FY2021 Q3 PROGRESS REPORT
FY2019–2021 STRATEGIC PLAN
Ensure Comprehensive High-Quality Healthcare

HIGHLIGHTS AND MILESTONES

- The US Supreme Court upheld the Affordable Care Act (ACA), protecting access to affordable and comprehensive health coverage for people with MS and others.
- The Biden administration reversed a 2020 rule that rescinded protections for LGBTQ patients under the ACA. The Society had filed an amicus brief with other patient groups in a case against this rule.
- 22 medical student mentorships were held virtually, providing medical students training on the comprehensive management of MS.
- During Congressional hearings on drug pricing, the high cost of MS disease-modifying therapies was a major focal point, further highlighting the need for immediate action.
- Congress showed a renewed focus around maintaining and expanding access to telehealth, an issue the Society has long identified as critical to ensuring proper MS care.

ADVOCACY PROGRESS

34,152 MS Activists
10,864 took action this quarter

380 District Activist Leaders keep in touch with local legislators about MS issues

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

83% plan to change practice or behavior (target: 80%)
97% report improved attitudes about MS care (target: 85%)
99% report increased knowledge about MS care (target: 95%)

Referrals to MS Navigator from healthcare providers
FY21 YTD: 6,032
FY21 target: 7,980
- Q3: 2,185
- Q2: 2,034
- Q1: 1,813

STATE PROGRESS ON ACCESS TO CARE LEGISLATION

- Bills we supported became law (total = 42)
- Bills we supported passed by a chamber of the state legislature (House or Senate) (total = 127)
- Bills we supported passed by a committee (total = 214)
- No advancement

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IMPACT SPOTLIGHT: ADVOCATING FOR HEALTHCARE ACCESS

Currently, 2.8 million people worldwide live with multiple sclerosis.

As a movement by and for people affected by MS, getting closer to a world free of MS requires a global effort from passionate people who want to make a difference.

After Nicole Febles, a student at the San Juan Bautista School of Medicine, learned there was a lack of healthcare providers to treat MS patients in Puerto Rico, she wanted to be part of the solution.

The Society’s MS Clinical Mentorship for Medical Students supports the next generation of MS healthcare providers by offering hands-on, patient-centered training and early career support. By working closely under the guidance of experienced MS providers, the mentorship lays the necessary foundation needed for future researchers and clinicians to provide comprehensive care to MS patients.

After completing her MS Clinical Mentorship for Medical Students at Northwestern Memorial Hospital in Chicago, Febles felt more prepared to provide personalized, high-quality MS care for Puerto Ricans.

“This opportunity to work so closely with MS patients has made a huge impact on me,” she says. “It’s given me a solid foundation on what it takes to be an excellent neurologist to help my island, which is in desperate need of neurologists and even more, of MS specialists.”

As a global movement, we will continue to break down barriers so that people everywhere living with MS have access to quality healthcare and can live their best lives.
Empower People Affected by MS to Solve Everyday Challenges

**HIGHLIGHTS AND MILESTONES**

- 404 newly diagnosed individuals connected to **MS Navigator**
- **Ask an MS Expert** provides timely MS information in English, Spanish, and to the MS Veteran’s community
- Held 6 support group led **Resilience Programs**, sharing strategies with people living with MS on how to develop resilience
- 179 new cases were opened 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

**GETTING WHAT YOU NEED WHEN YOU NEED IT**

- 27,674 searched **Find Doctors and Resources** on Society website
- 69,463 learned the latest by participating in the live or on-demand **Ask an MS Expert** series
- 11,753 connected with **MS Navigator** via phone, email or chat
- 6,418 engaged in **Facebook Social Learning Group**
- 153 had a listening ear through **MS Friends**

**PEOPLE WHO CONNECTED TO SOCIETY RESOURCES AND SUPPORT**

- 73% plan to take action based on what they learned (target: 80%)
- 90% believe the Society is a source of support where they can find solutions (target: 85%)
- 77% feel more confident in addressing challenges of MS (target: 75%)
- 76% made new connections to information resources, people and/or other sources of support (target: 80%)

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*I want to thank the National MS Society for their gracious gift of the lift for my van. I will finally have freedom that I have not had in so many years. The idea that I can now have my power chair with me and the ability to come and go is life changing."

– MS Navigator recipient
Effectively managing MS goes beyond doctor’s visits, medication and MRIs. Wellness strategies — such as a healthy diet and regular exercise — play an integral role in not only symptom management, but in helping those affected by this disease take control of their health.

“Being an active person in my early thirties, the thought of my entire way of life changing was very scary,” says Chris Riend, who was diagnosed with MS less than a year ago and has since experienced neuropathy, spasticity and fatigue. “Because of this, I’ve been taking the approach that more information is helpful, and it’s up to me to decide what to do with that information.”

To take charge of managing his disease, Chris registered for Pathways to Wellness in MS. This program equips those in the MS community with the tools, knowledge and resources they need to empower their decision making and live their best lives. Participants learn to integrate wellness strategies and evidence-based exercise and lifestyle physical activity recommendations, along with hearing the latest in MS research.

“Pathways to Wellness helped me feel welcome in this community and encouraged me to take my situation into my own hands as much as possible. When bumps in the road happen, I have more options and tools to adapt to those challenges.”

