

# PROGRESS REPORT

## FY2019–2021 STRATEGIC PLAN



**JOVANY (R)**  
DIAGNOSED IN 2016



National  
Multiple Sclerosis  
Society

The three years of this strategic plan, FY2019-2021, have been unprecedented. As we navigated a global pandemic, we persevered. We are resilient.

We kept people with MS connected to the best information about COVID-19 and MS. We gathered experts to make sense of the research and get people answers so they could take action. And we made sure the latest information was right at people's fingertips, through channels like Ask an MS Expert, the Society's website and social media.

We stayed connected and took care of each other. Self-help groups and other online communities provided a source of strength, breaking through feelings of isolation to that reservoir of resilience that exists in everyone. We held our first two Black MS Experience Summits, taking the place of six conferences we had to cancel, that brought together 800 people each year, 25 percent of whom had never before connected to their National MS Society.

For the first time in 30 years, we held our Public Policy Conference virtually, and we made the most of it. Three times as many people engaged in the conference compared to prior years. MS activists make life better for everyone, shining a light on the biggest problems and getting public policies to solve them.

This year we honed our expertise in virtual fundraising events and expanded into online fundraising through Stream to End MS, which reached 500,000 people, most of them for the first time.

The Society was honored as one of Fast Company's Best Nonprofit Workplaces for Innovators, validating our innovative approach and resilience.

And when it was safe to do so, we started coming back together for in-person events. We put robust safety measures in place and flexed our creativity and innovative thinking to redesign these experiences.

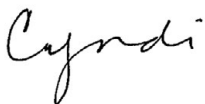
Remarkably, in spite of every obstacle thrown our way, we managed to raise \$144 million in FY2021—exceeding our revenue budget by over \$10 million.

The collective resilience and adaptability of our movement has never been more evident. The passion of our movement runs deep, and there's nothing we can't accomplish when we come together and rally around our mission: **We will cure MS while empowering people affected by MS to live their best lives.**

We are moving closer and closer to the destination we've been working toward for 75 years—a world free of MS. A cure for every single person.

Thank you for moving us forward in these extraordinary times. Together we are unstoppable.

Yours truly,



Cyndi Zagieboylo  
President and Chief Executive Officer





# Ensure Comprehensive High-Quality Healthcare

## ADVOCACY PROGRESS

**34,317**   
MS Activists

**388**   
District Activist Leaders keep in touch with congressional offices about MS issues

**7,772** **HEALTHCARE PROVIDERS** 

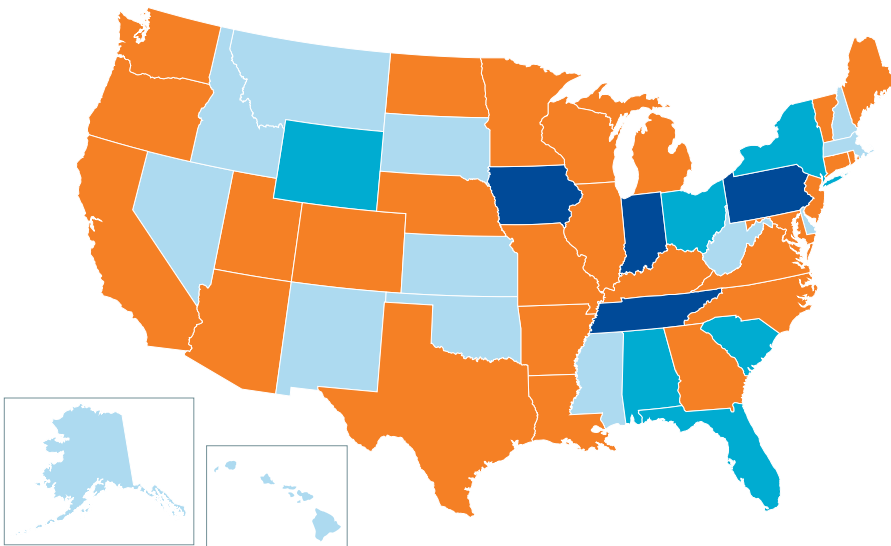
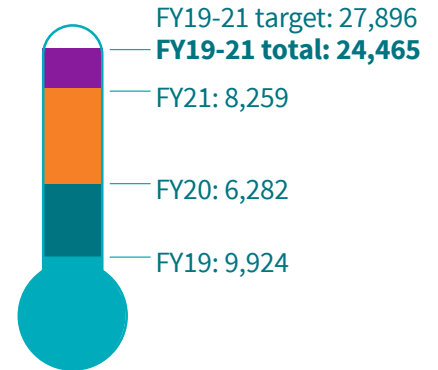
attended programs and are better equipped to take care of their patients with MS and promote the Society as a supportive partner

