

FY2019 PROGRESS REPORT

FY2019–2021
STRATEGIC PLAN



National
Multiple Sclerosis
Society

KAREN
DIAGNOSED IN 2007

Ensure Comprehensive High-Quality Healthcare

ADVOCACY PROGRESS

34,155 
Engaged MS Activists

325 
District Activist Leaders

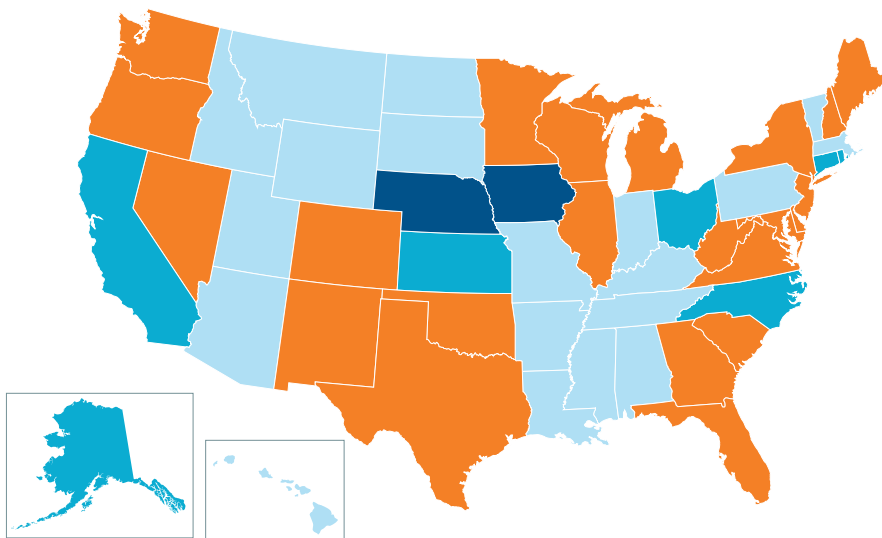
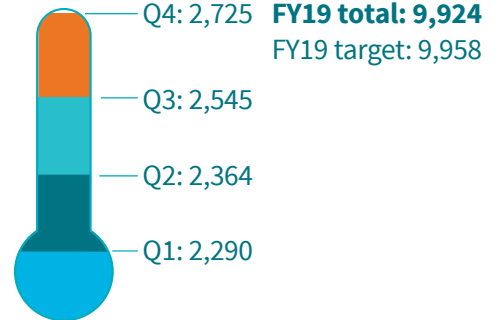
3,845 **HEALTHCARE PROVIDERS** 
PARTICIPATED IN PROFESSIONAL EDUCATION PROGRAMS

78%
plan to implement what they learned (target: 80%)





93%
report increased knowledge about MS care (target: 95%)

87%
report improved attitudes about MS care (target: 85%)

Referrals to the Society
from healthcare providers



STATE PROGRESS

-  Bills we supported became law (total = 52)
-  Bills we supported passed by a chamber of the state legislature (House or Senate) (total = 150)
-  Bills we supported passed by a committee (total = 262)
-  No advancement

HIGHLIGHTS

- 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
- The House Energy and Commerce Health Subcommittee passed the **CREATES Act**, which would help remove barriers to generic medications
- Executive Vice President of Advocacy, Bari Talente, testified on **access to medication** before the Congressional Education and Labor Committee
- Society staff spoke at a policy briefing marking the 15-year anniversary of **Medicare Part D** to highlight the experiences of people with MS on affordability and access challenges

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
- The U.S. Department of Health & Human Services will not enforce previously announced prohibition against health insurer practices that result in **higher out-of-pocket costs**

IMPACT SPOTLIGHT:

EMPOWERING PEOPLE TO SOLVE EVERYDAY CHALLENGES

Annie was so grateful for the information and support provided to her by the National Multiple Sclerosis Society's MS Navigator Program when she was diagnosed with MS in 2001, she became a ~~peer to peer~~ group leader in Burlington, North Carolina, until her husband's illness forced her to quit.

