



FIVE-YEAR

IMPACT REPORT



WHATEVER IT TAKES.

### 5 YEARS OF BREAKTHROUGHS

I am delighted to share the results of the National MS Society's Breakthrough MS® Campaign after the close of this historic five-year fundraising effort. Breakthrough MS was conceived to mark the beginning of the end of MS. It is a story of remarkable aspiration, dedication, resilience and belief that when we marshal the strength of our movement — our energy, our voices and our resources — anything is possible.

When we embarked on this campaign five years ago, it was time to seize the breakthroughs just beyond our grasp — ones that would change all aspects of life for people affected by MS. We knew the Society's comprehensive efforts to empower people, amplify voices and drive research discoveries would need attention and resources to achieve the impact we desired. What we didn't know is a once-in-a-lifetime pandemic would try its best to throw us off course. Despite the significant challenges we faced, we did not falter. We remained focused on changing lives and made unprecedented strides that have now positioned us to write the last chapter in our journey to end MS.

Through over \$900 million raised from 3.2 million supporters, with contributions ranging from \$35 to \$35 million dollars, we've achieved as much progress in the last five years as the 70 that preceded it.

With this generosity has come empowerment and optimism like we've never seen before. Lives have been changed through accessible one-on-one support available to all people whenever and wherever they need it. More people are connected to the Society and have the information and connections to live their best lives through innovative and inclusive programming. People are better equipped to seek the high-quality care they need through expanded resources, and more providers have the specialized knowledge to deliver care through new training opportunities.

And, with updated guidelines leading to quicker diagnosis and more treatment options than ever before, including the first-ever for primary progressive and pediatric MS, more people are experiencing fewer relapses and slower progression.

We share the success of Breakthrough MS with you because you've made it possible.

Whether you provided a special gift, attended or hosted an event, participated as a fundraiser, led an event team, amplified your voice with

elected officials, or volunteered your time and talent, you have turned ambition into action, agility into innovation, and most importantly, progress into breakthroughs.







Because of you,

the next chapter in our MS journey can be the last. Your support has ensured the breakthroughs ahead of us today will realize our first cures for MS and go down in history as the ones that helped end the disease forever. I look forward to continuing to recognize and celebrate what you made possible through Breakthrough MS and sharing more about our future as we embark on our next strategic plan.

With very best wishes and utmost gratitude,

Cyndi Zagieboylo President & CEO National MS Society



# THE IMPACT OF YOUR INVESTMENT: BREAKTHROUGH MS®

2021 marked 75 years of progress for the National MS Society — and thanks to your generous support of the Breakthrough MS Campaign, our progress has transformed the MS movement. Together, we achieved as much progress in the last five years as the 70 that preceded it.

Thanks to you, we've never been closer to a cure.

### **CAMPAIGN OVERVIEW**

In 2017, the Society launched Breakthrough MS — a bold fundraising initiative to accelerate breakthroughs for people affected by MS across all aspects of the Society's work. Through the generosity of over 3 million supporters, **the campaign achieved remarkable results**:

- Increasing the number of MS treatments and accelerating cures through global leadership
- Improving access to affordable, high-quality healthcare
- Empowering people affected by MS to solve everyday challenges
- Strengthening the MS movement through an expanded reach and deeper connections



WHATEVER IT TAKES.

### **KEY ACHIEVEMENTS**



- Society surpasses \$1 billion in MS research funding
- MS Navigator program launches nationwide ensuring all people affected by MS, regardless of location, have access to a supportive partner to overcome everyday challenges
- "McDonald Criteria" for diagnosing MS updated by Society Task Force, speeding time to diagnosis and helping ensure early treatment and slowed progression for many
- International Progressive MS Alliance launches its first Collaborative Network Awards bringing together leading scientists from across the globe to drive innovation and expedite drug discovery
- FDA approval of the first therapy for primary progressive MS

2018



- FDA approval of the first therapy for pediatric MS
- MS Activists help secure a unique 22% increase from Congress for the Lifespan Respite Program to provide accessible, community-based respite care services for family caregivers

2019

- Find Doctors & Resources online tool launches offering people easy access to MS specialists
- International MS Genetics Consortium confirms 233 gene variations that contribute to MS risk
- Pathways to Wellness in MS program launches providing people with the latest wellness and lifestyle information and solutions
- Society funds the **Atlas of MS update**, revealing there are an estimated 2.8 million people worldwide who have MS, with nearly 1 million of them living in the U.S.

