

What I Want My Legislators To Know About My MS



I was diagnosed with multiple sclerosis in October 2010. I was 27 and had a daughter who just started kindergarten. I was working full-time as a nurse in a busy local practice. I had just started dating the man who would later become my husband. As time went on after diagnosis, my family and I moved forward, and transparently fought our battle, sharing with everyone we came in contact with what life with multiple sclerosis was like for us.

Eight years after diagnosis, I started realizing that the majority of public policy discussed was having a direct impact on my life. I started to focus in on how vital talking with our legislators is and what I wanted my legislators to know specifically about my life with MS.

I want my legislators to know that I face financial uncertainty because of MS. I went to school, worked hard and had a career that I loved. I was forced to leave that career when the cognitive effects of MS negatively impacted my ability to be a safe and prudent nurse. Talking about financial hardship and uncertainty carries a stigma of shame, so many don't. I want the legislators to know that my husband is my caregiver, and he faces needing to take time off of work, outside of what may be approved.

I want our legislators to know that we are only in our 30s and 40s and are affected by what is currently a lifelong disease. I didn't get to retire; I was forced out of the workplace by MS. I am not looking for a handout, I worked hard for as long as I could. I hope one day to be able to return to the field I loved, but please recognize that MS can literally stop your career dead

in its tracks.

I want my legislators to know I need access to quality medical care, testing and medications in a timely manner. By the time symptoms of multiple sclerosis are recognized and a physician intervenes, I may have been battling for weeks or months. This need doesn't stop after diagnosis. Just because MS is chronic doesn't mean treatment should be delayed. Prior authorization reform is essential, because with MS, time equals disease progression.

I want my legislators to know that I may look okay, but I am fighting an invisible battle. Please protect me from falls or inability to go about my daily life, by making sure accessibility is ensured everywhere, remembering that everyone can access a ramp, but not everyone can access stairs. I want my legislators to know that along with a physical battle, there is a mental component also. Access to mental health resources and funding for mental wellness interventions protect me and are just as important as physical wellness.

I want my legislators to know that research is literally the future: where the cure is, where the restoration of what's been taken by MS is... waiting for discovery. Failure to pass budgets means my future is put on hold, or even set back. I want my legislators to know that I volunteer for research because I am investing the only thing I can: myself. Only they can ensure, by approving budgets that hold critical funding, that my investment isn't in vain.

I want my legislators to know this more than anything though: there are about one million people living in the United States with multiple sclerosis. We are your neighbors, coworkers and constituents. We need you to represent the needs of the multiple sclerosis community, because we are everywhere.

I want my legislators to know that only with their support, we can successfully continue to work towards a world free of MS.