



Erin and Jay Williamson and their daughter Kinley, who had surgery to disconnect the right side of her brain after suffering from seizures caused by hemimegalencephaly



Team Kinley, made up of family and friends, offered support and encouragement to the Williamson family on the day of Kinley's surgery

CARING FOR *Kinley*

Diagnosed with a rare brain disorder, our daughter underwent hemispherectomy surgery

Written by Erin Williamson

The happiest day of our lives was when our beautiful daughter Kinley was born. Believe it or not, the second happiest day of our lives was the day Kinley had half of her brain disconnected during a complex 12-hour surgery. Diagnosed with a rare brain disorder, she had suffered from epileptic seizures for so long that the surgery brought much-needed relief and healing to her.

Kinley's Diagnosis

At only 4 months old, Kinley began having seizures and was diagnosed with hemimegalencephaly, a rare brain disorder in which one side of her brain is bigger than the other. The doctors painted what seemed like a very bleak outcome in regards to surgery. They said it would leave her half-paralyzed, with no way to predict how the good half of her brain would react.

After the diagnosis, she was given anti-seizure medication and was responding well. It seemed like great news, but we discovered that recovery outcomes were better when surgery was performed at a young age. This weighed heavily on our minds. We had a great deal of support from families we met through the Hemi Foundation, but all of our new-found knowledge was hard to handle.

One afternoon in January, however, Kinley's seizures came back with a vengeance. The doctors spent the next several weeks struggling to control the seizures and finally agreed that the surgery we feared the most would be her only option.

We Love Kinley

Friends organized a We Love Kinley website to help coordinate and organize the support we received. Meals were brought in regularly, we were constantly surrounded by friends and family, fundraisers were being held to cover medical costs, and we received gifts, cards, and, most importantly, prayers.

Surgery day arrived, and we felt surprisingly calm. "Team Kinley" waited together, while Kinley had her surgery. I logged on to Facebook to help pass the time and every person we had ever met, and hundreds we didn't even know, had posted pictures of themselves dressed in pink to show us they were thinking about our sweet girl. After 12 hours, Kinley's surgeon came out to deliver the good news that her surgery was a success.

Our New Normal Life

We came home after two weeks, but Kinley had basically reverted to a newborn and was awake around the clock. The surgery had left her paralyzed on the left side and without her left peripheral vision. The left side of her brain had the seemingly impossible task of taking over everything the right side of her brain had previously done, and the hard work began.

We enrolled Kinley in therapy at Texas Children's Health Center in Sugar Land five times a week. She hated her first sessions and cried the entire time. This was torture for us to watch, but we knew it was necessary. Slowly, Kinley began to do amazing things and her therapists, who were now more like family, pushed Kinley into meeting one milestone after

the next. "When I first met Kinley, all she could do was lay down," recalls Jennifer Marusik-Cummins, Kinley's physical therapist. "Now, she stands up and swings both arms while dancing. She has come a long way."

Kinley has hand braces and leg braces, but is able to feed herself, stand, step with assistance, sit up, reach for objects, transition from laying to sitting, pull herself up, speak and sign to communicate over 50 words, and move her left side more than we ever expected. Even more surprisingly, she does everything with a smile, showing more love, affection, and patience than your typical 1-year-old. Even her few "bratty" habits, like throwing her food on the floor and telling us, "Uh oh," are taken in stride, as we secretly love that she has typical toddler ways.

A Bright Future

Kinley is continuously improving and has been seizure-free since surgery. Her medications are decreasing, and as for her development, only time will tell. She will probably never have full control of the left side of her body, but will learn to adapt. We are optimistic for a normal life. Even though this is not what we had planned for our beautiful baby girl, we have learned that everything happens for a reason and hope she will touch lives and help raise awareness of epilepsy. We have high expectations and Kinley has a long road ahead, but together, we are up for the challenge. **SLM**

ERIN WILLIAMSON and her husband Jay live with their daughter Kinley in Richmond. They have been married for six years.

