



CHLOE
DIAGNOSED
IN 1998

BREAKTHROUGH

MS[®]

WHATEVER IT TAKES.

**2020 ANNUAL
PROGRESS
REPORT**

MS[®]

National
Multiple Sclerosis
Society

OUR VISION

A world free of MS.

OUR MISSION

We will cure MS while empowering people affected by MS to live their best lives.



WESLEY
DIAGNOSED IN
2015

ABOUT MULTIPLE SCLEROSIS

Multiple sclerosis is an unpredictable disease of the central nervous system. There is currently no cure. Symptoms vary from person to person and may include disabling fatigue, mobility challenges, cognitive dysfunction, blindness and paralysis. An estimated 1 million people live with MS in the United States. Treatments are available and early diagnosis is critical to minimize disability.

ABOUT THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

The National MS Society, founded in 1946, is a global leader of a growing movement by and for people affected by MS which funds cutting-edge research, drives change through advocacy, and provides programs and services to help people affected by MS live their best lives. Connect to learn more and get involved: nationalMSSociety.org, [Facebook](#), [Twitter](#), [Instagram](#), [YouTube](#) or 1-800-344-4867 .



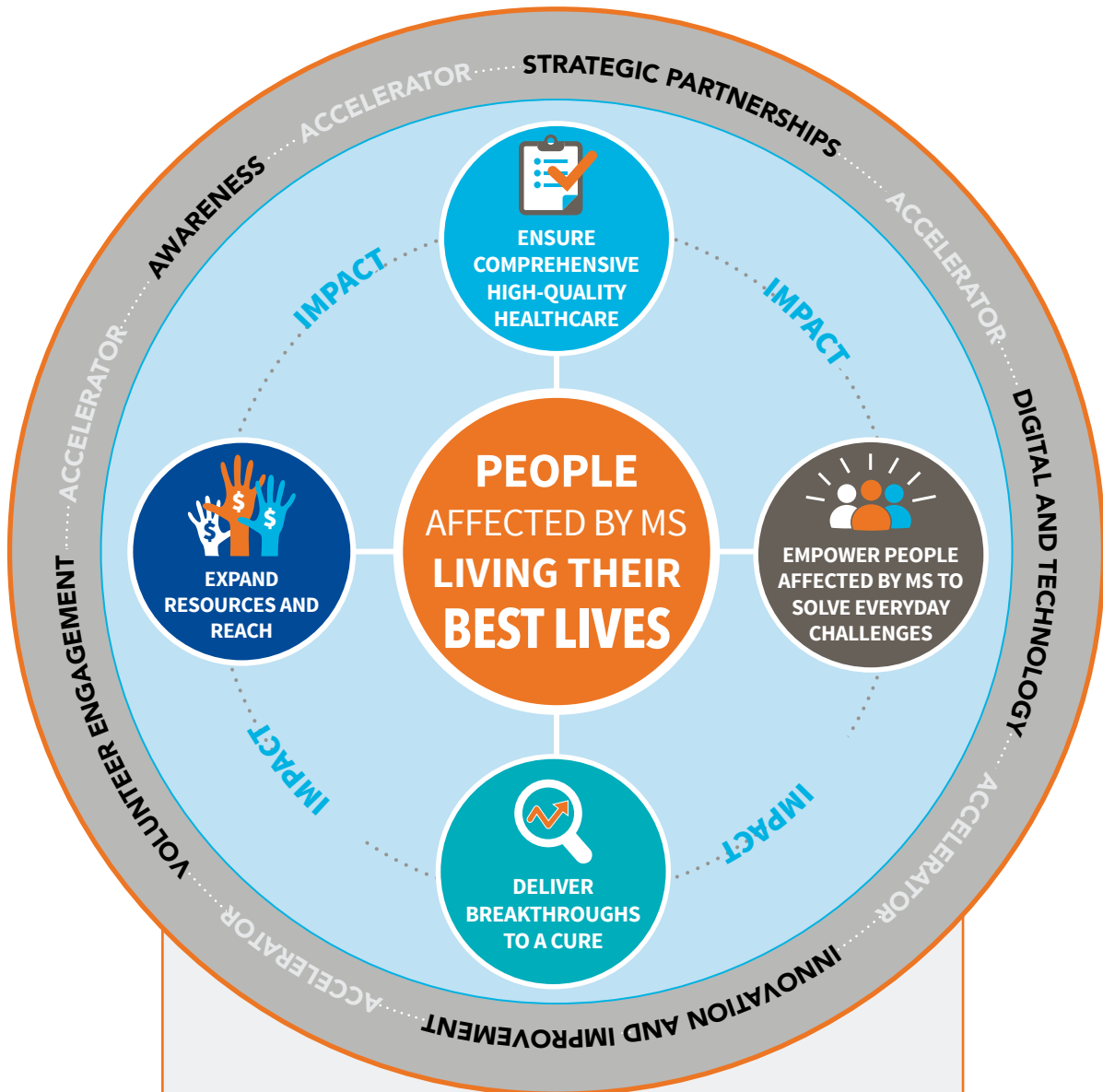
**National
Multiple Sclerosis
Society**

OUR FY2019-2021 STRATEGIC PLAN



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1999

The FY2019-2021 Strategic Plan establishes a roadmap for our movement through 2021.