2020



- ECHO MS launches for general healthcare professionals boosting the number of providers with MS specialty knowledge
- COVID-19 & MS Resource site, Ask an MS Expert and the Black MS
   Experience launch online offering timely, accessible and relevant forums for information, connections and support as the world changed
- Society fills an urgent need to understand the effects of COVID-19 on the MS population with COVIMS data collection and COVER-MS study



- FDA supports development of blood biomarker, neurofilament light, in clinical trials for progressive MS to speed drug development
- Society releases study **revealing the financial burden of MS** on people living with the disease and their families and the considerable cost of more than \$85.4 billion on the U.S. economy. Data equips the Society to support people and advocate for change.
- Society issues **Pathways to Cures** global scientific roadmap

Photos, top to bottom: Angela, MS Navigator; Joshua (center), diagnosed in 2015; Brian, diagnosed in 2012; Michelle, diagnosed in 2001; MS researcher.

#### EMPOWER PEOPLE AFFECTED BY MS TO SOLVE EVERYDAY CHALLENGES

Compared to five years ago, people with MS are more informed, connected and supported by loved ones, their communities and the Society so they can be more powerful than the challenges of MS. **Because of you, we:** 

### LAUNCHED THE MS NAVIGATOR®



nationwide program, **ensuring 100 percent** of people affected by MS, regardless of location, have access to a supportive partner to overcome everyday challenges



66 The MS Navigator service is help from people who just get me. The Navigator has your back, they see it from your point of view, are invested in you, finding a

solution to your problem. They do it without any judgment or without any preconceived idea of what the solution is. It's different from any kind of help I could get from anywhere else."

### - Rachel, diagnosed in 1993



As my MS progressed and I had to leave work, the emotional and financial strain on our lives was devastating. Then I met Dayna, and

my life changed. She negotiated the donation of an accessible van, and helped set me up with Medicaid and a neurologist. I'm now on disease modifying therapy and have home health aides."

- Patti, diagnosed in 2004

# RELEASED NEW VIRTUAL PROGRAMS



like **Ask an MS Expert, Pathways to Wellness** and the **Black MS Experience** to deliver timely and relevant information and connections through expanded channels that better meet the diverse needs of the MS movement



66 I am so honored to be a part of the Black MS Experience. It's an opportunity to be able to be open, vulnerable and transparent. Get some information that is much needed to help you better handle your MS."

- Tyler, diagnosed in 2007

Established the Society's website as

THE LARGEST AND MOST COMPREHENSIVE SOURCE OF COVID-19 AND MS

INFORMATION
AND RESOURCES



offering timely guidance during a turbulent time

66 [This pandemic has] also given us a lot of opportunities to connect in new ways. I appreciate everything going virtual, our support group has been able to meet more frequently and include more people from across the country...there are silver linings to this experience, too."

- Diane, diagnosed in 2010



#### **CAMPAIGN IMPACT BY THE NUMBERS**

MS Navigators supported **213 873** 

213,873 people to find lasting solutions

The Edward M. Dowd Personal Advocate program supported

**2,570** people with complex challenges

1,564

programs were delivered across the nation, both in-person and virtually, to

**107,570** people affected by MS

11,835

people have participated annually in self-help groups or peer-to-peer support

**80,741**people became part of our online connection communities

#### **ENSURE COMPREHENSIVE HIGH-QUALITY HEALTHCARE**

Since 2017, the Society has worked diligently to make comprehensive, high-quality healthcare and MS medications more affordable and accessible to all people with MS so they can live their best lives. **Because of you, we:** 

# GREW THE MS CLINICAL WORKFORCE



through **86 fellowships** to help more people access high-quality healthcare providers



66 I have decided on a specialty — I am looking at going into Neurology and then doing a fellowship in MS/ Neuroimmunology. This was largely due to the experience with the [Society's] mentorship program."

