



CHLOE
DIAGNOSED
IN 1998

BREAKTHROUGH
MS[®]

2019 ANNUAL
PROGRESS
REPORT



National
Multiple Sclerosis
Society

OUR VISION

A world free of MS.

OUR MISSION

People affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and **end MS forever.**



WESLEY
DIAGNOSED IN
2015

ABOUT MULTIPLE SCLEROSIS

Multiple sclerosis is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Symptoms vary from person to person and range from numbness and tingling, to walking difficulties, fatigue, dizziness, pain, depression, blindness and paralysis. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are leading to better understanding and moving us closer to a world free of MS. Most people with MS are diagnosed between the ages of 20 and 50, with three times more women than men being diagnosed with the disease. A recent study led by the National MS Society estimates that nearly 1 million people are living with MS in the United States; twice as many than previously thought.

ABOUT THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

The Society mobilizes people and resources so that everyone affected by multiple sclerosis can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. Last year, the Society invested \$35 million in MS research with more than 340 active projects around the world. Through its comprehensive nationwide network of services, the Society is focused on helping those affected by MS connect to the people, information and resources needed to live their best lives. We are united in our collective power to do something about MS now and end this disease forever. Learn more at nationalMSSociety.org.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your health care professional and contacting the National MS Society at nationalMSSociety.org or **1-800-344-4867**.



