Ensure Comprehensive High-Quality Healthcare

ADVOCACY PROGRESS

36,537 Engaged MS Activists

306 District Activist Leaders

905 HEALTHCARE PROVIDERS PARTICIPATED IN PROFESSIONAL EDUCATION PROGRAMS

81% plan to implement what they learned (target: 80%)

91% report improved attitudes about MS care (target: 85%)

95% report increased knowledge about MS care (target: 95%)

Referrals to the Society from healthcare providers

FY19 target: 9,958

Q3: 2,545

(7,199 total to date)

Q2: 2,364

Q1: 2,290

HIGHLIGHTS

• MS healthcare providers learned about the Edward M. Dowd Personal Advocate Program (case management) and MS Navigator service during a session, a booth and two posters at the Consortium of MS Centers Annual Meeting

• The Society is providing input to numerous Congressional committees that are working to address drug pricing and access and healthcare costs

• The U.S. Senate Health, Education, Labor and Pensions Committee voted to pass the Lower Health Care Costs Act, which would end surprise billing and require greater transparency and justification around drug price increases

• A new federal regulation will prohibit most healthcare plans from implementing programs that discourage patient assistance from contributing toward patients’ out-of-pocket costs

STATE PROGRESS

- Bills we supported became law (total = 50)
- Bills we supported passed by a chamber of the state legislature (House or Senate) (total = 139)
- Bills we supported passed by a committee (total = 250)
- No advancement

CHALLENGES

• Healthcare coverage gained through the Affordable Care Act is at risk with the decision regarding its constitutionality in the Fifth Circuit Court of Appeals

• Access to mental healthcare is a significant challenge due to a lack of knowledge about MS and availability of affordable treatment options
To Cermit Rickey, access to high-quality healthcare means seeing a healthcare provider who specializes in multiple sclerosis care. He had been seeing an MS specialist for 11 years but a new insurance company required him to change healthcare providers.

“My workplace changed insurance companies, and I was told I had to visit another neurologist,” Cermit says. “She was just a general neurologist. When I asked her how many MS patients she had, she said, ‘I have five’—that kind of scared me.”

His new neurologist told him she planned to send him to an MS specialist if he experienced an MS episode.

“I said, ‘No, I want to stay with the MS specialist that I'm seeing.’ I want to see the specialist that knows what they’re doing, not after the fact. I want to see them beforehand so I can continue to stay healthy.”

Cermit appealed the decision to his insurance company and eventually won.

“Having somebody that understands MS and knows what to do and what drugs are available, what symptoms you have and what you have to worry about, that's priceless.”
Empower People Affected by MS to Solve Everyday Challenges

58.5%

Or 535,000 of the estimated 914,000 of people with MS in the United States are connected to the National MS Society (FY19 target: 59%, 540,000 people)

SERVICES IMPACT

PEOPLE WHO CONNECTED TO SOCIETY SERVICES

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

89% believe the Society is a source of support where they can find solutions (target: 85%)

80% feel more confident in addressing challenges of MS (target: 75%)

85% made new connections (target: 80%)

HIGHLIGHTS

- 2,082 people in 54 communities participated in the Pathways to a Cure program, gaining knowledge on latest research trends and what they can do to improve their health and quality of life
- The Society joined 48 national organizations supporting caregiving legislation which passed the House and authorizes $200 million in funding over the next five years for the Lifespan Respite Care Program
- A small study suggests that coupling walking to music may be a promising rehabilitation strategy for improving walking and increasing physical activity in people with MS
- The National Institutes of Health has accepted and incorporated the Society’s proposal to look at creating a “gold standard” for rehabilitative research into their strategic plan

CHALLENGES

- Significantly long wait periods for government supported affordable and accessible housing is an ongoing challenge for people affected by MS

I learned a lot about how the National MS Society works with other service agencies. If I don’t know who to contact for a specific need, someone with the Society can point me in the right direction. There are a lot of resources available to me, which has made my diagnosis a little easier to deal with.

– MS Navigator services recipient

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When Lori Ann Jacobson was ten years old, her mother was diagnosed with multiple sclerosis. Since her father traveled for work, Lori and her siblings were left to care for their mother alone and without a much-needed support network.

Lori, who passed away January 31, 2018, never lost sight of those early challenges and recognized the importance of ensuring family members of people living with MS, particularly children, have the resources and support she lacked.

“Lori really wanted to give back and help,” says Lori’s husband, Jason. “Lori’s mother didn’t have the resources she needed back then, and the weight of that fell on her kids. It was important to Lori that there were programs for families and kids caring for someone with MS.”

Before Lori passed away, she made the decision to leave a bequest, in the form of a $150,000 designated IRA, to the National MS Society. Her legacy will provide families with the information, connections, and support they need to assume the role of caregiver. Her generosity will allow other children of parents with MS to rely on the Society as a supportive partner throughout their caregiving journey and as a place to forge meaningful connections with other people affected by MS so they don’t feel alone.
**HIGHLIGHTS**

- The 25th **John Dystel Prize for MS Research** was awarded to Prof. Anne Cross for translational research including early work on the key role of B cells in MS.

