

## MOVING FORWARD TOGETHER

It's hard to believe it's been more than a year since we've seen each other in person at a National MS Society gathering! As more people get vaccinated and we see an end to the pandemic, we are eager to ramp up to in-person opportunities again with the health and safety of participants in mind. Canceling and postponing so many events last year was heartbreaking. It's wonderful to feel optimistic about being in person again!

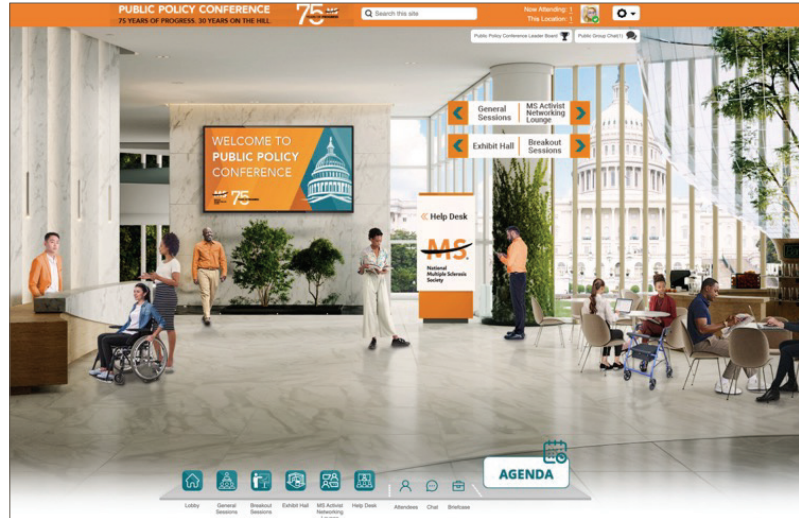
At the same time, we are proud of the swift action we took last year to pivot quickly and ensure continuity as we moved in-person gatherings to a virtual space. Thanks to your support, we worked together to find new and creative ways to engage more people than ever before and empower them with connections they needed to live their best lives. We heard from many that the increased accessibility is a positive outcome of being forced to go virtual.

We will take what we learned with us as we work towards meeting in person once again. Virtual components are here to stay. We want to continue building the MS movement with more options to engage. MS doesn't stop and neither will we.

Since safety is a top priority, we continually evaluate options for in-person opportunities and create protocols for safe gatherings. We also know far too well that situations change quickly, and we must be flexible and ready to adapt at all times.

As we move forward, we will expand our reach and deepen connections — meeting each individual where they are. For some that may be in person at a rest stop at Bike MS and for others, that might be online through a virtual support group. It depends on what is best for each person. I have confidence that this new blended approach to engagement, that considers unique needs and preferences, will further strengthen the MS movement and accelerate our progress.

We can see this progress in action already! With our first ever virtual Public Policy Conference (see pages 2 and 3) engaging three times more activists than ever before,



Public Policy Conference, virtual event



Dinner of Champions, drive-in event

and our fundraising events this spring offering both virtual and in-person options for participation.

Together, we overcome challenges and continuously evolve to meet the needs of people affected by MS. It's only possible with you. However we connect — in person, online, by phone — let's keep in touch!

Yours truly,

Cyndi Zagieboylo  
President & CEO  
National MS Society



# 75 YEARS OF PROGRESS. 30 YEARS ON THE HILL.

March 2021 saw the first ever virtual Public Policy Conference (PPC). While PPC is usually held in person in Washington, DC, this year required changes to gather MS activists to learn, connect with each other and engage with Congress, while also keeping everyone safe. Thanks to supporters like you, the Society was able to pivot quickly and invest in an interactive virtual platform to make the 30th annual PPC a great experience. With your help, we took the challenge, thought differently, acted boldly, and succeeded!

We engaged more people at one event than ever before with 888 participants, triple the number we can accommodate at the in-person conference. More than 70% rated their virtual PPC experience as excellent or extraordinary. This inspired 400 people to sign up as new MS activists, bringing our total to 34,222 Action Alert members. These record numbers make our movement stronger and our voices louder, leading to more meetings with elected officials, more opportunities to tell our stories and influence legislation to improve quality of life for people affected by MS.