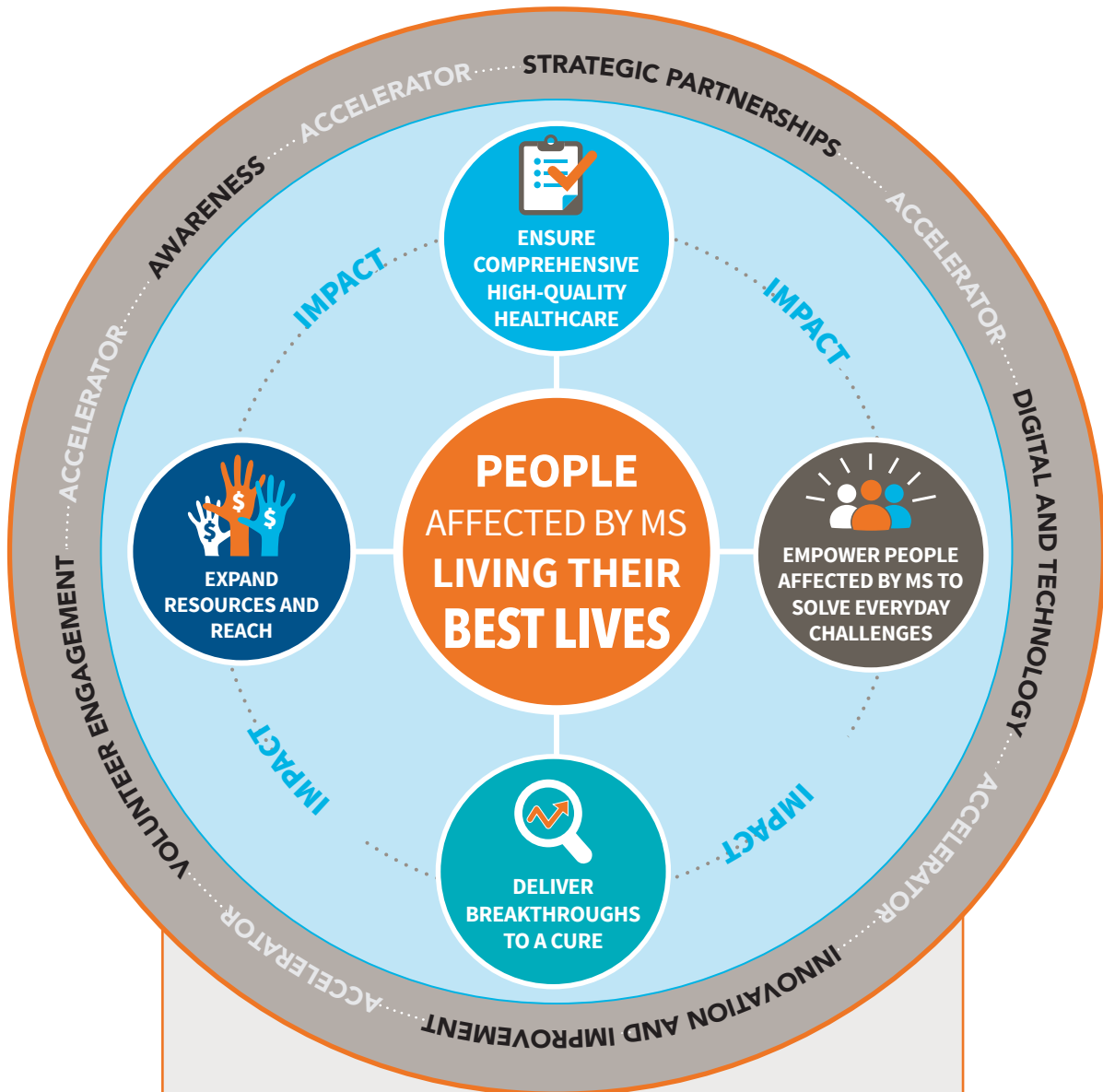
National
Multiple Sclerosis
Society

OUR FY2019-2021 STRATEGIC PLAN



KEVIN
DIAGNOSED IN
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

There were many things that made 2019 a big year for the MS movement, but perhaps none more pivotal than the release of our groundbreaking prevalence study which confirmed there are twice as many people living with MS in the United States than previously thought—**nearly 1 million people**. Our work now matters twice as much.

Now more than ever, it is important to forge connections and bring more people into our movement. This past year, we planned more than 550 fundraising events, which attracted more than 335,000 participants and volunteers. We partnered with RealTalk MS and held our first Facebook Live program during which 42,000 people tuned in to learn about research progress and wellness solutions. Throughout the past year, nearly 60,000 people connected to an MS Navigator and more than 1,000 community leaders facilitated MS self-help groups and wellness classes around the country—connecting 30,000 people and creating welcoming communities where people can live more powerfully, by learning from and being with each other.

While giving each person affected by MS the chance to feel connected and part of a community, we raised our collective voices to shape the decisions that affect everyone touched by this disease. We joined forces with 25 other national voluntary health organizations in supporting a bill to stabilize and strengthen the Affordable Care Act. Since launching our access to medications campaign several years ago, we continue to build our influence as a thought leader on the national stage. We brought our concerns surrounding the urgent need for lower drug prices and greater transparency about all the factors that influence cost and access to quality care before a congressional committee where we put a voice to the struggles of people living with MS.

Our relentless pursuit of a cure continued with urgency and focus. We are gaining global consensus on what it will take to cure MS—because we will get there faster as more people join the MS movement and collectively build pathways to a cure. Our body of knowledge around the precursors to MS is growing at a remarkable rate. We are getting closer to being

able to identify those at risk five to ten years before diagnosis. And if we know all the signposts to look for, that could mean more informed treatment plans, delaying onset of the disease, or even preventing MS altogether.

Through the International Progressive MS Alliance, we continue to galvanize the world to solve the biggest challenges of MS. Seventeen countries strong, we help lead a global effort to develop lifechanging treatments for people with progressive forms of this disease. In 2019, we learned how machine learning and artificial intelligence is being used to evaluate potential treatments, how bioinformatics and cell reprogramming are being used to discover new drugs, about progress being made to identify molecules that may have capacity to repair myelin and protect neurons, and how image analysis is being used to identify patterns across MRIs which could help predict progression and determine the best therapies to stop it.

Our movement must continue to reflect all those who are touched by MS. Diversity must come through in everything we do. Not just because everyone with MS should be able to connect to what they need—but because we will make better decisions, move more quickly and have greater impact, with more diverse perspectives at the table. We need more people in the MS movement—all kinds of people.

