My MMN Story

John Bennett – September 2019

It is thirty years since I first noticed that something was wrong. The thumb on my right hand was hard to move. I had no pain, but I was puzzled. So, I made an appointment to see my doctor.

He was sufficiently concerned to ask me to return that evening, when he would give me a full examination with a colleague. He also asked me to think about any other symptoms that might be similar. When I got home and sat down, I realized that I could not bend my left foot upwards.

When I was examined by the doctors, they did not tell me what they thought was wrong. They arranged for me to see a neurologist at a hospital. There was a bizarre incident where a junior doctor decided that the quickest way to get me to see the consultant was to have me admitted as an in-patient and the consultant was very annoyed. None of this resulted in a diagnosis.

When I moved to a new house, I was referred to another hospital. Here the consultant decided that I had Mononeuritis Multiplex which matched some of the symptoms I was experiencing, but it is different because it also involved loss of sensation and is painful. I stressed that I suffered from neither of these. Nevertheless, I was prescribed a course of steroids, which rapidly made my symptoms much worse.

I retuned to my doctor, who advised me to stop taking them and said that he would refer me to another hospital, to the neurologist, in fact, who had taught him when he was training.

I was then put through a range of tests which included conduction block (with electrodes placed on my skin to test the current passed along various nerves in my arms and legs), flashing lights and images to test my optic nerve and a nerve biopsy, where a small piece of nerve was removed, under general anaesthetic, from my ankle.

I had weakness in the finger and wrists of both hands and a foot drop on my left leg. I had great trouble walking on uneven surfaces where my ankle would give way (sometimes very painfully) or I would trip and fall over. I was never badly hurt but it was always embarrassing when there were other people around who came to see that I was all right and were reluctant to accept my assurances that I was OK and that this happened regularly. There were also times when I had little energy, could not sleep, and had cramp in the calf of my left leg. A doctor recommended a glass of tonic water each day, for this last symptom which proved highly effective.

The neurologist was still unable to give me a diagnosis, but I continued to see him regularly and he continued to check for conduction blocks in my nerves. This continued for a couple of years until he told me that he had attended a conference in Japan where a condition with my symptoms was not only described but also a treatment that alleviated the symptoms.

He asked if I would be willing to try it and I agreed. I was admitted to hospital and over a week was given intravenous immunoglobulin (IVIG). There was for the first time some improvement following the treatment. From that point I was able to receive IVIG on a regular basis. For some years it meant being admitted to hospital and spending the night in hospital. In later years, after I had moved again, I was able to go in the morning and come home in the afternoon.

For the last seven years I have been self-administering immunoglobulin subcutaneously once a week. I was trained to assemble the syringes with butterfly needles, push those needles under the skin either side of my midriff and then attach syringe drivers which can be slotted into holsters worn on a belt around my waist. I use four syringes (3 x 20ml and 1 x 10ml with 14g) each week. With setting up and administering the does it rakes about two and a half hours. I can do other things during the treatment. Because of the needles in my side sitting is not comfortable for long, so I either stand or kneel down if I need to type on my computer.

All that I need for this treatment is delivered every two to three months to my home and I keep it all in a cupboard in the kitchen.

In the United Kingdom we have a National Health Service which means that all medical treatments are free at the point of need, because they are paid for collectively out of general taxation. I am very thankful that I have not had to meet any of the cost personally over so many years.

I am 61 and I have been a minister in the Church of England for thirty-six years and I thank God for the fulness of life I have enjoyed.