**“I would have
been lost without
the Society,”
reflected Annie.**

When Annie's husband became ill, he lost his job and their health insurance. After he died, she lost his Social Security income. Because he handled all their finances, Annie didn't know where to start and turned to the Society for help.

**“The Society
has helped me
tremendously.”**

Vivian, Annie's case manager, helped Annie through a period of incredible change and difficulty by taking things step by step.

Vivian connected Annie to things as simple as a free eye exam and glasses, and as complex as applying for Medicaid, Medicare and food stamps, as well as home healthcare and transportation services. Vivian worked with the Society to secure emergency funding for food and other necessities, and helped Annie navigate selling her husband's estate.

“She restored a sense of confidence in me,” Annie said. “I'm very self-sufficient and optimistic, but I needed a little bit of reassurance without asking for it, and she picked up on that.”

Empower People Affected by MS to Solve Everyday Challenges



58.9% Or 538,000 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

79%

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

88%

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

79%

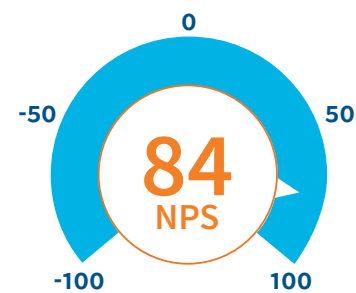
feel more confident in addressing challenges of MS (target: 75%)

85%

made new connections (target: 80%)

NET PROMOTER SCORE*

How likely is it that you would recommend the National MS Society to a friend or colleague?



Global Benchmark (average score from 127,000 organizations): 41

*Net Promoter Score is the leading metric for measuring constituent loyalty and trust

HIGHLIGHTS

- We 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
- **MS Navigators** connected 57,080 people to the information, resources and support needed to move their lives forward
- 28,896 people participated in 378 **Society programs**
- Life-changing **case management** services are now available in all 50 states and the District of Columbia

CHALLENGES

- Significantly long wait periods for government supported **affordable and accessible housing** is an ongoing challenge for people affected by MS
- **Capacity** to provide connections and resources to people affected by MS is an ongoing challenge to meet the demand



The MS Navigator gave me help and emotional support when I was having a very tough time. She helped me get a wheelchair, gave me contacts for other needs and followed up with emails. I honestly don't know what I would have done if not for her and the MS Society."

– MS Navigator services recipient

IMPACT SPOTLIGHT:

LEADING BY EXAMPLE TO ADVANCE RESEARCH



Alessia Tassoni, PhD

“We hope that this project will **promote the discovery of treatments** able to halt or repair visual loss in MS.”

Alessia Tassoni was just finishing high school when her mother began to have trouble seeing. Soon after, Tassoni’s mother was diagnosed with multiple sclerosis. Watching her mother live with MS led to Tassoni’s decision to pursue a career in research.

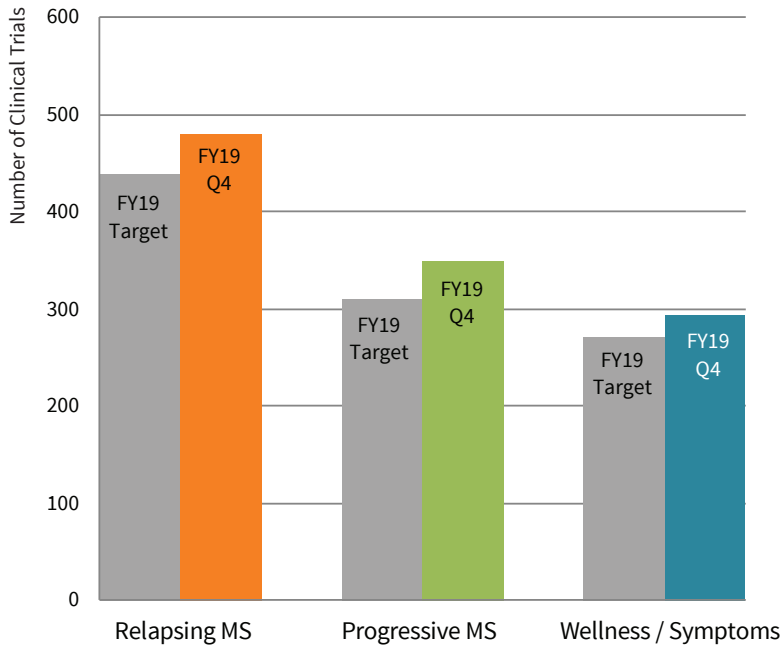
The Society trains and supports researchers and physicians like Tassoni who have completed their doctoral or medical degrees through nine types of research and clinical fellowships. Fellows train with seasoned MS scientists and physicians to gain the skills and training they need to become researchers and deliver breakthroughs to a cure.

