

## Jake

Jake was born after a normal 9-month pregnancy and birth. At 9 months of age, he had his first seizure. We had no idea what we were experiencing and little did we know that we were going to be thrown into the world of epilepsy. A brain MRI showed that Jake had a stroke during the pregnancy and the seizures were secondary to the brain damage caused by the stroke. Following a referral to a pediatric neurologist, Jake was started on medication. After a few drug trials, one medication seemed to keep his seizures under control with minimal side effects. We got Jake speech and occupational therapy and enrolled him in early intervention programs and we went about life.



When Jake was 5-years old the first "big one" hit. Jake went into status epilepticus (a medical emergency and a new word in my vocabulary). He was admitted to the PICU where, even with treatment, the seizures lasted more than 3 hours! That was the first of many 911/ambulance/PICU trips to hospital where we got to know the doctors in ER by their first names!

We continued down the medication road, trying various anticonvulsants but to no avail. The drug levels were getting higher and higher, and we added on more drugs to try and find the perfect combination to fight these awful seizures that were beginning to control our lives. We were on a merry-go-round that we wanted to get off and Jake was on a drug rollercoaster.

We didn't go anywhere without Jake's medication bag; it was filled with emergency medication that we would give at the onset of a seizure. We gave the meds orally, rectally and by injection. Sometimes we managed to stop a seizure; other times the drugs didn't dampen the raging brush fire in Jake's brain. We were close to inducing a coma a few times in hospital to stop the status episodes. They became life-threatening events. We had no life. We couldn't travel. Jake slept with us out of fear that one would hit in the night and they did

as always without warning. We spent our lives waiting for the "next one!" I had complete trust in our pediatrician and pediatric neurologist and yet we could not escape the seizures that plagued our lives.

We went for our first evaluation to consider brain surgery in 2002. The recommendation was a total left hemispherectomy (removal of the whole left side of the brain). How could we remove a whole side of our son's brain? Brain surgery was so scary and seemed so radical. There had to be another way. We weren't ready to accept surgery. We chose instead to try the Ketogenic diet. Jake was on the diet for over a year. It did reduce the number of seizures and we were able to back down on some of his medications, but it didn't eliminate the status episodes. We contemplated a vagal nerve stimulator, but we were informed that the likelihood of rendering Jake seizure free was slim.

We opted to get a second opinion on brain surgery at Cleveland Clinic. They had a center with a comprehensive epilepsy monitoring unit and a surgeon who specialized in pediatric epilepsy surgery, Dr William Bingaman. Immediately after meeting this team, we developed confidence in the surgeon and the neurology team. We discussed at length the options for Jake and the potential outcome of surgery. What parent wants to choose which part of their child's brain is going to be removed? Would Jake be the same Jake we knew and loved after this surgery? We had so many questions. At the end of the visit, we felt as comfortable with our decision as one can in such a situation.

The surgery took place when my son was 7-years old. His left occipital and temporal lobes were removed as well as a part of his parietal lobe. It was the hardest thing I have ever had to go through. The surgery took 6 hours and those were the longest 6 hours of my life! We were fortunate that everything went well and 5 days after major brain surgery, we were discharged! Almost immediately we saw a change in Jake. Oh, he was the same Jake with the same personality, sense of humor and memories, but it was like the light bulb had turned on and the fog had lifted. The nasty piece of short circuit wiring was removed from his brain. Jake had not missed a beat, we had removed 2/3 of one side of his brain and he was not only the same child but an improved one!

Jake was free of seizures after surgery for 2 years. We thought we had beaten the odds. However, just after his 2nd year anniversary, we started to see a few seizures. We knew that this was a possibility but it was hard to swallow after all we and Jake had been through. The seizures are mild in comparison to before the surgery and they stop after a few minutes. We still view Jake's surgery as a success. It has given Jake the chance of a more normal life and since surgery, he has come along leaps and bounds both socially and academically and continues to us and everyone around him. He just turned 11 and is growing up into a fine young man.

As hard as it was going through the decision to consent to brain surgery for our child, we don't regret our decision. We realize that we are one of the lucky ones. Many children with intractable epilepsy are not surgery candidates. We are thankful we had the opportunity to do this for our son and he is our hero.



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