**79%**  
plan to change practice or behavior  
(target: 75%)





**89%**  
report improved attitudes about MS care  
(target: 82%)

**94%**  
report increased knowledge about MS care  
(target: 90%)

## Referrals to MS Navigator from healthcare providers



## FY21 STATE PROGRESS ON ACCESS TO CARE LEGISLATION

-  Bills we supported became law (total = 106)
-  Bills we supported passed by a chamber of the state legislature (House or Senate) (total = 319)
-  Bills we supported passed by a committee (total = 584)
-  No advancement

## HIGHLIGHTS AND MILESTONES

- The Society was awarded with **Research!America's Paul G. Rogers Distinguished Organization Advocacy Award** for advocacy work to find solutions for people affected by MS
- Convened experts to develop **COVID-19 vaccine guidelines** for people with MS — globally adopted and endorsed by MS groups
- Annual increases in funding have led to a total appropriation of \$42M to the **MS Research Program** at the Department of Defense over the last three years.
- Society study **reveals the financial burden of MS** on families. Data equips the Society to advocate for change.
- Held **Public Policy Conference** virtually in 2021. A record 888 people sent 2,442 emails to members of Congress and held over 266 virtual meetings
- 328 healthcare professionals participated in **ECHO MS**, boosting the number of providers with MS specialty knowledge
- The Society is a recognized **advocacy leader** on the Hill and throughout the country

## IMPACT SPOTLIGHT:

# ACCESS TO HIGH QUALITY HEALTHCARE

### Society advocacy protects and expands access to affordable health insurance



**“Today’s ruling leaves in place the healthcare law’s critical access to quality health coverage for more Americans.”**

**– National MS Society and advocacy organizations**

Since the Patient Protection and Affordable Care Act’s (ACA) passage in 2010, this landmark piece of legislation has opened the door for access to affordable healthcare for many in the MS community through provisions such as the expansion of Medicaid, caps on annual out-of-pocket costs and protections for those with pre-existing conditions.

People living with MS need access to affordable, high-quality healthcare to get the care and treatments they need to live their best lives. But in late 2020, the Supreme Court heard oral arguments in the case of *California v. Texas*, which challenged the survival of the ACA.

Throughout the legal challenges, the National MS Society and MS activists across the country shared their stories and stood together to uphold the protections of the ACA for the MS community.

In June 2021, the Supreme Court upheld the ACA. Alongside more than a dozen patient advocacy organizations, the Society shared a joint statement in support of the Supreme Court’s ruling.

“This ruling is a victory for people with serious illnesses such as cancer, heart disease, stroke, lung disease, diabetes, neurological conditions, mental illness, and anyone suffering long-term effects from COVID-19. These patients and millions more rely on the law’s critical patient protections to obtain more affordable, comprehensive health coverage.”


Passionate MS activists continue to raise their voices as a collective unit to show policymakers that together, we are stronger than MS.

# Empower People Affected by MS to Solve Everyday Challenges

## GETTING WHAT YOU NEED WHEN YOU NEED IT — FY21 PROGRESS

- 113,938** searched Find Doctors and Resources on Society website
- 10,570** learned the latest by participating in the live or on-demand Ask an MS Expert series
- 34,376** connected with MS Navigator via phone, email or chat
- 7,283** engaged in Facebook Social Learning Group
- 760** had a listening ear through MSFriends

## PEOPLE WHO CONNECTED TO SOCIETY RESOURCES AND SUPPORT

- 77%**  plan to take action based on what they learned (target: 80%)
- 93%**  believe the Society is a source of support where they can find solutions (target: 85%)
- 81%**  feel more confident in addressing challenges of MS (target: 75%)
- 88%**  made new connections to information, resources, people and/or other sources of support (target: 80%)

