



Jacob's epilepsy began at 3 months old and, we suspect, possibly in vitro. Initially, Jacob would only have a seizure once every 3 to 4 months. As time went on, Jacob's seizures increased in duration from 3 minutes to 7, 10, up to 44 minutes, as well as clusters of seizures occurred despite giving him Clonazepam and Diastat. At one time Jacob was on a combination of 7 seizure drugs. He suffers from frequent respiratory infections, which lowers his seizure threshold. We had Jacob on the Ketogenic Diet for 16 months starting at the age of 4. Although it did not stop his seizures, his cognitive condition improved. Eventually we had to take Jacob off the diet because it complicated his care. At the age of 6, we tried the Vagal Nerve Stimulator (VNS) after he continued to fail approximately 10 drugs. This was one of our last possibilities for help. This also failed, even though we continue to scan the VNS at every seizure.

We have taken Jacob to Boston Children's, Dallas Children's, Texas Children's and Cook Children's to try and find help.

At this time Jacob is on a combination of Onfi, Felbatol, Klonopin, Stiripentol (from France) and Diastat. Jacob is 8 years old today, but functions as a 2-3 year old. He seldom goes a day without at least 1 grand-mal seizure, but most of the time he averages at least 5 seizures per day. We use his seizure rescue medication (Diastat) sometimes 3 times a week for seizures that won't otherwise stop.

We pray everyday for the miracle that will free Jacob from this life threatening life limiting Dravet Syndrome.