

**BREAKTHROUGH**

**MS**®

**2018 ANNUAL  
PROGRESS  
REPORT**



JIM, DIAGNOSED IN 1998

# 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.

JESSICA, DIAGNOSED IN 2012



# ABOUT MULTIPLE SCLEROSIS

Multiple sclerosis is an unpredictable, 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 can include numbness and tingling, walking difficulties, fatigue, dizziness, pain, depression, blindness, paralysis and more. 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, and three times more women than men have 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 \$44 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](https://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 healthcare professional and contacting the National MS Society at [nationalMSSociety.org](https://nationalMSSociety.org) or **1-800-344-4867**.

# OUR FY2016-2018 STRATEGIC PLAN



CHRIS, DIAGNOSED IN 2011

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
- **Strategy 8:** Equip volunteers and staff with tools and resources to achieve desired results

**We've just completed our 2016–2018 Strategic Plan, and what we accomplished is impressive.**

We transformed our organization to ensure we are the very best National MS Society we can be. The way we are organized now allows us to partner with people affected by MS in the ways they need.

Over the last three years, we've achieved some significant breakthroughs, including the approval of the first therapy for primary progressive MS. The momentum continues to build for progressive MS as earlier this fall a Phase 2 trial for ibudilast showed the oral therapy slows brain shrinkage in people with progressive MS by nearly half. The International Progressive MS Alliance is about to begin our next phase of work focused on developing new tools and methods to streamline the discovery and testing of treatments so we can get them to people faster. The future for people with progressive forms of MS is brighter than ever.

We tackle the complex challenges of MS from every angle—from providing information to lending our voices to affect change. Sometimes a phone call to an MS Navigator—or a visit to our website—can make all the difference. Other times we are activists, and we must advocate for solutions on a broader scale.

We believe that people with MS should have access to high-quality healthcare that is affordable. MS activists work diligently to expand and protect access to good health coverage that people can afford. Over the last three years we have been persistent—sending 20,000 emails to members of Congress, holding nearly 700 meetings, and sharing more than 800 stories about healthcare reform with legislators. Our bold initiative to make medications—and the process for getting them—easier, more transparent and more affordable, gained national attention. We've seen positive steps forward by the pharmaceutical industry and the government. Congress is focused on this issue now more than ever. We have also celebrated the passage of 25 state-level policies that increase access to medications.

It's important for people with MS to have a healthcare provider who's knowledgeable about MS. Someone who's in their corner. We've expanded the size and specialized knowledge of the MS workforce through clinical fellowships, professional education and the Partners in MS Care program. People affected by MS are more resilient and live better lives when they are connected with the National MS Society. This year alone nearly 10,000 MS care providers connected people with MS to the National MS Society.

We have made incredible progress over these three years, but until we reach a world free of MS, there is much work to be done. A recent study led by the Society estimates that nearly 1 million people are living with MS in the United States. That's more than twice the previously reported number. That's twice as many people who need solutions. Twice as many people who need a cure.

We must work twice as hard and we cannot do it alone. It's twice as important that people know about their National MS Society. It's twice as important to bring people into the movement. **Our work matters twice as much.**

Yours truly,



Cyndi Zagieboylo  
President and Chief Executive Officer



2018

# FINANCIALS



CAROL, DIAGNOSED IN 1991



## Income



**Total Revenue: \$208,969,582**

**Operating Revenue: \$203,553,688**

- Special Events (net of \$22,199,125 direct benefits to donors): \$110,375,923
- Contributions from Individuals, Corporations and Foundations: \$48,330,419
- Bequests: \$16,900,633
- Contributed Public Service Announcements, Services & Goods: \$11,123,668
- Endowment Contributions: \$12,000,000
- Advertising: \$4,677,800
- Investment Income from Operations: \$145,245

**Revenue from Non-Operations: \$5,415,894**

- Investment Return, Net: \$4,970,429
- Other Revenue: \$445,465

**Total Net Assets: \$104,445,347**

## Expenses



**Total Expenses: \$186,966,939**

- Research: \$38,933,324
- Public Education: \$40,297,354
- Professional Education & Training: \$5,742,797
- Client & Community Services: \$46,148,100
- Management & General: \$16,101,394
- Fundraising: \$39,743,970



