FY2021 Q1 PROGRESS REPORT
FY2019–2021 STRATEGIC PLAN

PETER
DIAGNOSED IN 2015
Ensure Comprehensive High-Quality Healthcare

**Advocacy Progress**

34,183 MS Activists took 5,224 actions

385 District Activist Leaders

**Highlights and Milestones**

- Convened experts to develop **COVID vaccine guidelines** for people with MS — globally adopted and endorsed by MS groups including Americas Committee for Treatment and Research in MS (ACTRIMS)
- The **work of MS Activists resulted in** $20M for the MS Research Program at the Department of Defense, $7.1M for the Lifespan Respite Program, and $42.9B for biomedical funding for the National Institutes of Health
- Congress passed legislation to **end surprise medical billing**, a top Society policy priority
- Our work to strengthen **access to telehealth services** resulted in $7B to expand broadband access
- The **Centers for Disease Control and Prevention** received $5M to continue its National Neurologic Conditions Surveillance System and its pilot programs on MS

**Healthcare Providers**

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

- 63% plan to change practice or behavior (target: 65%)
- 82% report improved attitudes about MS care (target: 82%)
- 92% report increased knowledge about MS care (target: 90%)
- 71% would recommend the Society to a friend or colleague (target: 75%)

**Referrals to MS Navigator from healthcare providers**

- FY21 target: 7,980
- Q1: 1,813

**Challenges**

- COVID-19 continues to present barriers for access to **telemedicine** as patients and providers are dealing with issues related to insurance coverage, affordability of devices and operable bandwidth
- The ongoing pandemic, the surge of cases and vaccine distribution has made it challenging to move other healthcare issues forward
- Due to the pandemic, states may be cutting funding from **2021 budgets** which could impact resources used by people living with MS
IMPACT SPOTLIGHT:

ADVOCATING FOR HEALTHCARE ACCESS

Lisa McRipley is passionate about ensuring everyone in the MS movement has what they need to live their best lives.

After being diagnosed with MS in 2010 and no longer able to work, Lisa moved back to Michigan, where she became an MS activist. She has been a volunteer organizer for all five Conferences for African American/Black Families Affected by MS in Detroit and helped organize the Society’s Black MS Experience Summit.

As an MS Activist, she shared her story about dealing with unaffordable MS medications with U.S. Rep. Rashida Tlaib, who presented Lisa’s story during the House of Representatives Oversight and Reform Committee’s hearing on drug pricing.

“She helped me understand the importance of advocacy,” Lisa says.

Being virtual did not slow Lisa’s advocacy efforts. When she did not attend Public Policy in 2020 due to the pandemic, she called and emailed representatives from home.

Lisa was an early adopter of the virtual state action day model and helped convince others that a virtual event had the potential to engage more activists and have greater impact on the Society’s priorities.
I am just so very grateful to have had the MS Society as a support when I have needed it over the 25 years I have lived with MS. The navigator program is a wonderful resource to those of us who need it."

– MS Navigator recipient
As an MS clinician and researcher, Dr. Jaime Imitola, MD, director of the MS Center at UConn Health, University of Connecticut, uses his unique position in healthcare to advocate for patients.

“I have two roles. I go to the lab and try to answer fundamental questions about progressive MS that I see in my patients. When I go to the MS center, I see the societal implications of living with MS and the tremendous gaps in delivery of care and education. My goal is to close the gaps to understand what is needed for optimal MS care” says Dr. Imitola.

He has been involved with the Society for years, launching an MS summit with his local MS Society office to identify unmet needs for patients. He is also a passionate mentor, attracting and training the next generation of MS doctors and scientists. When the COVID-19 pandemic hit, Dr. Imitola was a crucial partner in ensuring the success of the Society’s Ask an MS Expert program, where he helped facilitate sessions in English and Spanish.

He also worked closely with the local office to identify and advocate for at-risk communities to ensure they had what they needed to get through the pandemic — including orange masks, groceries and organizing mobile COVID testing.

“There is a great gap in the way we deliver care, especially to patients of diverse backgrounds and progressive MS. What has helped overcome these challenges is the sense of community we have built and the collaboration with the National MS Society.”
Deliver Breakthroughs to a Cure

HIGHLIGHTS AND MILESTONES

- The Society’s Wellness Research Work Group published recommendations on ways people with MS can stay well during the pandemic.
- A study of millions of medical records found that high blood pressure was 25% more common in people with MS.
- Society-funded researchers identified that two immune-related genes may explain the increased risk of MS in African Americans who have European ancestors.
- A study provided new information on the origins and types of pain in MS, which may lead to better treatment strategies.
- Study supported by the Society showed that stem cells derived from skin cells of people with MS make normal myelin, a plus for future repair strategies.
- Society-funded researchers showed how gut bacteria may help regulate immune attacks in MS.

