FY2016 GOAL & STRATEGY PROGRESS REPORT

FY2016–2018 Strategic Plan



National Multiple Sclerosis Society We are a movement. United in our collective power to do something about MS now and end this disease forever. The Society's FY2016–2018 Strategic Plan establishes a roadmap for our movement through 2018. It seeks to increase the empowerment of people affected by MS and provide worldwide solutions to the challenges they face.

Each of the three goals within the strategic plan has a set of strategies where clear impact is identified. People affected by MS will have more and better choices about living their lives to the fullest. They will be surrounded with what they need to move forward. They can be more powerful than the challenges of MS.

The Goal & Strategy Progress Report for FY2016 summarizes October 2015 through September 2016 progress in each strategic plan strategy and goal area. This annual report allows us to track our progress against the FY2016–2018 Strategic Plan. It also articulates how our impact better ensures 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. We are committed to measuring progress in a manner that allows for identification of gaps and opportunities for continuous organizational improvement that can lead to greater impact.



National Multiple Sclerosis Society

GOAL I:

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



STRATEGY 1:

Expand investments and worldwide collaboration to accelerate research

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)
- Patent applications and clinical trials of novel approaches for all forms of MS
 - FY16 strategy target:
 - 5% increase in MS-related patent applications = 9,364

- 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

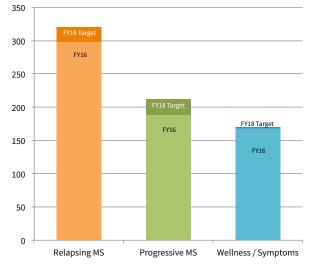
FY16 PROGRESS

9,630 TOTAL MS-RELATED PATENT APPLICATIONS

8% 2 👼 NEW MS-RELATED

PATENT APPLICATIONS

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



STRATEGY 2:

Seize opportunities and build pathways with government, communities, and the private sector so people with MS get what they need

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 Leaders¹ = 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

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MS ACTIVISTS

133,177 **Total Activists Registered** in the MS Activist Network²

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

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 NEW 29 HOUSE TOTAL • TOTAL 32 CO-SPONSORS 26 SENATE **Access to Complex Rehabilitation Technology** 9 TOTAL NEW 72 HOUSE TOTAL 32 CO-SPONSORS **SENATE Access to Complex Rehabilitation Technology Accessories** 150 NEW CO-SPONSORS 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

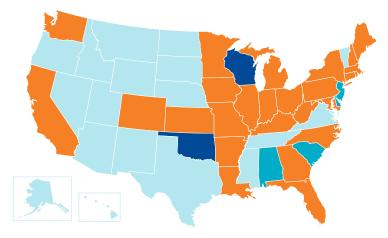
Lifespan Respite Care Program

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

State Progress

Bills supported by the Society in FY16:

- 92 Unified State Policy Agenda³ 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



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

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

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

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



5

STRATEGY 3:

Influence, lead and collaborate to expand resources to ensure access to healthcare

HEALTHCARE MEETS INDIVIDUAL NEEDS

Achieved through:

- People with healthcare that meets their needs
 - FY16 goal targets:
 - Institutional Clinician Training Awards and Individual Fellowships⁴ expand MS healthcare workforce
 - 10% increase in number of Partners in MS Care⁵ = 278

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."

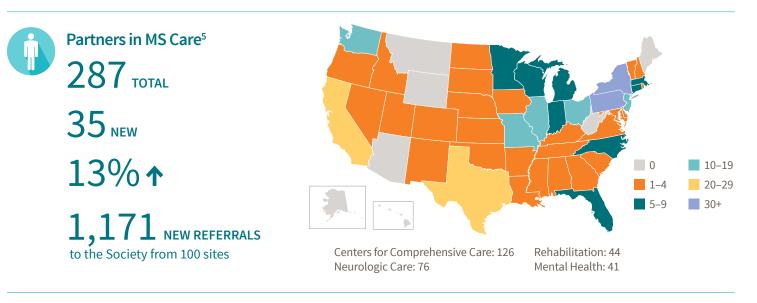
– Wellness Program participant

FY16 PROGRESS



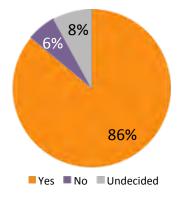
New physicians received **Individual Fellowships** to specialize in MS care — bringing the total of Society funded MS specialists to 72 **1**

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



Wellness Program Impact¹⁰

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



GOAL II:

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



STRATEGY 4 & STRATEGY 5:

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

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 Power⁶ (KIP)

FY16 PROGRESS

Newly Diagnosed MSconnection.org⁷ Members

S,619 TOTAL
975 NEW
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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.org⁷ membership = 43,000
 - FY16 strategy target:
 - 10% increase in MSconnection.org⁷ connections

FY16 PROGRESS

MSconnection.org⁷







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

Achieved through:

