

Our Story, Katie Hallstrom

Written by Kandy Hallstrom

Our daughter Katie was born in June 1990, three weeks earlier than her due date. We remember so well, what a quiet baby she was, slept so well, and seemed so content so much of the time. We spent the next two years with those feelings that something wasn't "quite right", as milestones were met a little later than other babies her age. But each time we'd have a checkup at the pediatrician's office, my fears would soon be calmed as she reached that milestone.

Katie walked at 14 months, but she never showed interest in playing purposefully, and by 18 months, she spent more time in her own little world, carrying as many toys in her arms as she could, walking endlessly through the house, and preferring to be alone. The crying jags would come on suddenly, sometimes would go on for a couple of hours, sometimes we could soothe her and stop her by removing her from a situation.

When she wasn't talking at her 2 year checkup, we began Early Childhood classes, and soon she had a diagnosis of Pervasive Developmental disorder, until the age of 4.5, when all at once she began to clench her fists, breath hold and hyperventilate. By 5, she began to have seizures and was clinically diagnosed in 1995 in Seattle, by Dr. Vanja Holme at Children's Hospital, just a few months short of her 5th birthday. Shortly after the Rett syndrome gene was discovered in 1999, we had her tested, which came back positive, with a mutation at C298G.

That same year, because she was walking and using her hands, we searched and found programs in a bigger city to help her maintain, and also relearn some skills that had gone away when seizures took over. We found ABA program and discrete trial programs were the best way to go for her, taking and building on the skills she was capable of. In her first months, she was able to return to picking up objects and putting them with matching objects, bending down to pick up and carry light things across the room, asking for snacks and drink, etc.

In 1996, her seizures were up to about 100 drops and other types combined, and after many medication trials, we put her on a ketogenic diet. She remained seizure free and med free for one year, and for the next 4 years, her seizures were well controlled with the continuation of a modified diet. By 2000, we had to put her back on medications, but her seizures were still pretty well controlled.

Katie has had her share of medical issues, including H-pylori in 2001, obstructive sleep apnea that lead to tonsil and adenoids removed in 2006, the same year that her seizures became harder to control.

In 2011, Katie turned 21, and transitioned out of school and intense therapies, into adult programs. For the first 5 years, we went through day program agencies, where employees were sent to our home to work on personal skills and take her out in community. While we had a few really good and caring people, we had more people who didn't want to work this hard, and in time, Katie's walking began to deteriorate, and hormonal seizures landed her in the hospital almost every month.

In 2016, we decided to take a leap of faith and switch to a Self-Direct program, where we hire our

own caregivers, and they are paid through the Medicaid system. We have a broker who helps us set up our budget and our care and learning plan, and will even help us make sure the plan is being followed. This gave us the freedom to train helpers in the way that we need for Katie, and soon, her health, and physical well-being began to improve once again. I would recommend Self Direct to anyone who is able to obtain this type of service, if they are struggling with their current help.

Katie is now 27 years old, she is back to walking on her own, she still is able to use her hands for spoon and cup, finger foods, picking up and handing us things that she wants. She has wonderful caregivers who give her very full and fun days, plenty of exercise and socializing. With the right combination of medications (Lamictal/Depakote/Onfi/bio-identical progesterone), her seizures are much better controlled. She is still on a low carb/low sugar/gluten free/dairy free diet that keeps her in good health. She is a happy girl, who loves to go for rides, watch Disney movies, be read too, loves to have soft music on as she takes a nap, loves to visit friends, and especially loves it when out of town family comes to visit!

Our helpful sites have been Idaho Health and Welfare to go through the steps for Self-Direct services
Consumer Direct
Idaho My Voice, My Choice

St. Luke's Neurology, Boise, Idaho- Dr. Sergei Kashirny (epileptologist)
Dr Robert Wechsler, Boise Idaho-epileptologist

Meridian Physical Therapy, Meridian, Idaho
Sawtooth Orthotics-Boise, Idaho (Amy Karisu)
Idaho Gastroenterology- Dr. Matthew Sericati, Boise Idaho
Stephanie Terrell, NP -OGA- helped us with Katie's bio-identical progesterone for hormonal seizures
Spinal Dynamics Chiropractics, Meridian, Idaho 208-888-0055
Scott Grant- Family Dentistry, Meridian Idaho