

# Q3 GOAL PROGRESS REPORT

FY2016–2018 Strategic Plan



National  
Multiple Sclerosis  
Society

# 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:
    - \$53.9 million in MS research investments
- **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

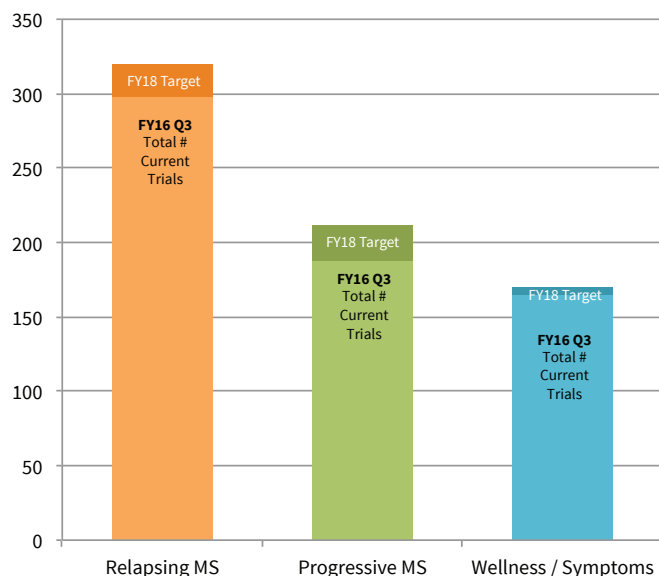
“Thank you for focusing on progressive MS. I was diagnosed with primary progressive MS nine years ago and until now no one seemed to care.”

– Debbie Schneider, National MS Society Facebook Page

## Q3 PROGRESS

**\$40.1 million**  
INVESTMENT IN MS RESEARCH 

### Active Clinical Trials



## Highlights & Notations

- Research investment is projected to be \$50 million versus a budget of \$53.9 million. This investment has been intentionally decreased due to the FY16 revenue projection being under budget.
- **PCORI committed \$19.6 million** for studies comparing the benefits and risks of MS therapies to help people make informed choices
- The FDA approved **Zinbryta™** (daclizumab) as a therapy for adults with relapsing forms of MS
- Antihistamine, **clemastine**, showed evidence of stimulating myelin repair in a small phase II MS trial
- **2016 John Dystel Prize for MS Research** went to Claudia Lucchinetti at the Mayo Clinic
- Clinical trials data from **Multiple Sclerosis Outcome Assessments Consortium** made available for the first time to qualified researchers
- Positive results from two studies of **bone marrow-derived stem cells** in people with aggressive, relapsing MS
- A phase 2 trial of **anti-LINGO**, an approach to repair myelin, did not improve physical function cognitive function, or disability, despite an earlier positive trial

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

## ADVOCACY RESULTS IN NEW AND EXPANDED RESOURCES

Achieved through:

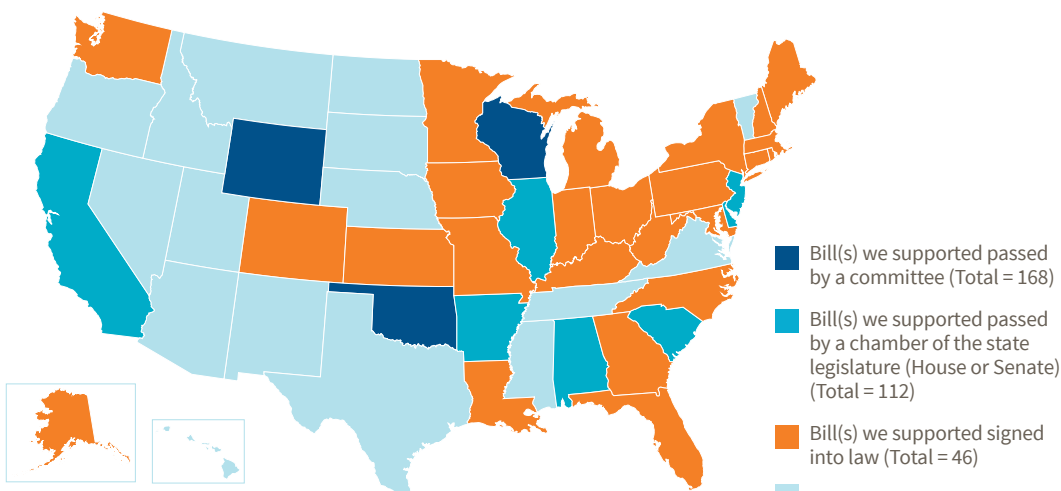
- **Increased engagement with policy decision-makers**
  - FY16 goal targets:
    - 20% increase of District Activist Leaders<sup>1</sup> = 251
    - Grasstops<sup>2</sup> relationships (reporting will resume in FY17)
- **New and expanded resources**
  - Ongoing goal target:
    - Legislation and regulations adopted at the state and/or federal level
- **Constituent retention and acquisition**
  - FY16 goal targets:
    - Increased number of activists (target in development)
    - Increased activist engagement (target in development)