Under her Society fellowship, Tassoni is using a new technology called Ribo-tag to study specific cells in the optic nerve, which connects the eye to the brain. She’s searching for any molecule in those cells that leads to vision problems.

If Tassoni finds a molecule and other studies confirm this, therapies that target these molecules can be developed and tested in clinical trials to prevent or reverse vision problems.

Deliver Breakthroughs to a Cure

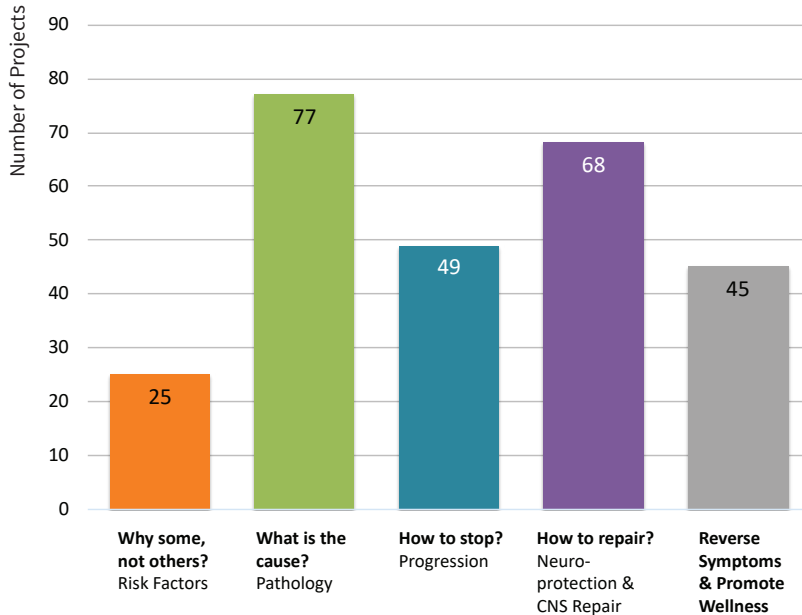
ACTIVE CLINICAL TRIALS



HIGHLIGHTS

- A novel method of estimating the **prevalence of MS** found there are nearly a million people with MS in the U.S. — twice as many as the previous estimate
- New **multi-year commitments** totaling \$38.7 million were made to 123 new research projects, including projects focused on benefits of exercise and cognitive rehabilitation for MS
- With Society funding, the International MS Genetics Consortium **confirmed 233 variations** in the human genome that contribute to the risk of developing MS
- Two new **disease-modifying therapies** (**Mayzent** and **Mavenclad**) were approved and positive results from four clinical trials of potential therapies were announced
- Clinical trials of **cell-based therapies** are testing their potential to protect the nervous system and enhance myelin repair in people with MS
- The **Barancik Prize for Innovation in MS Research** was awarded to Dr. Katerina Akassoglou for discovery of a blood factor that may trigger tissue damage in MS, which she is now translating into possible therapies
- A Society grantee found that a Mediterranean **diet showed improvements** in fatigue and quality of life for people with MS

