

Still in charge



Despite confusion and misperceptions about my disease, I'm showing MS who's the boss.

by Veronica Daniels-Lewis



Veronica Daniels-Lewis uses her voice to educate, support and fight for people with MS.

I was living a wonderful, busy life after college. I was in my early 20s, working toward an

exciting business career in one of Texas' largest cities. I felt like I was in charge of my destiny.

Fast-forward to my late 20s: After marriage, starting a family and working full time, I decided to become a stay-at-home mom because my husband's job meant we moved frequently. I was a driver, teacher, cook, laundry queen, classroom room mother, coach, along with many more roles.

I was there for my family wherever and whenever they needed me.

One morning I woke up and felt strange. I had a tingling sensation, weakness in my left hand and numbness in both feet. These feelings lasted for a couple of days, so I made an appointment to see my primary care physician. I was told I was showing signs of carpal tunnel syndrome in my hand. I was given a brace and told to watch my posture and the amount of time I spent on the computer and to take frequent breaks.

After a few months, the tingling sensation got better, but I never fully recovered feeling in my left hand. I still felt constant numbness, pins and needles and pain in my feet. But no one in the medical community would validate my annoying continuous pain and take me seriously. They made me feel like my symptoms were all in my head or a product of my active, fast-paced life.

In my mid-30s, I began to experience loss of balance, tripping and falling and dropping things. Again, many of the medical professionals I visited chalked up my symptoms to my busy lifestyle and family obligations.

In 1996, after experiencing symptoms since 1988, I found a doctor who finally diagnosed my multiple sclerosis. What a relief to know someone was listening and that I was not crazy!

I was happy to finally have a name for what I was feeling, but what exactly was MS? Why did they take so long to come up with this diagnosis?

From research, along with information provided by the healthcare community, I learned that MS was a disease believed only to affect Caucasian people from Northern European ancestry and not people of color. This theory confused me.

I'm sure many people of color living with MS have similar stories of their own or have heard such stories. This always made me wonder if that's why it took so long for me to be diagnosed.

I've also learned that many minorities have been diagnosed with other health issues before finally receiving a correct MS diagnosis. As a support group leader with the National Multiple Sclerosis Society, I've met many people of color — from those who were diagnosed years ago to those more newly diagnosed. It's devastating to hear them describe their traumatizing journeys through a range of misdiagnoses of everything from fibromyalgia to HIV/AIDS. The

signs and symptoms they reported were ignored or weren't even considered because of these preconceived notions about them.

Today, it's known that MS occurs in all ethnic groups, including African Americans, Asian Americans and Hispanics. Studies show higher numbers among these groups than previously thought. I'm glad to see more research, more education and information to help guide more accurate diagnosis and treatment.

I had always felt in charge of my destiny and sure of my life path, but MS, with its craziness and unpredictability, had entered my life and refused to leave. MS was trying to take control of my life.

I began to work closely with my neurologist on a healthcare plan. I was also advised to contact the Society for help, to connect with others living with MS and to get reliable information to manage my MS.

Reaching out to the Society was pivotal for me. I received the support and care for which I will be forever grateful. I am proud to say I have been involved with the Society since 1996. Reaching out also helped me make connections and adjustments to my new life.

As time passed and my kids grew up and started to create their own destinies, I decided to take on volunteer positions with the Society.

My first volunteer position was as an MS self-help group leader in my community. I could develop a safe environment for people of various backgrounds to get together to share information, thoughts and hopes. It gave me the opportunity to stand up and use my voice to lift other minorities' voices in the web of MS uncertainties. From my own experiences, it allowed me to share information about what people of color can do to receive proper care.

When the group first started, we had five or six members in Sugar Land, Texas, a suburb of Houston. I spread the word, and we grew fast. Today, we have an email list of more than 200 people living with MS of all ethnic backgrounds, from teachers to business executives, from teenagers to older adults. Parents sometimes join us because their young teenager is now living with MS and they are seeking support for them. We meet once a month, and we're an enthusiastic group. These people are all my extended family, and they help me as much as I help them on this wild journey.

We talk about the issues we face and also invite people from the healthcare community to come in to talk with us. This led to my second position with the Society as a Community Help Relations Representative to secure guest speakers such as neurologists, primary care physicians, occupational and physical therapists, social workers and others to provide updated information on managing care when living with MS. Establishing these one-on-one relationships with the minority community was huge.

Helping the healthcare and minority community understand each other and talk about the

lifestyle changes needed to live your best life with MS is crucial. We always leave the meetings feeling much more empowered.

I also am a District Activist Leader. I use my voice to inform government leaders about the legislation needed to help people living with MS and other disabilities live their best lives. I was even asked to be a member of a committee created by one of our local U.S. House of Representative offices to improve the lives of people living with disabilities in my city.

Even though MS tried to take charge of my life over 20 years ago, I am using my voice to help educate and give hope to other people living with MS. I am showing MS who is the boss. I'm staying in charge of my destiny and helping others stay in charge of theirs.

Veronica Daniels-Lewis of Missouri City, Texas, is a former independent sales consultant and new grandmother who has been living with MS since 1996.