STRATEGIES

-  Accelerate research
-  Maximize capacity and effectiveness
-  Provide resources, connections and support
-  Achieve \$1 billion Breakthrough MS fundraising campaign
-  Advocate to improve lives

IMPACTS

The four impacts describe what the world will be like for people with MS in 2021. They are displayed in a circular pattern as each is important and all are interconnected.



IMPACT 1 Ensure Comprehensive High-Quality Healthcare

Obtaining comprehensive, coordinated care and MS medications will be simple, transparent, affordable and available to all people with MS.

How we will measure success:

- Advances in legislation, health policy, and healthcare professional workforce
- Increased access to comprehensive high-quality, affordable healthcare as reported by people with MS



IMPACT 2 Empower People Affected by MS to Solve Everyday Challenges

People will be informed, connected and supported by loved ones, their communities and the Society so they can be more powerful than the challenges of MS.

How we will measure success:

- More individuals and families are connected to information, resources and communities of support, resulting in positive life changes
- People report increased confidence and success in addressing MS challenges
- The Society is recognized as an essential and trusted partner and source of support



IMPACT 3 Deliver Breakthroughs to a Cure

People will know what they can do right now to take control of their MS and life better while we relentlessly pursue a cure—stopping MS in its tracks, restoring what has been lost and ending MS forever.

How we will measure success:

- International consensus on pathways to a cure
- Solutions that help all people with MS live better — with new and better treatments, symptom management interventions and wellness approaches



IMPACT 4 Expand Resources and Reach

The Society will remain a financially strong organization that is trusted, relevant and transparent. We will engage more people in ways that fuel fundraising and progress to all our impact areas—growing the MS movement.

How we will measure success:

- Achieve \$1 billion Breakthrough MS campaign goal—driving special events, growing individual giving and continuously innovating and improving
- Increased awareness of how MS impacts people and of the work of the National MS Society
- Volunteers and staff are highly engaged and achieve annual objectives

STRATEGIES

Strategies describe how we get the work done. They work together to achieve the four impacts:



Accelerate research



Maximize capacity and effectiveness



Advocate to improve lives



Achieve \$1 billion Breakthrough MS fundraising campaign



Provide resources, connections and support

ACCELERATORS

Accelerators are levers that will increase our capacity and speed progress in each impact area and strategy.

- Strategic partnerships
- Digital and technology
- Innovation and improvement
- Volunteer engagement
- Awareness

LETTER FROM CYNDI

Over our 74-year history, the National MS Society has been through our share of challenges and crises. But never before have we have faced challenges like those in 2020. While no one expected a global event of this magnitude—we were prepared, even for this. We did not freeze in fear, and we did not make knee-jerk decisions. We moved swiftly to activate disaster recovery and crisis response teams. We responded, we innovated, we implemented.

More than 1,000 self-help group leaders from across the country learned new technology to host meetings virtually. And as the world became smaller for many people, these volunteer leaders, most with MS themselves, expanded the MS movement.

To address the critical need for timely, relevant information, we launched a COVID-19 resource hub and created the Ask an MS Expert weekly webinar series. The MS Navigator service which is a life-changing and sometimes, even lifesaving, service was uninterrupted. We helped connect people with MS to the information they needed to make informed decisions.

By amplifying the voices of the MS movement, MS activists made more than 30,000 connections with elected officials. Together, they helped pass 52 laws in states across the country to ensure access to telehealth and affordable health insurance. At the federal level, activists secured \$16 million from the Department of Defense to advance MS research—a \$10 million increase from the year before.

When there was no published data or forums for information sharing about MS and COVID-19, we became a go-to source for MS healthcare providers. We partnered with the Consortium of MS Centers to launch a monthly webinar series to improve MS patient care. We also partnered with the Consortium of MS Centers and the MS Society of Canada to create the COViMS registry—and we made it happen in 8 days. This registry is now the largest source of information about COVID-19 and MS in the world and is providing answers about the risks of COVID for people with MS.

We are an organization for ALL people affected by MS, and 2020 brought renewed focus on addressing disparities in healthcare and embracing diversity—ensuring inclusion and equity in everything we do.

We recognize that until we address these disparities, we simply will not achieve a world free of this disease. And until our movement fully includes the lived experiences of our entire MS community, we will not move forward quickly enough.

Our global leadership in the International Progressive MS Alliance never faltered. Nineteen MS organizations from 17 countries have joined the Alliance. People from around the world know that together we are stronger.