### Q3 PROGRESS

#### Federal Progress on Policy Priorities

- 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). The Senate voted to protect the CDMRP, by a vote of 66 to 32.
- New cosponsors for key Society federal legislation were added:
  - Advancing Research for Neurological Diseases Act: 12
  - Legislation improving access to complex rehabilitation technology: 8
  - Legislation improving access to complex rehabilitation technology accessories: 37

#### Progress on State Legislative Activity



These state legislatures do not meet in 2016:  
Montana, Nevada, North Dakota, Texas

“Great to see the U.S. Senate taking some action to protect MS Research. This only happens when people make sure that they contact members to inform them how important the issue is to them.”

– Tim the MS Bear  
Facebook Page

#### DISTRICT ACTIVIST LEADERS

269 TOTAL

25 NEW

3% IN Q3

29% YEAR-TO-DATE

113,976

#### Total Activists

Reflects the total number of people signed up in the grassroots network, regardless of action taken

29,030

#### Engagements

Defined as taking action by sending action alerts within Q3

# GOAL I:

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

## HEALTHCARE MEETS INDIVIDUAL NEEDS

Achieved through:

- **People with healthcare that meets their needs**

- FY16 goal targets:

- Institutional Clinician Training Awards and Individual Fellowships<sup>3</sup> expand MS healthcare workforce
    - 10% increase in number of Partners in MS Care<sup>4</sup> = 278

### Q3 PROGRESS



**5** Individual Clinical Fellowships  
Fellowships that address clinical gaps  
in MS care



**11** Institutional Clinician Training Awards  
Multi-year centers focused on MS clinical training

### Partners in MS Care

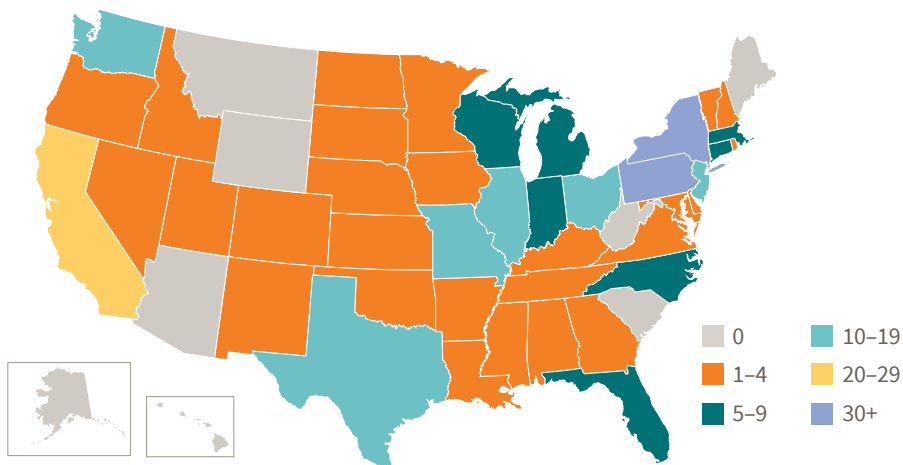


**274** TOTAL

**6** NEW

**2%** ↑ IN Q3

**9%** ↑ YEAR-TO-DATE



Centers for Comprehensive Care: 127  
Neurologic Care: 68

Rehabilitation: 38  
Mental Health: 41

### Healthcare Access Highlights

- Society wellness programs: 80% plan to make a change based on what they learned; 93% would recommend the program to others
- Society social programs: 87% would recommend program to others; 90% see the Society as trusted partner; 68% were able to engage in an activity they would not normally be able to
- Wellness webinar series (in collaboration with Can Do MS): 78% plan to make a change



