



Compassionate
Access for Epilepsy

Caeden

As a parent, anything that harms your child is scary. Not understanding what harms your child is nearly twice as scary. Without a name, you can't begin to sort how to fix it. Our son's name is Caeden. He was diagnosed with Dravet's Syndrome at the age 1 ½ years old, almost a year after he began having seizures as a 9 month old.

In 2008, Caeden was playing, and it was as if someone suddenly turned out the lights in his mind. He stared off in the distance, not responding to his mom's voice or physical contact. Then he fell over, and wouldn't be responsive again for minutes. He began to turn blue, and we found ourselves in a nightmare of sorts. Something had a hold of our child, and we didn't understand what it was. And this was the first of many such nightmares. Caeden's seizures occurred regularly, were tough to treat, and were presented in a number of different ways confused our doctors.

In 2008, Caeden had a seizure that lasted well over an hour. At this point in a seizure, the brain is akin to an engine running at redline with no oil. Damage occurs. And for children at this stage of 'status', the options are extreme amounts of anti-seizure drugs, or an induced coma. Luckily, the doctors were able to bring him out without inducing a coma. But it was a close call. During our 10-day stay at ICU, Caeden's neurologist finally had enough clues to diagnose him with Dravet's. We finally had a target. But despite that target, the doctors couldn't give us answers on treatment protocols, short and long term impact, or mortality.

Thanks to a tireless neurologist, Caeden has survived 7 years so far. We have tried every anti-epileptic drug combo on the market, including those we had to import from France and Mexico. Finally settling on a domestic cocktail, we now have a fair amount of control over seizures. But we do not have control of the punishment his body and his brain endure from the 38 cc's (10 vials, 1.3 fl oz) of drugs we have to give him each day.

Caeden is significantly delayed in speech, motor, and cognitive reasoning. This is largely in part to the fact that he is intoxicated on a mix of Topamax, Depakote, and Onfi. Topamax, nicknamed "Dopamax", is great for seizure control, but debilitating for someone trying to learn, or talk, or concentrate. And it's a mental jail that Caeden is forced to live with unless other treatments can be tested.

CBD represents an option that is working for others like Caeden. And despite 15 years as a Texas family, and despite a thriving career in Dallas, we are forced to consider uprooting to Colorado, Missouri, or Florida so progressive medicine can even be <tested> on our child.

For a state that prides itself on freedom and independence, Texas's stance on CBD is shocking. We are among 100,000 residents, mostly conservative, who are being told that our children can only find hope in other states. For those who don't have seizure control, Texas's laws loudly prefer extreme medical expenses and lifelong physical debilitations – even death – in favor of a known treatment that is accepted in several states around the country.

Research and education have been pivotal in recovering Caeden's quality and length of life. And it is because of the Dravet Syndrome Foundation and its families that our children are finding better care and more life options than ever before. We are now asking the State of Texas to join the cause for our child, and to enable the thousands of other Dravet families whose lives you are entrusted to protect.

Thank you for making a tangible difference in our lives. Support C.A.F.E. Texas.

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