Ensure Comprehensive High-Quality Healthcare

**ADVOCACY PROGRESS**

34,222

MS Activists took 5,182 actions

364

District Activist Leaders

**550 HEALTHCARE PROVIDERS**

attending programs are better equipped to take care of their patients with MS and promote the Society as a supportive partner

91%

plan to change practice or behavior (target: 80%)

84%

report improved attitudes about MS care (target: 85%)

91%

report increased knowledge about MS care (target: 95%)

Referrals to MS Navigator from healthcare providers

FY21 YTD: 3,847

FY21 target: 7,980

Q2: 2,034

Q1: 1,813

**HIGHLIGHTS AND MILESTONES**

- We worked on 18 state-level telehealth bills and 51 bills related to access to MS medications
- A record 888 Public Policy Conference attendees sent 2,442 emails to members of Congress and held over 263 virtual meetings
- Held 11 State Action Days with 736 total participants and 352 new MS Activists
- President Biden signed the American Rescue Plan Act of 2021, which includes the Society’s recommendations for continued support of people affected by MS to help address the COVID-19 pandemic and the resulting economic crisis

**STATE PROGRESS ON ACCESS TO CARE LEGISLATION**

- Bills we supported became law (total = 12)
- Bills we supported passed by a chamber of the state legislature (House or Senate) (total = 60)
- Bills we supported passed by a committee (total = 145)
- No advancement

**CHALLENGES**

- While we continue to cultivate relationships with healthcare providers virtually, it is not the optimal way to meet new providers or strengthen existing relationships
- Tight margins and political dynamics may limit how much Congress is able to get done this year
IMPACT SPOTLIGHT:

ADVOCATING FOR HEALTHCARE ACCESS

The National MS Society helps the MS community amplify their voices to champion policies that will help those affected by this disease live their best lives.

The annual Public Policy Conference brings us together to speak with one voice to raise awareness and educate elected officials about the needs of the MS community. This year’s virtual event welcomed a record 888 attendees. Together, MS activists across the country sent 2,442 emails to their members of Congress, and held over 263 virtual meetings to share their personal stories with MS. This powerful network encouraged policymakers to support $20 million in funding for the MS research program at the Department of Defense and expanding access to telehealth.

Stacy Barton, Chief of Staff for Rep. Steve Chabot (R-Ohio), has lived with MS since 2005, and has seen firsthand the importance and results from the work of MS advocates.

On those who may doubt that advocacy work can lead to real change, Barton says: “If people 20, 30 years ago held that belief, where would we be in terms of the options that we have as MSers, the treatments that are now available to us? Those things are only available because years ago, people were advocating that we need to know more about this disease. So, we’re benefiting from the work that other people engaged in.”

Because the area of public policy can make such a powerful impact, the Society’s advocacy work will continue to play a important part in getting us closer to a world free of MS.
Empower People Affected by MS to Solve Everyday Challenges

HIGHLIGHTS AND MILESTONES

- 373 newly diagnosed individuals connected to MS Navigator
- The ability to provide in-home case management services is increasing as COVID-19 vaccines are becoming widely available
- The generous donation from the Conrad Hilton Foundation increases our capacity to assist people with rent, mortgage, utilities, mental health, respite care needs and more
- Provided MS Navigators with continued education on navigating and managing mental health challenges experienced by people living with MS
- 389 people were supported through the Edward M. Dowd Personal Advocate Program (Case Management)

CHALLENGES

- People connecting to the Society report they are struggling with feelings of stress and anxiety related to vaccines, work and their family life

MEETING PEOPLE WHERE THEY ARE

29,612 Find Doctors and Resources searches

4,227 participated in Ask an MS Expert series

11,940 connected with MS Navigator via phone, email or chat

5,325 engaged in Facebook Social Learning Group

140 supported through MS Friends

PEOPLE WHO CONNECTED TO SOCIETY RESOURCES AND SUPPORT

80% plan to take action based on what they learned (target: 80%)

87% believe the Society is a source of support where they can find solutions (target: 85%)

81% feel more confident in addressing challenges of MS (target: 75%)

81% made new connections to information resources, people and/or other sources of support (target: 80%)

I want to thank you for all you have done to aid in the purchase of my scooter! What a wonderful thing that this has done for me. I’ve gone on a couple of medium size walks with the family which I would not have been able to do otherwise.”