... attending class with Maria felt like coming home...like a missing piece of my life was put back. I'm really happy to have this practice back in my life with even more understanding of how it can positively impact my life."

– Anonymous Wellness Program participant

# GOAL II:

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



**MICHELLE**  
DIAGNOSED IN 2003

## 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 (targets in development)
    - More people get information they need when they need it through **Knowledge Is Power (KIP)**<sup>5</sup>

### Q3 PROGRESS



**5,427** **TOTAL**  
Newly diagnosed  
MSconnection.org members

**219** **NEW**  
Newly diagnosed  
MSconnection.org members

**4% ↑** IN Q3

**18% ↑** YEAR-TO-DATE



**734** Newly diagnosed individuals contacted the  
Information Resource Center



**34,400** Newly diagnosed webpage views



**28,392** **Webpage views**  
KIP program more digitally accessible and  
more personalized, leading to nearly 400%  
increase in online KIP visitors over FY15



I'm new to MS and the MS community. I love the support, examples, stories, and helpful advice and guidance I have received so far. Your story really helped me come up with the decision to go back to school and finish my Master's Degree in Business Management."

– Stephanie, MSconnection.org member

# 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 TO THE SOCIETY FOR WHAT THEY NEED WHEN THEY NEED IT

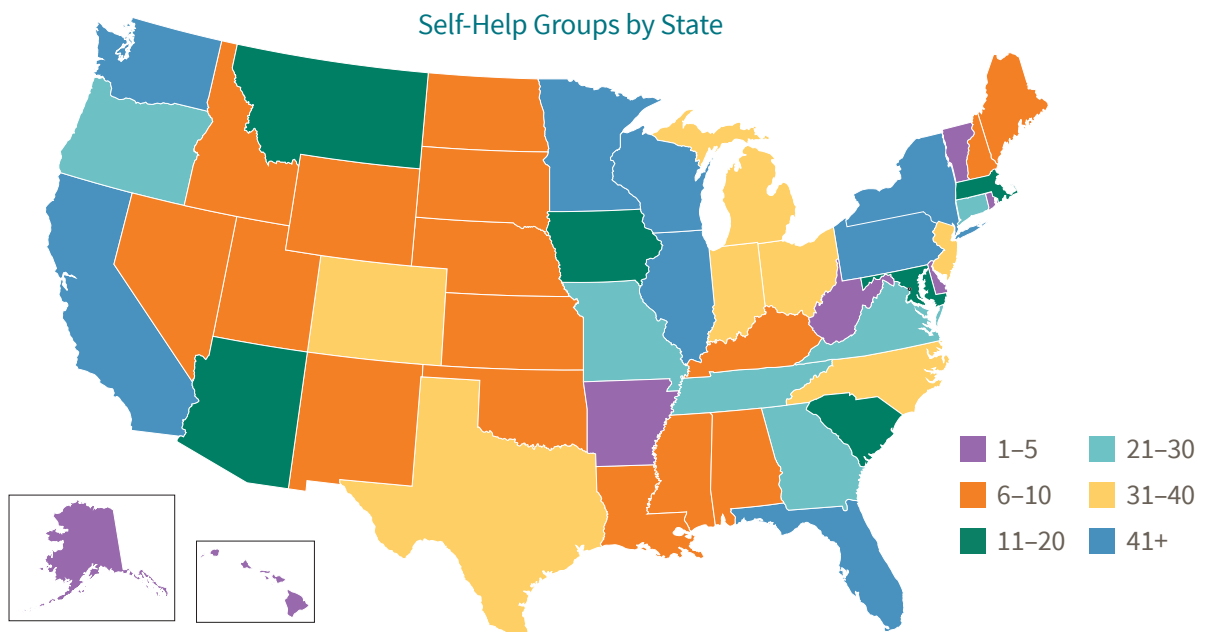
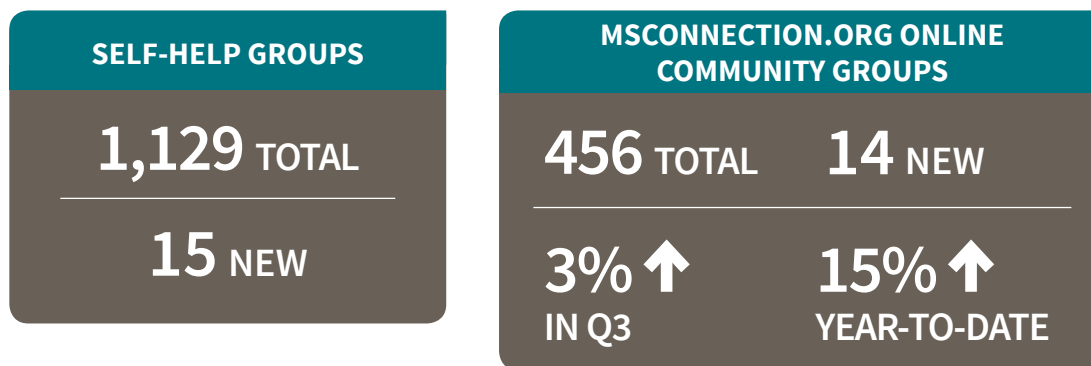
Achieved through:

