

CONNELL FAMILY

Our family story...



Rylan was born on April 6, 2017. After Rylan was delivered, we noticed bruising on his forehead and eyes. We thought it was from the lengthy delivery and the use of suction, but it quickly became clear it was more than that. Rylan has a Port Wine Birthmark, which we were informed could indicate some neurological issues, but that we'd likely see any complications before we even left the hospital, which wasn't true. We were sent home with our new baby boy to begin a long journey of unknowns.

I wish they had done a CT scan so we could better prepare for the journey ahead. Rylan had to begin Physical Therapy at 3 months old because he wasn't turning his head to both sides evenly, creating one side of his head to become flat. He was in PT until about 1.5 years old and did very well, remaining strong on both sides. He also had 6 laser treatments completed on his birthmark by a year old.

It wasn't until he was 5 months old that we realized Rylan had more to cope with. On September 7th, 2017, Rylan had his first seizure. It was an absence seizure, so at first we didn't know what was happening. His lips turned blue, he was not responsive to stimuli and would stare off to the left side. We rushed him to his pediatrician, where he had another seizure, and was then transported by EMS to the hospital. From there he was transported to the Medical University of South Carolina. They placed him on a Keppra drip, and when that didn't slow his seizures, a Phenobarbital drip was initiated. At that visit, we learned of Sturge-Weber Syndrome. They did an MRI, CT Scan, and EEG.

Our hearts were broken. Thankfully, Rylan still remained the happiest baby through it all. February of 2018 landed us back at MUSC for clustered seizures and more adjustments. Rylan had to endure many seizures and several trips to the local ER until the dosages, medications, and weights were worked out.



At a year old, I asked that he be taken off the Phenobarbital, as I had heard of it affecting growth/development. Rylan was then switched to Trileptal, which alone did not suffice, so Keppra was added. However, since having Flu A in February of 2020 when Rylan had a breakthrough seizure, he has been seizure free! That's 3.5 years! We see his Neurologist in Charleston every 6 months and his pediatrician every 3 months for medication management.

He has since started 1st grade on time and has kept amazing us every day. He does suffer from ADHD on top of SWS, so he is also taking Ritalin to help him get the most out of school. We tried different methods such as breaks, walks, choice seating, standing vs. sitting in the classroom, but eventually had to turn to medication. Rylan has also gained assistance from Behavioral Therapy and Occupational Therapy through his elementary school.

He truly is our superhero, and we are so proud to be his parents!



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