



National Multiple Sclerosis Society

2021 ANNUAL PROGRESS REPORT

OURVISION

A world free of MS.

OUR MISSION

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



National Multiple Sclerosis Society

Photos, front cover — left to right, top to bottom: Emma (left), diagnosed in 2018; Peter, diagnosed in 2015; Donna, diagnosed in 1989; Joshua, diagnosed in 2015; Hannah, diagnosed in 2017; Ellecia, diagnosed in 2011; Cermit, diagnosed in 1998; Doug, diagnosed in 2014; Crystal (center), diagnosed in 2010; Samir, diagnosed in 2005; Mike, diagnosed in 1983; Anqunette, diagnosed in 2013.

ABOUT MULTIPLE SCLEROSIS

Multiple sclerosis is an unpredictable disease of the central nervous system. Currently there is no cure. Symptoms vary from person to person and may include disabling fatigue, mobility challenges, cognitive changes, and vision issues. An estimated 1 million people live with MS in the United States. Early diagnosis and treatment are critical to minimize disability. Significant progress is being made to achieve a world free of MS.

ABOUT THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

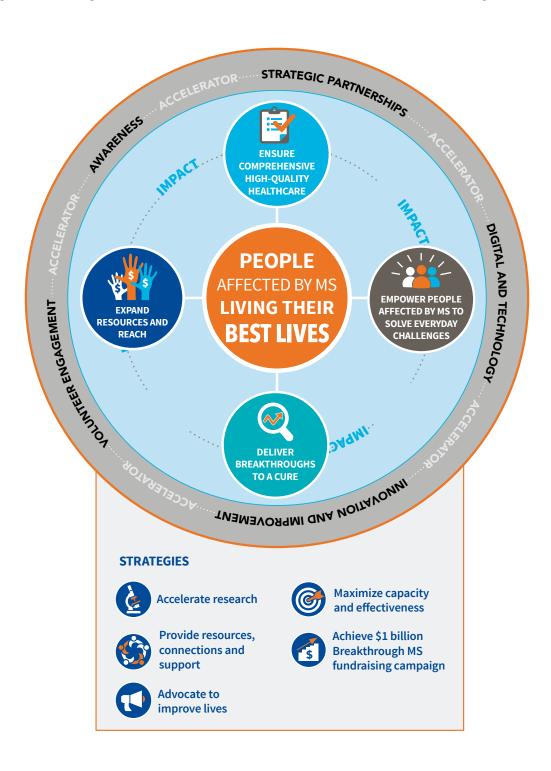
The National MS Society, founded in 1946, is the global leader of a growing movement dedicated to creating a world free of MS. The Society funds cutting-edge research for a cure, drives change through advocacy and provides programs and services to help people affected by MS live their best lives. Connect to learn more and get involved: **nationalMSsociety.org**, **Facebook**, **Twitter**, **Instagram**, **LinkedIn**, **YouTube** or 1-800-344-4867.



National Multiple Sclerosis Society

OUR FY2019–2021 STRATEGIC PLAN

Our integrated strategic plan establishes a roadmap for our movement through 2021.



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 highquality, 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

Dear Supporter of the National MS Society,

Seventy-five years ago, Sylvia Lawry, working to find solutions for her brother, Bernard, gathered 20 of the nation's most prominent research scientists and founded what would become the National Multiple Sclerosis Society. Since then, we have steadily built on her example, relentlessly pursuing — and achieving — life-changing results. Our commitment has never been more evident than in these years of global pandemic. Our mission remains clear: **We will cure MS while empowering people affected by MS to live their best lives.**

In 2021 we were persistent in pursuit of our goals. With in-person fundraising only intermittently possible, we honed our expertise in virtual fundraising. We innovated and adapted to the world around us. And remarkably, we raised \$144 million — exceeding our revenue budget by \$10 million.

