



# Zachariah

My name is Leslie, and I am the mom of twenty-four-year-old Zachariah, who has Dravet Syndrome. I am writing to tell you a little about Zach's life in the hope you will support legalizing cannabidiol (CBD) as a therapeutic treatment for intractable epilepsy.

Zach started having seizures at the age of two months. A few hours after he came home from getting his first round of shots, he had his first seizure, which lasted thirty minutes. We called 911, and he had another thirty-minute seizure on the way to the hospital and another at the hospital. We were told that the seizures had been caused by a fever, and Zach was sent home the next day.

This was the beginning of the journey that is still going on twenty-four years later. We have made many 911 calls over the years, one event that even resulted in air flight and Zach being put into a medical coma. He has had every kind of test over the years trying to find out why he has seizures. When Zach was twenty years old, we found the answer: Dravet Syndrome.

His longest seizure to date lasted more than nine hours, and he has many different kinds of seizures. Over the years, his doctors have tried numerous medications, vagus nerve stimulation (VNS), medical diets, and even brain surgery to try to help him. Many of the medications made him have even more seizures with awful side effects.

The brain surgery stopped his seizures for 36 blessed days. Some of these treatments have helped to a degree, but he has never gone more than six months of his life without a seizure. He is at a very high risk for sudden unexpected death in epilepsy (SUDEP), and each time he has one of his larger seizures, he still needs emergency medication to stop them. He needs large doses of emergency medication as often as six times a month in addition to three medications he takes daily. He also follows the ketogenic diet. At this time, we are without any other options.

Zach is a very loving young man who just wants a chance at a life without seizures. He has waited almost twenty-five years for an effective treatment.