

FY22 IMPACT REPORT

FY2022–2024 Strategic Plan



**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.



**National
Multiple Sclerosis
Society**

A Letter from Your President & CEO

As I reflect on the past year, there is so much to be proud of, but perhaps nothing more so than the perseverance, creativity and dedication of each member of our movement. Through the ups and downs of the past few years, you have found new ways to connect, to fundraise, to advocate, to give. You have shown up again and again to fuel our mission. And it has paid off!

After years of MS activists' efforts, landmark drug pricing legislation — the Inflation Reduction Act of 2022 — was signed into law on August 16. This legislation will help bring down the cost of medications for people enrolled in Medicare, including many living with MS, and it extends the insurance premium subsidies for those who purchase coverage through the marketplace. This win will result in thousands of people being able to afford their MS medication and the high-quality MS healthcare they need to live their best lives.

The world has rallied around the Pathways to MS Cures Roadmap — a global collaboration focused on the most promising research to cure MS for every person with the disease — which was published in the Multiple Sclerosis Journal in March. An initiative of this scale requires leadership and persistence and wouldn't be possible without the support of our Pathways to Cures Lead Investors who have collectively contributed \$17.6 million to bring this roadmap to the world and inspire action.

We hosted a Black MS Experience Summit in June, and our first bilingual Hispanic/Latinx MS Experience Summit in September, helping more people connect with one another and feel at home and supported by their National MS Society, expanding the MS movement and correcting false narratives about who gets MS.

We learned more about our community and what you need and want from the Society. Our survey and focus group research informed our plans for a comprehensive digital ecosystem. We are developing more and better ways to deliver relevant content and personalized experiences to empower people affected by MS to get what they need when they need it and to engage everyone who wants to join the movement or advance work toward cures.

We continue to learn and grow as the world around us changes. We've embraced new ways of doing our work, of connecting with one another, of accelerating progress. We've expanded the MS movement through new digital opportunities — and coming back together in-person where we can, which feels so good. We are making strides to be the inclusive organization we need to be for everyone affected by MS. All while staying focused on our mission to cure MS and empower people affected by MS to live their best lives.

Please read and experience the great progress described in this report. You will see your contributions reflected and I hope that you will feel the same sense of pride and hope that I feel. We are changing the world for people affected by MS, and this incredible progress wouldn't be possible without you. Thank you.

Yours truly,



Cyndi Zagieboylo



FY2022–2024 Strategic Plan

Diversity, Equity and Inclusion

The National Multiple Sclerosis Society is a movement by and for all people affected by MS.

Our voices and actions reflect diversity, equity, and inclusion.

We welcome and value diverse perspectives.

We actively seek out and embrace differences.

We want everyone to feel respected and be empowered to bring their whole selves to ensure we make the best decisions to achieve our mission.

Cultural Values

- Act with urgency to solve the challenges of people affected by MS
- Leverage our influence to provide collaborative, inspirational and intentional leadership
- Prioritize diversity, equity and inclusion
- Innovate and continuously learn
- Deploy resources to their greatest potential with integrity and accountability



Photos left to right, top to bottom: Damian, diagnosed in 2015; Sheel, diagnosed in 2014; Stephanie, diagnosed in 2004; Emma (L), diagnosed in 2018; Joseph, diagnosed in 2008; Jovany, diagnosed in 2016.

FY2022–2024 Strategic Plan

This integrated plan guides the impact we will achieve through 2024. It addresses the unique experiences of all people affected by MS and our role in reaching that future, while highlighting our firmly held belief—**together we are stronger.**



Strategic Plan Impacts

Impacts describe what the world will be like for people with MS in 2024. The four impact areas are displayed in a circular pattern as each is important and all are interconnected.



Improve access to personalized, affordable, high-quality MS healthcare

Comprehensive, personalized healthcare and MS medications will be easy to access and affordable.

