

Speaking out



People with MS advocate for changes in policies to improve the lives of everyone living with the disease.

by James Townsend

Every year, National Multiple Sclerosis Society volunteers visit their congressional representatives on Capitol Hill as part of the Society's Public Policy Conference to advocate for policies aimed at improving the lives of people with multiple sclerosis.

"People with MS have always been advocates, and in fact, the Society's first Washington, D.C., conference closely coincides with the Americans with Disabilities Act becoming law," says Abby Carter Emanuelson, associate vice president for advocacy and activist engagement with the Society.

In 2021, the pandemic forced activists to attend the conference and lobby Congress virtually. But the change turned out to be a success. "We really saw a surge of interest in attending the conference due to virtual communication," says Bari Talente, executive vice president for advocacy and healthcare access. "Before the pandemic, only about 300 people could attend in person. This time, meeting virtually, nearly 900 people participated over two days from their homes across the country, and content from the conference is available for the rest of the year."

During the conference, MS activists learned to tell their stories to government officials in the format that works best for them — meetings, phone calls, emails and social media. "We use a phrase," Talente says. "'Wow, how and now' to frame a successful outreach to policymakers. 'Wow' means sharing your personal story or a compelling fact. 'How' is how a policy or

legislation will affect the MS community. 'Now' focuses on the specific request or legislation we want elected officials to support."

Over the last three decades, the Society has supported activists' involvement on Capitol Hill. Three long-time activists discuss how they became involved and what they've been focusing on.



Frank Austin is working to secure funding for research and care for 33,000 veterans with MS.

Frank Austin

Since he was diagnosed with MS in May 1997, Frank Austin has become involved in advocating for dozens of pieces of legislation to benefit Americans with MS. A Navy and Vietnam veteran who spent four years teaching avionics and training other service members, Austin says, "I've never been a wallflower. I've done a lot of public speaking and don't mind being in front of people."

He grew up in Kansas but moved to California with his then-wife when he retired and later moved to Plainville, Kansas. On an activist trip to Washington, D.C., he visited the staff of Sen. Jerry Moran, an old school acquaintance, and then ran into him in the hall where they exchanged memories of their school days. "The older you get, the more you have experiences like this that seem to indicate you've made the right choice in what you're doing," says Austin, now 70.

Austin is proud of the things he's worked on to help pass legislation and is enthusiastic about how far medicine has come since he first learned he had MS 15 years after his first exacerbation. "In 1983, there were no MRIs, no way of diagnosing the disease, and when I first started dealing with my MS, there were only three drugs," he says, adding that today there are many more disease-modifying therapies (DMTs).

He has helped pass some significant legislation over the years. "About 15 years ago, I knew a county supervisor in Orange County, California, named Lou Correa, who had subsequently run for the state Senate. The legislature was considering implementing regulations on proper

disposal of syringes and needles, something MS folks know a lot about.” At the time, some 31% percent of what are called “sharps” were simply thrown into the trash. “When it came time for a vote, Sen. Correa cast the single swing vote that led to the bill’s signing into law.”

Austin says one of his biggest wins was helping get the 21st Century Cures Act signed into law on December 13, 2016. The act authorized creating the National Neurological Conditions Surveillance System (NNCSS) at the Centers for Disease Control and Prevention. “When I was asked what the one big thing I’d like to see happen was, I said, ‘big data.’ There was no database of information about people with MS at that time, no central collection of data. With it, there is now the potential to find something hidden in time that gave us MS, to find some trends that may lead to the answers.”

Austin is working on getting more funding for the Department of Defense’s research into MS and care for some 33,000 veterans with MS related to their military service. For instance, he says, “Before the first Gulf War, there was no MS in Kuwait. Now there is, and we need to find out why it started.”



Jennifer Gomez-Chavez, EdD, is a devoted volunteer with the Society’s advocacy program.

Jennifer Gomez-Chavez, EdD

When Jennifer Gomez-Chavez, EdD, was first diagnosed in 1995, she was devastated. She was a young professional starting her career at the University of New Mexico and was about to be married.

