

BREAKTHROUGH ~~MS~~ ^{MS}

**2016 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**

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 at least two to three times more women than men being diagnosed with the disease. MS affects more than 2.3 million worldwide.

ABOUT THE NATIONAL MS SOCIETY

The National Multiple Sclerosis Society mobilizes people and resources so that everyone affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. Last year alone, through our comprehensive nationwide network of services, the Society devoted more than \$100 million to connect approximately 1 million people affected by MS to the connections, information and resources they need. To move closer to a world free of MS, the Society also invested \$42 million to support more than 380 new and ongoing research projects around the world. 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.

OUR FY2016–2018 STRATEGIC PLAN

The FY2016–2018 Strategic Plan establishes a roadmap for our movement through 2018. Each of the three goals has a set of strategies where clear impact is identified.

GOAL 1:

People have effective treatment choices and solutions to the challenges of living with MS.

- **Strategy 1:** Expand investments and worldwide collaboration to accelerate research
- **Strategy 2:** Seize opportunities and build pathways with government, communities, and the private sector so people with MS get what they need
- **Strategy 3:** Influence, lead and collaborate to expand resources to ensure access to healthcare

GOAL 2:

People affected by MS connect to the individuals, information and resources they need to move their lives forward.

- **Strategy 4:** Connect people affected by MS to one another and share life experiences and solutions
- **Strategy 5:** Connect people to information and resources so that they can take fully informed actions

GOAL 3:

Individuals and organizations are mobilized to generate resources that accelerate progress and maximize impact.

- **Strategy 6:** Accelerate revenue growth and increase resources
- **Strategy 7:** Engage each person and organization in the MS movement at their highest level



National
Multiple Sclerosis
Society

We are a movement. United in our collective power to do something about MS now and end this disease forever. In order to change the world, we mobilize all possible human and financial resources to achieve results. Everything we do reflects urgency to find solutions.

We exist because there are people who live with multiple sclerosis, and we want a world free of MS. Sylvia Lawry established the National MS Society 70 years ago to find solutions for her brother, Bernard, who had an aggressive form of MS. As a 26-year-old convener, activist and loving sister, Sylvia brought together people who wanted to do something about MS.

Research to find a cure was the first priority for Sylvia Lawry and the National MS Society, and we continue to build our knowledge, year over year. The Society has played a key role in discovering all of the currently available MS disease-modifying therapies, and there will be more progress in the coming year. The Food and Drug Administration granted Ocrelizumab — the first therapy for people with primary progressive MS — breakthrough designation for priority review by the end of 2016.

The National MS Society funds more research than any private organization in the world. More has been accomplished in the last decade than in the preceding century, but we will not stop until we have solutions for all forms of MS. In an unprecedented global effort to end progressive MS, the **International Progressive MS Alliance** awarded three \$4.7 million Collaborative Network Awards for a total investment of \$14.1 million toward accelerating the pace of progressive MS research. These grants will lead to greater breakthroughs and innovations.

Breakthroughs take place everywhere, every day, not just in research, but also in people's lives. These happen in remarkable ways:

Everyday Matters — the Society's first core wellness program to be rolled out nationwide — helps people find their own resilience and apply it to the challenges and opportunities in their lives. Ninety-five percent of participants in Everyday Matters said that the program prepared them to accomplish goals to live their best lives; 71 percent reported increased happiness with less fatigue, less pain, and better sleep among many other benefits.

Throughout 2016, more than 100,000 **MS activists** helped pass 56 bills in state legislatures — leading to increased MS research, access to quality care, disability rights, long-term services and more. On June 7, 2016, the U.S. Senate protected important, innovative MS research funded by the Congressionally Directed Medical Research Program (CDMRP). This funding was in jeopardy and MS activists rallied when called upon, sending emails and letters and placing many calls to Capitol Hill.