How we will measure success:

- It will take less time to confirm an MS diagnosis
- There will be increased access to personalized, affordable, high-quality healthcare and MS medications
- There will be less disparity in treatment among ethnically diverse, low socioeconomic, and rural populations
- Legislation and health policy aligned with our Access to High Quality Healthcare Principles will advance
- Personalized, evidence-based treatment plans will be developed through shared decision-making and should include a disease modifying therapy, wellness strategies and lifestyle approaches



Empower people affected by MS to solve everyday challenges

People will be informed, connected and supported by loved ones, their communities, their healthcare providers and the Society so they can live their best lives.

How we will measure success:

- More people affected by MS and more healthcare providers will recognize the Society as an essential, trusted partner and source of support
- People with MS and their loved ones will be better connected to information, education, resources and communities of support, resulting in improved quality of life, increased confidence, new connections and positive actions taken
- Newly diagnosed, young, rural and ethnically diverse people affected by MS will connect with the Society
- We will solve MS challenges for more people through strategic partnerships



Accelerate cures through global leadership

We will rally the world to relentlessly pursue pathways to cures.

How we will measure success:

- Pathways to Cures will inspire global partnerships
- Research milestones, as described in Pathways to Cures, will be achieved
- People with MS will have fewer relapses, less disease progression and better quality of life
- There will be therapies to rebuild the nervous system and restore lost function
- There will be tools for early detection of MS and treatments for prevention will be under evaluation



Strengthen the MS movement through more and deeper connections

We will have meaningful, enduring relationships, leading to greater purpose, fulfillment and connection.

How we will measure success:

- There will be increased public awareness, trust and confidence in the Society
- We will be better able to predict what people want and need
- More people will be engaged and have meaningful experiences with the Society
- We will expand methods of revenue generation and increase revenue

Empower people affected by MS to solve everyday challenges

No one should face MS alone. The National MS Society is here so that no one has to.

8.2 MILLION 

people engage with the Society

FY22 target: 8.2 million people

60.8% 

556,395 of the estimated 914,000 people with MS in the U.S. are connected to their National MS Society

FY22 target: 61.6%



“Having a new diagnosis of MS was very scary and left me with many questions, even after consulting with my doctors and neurologist. The opportunity to meet with and talk to people just like myself was truly appreciated. The sense fostered by this interaction was that we are all in this together and can become stronger through this new community.”

– Mary Ann Dziak, Program Participant

391,608

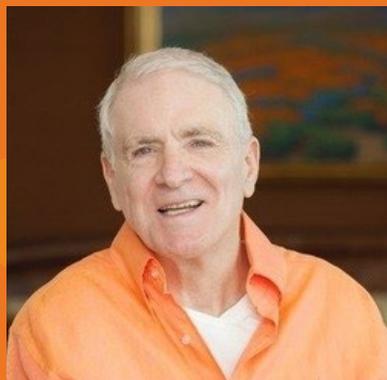
people connected with the Society for the first time

FY22 target: 400,000



23,354 

people who are newly diagnosed connected with the Society



In 2016, Edward M. Dowd helped the Society establish life-changing case management services through the **Edward M. Dowd Personal Advocate program** for those with advanced MS. In light of Mr. Dowd’s recent passing, the Society celebrates his profound legacy of changing lives. Since the program’s inception:

- **3,000+** people were supported across all 50 states and Puerto Rico
- **77%** of identified goals were either fully or partially met
- **89%** had the support needed to cope with their MS
- **86%** were able to take specific actions to help improve their situation

MS is a complex disease that requires many solutions. We help people piece it all together so they can live their best lives.

People who connected to Society resources and support

77% 

feel more confident in addressing challenges of MS

FY22 target: 75%

89% 

made new connections

- 71% to information
- 44% to resources
- 59% to people
- 27% to other sources of support

FY22 target: 80%

77% 

feel the National MS Society is a trusted source of support

FY22 target: 80%



We are proud to sponsor the **RealTalk MS** podcast which celebrated its 5th anniversary. Each week, host Jon Strum takes listeners on a journey and connects those affected by MS to breaking news, information and hot-button

issues. Jon's episodes have been downloaded more than 1.5 million times by listeners in over 100 countries around the world. The **anniversary episode** featured a conversation with CNN's John King.