Clear messages for change and tools to educate elected officials leads to advocacy success. PPC highlighted two big issues this year: expanded access to telehealth and continued funding of the Department of Defense MS Research Program (MSRP). Over the past year, we have all seen the benefits of telehealth and are urging our representatives to support expansion of telehealth, even after the pandemic. The Society is also advocating for \$20 million in funding for the MSRP, the only federal funding stream specifically for MS research.

## INCREASING FUNDING FOR HIGH-RISK RESEARCH CAN GARNER HIGH REWARDS

The MS Research Program (MSRP), part of the Congressional Directed Medical Research Program (CDMRP), in the Department of Defense is unique in that it seeks to fund high-risk, high-reward projects compared to other funding entities. By sponsoring projects with less preliminary data, the MSRP supports the most innovative research with high-impact outcomes that are critically important for making real changes in the lives of people with MS.

Since its conception in 2009, the MSRP has funded 111 awards, 98 projects, 4 clinical trials and 3 patents — all focused on improving the quality of life for people living with MS

At this year's PPC, we heard from Dr. Leigh Charvet, a neurology professor at the NYU School of Medicine, whose MSRP and Society-funded research focuses on whether non-invasive brain stimulation paired with rehabilitative exercises can improve learning in a hand training program. Thanks to this combined funding, her high-risk, high-reward project has great potential to help people with MS restore function.



Dr. Leigh Charvet

Incidentally, Dr. Charvet's research has also shown the importance of another key issue discussed at PPC this year: telehealth. With a background in telehealth, Dr. Charvet quickly pivoted to telerehabilitation to continue her study by administering treatment remotely throughout the pandemic. Dr. Charvet has seen firsthand the need for expanded telehealth services and has been inspired by how accessible rehabilitation can become when it, like so many other things in our world, goes virtual.

## EXPANDING TELEHEALTH EXPANDS ACCESS TO CARE

When in-person doctor's visits became a risk for COVID-19 exposure, but delaying a visit risked poor health outcomes, telehealth became the obvious solution to keep people safe and healthy. In response to the emergency situation of the pandemic, the federal government waived many restrictions that had previously limited telehealth. However, it is uncertain whether these temporary measures will continue after the pandemic, so at this year's PPC, MS Activists asked for their elected officials' support to expand access to telehealth as more evidence shows benefits for both patients and healthcare providers.

For Kristen O'Toole, who was diagnosed with MS in 2014, getting to a doctor's visit during the pandemic was challenging since she relies on public transportation, which did not seem like a safe option. When she scheduled her first virtual physical therapy appointment, she



Kristen O'Toole

was skeptical — how helpful could physical therapy be if it was not in person? However, after just one appointment Kristen found that not only was it vital in keeping her strength up, but it also helped her feel less isolated. When she recently resumed in-person therapy after a year of telehealth, she said, "I didn't miss a beat!" and feels more confident that she now has both options to choose from.

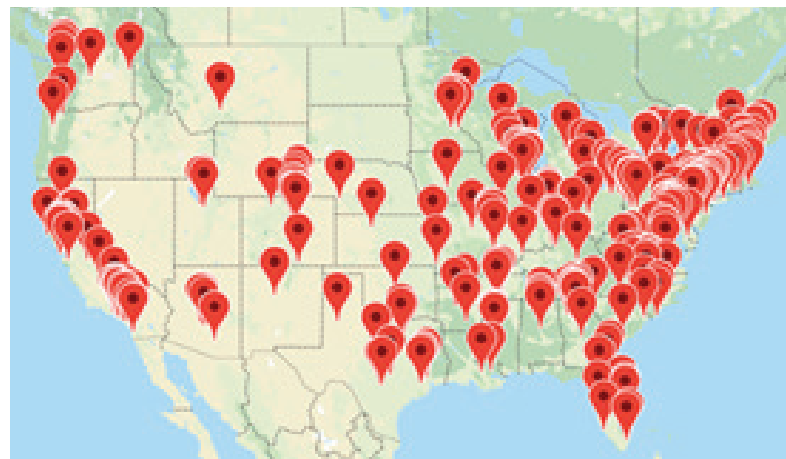
Kristen is not alone in seeing the benefits of telehealth: across the board, patients and providers are reporting that telehealth is a great option. Dr. Mitch Wallin, Associate Professor of Neurology at Georgetown University and Director for the Veterans Affairs MS Center of Excellence in the East, shared the results of a study polling people living with MS and healthcare providers about their telehealth experiences.

