

Audio file

[The Cryptid Sloth Show Episode 4: Road Part Trip 1](#)

Transcript Authored by Kenneth Raymond

Transcript

It was January 1986. I was 12 years old. It was mid-afternoon on a Saturday. I was at my friend Tony's house one block over from where I lived in Suburban Detroit. We were in his backyard. It was cold, very cold. It was grey and it was dreary. There were a few inches of snow on the ground. It was a typical Detroit dead-of-Winter day. It was nothing out of the ordinary. This, however, was about to change.

[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 my road trip to diagnosis.

There I was in Tony's backyard, in the dead of winter, in Detroit. For whatever reason, I decided to climb the giant oak tree that was in his backyard. Despite all my physical issues, I enjoyed climbing trees when I was a kid, even though I was never particularly good at it. I had a tough time climbing with all the reaching and the pulling, and I had a tougher time coming back down with all the hanging and dangling. But I was just a kid, and climbing trees is what kids did back in the day; and I just wanted to be like everybody else. This climb, however, was about to be completely unlike any previous tree climb, and it was the only one of its kind for me.

The lowest branch of the tree was just beyond my reach from the ground. Pulled a chair over from the patio and use that to boost myself up. Then up the tree I went. Tony stayed on the ground as he usually did, he wasn't much of a tree climber, just meandering around, doing whatever he was doing. I can't remember what he was doing, I'm old.

I slowly climbed higher and higher, carefully planning, and then executing each little move. When I was about even with the top of the roof of Tony's two-story house, about 20 feet up, or so, something happened, and nothing was ever the same again.

I had grabbed the branch that was just above shoulder height and slightly to my left. After grabbing it, I had to pull myself up a little while pushing up with my legs and then twist to the left just a little so that I could step up with my right foot, and then onto a branch that was just adjacent to where my feet were planted. I had my feet wedged into a "V" formation at the base of a couple of large branches. My left foot was just under my right. If you can picture it, I was basically standing on top of my left foot.

As I pulled up with my arms, I pushed up with my feet and twisted to my left, just a little bit, just as I had planned, just as I had done countless times before. As I twisted, my left foot remained wedged and stayed planted And, that's when it happened.

♪ POP! ♪

I could feel that my left kneecap, the one that had just caused that loud "pop," was now sitting on the side of my leg. Without thinking. I immediately crouched forcing that need to bend. As I crouched, my knee let out another loud "pop" and I felt my kneecap snap back to where it's supposed to be. This all happened from the first "pop," to the crouching, to the second "pop," in a split second. It was crazy fast.

The crouching while 20 feet up in the tree was an automatic response. It was not a conscious reaction. I think this crouching though is what made my kneecap snap back so quickly; and fortunately, in the middle of all of this, I actually had help from the tree.

I had been leaning against a large vertical branch as I was making this last move, thankfully, because the very instant that this pop happened, I crouched down with my foot still wedged. Had I not had that large branch to lean against at that very moment, there's no telling what would have happened. I may have even fallen out of the tree. There was also an adjacent branch just to

my left that I was able to grab on to for support. I was hella lucky, despite what had just happened. But what was it that just happened? Many of you have lived this. Many of you know this. My knee had dislocated and then relocated all on its own. It's a feeling and a sound that has stuck with me ever since. It's not a sound or a feeling that somebody can forget.

I've struggled over the years to find the right words to describe the exact feeling and sound I just experienced. I have yet to find them. I have never heard a similar sound that I could relate it to. The pain was excruciating, to say the least, and I have not felt anything else that comes close to that exact feeling of the process of what had just happened to my knee. It's a unique experience, to say the least.

♪ Bruh! ♪

There I was 20 feet up in a tree My knee had just dislocated for the first time, and, again, at 12 years old. Life had just changed forever. I was screaming in agony. The pain I was feeling to this day is indescribable. Tony, who remained on the ground, was freaking out because I was screaming. Go figure. He knew there was something wrong, but he had no idea what it was. It took several minutes, but I was able to calm down enough to holler down to Tony that my knee had just popped out and I couldn't bend my leg. My left leg was frozen stiff. I couldn't bend my knee even a little bit. Then, it hit me. How was I going to get out of this tree in one piece?

