# FY2017 GOAL PROGRESS REPORT

FY2016-2018 STRATEGIC PLAN



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 Progress Report for FY2017 summarizes October 2016 through September 2017 progress in each strategic plan 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.



## **GOAL I:**

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



## RESEARCH **ANSWERS QUESTIONS**TO ADDRESS UNMET NEEDS

#### **FY17 Progress**

#### **Research Investment**



\$40 MILLION

FY17 target: \$40 million

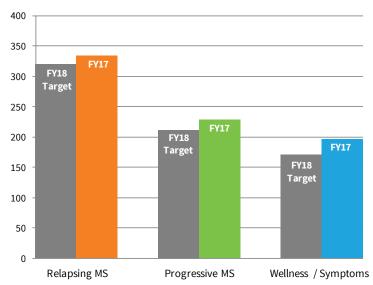
This represents funds distributed in 2017; many grants are funded for multi-years. We have commitments through 2025.



MS-RELATED PATENT APPLICATIONS

**11,765** TOTAL **2135** NEW IN FY17

#### **Active Clinical Trials**



#### **Highlights & Notations**

- The Society invested \$40 million for new and ongoing research and initiatives around the world, with 360 active projects
- The International Progressive MS Alliance launched three Collaborative Network Awards, with co-funding and leadership from the Society
- Society funding of early B cell research led to the first therapy for primary progressive MS
- The International MS Genetics Consortium published results identifying 200 genetic variations that influence the risk of developing MS
- Patient-Centered Outcomes Research Institute committed \$38 million for studies comparing the benefits and risks
  of MS therapies and rehabilitation, including two studies focused on fatigue four of the lead researchers funded are
  alumni of Society fellowship programs
- Research papers from Society-led initiatives focusing on wellness research, patient cohorts/registries, and clinical measures for tracking MS progression and benefits of therapies provide insight into the current landscape and guide funders and MS researchers on the best ways to speed answers



It's an exciting time for autoimmune research. I have had MS 32 years. Thanks to research, I have had medicine to keep me in remission the last 11 years. Thank you for all who are working toward a cure!"

- Stacey Baier Oldham



#### ADVOCACY RESULTS IN **NEW AND EXPANDED RESOURCES**

#### **FY17 Progress**





#### **District Activist Leaders**

**330 TOTAL** | **51 NEW** 

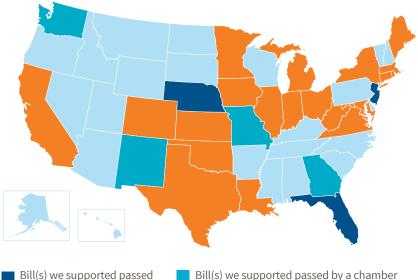
**18%** ↑ IN FY17

#### **Federal Progress**

- 21st Century Cures Act was passed, authorizing a data collection system to track incidence and prevalence of neurological conditions
- MS activists protected access to affordable, quality health coverage through robust engagement in the health reform debate — including 14,927 emails to Congress, 115 sign-on letters and ads and 444 Capitol Hill meetings
- Achieved a \$2 billion increase for the National Institutes of Health and \$6 million total for the MS Research Program through the Department of Defense

- The FAIR Drug Pricing Act was reintroduced in Congress with a new provision added by the Society to better encapsulate MS disease-modifying therapies
- Ocrevus entered the market at approximately 20% less than the average price of the MS disease modifying therapies — Genentech cited the Society's access to medications work in announcing the price
- Sanofi Genzyme released pricing principles which align with the Society's access to medications recommendations

#### **State Progress**



- by a committee (Total = 115)
- Bill(s) we supported signed into law (Total = 22)
- of the state legislature (House or Senate) (Total = 82)
- No advancement

#### 104 POLICY PRIORITY BILLS Supported By the Society

- Access and affordability of medications: 33
- Home modifications: 14
- Medicaid: 10
- Transparency of coverage: 8
- Network adequacy: 4
- Caregiver support and respite: 3
- Disability rights: 3
- Medical cannabis: 2
- Access to coverage: 2
- Access to rehab therapies: 1
- Other: 24