“Pathways to Wellness was a great reminder to be deliberate. There are things I can control that will help improve my situation, and I shouldn’t resign myself to letting MS pull me in whatever direction it wants to,” shares Chris. “There are tools I can use that don’t involve medications, medical imaging or visits to the doctor that can help me day-to-day.”
Deliver Breakthroughs to a Cure

HIGHLIGHTS AND MILESTONES

- **2021 Dystel Prize for MS Research** went to Professor Vijay Kuchroo of Harvard for unraveling the immune system mechanisms underlying MS.

- Society-funded study shows that **robotic exoskeleton exercise** can improve walking ability and thinking speed.

- A study funded by the International Progressive MS Alliance identified **new subtypes of MS** based on patterns of damage seen on MRI scans, which in future may inform treatment decisions and improve clinical trials.

- Studies add to growing evidence that **Black people with MS may experience worse disease**, and may **respond differently than white people to B-cell therapy** (such as Ocrevus and Kesimpta) in terms of how quickly their depleted immune cells recovered.

- An **FDA Letter of Support** to the International Progressive MS Alliance will encourage studies that advance a blood biomarker to speed clinical trials in progressive MS.

- Society supported research by the University of Buffalo was leveraged to gain **funding from the Department of Defense** to investigate if a drug being tested in cancer has potential to promote myelin repair 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 getting back to fuller capacity, but the pandemic has delayed progress on important research questions.

PATHWAYS TO CURES

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.

The number of published research studies focused on early detection of MS have more than doubled since 2019.
On June 17, ultracyclist Phil Fox set out on a 940-mile trek around Lake Michigan with two goals in mind: complete the journey in under 72-hours to break the World Record, and bring awareness to those living with multiple sclerosis. To date, Phil has raised $25,628 through his Bike MS fundraiser.

“Two of my best friends were diagnosed 10 years ago,” Phil said. “That next month, I took part in my first Bike MS event, the Bike MS: Tour de Farms in DeKalb, IL. It was my first 200K ride. In the years since, I've seen the challenges this disease entails through their experiences and continued participating with the Society through a variety of fundraising activities.”

“I wanted to find something that represented the ambition of the Society—a challenge as large as the effort to end MS,” Phil said. “With so much disruption to many Bike MS events during the pandemic, we wanted to make up for some lost ground.”

Phil rode almost nonstop, 23 hours a day, eating on the bike and getting only a couple hours of sleep.

“Do anything long enough without sleep and you'll go through a whirlwind of emotional states. But as hard as this was, it will not compare to the hardships that others have to live with,” Phil said. “And that's why my team and I were so determined to get this done. No mistakes. No excuses.”
Expand Resources and Reach

**Breakthrough MS Campaign Progress**
- **FY21 target:** $1 billion
- **FY21 YTD:** $108 million ($826 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 Q3:** $473,075 ($1.7 million raised to date)
- FY21 Q3: $609,925
- FY21 Q1: $617,000

**Q3 Gross Revenue by Sources**

**Engagement**

7.69 MILLION
PEOPLE ENGAGE WITH THE SOCIETY
FY21 target: 7.65 million

60.6%
554,389 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**
- **Partnered with Zwift**, a virtual indoor training program, and held our first Zwift training ride with over 400 participants
- Launched **Bike MS Cycling Challenge Series**, a virtual four-week local competition which allows us to engage Bike MS participants virtually ahead of their event
- The **43rd Annual Cohn Weil Memorial MS Outing**, the Society’s largest leadership event, has raised over $1.4M, far exceeding budget and target
- 4 virtual donor stewardship events engaged nearly 350 people
- Completed our **Walk MS** virtual series with 353 events, raising close to $22 million from over 39,000 participants
- Held 14 in-person **Bike MS** events, bringing together 8,500 cyclists. Year over year fundraising for these events is up 27%

**CHALLENGES**
- The virtual event fatigue and the uncertainty of the Delta variant continue to have financial implications

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*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

- 6,400 people are members of the Society Facebook Social Learning Group, making connections and increasing their knowledge.

STRATEGIC PARTNERSHIPS

- Collaborated with the MS International Federation, MS Society of Canada and International Pediatric MS Study Group to develop COVID-19 vaccine guidance for youth living with MS.
- Partnered with the Health Department in Puerto Rico to bring Case Management Services to residents of Puerto Rico.
- Through the International Progressive MS Alliance, we funded 19 Research Challenge Awards focused on new insights into MS progression.
- Through our data collection efforts with the Consortium of MS Centers and the MS Society of Canada, we have collected 3,306 cases from healthcare providers on outcomes of people with MS who developed COVID-19 infections.

INNOVATION AND IMPROVEMENT

- Volunteers living with MS conducted surveys of individuals receiving Case Management Services to identify the impact of our services and to identify areas for improvement.
- Completed two phases of enhancements to our Case Management software, creating more efficient invoicing and data tracking.

AWARENESS

- Distributed a newsletter to 515 contracted case managers with information about MS and Society resources.
- The Society is a go-to source for information on COVID and MS. We provided timely and reliable updates on our website, established guidelines for healthcare providers and people with MS, and provided extended outreach through webinars and social media (RealTalk MS, FaceBook, Ask an MS Expert).

VOLUNTEER ENGAGEMENT

- Recruited and trained the Community Review of MS Research Committee, which is designed to gain input from people affected by MS on research decision making.
- Gained input from the Scientific Advisory Committee on the Pathways to Cures manuscript, potential enhancements of postdoctoral research program, and ways to increase diversity and inclusion in MS research.
- 3,028 MS Activists made connections with lawmakers, and 924 activists participated in 10 State Action Days.