As exciting as this progress is, it's not enough. Not everyone with MS has a treatment that works; in fact, people with progressive forms are still largely without treatments at all. And people need more information and answers about the challenges in their way each and every day. We must do more for each and every person affected by MS. We want every person to experience the breakthroughs they need to move their lives forward — whether it is access to the right treatment, an exercise program that increases energy and mobility or a research discovery leading to new solutions to stop MS.

That's why we are launching **Breakthrough MS®**, a five-year, \$1-billion-dollar campaign that represents our largest and most comprehensive fundraising initiative. We want to ensure breakthroughs occur faster. Whether you walk or ride or volunteer or advocate or give you are vital to our success. With your leadership, determination and passion, we've done so much. And yet together, we must do more. It will take all of us and more to achieve a world free of MS.

Yours truly,



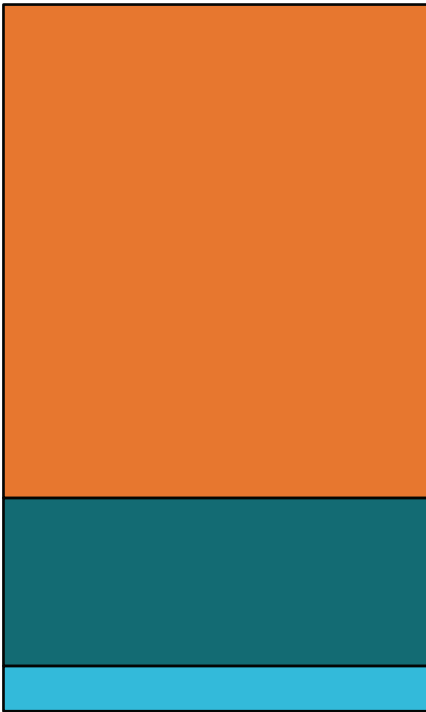
Cyndi Zagieboylo
President & Chief Executive Officer



**LEARN MORE
ABOUT THE
BREAKTHROUGH MS
CAMPAIGN**

2016 FINANCIALS

HOME OFFICE INCOME



Total Income: \$127,576,880

- Contributions from Chapters: \$88,898,564
- Contributions from Members & Others: \$30,157,377
- Interest & Miscellaneous Income: \$8,520,938

Total Net Assets: \$24,028,739



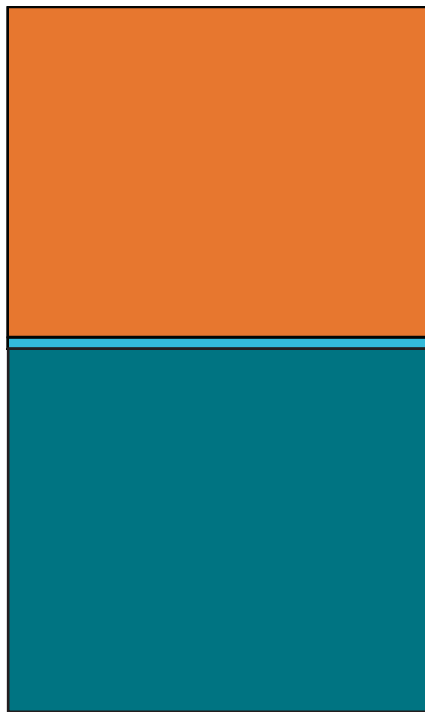
HOME OFFICE EXPENSES



Total Expenses: \$129,951,656

- Research: \$50,949,068
- Public Education: \$19,578,223
- Professional Education & Training: \$2,874,314
- Services to Chapters: \$27,149,840
- Client & Community Services: \$10,990,572
- Management & General: \$11,054,436
- Fundraising: \$7,355,203