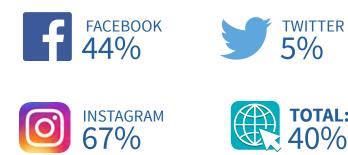
- Lasting connections through Society channels
 - FY16 goal targets:
 - Self-help group leaders and members are more deeply engaged, and gaps in support are intentionally filled
 - 10% increase in number of MSconnection.org⁷ online community groups = 435
 - FY16 strategy targets:
 - · People connect to others with similar experiences for support and to reduce isolation
 - 20% increase in social media followers
 - Maintain 40% social media engagement

FY16 PROGRESS



SOCIAL MEDIA ENGAGEMENT*

Engagement = actions taken in response to Society posts (e.g. likes, comments, retweets), divided by total number of social media followers



* Average engagement rates: Facebook business pages = 2%, Twitter top 25 brands = .07%, Instagram top brands = 4%

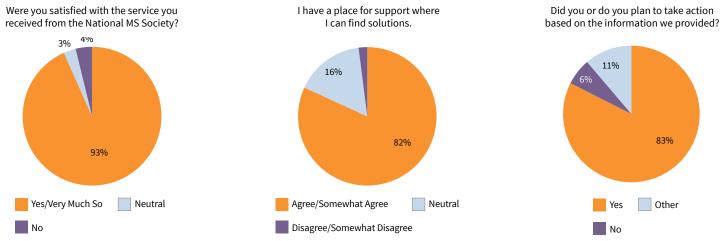


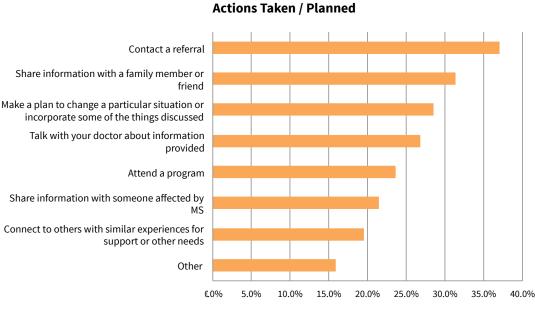
PEOPLE FEEL BETTER EQUIPPED TO MOVE THEIR LIVES FORWARD

Achieved through:

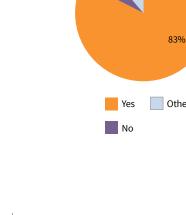
FY16 PROGRESS

- People reporting satisfaction/quality of connections made
 - Ongoing goal targets:
 - Minimum 95% satisfaction with MS Navigator services
- People take action as a result of receiving the information and/or resources they need
 - FY16 strategy target:
 - MS Navigator services lead to action
 - Email click-throughs











GOAL III:

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



STRATEGY 6:

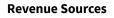
Accelerate revenue growth and increase resources

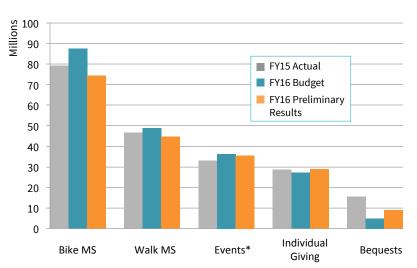
WE BUILD CAPACITY AND EFFECTIVELY GENERATE AND DEPLOY RESOURCES TO FUND THE STRATEGIC PLAN

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

FY16 PROGRESS





*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

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



STRATEGY 7:

Engage each person and organization in the MS movement at their highest level

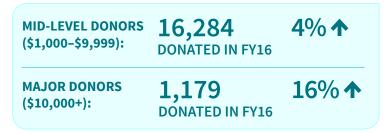
WE HAVE ENDURING RELATIONSHIPS THAT EXCEED CONSTITUENT EXPECTATIONS

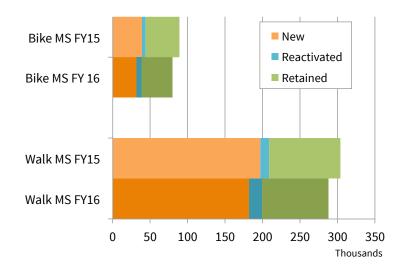
Achieved through:

- Constituent retention and acquisition
 - FY16 goal targets:
 - Increase number of mid-level donors)
 - Increase number of major donors)
 - Special event & individual giving retention & 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 strategy target:
 - 100% of offline donor transactions managed by the Constituent Information Center⁹

FY16 PROGRESS

Acquisition & Retention





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**⁹ 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

NATIONAL HEALTH COUNCIL HIGHEST LEVEL RATING

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

100% 🧇

of offline donor transactions managed by the Constituent Information Center



STRATEGY 8:

Equip volunteers and staff with tools and resources to achieve desired results

STAFF AND VOLUNTEERS ARE SUPPORTED SO THEY ARE MOBILIZED, FULLY ENGAGED, POWERFUL & EFFECTIVE LEADERS

Achieved through:

- Employees and volunteers aligned with the Strategic Plan and have the ability to develop and expand influence
 - Goal target:
 - Track and manage alignment plan status: Red, yellow, green

FY16 PROGRESS



Constituent Relationship Management (CRM)⁸: Red

• CRM tool implementation pacing will be re-evaluated as part of FY18 budget planning. Currently evaluating a small scale pilot to support revenue growth acceleration in FY17



