FY2020 Q3
PROGRESS
REPORT
FY2019–2021
STRATEGIC PLAN

National Multiple Sclerosis Society

WILLIAM (L)
DIAGNOSED IN 2002
Confronting Racial Injustice

As our country confronts the racial inequities, injustice and violence that has led us to this moment in our history, we know must do better. Following the brutal death of George Floyd, we expressed our commitment to anti-racism and our plan to do better for Black people affected by MS. These statements resonated with many in the Black MS community. Some called on us to do more, and many expressed their commitment to holding us accountable to these actions. The statements also sparked conversation about the relevance of publicizing a stance to our mission.

STATEMENT 1

June 3, 2020

We are outraged by the injustice and violence that led to the death of George Floyd and too many others in our country. This is not OK. Not today or any day.

We realize that our heartbreak and anger are not enough. We must do better. We must do more.

The National MS Society is committed to creating a world where everyone, of every race, can live a life free of MS and free of injustice and inequality.

We recognize the effects of MS on the Black community are magnified by the inequities in our healthcare system. We will not be successful in finding the cure until we confront and address these inequities. The disparities that keep Black people from receiving today’s care must not keep them from receiving tomorrow’s cure.

We are a movement by and for people affected by MS.

We are listening.

We stand with you today and every day.

STATEMENT 2

June 9, 2020

The National MS Society is here to end MS forever and ensure people affected by MS can live their best lives. And we know we’ll reach a world free of MS more quickly the more diverse perspectives we have at the table. Of the nearly 1 million people estimated to have MS in the United States, we have only connected with 540,000. That’s a clear signal we have more work to do to reach all those affected by this disease, including underrepresented populations across our communities.

Getting better is at the core of who we are as an organization. Here are some of the things we are focusing on…

• Diversifying our staff and volunteer workforce and equipping everyone with resources and training to ensure we are an anti-racist organization in everything we do.
• Partnering with a leading health education agency to develop and deliver MS programming specifically focused on the unique needs of the Black community.
• Investing nearly $2.4 million in research projects to deepen our understanding of how MS affects underserved communities and partnering with the Minority Research Engagement Partner Network to improve representation of Blacks in MS research studies.
• Expanding MS education in the Black community—building on our African American Conference series with a new nationwide virtual summit focused on disparities in healthcare and access among Black people affected by MS.
• Ensuring Black people affected by MS see themselves in the MS movement by increasing the representation of Black voices, perspectives and experiences throughout our content.

This isn’t our beginning, and it’s nowhere near our end. Engaging, valuing and empowering others strengthens the MS movement and fuels our mission.

We will continue to get better—together. And together we will create a world free of MS.

SOME REACTIONS

"Finally and thank you. We want to make this better with you. Thank you for seeing us. There are some amazing Black and Brown people who would love to help you create this brighter future."

"Glad to hear this! As a mother of a black teenage son that was recently diagnosed at 13, it does my heart good to know that your organization is ramping up its capability to represent and advocate for minority MS patients. Thanks @mssociety"

"I feel you should stick to MS related problems only."

"Black...a mother...a Chicagoan and have been diagnosed since 2008...thank you for this!"

"It’s a start...but NMSS has to do better"

"Stay out of politics! Please!"

"Thank you @mssociety! This is a great start!❤"

"We thank and appreciate you for hearing and listening to our voices! We are all learning together in many ways. We are all in this fight together! We look forward to the society’s future initiatives!"

"This is the kind of change I’m talking about!!!"
Ensure Comprehensive High-Quality Healthcare

ADVOCACY PROGRESS
35,492 Engaged MS Activists

361 District Activist Leaders

HEALTHCARE PROVIDERS
3,655 PARTICIPATED IN PROFESSIONAL EDUCATION PROGRAMS

- 73% plan to change practice or behavior as a result of participating in professional education programs (target: 80%)
- 89% report improved attitudes about MS care (target: 85%)
- 94% report increased knowledge about MS care (target: 95%)

Referrals to MS Navigator from healthcare providers
- FY20 total: 6,637
- FY20 target: 9,958
- Q3: 1,837
- Q2: 2,369
- Q1: 2,431

HIGHLIGHTS
- Surveyed people affected by MS to better understand the impact COVID-19 has on them and to identify their needs during the pandemic
- Urged Congress to address the needs of people with MS in future COVID-19 legislation to ensure they can maintain economic security
- Eleven letters to the editor on access to MS medications were placed by MS activists in advance of the presidential and primary elections

STATE PROGRESS
- Bills we supported became law (total = 28)
- Bills we supported passed by a chamber of the state legislature (House or Senate) (total = 72)
- Bills we supported passed by a committee (total = 100)
- No advancement

CHALLENGES
- Engagement of healthcare providers has shifted from in-person meetings to virtual visits as a result of COVID-19
- Federal regulators ruled that health insurers can refuse to apply copay assistance to individuals’ cost-sharing requirements, which will likely result in higher out-of-pocket costs for healthcare treatments and services for people with MS
- Delays in the Congressional appropriations process, which funds the federal government for 2021, could jeopardize vital programs and MS research funding
As the worldwide coronavirus pandemic unfolded, healthcare providers faced unprecedented questions. To empower people with MS to make the most informed decisions about their care, MS healthcare providers need to be equipped with the latest evidence-based information to advise and speak with their patients.