– MS Navigator recipient
Kelly was diagnosed with MS in 2000, and struggled climbing the stairs into her home safely. 

“Leaving my house became almost impossible, as I could no longer get up and down the stairs,” Kelly recalls. “I only left my house for necessary doctors’ visits, and felt as though all my freedom had been taken away.”

Through her healthcare provider, Kelly was referred to an MS Navigator who recognized the safety issue and quickly began the process of obtaining an affordable solution.

"When I contacted the Society, I was not sure what kind of assistance I would receive. I have always been hesitant to ask others for help,” Kelly confesses. “After being connected with my Navigator, I felt much more comfortable. She guided me throughout the entire process answering any questions I had.”

With the help of an MS Navigator and the generous support of donors, including the Hilton Foundation, a ramp was installed for Kelly within a few days.

Navigators connect those affected by MS, their families and carepartners to the information, resources and support they need to move their lives forward. This nationwide team is made up of compassionate, highly skilled professionals who work one-on-one to find lasting solutions for the unique and often complex challenges MS can bring, including insurance and prescription coverage, wellness strategies, emotional support resources, crisis intervention and more.

"Thank you so much for helping me get the financial assistance I needed for a ramp. I would never have been able to do this without the help of the National MS Society"
Deliver Breakthroughs to a Cure

HIGHLIGHTS AND MILESTONES

• Published results from the Society-led COViMS Registry showed that in people with MS, decreased mobility, being older, Black, male, or having other health conditions could lead to poorer outcomes after COVID-19 infection

• A Society-funded team showed that a compound that mimics aspects of thyroid hormone can stimulate repair of myelin in mice with MS-like disease, and may help prevent tissue damage

• The FDA approved oral Ponvory and a new form of Plegridy to treat relapsing forms of MS, and a portable nerve stimulator for use during physical therapy to improve walking in MS

• Society-supported researchers discovered a subset of brain cells that fight inflammation with instructions from gut bacteria, opening possibilities for new therapy approaches

• Positive results were announced from a small clinical trial, supported by a Fast Forward commercial investment, of NurOwn® cell therapy in people with progressive MS; more study is needed

CHALLENGES

• With scientific meetings being held virtually, there is less opportunity for informal interactions that often lead to new research collaborations

• Research labs are not back to full capacity, which may delay progress on important research questions

• Although telehealth is enabling some clinical trials to proceed during the pandemic, potential participants are reluctant to join trials that require in-person visits, delaying progress

• Many resources have been directed to urgent questions and needs caused by the pandemic

PATHWAYS TO CURES

The number of published research studies focused on early detection of MS have doubled since 2019

More researchers are focusing on developing the tools to detect MS in its earliest stages. This will accelerate progress towards our goal of ending MS and will create new and better ways to diagnose MS.
For years, it was a fairly common assumption that people are born with all the brain cells they will ever have. But Dwight Bergles, PhD, has spent years researching and pioneering the study of immature cells—specifically, oligodendrocyte precursor cells (OPCs).

“Occasionally, we encountered these mysterious cells,” Bergles says. “At the time, we didn’t know about the existence of these cells. We didn’t realize what they were, their properties or where they were found.”

Bergles, who is a professor at the Solomon H. Snyder Department of Neuroscience at Johns Hopkins University, is the proud recipient of the 2021 Barancik Prize for Innovation in Multiple Sclerosis Research for his groundbreaking work and dedication to the field of MS research.