HOME OFFICE & LOCAL OFFICES' COMBINED INCOME



Total Income: \$218,779,731

Received Directly:
\$206,041,625

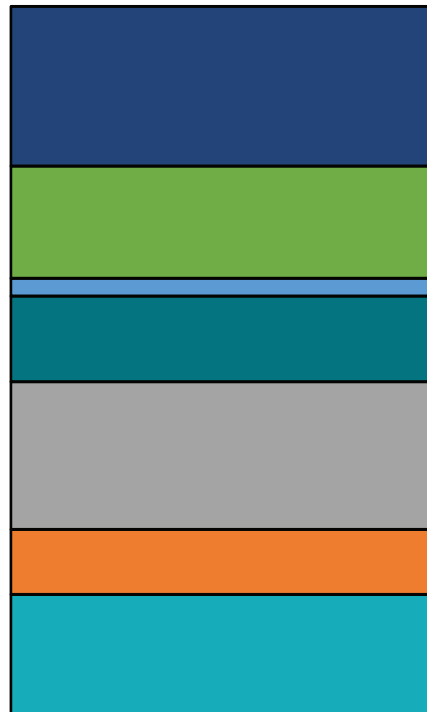
Received Indirectly:
\$440,082

Other:
\$12,298,024

Total Net Assets: \$75,111,119



HOME OFFICE & LOCAL OFFICES' COMBINED EXPENSES



Total Expenses: \$227,148,477

Research:
\$50,949,068

Public Education:
\$35,730,857

Professional Education & Training:
\$6,126,550

Services to Chapters:
\$27,149,840

Client & Community Services:
\$47,801,635

Management & General:
\$20,263,154

Fundraising:
\$39,127,373

GOAL I:

People have effective treatment choices and solutions to the challenges of living with MS

RESEARCH ANSWERS QUESTIONS TO ADDRESS UNMET NEEDS

Achieved through:

- **Investments in MS research**

- FY16 goal target:
 - \$47.7 research projects funding (revised from **total research investment**, which includes all expenses associated with scientific management; **funding for research projects** does not include convening expenses, staffing, travel or other allocated expenses)

- **Clinical trials testing new solutions**

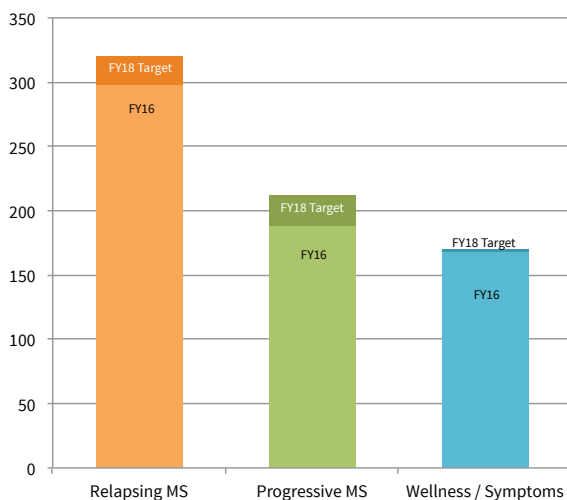
- FY18 plan-end goal target:
 - Increase in clinical trials (over FY15 year-end)
 - » 10% increase in relapsing MS = 320
 - » 20% increase in progressive MS = 212
 - » 10% increase in wellness approaches and symptom management = 170

FY16 PROGRESS

\$42.1 million 
MS RESEARCH PROJECTS FUNDING

Totals throughout the report are unaudited and subject to change

Active Clinical Trials



Pace of relapsing MS & progressive MS clinical trials is slightly lagging for achieving FY18 targets. Wellness / symptoms trials are exceeding pace for FY18 targets.

Highlights & Notations

- \$42.1 million funding 380 research projects. This was intentionally decreased from a budgeted \$47.7 million due to revenue shortfall and includes a \$1.8 million in returned payments from grants that were discontinued from prior fiscal years. Research investment does not include allocated costs estimated in prior reports. These will be allocated in the audit process.
- **International Progressive MS Alliance** awarded \$14.1 million to three new multi-year **Collaborative Network Awards** in a global effort to accelerate new treatments for progressive MS
- Two large clinical trials demonstrated an ability to modify the course of progressive MS: **ocrelizumab** in primary progressive MS and **siponimod** in secondary progressive MS
- Positive results from two studies of **bone marrow-derived stem cells** in people with aggressive, relapsing MS
- The allergy medicine, **clemastine**, showed evidence of stimulating myelin repair in small phase II trial
- Two studies of **dietary approaches for MS symptoms** were launched
- **Patient Centered Outcomes Research Institute committed \$19.6 million** for studies comparing the benefits and risks of MS therapies to help people make informed choices