- Sage Hewitt, Mentee in 2019

# LAUNCHED THE FIND DOCTORS & RESOURCES



online tool for **easy access** to MS specialists

#### LAUNCHED ECHO MS

connecting MS specialists with general care providers across the country through a mentorship model, **boosting the number of providers** equipped to deliver specialized care to people with MS



We had hired a physician's assistant who was in primary care and had not seen MS patients. By the end of the program, he became very proficient at managing MS and seeing new MS patients. I recommend this program more highly than almost any other educational opportunity for MS care providers."

 Dennis Dietrich, MD Great Falls, Montana



### ADVOCATED ON BEHALF OF PEOPLE AFFECTED BY MS

to **end surprise billing** and **increase access** to generic medications

66 The Society's advocacy work is making a real impact in my life and the lives of others living with MS. Our collective voice is a powerful tool to create change and make an impact."

- Lisa, diagnosed in 2010



#### **CAMPAIGN IMPACT BY THE NUMBERS**

### 43,061

healthcare providers received personalized outreach from the Society, and

### 19,019

participated in professional education programs

### 130

general healthcare providers have participated in ECHO MS to learn from MS specialists There are now

#### 382

Partners in MS Care around the country—
99 more Partners than 5 years ago

**86** early career clinicians received MS specialty training

**94** students participated in the Medical Student Mentorship program

#### **DELIVER BREAKTHROUGHS TO A CURE**

Compared to five years ago, we know more about what people can do right now to take control of their MS and live better while we bring cures for MS within reach — stopping MS in its tracks, restoring what has been lost and ending MS forever. **Because of you, we:** 





of the **first therapy** for primary progressive MS and pediatric MS

## DEVELOPED AND GAINED GLOBAL CONSENSUS



on the most promising pathway to MS cures through the **Pathways to Cures roadmap** 



66 The National MS Society is providing global leadership to set a path forward that can, with effective international collaboration and innovation in MS research, accelerate progress and ultimately achieve cures in MS."

 Professor Alan Thompson, Chair of the International Progressive MS Alliance's Scientific Steering Committee

### UPDATED THE "MCDONALD CRITERIA"

for diagnosing MS, speeding time to diagnosis and helping **ensure early treatment** to slow progression for many



Led the International Progressive MS
Alliance in the launch of
3 COLLABORATIVE
NETWORK AWARDS

bringing together leading scientists from across the globe to **drive innovation and expedite drug discovery** 

# EXPANDED THE MS RESEARCH WORKFORCE



with **115 new fellows** to support the next generation of experts

**66** The Fellowship was the necessary stepping stone for my research career."

- 2021 Postdoctoral Research Fellow

#### **CAMPAIGN IMPACT BY THE NUMBERS**

Invested \$179.8 million to support MS research breakthroughs

115

early career researchers received fellowship awards

11

new disease-modifying therapies for MS have been approved by the FDA since 2017

### **DELIVER BREAKTHROUGHS TO A CURE (CONTINUED)**





66 For many years, progressive MS patients have been told there is nothing else that can be done for them, but now there is something else we can try—there is hope! It's beautiful to hear that we have new options."

- Brian, diagnosed in 1999

# IDENTIFIED AND ADDRESSED RACIAL AND HEALTH DISPARITIES AND COVID-19

by **engaging** in strategic partnerships, **committing** to disparity research and **leading** the COVIMS data collection and COVER-MS study

This important project is providing key answers to help people living with MS and their healthcare providers navigate the challenges of the COVID-19 pandemic.