## HIGHLIGHTS AND MILESTONES

- **Black MS Experience Summit** provides a space for Black people with MS to learn and connect with one another. The two programs to date had 1,063 participants with 23% connecting to the Society for the first time.
- 2,300 people were supported through the **Edward M. Dowd Personal Advocate Program** (Case Management)
- **MS Navigator** service, including case management, was uninterrupted during the pandemic. Staff and contractors were prepared to work from their homes and the transition was seamless for people affected by MS.
- Shifted in-person programs to **virtual offerings** during the pandemic, ensuring people could continue to connect and build relationships
- The generous donation from the **Conrad Hilton Foundation** increased our capacity to assist people with rent, mortgage, utilities, home modifications, mental health, respite care needs and more

## CHALLENGES

- People connecting to the Society report they are struggling with **feelings of isolation and anxiety**, made worse by the COVID-19 pandemic

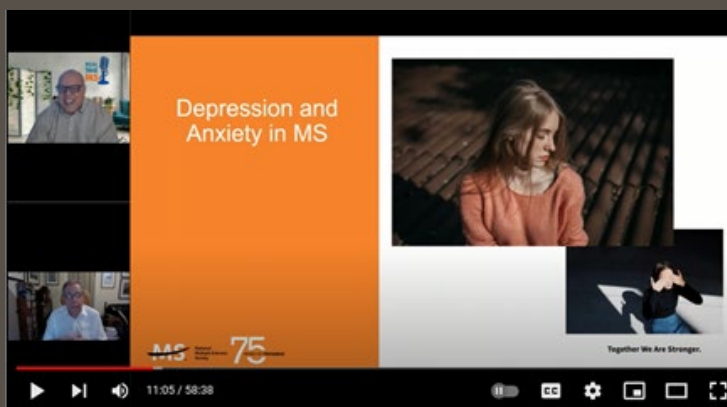
“ I wanted to say thank you for the your assistance for the lift we recently purchased. It was installed last Thursday, and has already been a game changer. I was able to get out each day, and it has made my mobility life easier. ”

– MS Navigator recipient

IMPACT SPOTLIGHT:

# EMPOWER PEOPLE TO SOLVE EVERYDAY CHALLENGES

The National MS Society is the go-to source for accurate, actionable information about MS



Trending topics evolve as breakthroughs in research, updates in the news and areas of interest raise questions on how to navigate life with this disease.

To empower people to make informed decisions about their health, the Society's weekly Ask an MS Expert program invites top MS experts to breakdown complex topics and answer urgent questions. Each week, Jon Strum, host of RealTalk MS podcast, guides a conversation on topics such as COVID-19 vaccines, stem cells, wellness, comorbidities, aging and much more.

**“Thank you for making me feel more comfortable to reach out to my [primary care physician] and [neurologist] about how I am feeling mentally.”**

**– Participant on the June 16, 2021 Depression and Mental Health Ask an MS Expert program**

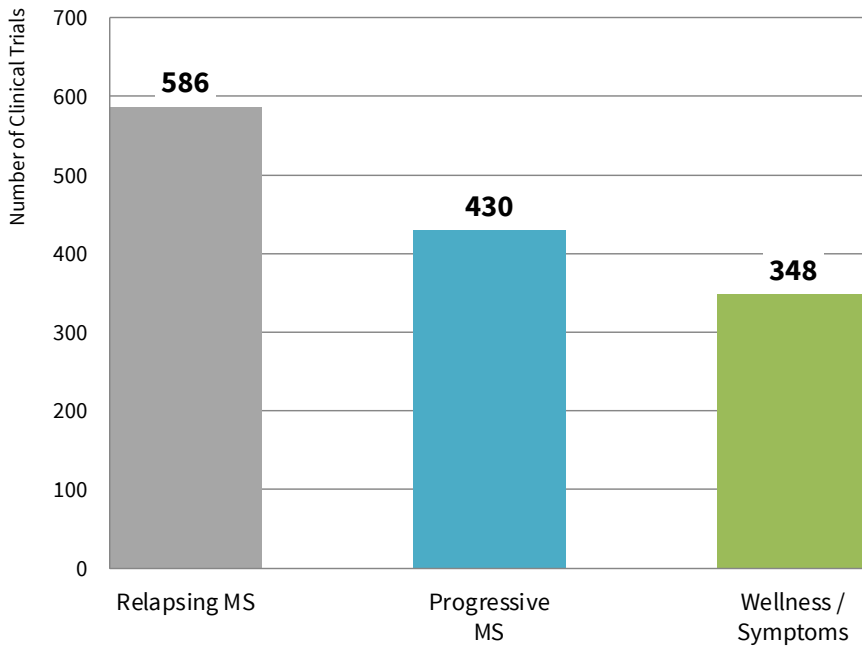
The program also offers a specialized series in Spanish and for veterans with recordings available to stream on-demand on the Society's YouTube channel.

