

Thriving in the Face of Adversity



When I was first diagnosed with multiple sclerosis it felt as though my world had been turned upside down. At the age of 25 I had a very clear idea of what my future held, and where I was going. MS threatened to take all of that away from me, and I quickly decided that I would not let it. At first there were plenty of people telling me what I could no longer do, and that I should give up on my ambitions. But I disagreed. I sought out others who strived to make the best out of life and to make a difference despite their disabilities. I ran across so many inspirational people and communities, and soon began to feel invigorated and ready to fight.

I am a nurse, and it just so happens that neurology has always been my passion. When I was diagnosed with MS, it was really eye opening to be on the receiving end of healthcare, instead of being the provider. I realized that I now had a unique opportunity to have a positive impact on others living with MS, and I set out to do just that. I became an MS certified nurse just six months after being diagnosed with MS myself, and I began to work for my own neurologist. Currently I am finishing graduate school, and focusing mainly on writing and educating people about MS through my own site, JustKeepSmyelin.com, and several other websites and publications.

Because I was diagnosed at a young age, there is a good chance that I will live more years with MS than I lived without it. I am currently on Tysabri after failing to respond to four other disease modifying therapies, and it concerns me that my options are already running out before my 30th birthday. Research is the only way to find better treatment options, what causes MS, and ultimately to find a cure for this disease within my lifetime. To me, participating in and advocating for research are my responsibility, and even my duty.

I have participated in several research studies to further our understanding of MS. I am also involved in the launch of an innovative new research effort called iConquerMS™. Our experiences truly have the power to accelerate research efforts, and this initiative allows everyone to share their experiences to do just that. The data gathered on the iConquerMS™ website will be used by researchers to identify trends that could potentially help us identify the causes of MS, determine who will best respond to various therapies, and find better treatments. iConquerMS™ is unique because the people with MS who participate get to interact one-on-one with researchers, and can even propose research questions. It is even governed by people with MS, like myself, making it a completely patient-powered research network.

I have also become very active as an MS activist and I serve on the Government Relations Committee and as a District Activist Leader for my local MS Society chapter. The highlight of my activism so far has been being able to participate in the Public Policy Conference (PPC) for the last two years. PPC is a great opportunity to meet with US representatives and discuss research funding, which is an issue near and dear to my heart. Additionally, I make it a point to visit and contact legislators throughout the year in my home state. It is incredibly rewarding to help get funding to the researchers who desperately need it for their groundbreaking research.

Throughout my encounters as an MS nurse and activist, I discovered that almost everyone I spoke with had some sort of personal connection with MS, and although very few of those people knew much about it, they were all eager to learn more. I began to work tirelessly to spread awareness about MS in every way that I could, and much to my surprise it began to get me some attention! Last year I was approached by some people who thought my work as an activist deserved to be brought to a larger stage, the TEDx stage to be exact! TEDx conferences are independently organized TED events where speakers give short, powerful talks about their “idea worth spreading”.

Participating in TEDxHerndon was easily both the most terrifying and most rewarding thing I’ve ever done. I tried to compensate for my inexperience as a public speaker by practicing harder than I have ever practiced for anything. I rehearsed for anyone who would listen, went through multiple rough drafts, and practiced my speech every day, often until I lost my voice. My goal was to captivate the audience with my story, to give them a better understanding of what MS is, and to include a universal message that everyone could learn from. I begin and end my talk with the same few lines:

“Life is going to challenge you at some point. It’s going to hand you something unfair, it’s going to take something from you, and it’s going to interfere with your plans. When this happens you have a few choices – deny, cope, or thrive.”

If you listen closely to my talk you will notice that I did all three. First, I denied that anything could possibly be wrong with me. Next, I tried to minimize it and not let it change me or my career goals. Finally, I let go and I allowed myself to thrive from it. We all have our own personal stories about our challenges and experiences. My hope is that we all find our own way of thriving in the face of adversity.