FY2019 Q2
PROGRESS REPORT
FY2019–2021 STRATEGIC PLAN

National Multiple Sclerosis Society

KAREN, DIAGNOSED IN 2012
Ensure Comprehensive High-Quality Healthcare

ADVOCACY PROGRESS

39,443 Engaged MS Activists

300 District Activist Leaders

700 HEALTHCARE PROVIDERS PARTICIPATED IN PROFESSIONAL EDUCATION PROGRAMS

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

91% report increased knowledge about MS care (target: 95%)

89% report improved attitudes about MS care (target: 85%)

Referrals to the Society from healthcare providers

FY19 target: 9,958

Q2: 4,654

Q1: 2,290

STATE PROGRESS

HIGHLIGHTS

• Two new disease modifying treatments were approved by the FDA for relapsing forms of MS, including active secondary progressive MS

• The House Energy and Commerce Health Subcommittee passed the CREATE Act, which would help remove barriers to generic medications

• Medicaid work requirements in Arkansas and Kentucky—a barrier to accessing care—were struck down by ruling of U.S. District Court

CHALLENGES

• The two new medications are priced at $88,500 and $99,500, a disappointing outcome as we continue working to make medications affordable and the process for getting them simple and transparent

• The Department of Justice is urging the Fifth Circuit Court of Appeals to uphold a ruling striking down the Affordable Care Act in its entirety, potentially leaving people with MS without access to health insurance

• Access to mental healthcare is a significant challenge due to a lack of knowledge about MS and availability of affordable treatment options

Referrals to the Society from healthcare providers
Retired educator Diane Whitcraft lives with MS and had been taking the same medication for more than 23 years. But the price of her prescription therapy jumped year after year, and her out-of-pocket costs were threatening to drain her savings.

“The truth is that the choices for retirees like me are not choices at all: paying exponentially rising costs or stopping a therapy that has helped me to be mobile and independent for decades. It is bad enough having multiple sclerosis without the extra burden of worrying about how to pay for it,” she says.

Knowing she could no longer afford her medication, Diane made the heart-wrenching decision to stop taking it in 2017.

“That’s when I became an MS activist. Because no one should have to pay that kind of money to live their best life.”

Diane has since tirelessly advocated in favor of lowering prescription drug prices. She connects with legislators to help them understand the effects of policy decisions on people living with MS and even joined Senator Tammy Baldwin at the 2019 State of the Union to increase awareness.

“MS robs you of some of the things you’re good at. Being an MS activist gives this disease purpose and gives me an opportunity to do good and help others.”
Empower People Affected by MS to Solve Everyday Challenges

58%

Or 531,000 of the 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

78%  
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%)

77%  
feel more confident in addressing challenges of MS (target: 75%)

84%  
made new connections (target: 80%)

HIGHLIGHTS

• Life-changing case management services are now available in all 50 states and the District of Columbia
• 1017 support groups and wellness classes are welcoming new members

CHALLENGES

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

"Receiving assistance for the lift I needed on my car has helped me so much with being independent. This has really been a miracle for me. I know I can go where I want to and will not be so fatigued when I am out. Thank you!"  
– MS Navigator services recipient
A recent study funded by the National MS Society has confirmed that nearly one million people are living with MS in the United States, more than twice the original estimate. This pivotal study provides a scientifically sound measure of prevalence to help us better understand the disease and its impact.

With twice as many people living with MS, the need for resources, advocacy, services and, most importantly a cure, are now twice as important. Our work matters twice as much. Until we end this disease forever, we will continue to do whatever it takes to accelerate breakthroughs.

“I think individuals living with MS will now have a larger group of people to identify with.”
– Tim Hilton, diagnosed 2003

“This news definitely makes me hopeful that as more connections are made, there will be more services, funding and understanding from the community for people living with MS.”
– Ann Marie Johnson, diagnosed 2002
Deliver Breakthroughs to a Cure

HIGHLIGHTS

- A novel method of estimating prevalence of MS found there are nearly 1 million living with MS in the US—twice as many as the previous estimate.
- Discoveries by Society-funded researcher Dr. Jim Salzer have led to the launch of a new company—GliXogen Therapeutics—focused on developing therapies for myelin repair.
- New multi-year commitments totaling $24.4 million to 64 new research projects, including a phase II clinical trial of individuals’ own bone marrow stem cells, thought to release growth factors to promote tissue repair and inhibit immune responses.
- The Barancik Prize for Innovation in MS Research was awarded to Dr. Katerina Akassoglou for discoveries of a blood factor that may trigger tissue damage in MS, which she is now translating into possible therapies.

