

# Waiting List Story May 2015: Charlie



Here you can see my "motherboard" is on the outside of my tummy, but it doesn't slow me down!

My name is Charlie and I live in Falls Church, Virginia with my mom, dad, and sister, Sophia. I've lived in this area my entire life. When my mom saw me on the ultrasound at 18 weeks in her pregnancy, she was told I wouldn't survive because of some significant medical complications, but I did! When I was born, my mom was told I wouldn't live very long. Instead, every day I prove that with the right supports, I am a thriving member of my community.

I am extremely medically fragile, so I was one of the first kids in the state to be approved for an EDCD Waiver to help fund my services. I eat through a tube in my tummy and I have an ileostomy bag all the time. I have been hospitalized over 220 times since I was born. I'm living with neuroendocrine cancer in my tummy and I'm in pain most of the time. You'd never know most of this if you met me because I'm a fun, happy guy, but I need nursing care 24 hours/day. Unfortunately, cuts to Medicaid have reduced my nursing hours. This means my mom can never be more than a few minutes away from me since she has learned to do all the things the nurses do to keep me safe and healthy. In fact she is the one the trains my new nurses!

Since my nursing has been cut, I can't go to school for a full day because there aren't enough funds to pay for my nurses to stay with me the entire time. My whole life (which was already pretty complicated!) is even harder.

I've been eligible for the ID Waiver since I was born and we're told we're at the top of the urgent list, but we were told that last year and the year before that, too. If I had an ID Waiver, I could have nursing when I needed it. I could go to school and do the things I want to do to be a kid! It would mean a big change for my whole family, especially my mom who has to be my mom, my case manager, my nurse, my scheduler, and do everything else it takes to hold all the pieces together.

You can change my future! Please fund the waiting list for ID and DD Waivers. End my wait, start my life.



I'm a fun happy kid who could have a great life with help from an ID Waiver