

O'REILLY FAMILY

Our family story...



Our story starts in the snowy mountains of Utah in January 2017. We relocated from our hometown of Charleston, SC to Salt Lake City, UT for David's job one year before having Sarah. Jessica had a normal pregnancy and Sarah Kate had a normal delivery at Intermountain Primary Children's Hospital one week before her due date. We were so excited to welcome our second daughter but knew something was different when the nurses were all whispering about her port-wine birthmark while weighing her. We were reassured by the pediatrician that her port-wine birthmark was purely a cosmetic issue and would fade over the next week. We relied on Google to learn about port-wine stains and read about Sturge-Weber syndrome, but since the doctor didn't bring this up we thought it didn't apply to us.

At 28 days old Sarah Kate had her first seizure. Unfortunately, I didn't immediately recognize it as a seizure as David and I have no seizure

experience. I took a video of her hand twitching and continued about my day with her. I had a bad feeling I couldn't shake and I put her in the car to drive to pediatrician. I told the front desk that I thought my daughter was having a seizure, a doctor mayday was sent out, she was swooped away to the ED, and our roller coaster officially started.

We had several in-patient visits her first few years of life. We landed on phenobarbital for seizure control, which stripped our family of sleep and Sarah of her personality (which we would come to realize only after we weaned her to a different medication).

She struggled to nurse, refused to take a bottle, and we had to rely on formula when it was time to start solid foods. We leaned heavily on The Sturge-Weber Foundation for support, education, and hope. The mini-summits were incredibly helpful and we traveled to two in-person conferences prior to Covid.



We relocated back to South Carolina in 2018 for family support. We established a great care team with Medical University of South Carolina and while we are still active learners, we have transitioned to more of an advocate role for Sarah. Behavioral issues (impulse control, tantrums, throwing toys, disinterest in playing with friends) that set different standards for Sarah vs. her two sisters and prevent us from being more socially active which is difficult. Sarah struggled with transitions (leaving library, going home after walks, certain clothes) and has been on an increasing dose of Solexa and Metadate to help some of her ADHD tendencies. We have seen some positive results and will continue adjusting dosing with our neuro psych team.

Seizures are generally well controlled with daily Trileptal. Her Trilpetal blood level was recently measured 29 and we've been titrating dose with her weight. Her last seizure was December 26th; she became limp and unresponsive with a hard stare up and to the right while eating lunch at home. She was given oxygen and came out of seizure on her own after ~2.5mins with little-to-no aftereffects. We

immediately increased her Trileptal dosing and have been seizure-free since. She has controlled glaucoma with Rhopressa, Cosopt, and Latanprost, but struggles with peripheral vision loss that causes occasional trips and falls. Her vision is her biggest mobility hurdle. She patches her right eye multiple hours per day.

Sarah has bilateral brain involvement, but the left side is significantly less impacted. As a result, her speech and social/emotional intelligence are strongpoints. She attended a general education Kindergarten class with a teacher aide providing assistance when necessary in a new school last year. David and I were initially concerned how her peers would accept her, but we were pleasantly surprised of how welcoming her friends were, how Sarah adapted to her new environment, and how much she grew socially. Unfortunately, we are transitioning to a low incidence class at another new school this year as teacher aides are not available beyond Kindergarten. Our goal is for Sarah to maximize her gen ed time to keep developing her social skills.

One area of great interest is a more in-depth look at parts of the affected brain and how we can mitigate those impacts. We are still unclear if behavioral issues are related to Sturge-Weber syndrome and are collaborating with behavioral pediatrics to experiment with the right meds. Help in this area would really allow our family a little more freedom to spend time together outside of the home.

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