

At 7 months old, our daughter, Charlotte, had her first seizure. It was 35 minutes long, and many more would follow suit. By 10 months old, Charlotte was diagnosed with an SCN1A sodium channel deletion, aka Dravet Syndrome.

Since Charlotte was diagnosed earlier than most at this age with this syndrome, her family and Epileptologist decided to start off with the anti-epileptic drugs that had the best success for other kids with Dravet Syndrome. Weaning off and back on drugs aren't fun, and knowing early about her syndrome meant that she could avoid drug changes for as long as possible. While this was a great decision for her, it ended up not helping me out very much when the Carly's Law trial began. Charlotte did not qualify for the FDA testing requirements because she had not failed 3 anti-epileptic drugs.

With the passage of Leni's Law in May of 2016, Charlotte could try cannabinoid therapy to see if it would help reduce some of her seizures. Her family, community, and medical team supported the decision for Charlotte to try this therapy.

In April of 2018, Charlotte was accepted into a clinical trial in Atlanta, Georgia to study the effects of artisan CBD oils when combined with a new seizure medication for Dravet Syndrome. This trial is one of the last before the FDA's stamp of approval. Charlotte was able to take advantage of this FDA trial opportunity because of her use of CBD oils and the laws in our home state allowing us to use cannabis oils. As of this day, Charlotte has had only 2 Grand Mal, tonic-clonic generalized seizures since beginning the trial in April 2018.

Before cannabis oils, our family never left the house. If we weren't recovering from a seizure, we were waiting on the next one to pass. Charlotte was sensitive to everything. Here I was with a toddler who couldn't play outside for fear she would overheat and seize. I had a little girl who couldn't swim because she couldn't be allowed in water because it would cause a seizure. Charlotte couldn't even bathe without seizing in the bathtub.

Today we swim, go camping, play on the playground, ride bikes, play in the sprinkler, go roller skating, bathe, and she loves attending birthday parties.

Our entire family got their life back!

Sincerely,

Gena Dalton, mom to Charlotte (age 6)  
Madison, Alabama



Note: In the picture on the left, Charlotte is on pharmaceutical drugs alone, and she is fully awake & not sleeping in this picture even though it would appear she is. This is just how her medications affected her life. In the picture on the right, she is taking both pharmaceuticals and low THC CBD oil, and she is in an FDA trial.