



Hi, my name is Tom Trovinger, I am 38 years old, and I was diagnosed with Friedreichs Ataxia or FA in 1997 at the age of 22.

Growing up, I was a fairly normal child, if there is such a thing as a normal child, and if you were to ask my parents they would probably beg to differ on the normal part. I was pretty athletic in school and played a good deal of football. I played throughout high school, and during my junior and senior year, people started mentioning that I had a bit of a limp, or I walked a little funny. I also had people mentioning to me how clumsy I seemed. Being your typical hard-headed male, I pretty much ignored this, justifying to myself that I was just a clumsy kid, or that people were just giving me a hard time.

When I graduated, a group of friends that I had played football with started a flag football team, and because I loved the sport and the team atmosphere so much, I was happy to join them. The comments about my walking continued, and my girlfriend at the time, who became my future ex wife, started mentioning it too. She often would always say “I know nothing's wrong, but you should go get it checked out to put my mind at ease”. Not being a huge fan of Doctor visits, I managed to dodge her attempts to get me to go. As time went on, my coordination seemed to be deteriorating. While practicing for my upcoming third season, I started to notice that I was not running around like I used to. I also noticed that I was having trouble coordinating my arms and legs enough to do a simple jumping jack. I decided that I had better go get this checked out. Of course, that made it seem like my girlfriend won, and I was going only because I gave in to her, thinking it would score me some brownie points.

I first paid my family doctor a visit. He examined me, and knew something wasn't right, but however didn't know what the something was. His theory was that perhaps I took one too many hits in football. He scheduled me for an MRI, and referred me to a local neurologist. A few days later, while I was at work at a retail store, my doctor called. He said to me words I'll never forget, I've got your MRI results, go home, stay off work, don't do any strenuous activity until we figure out what is wrong with you, I think you may have a tumor. Now I was always looking for ways to get out of work, but this wasn't the excuse I had in mind. A few days later, I had my neurologist appointment, and after examining me he told me that the good news is that I don't have a tumor, but I'm not sure what's wrong. He said I had a very unsteady gait, and my balance was off. All of this made me feel like I chose the wrong career path, because I could've come up with that diagnosis. He referred me to a neurologist in a neighboring city and for a cat scan. I arrived at this appointment, not very confident that I would get answers and feeling like I was wasting my money. This doctor began performing his exam and within 10-15 minutes he said, I think you may have something called Friedreich's Ataxia, to which I said well I think you're full of it, because that sounds made up. He said the only way to know for sure was a genetic test. I went to have blood drawn to have sent out for testing. When the results of the test came back, lo and behold, FA. The doctor explained to me what my future held, and it wasn't what I would call

a positive outlook. He told me about my health deteriorating, about the progressiveness of the disease, that I need to go to school to learn a job that I could do sitting down. Pretty much that my health was going to decline and I will never be as healthy as I was that day. Every person I talk to gets basically the same speech when they are diagnosed with FA. Here is what u have, here's what you have to look forward to, there's no treatment, no cure, nothing we can do, go home and good luck.

After that point, I made the decision to not accept that for my life and I've done my best to remain as independent as possible. I went to college and got a computer information systems degree, I live on my own in my own house, I've worked at a bank for 13 years, a job which has absolutely nothing to do with my degree, so if anyone knows of anyone taking applications, I'm available. I've also tried to stay active and maintain my strength as much as I can. I do a fair amount of travel, I work out and do physical therapy 10-15 hours a week. I walk in the pool, I've recently got a trike which I ride, and last year I went white water rafting in Colorado, which anyone who knows me will tell you is something I would never do. I love to do things that I'm afraid of and that I wouldn't normally have done, just to conquer my fears, and get that thrill I used to get from sports, and to prove to myself that no matter how diminished my health is, I am doing things that I would have never done before. One of my favorite things to say is that there is nothing better than the feeling you get from doing things that others say you can't do. My mom is convinced that the things I do are just to worry her to death and make her a nervous wreck, but its more a result of knowing FA is trying to steal my abilities and being determined to not let them be taken without a fight.