Terry Brisco came to the National MS Society soon after his diagnosis with relapsing-remitting MS in 2014. "I had no clue what MS was before it hit me," he says now, recalling those early days. "I asked the doctor how long I had to live. I knew that little about it."

A lack of knowledge was not the only obstacle he faced. He had also been forced to retire from his job as a bus driver — it was too dangerous to do with MS — and had maxed out all his credit cards while waiting to get approved for disability. "I really was at my wits' end," he says. "The Society pulled me through."

In addition to providing him with information, the Society helped him financially and connected him with others living with MS. With this support, Terry went back to school to become a professional voice actor.

Since beginning his new career in May 2021, he's already voiced commercials, video games, audiobooks, audio dramas, podcast intros and a web series. Eager to give back to the Society, Terry reached out to volunteer his voiceover talent and has since lent his voice to the Pathways to Cures videos.

Donating his talent is only where his generosity began. Terry is now an avid Society volunteer, sharing his inspiring story with others. Since there is no one-size-fits-all approach to MS, Terry feels a duty to contribute his voice to the movement. He shared his unique perspective during the Black MS Experience Summit and has provided invaluable mentorship to those who need it most.

Most of all, Terry wants others to know that it's possible to overcome whatever challenges come along. While life changes may occur, positive things can come from them — he's living proof!

Improve access to personalized, affordable, high-quality MS healthcare

The Society protects and expands access to personalized, affordable, high-quality healthcare.

A **new study** commissioned by the Society showed that for the nearly 1 million people with MS in the U.S., the average total cost of living with MS is **\$88,487** per year. The total estimated cost to the U.S. economy, including government, industry and individuals, is **\$85.4 billion** per year.

The **Inflation Reduction Act of 2022** was signed into law on August 16, helping bring down the cost of medications for people enrolled in Medicare, and is extending the insurance premium subsidies for those who purchase coverage through the marketplace.

Advocating for Healthcare

Over the last 30 years, disease-modifying therapies (DMTs) have transformed the lives of people with multiple sclerosis. However, rising medication prices have posed significant challenges for those who need these medications to maintain their health — something Steffany Stern, Vice President of Advocacy at the National MS Society, understands personally.

“I joined the Society as a staff member seven years ago but have been part of the MS community since I was a year old when my mom, Joan, was diagnosed with MS,” she shares.

For years, the National MS Society and its MS activists, including Stern, have worked to address the rising cost of MS medications. Stern shared her family’s story with the U.S. Senate Finance Committee.

“While we now have effective treatments, people like my parents struggle with their price. My parents moved to a smaller house, replaced their cars with less expensive options and cut every possible corner to make ends meet. My dad is 69 years old with his own health challenges and had to get a job driving a city bus just to pay the bills,” she shared during her testimony.

“The first medication my mom took in the mid-1990s was priced at \$11,000. Today, the price of the same DMT is more than \$111,000.”

The stories of families like Stern’s echoed in the chambers of Congress until August 2022, when the MS community celebrated a milestone advocacy victory with the passage of the Inflation Reduction Act. The new law incorporated many of the Society’s core priorities for tackling the high burden of drug prices for people with MS who are on Medicare.

While there is more work to be done, the passage of the Inflation Reduction Act marks an important turning point in addressing the cost of MS medications.



