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[The Cryptid Sloth Show Episode 5: Road Part Trip Conclusion](#)

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Transcript

I looked down at the sticky note that the doctor had handed me. In an instant, I remembered what the nurse at the clinic in 1994 had asked me. Suddenly, ah-ha! Everything started to make sense. What was it that the doctor wrote on that little sticky note though?

[Theme Music]

Stop standing there! Attention, everyone!

The Cryptid Sloth Show: Where CMT and Life Meet

With your host...

Kenneth Raymond

[Theme Music Ends]

Welcome to the Cryptid Sloth Show, everybody. I'm your host, Kenneth Raymond, I have CMT, and this is the conclusion of my road trip to diagnosis. If you haven't caught the first part, make sure you go back to the last episode and give it a listen. Today, we're picking up right where we left off.

In 1998, I moved from Detroit to Traverse City. If you're unfamiliar with Michigan, hold up your right hand, palm facing you. Detroit's at the base of your thumb, Traverse City's at the tip of your pinky. This is how you know somebody's from Michigan—you can hold up your right hand and point to where you're at. But I had left the automotive tech field prior to this because I just couldn't do the type of work any longer. Immediately after relocating, I went to work in a factory assembling car component parts. Go figure. Turn-signal switches, to be exact. I know, fascinating, right?

A few months later, I transferred to another factory the same company had in Traverse City. This factory was a high-speed metal stamping plant, and I became a machine operator there. I developed issues with my hands that were like Carpal Tunnel Syndrome, and by late 2000, people I worked with had developed Carpal Tunnel Syndrome, and their cases were determined to be work related. My hand issues were similar to theirs, and despite mine having been going on for years, they were obviously related to my job, too, right? I set up an appointment to find out and to get my hands fixed.

At the appointment at the Occupational Medicine Clinic because that's where you go for work related things, they took X-rays and performed a test that sends an electrical signal through a nerve in the arm, down to a finger, and makes the muscle jump. Now, we CMTers know this to be a nerve conduction study, of course, but I didn't know this at the time. They did the test on both hands, the tech who performed the test looked to be younger than me, and I was 28 at the time, kept making weird faces throughout the test, but he wouldn't say why, despite me asking him several times. And at the end of the appointment, I was given hand and wrist splints and told to wear them at work and scheduled for a follow up a month later. Pretty much standard stuff at the time.

At the follow up, they explained that the test they had previously performed showed that I had nerve damage in both elbows. They said they could not explain it, that it was not work related, and that there was nothing to be done about it. Interesting, right? Back to work I went, I put their findings out of mind, and I decided that it was just part of my normal. So be it.

In the middle of this, my primary care doctor referred me to the pain management program that was ran by the local hospital. My legs were always in constant and excruciating pain, and they had been since I was a kid. My doctor wanted me to hopefully get some relief, and he thought the pain clinic would be the right place for me. I was so tired of being in constant pain, and I was more than willing to see what could be done, if anything.

At my first appointment with these guys, which predates my Carpal Tunnel eval at Occupational Medicine, I told him I thought my leg pain problems were direct result of my knee issues. They didn't seem to disagree. They started me on pain meds, and they had me start physical therapy. I was on board with their approach, and I was optimistic. But, after about two years of physical therapy, knee injections that did nothing, several pain medication changes that included some hardcore opioids, were getting nowhere. Nothing had improved. They decided I should see an orthopedic surgeon for my bad knee, and in early 2001, I had the first appointment with that surgeon.

The first appointment with the surgeon appointments with an orthopedic surgeon. The surgeon checked me over, we talked about the previous surgery in 1990, took some X-rays, and then talked about what he thought were my best options. By the end of the appointment, I agreed with him that surgery would solve my issues. And, about two months later, in March 2001, I had my second surgery on my left knee.

The second surgery on my knee was an arthroscopic procedure. The surgeon did what's called a Lateral Release. A Lateral Release is a procedure in which the surgeon removes a piece of muscle from the lateral edge, or outside edge, of the knee. Dude also remove the screws from the previous procedure, removed a bone spur from the kneecap, and cleaned up the contact surfaces of the joint. Sounds like a lot, but I was awake for the procedure, and it took less than 30 minutes, start to finish.

