25 years of advocacy

Decades of nationwide activism create heightened impact during the Public Policy Conference.

by Vicky Uhland

It was 1991, and about 80 people were gathered in a hot room in Washington, D.C., for the National MS Society's first Public Policy Conference (PPC). They'd traveled from around the country with a single goal: to tell their congressional representatives what it's like to live with multiple sclerosis. By putting a personal face on the disease, they hoped to inspire legislation that would benefit everyone affected by MS.

Twenty-five years later, the PPC has grown to host thousands of activists who have attended the annual conferences, spurring Congress to pass a variety of healthcare and disability laws that directly affect people touched by MS. PPC activists have also helped secure millions of dollars in federal funding for MS research. This year's PPC will be held March 14–16. Clad in distinctive orange ties and scarves, more than 325 MS activists are expected to visit and educate nearly 400 congressional offices about priorities for the MS community. "

By sharing so many powerful stories over the last 25 years, we've established a strong and recognizable presence on Capitol Hill," says Laura Weidner, the Society's senior director of federal government relations. "The PPC affords us an important opportunity to come back year after year and strengthen relationships with key legislators to help advance federal policy that will improve the lives of people affected by MS."

In the past 25 years, the reasons people have become involved, and the legislation they've pursued, are as diverse as the MS activists themselves. Here are just three of their stories.

Stewart Ferry
Oakland, California

Stewart Ferry has a dual connection with MS. Now the Society’s state director of public policy for California, Nevada and Hawaii, he was hired a few months before the inaugural PPC. He attended that conference and has attended every one since then. His goal? To help ensure that future generations with MS have a better disease course than his mother did.

“She raised me and my two older brothers as a single parent in the 1970s. It was a very difficult time for people with MS,” Ferry says, noting that there were no effective therapies then.

Ferry says the impetus behind the first PPC was to encourage people affected by MS to be more engaged in public policy and more assertive in advocating for their needs. “We wanted to be less passive and more proactive,” he says. “At every PPC we’ve maintained an emphasis on the need for more research funding, comprehensive and affordable healthcare and protecting disability rights. It’s inspiring to see the Society continue to support this trio of issues as the foundation for advocacy all these years.”

Ferry is particularly proud of the PPC’s impact on disability rights legislation. The Americans with Disabilities Act (ADA) was in its infancy when the PPC debuted. “MS activists and the Society fervently supported its passage and continue to pose an incredibly strong commitment to ensuring equal rights and opportunities,” he says. “Through the PPC and year-round involvement with legislators at the state and federal level, we’ve protected the provisions of the ADA. We didn’t just see it passed and say, ‘Oh, that’s great,’ and then sit on the sidelines.”

Over the years, Ferry has seen the PPC evolve to become very strategic, with a focus on specific, timely messages and targeting influential members of Congress based on their committee assignments. In addition to visits to Capitol Hill, the PPC now includes a day and a half of strategy meetings for participants, with presentations from experts on how to talk to legislators about key issues—including educating them about the economic impact associated with a new law or program.

That advocacy has also spread beyond the PPC. Ferry says there are now a variety of opportunities for people living with MS to be politically engaged year-round, including joining the Society’s local government relations committees, District Activist Leader program and the MS Activist Network.

All of this has solidified the Society as a reputable, trusted source of information for elected officials, Ferry says. And in a time when virtually every organization has a lobbying group, he believes it’s vital that activism continues. “I’ve had members of Congress and state legislatures say if we don’t advance initiatives and events like the PPC and other advocacy work, it’s the equivalent of saying there’s no need to worry about people with MS when it comes to funding programs and passing legislation.”

Sarah Mayfield, in front of the nation's Capitol, makes trips to Washington, D.C., to advocate on behalf of people with MS, like herself. Photo courtesy of the National MS Society

Sarah Mayfield
Oxford, North Carolina
Sarah Mayfield had been living with MS for 21 years when she attended her first PPC in 1999, then called the Issue and Empowerment Conference. As an experienced self-help group leader, her local chapter asked, "Would you like to go to Washington and share your story?" she remembers. "And I thought, yes, I want my voice to be heard about the issues surrounding long-term care for people with MS."