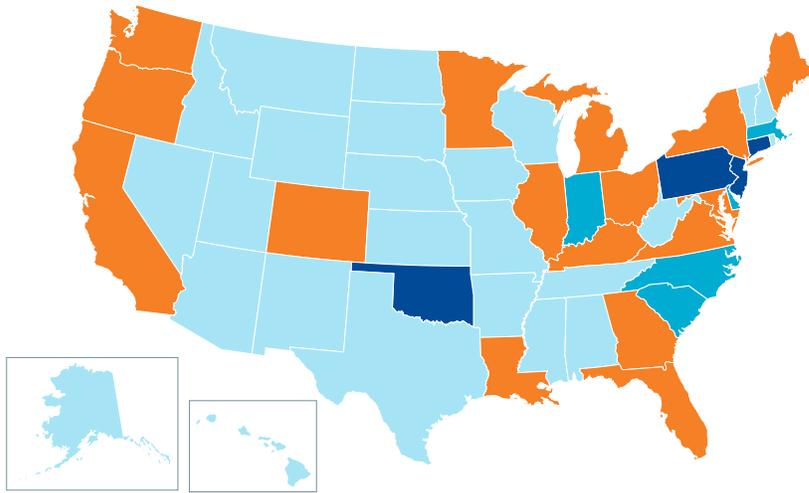
“My mom is one of the 85% of people with MS across the United States who want the federal government to do more to control the high cost of MS medications. The current system does not work in the best interest for people with MS and other chronic health conditions, and the status quo is not sustainable. Medications cannot change the lives of people who need them if they cannot access them.”

– **Steffany Stern, testimony at the U.S. Senate Finance Committee**

MS activists speak with one clear voice to advance federal, state and community policies and programs that benefit people with MS and their families.

We weighed in on **97** issues at the state level related to access to care, **35** of which became law — this included:

- **65** pieces of MS activist testimony
- **112** pieces of staff testimony
- **204** committee hearings

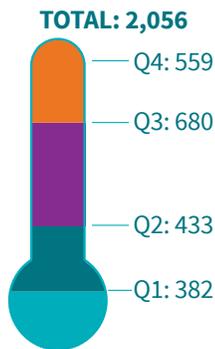


FY22 State Progress on Access to Care Legislation

- Bills we supported became law (total = 35)
- Bills we supported passed by a chamber of the state legislature (House or Senate) (total = 95)
- Bills we supported passed by a committee (total = 186)
- No advancement

Finding the best MS healthcare provider for you should be the least of your MS worries. The National MS Society eases the search by training MS specialists, forging partners in MS care, and connecting people with healthcare providers.

Referrals to MS Navigator
from healthcare providers



565

clinicians in the Society's **Partners in MS Care** network provided care to **103,360** people living with MS, **1,435** of whom were newly diagnosed

154

clinicians who participated in the **ECHO MS** program provided care for **5,291** people living with MS, **83** of whom were newly diagnosed

409

general neurologists that became newly engaged with the Society in FY22 provided care for more than **17,034** individuals living with MS, **391** of whom were newly diagnosed

ECHO MS increases the capacity of neurologists and other healthcare providers to diagnose and manage MS. The tele-mentoring program establishes a peer-to-peer knowledge sharing network with a goal of improving overall health outcomes for people with MS.

- **84%** of participants say it has increased their ability to diagnose MS in a timely manner
- **98%** say it has increased their knowledge of and about patient resources
- **100%** of participants indicated at least one change they will make in their diagnosis and/or treatment of people with MS



"The ECHO MS program has been an incredible learning experience. The program has made me rethink my approach to diagnosis and therapy and has stimulated me to be more involved in the MS community. I highly recommend the program, especially to general neurologists, to sharpen their skills and be more effective in the care of patients with multiple sclerosis."

– **Michael Morse MD**

Accelerate cures through global leadership

We are bringing the world together to cure MS for every single person—as fast as possible.