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.
Jennifer Frame, who has lived with MS for over 30 years, has worn many volunteer hats in the last 12 years: Walk MS® team captain, an MS ambassador at events, support group leader, local office volunteer and MS advocate.

“When I did my first (Walk MS event), we had a team of 7 people. I distinctly remember as the walk began, crying for the first 15 minutes or more at the gravity of the power of numbers and the emotions of not being alone as I saw many walking for themselves, friends and family. I was so overwhelmed with what we can do as a group to fight MS.”

Jennifer’s dedication to the National MS Society’s mission has ensured that no matter what, progress towards a cure continues with force.

As a support group leader, Jennifer is instrumental in helping her group members feel more connected to the MS movement, a responsibility she takes seriously. This year her group has pivoted to virtual, grown in members, incorporated new weekly activities and started meeting biweekly due to its success.

“I love being a resource to support and educate others with MS,” Jennifer shares.

“I know I am making a difference in small and big ways to spread the word about MS, to support others and myself with MS, and to support those working so hard behind the scenes. I will continue to do all I can to support others with MS and the awesome team at the Society!”
Expand Resources and Reach

Breakthrough MS Campaign Progress

- FY21 target: $1 billion
  - FY21: $38 million
    ($756 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 Q1: $617,000

Engagement

7.5 MILLION
PEOPLE ENGAGE WITH THE SOCIETY

FY21 target: 7.65 million

60.3%

551,163 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

- Giving Tuesday fueled $1M in donor support
- Year-end giving direct marketing online campaigns generated $2.3M and engaged 22,000 donors
- Walk MS is in the final stages of building a new interactive online platform to deepen engagement and sense of community
- Bike MS: Inside Out, our virtual cycling experience, has raised $8.5M, outperforming Q1 budget by over $2M
- Received $1.6M in funding to support Ask an MS Expert, the Black MS Experience Summit, MS Navigator, Pathways to Wellness in MS and our work in Health Equity
- Bristol Myers Squibb is supporting the Society’s health equity work at $125K

CHALLENGES

- The continued economic uncertainty caused by the COVID-19 pandemic and “virtual” event fatigue will continue to have financial implications

Q1 Gross Revenue by Sources

* Includes Leadership Events, Finish MS, DIY Fundraising MS, Climb to the Top, Challenge Walk MS and other events
** Includes Direct Marketing
ACCELERATING PROGRESS

DIGITAL AND TECHNOLOGY

- Launched Healthcare Providers Twitter account
- Engaged PatientPoint, a patient engagement organization, to include content relevant to community neurologists on their platform
- The Society website continues to be a source for timely and reliable information on COVID-19 and MS, including expert guidance on vaccinations (88K unique page views)

STRATEGIC PARTNERSHIPS

- Collaborated with International Women in MS network to support diversity and inclusion in MS research workforce
- Partnered with Juvenile Diabetes Research Foundation to co-fund two cross-autoimmune disease research projects
- The COViMS registry, developed with the Consortium of MS Centers and the MS Society of Canada, collected 2,000 cases from providers on outcomes of people with MS who had COVID-19
- Through the International Progressive MS Alliance, we participated in FDA meetings related to support of a biomarker for progressive MS

INNOVATION AND IMPROVEMENT

- Revamped the healthcare provider engagement survey
- Developed criteria for joining the Network of Pediatric MS centers and hosted a meeting for 20 interested providers
- Completed phase 1 and began testing of project to enhance capabilities of our Case Management Software which will enable us to better track and manage the work of contractors

AWARENESS

- Glamour.com shared a video highlighting the stories of three women living with MS
- The MS Navigator program was featured in a Healthline.com article on MS and suicide
- New mission statement: We will cure MS while we empower people affected by MS to live their best lives

VOLUNTEER ENGAGEMENT

- Convened a Telehealth work team to develop guidelines for people with MS to maximize their telehealth visits
- 26 expert peer reviewers evaluated 85 proposals to help identify the most promising research questions and trainees
- Supported 954 self-help groups and 25 new group leaders