In 2020 and 2021, 18,128 people tuned in live to watch one of our Ask an MS Expert programs, and over 1M people have revisited the series through the recordings. The program has reached people all over the world, with viewers in the U.S., U.K., Canada, Israel, Australia, South Africa and more.

A viewer of our Vaccines and COVID Update series shared: “Thank you for your time and effort in providing information that I see as most trustworthy over any other source available to me. Each week as I listen to the webinar, I can feel my stress level go down and my level of confidence in my next steps of action rise.”

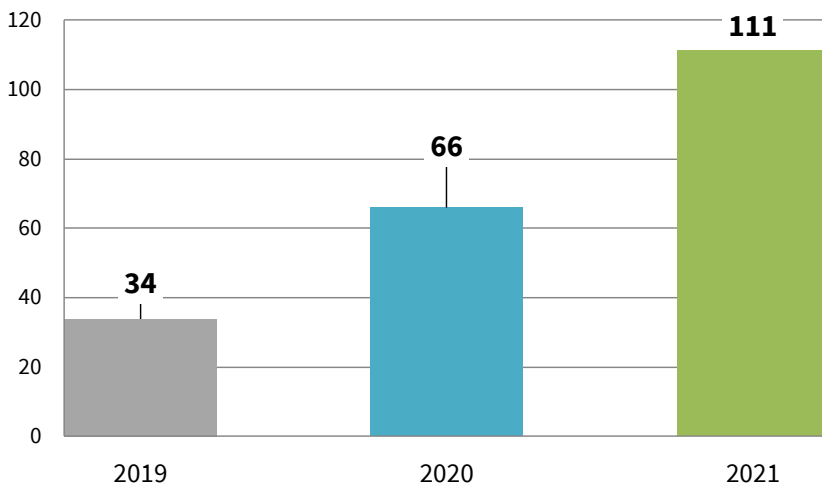
# Deliver Breakthroughs to a Cure

## Q4 FY21 ACTIVE CLINICAL TRIALS



## PATHWAYS TO CURES

More researchers are focusing on developing the tools to detect MS in its earliest stages. This will accelerate progress towards our goal of ending MS, and will create new and better ways to diagnose MS.



The number of published research studies focused on early detection of MS has tripled since 2019

## HIGHLIGHTS AND MILESTONES

- A novel method of estimating prevalence of MS found there are nearly **1 million living with MS in the U.S.** — twice as many as the previous estimate
- The FDA approved nine new disease-modifying therapies and issued a **Letter of Support to the International Progressive MS Alliance** that will encourage studies that advance a blood biomarker to speed clinical trials in progressive MS
- Studies add to growing evidence that Black people with **MS may experience worse disease**, and may **respond differently than white people to B-cell therapy** in terms of how quickly their depleted immune cells recover
- Study showed that **stem cells derived from skin cells** of people with MS make normal myelin, a plus for future repair strategies
- Convened experts to develop and publish recommendations for **promoting exercise and physical activity** in people with MS
- New information on the origins and **types of pain in MS** may lead to better treatment strategies
- Studies suggest that **changes in the nervous system** related to MS begin well before there are perceptible symptoms
- Declared **global consensus** on the Pathways to Cures roadmap
- Provided \$2.95M in **bridge funding** to ensure Society-supported research projects could restart after COVID shutdown

## CHALLENGES

- The COVID-19 **pandemic closed many MS research labs** and paused clinical trials, causing delays in the completion of many research projects
- **Revenue shortfalls** due to the pandemic constrained our ability to fund research
- There is a **workforce shortage** of biostatisticians and data scientists in MS
- There is a **critical unmet need for solutions** for people living with progressive MS
- There are not enough well-designed **rehabilitation and wellness studies** that translate into practical solutions