Despite all our progress—despite everything we’ve learned—there are 1 million people who wake up every day to the challenges and uncertainty of this disease. Every one of us has the power to achieve breakthroughs, uncover solutions and help create a world free of MS. We’ve never been closer to a cure, or to bringing solutions and treatments to every individual living with MS.

To reach people with MS today and into the future, we must adapt, we must branch out. We can’t do everything the way we’ve always done it—or even the way we’re doing it right now. We must band together and push forward with all our might. Because the future is now.

The next chapter in our story could be the last chapter for MS. We can be the generation that ends the disease and changes life for millions of people affected by MS today.

Together we are stronger.

Yours truly,



Cyndi Zagieboylo
President and Chief Executive Officer

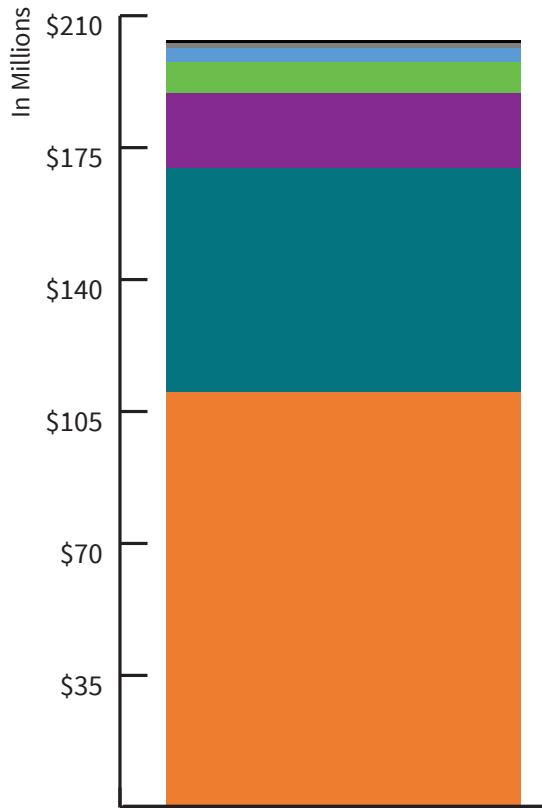


2019 FINANCIALS



ANTONIA
DIAGNOSED IN
2017

INCOME



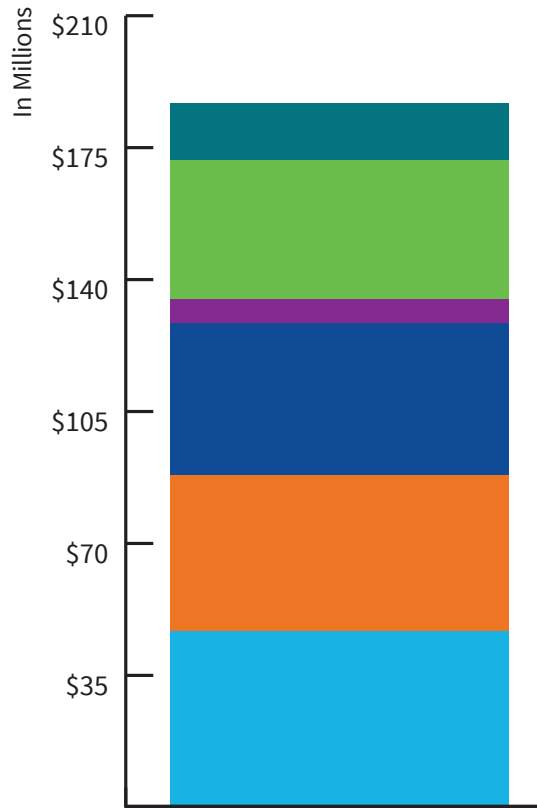
Total Revenue: \$203,488,716

Revenue from Operations: \$202,126,311

- Special Events (net of \$24,091,854 direct benefits to donors): \$109,937,172
- Contributions: \$59,333,163
- Bequests: \$20,261,299
- Contributed Public Service Announcements, Services & Goods: \$8,378,958
- Advertising: \$3,688,091
- Revenue from Non-Operations: \$1,362,405
- Investment Income from Operations: \$219,134