The cancellation of hundreds of fundraising events forced us to face a financial shortfall unlike anything we have ever experienced. But in order to achieve our vision, we must remain financially stable. So, we shifted from in person events to responding in force to check in with participants and donors virtually and offer support.

And we found that people want to contribute, they have a tradition of giving and helping. Through streaming video games, online auctions, bold asks to corporations and individuals—we learned people give to those they trust, to those who ask.

And we made difficult decisions, to cut back the organization preparing for smaller revenue with readiness to ramp up as soon as we are able. The financial stability of our organization is critical. We will be here to see through to a world free of MS.

We've learned a great deal since the onset of this global pandemic—being focused and practicing collective and individual resilience. We've tried new ways of doing things, embracing imperfection and new technology. Ensuring, first and foremost, that people affected by MS have what they need to live well. Expanding the MS movement through digital opportunities and making sure we are the welcoming, inclusive organization we need to be. Providing global leadership to advance MS cures.

Our vision of a world free of MS remains as clear as ever. But to get there, we must move forward as a changed organization. We must stay focused and harness the energy of every leader in the MS movement to continue to move forward and achieve our vision.

We enter the final year of this strategic plan in the midst of a pandemic with significant restrictions around social gatherings, an economic recession, greater awareness of racial disparity and heightened social unrest. 2021 will be just as hard to predict as 2020, but we are ready, we are disciplined, we are focused. We will maintain our approach, declaring our principles and living by them. Clarifying our ambitions and including everyone who wants to contribute. Thinking and planning big with our eyes wide open for those things outside of our control.

Nearly 1 million people and their families are counting on us. We must be a welcoming place for every person with MS. Let's make sure that no one has to face MS alone. Because MS doesn't stop. And neither will we.

Yours truly,



Cyndi Zagieboylo
President and Chief Executive Officer



2020 FINANCIALS



ANTONIA
DIAGNOSED IN
2017

INCOME



Total Revenue: \$158,693,746

Operating Revenue: \$158,693,746

- Revenue from Non-Operations: \$2,285,118
- Investment Return, Net: \$2,013,951
- Other Revenue: \$11,543

Total Net Assets: \$115,831,667

EXPENSES



Total Expenses: \$163,701,904

- Client & Community Services: \$44,396,626
- Public Education: \$36,968,620
- Research: \$32,126,615
- Professional Education & Training: \$5,849,032
- Fundraising: \$29,954,052
- Management & General: \$14,406,959



**VIEW COMPLETE
FINANCIALS**

FY2020 STRATEGIC PLAN PROGRESS REPORT



SARAH
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IN 2012

Ensure Comprehensive High-Quality Healthcare

ADVOCACY PROGRESS

35,937 

Engaged MS Activists

370 

District Activist Leaders

5,743  **HEALTHCARE PROVIDERS**

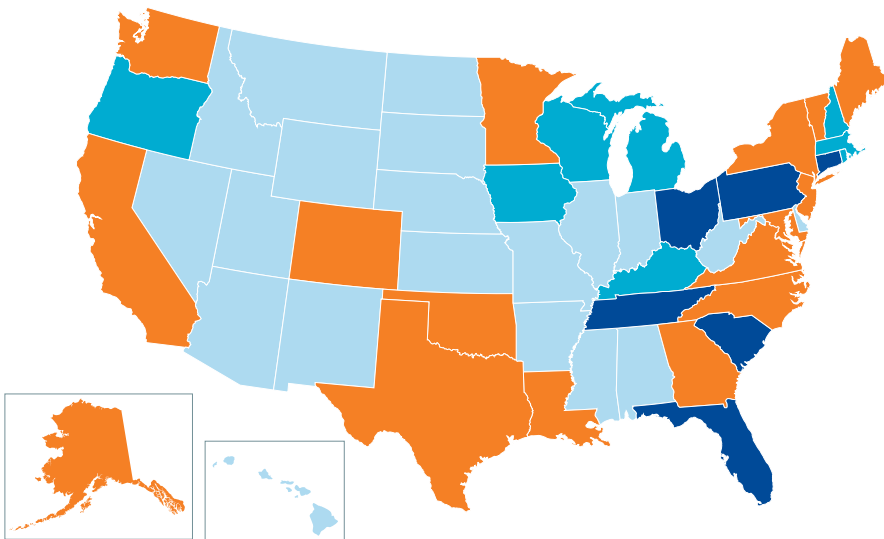
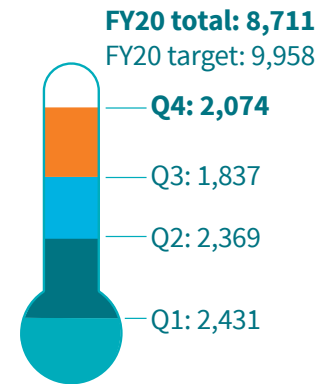
attending programs are better equipped to take care of their patients with MS and promote the Society as a supportive partner