- **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<sup>6</sup> online community groups = 435

### Q3 PROGRESS



# GOAL II:

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

## 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
    - MSconnection.org engagement (targets and metrics in development)

### Q3 PROGRESS

41,093 

TOTAL MSconnection.org members

1,697 

NEW MSconnection.org members

4% 

IN Q3

14% 

YEAR-TO-DATE

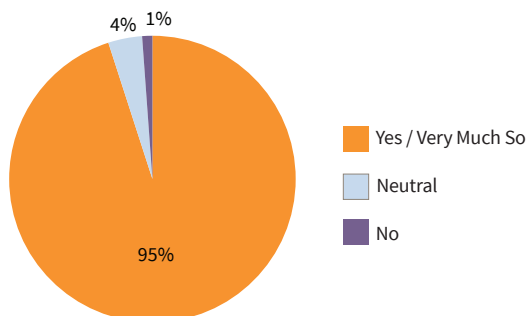
## PEOPLE FEEL BETTER EQUIPPED TO MOVE THEIR LIVES FORWARD

Achieved through:

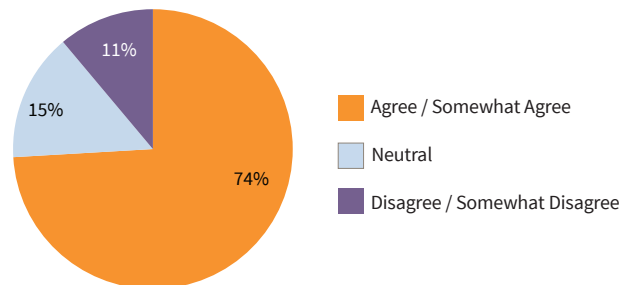
- **People reporting satisfaction/quality of connections made**
  - Ongoing goal targets:
    - Minimum 95% satisfaction with Information Resource Center services

### Q3 PROGRESS

How satisfied are you with the service you received from the National MS Society?



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



When I called, I felt lost, alone & hopeless... By the end of the call, I felt better emotionally, not quite as lost & not at all alone."

