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My disease first started as a funny little bar trick in 2006 - my twitchy thumb. We'd laugh as the *aductor pollicis brevis* would flutter and shake, my right thumb shaking faster than I could recreate intentionally.

As the months wore on the twitching got worse and soon my right thumb began to cramp up on me. The cramping was so severe that I would physically need to use my other hand to straighten my thumb back out. Certain that it was from all the typing at work I went to the doctor and filed a work comp claim.

The first doctor I saw told me I had tendonitis and prescribed a wrist brace and physical therapy. It was good in theory but in reality it only kept me from being able to manually straighten out my right thumb when it cramped up in side the brace.

I must have been the most frustrating patient for my therapist, Paula. Some days she would ask me to pull this cord, squeeze this ball, push this block and I would pass with flying colors. Other days it wouldn't matter what she tried, my hand would not cooperate.

One day I sat at my desk at work when "the moment" happened. It was the moment when I knew that this was no longer a funny joke, an odd coincidence, but a real problem. I looked at that right thumb and it refused to bend. *Bend, little thumb. Just bend* I willed it, but the connection between my brain and thumb had been lost. It was almost like the call had been dropped between the two. Panicked, I called my supervisor who sent me back to the doctor.

The next doctor specialized in carpal tunnel and other such disorders. His disinterest in my condition was disheartening. He said it wasn't anything he could fix and recommended I see an neurologist. That's then things got very scary very quickly.

The neurologist did the same battery of tests that we're all given. Stimulus. Reflex. EMG. To this day I tell people if anyone asks if you want an EMG the answer is no – those are the worst!

I remember "diagnosis day" so clearly. The doctor had done the EMG on one arm and one leg. I'd gotten myself put back together and he had asked me to wait in the room. He came in with a

resident who must have been there to learn how to deliver bad news. Her eyes and nose were red, tears trickled down her face, and she had a look of gut-wrenching sadness and pity. The doctor sat down, looked squarely at me, and asked if there was someone we could call. *Call? Why call someone?*

Distracted by the resident, the conversation began to swirl quickly out of my grasp. The doctor looked down, breaking his gaze, and told me with 90% certainty that I had ALS. The resident broke into full sobbing tears as I sat there alone. Lost. Confused. Did you have questions? *No*. Do you know what this means? *No*. He mentioned a second opinion and a referral to the Mayo Clinic in Rochester. His parting words: “just don’t Google it.”

After three long days of following the doctors orders I broke my Google vow. I sat at work trying to spell “amyotrophic lateral sclerosis.” The information I found seemed innocuous at first. ... generally affects people in their 40s to 60s but can present earlier ... causes a weakening of muscles ... once it presents death is likely within four years.

Four years? Four years! I was 25! I had more in me than just four years!

I broke down that day at my desk, sobbing uncontrollably until a co-worker called my best friend Scott to come and get me.

Those early days are so crystal clear to me. I remember Scott coming to pick me up and walking me to a bar up the street. We sat in the basement of “our bar” and drank beer and cried and toasted to the 10% chance that the doctor was wrong.

Six weeks passed until I was able to get in at the Mayo Clinic. Six weeks of thinking my death was imminent; of making plans to enjoy every moment; of preparing to die.

I’d been scheduled to spend three straight days with the doctors at the Mayo Clinic, however after only the first day a gentle doctor with a caring smile held my hands and gave me the wonderful/awful news – I have multifocal motor neuropathy with conduction block. I would live!

As anyone with MNN knows living with it isn’t always easy. A medication reaction left me hospitalized with blood clots in my leg and lungs for a week. My veins were so thin and weak from being regularly punctured that my IV injection sites had moved from my hands to my arms to my feet. I missed work – a lot of work in the beginning. When I moved and changed jobs I had to jump through hoops to get my IVIG covered. I had to explain to insurance companies that my medicine was “medically necessary” and not experimental. After having a port put in to make infusions easier I was hospitalized again with PE. The road was rough, but I pressed on.

Most people now don’t realize there’s anything different about me because I try damn hard to keep it from defining who I am. In fact since being diagnosed I’ve purchased three houses, lived

in three states, gotten married, and had two natural babies that I have breastfed for 14 months and 20 months (and counting).

A note on my pregnancies: pregnancy weakens the body and in an already weakened body like mine I found that my symptoms, especially weakness and cramping, were exacerbated with both pregnancies. I became weaker and weaker as my belly got bigger and bigger. Once my babies were born, though, my symptoms leveled out. Thankfully I was able to regain some strength after each one!

Ten years later I still get my infusion every three weeks. Luckily for me I can be infused at home on the weekends so I don't miss work anymore. My left hand has become weak and atrophied, but I still work full time with the aid of an ergonomic keyboard and Oval-8 braces when my fingers won't straighten out far enough. My right leg has begun to atrophy as well, but I've found that roller derby (Yes! Roller derby!) has become an excellent form of physical therapy for me. The repetitive weight bearing motions for my legs combined with the incredible support and pressure of my team (who don't know about my uniqueness) makes me both physically and emotionally stronger every day.

I've never succumbed to my disorder. I'm not an MMN patient and I don't "suffer" from it. I just happened to be a wife, mom, crafter, DIYer, Roller Girl with a quirky little neuropathy. Stay strong!