FY2020 Q2 PROGRESS REPORT
FY2019–2021 STRATEGIC PLAN

National Multiple Sclerosis Society
Ensure Comprehensive High-Quality Healthcare

**ADVOCACY PROGRESS**

**33,769**
Engaged MS Activists

**312**
District Activist Leaders

**546 HEALTHCARE PROVIDERS**
Participated in Professional Education Programs

- 77% plan to change practice or behavior as a result of participating in professional education programs (target: 80%)
- 93% report improved attitudes about MS care (target: 85%)
- 97% report increased knowledge about MS care (target: 95%)

**Referrals to MS Navigator**
from healthcare providers

- FY20 total: 4,800
- FY20 target: 9,958
  - Q2: 2,369
  - Q1: 2,431

**HIGHLIGHTS**

- The Society was awarded with Research! America’s Paul G. Rogers Distinguished Organization Advocacy Award for advocacy work to find solutions for people affected by MS
- Launched ECHO MS: COVID-19 virtual clinics to support healthcare providers learning about MS and COVID-19 through real case-based discussions
- Ensured that the needs of people with MS were addressed in the Congressional and Administration’s response to the COVID-19 pandemic
- Engaged more than 3,000 healthcare professionals in educational webinars on COVID-19, cultural competency and various other topics

**STATE PROGRESS**

- Bills we supported became law (total = 20)
- Bills we supported passed by a chamber of the state legislature (House or Senate) (total = 46)
- Bills we supported passed by a committee (total = 99)
- No advancement

**CHALLENGES**

- Congress and state legislatures have diverted their focus to handling the COVID-19 pandemic, which has resulted in the delay of priorities and possible veto of previously passed bills
- Lack of access to mental health care and social work services for children living with MS
- Community neurologists have varying levels of expertise and confidence in treating patients with MS
Over the last 20 years, disease-modifying therapies (DMTs) have transformed the lives of people with MS. But the cost of DMTs continues to increase. Between 2004 and 2015, the average price of MS medications has gone up 300%. These costs burden people like Eric and his family.

“Looking at the explanation of benefits when the statement comes, it’s a 10-pill dosage at $70,000. And I remember taking the first pill, and it’s a little tiny pill, and thinking like, this is $7,000,” he says. “It’s like a diamond in terms of value and size. How do people afford this?”

The Society works tirelessly to advocate for access to life-saving medication. In March, 270 MS activists from across the country gathered for the Society’s annual Public Policy Conference to advance legislation for affordable and accessible MS medications. In total, activists held over 340 meetings with lawmakers to spread awareness and educate Congress on what they can do to ensure no one has to face the high costs of MS medications.

The Society also conducted a nationwide survey to better understand how the high cost of MS medications affects those living with MS and their loved ones.

Survey results showed 40% of people living with MS have altered the use of their DMT, including taking less to stretch out their supply, skipping or delaying treatment, or stopping treatment altogether because of costs. New information like this will continue to fuel our advocacy work.

As a community, we are grateful for the advances in MS care through the years. But as Eric explains, “The drug company has probably invested significant amounts of money and research into creating that medication, but if people can’t afford to use it, it’s not doing anyone any good.”
Empower People Affected by MS to Solve Everyday Challenges

SERVICES IMPACT

PEOPLE WHO CONNECTED TO SOCIETY SERVICES

60%
546,297 of the estimated 914,000 of people with MS in the United States are connected to the National MS Society (FY20 target: 60%, 550,000 people)

HIGHLIGHTS

• 6,103 people participated in 61 Society programs
• Launched the "Ask an MS Expert" webinar series providing real-time information and updates on the COVID-19 pandemic. The three webinars to date have a combined 28,000 views.
• All MS Navigators and Case Managers are working remotely and continuing to deliver MS Navigator services amidst the COVID-19 pandemic
• Added 95 new Partners in MS Care who are now able to refer their patients directly to MS Navigator through an on-line referral form
• 495 newly diagnosed individuals connected with MS Navigator
• Created a COVID-19 resource page on the Society website with information and resources for people affected by MS
• Connected Society group leaders during the COVID-19 pandemic by hosting weekly drop-in calls for them to ask questions and get information on how to best support people living with MS

