

Waiting List Story: Meet Caroline!

Hi, my name is Caroline! I am seven years old, and I have a neurological disorder called Rett Syndrome



which keeps my body from doing what I tell it to. I cannot walk, talk, or use my hands. I still wear diapers, and can only eat pureed foods and drink out of baby bottles. I may need help with all my daily activities, but I am smart and I understand everything going on around me. I cannot respond in words so I use my eyes and make sounds to communicate. I also use a cool computer that tracks my eyes and talks for me! I love books about Dinosaurs, and my favorite movies are Tangled and Beauty and the Beast. I am full of love, life, and energy.

I was born healthy and strong, and I hit most of my milestones during my first year. I could play with my toys, I enjoyed feeding myself, and I could say words like “mama,” “all done,” and “ball.” Around my first birthday, my friends were already walking and exploring the world around them, but I was still unable to stand or move on my own. Soon, my mommy noticed I was clapping my hands a lot, and dropping my toys too. I also started losing my words; I still tried to say them, but I couldn’t get them out. My mommy and daddy were very worried about me and took me to see many doctors to figure out what was happening to me. At 17 months, I was diagnosed with Rett



Syndrome. The day of my diagnosis was so sad for my family, but my parents promised me that we would live a happy and full life no matter what. Every single day, they tell me how much they love me and how happy I make them.



Girls with my condition develop “normally” for the first 12-18 months before we lose our skills and begin repetitive hand movements like wringing, clapping, and mouthing. Rett also bring other complications. I take four different medications to control my seizures, but I still get them. Last year, I had 98 seizures over 12 months. I have tummy issues and I take medication so that I don’t vomit all the time. I also can’t sleep without medication because my body doesn’t know how to relax. In the last two years, I have been in the PICU five times with respiratory issues. Usually, I’m in the hospital for about 7 days, but a year ago, I was there for 17 days and I fought so hard to get better.

Everybody was worried about me and desperately wanted me to get better. My teacher made a video of my friends singing “Sweet Caroline” which made me smile even though I was too weak to even look up. My family described the day I finally got to go home as a miracle.

In order for me to stay out of the hospital, and also avoid a tracheostomy or a g-tube in the near future, my doctors put me on a daily regimen of lung therapies, including nebulizer treatments and machines that shake my lungs and help me cough. Also, since I often stop breathing when I’m sleeping, I now I have extra oxygen and use a Bipap machine to help me breathe at night. My doctors say that these therapies will increase the quality and length of my life.

As you can imagine, caring for my personal and medical needs is a full-time job and costs a lot of money, but thanks the EDCD Medicaid waiver, I have nursing care to help my mommy and



daddy for a few hours each day on weekdays (and sometimes on weekends). This allows them to work and take care of our family needs. I also have a lot of expensive medical costs and my EDCD Medicaid waiver helps cover the rental of the lung therapy machines and other medicines that are not covered by private insurance.



I’m currently on a long waiting list for a Developmental Disabilities waiver, which will help me get additional services that are important to my health and the quality of my life, like a case manager, more nursing, and the opportunity to adapt our house so I can get inside safely. It will also help provide therapies to keep my stiff body from permanently getting stuck in certain positions. There are more than 11,000 people like me that are also on the

waiting list and need your help. You have the power to improve or even save our lives. Please fund the waiting list for Developmental Disabilities Waivers! END THE WAIT, start a life!