



MY MMN STORY

by Jack Konings

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Hello. My name is Jack Konings and I have Multifocal Motor Neuropathy with conduction Block (MMN).

In about 1996 I started noticing difficulty holding onto things with my right hand. I also had mild shocks in my lower right arm. I consulted my family doctor who sent me to various specialists over a one-year period. One

of these specialists was Dr. Giles, a neurologist in Cambridge, Ontario. She did some strength tests and did a rudimentary EMG. This diagnosis led her to believe that I might have MMN. She referred me to Dr Hahn, a neurologist at London Health Sciences/University Hospital. Dr. Hahn also performed strength tests, blood work, and scheduled an MRI and a comprehensive EMG. These tests confirmed the MMN diagnosis.

The treatment prescribed was to try intravenous immunoglobulin (IVIG). A dose of 70 grams 5% solution was started. This was done by Bonnie Hogan, RN, at the IV Therapy Clinic at University Hospital in 1998. The first dose was spread out over 5 days at a very slow rate. After confirming that I tolerated the IVIG I was put on a 6-week rotation of 70 grams. The only side effects were mild nausea and headaches. These treatments took about 7 hours.

I saw Dr. Hahn and Nurse Practitioner Wilma Koopman annually to monitor my progress. It was eventually determined that a 4-week rotation of the same dose was more suitable.

After about a year, because of the travel time involved, I asked to have my infusions done in Cambridge. Because of the excellent reputation of Dr. J. Gowing, this request was allowed and I started receiving my IV treatments at the Medical Day Care Clinic at Cambridge Memorial Hospital.

I continued with the 5% solution until a 10% solution became available. This reduced the infusion time dramatically and I was able to get my infusion in about 4 1/2 hours at a maximum rate of 200 ml/hr.

In 2006 I decided to have a catheter port surgically implanted. This allowed the nurses to use a special right angle needle to access my bloodstream. The decision to install the port was made because of the level of scarring in my veins after repeated IV pokes over the years. The last straw for me was when I was poked 6 times in the same arm before a suitable vein was found.

I was still going to London annually for my check ups until Dr. Hahn retired. I then went back to Dr. Giles in Cambridge and eventually to Dr. D Stewart.

In the spring of 2016, I attended a GBS/CIDP seminar in Ottawa and was shown a new way to self-infuse called subcutaneous immunoglobulin (SCIG). I had heard of this procedure previously, but hadn't considered it until I heard the excellent presentation by Lynda Theoret, RN. I was sold.

My main reason for considering SCIG was the cost of flights back and forth to and from Florida where I go for a few months in the winter.

After consulting Dr. Stewart in Cambridge he referred me to Dr. Kimpinski, a neurologist at London Health Sciences/University Hospital. After an initial consultation with him and Wilma Koopman it was determined that I was a candidate. Government approval was also obtained.

I received my first infusion on October 7th. This was a 25% dose administered by myself under the supervision of a nurse from the drug company that supplied the IVIG. The next infusions were on my own with my wife as supervisor. The IVIG used is a 20% solution that is administered via the fat (subcutaneous) tissue in the stomach. So far all is going well.

How has MMN affected my life? There have been very few changes. I am no longer able to lift heavy objects that require both hands. My dexterity is limited for some tasks, such as cutting meat at dinner, cutting fingernails, using normal scissors etc..

My hand tends to remain partially closed or clawed. Sometimes I lose finger control and my finger or thumb will shake. I have a brace for my hand that prevents my fingers from hyper-extending. It also lets my fingers straighten out more. Just as anyone does, I have learned to cope.

MMN can only affect your extremities so there are no good and bad periods as there might be in GBS or CIDP. Progression is very slow and held in check once IVIG treatment is started. I hope my story helps others recently diagnosed with MMN learn about its long-term prognosis. The most important thing to remember is that life goes on.