Tony's parents weren't home. There was no adult supervision or assistance for getting me out of this tree. It was just Tony and me. Just a couple of 12-year-old kids. The climb down from the tree was slow, it was deliberate, and it was arduous. Tony and I worked as a team though. He helped me to keep my calm, talking me through each small maneuver. I followed each of those with a long break. I used each break to rest and for Tony and me to carefully plan out my next move. I don't know how long it took to get down from that tree, but it seemed like it took a lifetime.

When I finally got back down to my starting point, Tony grabbed a stepladder from the garage and he propped it up against the tree where I could reach it. Without the ladder, I would have had to have either jumped down to the ground from the lowest branch, something I would have willingly done prior to this day, or I would have had to have dropped from the branch to the chair I had used to start my climb. Given the state of my knee and leg, neither was an option. Thankfully, there was a ladder available.

Safely out of the tree back down on the ground, Tony helped me hobble home. After explaining to my mom what had happened, she took me to the hospital where I learned that my knee had dislocated. Duh, right? The doctor there told us that my knee dislocated because of a birth defect I had. This was the first mention of any kind of a birth defect, even with all the doctors who had laid eyes on me over the years, trying to figure out what was going on. According to this doctor, both of my kneecaps ride remarkably high - a condition called Patella Alta. He said that it's a birth defect and that I should expect this to happen again with both knees, that there was not much they could do about it. He said I just had to learn to be careful. Again, sound familiar?

We took in what the doctor had to say, and then we headed home. I would never again climb a tree. To this day I haven't climbed a tree, except for using an extension ladder to hang birdhouses, for my wife, in our big, huge maple tree. But that's a ladder, so it doesn't count, right?

♪ Bruh! ♪

The recovery from the knee dislocation took about six weeks. That recovery included crutches, a cane, a brace, and lots of physical therapy before I was able to use the leg normally and without any assistive device. Now that I was finally able to get around decently, and seven weeks to the day after that first dislocation, it happened again when going down the front porch steps at home. The doctor at the hospital was right. It did happen again. For the next five years, It would happen so often that knee dislocations became my normal. But at least it was only my left knee that would dislocate and not my right. So, there is that.

After this second dislocation, the family doctor sent me to an orthopedic surgeon. The surgeon disagreed with the emergency room doctor and felt that he could help, but he said we had to wait until after I was done growing. Yea! With each next dislocation rather than going to see the orthopedic specialist, my mom would just simply call his office, he would make a referral to physical therapy, and we would just go through the motions. It was literally just my normal.

One of my dislocations happened when I stopped and turned too quickly while running. Another one happened when somebody deliberately tripped me in the hallway at school. Fun times at school because I was that kid. I had a dislocation from rolling my ankle while walking across the front yard. After recovering from that one, and, while still wearing the brace that was supposed to prevent knee dislocations, yep, dislocated again. This one happened when walking down the sidewalk past two loose dogs, and one of them bounced off my leg. In all, my left knee would dislocate 8 times between 12 years old and 17 years old. Sometimes it would go to the outside,

and sometimes it would go to the inside. I can't remember how many for each, but most of my dislocations went to the outside.

With each dislocation, I would instinctively and immediately crouch, or bend my knee, causing the kneecap to snap back. I never had to have a doctor put it back in place. I was always fortunate in that regard. After the 8th dislocation and at 17 years old, I had surgery on my left knee to correct the dislocation problem.

I had a procedure on my knee called a patella realignment. This was in June 1990. As the name suggests, the surgeon realigned my kneecap by moving the tendon that holds the kneecap in place. The goal was to better hold the kneecap in place so that it would no longer dislocate. Makes sense, right? The good news is that the surgery achieved that goal. My left knee only partially dislocated, and only once since the surgery. Of course, true to form, this partial dislocation happened while still recovering, and during a post-op physical therapy session. However, that was the only time it happened since surgery. It's the only positive, actually, to come out of that surgery, too.

