## **Advocating... Virtually**



I was invited to join the National MS Society for California State Action Day at the end of March in Sacramento. We would be meeting face to face with our representatives to share our stories of living with multiple sclerosis.

I was thrilled! I was going to leave late Sunday night and be back late Monday night after spending the day in Sacramento for a quick overnight trip. My husband would get the kids to and from school. My parents would watch them while he was at work. I was going to have to figure out how to do a Lyft/Uber ride from the airport to the hotel. It was all worked out, and I was so excited!

The week before I was supposed to leave, the COVID-19 pandemic was unfolding rapidly before our eyes. I started to feel nervous and emailed my neurologist for his advice on going or not, and he shut it down. I wasn't really surprised at his reasoning. Northern California had a lot of active cases of COVID-19, and they were the first cities in California to order shelter-in-place. I was heartbroken. Then the next day, the National MS Society emailed us all to say they were cancelling any in person meetings, and they were hoping we could all meet in June instead.

As the pandemic continued on and states shut down all over the country, we received another email that said to mark our calendars because we would now be meeting virtually in May!

I joined the online training meeting to learn more. First, they recapped what they accomplished on last year's State Action day. The advocates helped get a bill passed to help make people's homes more accessible, instead of having to have seniors and people living

with disabilities move to nursing homes. Early prevention often saves money in healthcare costs in the long term and gives better quality of life to people so they can stay in their own homes.



Ready for the online training meeting!

Next, we discussed the two bills we would focus on help getting passed this year. The first, AB2730, will eliminate barriers to emergency evacuation for vulnerable populations during emergencies. In California's current disaster planning, the rescue workers know **where** to take people but not **how** to get them evacuated to those places. This bill will enable cities and counties to communicate and form partnerships for transportation services during emergencies. The second proposed bill, AB2064, would require all county emergency planning committees to include people living with disabilities to be included in the planning of the California Disaster plans. People with disabilities are two to four times more likely to be injured in a disaster.

I exited the online training excited to see what State Advocacy Day would bring.

I received a text message telling me to wear orange and meet online for our kickoff celebration. There were over 40 advocates on the video-meeting. John Strum of Real Talk MS podcast hosted the kick off. We re-capped what we would be messaging our representatives about, and we took a group photo (and that was the exact moment my computer froze!)

I received a text message that I just simply needed to enter my personal info, and it had an already generated email that once I pressed send, would go directly to my representatives. You could also edit the email to make it more personal before it was forwarded on. I chose to edit it. I believe both of these bills would be helpful to the people in California, and I shared why. We had a really bad fire season a few years back, and after the fire had ravaged homes

and they were searching the debris, they found numerous people who were disabled who died because they couldn't get out for various reasons and that had stuck with me.

I hope I get to go to Sacramento next year. But if not, this was a really easy way to advocate and participate to help bring changes that may improve the lives of people living with disabilities.

Editor's Note: The Society continues to be there for people affected by MS. For the latest information and resources related to COVID-19, please visit the Society's <u>Coronavirus</u>

<u>Resources Page.</u> Find additional resources through our <u>Ask an MS Expert webinar</u>

<u>series.</u>