And we marshaled our resources to improve thousands of lives and make progress toward cures:

- We were the go-to source of information on COVID-19 for the MS community. We gathered experts to make sense of the research and get people answers so they could take action. We provided timely and reliable updates on our website, established guidelines for healthcare providers and people with MS, and reached out through channels like RealTalk MS, Facebook and Ask an MS Expert, in English and Spanish.
- We mobilized MS organizations, scientists, donors and people living with MS across the world and issued the Pathways to Cures scientific roadmap. Through this collaboration, we are pursuing the most promising research pathways and closing in faster on a cure.
- We held our second Black MS Experience Summit, bringing together 800 people, 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 the results far exceeded our expectations. A record 888 people sent 2,442 emails to members of Congress and held over 266 virtual meetings. 106 of the bills we supported became law. With over 34,300 MS Activists working on behalf of people with MS, we continue to be an advocacy leader on the Hill and throughout the country.
- MS Navigator® services, including case management, increased their capacity to assist people with rent, mortgage, utilities, home modifications, mental health, respite care and other critical needs.

For more highlights, read our **FY 2019-2021 Strategic Plan Progress Report**. As we launch our **FY 2022-2024 Strategic Plan**, we are pleased to share that we are on track to meet our goal of raising \$200 million in 2024.

In our 75th year, we are making a bigger impact than ever on the lives of people affected by MS, and we have never been closer to a cure. We could not do it without you. Thank you for your support of the National Multiple Sclerosis Society.

Sincerely,

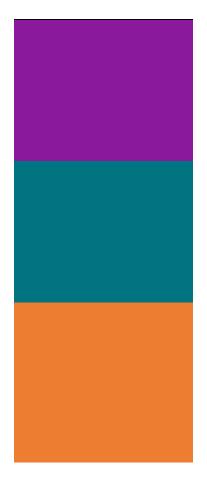
Cyndi Zagieboylo President and CEO







INCOME



Total Revenue: \$173,365,883

Operating Revenue: \$148,564,354

Revenue from Non-Operations: \$12,011,712

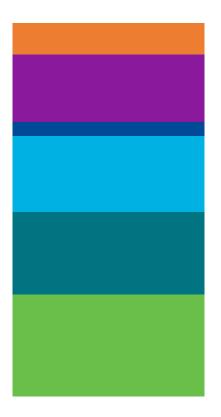
Investment Return: \$12,730,051

■ Other Revenue: \$59,766

Total Net Assets: \$134,223,635



EXPENSES



Total Expenses: \$142,184,098

Client & Community Services: \$38,651,674

■ Public Education: \$31,593,883

Research: \$28,798,792

■ Professional Education & Training: \$5,349,472

■ Fundraising: \$25,819,993

Management & General: \$11,970,284

FY2021 STRATEGIC PLAN PROGRESS REPORT



Ensure Comprehensive, High-Quality Healthcare

ADVOCACY PROGRESS

34,317 **MS Activists**

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

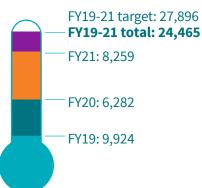
plan to change practice or behavior (target: 75%)

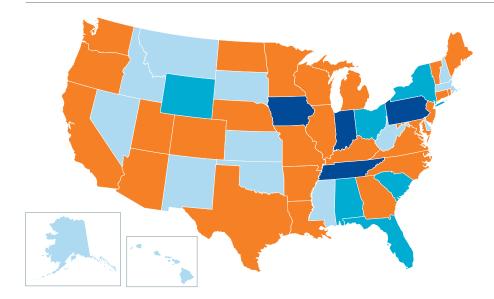
report improved attitudes about MS care (target: 82%)

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



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 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 preexisting 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, mortgages, utilities, home modifications, mental healthcare, 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 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."

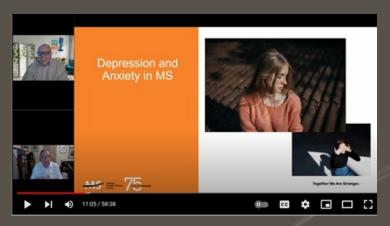
— MS Navigator recipient



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 break down 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.

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."