“I’d never heard of MS, and I didn’t want to accept myself as someone living with a disability,” she says. “I was concerned about how colleagues would perceive me and if I’d be able to have a family.”

In 2000, she says, “a neurologist who specialized in MS told me, ‘We don’t have any medication that will help you. So, walk, talk and see! Go live the best life you can, and when you get another big MS attack, come back and see me.’”

That gave her confidence to go ahead with all her plans. Then in 2008, reality set in again, and she spiraled into a depression for six months. “I knew then I needed a mentor, so I called the Society office in Albuquerque. They said, ‘We have the perfect member for you, a retired professor from the University of New Mexico named Caitlin Anderson.’ She told me, ‘I’m going to get you involved in volunteering with the Society’s advocacy program to help shift your negative energy into a positive mindset.’ That really helped me come out of the darkness I’d fallen into.

“Later, another woman living with MS, Jeanne Hamrick, chair of the Government Relations Advisory Committee for New Mexico, mentored me about policies and legislation, and before you know it, I became chair.” Four years ago, Gomez-Chavez received the Society’s National Volunteer Activism Award in recognition of her extraordinary efforts.

Ultimately, she says, her diagnosis led to a renewed passion for living and helping others. “Before MS, I was existing. Now I’m living. We have these things we want and our goals. When you get a diagnosis like MS, you realize ‘I’d better put this in gear today because every day matters.’”

Gomez-Chavez works full time at the University of New Mexico and also is a community leader, partnering with underserved communities, listening to their needs and being a channel to bring forth their concerns. In addition, she taught the psychology of hope for 10 years at the university. “My life is all about giving people hope to live another day,” she says. “I want to tell everyone that it’s never too late to go from existing to living.”



Briana Landis, diagnosed with MS as a young child, is a National MS Society Scholarship winner.

Briana Landis

Twenty-three-year-old MS advocate Briana Landis is remarkable in many ways. First, she was diagnosed with MS at the age of 4 after having migraine headaches and blurred vision. In those days, pediatric MS was extremely rare.

When she was 8 years old, she earned the Kohl's Kids Who Care Award, which led to her being invited to appear on the "Montel Williams Show" (Williams, who lives with MS, founded the Montel Williams MS Foundation). "When I was 8, I got a letter from North Carolina Rep. Richard Hudson thanking me for appearing on Williams' show," Landis says. "Then years later, while attending my first Public Policy Conference, I visited Rep. Hudson's office as an MS advocate and was surprised to see a photograph on his wall of where I did my research."

When she was in fifth grade, the North Carolina Research Campus was built near her house. Simon Gregory, MD, began doing MS research there on genetic and environmental factors surrounding MS. Fast forward eight years, and Landis, a four-time National MS Society Scholarship recipient, earned a degree in biology, along with a two-year internship with Gregory and his fellow MS researcher Sabrina Cote, PhD.

The MS community gave Landis a way to take control of her diagnosis. She felt a connection with all the people she met and remembers one in particular: "After I gave a speech two years ago in Atlanta, I was approached by an older woman who was the coolest ever. We had a great conversation, and she told me her name was Diann Geronemus and that she'd assisted in setting up the first MS treatment center in St. Barnabas Medical Center in New York. Then she dropped this bomb — that she'd been a caregiver for the brother of Sylvia Lawry, the founder of the National MS Society. That blew me away!"

Asked about something she's proud of, Landis says, "I'm proud of what I've become since my diagnosis. I lead a Walk MS team to fundraise for the Society's mission. I've advocated on Capitol Hill for pediatric MS clinics, MS Research funding, more affordable MS medications and improved healthcare access. When I was diagnosed, no one knew that could happen. There wasn't a role model to give me advice, so I've forged my own path."

The charming and upbeat Landis now lives in Greenville, North Carolina, and is planning a celebration for her 20th anniversary of having MS. "I've decided to celebrate instead of being afraid."

James Townsend is a writer in Boulder, Colorado.