Mayfield believes that America's communities need to be accessible and provide support services—like meal delivery, medical transportation and respite care—that allow people to stay in their homes with the people they love.

So Mayfield went to Capitol Hill and spoke with members of the North Carolina congressional delegation and her U.S. representative at the time, David Price. "I told him about my symptoms, which include numbness and vision problems. And I told him that when my disease progresses, what I really want to do is sit under my shade tree and visit with my family and friends," she says.

"Rep. Price told me he hadn't heard much about MS before," she says. "By the time I left, he said he would definitely support my ideas about long-term care for people with MS. I felt like I had made a difference." Since Mayfield's initial meeting with Rep. Price, other MS activists and the Society have maintained an enduring relationship with his office that has culminated in him co-chairing the Congressional MS Caucus in the U.S. House of Representatives, along with Rep. Michael Burgess from Texas.

Mayfield has been to eight conferences since 1999, and has been inducted into the Society’s Volunteer Hall of Fame for Advocacy. “I like helping someone else have a better quality of life, and it’s been good for me too. Learning how to talk to legislators has really gotten me connected with my own community. And it’s made me braver,” she says. “Now I’m not afraid to ask decision-makers for what people living with MS, my community or I need, whether I see them in their office or at the grocery store.”

Mayfield is proud of the legislation that MS activists have been instrumental in enacting with annual trips to Capitol Hill—particularly the Ticket to Work program, signed into law following her first PPC, which provides vocational rehabilitation and employment services for people with disabilities.

John Platt, who has MS, has channeled his energies into advocacy on the federal and state

levels. Photo courtesy of John Platt

John Platt Moon
Township, Pennsylvania
John Platt never expected his employment status to change drastically at the age of 33. He’d been diagnosed with MS two years prior, however, and faced decisions that ultimately removed him from his corporate job.

“I was pretty depressed,” he says. “I felt disconnected, like my MS had taken me out of the community and isolated me.” So he signed up for emails from the MS Activist Network in 2007, hoping that would make him feel more active and involved. Shortly thereafter, he received a message urging him to contact members of Congress about joining a newly formed Congressional MS Caucus.

Platt sent an email to his representative. “The next day I got a phone call. I checked the caller ID, and it said U.S. Capitol. It was my congressman’s office,” he says. Platt began to build a relationship with the representative, all the while educating him about MS—including the need for more research funding. Platt’s representative chaired the congressional subcommittee that oversees the Department of Defense’s medical research funding. As a result, Platt’s advocacy was key in securing MS research funding through the Congressionally Directed Medical Research Program (CDMRP), which finances peer-reviewed, high-risk, high-reward research. Since 2009, CDMRP has funded more than $33 million of MS research.

That started an advocacy journey for Platt that has included attending PPCs, meeting with state and federal legislators, and chairing his state’s Government Relations Committee. In fact, Platt has become such a dedicated activist that he’s been inducted into the Society’s Volunteer Hall of Fame for Advocacy.

But advocacy hasn’t always been easy for Platt. “It wasn’t until three to four years ago that I was able to talk about my MS to people I didn’t know. To specifically state my symptoms made me feel vulnerable and uncomfortable,” he says. “But I’ve realized that the PPC and other advocacy efforts give me a chance to voice something about my MS to individuals who can hopefully change and rectify some of the challenges we face.”

He’s also working on securing funding for in-home care for people with MS so they don’t have to move into assisted living facilities due to disability. And he’s dedicated to expanding the federal Multiple Sclerosis Centers of Excellence, where people can receive treatment and connect with others in the MS community. “

As long as we take a step forward, we’re better than we were,” Platt says. “The most empowering words anyone can say are ‘why not’? Why not change that law, why not send that email to a legislator? We need continuous activism. It can be a tweet, it can be a Facebook post, it can be attending a PPC. Just do something.”

Vicky Uhland is a freelance writer and editor in Lafayette, Colorado.

To get involved, join the MS Activist Network at nationalMSsociety.org/MSactivist.