These are some of the many reasons MS activists are seeking support from elected officials to expand access to telehealth so that people living with MS still have this as an option as we move forward.

**80%** of people living with MS who were surveyed said they'd want to continue telehealth after the pandemic

## YOUR GIFT CHANGES LIVES

The Public Policy Conference held in an engaging virtual environment this year, focused on the importance of telehealth and federal MS research funding and inspired many to reach out to their members of Congress and ask them to join the movement. Thanks to your support, we made history this year with record numbers of attendees and new MS activists. With every new MS activist who adds their voice, we can influence legislation that removes barriers, creates resources, and paves the way for breakthroughs that will change the world for people living with MS. Join us at <https://ntlms.org/advocate>. ■



MS Action Alert responses during the virtual Public Policy Conference



# AN INSPIRING COMMITMENT: MAKING LIFE BETTER FOR THOSE WITH MS

When Cathy Onufrychuk was diagnosed with multiple sclerosis 27 years ago, she and her husband Bill knew very little about the disease. There was no Google back then, so they turned to an encyclopedia to try to learn more about how this diagnosis would affect their lives and the lives of their three children.

Not finding what they needed, they connected with the National MS Society for help. This began their long and meaningful relationship with the Society, a place where they have received support, made lifelong friendships and united their friends and family in a combined vision to make life better for those with MS.

“We are so appreciative of the support we have received from the Society over the years,” says Cathy. “The personal interactions have been our lifeline and it has always been our greatest hope to help find a cure.”

Cathy currently has a diagnosis of progressive MS. After realizing that there was a lack of research and treatments for this form of MS, she and Bill dedicated themselves to raising awareness of progressive MS and rallying those around them to give back to help move research forward.

As top fundraisers for Walk MS®, Bill and Cathy know the importance of raising money to find a cure for MS. “My friends and family see me continuing to go about my life while using a cane, rollator or wheelchair when needed,” says Cathy. “What I say to them during Walk MS season is that if you know me and care about me, then please make a donation, no matter what size.”

Grateful for the support they’ve received from the Society, Bill and Cathy also give back in a number of other ways. Bill is an active board member for the Greater DC Maryland Chapter, and Cathy has been committed to the chapter’s On the Move Luncheon since its inception 17 years ago.

Additionally, Bill and Cathy are among the earliest Trust and Foundation members of the International Progressive MS Alliance fueling global efforts to uncover solutions for those affected by progressive MS. “Research on the progressive end is more complicated and overwhelming for small labs,” says Bill. “Bringing international researchers together through the Alliance is making a world of difference to the work being done.”



**“The Society has taken such a leadership role in MS research and we’re happy to play our part.” — Bill Onufrychuk**

Bill and Cathy Onufrychuk have been long-time supporters of the Society.

Bill and Cathy are particularly excited and hopeful about myelin repair progress. To them, this is the best chance to stop the progression of Cathy’s disease going forward. It’s been inspiring for this couple to attend conferences and listen to leading researchers speak about their work, and also to witness the brainstorming and lightbulb moments happening between scientists.

“Although we ourselves can’t figure out how to cure MS, we can provide resources so people who know what they are doing can figure it out,” says Bill. “We are so impressed with the progress that has already been made.”

**Bill and Cathy Onufrychuk have played a vital role in advancing the progress the Society has achieved in the 75 years since its founding. The Society is extremely grateful for their ongoing dedication to helping find a cure for MS while empowering people to lives their best lives with the disease.**

From Bill’s perspective, the strongest legacy they will leave as a couple will be from his inspiring wife. “Cathy is someone who is always doing her best, has a great smile and really does contribute everything she possibly can to help.” ■