The surgery was on a Thursday. The plan was to be off work for the weekend and to return to work that Monday, as though nothing happened, but with a brand-new knee. Yeah, that's not how it went. It's not how it went at all.

<Bruh!>

Following the surgery, I was supposed to limit how much I was on my feet the following day. By Saturday, I was supposed to be able to weight bear, and walk without much difficulty. By Sunday, I was supposed to be back to my normal, fully bending the knee, walking, handling stairs, doing everything that I would normally do. On Monday, I was supposed to head back to work in a job that required me to be on my feet for the full day, fully functional, with a brand-new knee that was supposed to be life changing. The reality, however, was far different.

The day after surgery, Friday, I couldn't bend my leg at all. It was locked up tighter than after a knee dislocation. The pain was just as bad as a dislocation. I couldn't put any weight on the leg either. Saturday was even worse. On Sunday, I started forcing myself to put some weight on it, and, I started to forcibly bend it. It was more difficult to bend than after dislocation. The movement I was able to get was minimal, despite my efforts. Monday, the day I was going back to work, it wasn't any better.

I was working afternoons, and I started my Monday morning by trying to bend my leg even more than on Sunday. I needed my leg for work. Couldn't do my job without it. However, no matter

how much I tried, the knee would not bend more than a couple degrees. I called the surgeons office to let them know and to see what the surgeon wanted me to do. The surgeon called back a little while later, told me that I just needed to put in more effort. Dudes, I couldn't even tie my own shoes because I couldn't bend my leg enough to reach the laces. Nonetheless, I still went to work. Luckily, I worked with a great group of people who were more than understanding and extremely helpful. I shouldn't have been there though.

My first post-op follow-up visit with the surgeon was two weeks after the surgery. I was still in an excruciating amount of pain. I still couldn't bend the knee more than a couple of degrees. I could barely weight-bear. I was in absolute misery. Surgeon told me that he gives me an A for effort, but a D minus for willingness. The surgeon blamed my situation on me, telling me that I was not trying hard enough, that my lack of progress was my own fault. I'll never forget this. I can still hear his voice saying it 20 years later. What was supposed to have been a short recovery period, turned into one that took several months of physical therapy and just soldiering through.

I finally decided in the Fall of 2001 that I had reached as full a recovery as I was going to get from the second knee surgery. My knee wasn't any better than before, I was grateful to have the screws from the realignment procedure gone, but that was my only highlight. The screws the second surgeon removed were the screws that the surgeon in 1990 used to reattach the patella tendon to the lower leg. There were two screws. Both screws were on the front of my leg at the top of the lower leg just below the knee. The screws were situated just perfectly so that whenever I kneeled down, I would kneel right on top of them. Every time I did this, the heads of the screws would stab me from the inside out. It was invigorating. Much like my first surgery had only one positive, removing the screws was the one and only positive to come from the second procedure. Like I had done several times before, I accepted my normal, and moved on. However, life would change forever again, about a year later.

I continued as a patient at the pain clinic. They were doing the best they could to help, but there wasn't much relief. Really, the only thing the pain clinic did was to create a legal addict, but that's for another episode. My legs were still my primary complaint. Everybody agreed that the root of this was still my bad knees. So, in August 2002, pain clinic had me see a different orthopedic surgeon just to get fresh eyes on my situation. Although this appointment started like the others, it ended very differently.

Orthopedic surgeon walked into the exam room. He was an older guy. He looked to be in his late 60s. He had a thing about him that said he was old school. He came across like he did things differently. We talked about my history extensively. He was more interested in my first knee surgery than he was my second. He looked at my shoes and asked about the heel wear pattern on the very outside edges of the soles. Nobody had ever asked or even pointed it out. It had always

been my normal, and I told him that. He then had me walk down a long hallway in his office, then back to him. He called over another doctor, and then he had me do the walk again. During the walk, I could hear him whispering something, but I couldn't make out any of it. He wrapped up the appointment right after that and he said he needed to send me for some testing, that his scheduler would get it taken care of while I was still there. So, I spent about 20 minutes and check out with staff setting an appointment for whatever this testing was. I didn't know what the testing appointment was going to entail, nor did I know with whom it was. I only knew there was going to be testing, and that it had something to do with my bad knee.

