

Full of Hope with a Rare Disease Charles Wood



The best way to explain the onset of Multifocal Motor Neuropathy is like someone had flipped a switch and all the electricity containing those very important messages flowing from my brain to the muscles in my arms and legs slowed down; the lights were dimming; the motor was slowly shutting down.

In 2009 at the age of 68, I was still a “regular guy”—working, taking care of my family and home... trying to squeeze in a few moments each day to stay in shape. Little did I know that an *insidious neuropathy diagnosis* was going to change my life “forever” It all started with a reduction in my grip strength, then in 2010 at the age of 69 I noticed the first two fingers on my right hand beginning to curl under, My family doctor could not give me a diagnosis, so with a referral to a hand specialist and neurologist followed by a series of X-rays, MRI's, EMG's NCV's, (nerve conduction velocity tests), followed by an operation where the specialist reported finding a badly bent nerve. He straightened it and recommended electro stimulation therapy (no positive results ensued). Then a visit to yet another “Specialist” who ordered the usual battery of tests including a bone marrow biopsy this time, the prognosis was the same “*it's so complicated.*”

By 2013 (now 72) the symptoms were getting worse, both hands were in fists, my wrists dropped, and my feet were beginning to drop making walking a problem. I could not even sign my name (thank goodness for ATM's) or button a shirt. All my hobbies were now challenges. Then the realization I could not even shave or feed myself. I was referred to another neurologist (my 4th) who, armed with my previous test results spent 90 minutes questioning and examining me before telling me that I may have ALS or some form of peripheral neuropathy.

She referred me to another neurologist whom she considered to be “one of the best in this field”. A couple of weeks later I secured an appointment, he examined me and rendered the diagnosis: I had “Multifocal Motor Neuropathy”. He informed my wife and me that there was no cure, only a treatment that blocks the symptoms and that I should see significant improvement and eventually only need periodic booster infusions for the rest of my life or until a cure is found. I started my first two-day course of “intravenous immunoglobulin” (IVIG) treatment in January 2014. After some 4 treatments (16 weeks), improvements began to materialize, by August 2014 I was probably back to 80% of my abilities. By November I was at probably 95% and out on the golf course once again. My dosage is now being reduced and I am down to one day every 4 weeks until I reach the level of sustainable health with the minimal amount of treatment.

Right after I was diagnosed. I was having a hard time remembering the long and unusual name of the diagnosis, other than the acronym MMN. What seems so outrageous to me now when I think about this experience is that until my last visit to the neurologist, I was given no written information, no fact-sheet about neuropathy diseases, and no brochure with the names of resources and support groups ... not even a scrap of paper with the words “Multifocal Motor Neuropathy” scratched across it. The stories I read on the Internet saturated me with a series of worst-case-scenarios.

My life with neuropathy is more stable and a little easier now. There were setbacks, one of which was finding suitable insurance coverage once my employer provided insurance ceased. I enrolled in Medicare with a supplemental plan to take care of the uncovered costs by Medicare. At this point we discovered that the Gov't had changed the way treatment was being funded, ie. The IVIG infusion centers were now underfunded to where they could no longer breakeven on their costs and the portion of their funding that was cut was awarded to Hospitals offering IVIG outpatient clinic treatment

centers. We continue to fight, ask questions, seek out answers, and stay strong. I know I have a lot more people to thank, particularly all the plasma donors and people involved in making my IVIG treatments possible and thanks to them in part we now have a fighting chance. Researchers and drug companies continue to work on developing new treatments, "gene therapy" is being investigated as well. Perhaps a cure will be possible soon. The future is full of hope.