Total Net Assets: \$118,554,707

EXPENSES



Total Expenses: \$186,379,356

- Client & Community Services: \$48,052,857
- Public Education: \$41,601,442
- Research: \$40,897,967
- Professional Education & Training: \$6,326,821
- Fundraising: \$37,038,684
- Management & General: \$15,461,585



**VIEW COMPLETE
FINANCIALS**

FY2019 STRATEGIC PLAN PROGRESS REPORT



SARAH
DIAGNOSED
IN 2012

Ensure Comprehensive High-Quality Healthcare

ADVOCACY PROGRESS

34,155 
Engaged MS Activists

325 
District Activist Leaders

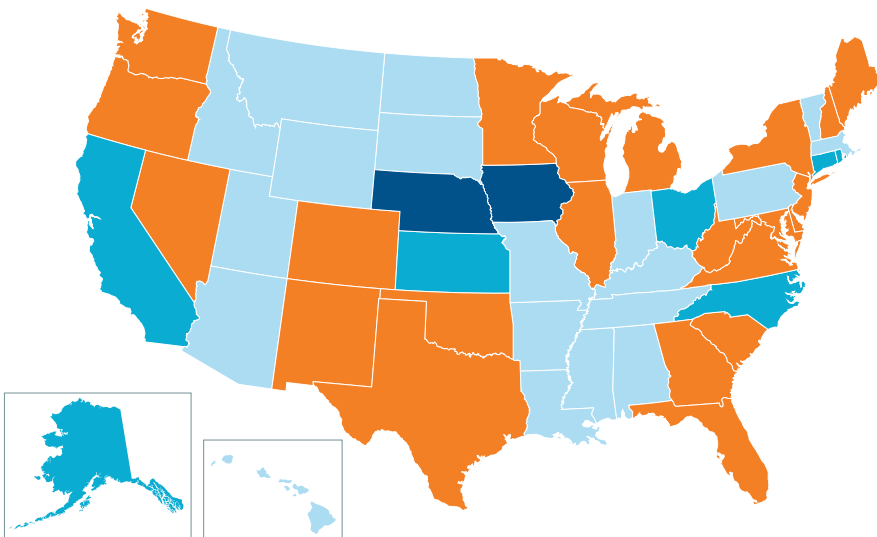
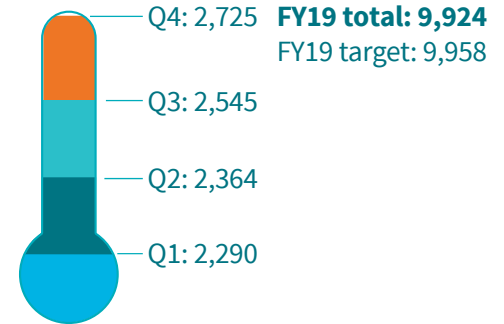
3,845 **HEALTHCARE PROVIDERS** 
PARTICIPATED IN PROFESSIONAL EDUCATION PROGRAMS

79%
plan to implement what they learned (target: 80%)





94%
report increased knowledge about MS care (target: 95%)

88%
report improved attitudes about MS care (target: 85%)

Referrals to the Society
from healthcare providers



STATE PROGRESS

-  Bills we supported became law (total = 52)
-  Bills we supported passed by a chamber of the state legislature (House or Senate) (total = 150)
-  Bills we supported passed by a committee (total = 262)
-  No advancement

HIGHLIGHTS

- The **Lower Health Care Costs Act**, which would end surprise billing and increase transparency and justification around drug price increases, was passed by a Senate committee and is one step closer to becoming law
- The House Energy and Commerce Health Subcommittee passed the **CREATES Act**, which would help remove barriers to generic medications
- Executive Vice President of Advocacy, Bari Talente, testified on **access to medication** before a subcommittee of the House Education and Labor Committee
- 24 medical student mentorships** and **17 clinical fellowships** provided medical students and physicians training on the comprehensive management of MS

