So we went to Johns Hopkins to try medical diets, but I was on sodium-channel blocker drugs that caused me to have more seizures.

At five I went to a new doctor, Dr. Jack Pellock, who was really smart. He tried more combinations of medications. Two years later, I was diagnosed at 7 years old with Dravet syndrome, a severe and catastrophic form of epilepsy. It came as a relief to my mommy and daddy because we had a name. My seizures have ranged from being only a few seconds long up to almost an hour long. I have had as few as one in a day and up to 30 grand mal seizures in one day. My seizures had taken a toll on the family. My mommy could no longer work. My brothers never had two parents at any of their sporting events. Mommy and Daddy have never been away from me overnight in my entire life. My seizures affected the whole family.

When I reached my teen years I was averaging about 300 Grand Mal seizures a year. I had tried and failed 17 different pharmaceuticals and combinations of them. In 2013 I had surgery to implant a medical device, a Vagus Nerve Stimulator (VNS), in my body. It works like a pacemaker for the brain. That seemed to help a little. However in 2014 my seizures more than doubled. **I had over 1023 grand mal seizures despite being on three pharmaceuticals and having the VNS.** All I did during these years was sleep about 16-18 hours a day. I had no fun...That year my neurologist at VCU told my mom that there was **NOTHING LEFT** for me to try, and IF he was free from prosecution at the state and federal level, he **would** prescribe CBD oil for my condition. We were encouraged because the Epidiolex trial was supposed to start at my hospital,

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VCU, in the late Fall or Winter of 2014. My medical team told my mommy that there was red tape to get through and the study was delayed. That was when my mommy got together with other moms and decided to take matters into their own hands. My old Neurologist, Dr. Northam, was now the Lt. Governor and he encouraged my mommy to fight for access to CBD oil for me and kids like me.

In 2015 my mommy and I changed a lot minds in VA and we changed a law in Virginia. I started CBD oil in March of 2015 and immediately was able to stay awake all day. My neurologist had thought my pharmaceuticals were making me so lethargic, but he then said perhaps it was probably my brain shutting down to recover from all the seizures. He went on to say that **the oil was definitely doing something**. I was able to lower some of my normal medications and my whole family's life got better. We did more things together and mommy and daddy are not as stressed.

My parents, therapist, teachers, and friends have all seen great cognitive advances in my development, and **my seizures are down by about 50%**. Mommy and my pediatrician both say I am meeting "milestones" that I should have met in my younger years. **Over all my quality of life and my family's life is much improved**. Because I have been doing so well, my mom and dad even took my brothers and me on a Disney Cruise for Christmas!

When I was first diagnosed with Dravet syndrome, none of my medical treatment team outside my neurologist had heard of it. My mom had to spend a lot of time educating herself in order to educate those taking care of me. When I would end up in the ER, the doctors thought she was a nurse...but she's just my mom. I am glad that lack of knowledge is changing. Due to this study there has been an increased awareness of my condition. Approving the medication will also continue to raise awareness of Dravet syndrome and help other little kids get diagnosed in a timely manner.