

# Haley M. Smith

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My name is Haley Smith and I am 16 years old, but I function at the level of a 3-5 year old. I have had seizures since I was 5 months old. My parents took me to all the top doctors on the East coast, but no one was able to diagnose me properly until I was 7 **years** old. After 6 1/2 years, over 17 different pharmaceuticals and combinations of them, and two medical diets it was found that I suffer from a rare and catastrophic form of epilepsy called Dravet syndrome (*pronounced Dra-vay*). There is no known cure for Dravet and not even an accepted treatment. Every year the seizure count increased into the hundreds of seizures limiting my life and that of my family. At the age of 13, I had tried nearly every drug available, I had a medical device implanted (Vagus Nerve Stimulator, VNS, which works like a pacemaker to the brain), and still there was no relief from the relentless seizures. At this point in my life I slept about 16 hours a day and while I slept I continued to have seizures. When I woke up I would stop. There were other “off-label” drugs that I could try, but with epilepsy after three failed drugs the chance of the next one working **is less than 0.1%**

In 2014 my seizure count was well over 1,000 seizures a year! My neurologist announced there was nothing left and that *if he would not be prosecuted* at the state and federal level he would prescribe cannabis as a viable treatment for me. My mom took that statement to heart and in 2015 she worked along side other parents to change the law in Virginia that would allow an affirmative defense for possession of CBD and THC-A oil. I started on CBD oil in March 2015 and the results were immediate, my seizures decreased by 40-50% and I was able to stay awake all day. When we returned to my neurologist after being on the oil for a few months and we had not touched the pharmaceutical, he said it is “obviously doing something! We thought that the pharmaceuticals were causing all the lethargy, but it probably was subclinical seizures and her brain just needed to rest. But the sleep brought on more seizures...”. We have since been able to lower two of her pharmaceuticals and completely removed a third.

The lowered seizures count has been great, but the biggest bonus is my cognitive gains. I am now able to learn! I have give and take conversations vs. speaking in set phrases. I remember people I’ve met and places I have been, and ask about them when I am not there. I am meeting developmental milestones that I should have hit in my toddler years. **Basically I have gone from merely existing to truly living.** You can see the difference in my eyes in the picture above. My “Mimi” and many of my teachers and therapists all echo that I am “more present”. I still have almost daily seizures, but my life is so much better!

Despite all these positive effects, my parents live with the fear of federal prosecution. My mom and dad are small business owners and I have brothers who are twins. My parents worry losing custody of us and all they have worked for. Congressman Garrett’s Bill HR 1227 will address these worries. We support legislation that will help to provide appropriate access to this life-saving treatment. With these regulations in place, further research can be done. As more accepted research is performed our doctors can have more input on our daughter’s care and we can work as a team. We thank all the legislators who have joined to help us in this fight to help save other families like mine!