



Compassionate
Access for Epilepsy

**Matthew
& Tyler**

Our story begins with my friend Suzy who grew up across the street from us and was my sister's best friend when she began having seizures. We were one of the few places she was allowed to go and be with friends. During, this time, my mother told us that she too had epilepsy as a child but outgrew it. Her parents actually hid her diagnosis from her and she was not told what she had until she was grown and married. Luckily my mom outgrew her epilepsy in her teen years. Sadly, Suzy died from Sudden Unexplained Death in Epilepsy (SUDEP) at age 30 in 2000, from a seizure in her sleep.

1996: Our oldest son, Matthew, was almost four years old when we were given the diagnosis of epilepsy after months of concerns and a grand mal seizure at his daycare. The first medication caused a change in his personality, behavior, for the worse and we decided to wean him off of it because it was so terrible. Matthew would have 2-3 grand mal seizures per year. In 2011, after being seizure free for a year, we allowed Matthew to go on a student ambassador trip to Greece and Italy the summer after he graduated high school. We got the awful call that he had a seizure on the beach in Crete, Greece. He finished the 3 week trip despite the setback. He is on 2 medications now and has been seizure free since October 2013.

2002: Our son, Tyler, at age 4, was diagnosed with petit mal seizures/epilepsy. Those are the blank staring spells that can last seconds. I thought "those are the easy kind". Wrong. He was having hundreds per day which affected his learning. He did not learn to read until 3rd grade.

2011: At age 12 the grand mal seizures started for Tyler, despite being on medication and having the vagus nerve stimulator implant which was implanted two months after his first grand mal seizure. Tyler's seizures are considered intractable epilepsy (not controlled by medication). We have swiped the magnet over his implant, thinking that stopped the seizure, then only to realize he has stopped breathing completely, and in that awful moment have had to start CPR on our own child with his older brother looking on in disbelief.

Both boys have lost friends to seizures whom they met at Camp Spike and Wave (camp for kids with epilepsy). Lucas was 8 and Seth was 19. Tyler has had to take a month off from his high school swim team recently due to his seizures being so bad. It is robbing him of what he loves and it breaks my heart. As parents, we strive to allow them to be as independent as possible but it is difficult when safety is also an issue. Matthew, now 22, moved to Austin in February so he can be more independent and use the public transportation system and have more job opportunities. He is living in a housing co-op with other roommates so he is not alone all the time but still not dependent on mom and dad to drive him everywhere. There is no public transportation, not even a taxi, in our town and they cannot drive due to the seizures. Neither of our sons qualify for any public assistance and our out of pocket medical expenses are very high. Bruises, concussions, multiple ER visits, falling behind in school, loss of independence, are just some of the consequences of living with epilepsy.

Living with epilepsy is like waiting for a terrorist to attack. We live with the fear that we could outlive one or both of our sons if more treatment options are not explored and allowed.