You see, unbeknownst to anybody at the time, I had CMT 1A. Had we known at the time that I had CMT, I don't know if it would have informed the decisions of the surgeon, nor do I know if my CMT contributed to the subsequent issues that developed immediately following surgery. It might be a safe bet that my CMT did contribute, but we don't know for sure. I do know though, that during the procedure, the surgeon, when reattaching the patella tendon, did not pull the tendon down enough before reattaching it. This has caused my kneecap to ride even higher than it already was.

I have had significant mobility issues with the leg since surgery, my left foot has flopped since immediately following the surgery, and the knee has not bent normally since the surgery. Within all this bad, the knee has not dislocated since I was 17 though, and I'm OK with that, all things considered. My right knee has dislocated but I can count the number of times it's done so on one hand, and each of those dislocations were minor with no downtime. Again, I've been lucky.

♪ Bruh! ♪

By the mid-90s, I was working as an automotive tech for a company that did prototyping for one of the Detroit automakers. While at work, I had a fall that happened because of an ankle roll. Go figure. The company insisted that I go to their clinic for an evaluation, even though I felt I was fine. I had bruised my pride because of the audience I had when I blew out my ankle, but I was

otherwise fine. The whole incident was just part of my normal, but, the company insisted that I get a checkup, so off I went.

While at the clinic, the nurse triaging me asked an interesting question. I was sitting in the exam room on the gurney with my feet dangling. The nurse came in, asked about what brought me in, and I filled her in with all the details and I let her know that I'm fine that I'm only there because the company required it. She had me kick off my shoes so that she could check out my ankle. After doing her thing, checking range of motion, and all the hoopla, she asked me if I had a long-winded name of a disease. I had never heard of what she asked. And, I told her no. She said that that was strange because my feet looked exactly like I should have that disease. She also told me that ankle rolls, the very reason why I was even there, were very common with that disease. Again though, I had nothing to give. I was clueless. Interesting, right?

After some X-rays, it turns out I had a mild ankle sprain, but no other injury. I went back to work afterwards with no issues. But, did I just unexpectedly receive a diagnosis for a strangely named disease? I better check with my own doctor, right? Y'all probably know where I'm going with this, too.

Few days later, I set an appointment with my family doc for the following week. At the appointment, I told my doctor about why I was there by giving him the full account, the whole ankle roll, and everything, and he didn't seem to be very interested in what I had to say. I was OK with that though. I did get his attention though when I mentioned the long-winded and strangely named disease that the nurse at the clinic thought I might have.

He gave me a quick once over, then schooled me on how the nurse had no business asking me if I had any disease or condition because she didn't have the education nor the experience to know if I had whatever it was, blah, blah, blah; yadda, yadda, yadda; this, that, and the other thing. You know how this goes. By the end of the appointment, he decided that I may, possibly, might have some form of muscular dystrophy, but said that even that was a stretch. Huh... He didn't test any further, nor did he refer me to somebody who would be able to figure it out.

I laughed about the whole idea of M-D because other doctors had previously told me that I had muscular dystrophy, that I had multiple sclerosis, that I had all kinds of other stuff, including that it was all in my head. So, hearing those words never amounted to anything for me at that time. Nevertheless, I was fine with all this and went on with life, not giving any of it a second thought.

Now, the time all of this was taking place was before the advent of the internet. Information was not as readily accessible as what it is now. I didn't have the drive nor the know-how to push the matter any farther. It was a different time, and it was a different way of life. As I went about my daily life, I forgot the name of that weird disease the clinic nurse had mentioned, I didn't write it down, and I never went to the library to look up any of it. Although I didn't give the incident and short sequence of events much thought after they took place, I never did forget about them. Then, it happened.

Eight short years later, it all came rushing back in an instant.

Welp, that's all the time for today, everybody, and this where we're going to have to leave off. Make sure you join in next time for the conclusion of my diagnostic road trip. The ah-ha moment is truly fascinating.

♪ Bruh! ♪

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.