



## *A DOCTOR WITH CIDP FOR 28 YEARS*

*by Dr. Kenneth Shonk*

*Originally Published 2016 Spring/Summer  
Newsletter*

I have been asked to write an article about my experience with CIDP over the last 28 years. It was actually in April of 1988 that I first developed my symptoms and coincidentally they started about 2 weeks after a hepatitis B shot. I had been disgustingly healthy up to this point with missing one week of school in Grade One with the chickenpox and not having another sick day for almost 40 years. I was your typically stubborn male who ignored the tingling and numbness in my legs until I also developed muscle weakness. I was helping to coach my son's hockey team and at the practice I skated onto the ice, fell down, got up and fell down again. I was not Wayne Gretsky but I had played hockey for several years and when I had to crawl off the ice, I realized that something was amiss. I had all kinds of ideas about what was wrong with me and they were not the optimistic kind. I have looked after a fair number of doctors as a family physician and sometimes their anxiety levels are higher than normal because they know all about the worst-case scenarios. I had myself with ALS and a few other doomsday diseases.

Knowing that a doctor who treats himself has a fool for a patient and a fool for a doctor, it was time to seek expert help. The first neurologist I saw did not know what I had either so I felt better about my ignorance. He did however make the appropriate referral to London where I saw Dr. Hahn. I think she had me pegged with CIDP within a few minutes. At this point I was unable to walk and in a wheelchair. I will freely admit that even as a doctor I had never heard of CIDP. I did not feel so bad when Dr. Hahn informed me that it was quite a new diagnosis and if I remember correctly, she said that there had only been 15 cases diagnosed to that date. (I certainly stand to be corrected here as I am going back 28 years) I began describing my symptoms in medical terms and was instructed to use non-medical terms. By using medical terms, you tend to favour the terms that correspond to your predetermined diagnosis and this can lead to misdiagnosis. I was admitted to Victoria Hospital where I had trained as a student and even presented at neurology rounds. The doctor truly becomes the patient.

I had a number of plasmaphoresis treatments and was started on a high dose of prednisone. When I returned to see Dr. Hahn in a couple of weeks I was now walking with a cane and I did a little Charlie Chaplin routine for her. Remembering that I was in a wheelchair on my first visit, Dr. Hahn was worried that I had become manic on the prednisone but my wife informed her that this was normal for me.

I was also asked to mention my sideline interest in humour, which incidentally started at about the same time in 1988. I have been speaking about humour publicly now for 28 years and have completed over 900 presentations to just about any group that you can mention including several of the GBS/CIDP Conferences. I am continually amazed at the diverse groups interested in this topic. A few years ago, I spoke at the International Plowing Match here in Roseville and three days later spoke at Grand Neurology rounds at the University of Alberta in Edmonton. I did clean the manure off my shoes before heading to Edmonton! I have observed that while speaking I usually don't notice any of my CIDP symptoms other than my balance deficits. Mind over matter?

I have had at least a half dozen relapses of my CIDP and even as a physician I have been unable to pin down what triggers them. I am to have a reassessment next week in London. Wilma Koopman

has put up with me for all of the 28 years and has had to listen to my lousy jokes. Which allows me to tell you about the 104 year-old lady who was asked what was good about being 104? She quickly replied:” No peer pressure.”

Adjusting to my CIDP symptoms has been somewhat of a challenge. I was the male athlete of the year in Grade Thirteen (albeit a rather small high school) and to not be able to run or even walk very fast is certainly an adjustment. Fortunately, I was able to play hockey, slow- pitch baseball, basketball, windsurf, sail, kayak, ski, and white water canoe for the years before my illness. I have continued to canoe on a smaller scale and on my own I have found that cycling and swimming do not require a lot of peripheral balance.

I have also been fortunate in that my wife and I have done a lot of travelling early on and I would encourage younger people to take those trips when you are young and healthy enough to truly enjoy the experience. Don’t leave everything for the retirement years. My wife and I have also recently moved to a retirement community and now have a bungalow with a walk-in shower, wide doorways and lots of handrails in case things get worse. Having a daughter who is an Occupational Therapist doesn’t hurt either.

Family support is also extremely important and we are fortunate in having all three children and the nine grandchildren within 30 minutes of our new home. I actually get as much pleasure out of watching the grandkids hockey, baseball and soccer games as I got when I played myself.

I think that my overall message is that your life does not end with a diagnosis of CIDP and that you need to focus on what you can do and not on what you can’t do. Take that anger, frustration and depression and channel that energy into what you can still manage to do. I would also encourage you to be willing to laugh at yourself. If you can truly laugh at yourself, it means that you are comfortable with who you are. I tend to fall a fair bit because of my proprioception loss in my legs. I recently made a trip to the bank and it was a snowy and icy day. On the way to my car I passed an older lady who I thought really shouldn’t be out walking and as I passed her, I stepped in a hole and went down very unceremoniously on my butt. I had a flicker of anger and then I started to laugh at my own stupidity.

My overall message is that we were given the ability to smile and laugh for a reason and a lot of us just don’t use it often enough.

As Jeanne Banks said:” LAUGHTER WILL HELP INNOCULATE YOU AGAINST THE GRUMPS AND WILL DECREASE THE NUMBER OF SCOWL MOVEMENTS YOU HAVE EACH DAY.”

Yours laughingly, Dr. Ken Shonk.