“ I am thankful for the innovation that has occurred over the last 31 years since I was diagnosed. As a result, I am able to stand up and motor a bit and use a scooter for longer distances ... thank you to the many who are walking, researching, and so much more for those of us with MS. ”

– Stacey Oldham, National MS Society Facebook Page

ADVOCACY RESULTS IN NEW AND EXPANDED RESOURCES

Achieved through:

- **Increased number of engaged activists**
 - FY16 goal targets:
 - Increased number of activists
 - Increased activist engagement
- **Increased engagement with policy decision-makers**
 - FY16 goal targets:
 - 20% increase of District Activist Leaders = 251
- **New and expanded resources**
 - Ongoing goal target:
 - Legislation and regulations adopted at the state and federal level
 - Improvement in 25% of elected official relationships

FY16 PROGRESS



MS ACTIVISTS

133,177

Total Activists
Registered in the MS
Activist Network

5% ↑

36,111

Messages sent to elected
officials to advance federal
and state legislation

185

In-district meetings held
with congressional offices to
discuss legislative priorities

400

Meetings with congressional
offices on Capitol Hill to advance
legislative priorities

103

Committee testimonies
regarding state legislation
delivered by MS activists



DISTRICT ACTIVIST LEADERS

279 TOTAL 70 NEW 34% ↑

U.S. REPRESENTATIVE RELATIONSHIPS

84%

- Average, somewhat strong, or very strong
- **“Very strong relationship”** rating increased from 1% in FY15 to 14% in FY16

U.S. SENATOR RELATIONSHIPS

75%

- Average, somewhat strong, or very strong
- **“Very strong relationship”** rating increased from 0% in FY15 to 10% in FY16

ADVOCACY RESULTS IN NEW AND EXPANDED RESOURCES FY16 PROGRESS (CONTINUED)

Federal Progress

- An initiative launched by the Society to **make MS medications affordable, simple and transparent** is gaining nationwide attention, including coverage by **The New York Times** and **Politico**
- Senate committee unanimously approved the **Advancing Research for Neurological Diseases Act**
- MS activists successfully advocated for the removal of language in the **Senate Defense Authorization bill** that would threaten MS research through the Congressionally Directed Medical Research Program (CDMRP)
- Achieved **one-year delay of harmful Medicare policy**, protecting access to Complex Rehabilitation Technology power accessories

KEY SOCIETY FEDERAL LEGISLATION

Advancing Research for Neurological Diseases Act

32	129	26
NEW CO-SPONSORS	TOTAL HOUSE	TOTAL SENATE

Access to Complex Rehabilitation Technology

32	172	19
NEW CO-SPONSORS	TOTAL HOUSE	TOTAL SENATE

Access to Complex Rehabilitation Technology Accessories

150	144	24
NEW CO-SPONSORS	TOTAL HOUSE	TOTAL SENATE

FEDERAL AGENCY FUNDING

National Institutes of Health (NIH)

- \$2 billion increase
- \$32.1 billion total in FY16

Social Security Administration

(includes timely review, approval and management of disability claims)

- \$350 million increase
- \$12.2 billion total in FY16

Food and Drug Administration

(includes timely review and approval of new therapies)

- \$120 million increase
- \$2.7 billion total in FY16

FEDERAL PROGRAMS

MS Congressionally Directed Medical Research Program (CDMRP)