85%
plan to change practice or behavior
(target: 80%)





79%
report improved attitudes about MS care
(target: 85%)

86%
report increased knowledge about MS care
(target: 95%)

Referrals to MS Navigator
from healthcare providers



STATE PROGRESS

-  Bills we supported became law (total = 38)
-  Bills we supported passed by a chamber of the state legislature (House or Senate) (total = 82)
-  Bills we supported passed by a committee (total = 128)
-  No advancement

HIGHLIGHTS

- Released survey results demonstrating the **impact of drug prices on people with MS** and conducted a campaign targeting presidential candidates and party platforms to inform their policy positions around drug access
- The work of MS Activists resulted in \$16 million for the **MS Research Program** at the Department of Defense — up \$10 million from FY19
- 118 MS providers participated in our **ECHO MS telelearning program**, which helped providers navigate MS care during the pandemic
- Supported training of 13 **MS clinical fellows** who are now providing MS specialty care; 2 are in underserved communities

- The House of Representatives Oversight and Reform Committee held a hearing on their investigation of high prescription drug cost, including 2 MS medications, **based on data from the Society**

CHALLENGES

- Congress did not incorporate financial relief for mid-sized nonprofits into **COVID-19 relief packages**
- The future of the **Affordable Care Act** continues to be at risk, with the decision currently in the hands of the Supreme Court

EMPOWERING PEOPLE TO SOLVE EVERYDAY CHALLENGES

The face of MS is changing. Once thought of as a disease that affects predominantly those of Caucasian descent, breakthroughs in research have shown that those in the Black community — primarily women — may have higher risk of developing MS compared to white people with MS.

As a movement by and for people affected by MS, we held the first nationwide virtual Black MS Experience Summit as a continuation of our commitment to building a more diverse and inclusive MS movement. This three-day Summit addressed the unique challenges and experiences the Black community faces in living with MS, and provided solutions to help them live their best lives, today.

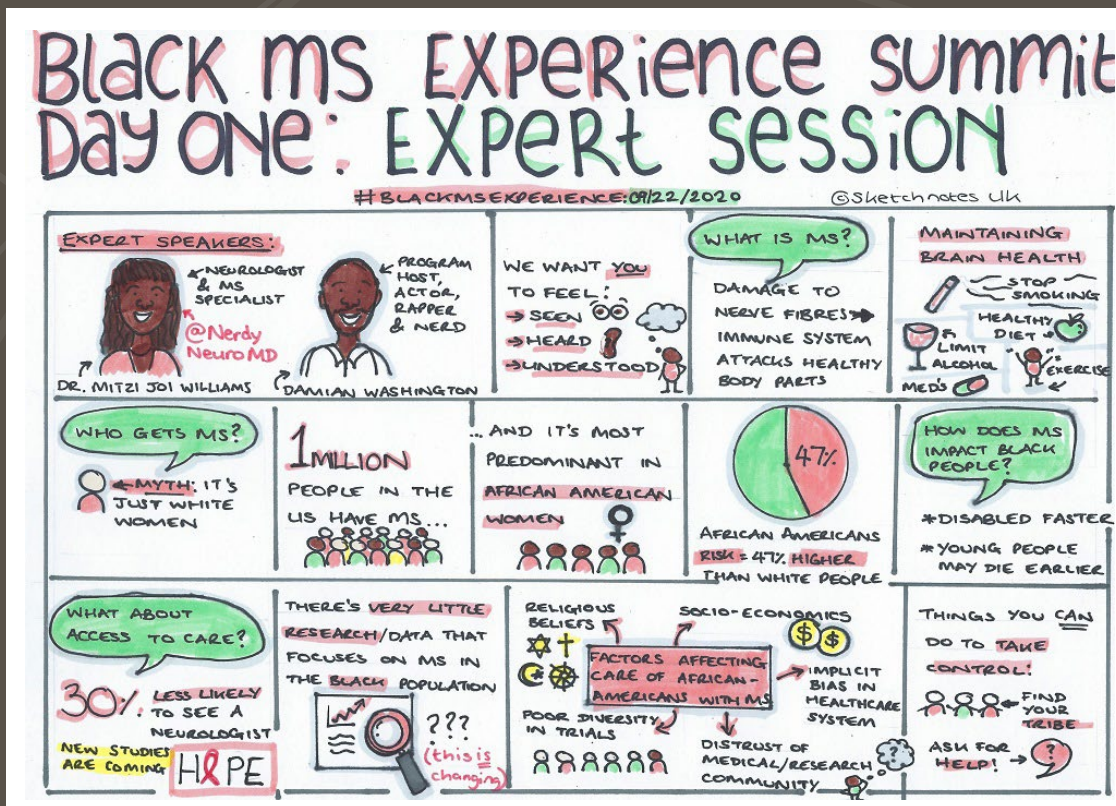
Nearly 600 participants came together from screens across the country — with 20% connecting with the Society for the first time — to hear expert sessions led by Black MS professionals, participate in engaging

breakout rooms and ask questions. The program was also simulcast to 13,000 individuals through **BlackDoctor.org** and 655 people on Facebook.

