



My daughter is Kaia Page. Kaia was born on July 10, 2002 and was developing as expected until Dec 11, 2002. On this day, I was giving her a bath and I noticed her "shivering." I thought she was cold, so I finished quickly and got her out, dried her off, but the shivering didn't stop. I checked and saw her eyes were zig-zagging from right to left very rapidly. I recognized this was a seizure, and yelled for my son to call 911. Waiting for EMS to arrive, the whole time she was shaking, and it seemed like forever. This was her first seizure and her first ride in the ambulance, but sadly, it wouldn't be the last of either one. We traveled to Christus Santa Rosa Children's Hospital (little did I know we would soon be spending many days/nights there) where she was subjected to countless tests, scans, even a spinal tap. All the tests came back negative. A neurologist came to visit us and prescribed her the first of the many, many anticonvulsant medications she would try, all of which have failed to help control her seizures. We went home, only to return a week later. More tests, no answers. "Let's try another med" is the phrase I've been hearing for 12 years now.

Her seizures developed a pattern. She would go 3 weeks, almost to the day, and then she would cluster for about a week. So, like clockwork, every 3 weeks she was spending a week in the hospital. All the while, Kaia was having speech, physical, and occupational therapy to try to stop the regression beginning in her development. One of the times she was hospitalized she had an adverse reaction to one of the new meds the doctor wanted to try. A nurse gave Kaia Benadryl IV, and Kaia immediately arched her back, then stiffened up, and turned blue and started to seize. She seized for an hour, and had to be intubated. During this hospital stay, they also discovered that Kaia's meds were cancelling themselves out. So we started giving the meds separately, and sure enough, her levels slowly started to rise. She remained in the hospital until the meds were at a therapeutic level, then we went home. By this time, our neurologist was at a loss. He had done EEGs, tried several meds and ran every test he thought necessary. He thought it would be to our benefit to see an epileptologist. Our new doctor admitted Kaia and did a week long video EEG. This, along with the many, many more EEG's she would have in the future, showed there was no focal point - meaning that her seizures were originating from all over her brain. These results meant that the seizures would be challenging to treat with medication, and that surgery would probably not be an option. Kaia has had MRI's, CAT scans, Ictal scans, Interictal scans, PET scans, and most recently, she had a MEG scan. She had a Vagus Nerve Stimulator (VNS) surgically inserted in August 2004. In October she had a "drop seizure" and fell forward hitting the VNS and got cellulitis. Despite spending a whole month in the hospital receiving the strongest IV antibiotics, Kaia still had to have the VNS surgically removed. The epileptologist decided to refer Kaia to a pediatric neurologist new to San Antonio. This doctor thought we should again try the VNS, so Kaia had another surgery in 2011 and she currently has the VNS. After further research I found a doctor in Austin, and this is her current doctor.

In between all of this, Kaia started school. She had testing done through the school district, and is considered mentally retarded. Kaia did start to talk, but every time she has clusters of seizures, she regresses in her skills. She is currently about to enter the 8th grade and attends a life skills class. She currently takes Onfi, Depakote, and Vimpat on a daily basis. Her rescue med is Diastat 20 mg, rectal suppository. At this time, Kaia's seizure pattern is seizure free for a week, week and a half, then for 3 or 4 days she will seize all night long (most of her seizures are at night). On a typical night she will have 8-12 seizures. She has maybe 15-20 words she uses. She needs help dressing, bathing, eating, walking and is incontinent. She can't really do any outside activities because if she gets too hot it will throw her into a seizure. Her quality of life could be so much better. All I want is a chance for her to live a normal life. Her life is her normal, it's all she knows, but it's not fair. If there is something (CBD oil) that can help improve her quality of life, she deserves to have it! I understand it may not "cure" her, but if it can help at all, without all the side effects that the prescribed medications have, I want her to have the chance to try it. I cannot pick up and move to Colorado as many families have done. I don't think she should have to leave Texas to receive the care she deserves!