I arrived at the appointment and the sign on the building said they were a rehabilitation and physical medicine facility. I had never heard of such a place. Staff listings on the wall inside the place included physical therapists, occupational therapists, and physiatrists. I knew what the former were, but I had never heard of a physiatrist, and I had no idea what they did. However, I quickly learned at check-in I was there to see a physiatrist, who, by the way, is a physician who specializes in physical and rehabilitative medicine. Things are getting interesting now, right?

After check-in they called me back within a few minutes and drop me into a small, dimly lit exam room. A few minutes later, a tall, gangly mid-50s guy walked in. He wore large and thick eyeglasses. He spoke with a slur that is common with hearing impairment. He was the exact opposite of all the doctor stereotypes. I was not expecting him to even be the doctor until he introduced himself. I thought it was going to be a tech of some sort, being that in that room there was a computerized machine with lots of wires attached to it.

An assistant had come in with the doctor. The doctor had me kick off my shoes and socks, performed what I would learn to be a typical neurological exam, with his assistant jotting things down as he blurted out numbers that were between 1 and 5. Doctor checked my reflexes and that's when the mood changed in the room. I have no deep tendon reflexes. I never have. Deep tendon reflexes are the reflex responses that happen when a doctor taps on the various joints with their little reflex hammer. No doctor had ever gotten a response from me.

By this point, the doctor had already told his assistant that my feet have high arches. His exact words were, and I remember them clear as ever to this day, "Those are what high arches look like. We're just appeasing everybody who comes in here complaining about high arches. But these are what high arches look like." I knew my arches were higher than others I had seen, I just never gave it any thought, and no doctor had ever pointed it out. But when checking my reflexes got this doctor's attention, I started to pay attention, too.

The doctor started at my elbows with his little hammer, first the right, then the left. He said, "C7 absent." Then, with his thumb wrapped around the bend of my arm he tapped his thumb. First my right arm, then the left. "C-5 absent. Hmmm." Next, the knees. First the right, then the left. "L-4 absent. Huh." Finally, the ankles. He says, "Just as I thought, S-1 absent." Then he asked how long have I not had any reflexes, and if it was something new. Of course, I told him nobody has ever gotten a reflex response out of me. He replied with a simple, "huh."

After this little exchange, he had me lay back on the exam table and started to perform the same test I had done a couple years earlier on my hands when I was being evaluated for Carpal Tunnel Syndrome. This time was different, though. The doctor seemed to be doing things more deliberately and this time was much more involved, testing more in my hands and forearms, and he performed the test on both legs and feet, not just my hands, as I had previously done. And, you all probably know what's coming up next, right?

After the doctor finished performing the test, he had me sit up. He then told me he knew exactly what was causing my issues, and he knew exactly why the orthopedic surgeon referred me to him. He wrote something on a sticky-note and, as he handed it to me, he explained that I have something called... You ready?, "Charcot Marie Tooth disease, or CMT for short." He explained that the disease is caused by a gene mutation, that is something I was born with, that there is no treatment or cure, and that it is not something that is considered to be fatal. He explained that CMT is rare, that there are a couple of types, and that the test had just performed the good old nerve conduction study that we all know, indicates what is known as CMT Type 1. He then told me that he needed to order some blood work to see if he can figure out the specific type.

I asked if he was confident about me having the CMT thing. He explained that he was 100% certain, and that I have always had it. He further explained that he was absolutely certain that I have CMT Type 1 based on the N-C-S findings, and he explained that he was fairly confident that I had CMT1A because that is the most common type of CMT. He also explained that the blood work he ordered he ordered should be able to determine if I had what he called 1A. Continuing, he told me that he knew when he first looked at my feet that I had CMT. In telling me this, he explained that my high arches, hammertoes, how my feet turn in, and how having no reflexes are all telltale signs. Suddenly, everything from the Fall of 1994 came rushing back.

<Bruh!>

I looked down at the sticky-note from the doctor. What did he write on it? "Charcot Marie Tooth disease Type 1." In an instant, I remembered what the nurse at the clinic in 1994, had asked me. Remember the nurse? She had asked, "has anybody ever told you you have Charcot Marie Tooth

disease?" I told the doctor the condensed version of the story. He was in utter disbelief that my primary care doctor at the time dismissed it as nothing. I then remembered my eval for Carpal Tunnel Syndrome, and I asked him for his thoughts on that.

