Ensure Comprehensive High-Quality Healthcare

ADVOCACY PROGRESS

32,550 Engaged MS Activists

328 District Activist Leaders

977 HealthCare Providers participated in professional education programs

76% 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 target: 9,958

Q1: 2,431

HIGHLIGHTS

• The work of MS Activists resulted in $16 million for the MS Research Program at the Department of Defense in FY20 — up $10 million from FY19. Our EVP of Research, Bruce Bebo, will help determine what research the program will fund

• 81 people attended the first webinar of the new healthcare professional series, which focused on disease-modifying therapies

CHALLENGES

• Healthcare coverage gained through the Affordable Care Act is at risk with the decision currently in the hands of the Supreme Court
Antonia was a healthy 27-year-old passionate about equestrian jumping when an emergency room visit changed her life forever.

“I fell off my horse and three weeks later, I was still feeling weird,” Antonia says. “I went into the ER because I was numb. I got there, and they told me it wasn’t a pinched nerve. They told me I needed an MRI. After the MRI, a resident came out and said, ‘I don’t know how to tell you this, but you have MS.’” Antonia says.

With her limited knowledge of MS, Antonia was shocked when she quickly began experiencing symptoms.

“I got progressively worse. Over that week, I stopped being able to work. My left arm stopped working. You don’t understand what they’re saying until you’re experiencing it.”

A chance meeting with a National MS Society volunteer inspired her to get involved and changed her outlook on the disease.

“I connected with this lady who is on the board, and she can’t walk anymore due to her MS — so looking at her and seeing how involved she was, seeing what she was doing for others like her — was super motivating.”

Antonia signed up for Walk MS and was blown away by the sense of community she found in the Society.

“I got there and started bawling,” Antonia said. “I started crying because I just couldn’t believe this many people supported the Society and supported people living with MS. It’s been the hardest two years of my life but also most rewarding because I now have a new sense of who I am. We’re all (people living with MS) the best versions of ourselves because we don’t have a choice.”
Empower People Affected by MS to Solve Everyday Challenges

59%
539,930 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)

SERVICES IMPACT
PEOPLE WHO CONNECTED TO SOCIETY SERVICES

77% 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%)

79% feel more confident in addressing challenges of MS (target: 75%)
83% made new connections (target: 80%)

HIGHLIGHTS

• 7,119 people participated in 66 Society programs

• Through a strategic partnership with the Direct Employers Association more than 12,000 people visited our job search site and 2,000 people applied for jobs found through the site

• 232 people with MS received in-depth Medicare Plan support from MS Navigators during Open Enrollment

• A new software tool was implemented to improve the coordination of case management services

CHALLENGES

• Long wait periods for government supported affordable and accessible housing

• Lack of access to mental health care for people with MS complicates the ability to provide them with long-term support

The Navigator that I worked with at the MS Society was more than just helpful, she went out of her way to find information for me and always returned my calls. I really got to know her and she felt like a real friend."

– MS Navigator services recipient
IMPACT SPOTLIGHT:  

LEADING BY EXAMPLE TO ADVANCE RESEARCH

This year’s Tykeson Fellows Conference brought together 100 MS researchers and clinicians to inspire collaboration and better serve those who live with MS. For Dr. Kirsten Evonuk, who has a Society-funded Kathleen C. Moore Fellowship, the conference presented the perfect chance to make valuable connections and push her own research on progressive forms of MS forward.

Dr. Evonuk’s research focuses on looking for new ways to help people with progressive forms of MS. She hopes that her investigations will lead to new therapies that will protect brain cells from being damaged.

The bi-annual Tykeson Fellows Conference is recognized internationally among the scientific community for bringing together MS research fellows to share their latest research discoveries, learn from their peers, explore new partnerships, and gain insights on MS career development. The conference is vital to driving progress toward uncovering answers and delivering life-changing solutions for people living with MS.

“Connecting with other scientists helped me to shape and focus my own research,” says Dr. Evonuk. "After the Tykeson conference, I was so energized to get back to work to help people living with MS.”

“Being a fellow has given me the chance to pursue so many interesting avenues of research,” Dr. Evonuk said. “This could lead to a new understanding of how MS develops and how to use therapies to get rid of symptoms.”

Dr. Kirsten Evonuk
Deliver Breakthroughs to a Cure

**ACTIVE CLINICAL TRIALS**

- **Relapsing MS:** 501
- **Progressive MS:** 363
- **Wellness / Symptoms:** 305

**RESEARCH PROJECTS BY PRIORITY AREA**

- **Why some, not others? Risk Factors:** 56
- **What is the cause? Pathology:** 72
- **How to stop? Progression:** 66
- **How to repair? Neuro-protection & CNS Repair:** 56
- **Reverse Symptoms & Promote Wellness:** 86

**HIGHLIGHTS**

- The **FDA approved Vumerity**, an oral disease-modifying therapy for people with relapsing forms of MS, including people with secondary progressive MS who continue to experience disease activity.
- New **multi-year commitments** totaling $14.6 million were made to 43 new research projects, including new approaches to treat progressive MS, the role of diet and gut bacteria, and novel approaches to repair myelin.
- **Mouse studies** funded by the Society, the International Progressive MS Alliance, and others offered clues to how MS is triggered and new pathways to treat progressive MS.
- Up and coming MS researchers shared their findings and excitement at the Society's **Tykeson Fellows Conference**.
- A **publication** from experts convened by the Society and the European Committee for Treatment and Research in MS (ECTRIMS) focused on ways to improve the collection, quality, and coordination of data that tracks the health experiences of people with MS.