- \$1 million increase
- \$6 million total in FY16

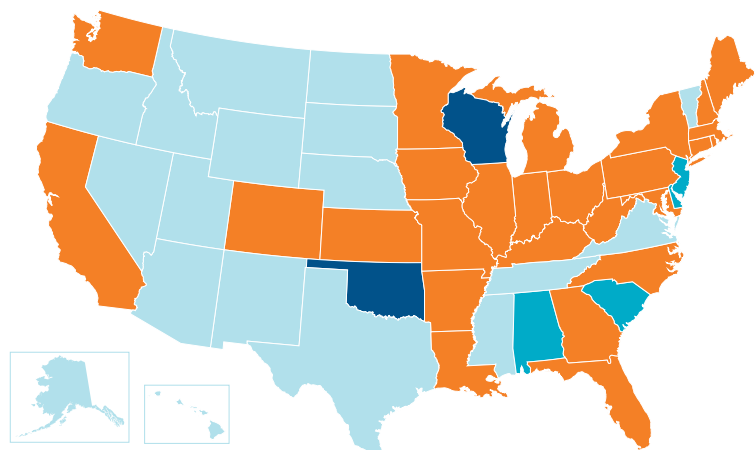
Lifespan Respite Care Program

- \$1 million increase
- \$3.4 million total in FY16

State Progress

Bills supported by the Society in FY16:

- 92 Unified State Policy Agenda bills focused on:
 - Improving healthcare transparency and access: 40
 - Improving insurance network adequacy: 15
 - Medicaid expansion: 16
 - Home modifications assistance: 20
 - Partnerships with state agencies: 1
- 64 other bills



Dark Blue: Bill(s) we supported passed by a committee (Total = 184)

Medium Blue: Bill(s) we supported passed by a chamber of the state legislature (House or Senate) (Total = 118)

Orange: Bill(s) we supported signed into law (Total = 56)

Light Blue: No advancement
Montana, Nevada, North Dakota and Texas legislatures did not meet in 2016

HEALTHCARE MEETS INDIVIDUAL NEEDS

Achieved through:

- **People with healthcare that meets their needs**
 - FY16 goal targets:
 - Institutional Clinician Training Awards and Individual Fellowships expand MS healthcare workforce
 - 10% increase in number of Partners in MS Care = 278

FY16 PROGRESS



5 New physicians received **Individual Fellowships** to specialize in MS care — bringing the total of Society funded MS specialists to 72