CHALLENGES

- Healthcare coverage gained through the **Affordable Care Act** is at risk with the decision regarding its constitutionality in the Fifth Circuit Court of Appeals
- Lack of access to mental health care** for people dealing with the common MS symptoms of depression and anxiety
- The U.S. Department of Health & Human Services is refusing to enforce prohibitions on health insurer practices that result in **higher out-of-pocket costs**

IMPACT SPOTLIGHT:

EMPOWERING PEOPLE TO SOLVE EVERYDAY CHALLENGES

Annie was so grateful for the information and support provided to her by the National Multiple Sclerosis Society's MS Navigator Program when she was diagnosed with MS in 2001, she became a group leader in Burlington, North Carolina, until her husband's illness forced her to quit.

“I would have
been lost without
the Society,”
reflected Annie.
“The Society
has helped me
tremendously.”

When Annie's husband became ill, he lost his job and their health insurance. After he died, she lost his Social Security income. Because he handled all their finances, Annie didn't know where to start and turned to the Society for help.

Vivian, Annie's case manager, helped Annie through a period of incredible change and difficulty by taking things step by step.

Vivian connected Annie to things as simple as a free eye exam and glasses, and as complex as applying for Medicaid, Medicare and food stamps, as well as home healthcare and transportation services. Vivian secured emergency funding for food and other necessities, and helped Annie navigate selling her husband's estate.

“She restored a sense of confidence in me,” Annie said. “I'm very self-sufficient and optimistic, but I needed a little bit of reassurance without asking for it, and she picked up on that.”

Empower People Affected by MS to Solve Everyday Challenges



58.9%

Or 538,000 of the estimated 914,000 of people with MS in the United States are connected to the National MS Society (FY19 target: 59%, 540,000 people)

SERVICES IMPACT

PEOPLE WHO CONNECTED TO SOCIETY SERVICES

79%



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%)

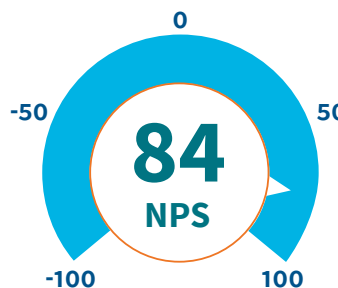
85%



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

- We joined 48 national organizations supporting **caregiving legislation**, which passed the House and authorizes \$200 million in funding over the next five years for the Lifespan Respite Care Program
- **MS Navigators** connected 57,080 people to the information, resources and support needed to move their lives forward
- 28,896 people participated in 378 **Society programs**
- Life-changing **case management** services are now available in all 50 states and the District of Columbia

CHALLENGES

- Long wait periods for government supported **affordable and accessible housing**



The MS Navigator gave me help and emotional support when I was having a very tough time. She helped me get a wheelchair, gave me contacts for other needs and followed up with emails. I honestly don't know what I would have done if not for her and the MS Society."

– MS Navigator services recipient

IMPACT SPOTLIGHT:

LEADING BY EXAMPLE TO ADVANCE RESEARCH



Alessia Tassoni, PhD

“We hope that this project will **promote the discovery of treatments** able to halt or repair visual loss in MS.”

Alessia Tassoni was just finishing high school when her mother began to have trouble seeing. Soon after, Tassoni’s mother was diagnosed with multiple sclerosis. Watching her mother live with MS led to Tassoni’s decision to pursue a career in research.