#### **HEALTHCARE MEETS INDIVIDUAL NEEDS**

#### **FY17 Progress**



#### **17 NEW**

Physicians received Individual Fellowships to specialize in MS care — bringing the total of Society funded MS specialists to 110



#### **12 NEW**

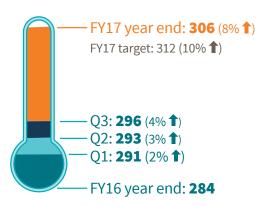
Medical students participated in Medical Student Mentorships — 64 students since inception of program



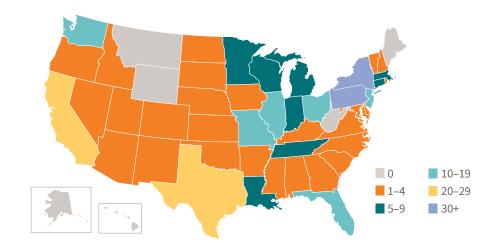
#### 8 NEW

Doctoral physical therapy students received **scholarship funds** to take an extra-curricular MS education

#### **Partners in MS Care**







Centers for Comprehensive Care: 133 Rehabilitation: 51 Neurologic Care: 80 Mental Health: 47



Not only did I learn an immense amount about multiple sclerosis, neurology, and immunology, but I also got a first-hand glimpse of what my career might be like as a future neurologist. My mentors were wonderful teachers."

- Medical Student Mentorship Participant



## **GOAL II:**

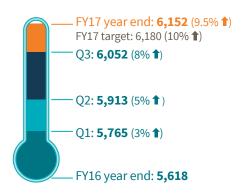
People affected by MS connect to the individuals, information and resources they need to move their lives forward



## PEOPLE WITH MS ARE **CONNECTING EARLIER** IN THEIR MS JOURNEY

#### **FY17 Progress**

Newly Diagnosed MSconnection.org Community Members



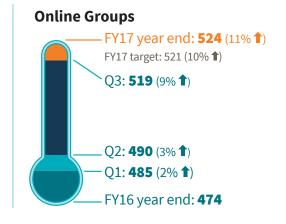


## PEOPLE AFFECTED BY MS ARE CONNECTING TO THE SOCIETY FOR WHAT THEY NEED, WHEN THEY NEED IT

#### **FY17 Progress**

**Self-Help Groups** 

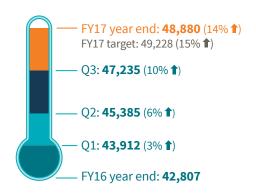
**1,138 TOTAL** 



## PEOPLE FIND THE CONNECTIONS THEY NEED TO LIVE THEIR BEST LIVES

#### **FY17 Progress**

**MSconnection.org Community Members** 



I was so moved, encouraged, and able to be honest with myself after this program. I have had MS for over 20 years. The hardest part has been losing my career. I realized I never fully grieved for that loss and was in a limbo. I felt like I had no identity after MS took my career away. I can be more than a heathcare worker. I can be many things."

- Resiliency Program Participant

#### **MS Friends**

**42**VOLUNTEERS
PROVIDED
SUPPORT TO

805
CALLERS
PER MONTH

**Peer Connections** 

**52**VOLUNTEERS
PROVIDED
SUPPORT TO

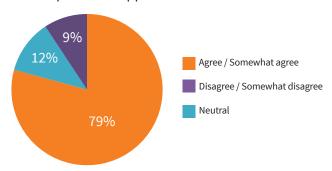
386
PEOPLE



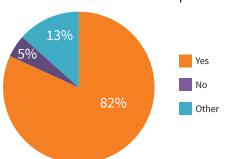
## PEOPLE FEEL BETTER EQUIPPED TO MOVE THEIR LIVES FORWARD

#### **FY17 Progress**

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



Did you or do you plan to take action based on the information we provided?