11 Centers focused on MS clinical training received **Institutional Clinical Training Awards**

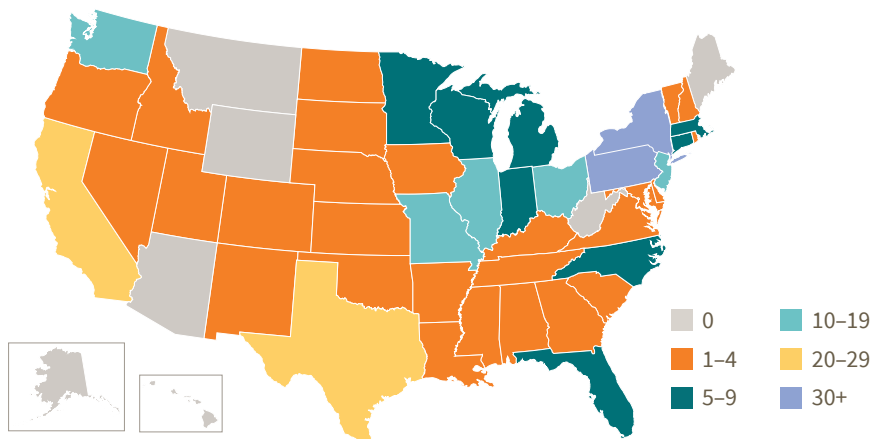


Partners in MS Care

287 TOTAL

35 NEW

13% ↑

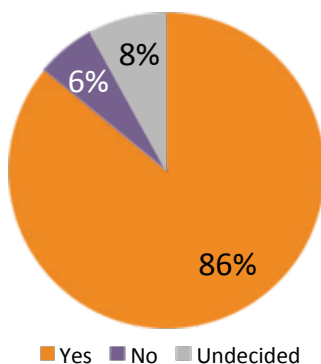


Centers for Comprehensive Care: 126
Neurologic Care: 76

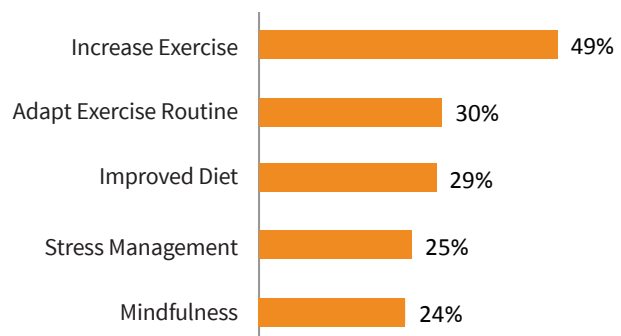
Rehabilitation: 44
Mental Health: 41

Wellness Program Impact

As a result of the program have you changed or do you plan to make any changes in your life?



Top 5 Behavior Changes



Data based on surveys completed by 547 wellness program participants

“ I feel the MS Wellness Program has made a big change in the way I can live with MS. I feel more self confident with what I can do. It keeps me in the best condition I can be in with physical problems due to MS.”

– Wellness Program participant

GOAL II:

People affected by MS connect to the individuals, information and resources they need to move their lives forward

PEOPLE WITH MS ARE CONNECTING EARLIER IN THEIR MS JOURNEY

Achieved through:

- **People newly diagnosed who report knowledge of the Society and connect**
 - Ongoing goal targets:
 - Increase in people newly diagnosed connecting online
 - More people get information they need when they need it through **Knowledge Is Power (KIP)**

“Although our symptoms may differ, your words comforted me in the knowing that I am not alone, not isolated, not left to cope on my own with the struggles that others cannot understand.”
– Gloria, MSconnection.org member

FY16 PROGRESS



Newly Diagnosed MSconnection.org Members

5,619 TOTAL 975 NEW 21% ↑



2,805

Newly diagnosed individuals contacted the Information Resource Center



67,882

Visitors

KIP program more accessible and personalized, leading to nearly 400% increase in online KIP visitors

PEOPLE WITH MS ARE CONNECTING TO THE SOCIETY FOR WHAT THEY NEED WHEN THEY NEED IT

Achieved through:

- **Lasting connections through Society channels**
 - FY16 goal targets:
 - Self-help group leaders and members are more deeply engaged, and gaps in support are intentionally filled
 - 10% increase in number of MSconnection.org online community groups = 435

FY16 PROGRESS

SELF-HELP GROUPS

1,183 TOTAL 93 NEW

MSCONNECTION.ORG
ONLINE COMMUNITY GROUPS

474 TOTAL 79 NEW 20% ↑


PEOPLE FIND THE CONNECTIONS THEY NEED TO LIVE THEIR BEST LIVES

Achieved through:

- **Lasting connections through Society channels**
 - FY16 goal targets:
 - 20% growth in MSConnection.org membership = 43,000

FY16 PROGRESS

MSConnection.org

42,680 
TOTAL MEMBERS

6,502 
NEW MEMBERS

18% 

“ I came out of the experience feeling more connected and positive than I have felt in a long time. My significant other is also interested in this, too. We are already telling each other our three positive things about the day each night, and we enjoy that. I am looking forward to all the positive changes that are headed my direction.”
– Everyday Matters program participant

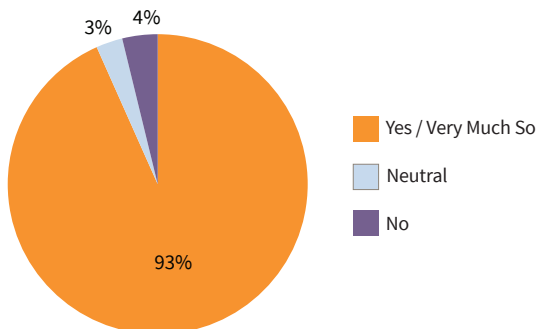
PEOPLE FEEL BETTER EQUIPPED TO MOVE THEIR LIVES FORWARD

Achieved through:

