

Never Give Up!

Gary Croll - May 23, 2018



My name is Gary Croll and I am 66 years old. My story starts as a teenager when my hands started locking up & I wasn't able to release objects I was holding. Our family doctor, (a DO), was the only medical help available to me and eventually the problem subsided on it's own. I was aware at even that young age there was a problem because I had an awkward gait and tended to fall easily.

Fast forward to the mid 70's, I'm married, working and starting to have the locking problem again. I went to a neurologist, had the nerve conduction studies done, was hospitalized a week for testing, and the diagnosis, I'm "wired wrong".

Years later I was living in California and was having problems again and started seeing a neurologist for hand locking, headaches, balance issues, etc. The diagnosis, I'm "wired wrong".

Now we're in the early 2000's, I'm in Arizona and the same problems are starting again. There are 3 neurologists in our town & I've seen 2 of them. They did their testing, physical exam, EMG, (nerve conduction), muscle biopsy, etc. The diagnosis, I'm "wired wrong". By now I have found an extremely good internal medicine doctor who has taken a personal interest in my case. It turns out I am a type 2 diabetic with some peripheral neuropathy. I also told him of my neurological issues and he referred me to the 3rd neurologist in town.

In 2017 I began seeing my current neurologist. My most recent neurologist had forwarded him my file. On my first visit, he seemed very confused saying he didn't expect to see me walking into his office. He said typically, patients with EMGs like mine weren't able to walk. He did a thorough exam & repeated the EMGs. By now I was also having contracture of the right hand, muscle atrophy, and more balance issues. I had hand surgery in March, (no help), followed up by 8 months of physical & occupational therapy, (also no help). By now my neurologist had made the diagnosis that I had CMT, Charcot-Marie-Tooth), disease, a degenerative neuro-muscular disease in the MD family. As I did the research on CMT, I was devastated, no treatment, no cure, no hope.

I had my regular checkup with my neurologist several months ago and he told me after further studies, he's not convinced I have CMT but it would take genetic testing to know for sure. I had the testing and the marker for MMN was 16 times normal. I began my IVIG treatments last Friday and I have an appointment with Dr. David Saperstein, (one of the nations recognized specialists in MMN), on June 5th.

My journey has certainly not been typical, I've been able to lead a full, active, and productive life and I look forward to many more years traveling with my wife & dogs in our RV. I cannot emphasize enough, NEVER GIVE UP! If you are not getting the answers & treatment you need then keep looking. Do your own research and most of all, find a doctor who will actually listen to you and not just brush you off.