

Ending Epilepsy - Brooklyn's Story

For 10-year-old Brooklyn Johnson, her fourth grade school year is coming to an end. She is looking forward to a fun-filled active summer, alongside her parents and little brother Roman. Not that long ago, however, life looked a lot different.

In early 2019, Brooklyn began suffering from uncontrollable seizures. Her seizure activity came in the form of absence seizures, a type of disturbance in the brain that involves staring spells and loss of awareness. It left her family looking for answers.

SOT

Taryn Johnson, Brooklyn's Mom

"It just came out of nowhere, so it was frustrating," recalled Taryn Johnson, Brooklyn's mom. "We couldn't find answers. It was heartbreaking because she couldn't have a normal childhood. It's just like a constant worry. You're always on alert."

Johnson said Brooklyn would seize throughout the day – sometimes up to 20 times in a 24 hour period. She could no longer do simple things on her own like bathing or brushing her teeth, and she was unable to attend school, play with friends, or simply lead a normal life for a kid her age.

SOT

Taryn Johnson, Brooklyn's Mom

"Between her medications and her seizure activity, she was sleeping probably 17-18 hours a day. She didn't really have much of a childhood, because I would always be asking her, 'Are you okay? Are you having a seizure?'"

The Johnsons' search for answers and treatment led them to OSF HealthCare Illinois Neurological Institute's (INI) Epilepsy Center. After rounds of diagnostic testing, it was decided that Brooklyn was a good candidate for surgical intervention for her epilepsy, with an ultimate goal of making her seizure free.

SOT

Dr. Andres Maldonado, OSF HealthCare INI Neurosurgeon

"Without surgical intervention, it is very possible that she would have continued with seizures for the rest of her life."

After an MRI showed two abnormal spots in Brooklyn's brain, Dr. Maldonado moved forward with intra-cranial monitoring.

Intra-cranial monitoring is a procedure that allows surgeons to understand where exactly the seizures are coming from. Using robotic assistance, Dr. Maldonado and the surgical team at INI implanted electrodes into Brooklyn's brain. After the electrodes were implanted, Brooklyn was monitored closely for days.

SOT

Dr. Andres Maldonado, OSF HealthCare INI Neurosurgeon

“We can very accurately tell where the seizure focus is, and then after we find enough data, we gather enough data telling us where those seizures are coming from, we remove the electrodes and the patients can go home the next day.”

After Brooklyn was monitored, it was decided that she was an excellent candidate for surgical intervention.

Surgeons proposed a plan to resection, or remove, the small area of Brooklyn’s brain that contained the abnormal tissue causing her seizures. Both Brooklyn and her mom were cautiously optimistic prior to surgery.

SOT

Brooklyn Johnson, Epilepsy Patient

“It was scary and also exciting because I was going to get my seizures out of my head.”

SOT

Taryn Johnson, Brooklyn’s Mom

“With the reassurance between Dr. Maldonado and the rest of her neurology team, I was very much at ease. They explained in great detail what was going to happen.”

In January of 2020, Brooklyn had a resection of her right temporal lobe. After a three day recovery in the hospital Brooklyn went home, and she has been seizure free since. According to Johnson, it was like getting her daughter back.

SOT

Taryn Johnson, Brooklyn’s Mom

“She has been able to start school again, she has been able to go out and play with her friends, with her brother, and actually have conversations,” smiled Johnson. “Before it was just like yes or no answers. Now she is able to explain how she is feeling, not just with anything going on with her seizures, or no seizures at this point. She is just able to communicate a lot better. She is able to form those thoughts and get them out and talk to us. It’s just been really nice, and it’s like she can be a kid again, and I missed that.”

SOT

Dr. Andres Maldonado, OSF HealthCare INI Neurosurgeon

“That is exactly one of the main goals for this type of procedure, to give them back that opportunity to enjoy their family members in a healthy way, without the suffering of the seizures that epilepsy can cause.”

It takes six months post-surgery with no seizures for a patient to officially be considered seizure free.

While not all epileptic patients are candidates for intra-cranial monitoring or tissue resection, Dr. Maldonado says getting seizures under control, either via medication or surgical intervention is imperative, especially for kids.

SOT

Dr. Andres Maldonado, OSF HealthCare INI Neurosurgeon

“Over time, the number of seizures really has a significant negative impact on the brain function, particularly on the neuropsychological development, especially in kids.”

For those with uncontrollable seizures, there are many surgical treatment options available at OSF Illinois Neurological Institute. To learn more speak to your doctor, or visit INI.org and click on epilepsy.

The OSF INI Epilepsy Center is the only Level 4 facility in Illinois, outside of Chicago. This designation is awarded by the National Association of Epilepsy Centers (NAEC) to facilities that offer cutting-edge comprehensive epilepsy treatments.