**VIEW COMPLETE FINANCIALS**



# 2016-2018 STRATEGIC PLAN PROGRESS REPORT



YVETTE, DIAGNOSED IN 2014

# GOAL I:

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

## Research answers questions to address unmet needs

### FY16–18 Progress

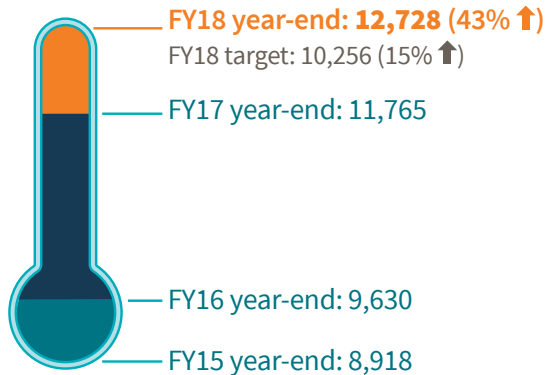
#### Research Investment



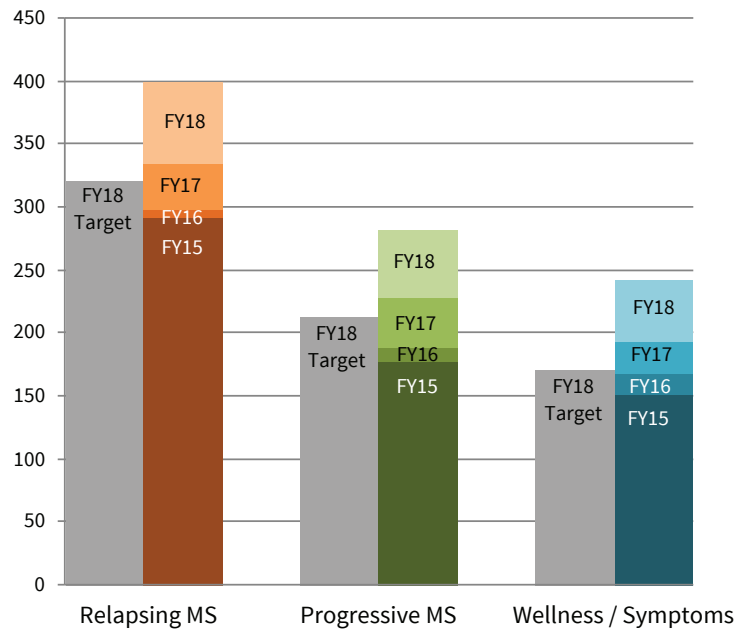
## \$116 MILLION

This represents funds distributed in 2016, 2017 and 2018; many grants are funded for multi-years. We have commitments through 2025.

#### MS-RELATED PATENT APPLICATIONS



#### Active Clinical Trials



#### Highlights & Notations

- Society funding of early B cell research led to the **first therapy for primary progressive MS**
- International Panel on the Diagnosis of MS revised the **MS diagnosis protocol** to make the diagnosis of MS faster, easier and more certain
- **FDA expanded the use of Gilenya** (fingolimod) for children and teens 10 years and older with relapsing MS — the first approved therapy for pediatric MS
- Positive results from two studies of **bone marrow-derived stem cells** in people with aggressive, relapsing MS
- Society co-funded **phase 2 trial of ibudilast** suggested it reduces brain atrophy, a marker of disability, in progressive MS
- The International MS Genetics Consortium published results identifying **200 genetic variations** that influence the risk of developing MS
- The International Progressive MS Alliance launched three **Collaborative Network Awards** totaling \$14.1 million to accelerate the pace of progressive MS research and convened a **Scientific Congress** on symptom management and rehabilitation
- Two clinical trials of **dietary approaches for MS symptoms** were launched, and studies showed programs promoting resilience and mindfulness increased wellbeing in people with MS



