

Meet the Congressional Chief of Staff living with MS



From her home office, Stacy Barton gets ready for another day of juggling — juggling an interview, updates from Capitol Hill, her family... and living with multiple sclerosis. As a chief of staff for U.S. Rep. Steve Chabot (R-Ohio), Stacy has had a uniquely long career on the Hill and an equally unique personal journey. She sat down for a conversation about her work, MS and the importance of advocacy for the MS community.

How did you start your career in politics?

Someone told me about a fellowship through the Congressional Black Caucus. I was in grad school, and I did not like it. I was really looking for a way to get out, and I didn't want to just leave because I didn't want to disappoint my family. I was surprised to have been selected, and I got a chance to work in Congresswoman Eleanor Holmes Norton's office. I was answering constituent phone calls and whatever little assignment people would drop in my lap, because when you're a fellow, you're basically kind of a suited-up intern.

Before the official fellowship started, I was sitting in the lobby, and I heard a woman's voice. She was giving some poor soul the business. Looking back now, she was probably talking to a news reporter. I later learned she was the chief of staff and in charge of the entire office. I could just feel her energy emanating from that office, and I knew that I wanted what she had. I knew that Capitol Hill was where I wanted to be — and that was really the start of it.

How were you diagnosed with MS?

I was diagnosed with multiple sclerosis in 2005. I had two children at the time, a daughter with autism, and I had just started my tenure on Capitol Hill as the chief of staff to Congressman Mike Turner. Following the birth of my first child, and off and on since then, I

had been experiencing the weird symptoms that we all experience throughout our journey before finally getting a diagnosis (e.g., numbness on one side of my back and torso, tingling of hands and feet).

The final straw, when I could clearly see something was really wrong, was when I began experiencing extreme fatigue in conjunction with labored walking. I had a difficult time getting up and down the steps at my home. At work, I walked with one hand on the wall to get to and from my office. In those early days, I was not unlike many of you who had gone to various doctors, and no one could figure out what was going on with me. Part of me chalked it up to stress. Capitol Hill is a stressful place, especially when you have two children, including one with a disability.



Stacy and her neurologist, Dr. Becker.

The father of a close friend and colleague, Andy Bloom, had done extensive work in the field of multiple sclerosis. So, Andy set up a phone call between me and his dad, a now-retired doctor and researcher. I shared my symptoms. He said, "Obviously, not being able to see each other face-to-face [I can't make a diagnosis, but] I can tell by many of the symptoms that you've described that this sounds a lot like multiple sclerosis." He told me that I needed to see a doctor that specialized in MS and that he would find one for me. He did just that, and I set up an appointment at George Washington University's MS center (coincidentally, my husband had been touring GW's facilities for work, and around this same time had also seen GW's MS center and was actually the one who scheduled the appointment before Andy's dad could get back to me). I arrived at the appointment, limping, having come straight from work. The doctor took one look at me, sighed and said, "What are you doing here? How is it that you are even walking?" He directed my husband to take me to the emergency room, where I would spend the next week getting an official diagnosis and starting a treatment plan.

How does MS affect your day-to-day life?

I would say the biggest impact on my day-to-day life is the fatigue and the resulting effort that literally goes into every function of your day. I think people who don't have MS or some other chronic illness might not be aware of the enormous amount of energy it takes to complete life's most basic tasks. When you live with MS, the physiological acts of getting up, taking a shower, brushing your teeth, doing your hair, putting on makeup, getting dressed and taking your meds is exhausting, and you haven't even gotten to your car yet. What I've noticed with COVID and its restrictions, not having to do just those basic things under a deadline helps because it preserves an enormous amount of energy — and with MS, every bit of expended energy just chips away from your already limited reserve.

What are you most proud of in your work for the MS community?

What I think I'm most proud of is to have people — not just with MS, but people with any sort of physical ailment — meet with me and talk to them and be able to understand where they're coming from. My favorite part of my job is really just sitting across from someone and being able to connect with them on a very emotional and empathic level. I understand the energy that it takes to get on that plane and fly all the way to D.C. And when someone sits down with their member of congress or staff, they want to know that the person they're meeting with gets it and that they're not just another meeting, but were heard. I love making those connections and am honored each time I have an opportunity to do that, especially in the MS community.

What's happening right now that the MS community needs to be aware of?

The obvious thing is just the impact of COVID and providing information to people that gives them the confidence they need to get the vaccine and to know that it is safe for them. I know that different communities likely have their own anxieties about the vaccine. So, all of the discussions regarding the manufacturing of the vaccine and the safety protocol — those are important issues for the MS community.



Why do you think advocacy is important?

I think individually, there are likely people with MS whose families don't really know the fullness of how difficult this disease is. If the people you live with have a very cursory understanding and don't even know the fullness of it, why would you assume that your elected leaders understand? The only way that people are going to know what we need is if

we tell them and keep telling them and keep pushing for research. Also, the DMTs that are now available are the result of advocacy.

What does a good relationship with an elected representative look like?

Any relationship is built on more than one visit. So, advocating and building that relationship with your elected representative is really no different. You have to continue to be in communication with both the staff and the member of congress throughout the year.

For an effective meeting:

- **Be armed with information that's actionable, true and accurate.** The National MS Society does a great job of providing advocates with all of the information you need.
- **Be specific.** All across Washington, any number of constituent groups are meeting and having these same kinds of conversations, so make sure that there is a specific item, a specific deliverable that you expect from your member of Congress, whether it's as simple as supporting a specific piece of legislation, signing on to that legislation as a co-sponsor or it could be asking your member of Congress to sign on to a letter. It could be asking your member of Congress to sign on to the MS caucus.
- **Always follow up afterward.**

What is something you would share with someone who is newly diagnosed?

On the day that I was diagnosed, a friend and fellow chief of staff left me a voicemail message, which basically said if there is any time to have MS, now is the time because you have options that were not available 20 years ago or even 10. He said we are learning more and more about MS every single day and know more today than we did yesterday. This sentiment is what motivates me, and I hope that it's comforting to others.

My Typical Day

Stacy shares a rundown of what a typical day might look like for her.

- The alarm goes off, grab the phone from bedside table to check texts (it's never turned off! My daughter lives on campus, and the mom in me can't turn it off when she's not at home)
- Turn on the morning news and the Keurig — no day begins without coffee
- Meds and breakfast standing in front of the TV, watching the news
- Weekly meeting with Steve and staff to review schedule for the week, and monthly chief of staff meeting via Zoom
- Monthly blood draw (required following my Lemtrada treatment — luckily, phlebotomist comes to my house)
- Bipartisan Zoom panel with the fellow chief to discuss how we became chiefs with the Women's Congressional Staff Association
- Crisis du jour — there is always one... or 10

- My son Miles is in between remote college classes and stops by to chat and pet the dog, who is always wherever I am
- Miles pops a frozen pizza in the oven and that's lunch (don't worry, whole grain thin crust!)
- Virtual meeting with Autism Speaks
- Review vouchers and office admin stuff — have to pay the bills
- Dinner while watching the evening news
- Telephone townhall with Steve, staff and a few thousand constituents
- Every day ends with an audiobook — sleep comes whenever I can pull myself away from the story