RESEARCH PROJECTS BY PRIORITY AREA



CHALLENGES

- There is a **workforce shortage** of biostatisticians and data scientists in MS
- Lack of **representation in clinical trials** caused by ongoing difficulties in recruiting diverse participants
- While the development of new therapies is welcome, they do not provide **solutions for all forms of MS**
- Despite some gains and a Society fellowship program to train rehabilitation researchers, there are still not enough **well-designed rehab and wellness studies** that translate into practical solutions

IMPACT SPOTLIGHT:

EXPANDING RESOURCES AND REACH



From left to right, Cyndi Zagieboylo, Josh Halpern and Beverley Stafford.

"We are fundraising so others that have the disease are going to live normal lives; we will hopefully find a cure."

Complete with great company, auction items and a clear mission to raise money to end MS, the event raised \$18,000 its first year at the family's jewelry store.

"Our family is very competitive, we always go full in, put in the extra effort, I would say we're over achievers," says Josh. "We work hard in everything we do. And with this event, it's about how many we can touch."

The Halperns continued to steadily grow the event, but when Society staff informed them the auction was the Society's third largest private event in the entire United States, the family pushed their competitive spirit into overdrive.

Sixteen years later, Albert's MS Auction took place in a 6,500-square-foot exhibit hall, raised over \$350,000 in a single afternoon and became the Society's largest private DIY fundraiser.

"When you see people do good things, you want to be a part of it," says Josh. "We've run into very thoughtful, generous, caring people in this world who want to support our cause and be with us."

With the support from the community and their unrelenting resolve, the Halperns have made an impressive mark on the MS community.

DIY Fundraising MS gives passionate people like the Halpern family opportunities to raise funds for the National MS Society in creative ways.

When Josh Halpern's mother, Donna, was diagnosed with MS over 40 years ago, he and his father, Fred, along with the support of staff from their family-owned store, Albert's Diamond Jewelers, decided to take action.

The Halpern family prides themselves on being philanthropic. They give to numerous charities, and have raised funds for Society in several ways, including individual giving and Walk MS. But it wasn't until 2003, when Donna's condition began to worsen, that they decided to increase their efforts by organizing their first DIY fundraiser, Albert's MS Auction.

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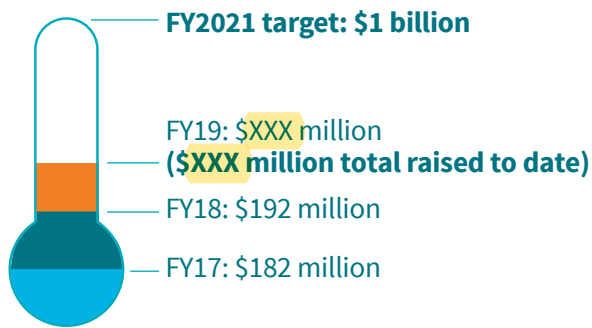
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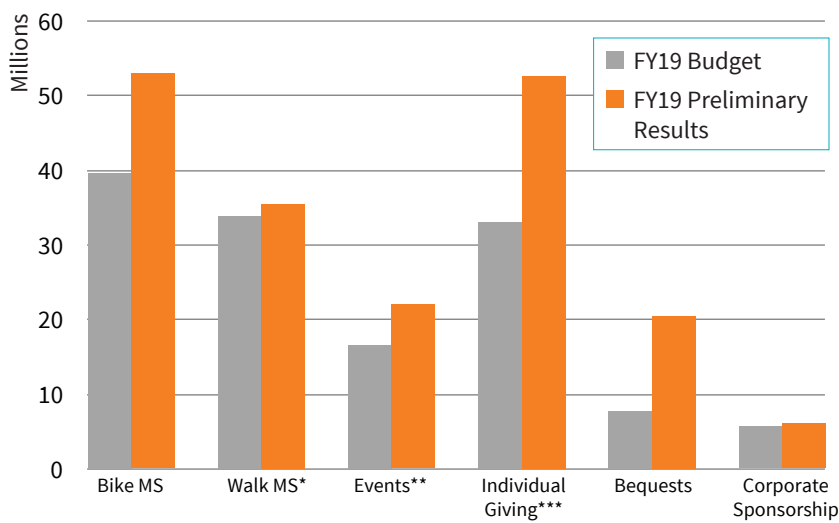
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Expand Resources and Reach