# Healthcare meets individual needs

## FY16–18 Progress



**36 NEW**

Physicians received **Individual Fellowships** to specialize in MS care — bringing the total of Society funded MS specialists to 120



**41 NEW**

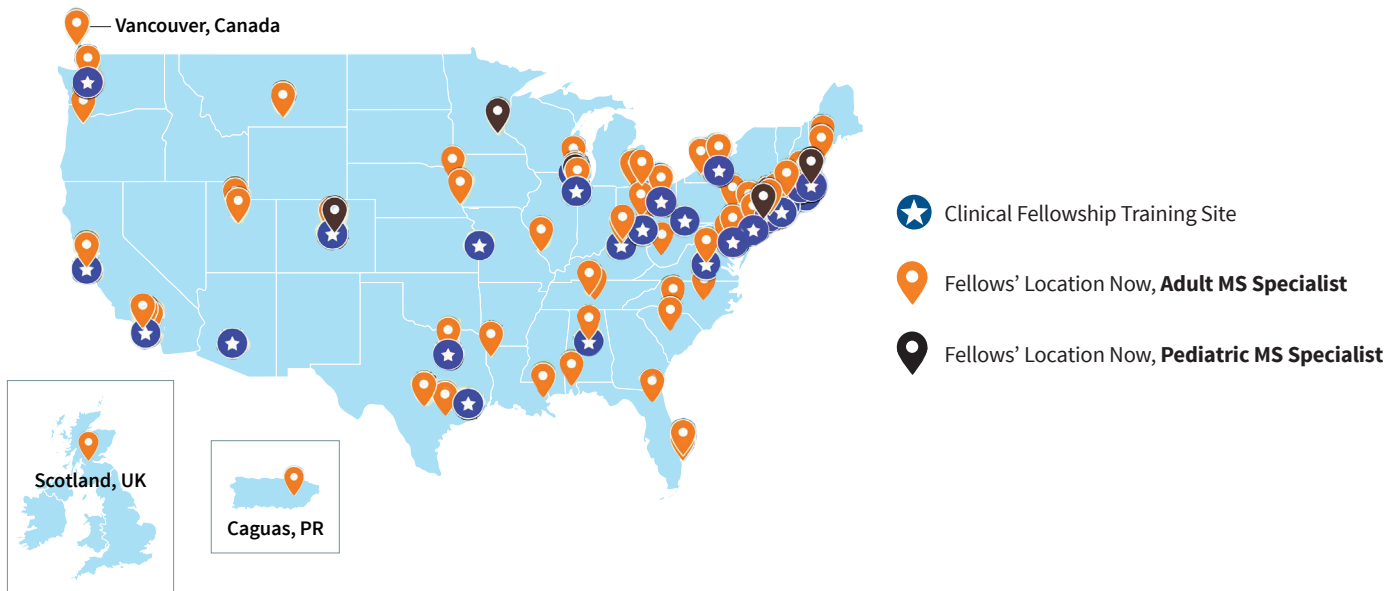
Medical students participated in **Medical Student Mentorships** — 78 students since inception of program



**16 NEW**

Physical therapy doctoral candidates received **fellowships to specialize in MS** — 40 students since the inception of the program

### Clinical Fellowships



## FY18 Progress (Data not available for FY16-17)



**4,657**

**Healthcare Providers**

received in-person outreach from the Society and provided

**9,053**

**Referrals**

to the Society

### Professional Education Programs

**280** Healthcare Provider Educational Events

**75%** Plan to apply something they learned to their practice (Target: 75%)

**90%** Report increased knowledge about MS (Target: 75%)

**86%** Reported improved attitude about caring for people with MS (Target: 75%)



This experience was far beyond my expectations. It was wonderful and reinvigorated my excitement for medicine and confirmed that I really love neurology. I had never shadowed or worked with neurologists prior to the mentorship, however I plan to follow up this experience with finding a local mentor in neurology, possibly one who specializes in MS."