The **Pathways to MS Cures Roadmap**, published in the Multiple Sclerosis Journal, establishes the first global MS research agenda. The plan features the most promising areas of research to cure MS. Bold efforts to rally the world around Pathways to Cures are underway:

- **29** endorsements include all leading MS research organizations globally
- Pathways to Cures inspired **11** donors to be Lead Investors, contributing **\$17.6 million**
- **27** new Pathways to Cures Research Grants were launched relevant to the Stop, Restore and End pathways, representing **\$15.9 million** in new multiyear investments



The **International Progressive MS Alliance** published its **global scientific strategy for progressive MS** and released its strategic roadmap focusing on understanding, preventing and reversing progression, speeding and improving clinical trials, improving wellbeing, and enhancing collaboration



BRIAN, DIAGNOSED IN 2012



JOHANIE, DIAGNOSED IN 2015



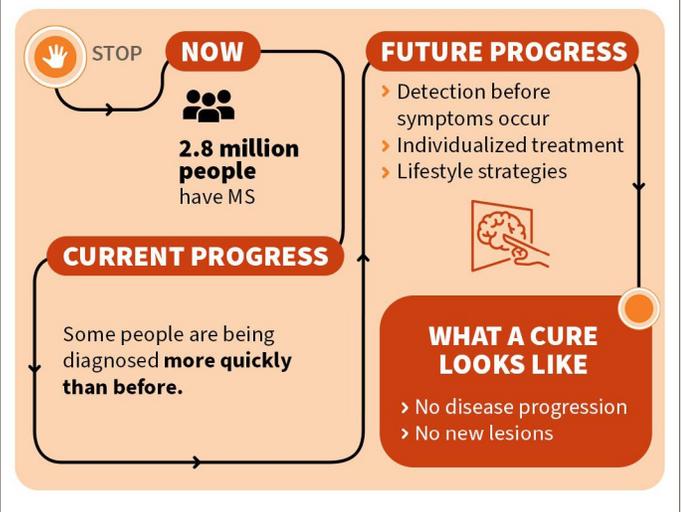
MIKE, DIAGNOSED IN 1983



STOP Pathway

- **International MS Microbiome study** linked gut bacteria to MS susceptibility, severity and treatment in novel study
- A **new study** refuted the once-held belief that MS is a disease of mostly white people
- An international committee **identified knowledge gaps** that, when filled, could improve care and slow the disease in women
- Published research priorities for earlier detection of MS symptoms to decrease time between diagnosis and treatment

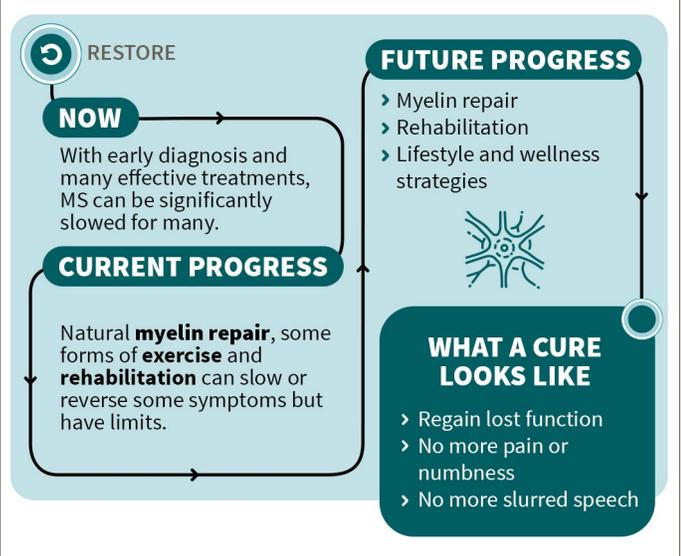
A cure for MS is different for every person. What does it mean to Stop MS?



RESTORE Pathway

- A study testing a computer program was found to **improve information processing speed** in people with MS, and the benefits were maintained six months later
- Launched a targeted commercial research funding opportunity to address therapeutic development opportunities for myelin repair
- At least 10 clinical trials are underway testing myelin repair strategies in people living with MS