Development: Yellow

• 2016 staff alignment prevents optimum deployment of talent to drive revenue growth: key staffing gaps in high potential markets

Finance: Green

- All processing centers are fully staffed and all chapters have fully migrated to the processing centers
- New chart of accounts rolled out effective 10/1/16
- Transitioned to one employee identification number effective 10/1/16
- The National Board of Directors approved the first ever Society-wide budget for FY17
- 100% of offline donations are being processed through Constituent Information Centers. Focusing on expedited donation entry to support post event marketing efforts



A Human Resources: Green

- Leading the staff alignment throughout the organization
- A health benefits plan was selected for the entire organization that will go into effect 1/1/17
- Preparing for Department of Labor changes to overtime pay

GREEN STATUS:

Milestones to achieve outputs are within 0–29 days of plan. Budgeted/nonbudgeted resources must also be less than 5% of the total project expense, or less than \$50,000 (whichever is greater).

YELLOW STATUS:

Two or more milestones to achieve outputs are between 30–60 days past plan due date.

RED STATUS:

One or more milestones to achieve outputs is more than 60 days past plan due date, and/or implementation date is delayed by more than 60 days.





Legal and Risk Management: Green

- Began process for 2017 insurance renewal
- Negotiated new contract for peer-to-peer fundraising tool with no increases for FY17
- Proactive driver training for staff and volunteers led to a reduction in automobile claims by 66% since 2010

Marketing: Green

- Implementation is underway and on track for all aligned Society Marketing roles, including digital marketing and experience, social marketing, communications, brand and reputation management, creative and materials production, marketing strategy, content acquisition and development, and direct response marketing
- The Society's new awareness campaign, Together We Are Stronger, launched during MS Awareness Week in March

Services: Green

- Broadly defined nationwide scope of services so that we can talk about the intended impact on people's lives
- Individual chapter-developed programs are being reviewed and considered for Societywide implementation or to be thoughtfully phased out
- Leaders for one staff team to develop and implement programs and services nationwide are in place



Technology: Green

- Implementing Master Data Management solution to ensure data quality
- Moving documents to a centralized location in order to accommodate file sharing across the Society

GREEN STATUS:

Milestones to achieve outputs are within 0–29 days of plan. Budgeted/nonbudgeted resources must also be less than 5% of the total project expense, or less than \$50,000 (whichever is greater).

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Research is vital to improving the lives of people living with MS, and Bill and I are dedicated to speeding the pace of discovery. Now is the time to be bold and take action. We made our gift to progressive MS research and we challenge you to do so too."

- Cathy Onufrychuk, Major Gift supporter



APPENDIX

- 1. **District Activist Leaders** build and foster critical, lasting relationships with their elected officials (in their legislative districts) that will help the MS movement influence policy issues at the federal, state and local level. District Activist Leaders serve as the liaison between the Society and their local MS community.
- 2. The **MS Activist Network** is the Society's grassroots network of volunteer MS activists who receive and take action on advocacy news and action alerts.
- 3. Unified State Policy Agenda is a platform of issues from which the Society advocates in all states.
- 4. Fellowship opportunities for healthcare providers -

Institutional Clinician Training Award: Five-year awards to mentors and institutions to provide training for board-certified/eligible neurologists and psychiatrists in MS specialist care. Training will include new and follow-up patient consultations and treatment under the supervision of an MS specialist physician along with participation in a multidisciplinary team, lectures, and professional meetings.

Individual Fellowships: One-year, post-residency MS clinical fellowship program designed to train board-certified/eligible neurologists or psychiatrists in specialized MS clinical care. This 12-month program provides fellows with the opportunity to perform new patient consultations and follow-up evaluations under the supervision of an MS specialist.

- 5. The **Partners in MS Care** program recognizes and acknowledges committed healthcare professionals whose practices improve access to high-quality care for people with MS to live their best lives. Partners include healthcare professionals in the areas of neurology, mental health and rehabilitation, as well as sites that provide multidisciplinary healthcare.
- 6. **Knowledge Is Power** (KIP) is an introduction and guide to living with MS for those who are recently diagnosed or have a loved one who was recently diagnosed.
- 7. **MSconnection.org** is a social networking website and online community for people living with MS, their loved ones and experts to connect in a safe and secure environment.
- 8. **Constituent Relationship Management** is a term that refers to practices, strategies and technologies that the Society leverages to engage each person and organization in the MS movement at their highest level through a seamlessly connected constituent experience.
- 9. The **Constituent Information Center** is a centralized operation with the staff expertise and focus to maintain high standards of excellence with our constituent information. The Information Center manages donor and team gifts made through the mail, at chapter offices or at events and then translates this donor and gift information into our database so we maintain a history of a donor's giving over time. The Center also manages the acknowledgment of these gifts in conjunction with staff at chapters.
- 10. **Wellness programs** including yoga, aquatics, mindfulness-based stress reduction, fitness and healthy eating share a common goal of addressing one or more of the six dimensions of wellness and aim to enlighten, encourage and empower participants to develop and improve wellness behaviors.

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