CHALLENGES

• The COVID-19 pandemic resulted in the cancellation or delay of many in-person programs
• Case management services being delivered telephonically as case managers are unable to make home visits during the COVID-19 pandemic

76%
plan to take action based on what they learned (target: 80%)

92%
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%)

84%
made new connections (target: 80%)

The stair lift was put in yesterday and it works like a dream! Now I can do my laundry as well as access my belongings downstairs. I can't thank you and your associates enough for all the hard work you did to make my dream come true" – MS Navigator recipient
To empower people with MS to overcome everyday challenges, the National MS Society partnered with Jon Strum to bring greater visibility to his podcast, RealTalk MS.

Every podcast episode features an interview with MS researchers, clinicians, advocates and policymakers who are committed to making a difference in the lives of people with MS. Episodes explore the latest in MS news, including research, advocacy and support for people living with the disease and their carepartners.

“This is a great fit for us,” said Ron Zwerin, the Society’s Executive Vice President of Marketing and Brand. “The Society and 'RealTalk MS' share common goals; we inform people affected by MS, enable them to live their best lives, and we educate and engage influencers across a wide spectrum that includes policy makers, providers, and fundraisers.”

In recent episodes, Jon explored the coronavirus (COVID-19) and recommendations from the National MS Society’s Medical Advisory Committee for disease-modifying therapies (DMTs). He discussed a new DMT (Ozanimod) that recently received FDA approval. He also talked about a clinical trial for a potential DMT for progressive MS that fell short of achieving its goals.

Jon knows firsthand how multiple sclerosis affects loved ones and their families. His wife, Jeanne, was diagnosed with secondary progressive MS in 1997, and lost her battle with the disease in February 2020. His love for his wife and his determination to do something to help her and others living with MS inspired him to start RealTalk MS in 2017.

“My goal is simple—to keep our conversation going until there’s no longer a need to talk about multiple sclerosis, except in the past tense.”

“I embrace all of these activities—from encouraging and funding cutting-edge MS research to advocating on behalf of everyone affected by MS to speaking at conferences and events around the world—in the hopes that my efforts will somehow play a small part in marking sure that other families won’t have to experience everything that Jeanne and I have,” Jon says.
Deliver Breakthroughs to a Cure

**ACTIVE CLINICAL TRIALS**

<table>
<thead>
<tr>
<th>Clinical Trials</th>
<th>Relapsing MS</th>
<th>Progressive MS</th>
<th>Wellness / Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Clinical Trials</td>
<td>512</td>
<td>374</td>
<td>314</td>
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</tbody>
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**HIGHLIGHTS**

- Harvard researcher Francisco J. Quintana, PhD, received the Barancik Prize for Innovation in MS Research for work toward understanding what triggers MS and how to stop it.
- The FDA-approved Zeposia as an oral disease-modifying therapy for adults with relapsing MS.
- Society-funded researchers found that eliminating a molecule named PAR1 promoted repair of myelin in mice.
- Positive results were announced from a trial of oral masitinib in people with non-active progressive MS.
- Studies suggest that changes in the nervous system related to MS begin well before there are perceptible symptoms.

**CHALLENGES**

- The COVID-19 pandemic has closed many MS research labs and paused clinical trials, which will likely delay the completion of many research projects.
- The financial implications of COVID-19 will affect our ability to support future research.
What triggers multiple sclerosis? Professor Francisco Quintana wants answers. Quintana is the recipient of the 2019 Barancik Prize for Innovation in MS Research, and is a professor of neurology at the Anne Romney Center for Neurologic Diseases at Brigham and Women’s Hospital, Harvard Medical School.

Quintana studies how external elements can affect the onset and progression of MS as well as what causes inflammation in the central nervous system. To shed light on these unanswered questions, he has used new and innovative technologies to examine internal functions of the body that lead to the disease.