The Summit featured honest discussions and presentations about inequities in care and treatment, the importance of mental health and representation in clinical trials.

One of the Summit’s featured speakers, Tyler Campbell, who was diagnosed in 2007, shared: “I am so honored to be a part of the Black MS experience. It’s an opportunity to be able to be open, vulnerable and transparent.”

The disparities that keep Black people from receiving today’s care must not keep them from receiving tomorrow’s cure. We continue to listen and amplify the voices of everyone in this movement to get us closer to a cure.



Empower People Affected by MS to Solve Everyday Challenges



60%

549,940 of the estimated 914,000 of people with MS in the United States are connected to their National MS Society (FY20 target: 60%, 550,000 people)

SERVICES IMPACT

PEOPLE WHO CONNECTED TO SOCIETY SERVICES

76%

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%

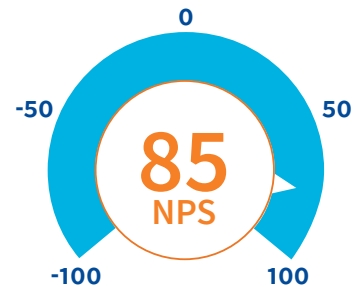
feel more confident in addressing challenges of MS (target: 75%)

81%

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 (NPS) is the leading metric for measuring constituent loyalty and trust. Our score is an aggregate of scores from surveys across the organization.

HIGHLIGHTS

- The **Ask an MS Expert webinar series** provided actionable, breaking news on COVID-19 and MS. The 26 webinars had 2,200 unique participants.
- **MS Navigator** service, including case management, was uninterrupted during the pandemic. Staff were prepared to work from their homes and the transition was seamless for people affected by MS.
- 538 **Society group leaders** joined the weekly drop-in calls to ask questions and get information on how to best support people living with MS
- Provided in-depth support for 232 people signing up for **Medicare** during Open Enrollment
- The proactive shift from in-person **programs** to virtual offerings ensured people could continue to connect and build relationships with other participants
- 859 individuals were supported through the **Case Management program** with 75% of them indicating that the Society is a source of support where they can find solutions

CHALLENGES

- The pandemic resulted in the **cancellation** of in-person programs, minimizing our ability to connect and build relationships with program participants
- **Case management services** provided through the Edward M. Dowd Personal Advocate Program are being delivered telephonically as case managers are unable to make home visits
- The **economic downturn** is taxing community resources, increasing the severity of poverty for people affected by MS who are already vulnerable



The MS Navigators are a blessing to me as a person with MS. I call with my needs and questions and always hang up with many answers. In this MS world of irregularities and unknowns, it's a lifesaver to get the answers that help me so much with all my needs."

– MS Navigator recipient

IMPACT SPOTLIGHT:

LEADING BY EXAMPLE TO ADVANCE RESEARCH



Ian Duncan, PhD

“People with MS are looking for a number of things. They want to stop ongoing disease, that’s for sure. But almost equally, they’d like to have some improvement. They would like to be less tired, they’d like to be more mobile, have better balance and see normally. So we can’t just stop the disease. We need to actually improve people’s function.”

For decades, Ian Duncan, PhD, has investigated how to repair myelin, the protective coating of nerve fibers in the central nervous system that get damaged during MS attacks. To recognize his groundbreaking work on remyelination, Duncan has been awarded the **2020 John Dystel Prize for Multiple Sclerosis Research**.

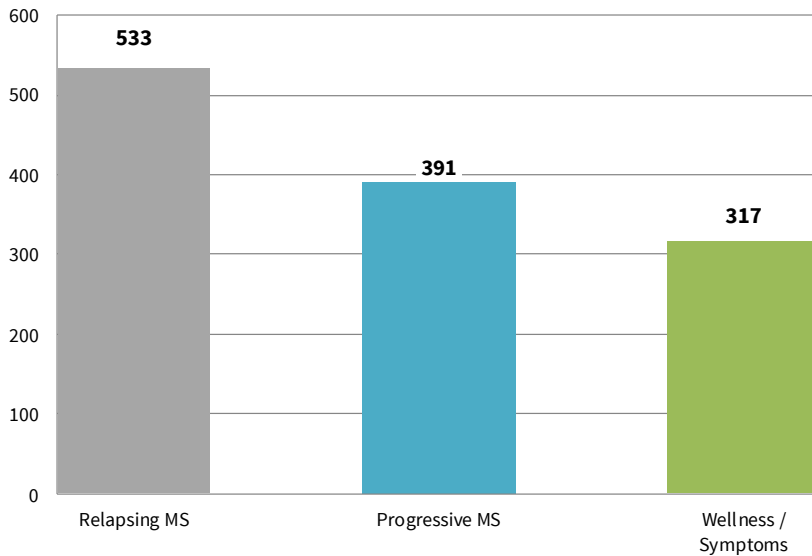
“Dr. Duncan was one of the earliest investigators to tackle central nervous system repair in demyelinating disease and to uncover leads as to how to best achieve this,” writes Stanford University professor Lawrence Steinman, MD, in a letter nominating Duncan.