He explained that he was not surprised the people at the Occupational Medicine clinic didn't know what they were looking at. He told me that the training for the techs at those clinics only covers things like Carpal Tunnel Syndrome, and if anything else is showing, they decide that everything is fine. He also explained that the physicians at those clinics who review test results like what was done on my hands for Carpal Tunnel Syndrome aren't trained to recognize when something is not Carpal Tunnel Syndrome, when something is CMT, on their nerve conduction studies. He further explained that the reason they thought I had nerve damage at my elbow was because the nerve they were testing, the ulnar nerve, which runs across the back of the elbow, and my nerve conduction speeds are one-third of normal speed. Normal is around 60 meters per second. Mine are 19. He explained that there was no way a tech at that clinic could have known what the finding indicates because the training they receive does not cover anything beyond something like Carpal Tunnel Syndrome. He further explained that the doctors there aren't going to know what it indicates, and it's really not their job to refer you out to everybody else that could otherwise help you. It's only their job to determine if something is work related or if it's not work related. Nothing more than that.

I wasn't expecting a diagnosis for anything, especially not for something that has no treatment or cure. However, hearing the diagnosis was relieving. It provided answers to questions I had always had. The diagnosis, while my knowledge base was nonexistent, but after the doctor explained everything, fit what I had spent my lifetime dealing with. The nurse at the clinic my employer sent me to 8 years earlier, was right. My orthopedic surgeon who sent me to the physiatrist, saw something but didn't say anything, instead, opting to send me to somebody who would know for sure. The orthopedic surgeon would tell me at my follow-up with him that he knew what I had based on what he saw with my feet, what he noticed with my walking, and with what my complaints were. But that he didn't have the tools or skill for being sure. This diagnosis, even though it was something that has no treatment or cure, was nothing but good. Finally having an answer, as great as it was, however, was also kind of sad.

You see, my mom, who had done everything she could to find the answers that would explain my physical issues, died two years prior to my diagnosis. She didn't get to know the answers. When there were no answers, she blamed herself for having done something wrong. Receiving my diagnosis after she died just wasn't fair. She should have been able to know that all the doctors through the many years were wrong, very wrong, that there was something actually going on and it is something that nobody had any control over. She should have been able to know that my issues were not because she did something wrong. My mom should have been able to know this especially since, I would learn in 2004, that I inherited my CMT from my dad. As it

turns out, her efforts to find the answers were not in vain though, because now I have the answers to so many whys. I find solace in knowing this.

There were so many missed opportunities on this road trip. An Occupational Medicine clinic nurse in 1994 knew what was up, but my doctor dismissed it. In 2001, Occupational Medicine, again, saw that something wasn't right, but didn't know what they were looking at and didn't know how to proceed. I was genetically confirmed to have 1A in 2003. One of the hallmarks of 1A is that nerve conduction characteristics are pretty much locked in by the time the CMTER is 5 years old, regardless of being symptomatic, and these characteristics are uniform within each peripheral nerve. The ulnar nerve in the arm will exhibit the same conduction characteristics as the sural nerve in the lower leg, with 1A. Had somebody at some point over the years with all the doctors I saw I saw to have this stuff checked as a kid, somebody would have seen that something wasn't quite right. All of these missed opportunities, however, are not uncommon for CMTERs. A missed diagnosis and a wrong diagnosis are far too common in the CMT patient community.

<Bruh!>

And my diagnostic road trip is not unlike most CMTER's road trips. To quote Paul Harvey, "And now you know the rest of the story."

That's all I have for today everybody. Thanks for letting me climb inside your earball and I look forward to chatting with you again really soon.

As we close, no matter who you are, no matter where you're listening from, although so very few people have ever heard of CMT, I want you to know that you are not alone, and that we're in this fight together. Thanks for tuning in. Make sure to visit the website at thecryptidsloth.com, a website dedicated to all things CMT, where you'll find our show notes, the episode library and The Cryptid Sloth Blog. Follow us on your favorite social media, and you can find me, your host, Kenneth Raymond, in many of the Facebook CMT groups. Thanks again, and I look forward to talking to you really soon.

This has been The Cryptid Sloth Show Podcast: Where CMT and Life Meet.