Quintana said of his research: “I recently completed what is so far the largest single-cell analysis of central nervous system cells in MS and [experimental autoimmune encephalomyelitis] models... Since this work generated one of the largest datasets currently available, it provides a unique resource for the study of the [central nervous system] in health and disease. Thus, we expect these datasets and novel methods to have a deep impact on MS research.”

“I am deeply honored to be selected for the Barancik Prize, and thank the award committee for recognizing our work,” Quintana said.
Expand Resources and Reach

Breakthrough MS Campaign Progress

FY2021 target: $1 billion

FY20: $81 million
($646 million raised to date)

FY19: $193 million
FY18: $191 million
FY17: $181 million

Q1 Gross Revenue by Sources

Going into March 2020 the Society was showing strong financial results and ahead of budget. The financial impact of COVID-19 began during the last two weeks of March and is reflected in the combined $5 million drop in Bike MS and Walk MS results.

Corporate Teams

1,936
TEAMS RAISED
$8.4 MILLION
FY20 target: 2,650 teams, $26.5 million raised

Community Councils

76
IN 30 CHAPTERS
FY20 target: community councils all 35 chapters

Engagement

7.4 MILLION
PEOPLE ENGAGE WITH THE SOCIETY
FY20 target: 8 million

Social Media

831,771 FOLLOWERS
FY20 target: 861,000 followers

Facebook Fundraisers

24% $5 MILLION
USAGE RAISED
FY20 target: 25% usage, $20 million raised

$2.9 MILLION
RAISED FY20 target: $6.5 million raised

* Linked fundraisers are available to event participants and count toward fundraising totals
** Non-linked fundraisers do not sync with our system and do not count toward fundraising totals

HIGHLIGHTS

• Added a virtual experience to canceled spring Walk MS, Bike MS, and Leadership events in order to preserve relationships and revenue until we can be together again

• Virtual Walk MS celebrations on Facebook Live reached over 31,000 people

• 40 donor prospects were engaged in RPAC and ACTRIMS, which resulted in major gifts including a $250,000 gift and a planned gift commitment

• Launched a COVID-19 Response Fund to help respond to the unique and urgent needs of the MS community during this crisis

CHALLENGES

• The COVID-19 pandemic and our inability to host various in-person events will continue to have financial implications
ACCELERATING PROGRESS

DIGITAL AND TECHNOLOGY

• Adopting a new digital advocacy tool, Phone2Action, allowed us to easily engage MS activists

• Completed the integration of iHealthHome, a software to improve the coordination of case management services

• Our pilot with Happy the App will launch in Q3 and provide on-demand, 24/7 emotional support for people affected by MS

STRATEGIC PARTNERSHIPS

• Partnered with the MS International Federation to develop COVID-19 disease modifying therapy guidelines

• Launched a registry with the Consortium of MS Centers for healthcare providers to track on the COVID-19 status of their MS patients

• Signed a memorandum of agreement with the International Women in MS group to support diversity and inclusion in the MS work force

• Hosted webinars for professionals and people affected by MS with organizations such as the MS Coalition, the Consortium of MS Centers, CanDoMS and the Veterans Administration

AWARENESS

• Our MS Awareness Week social media posts reached more than 4.1 million people

• Our targeted public relations efforts results in 981 earned media stories with an audience reach of 485 million

ERIC, DIAGNOSED IN 2003

DAWNIA, DIAGNOSED IN 2006

INNOVATION AND IMPROVEMENT

• The Clinical Management mobile app was updated with new interactive and responsive features

• The innovation and improvement pilot program was completed and a work team has evaluated and shared recommendations for future improvements

VOLUNTEER ENGAGEMENT

• 270 activists held more than 340 Capitol Hill visits during the Public Policy Conference

• Nearly 400 MS Activists participated in State Action Days

• 1,600 MS Activists, Board of Trustee members and Society staff sent nearly 7,000 messages urging Congress to address Society priorities in deliberations over the CARES Act. 740 of respondents were new to MS activism

DAWNIA, DIAGNOSED IN 2006

ERIC, DIAGNOSED IN 2003