Duncan has re-examined fundamental questions related to myelin repair. Definitive proof that remyelination in MS and animal models results in neurologic recovery had been lacking until Duncan’s demonstration in a lab model. He and his colleagues also studied surviving myelinating cells known as oligodendrocytes and their role in remyelination; this had previously been thought unlikely, and researchers have since identified this cell as an additional target for future remyelinating drugs.

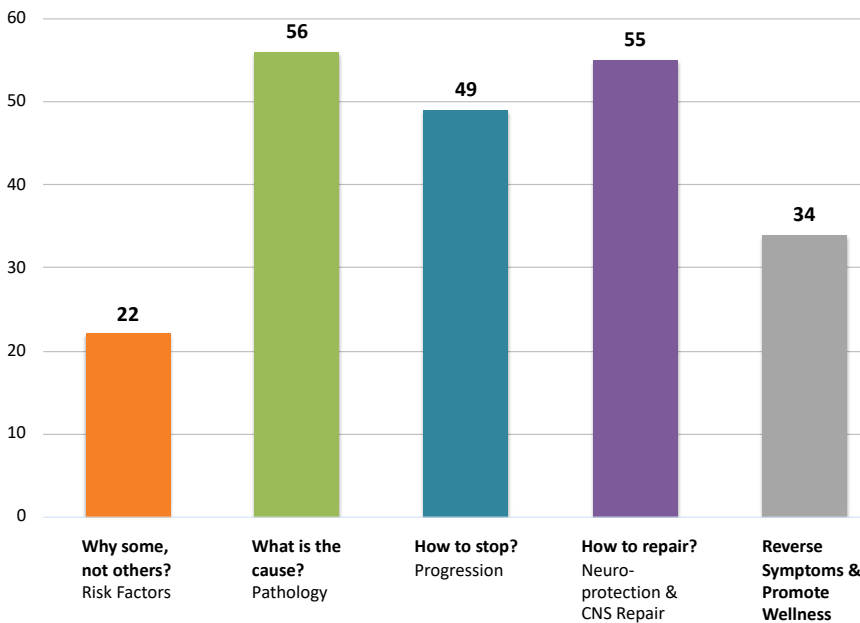
“In a complex war, the more diversified soldiers you have, the better chance you have for winning, if I can make that analogy,” Duncan says. “The final cure in MS will probably not be a single treatment, but rather a multi-treatment solution.”

Deliver Breakthroughs to a Cure

ACTIVE CLINICAL TRIALS



RESEARCH PROJECTS BY PRIORITY AREA



HIGHLIGHTS

- The **FDA approved** 5 new disease-modifying treatments for MS, including Vumerity, Bafiertam, Zeposia, Kesimpta and a generic form of Tecfidera
- Positive results were announced from a trial of **oral masitinib** in people with non-active progressive MS
- **Society-funded researchers** found that eliminating a molecule named PAR1 promoted repair of myelin in mice
- Researchers in Germany found more links between the **Epstein-Barr virus and MS**
- Convened experts to develop and publish **recommendations for promoting exercise** and physical activity in people with MS
- The updated **Atlas of MS**, led by the MSIF with funding from the Society and others, revealed there are now 2.8 million people worldwide who have MS, with nearly 1 million of them living in the U.S.
- Studies suggest that **changes in the nervous system** related to MS begin well before there are perceptible symptoms

CHALLENGES

- The pandemic closed many **MS research labs** and paused **clinical trials**, which will delay the completion of many research projects
- 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
- There is a **workforce shortage** of biostatisticians and data scientists in MS

IMPACT SPOTLIGHT:

EXPANDING RESOURCES AND REACH



Lia made Bike MS: Inside Out her own this year.

“I am so proud of all the cyclists, and am especially proud of our Team CYCLESAVAGES. My small team consisted of myself, my husband, my twin, our dogs and a random lady team from Switzerland”

– Lia Oakley, Bike MS: Inside Out participant

COVID-19 forced us to cancel almost every in-person Bike MS event and put vital funds at risk. But with nearly 1 million people living with MS counting on us, we turned Bike MS inside out and created the Society’s first nationwide build-your-own-adventure ride.

Bike MS: Inside Out brought together 40,000 participants and raised nearly \$9 million to support those affected by MS. Participants came together — virtually — and showed the world that while we may not be gathering in person, the Bike MS community has never been stronger, our passion never more evident.