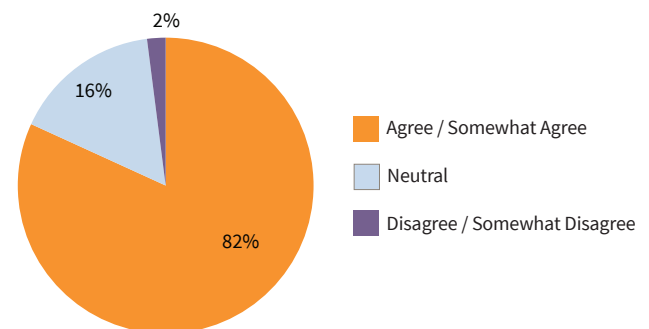
- **People reporting satisfaction/quality of connections made**
 - Ongoing goal targets:
 - Minimum 95% satisfaction with MS Navigator services

FY16 PROGRESS

Were you satisfied with the service you received from the National MS Society?



I have a place for support where I can find solutions.



GOAL III:

Individuals and organizations are mobilized to generate resources that accelerate progress and maximize impact

WE BUILD CAPACITY AND EFFECTIVELY GENERATE AND DEPLOY RESOURCES TO FUND THE STRATEGIC PLAN

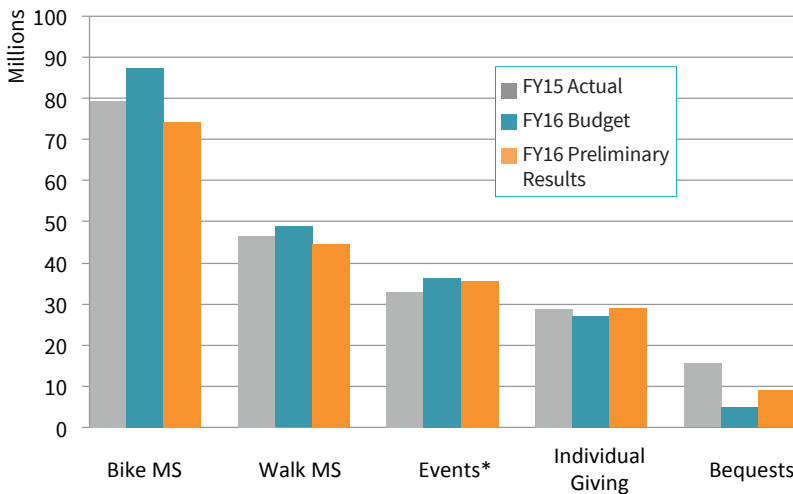
Achieved through:

- **Revenue goal met or exceeded**
 - FY16 goal targets:
 - Individual giving will grow by 5% raising \$32.1 million
 - Walk MS will grow by 4.9% raising \$48.8 million
 - Bike MS will grow by 6.5% raising \$87.4 million

“Unfortunately there were not effective treatments for my mom when I got married. This is why I continue to support the Society and ride Bike MS every year — for new treatments and eventually a cure.”
– Bike MS participant, Seth Talbot on not being able to dance with his mom at his wedding

FY16 PROGRESS

Revenue Sources



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

Highlights & Notations

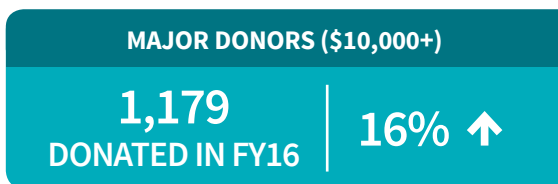
- **Bike MS** was down 11% in registration and \$5 million in revenue. Weather-related cancellations of our two largest Bike MS events in Houston and Philadelphia as well as the decline in the energy industry impacted team recruitment and revenue with an estimated impact of \$4 million
- **Walk MS** revenue was down \$2 million and registrations were down 5%
- **Individual Giving**, bolstered by focused effort in key markets, saw gains in mid-level and major giving programs; revenue increased by \$200,000 over FY15 and \$1.8 million over FY16 budget
- **Leadership events** accounted for over \$13 million in revenue, a \$2.8 million increase
- Nearly **\$9 million in bequests** received from 171 estates