– Anonymous caller, Information Resource Center

# GOAL III:

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



"I RIDE WITH MS" PROGRAM PARTICIPANT

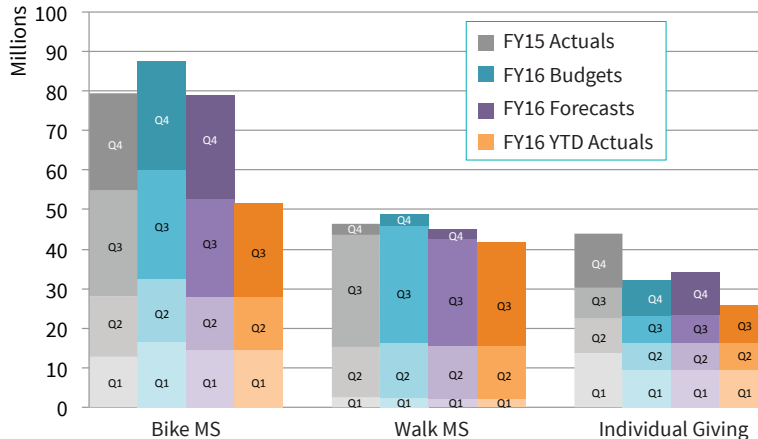
## WE BUILD CAPACITY AND EFFECTIVELY GENERATE AND DEPLOY RESOURCES TO FUND THE STRATEGIC PLAN

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

### Q3 PROGRESS

#### Revenue Sources



#### Highlights & Notations

- **Individual Giving** revenue currently exceeds budget by \$2.74 million
- **Walk MS** revenue is down 3.9% or \$1.7 million from FY15. Staff is working on post event follow-up, including letters and emails focusing on milestones, matching gifts and outstanding donations.
- Our largest ride, **Bike MS Houston to Austin**, has experienced declining participation (both teams and team size) and revenue (down by \$4 million), as well as **Bike MS Colorado** (participation decline of 8% and revenue decline of 5%), both largely due to the impact of the energy industry.
- All other rides combined are down about 7% or \$1.4 million, with **Bike MS** registration down overall 12%. More than 47 rides remain, some being our largest, where we are focused on teams and top fundraiser activation.
- Teamwork among staff across markets continues to drive corporate relationship expansion, new teams, and revenue growth among Society **National Teams**

“This is my 30th year of riding. I have enjoyed all of the rides even in the rain... I am 85 years of age and it takes a lot of riding to get this old body ready to ride the 150 miles.”

– Bud Cherry, Bike MS participant



# GOAL III:

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

## WE HAVE ENDURING RELATIONSHIPS THAT EXCEED CONSTITUENT EXPECTATIONS

Achieved through:

- **Constituent retention and acquisition**

- FY16 goal targets:

- Increase number of mid-level donors (targets in development)
    - Increase number of major donors (targets in development)
    - Special event and individual giving retention and acquisition (targets in development)
    - 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 (targets in development)

### Q3 PROGRESS

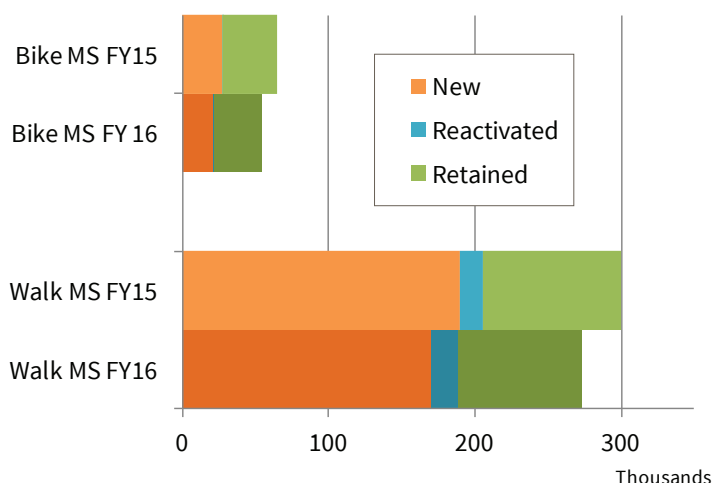
MID-LEVEL DONORS (\$1,000–\$9,999)	
12,280 TOTAL	5,341 DONATED IN Q3