## IMPACT SPOTLIGHT:

# PATHWAYS TO CURES

## The National MS Society leads a global movement toward cures

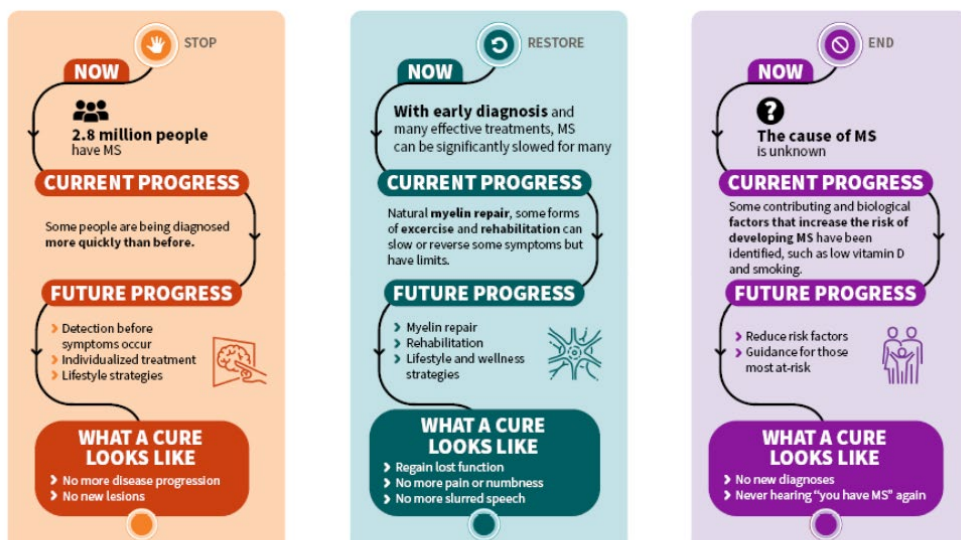
By convening MS organizations, scientists, donors and people living with MS across the world to collaborate on the most promising research pathways, we can close in faster on a cure for every person with MS.

Just as the experience of living with MS is different for every person, every person's cure for MS may look different. We have never been closer: to understanding

how to prevent the disease and reverse its course, to finding treatments for progressive MS as effective as those we've discovered for relapsing-remitting MS and to bringing life-changing solutions and treatments to everyone with MS.

Explore the Pathways to Cures roadmap: [pathwaystocures.org](https://pathwaystocures.org).

## How We Reach Cures for MS



**Power the Pathways to Cures.**  
Join in at [PathwaysToCures.org](https://PathwaysToCures.org)

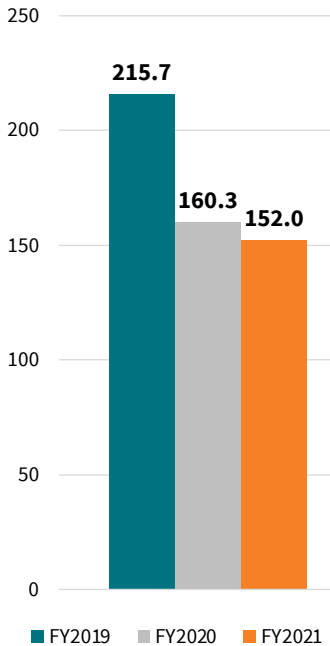
"The National MS Society is providing global leadership to set a path forward that can, with effective international collaboration and innovation in MS research, accelerate progress and ultimately achieve cures in MS."

– Professor Alan Thompson, Chair of the International Progressive MS Alliance's Scientific Steering Committee



# Expand Resources and Reach

Total Gross Revenue (in millions)



**FY19:** Strong revenue position with growth in Individual Giving, Bike MS, and Walk MS.

**FY20:** Walk MS was \$1 million ahead of budget and Bike MS was pacing ahead. In March, the pandemic hit. Hundreds of in-person Walk MS events moved to a virtual environment. Hundreds of other fundraising events, volunteer and donor activities followed. As one unified organization, we adapted quickly and adjusted staff and expenses for steep revenue decline.

