

# MY MMN STORY

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I started my MMN journey about 5 years ago, before I even knew what MMN was. I was almost 25 years old with 2 young boys and one more on the way, working full time and then some. I didn't have time to slow down, but life had other plans.

At first it was just an odd feeling in 2 fingers. As the months went by, I noticed I was losing strength in my hands, my writing was getting sloppy and eventually I could no longer fully extend the fingers of my right hand. I showed this to my family doctor one day and he said "That's weird." I would hear this a lot over the coming years. I was referred to a specialist for an EMG, which led to many more tests. After over 3 years of head-scratching, "Let's see how you are in a few months,"

and no clear answers, I was referred to my current neurologist. 14 months later, I was diagnosed with MMN and began IVIG treatment every 3 weeks.

IVIG made me feel exhausted and sometimes gave me headaches and other side effects. I was supposed to switch to SCIG after 2 months because I lived so far from the hospital but due to an immunoglobulin shortage, I had to wait an extra 4-5 months. This meant more travel, more side effects and more time away from my kids than necessary. My hubby worked afternoons so I was essentially a single mom after 2 p.m. I would come home from treatment, get my youngest from his Nana, snuggle up to watch cartoons and rest as much as I could until my older boys came home from school.

As the saying goes, "You never know how strong you are until being strong is the only choice you have." Trying to raise kids when you have a chronic illness is tough. Aside from the daily struggle to keep up with meals, laundry, cleaning and trying to still have enough energy to play,

MMN takes an emotional toll as well. I did not respond well to treatment and continue to slowly progress. I have had to adapt my parenting over the years because of this progression and it has brought me a lot of guilt.

I was healthy when I chose to bring my children into the world. I had high expectations for the mother I planned to be. For the first 6 or 7 years, I was able to be that mom, but

eventually I had to let that go. That has been the hardest part about living with MMN for me; not only does it affect my body, it affects my kids.

At times I've felt like life is all downhill from here. If you're reading this as a patient, I want you to know that it's okay to feel that way sometimes. You don't have to put on a brave face every day to make others feel comfortable. It's okay – and sometimes necessary to grieve the life you had before diagnosis. I also want you to know that it isn't all downhill from here, it's just different.

I may not be able to chase my boys around the yard like I used to, but we can snuggle up for family movie night. I may not be able to make Pinterest-perfect birthday cakes for them, but we can have deep conversations about life. I walk slower and my body gets tired easier, but I listen longer, I cheer louder and I hug them tighter. For everything I feel my children have lost to MMN, they have gained in appreciation, compassion, nurturing and resilience and I take comfort in knowing it will make them better men.