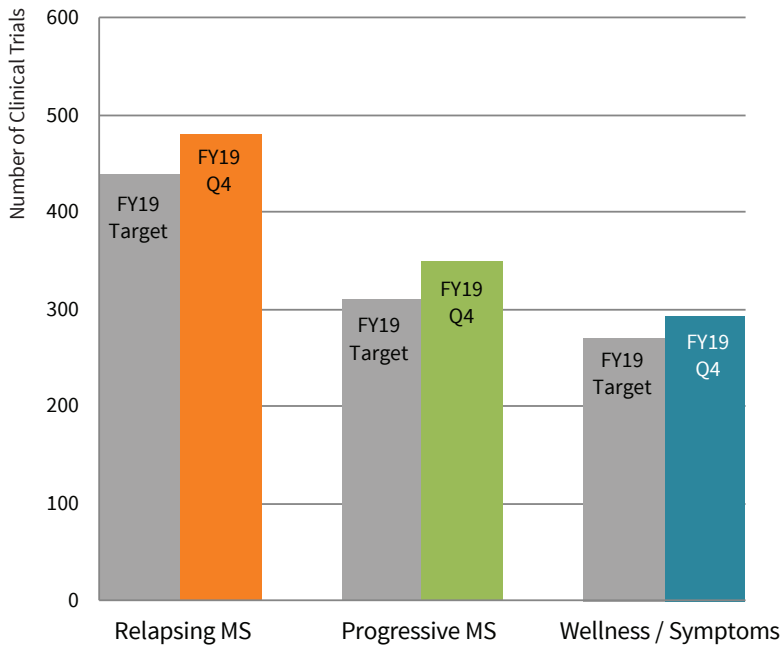
The Society trains and supports researchers and physicians like Tassoni who have completed their doctoral or medical degrees through nine types of research and clinical fellowships. Fellows train with seasoned MS scientists and physicians to gain the skills and training they need to become researchers and deliver breakthroughs to a cure.

Under her Society fellowship at UCLA, Tassoni is using a new technology called Ribo-tag to study specific cells in the optic nerve, which connects the eye to the brain. She’s searching for any molecule in those cells that leads to vision problems.

If Tassoni finds a molecule and other studies confirm this, therapies that target these molecules can be developed and tested in clinical trials to prevent or reverse vision problems.

Deliver Breakthroughs to a Cure

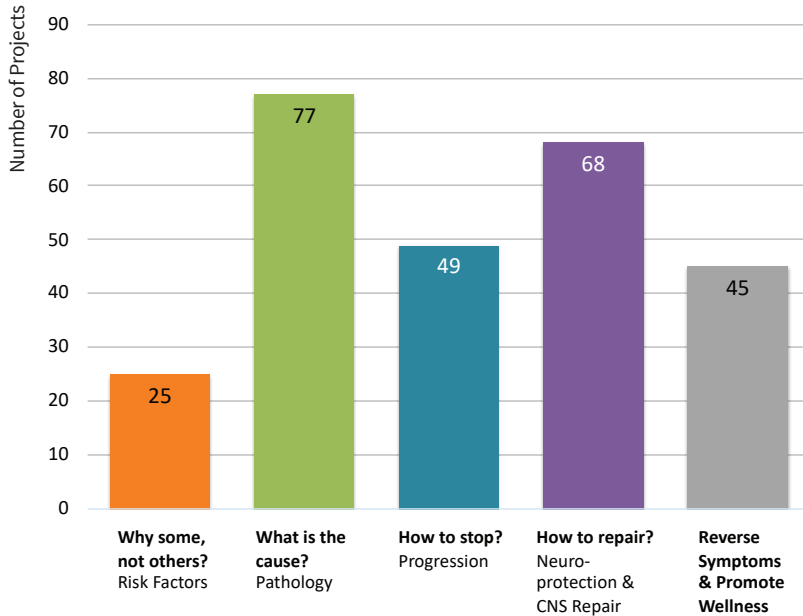
ACTIVE CLINICAL TRIALS



HIGHLIGHTS

- A novel method of estimating the **prevalence of MS** found there are nearly a million people with MS in the U.S. — twice as many as the previous estimate
- New **multi-year commitments** totaling \$38.7 million were made to 123 new research projects, including projects focused on benefits of exercise and cognitive rehabilitation for MS
- With Society funding, the International MS Genetics Consortium **confirmed 233 variations** in the human genome that contribute to the risk of developing MS
- Two new **disease-modifying therapies** (**Mayzent** and **Mavenclad**) were approved and positive results from four clinical trials of potential therapies were announced
- Clinical trials of **cell-based therapies** are testing their potential to protect the nervous system and enhance myelin repair in people with MS
- The **Barancik Prize for Innovation in MS Research** was awarded to Dr. Katerina Akassoglou for discovery of a blood factor that may trigger tissue damage in MS, which she is now translating into possible therapies
- A Society grantee found that a Mediterranean **diet showed improvements** in fatigue and quality of life for people with MS

RESEARCH PROJECTS BY PRIORITY AREA



CHALLENGES

- There is a **workforce shortage** of biostatisticians and data scientists in MS
- Clinical trials continue to have poor **representation of diverse populations**
- 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

IMPACT SPOTLIGHT:

EXPANDING RESOURCES AND REACH



From left to right, Cyndi Zagieboylo, Josh Halpern and Beverley Stafford.