#### Top 5 Actions Taken / Planned











#### **Wellness Programs**

**85% OF PARTICIPANTS**plan to make a change

90%
OF PARTICIPANTS
feel better able to cope
with the challenges of MS

#### **TOP 5 BEHAVIOR CHANGES:**

1 Increase exercise

Mindfulness

Improve diet

Mindfulness

Intellectual activities



The wellness programs are the best of the Society. They reach people at different points on the wellness spectrum and provide grounding and a sense of social support that you can only get from others managing their own personal journey with MS."



### **GOAL III:**

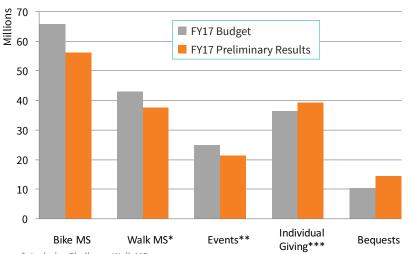
Individuals and organizations are mobilized to generate resources that accelerate progress and maximize impact



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

#### **FY17 Progress**

#### **Revenue Sources**



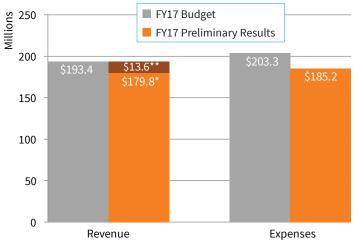
6,248
BIKE MS TEAMS

FY17 target: 6,970

25,988
WALK MS TEAMS

FY17 target: 28,603

#### **Society Revenue & Expenses**



- \* Operational Revenue
- \*\* Non-Operating Revenue (investment income and prior year research grant adjustments)

#### **Highlights & Notations**

- FY2017 operating revenue was \$13.5 million under budget which has been offset by a \$16.8 million reduction in expenses, resulting in a \$3.2 million favorable variance to budget an additional \$13.6 million in revenue from non-operations resulted in a total change in net assets of \$7.4 million
- **Bike MS** registration was down 5% and team recruitment was down 6%
- **Walk MS** registration was down 9% and team recruitment was down 9%
- Do It Yourself Fundraising and Finish MS met budget and registration targets
- **Individual Giving** exceeded revenue budget by 8%
- **Leadership Events** exceeded revenue budget by 5%



Even on days when I'm fatigued or something and my run doesn't go well, just the fact that I'm out there doing it, that elevates my mood and really, really helps me get through the day."

<sup>\*</sup> Includes Challenge Walk MS

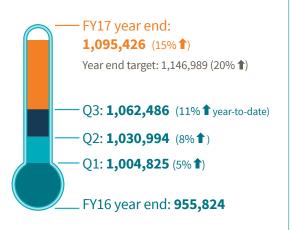
<sup>\*\*</sup> Includes leadership events, MuckFest MS, Finish MS, DIY Fundraising MS and other events

<sup>\*\*\*</sup> Includes Direct Marketing

## WE HAVE ENDURING RELATIONSHIPS THAT EXCEED CONSTITUENT EXPECTATIONS

#### **FY17 Progress**

#### **Social Media Followers**



#### Social Media Engagement\*









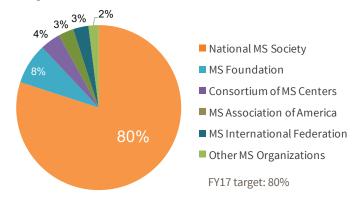
#### Average engagement rates:

- Facebook business pages = 2%
- Twitter top 25 businesses = .07%
- Instagram top businesses = 4%
- \* Engagement = actions taken in response to Society posts (e.g. likes, comments, retweets), divided by total number of social media followers

#### **Media Mentions**



#### MS Organization Media Mentions



#### **Highlights & Notations**

- Reporter Ellie Dolgin from Nature, the top journal across all scientific disciplines, interviewed Tim Coetzee on Ocrelizumab and International Progressive MS Alliance for an article about potential therapies for progressive MS
- The FDA approval of Ocrevus including quotes from Society leadership was covered by Wall Street Journal, Reuters, NBC, CNN and more
- NHL player Brian Bickell's return to the ice five months after his MS diagnosis which coincided with his team's surprise participation in Walk MS garnered extensive media coverage



We don't seem to be the forgotten group anymore. There's some attention coming our way — and that helps."