— Kaiulani Houston, PhD, 2018 Medical Student Mentorship program participant

# GOAL II:

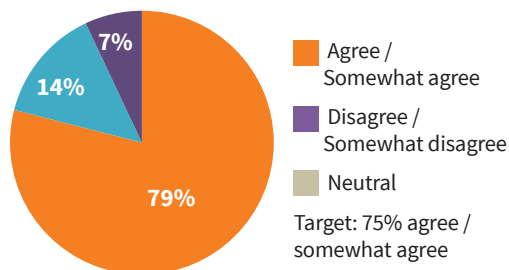
People affected by MS connect to the individuals, information and resources they need to move their lives forward

## People feel better equipped to move their lives forward

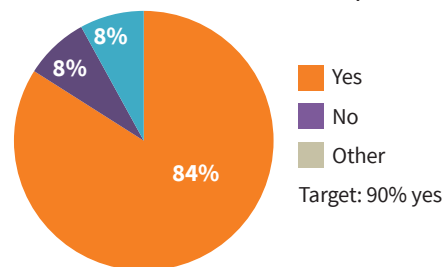
### FY16–18 Progress

#### MS Navigator Connections

The MS Society is a source of 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

- Contact a referral**
- Share information with a family member or friend**
- Make a plan to change a particular situation**
- Share information with someone affected by MS**
- Talk with doctor about information provided**

**50,272** People

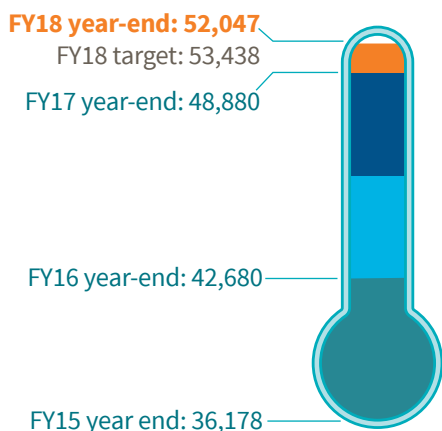
supported by MS Navigators in FY18  
(Data not available for FY16-17)

In FY17, we launched the Edward M. Dowd Personal Advocate Program, which provides comprehensive case management services when challenges are especially complex and overwhelming.

### People find the connections they need to live their best lives

#### FY16–18 Progress

#### MSconnection.org Community Members



### People affected by MS are connecting to the Society for what they need, when they need it

#### FY18 Progress (Data not available for FY16-17)

#### Program Participants

- 29,882** People participated in **391** Community Programs\*
- 72%** Plan to make a change (Target: 85%)
- 91%** Made new connections (Target: 85%)
- 78%** Feel better able to cope with the challenges of MS (Target: 85%)

\*Includes Live Fully Live Well, Everyday Matters, Impact Series, General Education and General Wellness in-person programs

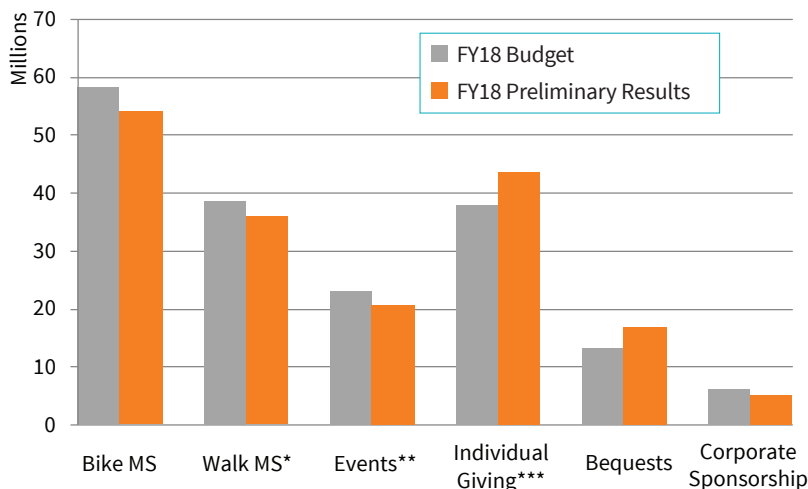
# GOAL III:

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

We build capacity and effectively generate and deploy resources

## FY16–18 Progress

### FY18 Revenue Sources



\* Includes Challenge Walk MS

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

\*\*\* Includes Direct Marketing

**1,447**

**Bike MS Teams  
with 10+ Members**

FY18 target: 1,503

**10,328**

**Walk MS Teams  
with 6+ Members**

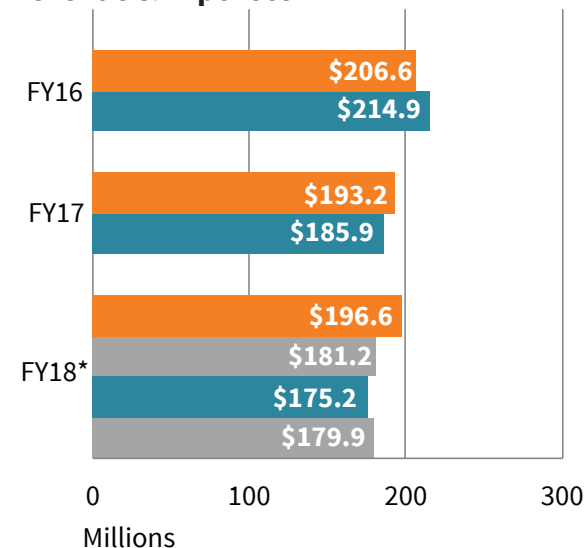
FY18 target: 11,281

**2,857**

**\$1,000+  
Donors**

FY18 target: 3,029

### Revenue & Expenses



Revenue

Expenses

Budget

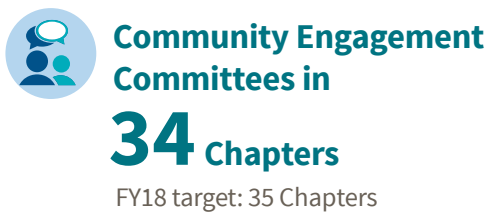
\* Preliminary financials pre-audit

### Highlights & Notations

- Bike MS** has raised over \$1 billion since it began. With 77 events in the series and more than 65,000 participants, it continues to be the #1 fundraising cycling event and the #7 peer-to-peer fundraising event in the nation. In FY17, staff was aligned into one functional team for greatest impact in increasing future revenue, and in FY18, a unified Bike MS plan was developed. Because we focused on relationship development work and on the execution of an extraordinary Bike MS experience, we continue to have one of the strongest retention rates in the industry—and activation, participant fundraising and self-donor rates increase year-over-year.
- Walk MS** continues to rank among the top 10 walk/run peer-to-peer fundraising events in the nation. In FY18, Walk MS is hosted in more than 400 communities nationwide and attracts nearly 300,000 participants. In FY17, staff was aligned into one functional team for greatest impact in increasing future revenue, and in FY18, a unified Walk MS operational plan was developed. Early success includes the execution of a single, Society-wide promotion that generated more than 50,000 registrations and nearly \$6 million in revenue.
- DIY (Do-It-Yourself) Fundraising MS** continues to be a growing source of revenue. In FY18, there were more than 3,000 events generating \$4 million dollars. Recognizing this as a growing revenue area, additional features were added: a ‘do-your-own challenge’ option for endurance athletes, a DIY program for community engagement and community councils, and work to enhance the online tool that supports people engaged in this type of fundraising was launched.
- We successfully closed the largest **Individual Giving** research campaign in history and launched the largest campaign in MS fundraising history—the \$1 billion Breakthrough MS campaign. In the first two years of the campaign, we secured 33 six-figure gifts, 7 seven-figure gifts and the Society’s first eight-figure gift.
- National Corporate Sponsorship** increased by 15% over FY17. New Bike MS and Walk MS unified sponsorship strategies were created, and new tools and resources are being developed in FY19. Sponsorships from pharmaceutical companies increased, supporting special events, Services, MS Navigator, Clinical Fellowships and MS Breakthroughs.