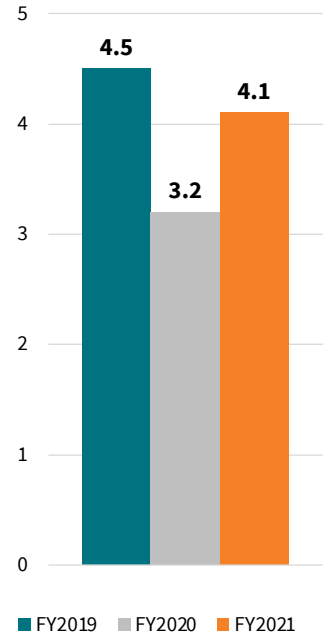
The changes to plans and ways of fundraising were swift, to meet urgent needs of the MS community in this time of crisis. A COVID-19 Response Fund was launched with a lead gift of \$4 million.

We created a virtual Bike MS experience and developed a framework to be prepared to assess each in-person event, activity, and meeting to manage the risk and decide when it was safe to come back together.

**FY21:** Walk MS was virtual again. By May 2021, we held the first in-person Leadership Event and shortly thereafter, Bike MS events. We focused on connecting new people to the MS movement and on deepening relationships with those already connected. The strength of our fundraising is due to devoted participants, the diversity of revenue sources, and the many ways people can contribute.

As we enter **FY22**, we are planning for revenue growth to achieve \$200 million in FY24.

Board Appeal (in millions)



Board leadership and approximately 850 Directors and Trustees gave \$11.8M over three years through the Breakthrough MS Board Appeal.

## Engagement

# 7.79 MILLION

PEOPLE ENGAGE WITH THE SOCIETY

FY21 target: 7.65 million

# 60.8%



556,114 of the estimated 914,000 people with MS in the United States are connected to their National MS Society (FY21 target: 61.3%, 560,000 people)

## HIGHLIGHTS AND MILESTONES

- **Walk MS** ranks among the top five walk fundraising events in the nation. Since FY19, 348,000 people have participated, and we have raised \$88.6M.
- 145,000 people participated in **Bike MS**, which has raised over \$1B since it began and remains the number one fundraising cycling series. In 2021, **Bike MS: Inside Out**, a virtual cycling experience created as a result of the pandemic, raised \$13.8M.
- Over the last three years, volunteer leaders and donors rallied together in person at 200 **Leadership Events**, while others created compelling digital experiences to engage their audience, raising \$39.9M
- Received \$1.5M in funding to support **Ask an MS Expert** and the **Black MS Experience Summit**
- The **Corporate Healthcare Roundtable** continues to grow and expand in its second year. Members include representatives from nine **companies**.
- The **National Team** program has raised \$12.9M since FY19, reflecting the work and partnership of National Team captains and local team captains across the country. Top National Teams include: Team Left Hand (Left Hand Brewing Co.), EOG Resources, KPMG, Leaders in Motion, Meat Fight, Microsoft, Salesforce and Team in Motion.

## CHALLENGES

- The **COVID-19 pandemic** and **virtual event fatigue** have negative financial implications and returning to in-person gatherings is complex in a pandemic environment

# ACCELERATING PROGRESS

## DIGITAL AND TECHNOLOGY

- Jon Strum, host of the RealTalk MS podcast, brings MS news to a weekly audience of 10,000+
- Find Doctors & Resources online tool offers people easy access to MS specialists and resources
- Ask an MS Expert, Pathways to Wellness in MS and the Black MS Experience Summit launch online with timely, accessible and relevant forums for information, connections and support



TRACEY, DIAGNOSED IN 2009

## AWARENESS

- New mission statement: We will cure MS while empowering people affected by MS to live their best lives.
- The Society is a go-to source for information on COVID-19 and MS. We provided timely and reliable updates on our website, established guidelines for healthcare providers and people with MS, and reached out through webinars and social media posts (RealTalk MS, Facebook, Ask an MS Expert).



JOSEPH, DIAGNOSED IN 2008

## STRATEGIC PARTNERSHIPS

- Collaborated with the MS International Federation, MS Society of Canada and International Pediatric MS Study Group to develop COVID-19 vaccine guidance for youth living with MS
- Partnered with the Health Department in Puerto Rico to bring Case Management Services to residents of Puerto Rico
- Signed a memorandum of agreement with the Veterans Administration, formalizing our collaboration on resources for veterans, professional education for providers, and other resources
- Created the COViMS registry in partnership with the Consortium of MS Centers and MS Society of Canada, which collected outcomes for people with MS who developed COVID-19. It is now the largest registry of its kind in the world.

