

I have a progressive genetic disease. Should I get a test to determine how severe it is?

[Charcot-Marie-Tooth, or] CMT disease runs in my family, and many of my relatives have chosen not to be officially diagnosed. Some have concerns about insurance and privacy, but others just feel like, “What’s the point? Isn’t it better not to know?”

For me? Is it better not to know? Not at all. And maybe not for you either.

I know a man who thought he had CMT for decades but never had a confirmed genetic diagnosis.... Eventually he travelled to see a CMT expert and agreed to undergo formal testing. The tests came back, and the expert told the man that he didn’t have CMT at all! He had another disease that was easily treatable, and could have been treated decades earlier.

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Because I know I have CMT1A, I’m ready for it. I’ve made sure I’m in the system. I’m on the email lists, I’m signed up for the Google alerts, and I’m on the patient registry so that I will be notified about clinical trials that I’m eligible for.... Having a progressive disease can be a powerless place to be, but knowledge gives me back some of that power.

[\*\*This is an excerpt. Read the original post here.\*\*](#)