At the beginning of the pandemic, providers had few places to turn to for education. There was no published data or organizations hosting forums for discussion or information sharing regarding COVID-19 and multiple sclerosis.

The Society partnered with the Consortium of MS Centers (CMSC), the leading organization for multidisciplinary MS professional education in North America, to respond to this need. The monthly webinar series, MS and COVID-19 Webinar Series for Health Providers, gives an opportunity for providers to connect with one another and learn. This engaging virtual program was designed for MS healthcare providers, such as neurologists, physician assistants and nurse practitioners, to deepen their knowledge of MS care through the lens of the COVID-19 pandemic. Over 3,000 people have come together to hear the latest information about COVID-19, treatment recommendations, research and more.

With interactive discussions rooted in available data and individual expertise, 95% of participants agree that the webinar improved their knowledge of COVID-19, and over 80% stated that they feel more confident discussing topics related to COVID-19 with their patients.

Carole Muto, CRNP, MSCN, a nurse practitioner at Thomas Jefferson Hospital, an MS comprehensive care center in Philadelphia, shares: “Excellent and informative webinar — well presented. Thank you!”

As the world changes and new needs arise, healthcare providers and their patients can continue to depend on the Society to be a supportive partner and to provide connection and education.
Empower People Affected by MS to Solve Everyday Challenges

SERVICES IMPACT

PEOPLE WHO CONNECTED TO SOCIETY SERVICES

60%
548,816 of the estimated 914,000 of people with MS in the United States are connected to their National MS Society (FY20 target: 60%, 550,000 people)

HIGHLIGHTS

• The Ask an MS Expert webinar series provided real-time information and updates on relevant topics for people affected by MS. The 16 webinars in Q3 had a combined 150,000 views.

• All MS Navigators and Case Managers are working remotely and continuing to deliver MS Navigator services amidst the pandemic

• 482 Society group leaders joined the weekly drop-in calls to ask questions and get information on how to best support people living with MS

CHALLENGES

• The pandemic resulted in the cancellation of in-person programs through the remainder of FY20, minimizing our ability to connect and build relationships with program participants

• Case management services provided through the Edward M. Dowd Personal Advocate Program are being delivered telephonically as case managers are unable to make home visits

• The economic downturn is straining communities resources creating additional challenges in securing community resources and financial assistance

My MS Navigator was able to provide me with so many resources, more than I thought I could get just from a call. I was hesitant to call and speak about my illness and disability over the phone, but I was confident in myself after speaking to her.

— MS Navigator recipient
Multiple sclerosis doesn’t stop because of a crisis. And amidst a global pandemic, people living with MS have to continue living with a chronic disease while navigating a new and unpredictable world.

“We are still living with this day to day,” says Jennifer Frame, who was diagnosed with MS in 1989. “We still need education and support; we need the normalcy of everyday life. MS is part of our everyday lives. And we want to continue to move forward.”

In March, the Society launched its **Ask an MS Expert** weekly webinar series to meet the emerging needs of the MS community and to help people like Jennifer continue living their best lives during the COVID-19 pandemic. Moderated by RealTalk MS podcast host, Jon Strum, the webinar shares crucial information about COVID-19 and MS, and ensures the continuation of quality service and programming no matter what.

Every Friday, hundreds of people in the MS community tune in to connect and learn. Experts share the newest information regarding COVID-19, including updates on treatments, social distancing recommendations and trending questions, and weigh in on hot topics related to life with MS — ranging from healthy living, research updates and symptom management. The webinar concludes with a robust live Q&A section.

For Jennifer, the Ask an MS Expert series has helped her feel connected and grounded during uncertain times.

“You get the chance to hear from MS specialists and other experts from all over the country that normally we wouldn’t have access to,” she says. “And there’s so much misinformation out there, it’s overwhelming. The talks on COVID-19 have been factually driven, reassuring and relevant.”
Deliver Breakthroughs to a Cure

HIGHLIGHTS

- The John Dystel Prize for MS Research was awarded to Society-funded researcher Dr. Ian D. Duncan for his work on how nerve-insulating myelin develops, is damaged, and may be repaired.
- The FDA approved Bafiertam as an oral disease-modifying therapy for people with relapsing forms of MS.
- Society-funded researchers identified new potential targets for stopping nerve loss in MS.
- Researchers in Germany found more links between the Epstein-Barr virus and MS.
- Published recommendations for promoting exercise and physical activity in people with MS.
- Evidence suggests that addressing comorbidities (other health issues like diabetes and obesity) may improve MS disease activity.

