

This Is The Story of My Journey With MMN

Michael Aylward



In late October 2013 was my first sign of muscle weakness in my right arm. I didn't think much of it at the time. A couple of weeks after that, I couldn't extend my fingers on my right hand. This was the first time I was concerned that something was wrong. I thought it would be nothing more than carpal tunnel because of my work.

As Christmas approached, and I was losing more arm function, I tried not to be afraid of what it could be.

January 2014 - I was told that I had ALS. So, went for a second opinion, but still had that nugget of doubt and fear that ALS could be a possibility. This is when we met the amazing Dr. Barboi who let us know by the end of the visit that it was not ALS. More tests needed to be done to determine the correct diagnosis.

While I was going through all the tests to get a confirmed diagnosis, I tried acupuncture, meditation, massage, and traditional physical therapy. The physical therapy was working because I was regaining strength and endurance.

June 2014 - I got the confirmed diagnosis Multifocal Motor Neuropathy (MMN) and boy that was a large weight lifted off my shoulders because it's not fatal and it is treatable. The treatment is an IV infusion.

August 2014 – My first infusion treatment. I still didn't have any fear, but I knew it was not going to be an easy fight.

I kept working during this time and was able to drive until November. Tom our son had moved home at this point. He gave up his apartment and put aside his career because he saw Jeannie couldn't physically do it all anymore. If I fell, she couldn't pick me up and it was getting harder on her helping me to get up and down the stairs. So, Tom started to drive me to work every day and pick me up. It was an hour drive each way, just so I could keep working.

February 2015 - My work had to let me go because I was a liability after falling twice in a week because my walking had deteriorated, and I couldn't get off the floor on my own.

A good thing that was happening at that time was that I started doing aquatic physical therapy. I found that in the pool, I had a lot more movement and ability to do things. The disease had plateaued, and I was gaining some strength and endurance back.

August 2015 - I went to the hospital after feeling some pain in my rib cage. The doctor found blood clots in my lungs and then one on my leg. While I was in the hospital, I could feel my legs get even weaker, which devastated me. Within a few weeks of getting home, I could no longer walk.

Unfortunately, I had lost what I gained in my physical therapy, because during the recovery I couldn't do therapy.

In 2016, we purchased two patient lifts because it was a physical struggle to transfer me from chair to chair and get me in/out of bed. I didn't have the strength to stand on my own. During this whole time, Tom was and still is my caregiver. While Jeannie's at work, he takes full care of me, doing everything I need.

2017 - I was still receiving my infusions and getting physical therapy on a regular basis since October 2016. This was the year I decided it was my mission to raise awareness, not just to help myself, but also to help others that are going through this struggle.

2018 - I have PT 2 times a week and receive my 5-hour long infusions every other week. I am not able to use my arms, hands, feet, or legs as of now. Not enough muscle and nerve connections to do anything for myself. However, I have started to see some small improvements. I am now able to move my left pinkie finger, which I haven't been able to do in a year. Also, now with my therapy at a new larger pool I have been able to do more things like standing; and with help, propelling myself several lengths of the pool. Now if I could just do those things on land!

I will continue to fight each day to improve my health and ability. I will continue my mission to raise awareness about a disease that makes most doctors say "Huh?"

Michael vs Multifocal Motor Neuropathy - <https://www.facebook.com/groups/780747535439179/>

"I am on a mission to raise awareness about Multifocal Motor Neuropathy (MMN), and my personal battle with it. I hope to help reach and inform as many people as possible about MMN, hopefully sparking interest in looking for a cure and cause. To also inspire and help others who are going through a similar situation." ~
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