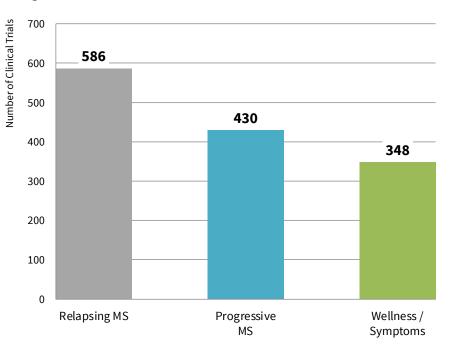
"Thank you for making me feel more comfortable to reach out to my [primary care physician] and [neurologist] about how I am feeling mentally."

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



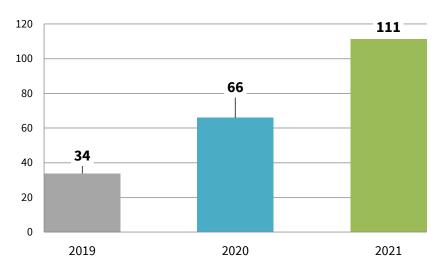
Deliver Breakthroughs to a Cure

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:

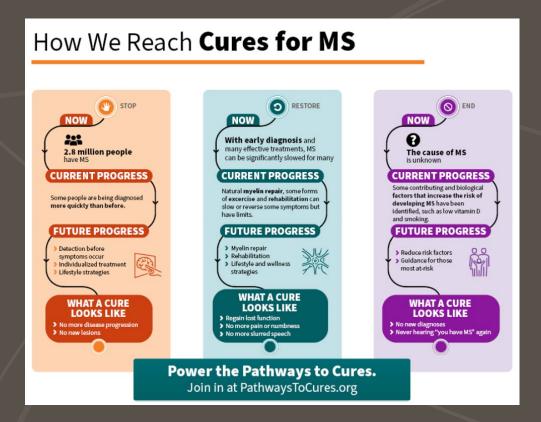
PATHWAYS TO CURES

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.



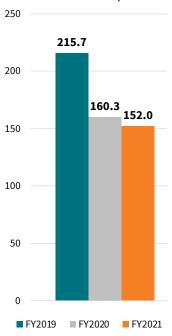
"The National MS Society is providing global leadership to set a path forward that can, with effective international collaboration and innovation in MS research, accelerate progress and ultimately achieve cures in MS."

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.

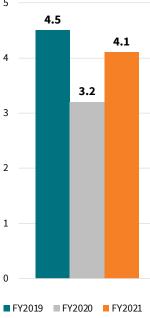
The changes to plans and ways of fundraising were swift, to meet urgent needs of the MS community in this time of crisis. A COVID-19 Response Fund was launched with a lead gift of \$4 million.

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) 4.5



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.

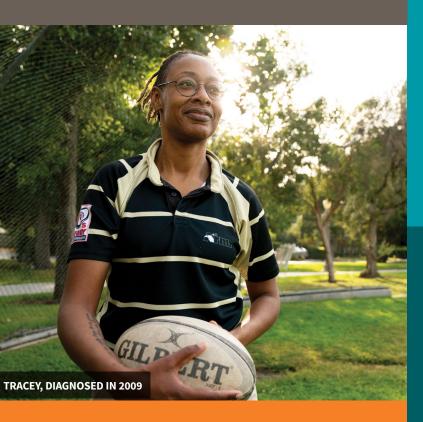
CHALLENGES

 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



AWARENESS

- New mission statement: We will cure MS while empowering people affected by MS to live their best lives.
- The Society became 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).



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

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 its first 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



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



- Find Doctors & Resources online tool launches offering 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.



- **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 launch online offering timely, accessible and relevant forums for 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



- 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 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

Photos, top to bottom: Angela, MS Navigator; Joshua (center), diagnosed in 2015; Brian, diagnosed in 2012; Michelle, diagnosed in 2001; MS researcher.



OFFICERS

Chair: Richard Knutson

President and CEO: Cyndi Zagieboylo

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Treasurer: Peter Porrino

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National Multiple Sclerosis Society

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