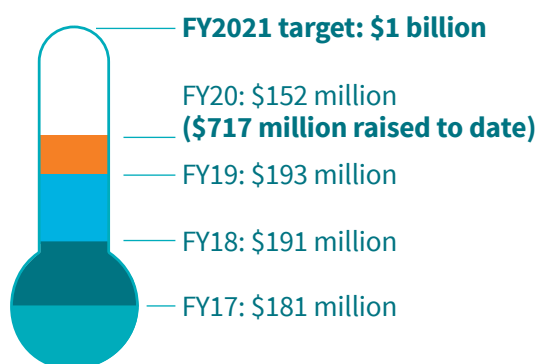
On ride day, participants across the country tuned in to their Fundraising Centers, Facebook and YouTube for a live opening ceremony before climbing into the saddle and setting out on a course and mileage right for them. Cyclists chose to ride inside or outside using two of the leading cycling apps, Zwift and Strava, or scrapped the apps all together and created their own challenge.

Gamified fundraising, leaderboard acknowledgements, unique challenges and scheduled rest stops throughout the day helped cyclists reconnect online and in person. “On our breaks we made coffee!” said Lia Oakley, a Bike MS: Inside Out participant.

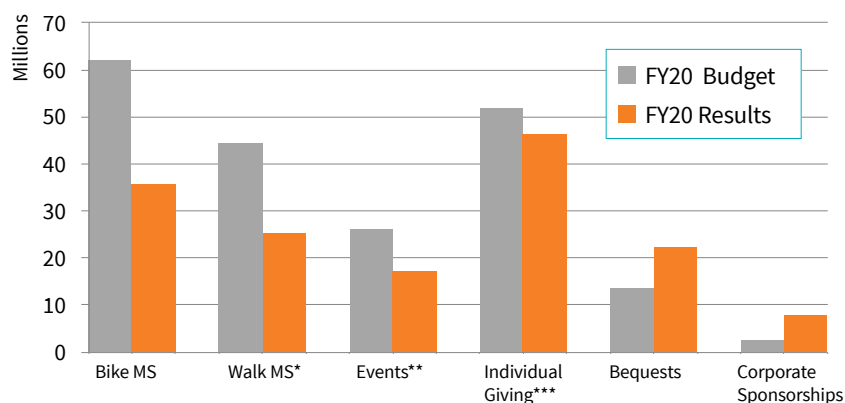
Bike MS may have looked different this year, but the reimagined ride invoked the same camaraderie that has made Bike MS the largest fundraising cycling series in the world.

Expand Resources and Reach

Breakthrough MS Campaign Progress



Year-End Gross Revenue by Sources



* Includes Challenge Walk MS

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

*** Includes Direct Marketing

HIGHLIGHTS

- We secured five **7-figure gifts** by deepening donor relationships
- Designed and launched **Bike MS: Inside Out**, an interactive nationwide experience with new strategic partners, Zwift and Strava. The Bike MS series raised \$35.6 million.
- **Corporate funding** increased 72% over last year. Catapult, an unrestricted campaign, raised \$5.1 million thanks to the generosity of Genentech, Biogen and EMD Serono.
- **Walk MS** raised \$24.1 million and engaged over 80,000 of our most committed participants
- With increased staff focus and enhanced marketing efforts, **planned giving** revenue continues to grow and is forecasted to raise \$22 million, which includes a \$5 million bequest

Corporate Teams

2,491

TEAMS RAISED
\$13.4 MILLION

FY20 target: 2,650 teams,
 \$26.5 million raised

Community Councils

78

IN 32 CHAPTERS

FY20 target: community
 councils in 34 chapters

Engagement

7.4 MILLION

PEOPLE ENGAGE WITH THE SOCIETY

FY20 target: 8 million

Social Media

858,005 FOLLOWERS

FY20 target: 861,000 followers

Facebook Fundraisers

LINKED*

24% **\$8.5 MILLION**

USAGE RAISED

FY20 target: 25% usage, \$20 million raised

NON-LINKED**

\$6.3 MILLION RAISED

FY20 target: \$6.5 million raised

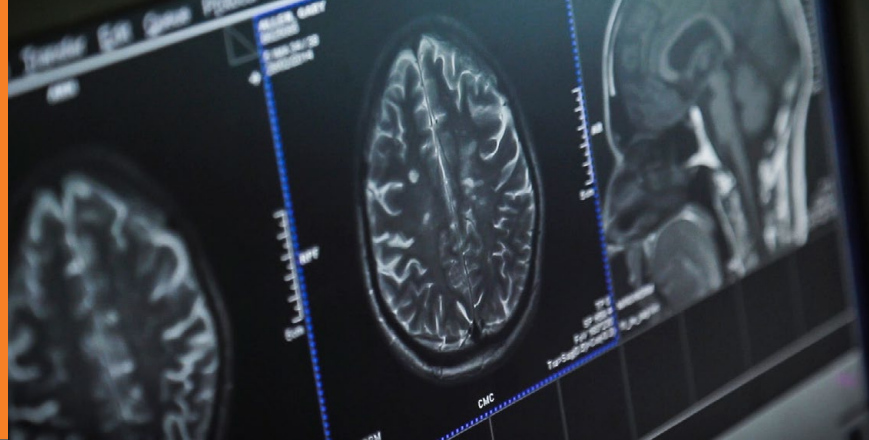
* Linked fundraisers are available to event participants and count toward fundraising totals