CHALLENGES

- Two new MS medications, while welcome, do not provide solutions for many people living with secondary progressive MS, for whom there are few treatment options.
- Clinical trials of new therapies are not recruiting a diverse population of participants, and recruitment lags in general are slowing trial completion.
**Society-funded researcher, Dr. Katerina Akassoglou received the 2018 Barancik Prize** for innovation in MS Research for her work leading a series of cutting-edge studies that could lead to a novel solution for people experiencing MS disability and progression.

“I nominated Dr. Akassoglou because her work is innovative, creative and significant,” says Dr. Daniel Reich, the 2016 Barancik Prize recipient. “The work that she is doing will help us understand MS and also help us to fill unmet needs that patients have.”

Each year, the award honors an individual who has made a significant scientific contribution that holds great promise to impact the lives of people living with MS. Dr. Akassoglou’s research focuses on how the blood brain barrier can contribute to MS symptoms, while trying to answer existing questions about how the blood affects the MS brain.

“I am curious to understand the mechanism of communication between the brain and the immune system and how they work together to induce pathology in the brain,” Dr. Akassoglou said. “I’m inspired by the impact that new discoveries could make in the lives of MS patients. I’ve seen how much this research means to people living with MS. They put hope in our hands to be able to develop a cure.”
**Expand Resources and Reach**

**Breakthrough MS Campaign Progress**

FY2021 target: $1 billion

$456 million raised to date

**Revenue Sources**

- **Walk MS 6+ Teams**
  - TEAMS RAISED
  - $7.8 MILLION
  - Q1 target: 5,327 teams, $7.3 million raised
  - FY19 target: 10,500 teams, $24.4 million raised

- **Bike MS 10+ Teams**
  - TEAMS RAISED
  - $13.9 MILLION
  - Q1 target: 1,009 teams, $13.7 million raised
  - FY19 target: 1,500 teams, $42.5 million raised

- **$1,000+ Donors**
  - DONORS RAISED
  - $21.8 MILLION
  - FY19 target: 2,900 donors, $17.5 million raised

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

- **Community Engagement**
  - 6.7 MILLION
  - PEOPLE ENGAGE WITH THE SOCIETY
  - FY19 target: 7 million

**HIGHLIGHTS**

- Stewardship of individual giving donors led to $1 million in new revenue from mid-level giving program. Received additional $2 million gift from the Hilton family, bringing their total giving to $18.5 million.

- Two of our top three Bike MS events are up in registration—Houston to Austin is up 4% and Colorado is up 15%.

- Climb to the Top NYC will reach $1 million in revenue for the first time in five years and the series will achieve target revenue. We have secured the Salesforce Tower in San Francisco to expand to the West Coast in 2020.

- Walk MS national corporate sponsorship grew by $1 million over 2018 and four corporate partners have committed to start national teams.

**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.
ACCELERATING PROGRESS

DIGITAL AND TECHNOLOGY
• We launched a Find Doctors & Resources tool to provide 24/7 online access to healthcare providers and MS-related resources
• $5.8 million raised through Facebook Fundraisers in Q2
• @mssociety Instagram surpassed 50,000 followers and @bike_ms surpassed 10,000 followers

STRATEGIC PARTNERSHIPS
• We joined 25 other leading national voluntary health organizations in supporting a bill to stabilize and strengthen the Affordable Care Act
• We signed a memorandum of agreement with the Veterans Administration, formalizing our collaboration on resources for veterans, professional education for providers, and other resources

INNOVATION AND IMPROVEMENT
• We are developing a definition and model for innovation at the Society
• 156 pages of our website have been updated with information that is up to date, accurate and reflective of current language

AWARENESS
• 71% of people who visited our website during MS Awareness Week were first-time visitors
• A prevalence data briefing was held on Capitol Hill to educate media and members of Congress about the new study
• We secured several high-profile media placements including Fox and Friends, Good Morning America, the New York Times and Los Angeles Times

VOLUNTEER ENGAGEMENT
• 280 activists held more than 300 Capitol Hill visits during the Public Policy Conference
• At a joint meeting of the Research Programs Advisory Committee and National Board of Directors, members discussed definitions, strategies and metrics related to pathways to a cure as they considered how best to gain international input and consensus