

My MMN Story

Rabbi Nina Perlmutter – February 2020



It's been almost seven years since my MMN was finally diagnosed accurately, and since I began my two full-days-a-month IVIG treatments. Indeed, this is being written while I'm hooked up at the hospital Infusion Center, a bit drowsy with treatment and Benadryl. Looking around, I have great appreciation for the team of kind nurses I've come to know pretty well. And gratitude, too, for MMN being far more manageable than some conditions other patients here are fighting.

Like so many others, I was first told my symptoms seemed likely to indicate ALS: muscle weakness, balance issues, hand weakness and an inability to button or zip, etc. Those early months were extremely depressing and scary. A few doctors later—and many tests later-- the accurate diagnosis was delivered. Even now, if ever moved to feel sorry for myself, I remember that my MMN involves no real pain, it's not ALS, and it's not going to kill me. This definitely helps keep things in perspective!

A major turning point in my MMN adventure was eventually agreeing to have a port installed. It took a while. Maybe I was still in denial about the long-term prognosis. What I always dreaded most on treatment days was the poking. MMN shrinks muscles and nurses here are allowed to poke only twice. If they cannot access, another nurse is called to do so. One day it took four nurses to succeed with me, and they rebelled. The facility's director called my neuropathy doctor saying they would no longer serve me unless I got a port.

I had no other choice. That changed everything for the better. With a port, my treatment experience is virtually painless. The port helped me accept reality---that MMN is not likely to go away any time soon, and that I deserve the most comfortable treatment possible. Unfortunately, my port stopped aspirating only a few months after installation. But because this could happen again to a new port, the doc recommended keeping this one for now. So, the phlebotomist draws blood every three months for tests.

In recent times, my biggest challenge is that the hospital claims to be unable to obtain Octagam, the most effective-for-me treatment. The substitute I'm on takes less time, but I'm still hoping to return to Octagam for it was more effective at treating symptoms, and far more comfortable while on IVIG. (Dominick Spatafora and NAF have been most helpful as advocates, and I'm hopeful.) When a semi-truck filled with almost a million dollars of Octagam was high jacked in Tennessee last year, I sighed, and literally laughed out loud! The truck was found, but the Octagam was not. I joked that I might be willing to track down the black-market stuff.

In addition to missing Octagam, another challenge I'm dealing with is how to most effectively time my treatments. When symptoms improved we tried stretching out treatments to two days every six weeks. That was too much time, so I'm back to two days monthly. Some MMN folks have treatments more frequently, and that might be my routine down the road. Also, I'm contemplating subcutaneous treatments at home, but for now I still prefer having a nurse to call upon if questions or concerns arise.

By now, I hardly remember life before MMN and IVIG. It was sad when I decided to minimize my work as a rabbi in great part because I could no longer be on call at all times for my congregation. But it was the right decision.

Every month envelopes arrive from the hospital, Medicare and my supplementary drug plan, and I'm always nervous about opening them because of the enormous cost of treatment. Fortunately, I've paid virtually nothing, having been diagnosed after getting on Medicare. So, I'm grateful for that, and for all who pay taxes! I can hardly imagine what it must be like for others who cannot afford out-of-pocket expenses.

And I'm grateful for NAF and Dominick and for knowing Charles Wood--the only other MMN patient I've ever met here in Arizona. Those who have the condition can share and understand in ways that others cannot.

Friends (and I) used to feel sorry for my needing to be in the hospital Infusion Center two days a month. Now I see it differently. I acknowledge positives in addition to the helpful treatment. After all, I have two days off from other responsibilities, time to slow down, some ways to see how I'm quite fortunate, and of course the miracle of modern medicine.

In the beginning I thought MMN was getting in the way of my life. Now I say this IS my life, with much to be grateful for.

--Rabbi Nina Perlmutter, Chino Valley, AZ