CHALLENGES

- The pandemic has closed many MS research labs and paused clinical trials, which will likely delay the completion of many research projects.
Mary Rouvelas is challenging social barriers that leave people who are affected by MS feeling lonely and socially isolated by advocating for better services, celebrating support networks and championing self-care.

“My particular area of expertise is public policy and advocacy,” Mary says, “and if I can do some good for people with MS in that arena, I want to do as much as I possibly can.”

Mary began advocating for the National MS Society in 2014 when she was doing public policy work for the American Cancer Society Cancer Action Network in connection with challenges to the Affordable Care Act. “I felt the National MS Society should have the chance to be represented in the work I was doing as well,” she recalls. “I wanted to represent MS patients in court battles about the Affordable Care Act, so I reached out to the Advocacy team at the Society.”

Today, Mary is senior counsel for the American Cancer Society Cancer Action Network and the in-house coordinator for 20 different patient groups, including the National MS Society, which filed a brief with the U.S. Supreme Court in May 2020 urging the high court to uphold the Affordable Care Act.

The brief cites the devastating and lasting effects people would face if the Affordable Care Act is struck down. It provides extensive scientific data showing that access to health insurance improves medical outcomes for a wide range of conditions and studies showing that the health law has made a measurable difference in prevention and care.

In addition to lending her time and talent, Mary also financially supports the Society because she believes strongly in the Society’s mission.

“I support the National MS Society because I’m a huge fan. It really fills the need for information, outreach and family programs which improve the quality of life for people with MS.”
Expand Resources and Reach

Breakthrough MS Campaign Progress

- FY2021 target: $1 billion
- FY20: $116 million
- FY19: $193 million
- FY18: $191 million
- FY17: $181 million

($681 million raised to date)

Q3 Gross Revenue by Sources

<table>
<thead>
<tr>
<th>Source</th>
<th>FY20 Q3 Budget</th>
<th>FY20 Q3 YTD Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bike MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walk MS*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Events**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual Giving***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Requests</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corporate Sponsorships</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Millions

- Corporate Teams
  - 2,097 teams
  - FY20 target: 2,650 teams
  - $26.5 million raised

- Community Councils
  - 78 in 32 chapters
  - FY20 target: community councils in 34 chapters

Engagement

- 7.4 MILLION people engage with the society
  - FY20 target: 8 million

Social Media

- 841,554 followers
  - FY20 target: 861,000 followers

Facebook Fundraisers

- 23% usage
  - $7.3 MILLION raised
  - FY20 target: 25% usage, $20 million raised

- NON-LINKED**
  - $4.2 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

- The COVID-19 Response Fund has secured more than 1,000 gifts totaling $400K
- Catapult, a new fundraising initiative, invites our pharmaceutical partners to make additional contributions, which has resulted in a $4M gift from Genentech and a $1M gift from Biogen
- Walk MS fundraisers saw higher average fundraising and percentage of self-donors than it has in the last four years
- Launched Bike MS: Inside Out, an interactive experience where cyclists ride on their own and are connected to other participants from around the country
- Jim and Kathleen Skinner continued their commitment to the MS Navigator program with a $3M gift

CHALLENGES

- The economic downturn caused by the COVID-19 pandemic and our inability to host in-person events will continue to have financial implications
ACCELERATING PROGRESS

DIGITAL AND TECHNOLOGY

- 1,454 members joined the Society Facebook Social Learning Group to make connections and increase their knowledge
- Launched the Stream to End MS platform to bring together online content creators and raise funds and awareness for the Society
- Launched pilot with Happy the App to provide on-demand, 24/7 emotional support for people affected by MS

STRATEGIC PARTNERSHIPS

- Partnered with other nonprofit organizations to urge congress and regulators to revise the criteria for the forgivable loan program to ensure mid-sized nonprofits are eligible
- Collaborated with the Juvenile Diabetes Research Foundation to solicit and prioritize cross-autoimmune disease research proposals for possible co-funding
- Hosted webinars for professionals and people affected by MS with organizations such as the Consortium of MS Centers, CanDoMS and the Veterans Administration

INNOVATION AND IMPROVEMENT

- Launched the Ask the MS Expert programs in Spanish to reach and engage the Hispanic and Latino community
- Launched a Society-wide innovation challenge to identify creative ways to reduce expenses and increase revenue
- The Society crisis and support team trained 305 staff on managing difficult conversations

VOLUNTEER ENGAGEMENT

- 300 MS activists participated in virtual State Action Days
- Convened a group of experts to develop exercise and physical activity recommendations for people with MS
- The Research Peer Review Committee and Research Programs Advisory Committee met virtually to advance our scientific priorities
- 482 group leaders attended the Group Leader weekly drop-in calls to share information, resources, and connect with other leaders

AWARENESS

- The Society continues to be a source for timely and reliable information on COVID-19
- On World MS Day the global community came together to share stories and raise awareness about MS
- Hosted an Ask an MS Expert program focused on health disparities to build awareness of existing challenges