C.A.F.E. TEXAS
Compassionate Access for Epilepsy

Travis

Travis was born a perfectly normal and beautiful baby boy on December 3, 1998. He was about 6 weeks premature, but otherwise his beginning was uneventful. He developed fine and met his normal milestones. Then, at 18 months old, everything in our world changed dramatically--he had his first Grand Mal or Tonic Clonic seizure. About 3 months later he had another one and then a third one. He was started on anti-seizure medications before the age of 2, but they had little to no effect on him. His seizures persisted and after many medications and combinations of meds, he had surgery to implant a Vagus Nerve Stimulator. He was only 4 years old. A VNS device is much like a pacemaker, but it is for the brain. It delivers an electrical stimulation to Travis' brain on regular intervals to help control the seizures. This worked for a short while and then the seizures returned and with a vengeance. He started having seizures every 3-5 days and sometimes multiple seizures in a day. One time he had 14 grand mal seizures in a little over 24 hours.

In an effort to explore other options, I contacted the wonderful staff at Children's Memorial Hermann Hospital. They were very proactive and started testing Travis immediately for other treatment options. Travis was admitted to the hospital and it was discovered rather quickly that Travis' original diagnosis was not completely correct and diagnosed him with a condition known as Myoclonic Astatic Epilepsy (Doose Syndrome) and later diagnosed with Dravet Syndrome, a severe and often progressive disorder.

This diagnosis was confirmed with a series of blood tests since it is a genetic disorder. During his hospital stay, it was also found that Travis' high blood pressure problems, that had been dismissed as a side effect of his medicines, was actually due to a congenital heart abnormality. He had what is known as a Coarctation of the Aorta ~ or a narrowing of the Aorta. On February 11, 2008 Travis had Balloon Angioplasty to repair the Aorta malformation, and on February 28, 2008 he had another surgery to replace his worn out VNS device, since the device was working at such a high level to unsuccessfully control his seizures.

As his seizures persisted unrelentingly, it was decided Travis needed to have a Corpus Callosotomy, or split brain surgery, to sever the Corpus Callosum which is the connective tissue between the right and left hemispheres of his brain, in order to keep the seizures on one side of the brain or the other. This surgery was performed on May 8, 2008. Even so, he had a grand mal or Tonic Clonic seizure within 24 hours after the surgery. Also due to the surgery, Travis suffered what is known as Disconnection Syndrome and had to undergo intense physical therapy in order to walk and even talk again. It was a busy, trying time for all of us.

Unfortunately, once again, his seizures returned and at an alarming rate. Travis underwent another series of testing at Children's Memorial Hermann Hospital, and on January 20, 2010 had brain surgery to implant EEG leads directly on his brain. The results of these test led to a partial Lobectomy and Travis had resection brain surgery of his left temporal lobe, frontal lobe and removal of his Amygdala on January 25, 2010...again to try to decrease the frequency of his seizures and give him a better quality of life. However, his seizures returned almost immediately, and today he suffers almost daily Tonic Clonic (grand mal) seizures, often having multiple seizures in a single day despite multiple medications with debilitating side effects.

He is confined to wearing a protective helmet anytime he is up an moving to ensure his safety. Developmentally, Travis is only about a 4 year old little boy and his academic skills are limited to a preschool level due to the thousands of seizures he has had. His delayed fine and gross motor skills limit him tremendously. He needs help performing the easiest tasks. Even so, his smile is ever present and his love for others is unforgettable.

To this day, traditional medications, surgeries and treatment options have failed my sweet Travis. Without the support of our State and the use of CBD Oil as an option, there is little Hope. Unlike traditional medications, CBD oil is all natural and has no debilitating side effects. The results that others have experienced are nothing short of miraculous. My son, as well as many others who suffer from epilepsy, deserve the right to CBD oil as a treatment option if their doctor determines it to be appropriate.

One might think that the constant, daily care for a child like Travis is overwhelming not to mention what he endures. Yes, it is very difficult and sometimes it does take its toll on the entire family. However, in my heart, I truly believe that Travis is a gift from God and he is perfect in every way. I believe Travis was given to our family to care for while he is on Earth to do God's will. He is wonderful and doesn't make mistakes. People tell me all the time how Travis has touched their lives and every time I hear things like that I know that God is in control.

We continue the fight and pray that one day we will win!! We might get down, but we will never be defeated!

~ Travis' Mommy