

Importance of A Knowledgeable Neurologist

Diane Punzo – June 2018



I often go online to see if there is anything new on Multifocal Motor Neuropathy (MMN). I was lucky enough to come across the GBS/CIPD Foundation International and the Neuropathy Action Foundation (NAF). I explained to them my very long search for information, many doctors, many tests, useless surgeries (two ulnar nerves) starting in 1986 for an answer to my issues with my hands cramping and shaking and was finally diagnosed with MMN in 1991.

I looked up the NAF Founder's video who also has MMN and was so moved by his video on Plasma Donors, I never thought about it like that - very moving! I have never met or spoke to anyone with this disease. I am so used to trying to explain this disease to my friends.

Since 1989 I was diagnosed with many diseases, called crazy, and told they thought I had ALS. I live in Biloxi, MS and saw all the neurologists in this area, sent to New Orleans LSU and Tulane. I was lucky enough for my chart to be sent to Dr. Appel in Houston in 1996. After three long days of tests he came in and said I have good news and bad news. The good news was that I did not have ALS (due to spinal tap and muscle biopsy) and the bad news is that I have MMN and there is no cure.

Within a month I was in Houston again doing rounds of IVIG, Rituxium, plasmapheresis, and Cytoxan. Which I continued back home for many months. For a couple of years, I continued to drive to Houston for check-ups. I felt that Dr Appel was happy with me and I felt he was done with me. Most of his patients had ALS. A doctor in Biloxi picked me up and sent me to a new neurologist in our area. Dr. Bowen, who I love! He did some research and sent my records to Dr. Pestronk in St Louis, MO. By this time, it was 2004. I have been receiving IVIG every two weeks and several rounds of Rituxium (which I just finished my two year-round). I currently see Dr Pestronk in St Louis two times a year and monthly visits to my hometown Dr Bowen. I tell people that if you ever feel not right about a doctor's diagnosis to keep looking!

Since 1988 I have lost the movement in my left thumb, have very weak fingers and atrophy. I was 30 when this started and am now 66. I had to switch well paid jobs for entry level jobs to just have insurance. I was very lucky that I had long term disability and had to leave again a very good job (I could not do the hand work necessary in management at a local casino). I applied for Social Security Disability, which took me three years to get approved. I am VERY lucky now that I have Social Security and a second policy. I never had to pay one cent for care.

I consider myself to be very lucky that I have great friends that help me when I am with them. They carry my drinks or plates and they even lean over and cut my meat when they see me trying to hold my knife and fork. I think they are scared the meat will fly off my plate!

I also have a wonderful, loving husband of 46 years. I blame my backache on all the things I have to pick up daily that I drop or goes flying out of my hand. He tells me to leave everything alone and he will pick up when he comes in. Sometimes you just have to smile, MMN is part of me now, you must keep going.