

MY JOURNEY THROUGH CIDP

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Early in 2016 I noticed numbness in the soles of my feet. Someone suggested “cool laser” treatments. After 15 appointments with no results, I gave it up. I was kayaking, riding my bike along trails, and playing with a band. I was 81 years old.

My wife and I celebrated our 25th anniversary August 8, 2017, so we booked a Danube River cruise. Disembarking from the aircraft in Frankfurt there was, as usual, a crowd pushing for the exit. I failed to notice the six-inch drop from the aircraft to the ramp. With no feeling in the soles of my feet, I must have put my foot half-way off the step and fell on the ramp. Attempting to get up, before I got trampled, I had severe pain in my right foot.

There was nothing to do but carry on to the bus and on to the boat. I limped around until a lady loaned me a cane. This helped, but we missed out on the walking tours in Vienna, Budapest and other places.

When we got home, I saw my doctor, who had trained as a neurologist in Ireland, but was now a GP. He told me I had broken my metatarsal bone. He attended to it and made an appointment for me with Dr. K, an experienced neurosurgeon. This was Sept 26, 2017. I was using a cane.

My first MRI was November 12 in Hamilton on what Dr. K called the lower gut. I was back in D. K's office December 27 as nothing was determined. My next appointment was January 3. By now I was using a walker. D. K asked me if I could go into the US. I said yes and he told me about the Seton clinic in Amherst, NY. My second MRI was the next day on the middle gut and cost \$760 US. I saw Dr. K again January 11. This time I fell flat on my face in front of the doctor, his receptionist, my wife and the other patients – a bit embarrassing. Dr. K commented, “Next time I see you, be in a wheelchair.” From then on, I used a wheelchair.

We were living in a brick bungalow in the north end of St. Catharines, with a big covered deck, breezeway leading to the garage, a 150-foot backyard, trees, shrubs, flower, etc. We had planned to stay there forever. Of course, it wasn't suitable for a wheelchair. We found a single-story townhouse with wide doors. I was unable to climb the two steps from the garage to check the place out. Luckily the realtor and my wife got me in. We obtained a lift for the garage and a stair chair to go downstairs and had the tub removed and an accessible shower installed.

I had an emergency MRI on January 13 in St. Catharines on the upper gut and was back in Dr. Ks office three days later. Next it was St. Catharines hospital January 29 for a CT

scan and back to Dr. K on Feb 2. Okay, enough is enough. I took it upon myself to phone the Seton clinic for an MRI on the brain, on February 6. Back to Dr. K three days later, but all they found was a narrowing of an artery in the brain – the least of my problems. Next was an appointment for a spinal tap on February 26 with Dr. K. As soon as he looked at the fluid, he mentioned that my problem looked like CIDP. On March 7 he made the firm diagnosis. Wow, what a trip!

I was set up with IVIG in the St. Catharines hospital starting April 11. Each visit took about four and a half hours. I got a lot of reading done but never met another CIDP patient. Apparently, privacy is a big deal even though I told the nurses to give them my name. CIDP is a lonely journey.

So, IVIG from April 11, 2018, every three weeks until June 13, 2019. Then Dr. K took me off the treatments saying, "That's as good as you're going to get."

So, now I'm in remission. When Dr. K retired, he asked Dr. B to look after me. I went to the clinic in Hamilton twice, for strength tests, electric current, etc. My last contact was summer 2020. Dr. B wished me well and removed me from his patient list.

The only problem I have is with my left knee. It got crunched when I fell between the bed and the wall, too small a space for me. I stretched ligaments in my knee and wear a brace now. So, here I am, 86 years old and in remission. I feel very fortunate as very few achieve this.

I'm a woodcarver. I did songbirds for a few years, but carve aircraft now (33 years in the RCAF). I play my harmonicas in a band. Well, until Covid is done with us, I stay home or go shopping with my wife – wearing our masks.

I realize I am extremely fortunate in so many ways. I wish there were a secret I could share, but it appears to be simply luck.

My thanks go out to Dr. Matt Greenway, my GP. who had the wisdom to send me to a neurologist, Dr. Ed Klimek who didn't quit until I was walking, and Dr. Steven Baker, who put the finishing touches on my CIDP journey.