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Hereditary ataxia

Finding balance

Denise Drake, Donna Guillory

For years I'm sure people who didn't know me thought I was something of a klutz. Even my grandmother would tell you nothing was wrong with me, that I was just clumsy and wanted attention. But my problem was more serious than that.

As a child I enjoyed running and had the track ribbons to prove it. But I had a noticeable hand tremor, and remember taking some kind of nerve medicine to help control it. I spent the long, hot Louisiana summers with an aunt who had a swimming pool. She noticed my diving form was certainly not going to win me any medals, but then neither was my milk pouring skill.

By the time I was 10 years old, I was having trouble with my balance and coordination, and my speech was beginning to slur. Something was definitely wrong. I was lucky, I guess, for not having to endure years of misdiagnoses and ridicule, as many have. A paediatric neurologist confirmed the suspected diagnosis, Friedreich's ataxia, when I was about 12. I remember vividly hearing the unvarnished truth about this disease—that I might not be able to have children and that I might die from heart failure. I felt pretty shocked, I mean what 12 year old is even thinking about having children or dying? Strange as it sounds, hearing the bare-boned truth, even at that age, was the best thing that could ever have happened to me. Despite how it seems, my doctor was never really negative, just direct. He made sure I understood that there would be limitations to what I could do with my life, but that ultimately I could be the judge of the degree of those limitations. I feel that getting the correct information straight away coloured my perceptions of the realities of this disorder. It also opened my eyes to the choices that allow a person to live their life to the full.

When my doctor retired, I saw other neurologists, but they offered me absolutely no hope for the future. I remember being told by one neurologist that if I wanted to participate in physical therapy or other activities I could, but they were not going to help me. I remember the intense feeling of being defeated and crying in the lift every time I left his office.

Even though my parents were told that I'd probably be wheelchair-bound by the age of 15, they never gave up hope of finding something to help me. They kept up with any news they could find. When they read a "Dear Abby" article describing the symptoms of ataxia, which had a number to call for information, they jumped at the chance to learn more. The National Ataxia Foundation (NAF) told them of a local neurologist sponsoring ataxia clinics sanctioned by them. I agreed to see him, but didn't expect much. I was surprised when he told me that he honestly didn't know everything and that he didn't have all the answers, and that I would have to be the one to educate him. He suggested that I get involved with the local group of the NAF, and just said, "make of it what you will". I wanted to share experiences, truth, and hope, and learn about my disease at the same time.

Although Friedreich's ataxia is an inherited disorder, I've never blamed anyone for my disease. I accepted long ago that this disease is what happened to me, and I could choose to deal with it or not. The ability to make decisions is what is most important to me. We all make them. I choose to live my life the same way you choose to live yours. I have a disease that keeps me from walking, not from living. This disease is not my

life. Yes, it forces certain adaptations and can be discouraging, but it doesn't define who I am.

I've used a wheelchair since I was 25 years old. Limiting, perhaps, but the opportunities of living are limitless. I talk, use a computer, enjoy the arts and music, and have travelled to Italy, England, Canada, and Tahiti (figure). I have friends all over the world. Although I couldn't stand on a balance beam or play tennis in high school, I could square dance. A company that knew of my diagnosis hired me to work for them, and only let me go years later because I couldn't operate a forklift. I've had boyfriends and have had my heart broken--before and since being in a wheelchair.



A hot day in Tahiti

Judy LaBorde, New Orleans

To date, this disease cannot be "fixed". But medical people might be able to help "fix" the affected person. Attitude affects behaviour. If a clinician doesn't have a positive attitude, why should the patient? Support and encouragement is essential. They might actually be the most important part of care giving.

But, of course, help doesn't stop there. My family and friends have always been a constant source of support and encouragement. They have never focused on what I can't do, but rather on what I feel able to do. I know that there are limitations, and many things I am not able to do. But I bet there are things that you can't do too.



Denise Drake (photo) was diagnosed with Friedreich's ataxia when she was 12. She is on the Board of Directors of the National Ataxia Foundation, MN, USA, and is president of the Louisiana Chapter of the National Ataxia Foundation. Donna Guillory has a BA and an MA in communications, and hopes to work in some aspect of medical communication that addresses challenges in public health.

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