### RECEIVED FDA SUPPORT

for the development of blood biomarker, neurofilament light, in clinical trials for progressive MS to **speed drug development** 

## ADVOCATED FOR RECORD-BREAKING FEDERAL RESEARCH FUNDING

**to increase MS breakthroughs,** including \$54 million from the MS Congressionally Directed Medical Research Program



#### HIGHLIGHTS OF BREAKTHROUGH STUDIES FUNDED BY THE SOCIETY:

- Larger-phase trials of antioxidant Lipoic Acid and statins to further evaluate their potential to reduce brain atrophy and rate of worsening for people with progressive MS
- New trials of cell-based therapies to test their ability to protect the nervous system and enhance myelin repair in progressive MS
- Recommendations for promoting exercise and lifestyle physical activity in people with MS at all disability levels
- Researchers discover a subset of brain cells that fight inflammation with instructions from gut bacteria, opening possibilities of new therapy approaches
- International Progressive MS Alliance studies advance biology-based MS disease subtypes and first hints of new approaches to boost myelin

#### **CAMPAIGN IMPACT BY THE NUMBERS**

MS Activists secured

### \$54 million

for the MS Research Program at the Department of Defense and helped secure a

\$194.3 billion

in increased funding from the National Institutes of Health

Committed

### \$25 million

to the International Progressive MS Alliance to expedite new therapies for progressive MS

#### **EXPAND REACH OF THE MS MOVEMENT**

Since 2017, the Society has made great strides in understanding the number of people living with MS and increasing the connections we have with these people to provide trusted, relevant information and support and to amplify their voices to drive change. **Because of you, we:** 



## FUNDED THE ATLAS OF MS UPDATE

revealing there are an estimated

2.8 million people worldwide

who have MS, with nearly 1 million
of them living in the U.S.

# AMPLIFIED THE VOICES



voices of over **34,000 people** affected by MS to advance life-changing legislation



**66** I take pride and get so much joy in being that connector and bringing people into this amazing movement to find solutions for some of the most challenging issues people with MS face, including myself."

- Janet, diagnosed in 2004



# **553,000**

people living with MS so **no one has to** face **MS** alone



- **66** The Society, to me, is a rock. They're there for you whenever you need."
- Elysa, diagnosed in 1989



## RELEASED THE ECONOMIC BURDEN OF MS

study revealing the cost of living and caring for someone with MS was **previously** 

**underestimated**. This data strengthens the evidence needed for the Society to better support people and for MS activists to **drive legislative change**.



- certirees like me are not choices at all: paying exponentially rising costs or stopping a therapy that has helped me to be mobile and independent for decades. That's when I became an MS activist. Because no one should have to pay that kind of money to live their best life."
- Diane, diagnosed in 1979

### **CAMPAIGN IMPACT BY THE NUMBERS**

Engaged **336**District Activist Leaders, **34,222** MS Activist
Network members and
delivered **100,000**messages to elected
officials

229

state-level issues became law thanks to the support of the Society The first ever Virtual Public Policy Conference in 2021 engaged

**3x more** participants than previous years

7.5 million people engaged with the Society—
2 million more than in 2017

**553,000** people with MS are connected to the Society, nearly 50,000 more than five years ago

## **THANK YOU**

Breakthrough MS® has transformed life for people affected by MS. This is a direct result of dedicated supporters like you who are devoted to doing something about MS and have confidence in the National MS Society's ability to drive progress forward.

We now know the next chapter in our journey to end MS could be the last. It's only been possible with you.

nationalMSsociety.org





**Photos, front cover — left to right, top to bottom:** Damian, diagnosed in 2015; Peter, diagnosed in 2015; Donna, diagnosed in 1989; Joshua, diagnosed in 2015; Johanie, diagnosed in 2015; Ellecia, diagnosed in 2011; Cermit, diagnosed in 1998; Doug, diagnosed in 2014; Crystal (center), diagnosed in 2010; Samir, diagnosed in 2005; Mike, diagnosed in 1983; Anqunette, diagnosed in 2013.

**Back cover** — **left to right, top to bottom:** Hannah, diagnosed in 2017; Eric, diagnosed in 2003; Rebecca, diagnosed in 2013; Jennifer, diagnosed in 1999; Brian, diagnosed in 2012; Jennifer, diagnosed in 2000; Angela, diagnosed in 1992; William, diagnosed in 2002; Beth, diagnosed in 2009; David, diagnosed in 1998.

