

Tyler Nye's Story



Tyler was born on June 22, 2012, a 30-week preemie. He and his twin sister were taken to save his life. Tyler weighed 880 grams at birth. He was as small as a barbie. Tyler was born with polydactyly, pectus carinatum, and suffered an IVH grade 1 at 9 days old. Even though he was born early and started with delays in grasping things and so on. Once he had surgery to remove his extra webbed digit, he was able to meet every single milestone and blossomed into a healthy neuro-typical child.

At 2 years old in 2014 Tyler suffered a grand-mal seizure. He was rushed to the hospital where we were told that it was not a seizure and he passed his neuro-focal exam. We followed up as we were told and did many tests where it was ruled that he was completely fine and had no long-lasting effects of being a preemie. Years later it would become known to us that this seizure was the beginning of what we never saw coming.

In August 2017 Tyler developed a relatively mild stutter. Within a few weeks that stutter became a greater concern and while at his 5-year checkup before Labor Day we decided it was best that we get a speech evaluation done. On Labor Day evening we put a Neuro-typical 5-year-old to bed and the following morning we woke up to a 1.5-year-old baby. He lost his ability to communicate and lost cognitive and overall functioning. I rushed to the hospital where it was found that Tyler had CSWS, Continuous spikes and waves during sleep is a rare epileptic encephalopathy of childhood characterized by seizures, an electroencephalographic (EEG) pattern of electrical status epilepticus in sleep (ESES) and neurocognitive regression in at least 2 domains of development. At first the doctors at the ER did not believe that he only had a stutter the previous day. They truly believed that he was like this for his whole life. He started seizure medication and went home after three days. We would begin the task of many tests being done to see how severe the regression was. The regression would continue but not at the rapid pace it was. The medication helped

give him some speech back. For the next year we continued with tests, doctors and more hospital visits to determine how undiagnosed epilepsy can do this to someone. I automatically thought back to 2014 when I rushed him to the hospital for having had a seizure and they thought I was wrong.

In 2018 Tyler was diagnosed with Landau-Kleffner Syndrome. Landau Kleffner syndrome (LKS) is a rare childhood disorder characterized by the loss of language comprehension (auditory verbal agnosia) and verbal expression (aphasia) in association with severely abnormal electroencephalographic (EEG) findings during sleep and clinical seizures in most patients. Tyler would go into the hospital every 4 to 6 weeks for the next year for IV-SoluMedrol to attempt to slow down the regression and stall it. His EEG's were becoming worse but his cognitive functioning was improving. We were able to see one of two doctors in the country who studies LKS in Boston in the fall to help us determine what to do from here as the solumedrol did help but it maxed out Tyler's progress. Tyler could not count to 5 in October 2017 and now he can count to 15 again, something he could not do since around the time he turned 5. We will return to Boston in April to go over the genetic testing done to see what genes may be more prominent for his rare epilepsy. Every year he has his neuro-psychological exams done to see how he is doing.

Tyler has defied all the odds against him since the day he was born and will continue forever. We will never stop believing! God gives special needs children to special parents for a reason. While it has not been easy, we will continue to strive for the best in him, his healthcare and his education. We have two special needs boys and one very neuro-typical daughter. God has graced us with so many blessings and we are very thankful to have our children with us every day. "Remember not all disabilities come with an outward appearance, remember a disability does not define the person and above all be kind and courteous for tomorrow is never promised"

