

I am here to be an advocate for Rare Disease Day. 300 million people have rare diseases worldwide. I am one of those people. My disease is classified as rare because as of 2004, the year I was born, there were only 3 recorded cases of it in children. I have Myofibrillar Myopathy. This means I have low muscle tone, which makes my entire body extremely weak.

As a baby, the doctors told my parents I would never walk, but I proved them wrong. I used a walker for about the first three years of my life. As I got older, my muscles got tired quicker, so I began to shift my weight more dramatically causing me to rock from side to side. This eventually caused me to get scoliosis, having a curved spine. When I turned ten, my curve got worse, needing me to have surgery to stop the curving from progressing. I was in the hospital for two months of recovery. I was lucky to have my friends, family, teachers and staff here at OLSS praying and supporting me. After the surgery, I was left completely wheelchair bound. My muscles are getting stronger everyday. I go for physical therapy everyday with the hopes of walking again.

The one muscle that works the same as all of yours does is my brain. Sometimes people are fearful to be near a disabled person, but I'm just like you. People talk down to me and treat me like I'm invisible. What they don't understand is just because I'm sitting doesn't mean I don't have feelings. I know they don't mean it, but some people talk over me and to each other making it difficult for me to be part of the conversation. It is never meant to be mean. It's natural to talk that way. I learn and think just like you do. I read and understand things the same way you do. My disease does not stop me from living a happy life like everyone else.

This week of awareness is to help open our eyes to the every day things that are around us and the struggles, both big and small, of the people with rare diseases. I am happy to say that in the 10 years that I have been at OLSS, I have never been made to feel small but have always been encouraged by my teachers to strive for my absolute best. I have always been supported and loved by the friends that I have made here. Thank for your time, help, and support. Don't forget to donate from today February 14th to February 21st!