"We are fundraising so others that have the disease are going to live normal lives; we will hopefully find a cure."

\$18,000 its first year at the family's jewelry store.

"Our family is very competitive, we always go full in, put in the extra effort, I would say we're over achievers," says Josh. "We work hard in everything we do. And with this event, it's about how many we can touch."

The Halperns continued to steadily grow the event, but when Society staff informed them the auction was the Society's third largest private event in the entire United States, the family pushed their competitive spirit into overdrive.

Sixteen years later, Albert's MS Auction took place in a 6,500-square-foot exhibit hall, raised over \$350,000 in a single afternoon and became the Society's largest private DIY fundraiser.

"When you see people do good things, you want to be a part of it," says Josh. "We've run into very thoughtful, generous, caring people in this world who want to support our cause and be with us."

With the support from the community and their unrelenting resolve, the Halperns have made an impressive mark on the MS community.

DIY Fundraising MS gives passionate people like the Halpern family opportunities to raise funds for the National MS Society in creative ways.

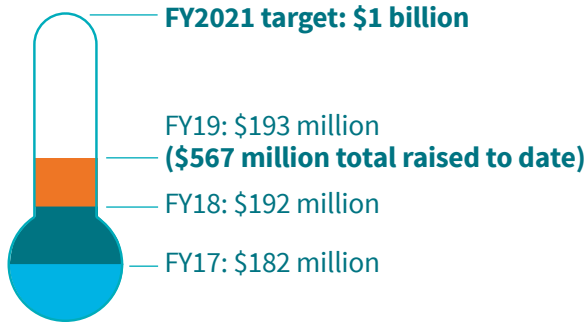
When Josh Halpern's mother, Donna, was diagnosed with MS over 40 years ago, he and his father, Fred, along with the support of staff from their family-owned store, Albert's Diamond Jewelers, decided to take action.

The Halpern family prides themselves on being philanthropic. They give to numerous charities, and have raised funds for Society in several ways, including individual giving and Walk MS. But it wasn't until 2003, when Donna's condition began to worsen, that they decided to increase their efforts by organizing their first DIY fundraiser, Albert's MS Auction.

Complete with great company, auction items and a clear mission to raise money to end MS, the event raised