MAJOR DONORS (\$10,000+)	
874 TOTAL	328 DONATED IN Q3

### Highlights & Notations

- **\$3 million multi-year gift** from Ed Dowd for the **Personal Advocate Program**
- **\$1.35 million** awarded from the Hilton Foundation for The Marilyn Hilton MS Achievement Center at UCLA
- Over **\$1 million in bequests** received from 8 estates
- **Walk MS** participation is down over 25,000 participants and 2000 teams so **acquisition** of new participants and teams will be critical in FY17. Year-round cultivation plans are in place to include centralized emails 30 and 60 days post event that focus on the impact fundraising dollars make.
- A **Bike MS** digital media campaign is currently focused on **acquisition** through targeted advertising and is positively impacting **retention** as well. Bike MS **retention** is currently up, likely due to improved operational reports, utilization of event-specific portfolios and increased focus on relationship development.
- The **Constituent Information Center**<sup>®</sup> is expediting data management work across all Bike MS and Walk MS focus markets to ensure positive constituent experience, support post event marketing efforts and improve event retention rates.

### Acquisition & Retention



- Bike MS retention: 68.6% (64.4% in FY15 Q3)
- Walk MS retention: 45.6% (45.6% in FY15 Q3)

NATIONAL HEALTH COUNCIL

## HIGHEST LEVEL RATING



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

# GOAL III:

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

## STAFF AND VOLUNTEERS ARE SUPPORTED SO THEY ARE MOBILIZED, FULLY ENGAGED, POWERFUL AND 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

### Q3 PROGRESS



#### Constituent Relationship Management (CRM)<sup>7</sup>: Yellow/Green

- Currently evaluating pacing prioritization of the CRM tool implementation, which may change pace or scope of this project (yellow)
- 100% of offline donations are being processed through Constituent Information Centers<sup>8</sup> (green)



#### Development: Yellow/Green

- Challenged by current staff alignment to deploy talent to our best revenue growth potential (yellow)
- On track for staff alignment in FY17 for all Development staff (green)



#### Finance: Green

- Denver processing center almost fully staffed and 17 chapters have migrated to it. Two more chapters will migrate in July and another two in August.
- New York processing center is staffed and chapter migrations are underway. Houston will begin processing for chapters in July with all chapters migrated by the end of August.
- Society budgeting process underway targeting National Board approval by September 9
- Continue work to transition to one employer identification number (EIN) effective FY17



#### Human Resources: Green

- Leading the work in staff alignment throughout the organization
- RFP conducted for Society medical and dental benefits plan. Further discussions will take place with finalists at the end of July.
- Staff leadership participating in diversity and inclusion exercise
- Preparing for Department of Labor changes relating to overtime pay effective December 1

#### GREEN STATUS:

Milestones to achieve outputs are within 0–29 days of plan. Budgeted/non-budgeted 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.

# GOAL III:

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



## Information Technology: Green

- Conduct cyber security evaluation and enhance Society's preparedness relating to disaster recovery
- Data warehouse transition continued, fully supported by Society staff



## Legal and Risk Management: Green

- Conduct RFP for insurance broker
- Select new software with mobile capabilities for incident tracking



## Marketing: Green

- Implementation is underway and on track for all Society creative and materials production, including MSConnection newsletters; roles finalized and positions are being filled.
- Alignment teams now working in areas of: social marketing, digital marketing, digital experience (particularly the online fundraising experience), and PR and media relations.
- A fully aligned (FY18 vision) marketing organizational chart has been drafted and communicated for planning



## Services: Green

- Work is continuing define an FY17 scope of services that would be available to all people with MS regardless of location
- Chapter developed programs have been inventoried and a process is in development to tweak each program for greater impact, consider for society-wide use or phase out thoughtfully
- A detailed services organizational chart has been developed, Vice Presidents hired and additional work underway to develop job descriptions and post positions

### GREEN STATUS:

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I realize the value of services for people with limitations. I have help navigating life with MS, but I often wonder how people without sufficient resources manage even the day to day tasks."

– Ed Dowd, Major Donor

# 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. A **Grasstops volunteer** is someone who has a close, personal connection with a local official, a state or federal legislator or official, an individual serving at a key government agency, or an influential staff person for any of the above figures. From time to time, grasstops volunteers may be called upon to leverage relationships on behalf of the Society and our mission, and/or facilitate an introduction with Society staff.
3. **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.
4. 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.
5. **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.
6. **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.
7. **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.
8. 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.

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