## INNOVATION AND IMPROVEMENT

- The Society was recognized by Fast Company as a Top 5 Nonprofit Workplaces for Innovators
- Increased engagement with the Hispanic/Latinx community by launching a Spanish version of Ask the MS Expert and translating five publications into Spanish
- Moved programs and events to virtual environment so people affected by MS have access to information, resources and connections throughout the pandemic

## VOLUNTEER ENGAGEMENT

- The Diversity Advisory Committee rolled out an updated **Diversity, Equity and Inclusion Statement**
- New Community Review of MS Research Committee ensures people affected by MS provide input on research decision making





# THE IMPACT OF YOUR INVESTMENT: BREAKTHROUGH MS®

2021 marks 75 years of progress for the National MS Society — and **thanks to your generous support of the Breakthrough MS Campaign**, our progress

has transformed the MS movement. Together, we achieved more progress in the last five years than in the 70 that preceded it.

**Thanks to you, we've never been closer to a cure.**

## CAMPAIGN OVERVIEW

In 2017, the Society launched Breakthrough MS — a bold fundraising initiative to accelerate breakthroughs for people affected by MS across all aspects of the Society's work. Through the generosity of over 3 million supporters, the campaign achieved remarkable results:

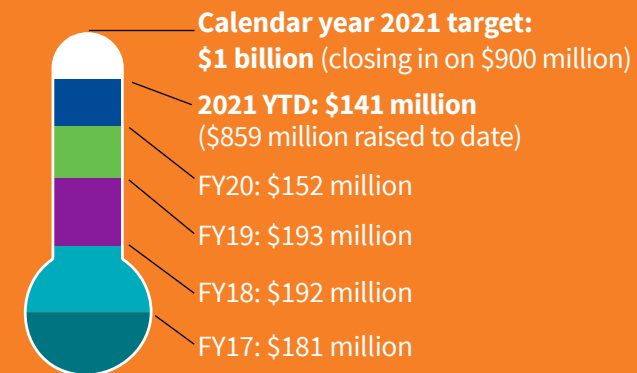
- Increasing the number of MS treatments and accelerating cures through global leadership
- Improving access to affordable, high-quality healthcare
- Empowering people affected by MS to solve everyday challenges
- Strengthening the MS movement through an expanded reach and deeper connections

 **\$878 MILLION**  
RAISED TO DATE

 **3.2 MILLION**  
SUPPORTERS

 **5.7 MILLION**  
GIFTS

## BREAKTHROUGH MS CAMPAIGN PROGRESS



## KEY ACHIEVEMENTS



- Society surpasses **\$1 billion in MS research funding**
- **MS Navigator program** launches nationwide ensuring all people affected by MS, regardless of location, have access to a supportive partner to overcome everyday challenges
- “McDonald Criteria” for diagnosing MS updated by Society Task Force, **speeding time to diagnosis** and helping ensure early treatment and slowed progression for many
- International Progressive MS Alliance launches **Collaborative Network Awards** bringing together leading scientists from across the globe to drive innovation and expedite drug discovery
- FDA approval of the **first therapy for primary progressive MS**

2017



- FDA approval of the **first therapy for pediatric MS**
- MS Activists help secure a **22% increase from Congress for the Lifespan Respite Program** to provide accessible, community-based respite care services for family caregivers

2018



- **Find Doctors & Resources online tool** provides people easy access to MS specialists
- International MS Genetics Consortium **confirms 233 gene variations** that contribute to MS risk
- **Pathways to Wellness in MS** program launches providing people with the latest wellness and lifestyle information and solutions
- Society funds the **Atlas of MS update**, revealing there are an estimated 2.8 million people worldwide who have MS, with nearly 1 million of them living in the U.S.

2019



- **ECHO MS launches** for general healthcare professionals boosting the number of providers with MS specialty knowledge
- **COVID-19 & MS Resource site, Ask an MS Expert** and the **Black MS Experience Summit** online provide timely, accessible and relevant information, connections and support as the world changed
- Society fills an urgent need to understand the **effects of COVID-19 on the MS population** with COViMS data collection and COVER-MS study

2020



- FDA supports **development of blood biomarker**, neurofilament light, in clinical trials for progressive MS to speed drug development
- Society releases study **revealing the financial burden of MS** on people living with the disease and their families and the considerable annual cost of more than \$85.4 billion on the U.S. economy. Data equips the Society to support people and advocate for change.
- Society issues **Pathways to Cures** global scientific roadmap

2021