Bergles has studied OPCs because of their ability to mature into oligodendrocytes, which make up myelin. While most nervous system development and maturation is completed early in life, OPCs change throughout a person’s life, turning into myelin-making oligodendrocytes in response to injury—why OPCs sometimes transform and sometimes do not is still unknown, particularly through the lens of MS.

However, Bergles and his team of researchers—with the continued support of the MS community—are hopeful that in the future, remyelination may be possible.
Expand Resources and Reach

Breakthrough MS Campaign Progress

- **FY21 target:** $1 billion
- **FY21 YTD:** $68 million ($786 million raised to date)
- **FY20:** $152 million
- **FY19:** $193 million
- **FY18:** $192 million
- **FY17:** $181 million

Breakthrough MS Board Appeal Progress

- **FY21 target:** $4 million
- **FY21 Q2:** $609,925 ($1.2 million raised to date)
- **FY21 Q1:** $617,000

Engagement

- **7.5 MILLION**
  
  PEOPLE ENGAGE WITH THE SOCIETY

  - **FY21 target:** 7.65 million

  - **60.5%**

  - 553,128 of the estimated 914,000 people with MS in the United States are connected to their National MS Society (FY21 target: 61.3%, 560,000 people)

HIGHLIGHTS AND MILESTONES

- 17,500 people registered for the newly designed Bike MS experience, with 56 events planned to be in-person this year
- Walk MS kicked off with a new virtual component designed to enhance the experience for sponsors and participants. The event has attracted $3M in national sponsorship and nearly $1M in local corporate sponsorship
- Three virtual donor engagement events raised nearly $500K
- Major League Baseball pitcher, Dane Dunning, hosted a Stream to End MS event which had 240K unique views, the largest digital viewerhip the Society has ever had, and raised $15K
- Johnson & Johnson/Janssen Neuroscience, Microsoft and Optum became new National Team partners, participating in 19 team fundraising events throughout the country

CHALLENGES

- The virtual event fatigue and economic uncertainty caused by the pandemic continues to have financial implications
ACCELERATING PROGRESS

DIGITAL AND TECHNOLOGY

• Using an engaging virtual platform, the Public Policy Conference had triple the number of participants than we’ve been able to accommodate in the past

• Ask an MS Expert continues to be offered monthly in Spanish and weekly in English through our website, YouTube and Facebook. The program was accessed in 27 countries

• 118 MS providers participated in ECHO MS (Extension for Community Healthcare Outcomes), connecting MS experts at academic centers with community providers to share best practices and increase access to quality MS care

STRATEGIC PARTNERSHIPS

• Partnerships with Happy the App, a phone service app offering emotional support, and Pack Health, a health coaching tool, allow us to expand referral resources offered to people living with MS

• Launched COVER-MS with the Accelerated Cure Project to collect outcomes from people with MS who receive a COVID-19 vaccine

• Through the International Progressive MS Alliance, we completed final stages of research application review of new projects, and published two expert opinion papers on research priorities

INNOVATION AND IMPROVEMENT

• Healthcare Provider Councils are now offering virtual educational opportunities to increase knowledge of MS among healthcare providers

• Developed materials for the Community Review of MS Research Committee, designed to gain input from people affected by MS in research decision making

VOLUNTEER ENGAGEMENT

• Engaged volunteers to evaluate our online chat and Find Doctors and Resources tool to gain insight on their effectiveness

• The Scientific Advisory Committee provided input on a targeted research initiative on early detection of MS to support Pathways to Cures priorities

• 1,467 MS Activists made connections with lawmakers

• The Diversity Advisory Committee rolled out an updated Diversity, Equity & Inclusion statement

AWARENESS

• Increased awareness of Veterans with MS through webinar partnership with the Paralyzed Veterans of America and the MS Centers of Excellence—62% of program registrants were new to the Society

• The Society is a go-to source for information on COVID and MS. We provided timely and reliable updates on our Society website, established guidelines for healthcare providers and people with MS and extended outreach through webinars and social media (RealTalk MS, FaceBook, Ask an MS Expert)