



Sammy's Story

Sammy is our 4th son. We wished for our sweet Sammy and on 5/21/10, I gave birth to a beautiful and healthy baby boy. At his 6 week check-up, I was sent to the hospital where it was confirmed Sammy was anemic. 2 weeks later, July 29th, Sammy had his first seizure and had 10 more the very next day.

From that day forward, Sammy has suffered 1000's of seizures and endured different AED's (Anti-Epileptic Drugs) without success. He was diagnosed with cryptogenic Infantile Spasms at 6 months old and put on a medication that could lead to vision loss. We then moved on to daily injections of steroids which didn't work. Our miracle drug was Depakote and we enjoyed 2 whole years with no seizures and clearer EEG's. We had hoped that he would develop and be "normal" like his brothers.

July of 2013, the seizures returned with a vengeance. Sammy was suffering multiple daily seizures which stopped him from being able to attend school and progress. In December of 2013, we took a radical approach. At 3 years old, Sammy had brain surgery in an effort to stop the seizures from attacking his whole brain. Sammy had a full Corpus Callusotomy-we cut his brain in half! Weeks after his surgery, Sammy walked for the first time all by himself! Seizures were greatly minimized and we had our baby back!

Months later, I received a call from our neurologists giving me the results of a genetic test we had done months prior. We were given the news that Sammy had CDKL5-a disorder that effects the protein needed in the brain to develop normally.

At almost 8 years old, Sammy can walk independently but needs close supervision. He can babble, drink with a straw and feed himself with a fork. He is a student at Lincoln Ave. in the PALS program and thriving more than ever being in the Sayville Schools.

While CDKL5 is a devastating disorder, we now have something to chase down and with this seemingly catastrophic diagnosis, we are finding hope. This is our new "normal" and we are learning to never put limits on what Sammy can achieve. With more research, we get closer and closer to the possibility of healing our baby, of finding a cure for CDKL5, of helping him live a long and healthy life. Please consider attending our 3rd Annual fundraiser: Sayville Supports Sammy Sands April 27, 2018 at Lands End in Sayville. **ALL PROCEEDS GO DIRECTLY TO IFCR-International Foundation for CDKL5 Research to help find a cure. A cure is possible!!!!**

HOPE♥LOVE♥CURE