**CHALLENGES**

- Clinical trials continue to have poor **representation of diverse populations**.
- Despite some gains and a Society fellowship program to train rehabilitation researchers, there are still not enough **well-designed rehabilitation and wellness studies** that translate into practical solutions.
Meredith Polk founded Miles of Scarves when she was in the fifth grade as a way of raising money for the National MS Society. She taught some friends how to knit and set a goal to raise $1,500 to sponsor a rest stop at Bike MS: Colonial Crossroads that first year.

Two years later, when Meredith was in the seventh grade, her mom revealed she had secretly been living with MS for years.

"I thought that can’t be true. You can see perfectly, you can walk normally, you go for a run every morning, you … you can’t have MS. I was scared and kind of numb. It didn’t feel real," Meredith recalls. "Learning my mom has MS, and seeing her live her best life despite it, inspires me to work even harder at Miles of Scarves.”

Meredith’s idea ten years ago now spans three Miles of Scarves chapters with over 70 members. To date, they have knitted and sold countless scarves and raised more than $100,000 to fund research for a cure.

Their fundraising has allowed them to sponsor a rest stop at Bike MS: Colonial Crossroads each year, with nearly 20 members volunteering during the ride weekend. They’ve become known as the cookie rest stop because each girl makes seven dozen cookies to treat the riders.

“In addition to being inspired by knowing we’re doing something good for people with MS,” reflects President Isabella de Cunha, “Miles of Scarves has given us a way to meet even more people in the MS Movement.”

“It’s amazing to see the progress in treatments and research first-hand,” says Meredith, “and to get to see how our fundraising is really changing lives.”
**Expand Resources and Reach**

**Breakthrough MS Campaign Progress**

- **FY2021 target:** $1 billion
- **FY20:** $41 million ($606 million raised to date)
- **FY19:** $193 million
- **FY18:** $191 million
- **FY17:** $181 million

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**Corporate Teams**

- **1,015 TEAMS RAISED**
- **$4.6 MILLION**
- **FY20 target:** 2,650 teams, $26.5 million raised

**Community Councils**

- **69 IN 32 CHAPTERS**
- **FY20 target:** community councils all 36 chapters

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**Engagement**

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

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**Social Media**

- **814,865 FOLLOWERS**
- **FY20 target:** 861,000 followers

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**Facebook Fundraisers**

- **LINKED***
  - **20% USAGE**
  - **$637,138 RAISED**
  - **FY20 target:** 25% usage, $20 million raised

- **NON-LINKED**
  - **$1.4 MILLION RAISED**
  - **FY20 target:** $6.54 million raised

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

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**HIGHLIGHTS**

- The late William Barron Hilton was recognized as our first **Founder’s Circle** ($25 million) member
- **Climb to the Top** coast to coast series kicks off in Boston, has a new building in New York and is in its inaugural year in San Francisco
- **Bike MS** revenue for fall events through December 31 is the highest it has been in three years, performing 1% over budget
- We have secured $1.35 million in **Walk MS** sponsorships from three returning corporate partners

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**CHALLENGES**

- The tenure of early career non-profit fundraising staff continues to shrink; **staff turnover** is costly
- **Timing shifts** of four of our 84 events affect first quarter results
- The discontinuation of Facebook’s giving incentive has led to declines in monthly giving through **non-linked Facebook Fundraisers**

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ACCELERATING PROGRESS

DIGITAL AND TECHNOLOGY
- We teamed up with Jon Strum, host of the "RealTalk MS" weekly podcast, to bring MS news and information to a larger audience.
- We signed a strategic partnership agreement with the app, Happy, and will begin a pilot program this year to assess the value of peer support through this channel.

STRATEGIC PARTNERSHIPS
- We joined 23 other organizations in a statement supporting a request to the Supreme Court for an expedited review of the December ruling of the Affordable Care Act.
- The Society-supported International MS Outcome Assessments Consortium published a study of 4 clinical measurement tools, validating their ability to track MS progression.
- Through our Fast Forward program, we invested in new biomarker studies to speed the testing of new MS therapies.
- The Disabled Veteran Program was included in the Congressional funding bills for FY20 after support from the Society and other groups.

INNOVATION AND IMPROVEMENT
- The Health Care Access team participated in training to develop new skills and learn strategies to engage community neurologists.
- The innovation and improvement process and resources have been approved and a pilot program is in development.

AWARENESS
- More than 400 staff and volunteer leaders came together at the Society Leadership Conference to connect, learn new ways to increase impact and celebrate the progress we’ve made together.
- Chef Chris Holland participated on the Food Network’s Chopped program and donated his $10,000 winnings to the Society.
- Dr. Marwa Kaisey, past Society funded fellow and neurologist, shared Society resources on Instagram stories, which received 5,366 views.

VOLUNTEER ENGAGEMENT
- Engaged 107 expert peer reviewers to evaluate 359 research grants, fellowships and pilot grant proposals to help us identify the most promising research investments.
- The Activism Advisory Committee, comprised of MS Activist leaders, recommended the final 2020 public policy priorities.
- Convened the Community Engagement in Research Task Force to develop ways we can enhance involvement of people affected by MS in research decision making.
- MS Activists sent over 2,800 emails to members of Congress asking for support of our federal funding priorities.
- FY2022–2024 Strategic Plan Development Advisory committee and the Development Advisory committee were established to develop the Society’s next strategic plan and guide our fundraising activities.