Expand Resources and Reach

Breakthrough MS Campaign Progress



Walk MS 6+ Teams

10,385

TEAMS RAISED
\$23.9 MILLION

FY19 target: 10,500 teams,
\$24.4 million raised

Bike MS 10+ Teams

1,409

TEAMS RAISED
\$41.6 MILLION

FY19 target: 1,500 teams,
\$42.5 million raised

\$1,000+ Donors

2,799

DONORS RAISED
\$18.4 MILLION

FY19 target: 2,900 donors,
\$17.5 million raised

Community Councils

73

IN 30 CHAPTERS

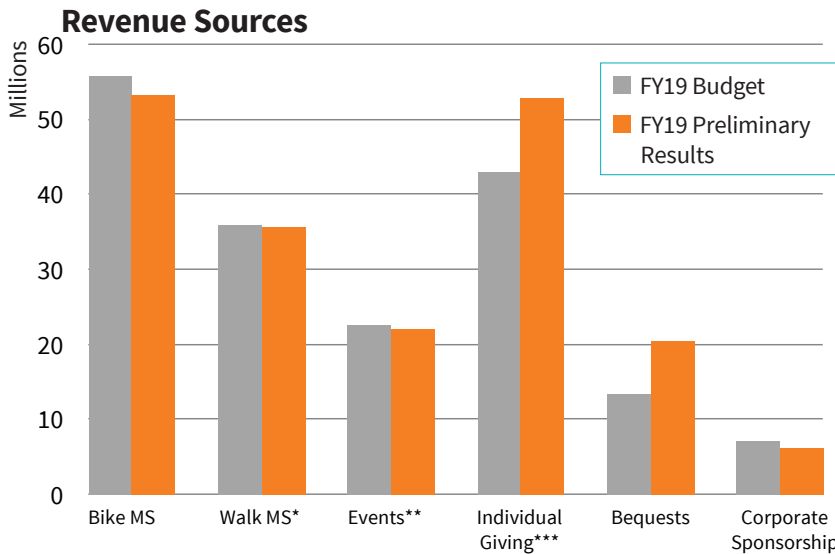
FY19 target: community
councils all 36 chapters

Community Engagement

7.2 MILLION

PEOPLE ENGAGE WITH THE SOCIETY

FY19 target: 7 million



* Includes Challenge Walk MS

** Includes leadership events, MuckFest MS, Finish MS, DIY Fundraising MS and other events

*** Includes Direct Marketing

HIGHLIGHTS

- **Bike MS** remains the number one fundraising cycling event and the sixth largest fundraising event in the U.S.
- We exceeded the **individual giving** budget by deepening donor relationships, including the Hilton family who continue to support the Society, with their total giving exceeding \$25 million
- **Walk MS** and **Challenge Walk MS** achieved budget; reversing a nearly decade-long revenue decline
- **Do It Yourself** fundraisers exceeded budget by more than \$500,000
- We have conducted more than 585 **fundraising events**, engaging more than 333,600 people in the MS movement

CHALLENGES

- The tenure of early career non-profit fundraising staff continues to shrink; staff turnover is costly
- **Changes in tax laws** may impact an individual's giving, creating a possible decline in charitable donations in gifts of \$5,000 and below

ACCELERATING PROGRESS



CARLOS, DIAGNOSED IN 2001

DIGITAL AND TECHNOLOGY

- \$16 million raised through event-related Facebook Fundraisers
- We launched a Find Doctors & Resources tool to provide 24/7 online access to healthcare providers and MS-related resources
- We expanded into the digital program frontier with our first Pathways to a Cure Facebook Live program

STRATEGIC PARTNERSHIPS

- As lead agency for the International Progressive MS Alliance, we ensure a global and strategic focus on identifying treatments for progressive forms of MS
- We signed a memorandum of agreement with the Veterans Administration, formalizing our collaboration on resources for veterans, professional education for providers, and other resources
- We joined 25 other leading national voluntary health organizations in supporting a bill to stabilize and strengthen the Affordable Care Act

INNOVATION AND IMPROVEMENT

- Columbia Business School selected the Society's Innovation Study as a project for their MBA Leadership Program
- We defined innovation and improvement and formed a committee to lead the next phase of this work



HANNAH, DIAGNOSED IN 2017



ELLECIA, DIAGNOSED IN 2011

AWARENESS

- Our campaign to connect to more people living with MS resulted in 13,325 visits to the campaign landing page and almost 2,000 new connections, a conversion rate of over 14%
- Executive Vice President of Advocacy, Bari Talente, and MS Activist, Tod Gervich, were interviewed by NPR about the **cost of MS medications**
- 71% of people who visited our website during MS Awareness Week were first-time visitors
- We created a new belief statement and **video** based on what we've heard from thousands of people affected by MS

VOLUNTEER ENGAGEMENT

- We engaged 80 expert peer reviewers to evaluate 520 research grants, fellowships and pilot grant proposals to help the Society identify the most promising research investments
- We engaged over 50,000 volunteers across the country
- 280 activists held more than 300 Capitol Hill visits during the Public Policy Conference
- Volunteer support group leaders led 1,014 groups, connecting to people with MS across communities

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IN 2010

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BREAKTHROUGH

MS[®]



- 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[®]**, or **Do It Yourself Fundraising 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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