Breakthrough MS Campaign Progress



Revenue Sources



* Includes Challenge Walk MS

** Includes leadership events, MuckFest MS, Finish MS, DIY Fundraising MS and other events

*** Includes Direct Marketing

HIGHLIGHTS

- **Bike MS** remains the number one fundraising cycling series and the sixth largest fundraising event in the U.S.
- **Walk MS** raised over \$36 million, which is 3% ahead of last year and reverses a decade-long decline in revenue
- Deepening donor relationships led to **individual giving** success across the country, including the Hilton family who continue to support the Society, with their total giving exceeding \$25 million
- **Climb to the Top** NYC reached \$1 million in revenue for the first time in five years. To build on that success, we are adding a San Francisco Climb to the Top in FY20.
- We have conducted more than 585 **fundraising events** throughout the country, engaging more than 33,600 people in the MS movement

Walk MS 6+ Teams

10,385

TEAMS RAISED
\$23.9 MILLION

FY19 target: 10,500 teams,
\$24.4 million raised

Bike MS 10+ Teams

1,409

TEAMS RAISED
\$41.6 MILLION

FY19 target: 1,500 teams,
\$42.5 million raised

\$1,000+ Donors

2,799

DONORS RAISED
\$18.4 MILLION

FY19 target: 2,900 donors,
\$17.5 million raised

Community Councils

XX

IN XX CHAPTERS

FY19 target: community
councils all 36 chapters

Community Engagement

7.2 MILLION

PEOPLE ENGAGE WITH THE SOCIETY

FY19 target: 7 million

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

ACCELERATING PROGRESS



CARLOS, DIAGNOSED IN 2001

DIGITAL AND TECHNOLOGY

- \$16 million raised through event-related Facebook Fundraisers
- We launched a Find Doctors & Resources tool to provide 24/7 online access to healthcare providers and MS-related resources
- We expanded into the digital program frontier with our first Pathways to a Cure Facebook Live program

STRATEGIC PARTNERSHIPS

- We partnered with Can Do MS to provide 12 educational webinars
- We signed a memorandum of agreement with the Veterans Administration, formalizing our collaboration on resources for veterans, professional education for providers, and other resources
- We joined 25 other leading national voluntary health organizations in supporting a bill to stabilize and strengthen the Affordable Care Act

INNOVATION AND IMPROVEMENT

- Columbia Business School selected the Society's Innovation Study as a project for their MBA Leadership Program
- We defined innovation and improvement and formed a committee to lead the next phase of this work



HANNAH, DIAGNOSED IN 2017

AWARENESS

- Our campaign to connect to more people living with MS resulted in 13,325 visits to the campaign landing page and almost 2,000 new connections, a conversion rate of over 14%
- Executive Vice President of Advocacy, Bari Talente, and MS Activist, Tod Gervich, were interviewed by NPR about the **cost of MS medications**
- 71% of people who visited our website during MS Awareness Week were first-time visitors
- We created a new belief statement and **video** based on what we've heard from thousands of people affected by MS



ELLECIA, DIAGNOSED IN 2011

VOLUNTEER ENGAGEMENT

- We engaged 80 expert peer reviewers to evaluate 520 research grants, fellowships and pilot grant proposals to help the Society identify the most promising research questions and trainees
- We engaged over 50,000 volunteers across the country
- 280 activists held more than 300 Capitol Hill visits during the Public Policy Conference