

Advocating for My Father, Myself, and My Children's Future



I was 7 years old when I was invited to attend my first father-daughter dance, a rite of passage for many young girls. I remember standing in our living room, twirling in the new dress we had bought, feeling like a princess. That's when I was told we wouldn't be able to attend. My young mind could not comprehend why my father, who was living with secondary progressive multiple sclerosis, could not take me to the dance. I wouldn't hear the words "multiple sclerosis" for the first time until a year later as an eight-year-old standing in our family kitchen. To this day, tears fill my eyes as I picture the dance invitation and think about my own daughter attending her father-daughter dance. The only difference is that today I am keenly aware of the struggles of MS - as I too was diagnosed with MS just one month after my daughter's birth.

My father's symptoms began in 1978, but with the lack of MRIs or therapies for MS, he went undiagnosed until 1983. In the early 1990's the first disease modifying therapy came onto the market, but the disease progressed quickly, and by 1996 he was using a wheelchair permanently. At the age of 19, just three years later, I experienced my first MS attack. Years later, neurologists found over 10 lesions on my brain and I too heard the words, "You have MS," just like my dad had 43 years before me.

As the mother of a young daughter (with a second child on the way!) I can't help but wonder about the chances of her hearing those words from a doctor as well. Without any centralized data about the number and type of people like me around the country who have MS, MS researchers have had trouble verifying whether MS is on the rise, and have difficulty

following up potential leads to environmental or viral triggers that may increase chances of developing MS. This year, the U.S. House and U.S. Senate have introduced the [Advancing Research for Neurological Diseases Act](#) (H.R. 292/S. 849) which bridges the gap between data and research for diseases like MS. The neurological data bill will create a nationwide system for tracking the incidence and prevalence of neurological diseases, which could one day lead to a cure.

As a child, my father's neurologist told my family that I had a 1% higher chance of being diagnosed with MS because of my father's diagnosis. My current neurologist tells me that my children have a 1 in 40 chance. Without research we simply cannot know. There are no words to describe the lengths any mother will go to to protect her child, and by supporting the Advancing Research for Neurological Diseases Act, I am protecting mine. I want my children to grow up in a world where the phrase "you have MS" is a thing of the past. I want my children to never be afraid of MS or of visiting a neurologist. I want my children to become strong advocates for their mom, for their grandpa, and for everyone affected by MS.

As we prepare to welcome our second child into the world, the words "multiple sclerosis" are constantly on my mind. But rather than letting fear take over - I'm becoming more passionate than ever about fighting this disease, finding new ways to advocate for change, and fundraising so that MS research is supported across the country. Will you join me?

Editor's Note: Join Rebecca to further MS research by becoming an [MS Activist](#).