

State Action Days make a difference



Ordinary people influence legislation that affects the MS community.

by Shara Rutberg

Marcillene Dover broke down in tears the day in 2014 when she told Kansas state representatives what it was like to live with multiple sclerosis without health insurance. She wasn't the only one in the room with wet eyes. Her story drew tears across the audience, too.

Dover, then 22, had been diagnosed with MS just months before she agreed to share her story with legislators during the National MS Society's State Action Day in Kansas. Dover was ineligible for KanCare, the state's Medicaid program, because she didn't qualify yet as disabled and had no children, yet she also lacked enough income to qualify for subsidized healthcare under the Affordable Care Act. She was caught in what's known as "the Medicaid gap," and as a result, had to pay for medication and her doctors' appointments out of pocket. She was still a college student at the time. Speaking at the state capitol as part of the Society's State Action Days, Dover urged legislators to expand KanCare to include people with lower incomes.

Though the state's House leadership blocked the expansion bill she promoted, Dover has no regrets about speaking up: "Being able to share my story like that and be vulnerable worked as a strange kind of coping mechanism for me, especially as I did it so soon after I was first diagnosed. Going out there and talking about some of the things that were happening to me let me do something about MS. It made me feel like I had some power over it."



Marcillene Dover, then 22, speaks of living with MS without health insurance at the State Action Day in Kansas in 2014. The experience of speaking out was empowering, she says. Photo courtesy of Marcillene Dover

The Society organizes State Action Days to help volunteers with MS share their stories with policymakers, harnessing the strength of their personal experiences to promote legislation that helps people affected by the disease. Activists meet one-on-one with lawmakers, and some participate in hearings, explains Karen Mariner, vice president of state and local government relations for the Society. Advisory committees focused on government relations pick one to three issues or pieces of legislation to focus on during each session, and provide training and tools to help activists feel more comfortable speaking to lawmakers. Action Days, generally held in the spring, are scheduled around each state's legislative calendar. Last year, about 1,000 volunteer activists participated nationwide.

Do you need to be a political science expert or understand the ins and outs of government policy to join the effort and create change? Absolutely not, says Mariner. "We have a lot of first-time participants who think they need to understand the nuances of moving a bill through the state House, or inside policy-speak, but that's not the case at all," she says. "They are the experts. They are the ones who understand what living with the disease is like. Their personal stories are incredibly powerful tools to increase awareness and facilitate change."

Society activists bring legislation to life for policymakers. Mariner has seen activists convert lawmakers to their side of a bill in one conversation. That's what happened when Michigan volunteer Kathleen Roberts sat down with her representative to tell him about how a home modification tax credit bill would affect her entire family. "He decided right there to carry the bill in session," says Mariner.

Society staffers who had helped Dover find programs to fund her medical care told her about the opportunity to take part in an upcoming State Action Day. Learning she was among 150,000 Kansans struggling in the Medicaid gap compelled her to tell her story. “I’ve always believed people should have a say in their government process,” she says. “I knew I could be that voice.”

Dover, now a high school physics teacher who is comfortable speaking in front of people, says the crowd in Topeka, the state capital, was very welcoming. She has since taken part in another State Action Day and also testified before her county commissioners in support of a local nonprofit that helped fund her medical costs.

“People often feel empowered by their experiences at State Action Days and begin to advocate year-round,” says Mariner. “Our hope is that people come, have an extraordinary experience, feel empowered and remain engaged.”

State Action Days, and the further advocacy they can lead to, are also great ways to meet other people living with and affected by MS, says Mariner, who has seen many friendships develop among activists.

Coming together with other activists is one of the keys to State Action Days. Volunteers are able to unite on the legislative front lines to advance policies and programs that help people with MS and their families. “It’s not just about raising awareness,” says Dover. “It’s about giving yourself a voice and a feeling of control over MS. And it’s as much about doing for others as doing for yourself,” she says, because, “Together, we are stronger.”

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To learn about your state’s Action Days, visit nationalMSSociety.org/StateActionDay.

To learn about other ways to get involved, visit [Advocate for Change](#).