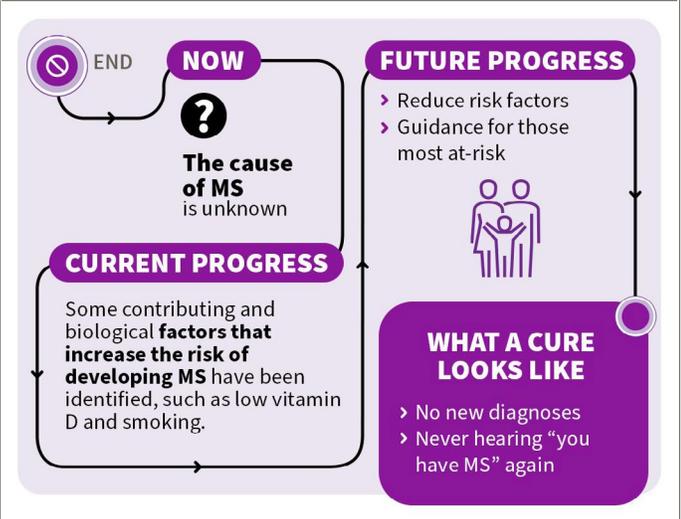
A cure for MS is different for every person. What does it mean to Restore lost function?



END Pathway

- Researchers at Harvard published the strongest evidence yet that the common **Epstein-Barr virus (EBV) can trigger MS** when other risk factors are present
- Researchers supported by a special initiative of the JDRF, Lupus Research Alliance, and the National MS Society, found a **potential mechanism** for how Epstein-Barr virus may trigger immune attacks in MS
- We have begun exploring the feasibility of an MS prevention study

A cure for MS is different for every person. What does it mean to End MS?



The National MS Society advanced the careers of over 1,000 researchers who have been behind nearly every major breakthrough and treatment in MS.



This year alone we launched **28** new research fellows into the MS workforce to pursue critical questions that will lead to advances toward MS cures.

A survey of recent alumni shows:

- **73%** of past postdoctoral fellows are still actively doing MS research
- **95%** of clinician scientist development awardees are still active in MS

What a Cure Means to Me

Just as the experience of living with MS is different for every person, every person's cure for MS may be different. The National Multiple Sclerosis is bringing the world together to cure MS for every single person — as fast as possible.

Learn more at pathwaystocures.org.



"For me, a cure means no more mobility aides."

– Faith, diagnosed in 1999



"A cure would be freeing for me. I would be able to plan for my future again and actually feel optimistic that I can do more to achieve my goals in reasonable amount of time."

– Deej, diagnosed in 2019



"A cure for MS would look like heaven. It would look like more days that I can get out of the bed and not be in pain. It would look like more yeses and less nos. It would look like less apprehension and the ability to just be vulnerable. A cure for MS looks like more spontaneity in my life."

– Kresence, diagnosed in 2016



"A cure for MS would mean that my anxiety is over. And if my MS was cured, I want to know if all of my systems could be repaired through stem cell."

– Kenneth, diagnosed in 2014

Pathways to Cures Lead Investors

The Society is grateful to the following Lead Investors whose extraordinary generosity is helping create the awareness and momentum needed to inspire the world to take action on cures. Lead Investors allow the Society to follow the best science along the most promising pathways to cures and apply funding where and when it's needed to drive discovery, influence the funding of others and forge global collaboration to accelerate progress.

Jim and Kathleen Skinner
Karen Daniels
The Goodyear Family

Laura Larson
Donald C. McGraw Foundation
Bill and Cathy Onufrychuk

Water Cove Charitable Foundation
Anonymous (4)



"A complex disease like MS requires an organization that is in touch with people who have the disease and what they want in their lives — this is apparent in the Pathways to Cures plan. Cures are described clearly, and the discoveries needed to achieve each cure

are laid out. We are pleased to be at the front of this incredible work and have confidence that the National MS Society has what it takes to provide leadership in the global MS movement."

– **Jim and Kathleen Skinner**



"I've always been grateful for the Society's warmth when MS turned my life upside down. Its programs taught me what was going on inside my body, taught me coping skills and connected me with others who had MS. Most of all, it gave me hope that there

WAS a cure, just waiting to be found. The discoveries since my diagnosis nearly 30 years ago have been astounding, and we are very close to unlocking the remaining secrets of MS. I want to help us get there. The reason I donate to the National MS Society is simple ... so one day no one will hear the words my doctor said to me."