** Non-linked fundraisers do not sync with our system and do not count toward fundraising totals

CHALLENGES

- The economic downturn caused by the COVID-19 pandemic and our inability to host **in-person events** will continue to have financial implications

ACCELERATING PROGRESS



DIGITAL AND TECHNOLOGY

- 2,897 members joined the Society Facebook Social Learning Group to make connections and increase their knowledge
- Teamed up with Jon Strum, host of the "**RealTalk MS**" podcast, to bring MS news and information to a larger audience
- Completed the integration of iHealthHome, a software to improve the coordination of case management services



JOSEPH (L), DIAGNOSED IN 2008

AWARENESS

- The **Society website** continues to be a source for timely and reliable information on COVID-19
- Connected with our community through social media and hosted livestreams for events and programs that shifted to a virtual format
- Leveraged Giving Tuesday Now and monthly Facebook fundraisers to engage new donors and drive revenue

STRATEGIC PARTNERSHIPS

- Launched the Corporate Pharmaceutical Roundtable, bringing together our corporate pharmaceutical partners to work collaboratively, provide feedback and contribute to actionable outcomes. Members are listed **here**.
- Partnered with the Consortium of MS Centers (CMSC) and the MS Society of Canada to create the COViMS registry, which collects outcomes for people with MS who developed COVID-19
- Through our Fast Forward program, we invested in new biomarker studies to speed the testing of new MS therapies
- Hosted webinars for professionals and people affected by MS with organizations such as the MS Coalition, CMSC, CanDoMS and the Veterans Administration

INNOVATION AND IMPROVEMENT

- Increased engagement with the Hispanic/Latino community by launching a Spanish version of Ask the MS Expert and translating 5 publications into Spanish
- Launched a Society-wide innovation challenge and implemented the top themes aimed at reducing Society expenses and increasing revenue

VOLUNTEER ENGAGEMENT

- Engaged over 3,000 healthcare providers in educational webinars on COVID-19, cultural competency, and a variety of other topics
- 3,500 activists engaged in two or more advocacy alerts, generating more than 6,000 connections to lawmakers
- Supported over 1,000 groups, 1,461 leaders and 100 MS Friends through focused relationship management, weekly drop-in calls, training, outreach and education
- Over 400 volunteers held a record 190 virtual meetings with Congressional offices this summer
- Engaged 112 expert peer reviewers to evaluate 566 research grants, fellowships, pilot grants and strategic initiative proposals

2020 NATIONAL BOARD OF DIRECTORS



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DIAGNOSED
IN 2010

OFFICERS

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Nannette L. Reid — U.S. Bank
Portland, OR

Elizabeth “Liz” Rodriguez —
Senior Project Manager, JLL’s Project and Development Series
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and Insurance Services, Inc.
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Malcolm P. Wattman, Esq. — Retired Partner, New York
City Law Firm of Cadwalader, Wickersham & Taft, LLP
Palm Beach Gardens, FL

Mitzi Williams — Neurologist — Founder and CEO,
Joi Life Wellness Group
Newman, GA

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BREAKTHROUGH

MS[®]

A woman with long braided hair, wearing a black headband, a black choker, and boxing gloves, is shown from the waist up. She is wearing a dark grey long-sleeved shirt and black pants. She has a determined expression and is looking directly at the camera. The background is white with a blue and orange diagonal graphic element at the bottom right.

WHATEVER IT TAKES.

- Receive support to navigate the challenges of MS by calling **1-800-344-4867**
- Learn more about MS and the many ways we address it with regular visits to **nationalMSSociety.org**
- Become a research champion at **nationalMSSociety.org/research**
- Make a donation of any size — in cash, by check or at **nationalMSSociety.org/donate**
- Get the Society's email newsletter to keep up with breaking news, research developments, and available resources and services at **nationalMSSociety.org/signup**
- Meet others in the movement on **Facebook, Twitter** or **Instagram**
- Participate in a **Walk MS[®], Bike MS[®], Challenge Walk MS[®], Climb to the Top MS, Do It Yourself Fundraising MS, Stream to End MS** event, and ask everyone you know for donations
- Apply for upcoming and ongoing volunteer opportunities at **nationalMSSociety.org/volunteer**
- Be part of the MS Activist Network to start receiving updates and Action Alerts at **nationalMSSociety.org/MSactivist**
- Remember the Society in your will or estate plan; call Individual Giving at **1-800-923-7727** to learn how
- Correspond with President and CEO Cyndi Zagieboylo at **cyndi@nmss.org**

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