WE HAVE ENDURING RELATIONSHIPS THAT EXCEED CONSTITUENT EXPECTATIONS

Achieved through:

- **Constituent retention and acquisition**
 - FY16 goal targets:
 - Increase number of mid-level donors
 - Increase number of major donors
 - Special event and individual giving retention and acquisition
 - Top level rating among organizations that rate and rank nonprofits, instilling constituent/donor trust and confidence in the Society special event and individual giving retention and acquisition

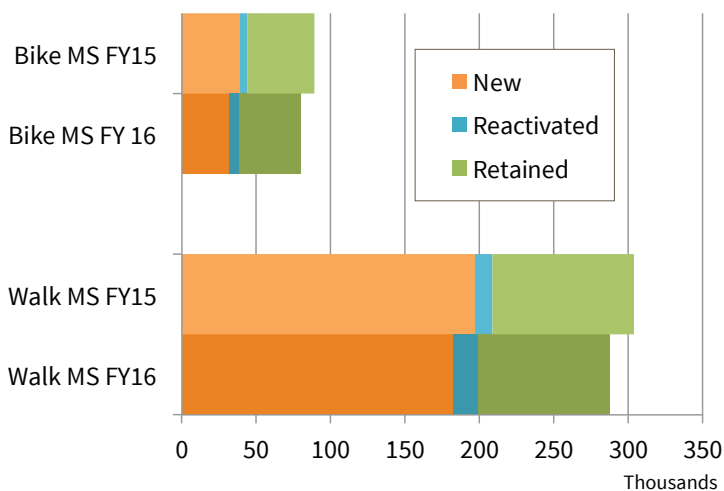
FY16 PROGRESS



Highlights & Notations

- Individual Giving program received its largest individual donor commitment of \$3 million, one of several multi-year pledges, all lead gifts for the Society’s first ever comprehensive fundraising campaign, **Breakthrough MS**. International Progressive MS Alliance also inspired an increase in giving.
- While overall **Bike MS** and **Walk MS** acquisition was down, digital media resulted in 6,123 registrations against a goal of 3,817 for Bike MS and 20,143 registrations against a goal of 11,000 for Walk MS
- The **Constituent Information Center** successfully completed the centralization of offline donation processing with a focus on expediting donation entry to ensure positive constituent experience to support post-event participant communication and to improve event retention rates

Acquisition & Retention



NATIONAL HEALTH COUNCIL

**HIGHEST
LEVEL RATING**



The National MS Society meets the highest standards of accountability, ethical practice, organizational effectiveness, and good public stewardship

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New Jersey

Greater Delaware Valley

New Jersey Metro

New Mexico

South Central

New York

Long Island

New York City-Southern New York

Upstate New York

North Carolina

Greater Carolinas

North Dakota

Upper Midwest

Ohio

Ohio Buckeye

Ohio Valley

Oklahoma

South Central

Oregon

Oregon

Pennsylvania

Greater Delaware Valley

Pennsylvania Keystone

Rhode Island

Greater New England

South Carolina

Greater Carolinas

South Dakota

Upper Midwest

Tennessee

Mid South

Texas

South Central

Utah

Utah-Southern Idaho

Vermont

Greater New England

Virginia

Greater DC-Maryland

Virginia-West Virginia

Washington

Greater Northwest

Oregon

West Virginia

Virginia-West Virginia

Wisconsin

Wisconsin

Upper Midwest

Wyoming

Colorado-Wyoming



WHATEVER IT TAKES.



ANQUETTE, DIAGNOSED IN 2013



JOSEPH, DIAGNOSED IN 2008

- Receive support to navigate the challenges of MS by calling 1-800-344-4867
- Learn more about MS and the many ways we address MS 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 online at: nationalMSSociety.org/donate
- Defy MS by connecting with people around the world striving to live their best lives on MSconnection.org
- 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®, MuckFest MS®, or Do It Yourself Fundraising MS event, and ask everyone you know for donations
- 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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