– **Laura Larson**



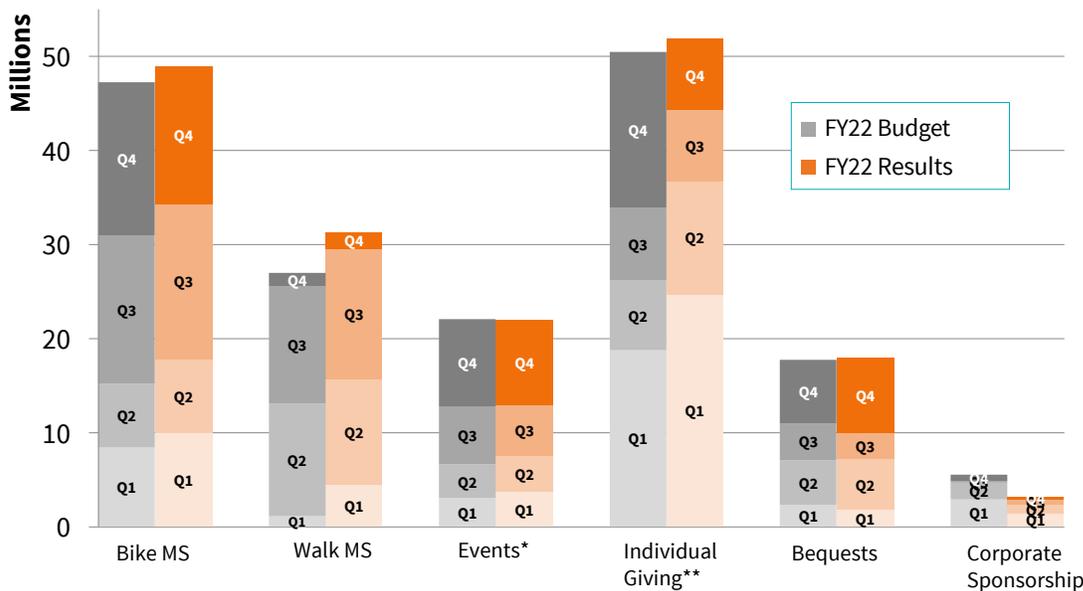
"We have been actively involved with the National MS Society for 28 years and have never been as optimistic about the potential for real progress toward our goal of finding cures for MS. With the advances in science and technology along with the commitment of some of the most noted researchers in the world, NOW is the time to go big so that we can do our part to end MS forever."

– **Bill and Cathy Onufrychuk**

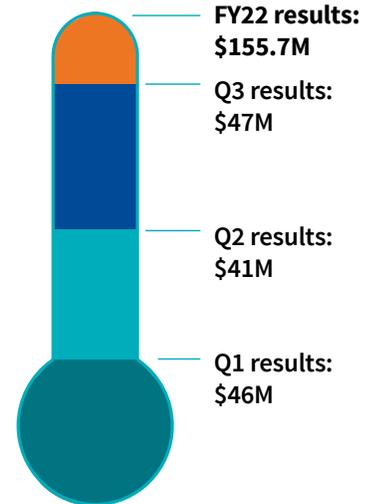
Strengthen the MS movement through more and deeper connections

To reach a world free of MS it will take all of us—our time, our energy, our resources. Together is the only way forward.