# Staff and volunteers are supported so they are mobilized, fully engaged, powerful and effective leaders

## FY18 Progress

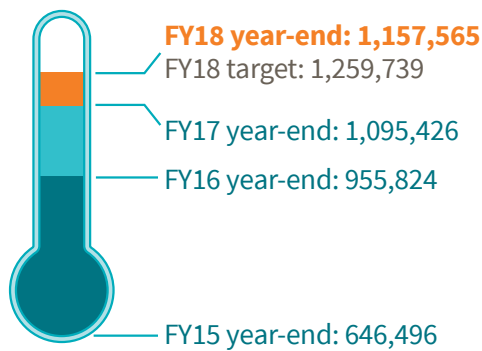


# We have enduring relationships that exceed expectations

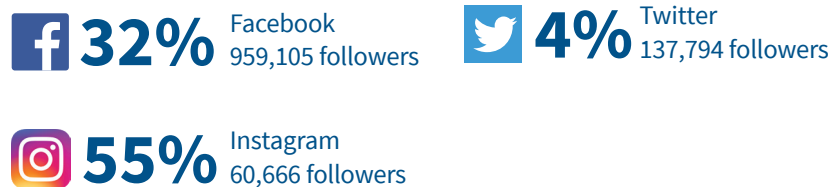
## FY16–18 Progress

### Social Media

#### Followers



#### Engagement

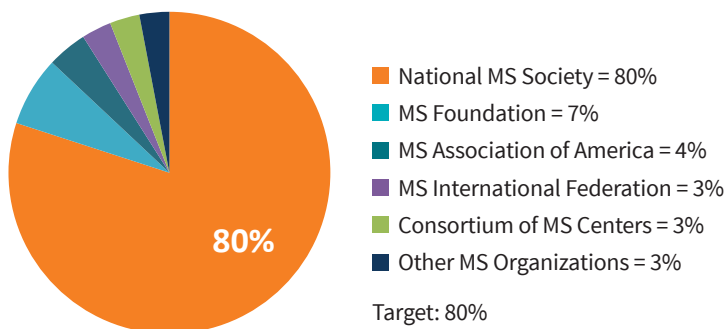


Engagement = actions taken in response to Society posts (e.g. likes, comments, retweets), divided by total number of social media followers

### Media Mentions



#### MS Organization Media Mentions



### Highlights & Notations

- We continued to strengthen our strategic partnership with Facebook allowing us to pilot new products such as **Facebook Fundraisers**—12% of Society event participants used this new fundraising tool, raising \$8.4 million between September 2017 and September 2018. An estimated 30% of the money generated from Facebook Fundraisers is from new donors.
- The Society was the go-to source for comment when the FDA approved Ocrevus, with stories in the **Wall Street Journal**, **Reuters**, **NBC News** and **CNN**
- **Bicycling Magazine** ran a **full-page story about Bike MS**, featuring some of our signature rides
- **Fox News**, **Billboard** and **Daily Mail** shared our statement supporting MS ambassador Noah Shebib and all people with disabilities in a controversy involving two hip-hop artists—increasing awareness in an industry and community where we don't have a big presence

2018  
**NATIONAL BOARD**  
**OF DIRECTORS**



KEVIN  
DIAGNOSED IN 1999



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[info@nationalMSSociety.org](mailto:info@nationalMSSociety.org)

# BREAKTHROUGH

# MS<sup>®</sup>

- 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](https://nationalMSSociety.org)**
- Become a research champion at **[nationalMSSociety.org/research](https://nationalMSSociety.org/research)**
- Make a donation of any size — in cash, by check or at **[nationalMSSociety.org/donate](https://nationalMSSociety.org/donate)**
- Defy MS by connecting with people around the world striving to live their best lives on **[MSconnection.org](https://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](https://nationalMSSociety.org/signup)**
- Meet others in the movement on **Facebook, Twitter** or **Instagram**
- Participate in a **Walk MS<sup>®</sup>, Bike MS<sup>®</sup>, Challenge Walk MS<sup>®</sup>, MuckFest MS<sup>®</sup>, 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](https://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](mailto:cyndi@nmss.org)**