- New **multi-year commitments** totaling $10.9 million to 18 new research projects and 2 strategic initiatives, including an international trial of exercise and cognitive rehab in progressive MS.

- The International Pediatric MS Study Group, with support from the Society and MS Society of Canada, published **updated recommendations** on conducting clinical trials in children and adolescents with MS.

- A study funded by the MS Society and others showed that **diet may impact MS disease activity**.

**CHALLENGES**

- A **workforce shortage** of biostatisticians and data scientists in MS is compelling the development of new early career research awards to attract these types of experts to the MS field.

- Lack of **representation in clinical trials** is caused by ongoing difficulties in recruiting diverse participants.
Dr. Anne Cross received the 2019 John Dystel Prize in recognition of her research in identifying the role of B cells in driving MS immune attacks.

“I’m thrilled,” Cross said. “(Winning the Dystel Prize) lets me know that my career’s work has led to something meaningful.”

Dr. Cross’s career was launched with fellowship support from the National Multiple Sclerosis Society, including a Harry Weaver Neuroscience Scholar Award in 1990.

With funding from the Society, she pioneered the first clinical trials of rituximab, a B cell depleting therapy, in people who were not doing well with other treatments. Her studies proved B cell depletion can be beneficial for treating MS. This research helped pave the way for the Food and Drug Administration’s 2017 approval of ocrelizumab (Ocrevus), the first approved therapy for targeting B cells in individuals with primary progressive MS and relapsing forms of MS.

“The National MS Society has been phenomenally supportive throughout the years,” Anne said. “I wouldn’t have my career without the Society.”
Expand Resources and Reach

**HIGHLIGHTS**

- **Bike MS** remains the number one fundraising cycling series and the sixth largest fundraising event in the U.S.
- **Walk MS** participation, average fundraising and total revenue are up over FY18 results, reversing a 5-year decline in revenue
- Building on the success we have seen in **Climb to the Top**, we are adding a San Francisco Climb to the Top in FY20
- We have conducted more than 450 **fundraising events** throughout the country, engaging more than 300,000 people in the MS movement
- During May **leadership meetings**, volunteers identified 60 new corporate connections for exploratory conversations about potential Society involvement

**CHALLENGES**

- Low unemployment rate and high competition in the labor market continue to make it **difficult to fill positions**, especially in the development department
- **Changes in tax laws** may impact an individual’s giving, creating a possible decline in charitable donations in gifts of $5,000 and below

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**Bike MS Campaign Progress**

- FY2021 target: $1 billion
- FY19: $157 million ($531 million total raised to date)
- FY18: $192 million
- FY17: $182 million

**Revenue Sources**

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**Walk MS 6+ Teams**

- **10,181** TEAMS RAISED
- **$23.4 MILLION**
- Q3 target: 10,091 teams, $23.1 million raised
- FY19 target: 10,500 teams, $24.4 million raised

**Bike MS 10+ Teams**

- **1,291** TEAMS RAISED
- **$30.1 MILLION**
- Q3 target: 1,297 teams, $29.7 million raised
- FY19 target: 1,500 teams, $42.5 million raised

**$1,000+ Donors**

- **2,520** DONORS RAISED
- **$17.4 MILLION**
- FY19 target: 2,900 donors, $17.5 million raised

**Community Councils**

- **74** IN 30 CHAPTERS
- FY19 target: community councils all 36 chapters

**Community Engagement**

- **7.1 MILLION** PEOPLE ENGAGE WITH THE SOCIETY
- FY19 target: 7 million
ACCELERATING PROGRESS

DIGITAL AND TECHNOLOGY

- Recently launched Facebook non-linked fundraising tools (birthday fundraiser, etc.) continue to outperform expectations and are projected to contribute $2.8 million in FY19
- We partnered with healthcare providers to develop educational videos for people living with MS

STRATEGIC PARTNERSHIPS

- Three Collaborative Networks supported by the International Progressive MS Alliance reported excellent progress at the midpoint of the research projects, focusing on speeding discovery and testing new, breakthrough therapies for progressive forms of MS
- At the Consortium of MS Centers Annual Meeting, we met with the Veterans Administration, the MS Foundation of Puerto Rico, Can Do MS and others to discuss collaboration opportunities

INNOVATION AND IMPROVEMENT

- We have defined innovation and improvement, and identified our priorities and key elements that increase innovation
- An innovation and improvement committee has been formed to lead the next phase of this work

AWARENESS

- Executive Vice President of Advocacy, Bari Talente, and MS Activist, Tod Gervich, were interviewed by NPR about the cost of MS medications—the story was picked up by a number of other outlets
- On World MS Day the global community came together to share stories and raise awareness about MS

VOLUNTEER ENGAGEMENT

- A volunteer work team finalized its review and recommendations for new tools to assist healthcare providers with health insurance appeals
- We engaged over 30,000 volunteers to ensure excellent event experiences across the country
- 395 group leaders attended the All Society Group Leader call in April to share information, resources, and connect with other leaders