Gross Revenue by Sources



FY22 target: \$154M



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

** Includes Direct Marketing

- **234** in-person Walk MS events held across the country from February through June, along with a new virtual ‘Walk MS: Your Way,’ engaged more than **101,400** participants and **6,500** volunteers and raised **\$30 million**
- **57** Bike MS events held across the country from March through September engaged nearly **40,000** cycling participants and raised **\$49 million**. **16** Bike MS events raised **\$1,000,000** or more, and Bike MS remains the largest charity cycling series in the world.
- **60** in-person Leadership Events held across the country raised over **\$14 million** through dinners, luncheons, golf events, cocktail events and more. The Together for a Cure: MS Luncheon launched this year and brought together other former luncheon names under one new brand to create consistency across the country and offer new sponsorship opportunities.
- Over **\$500,000** was secured to advance our health equity efforts through corporate support of the Black MS Experience Summit, the Hispanic/Latinx MS Experience Summit and the New to MS program received **\$150,000** in corporate sponsorship in its first year

KPMG, one of the Society’s largest National Teams, celebrated the firm’s 125th anniversary with a nationwide day of volunteerism. The Society received a grant of \$20,000 from the KPMG Foundation, and hundreds of KPMGers rallied around the Society’s mission by making 1,600 thank you calls, writing hundreds of thank you notes, and creating motivational signs for event participants. The day also featured an impactful mission broadcast featuring Dana Foote, Society National Board Director, and was attended by over 200 people.



This year marked the 15th anniversary of Challenge Walk MS®: Door County — a 50-mile, 3-day endurance event to raise awareness and funds for the National MS Society. For 15 years, every step taken, every connection made, and every dollar raised through this event has moved us closer to a world free of MS and Pat Heller has been there with her husband, Tom, since day one.

Shortly after being diagnosed with MS in 2005, Pat came upon a small ad in the local newspaper promoting the event. Wanting to get involved but realizing she wouldn't be able to walk 50 miles, she and Tom signed up to host a rest stop. At the time, she said "there were at most 50 participants."

Every year since, she has recruited a team that consists of family and friends to facilitate a rest stop – providing donuts, coffee and a sense of community to those participating. Pat and Tom have been paramount in helping to grow the once small event into what it is today, a celebration with more than 150 walkers raising over \$300,000.

"It's given Tom and I our purpose." Pat said, "It is something that we can do together. It's brought our family closer and all of our friends closer. They're excited and happy to be together. It's a reunion every year."

She wants everyone to know that it doesn't take a 50-mile commitment to participate.

"We really want to emphasize that whether you walk a mile or whether you walk 50, it doesn't matter," she says. "It's not a race. It's not about how many miles. It's about coming together as a group of people to support each other."

Throughout the year leading up to the event, Pat fundraises by selling her watercolor paintings, handknit items and greeting cards, both through her website PatriciaHellerDesigns.com, and at local businesses in northeast Wisconsin.

In 2021, Pat and her team hit the remarkable milestone of surpassing \$500,000 in lifetime fundraising. An achievement that didn't signal an end to her efforts, it has only motivated her to reach higher, setting a new lifetime goal of \$1 million.

A former educator, Pat has also found motivation in inspiring young people to get involved. She helps them with fundraising and finding their place in the MS community. Her positive energy, adaptable spirit and creativity serve as a shining example of the difference one can make by strengthening connections through our movement.



"... It's about coming together as a group of people to support each other."

– Pat Heller

YOU MAKE IT ALL POSSIBLE. THANK YOU.



Whether you give, raise funds, volunteer or advocate, you are changing the world for people with MS. This year:

- **706,037 donors** across individuals, corporations and foundations generously contributed **\$155.7 million**
- **381,723 event participants** raised **\$72.5 million** from their networks
- **55,000 volunteers** dedicated their time and talent to deliver hundreds of events, connect people affected by MS to each other, provide relevant information and education to communities, raise awareness and more.
- **41,182 MS activists** sent over **36,000 communications** to legislator offices and held over **320 meetings** with elected officials resulting in the passage of over **35 pieces** of legislation

Photos left to right, top to bottom: Top fundraisers, Climb to the Top MS; Mal and Donna Wattman, donors; Kent Griswold and family, donors; Lisa McRipley, MS activist; Volunteer, Bike MS®; Jennifer Frame, Walk MS® fundraiser; Donald C. McGraw Foundation, donors; Phil Fox, DIY MS fundraiser.



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