

Making voices heard



Virtual State Action Days empowered more activists during the pandemic.

by Robert Lerosé

Making things better for others is second nature for 36-year-old Diane Kramer. Growing up, she spent Thanksgiving holidays with her parents, pitching in at the USO and brightening the holidays for people who couldn't get home.

"Being of service is my love language. That's what I do," Kramer says.



Diane Kramer, diagnosed with MS in 2010, is part of the National Multiple Sclerosis Society's MS Activist Network and participates in State Action Days.

She was working as a licensed practical nurse when she was diagnosed with multiple sclerosis in October 2010. When she started having cognition problems and became unsure of how they would affect her work, she took a medical retirement in 2017. She came up with a new way to serve: being part of the National Multiple Sclerosis Society's MS Activist Network and attending State Action Days.

"These are days for our MS activists to go to their state capitol to engage with their lawmakers, usually on a particular issue or priority that we're trying to keep moving in the legislature," says Abby Emanuelson, associate vice president of advocacy and activist engagement for the Society. "It builds relationships with their state lawmakers and gives activists a sense of empowerment in the public policy-making process."

Instead of the usual in-person meetings, activists held virtual State Action Days in 2020 because of COVID-19 restrictions. Meetings using different digital platforms were scheduled for five state legislatures still in session during the spring of 2020.

"It meant that I do more virtually than I ever could do physically. I could see more people and have more meaningful conversations than if I was running from one end of the capitol to the other," Kramer says.

Kramer had already established a relationship with her legislators in Harrisburg, Pennsylvania, before her April 2020 State Action Day, so the tweets she sent throughout the day were warmly received. She also had an appointment with a staffer in her state senator's office and used Zoom — a first for both of them that made them feel proud. The meeting went longer than usual, and Kramer was able to get real-time answers to questions, discussing such issues as access to affordable medications. "Our conversation was so productive," Kramer says.

Father-and-son teamwork

James Dearing had his dream job as the director of marketing and health and wellness at a hospital in Illinois. It was the latest position in a career devoted to helping others, starting when he worked in a nursing home at age 15.



James Dearing and his son Jack talked with state representatives over the phone during the 2020 State Action Days.

He was put on medical leave before being let go following his 2011 MS diagnosis. “The day I was diagnosed, all I heard was, ‘You have a disease that doesn’t have a cure.’ It was an out-of-body experience where the room got dark, and I was stuck on the freaking disease as progressive. It was a pretty stressful day,” 45-year-old Dearing says.

When he attended his first State Action Day three years ago, he brought his son Jack to show him how to talk to legislators, get his voice heard and discuss important issues. Now 13, Jack might be Dearing’s secret weapon: Legislators remember his 6-foot-1-inch son.

For the 2020 virtual State Action Day in Illinois, Dearing chose to engage with his representatives by telephone, allowing him to get his points across while working from prepared notes and without feeling rushed. Urging his state representative to co-sponsor a bill that limits out-of-pocket costs, copays and deductibles for prescription drugs was a priority. “I was a little hesitant, but it was a great experience. It was a little more laid back, probably because we were able to talk a little longer,” Dearing says. And Jack was at his side.

Setting her own pace

As a former journalist, 62-year-old Elaine Shelly knows how to cover the many sides of a story, including her own. Before her MS diagnosis in September 1991, “I was that person who wouldn’t even take an elevator. I would just run up the stairs. Now I’m a full-time wheelchair user, and just getting through the day can be challenging at times,” she says.

Shelly volunteers as a District Activist Leader for the Society, where she tracks state and federal legislation related to MS. She also became a member of the Government Relations Advisory Committee in 2020 to help the Society come up with legislative priorities. In addition, she participated in California’s State Action Day in 2020 for the first time.

Shelly used Twitter to reach out to her legislators and followed-up with a Zoom visit. “Social

media is good for getting the word out about issues, but I think to be effective and impactful, you need that personal contact. I'm in the process of building relationships with staff people in my legislators' offices," she says.

When Shelly woke up on State Action Day, she knew it would be an "MS day." That day, she was experiencing a lot of fatigue, and her aide had to help her complete her shower. Had there been in-person meetings in Sacramento, she wasn't sure she would have been able to handle them, traverse the capitol and discuss protecting programs that help people with MS stay in their homes.

"But since I was at home, I was able to do things at my own pace and stop when I needed to. It made the day much more manageable for me. I think I can get my work done better online," she says.

As of June 2020, 300 people had participated in virtual State Action Days in five states, with one more virtual event scheduled for September in New Jersey. "I see us doing more of these events. We have a whole system of low-cost tools that people can engage with [to] show their strength in numbers on issues that affect them," Emanuelson says.

Robert Leroise is a freelance writer in New York.

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