



# QUARTERLY UPDATE

SPRING 2019

## NEW STUDY CONFIRMS: TWICE AS MANY LIVING WITH MS IN THE U.S.

We've accomplished so much over the last two years—thanks to donors like you. Breakthrough MS® funding fuels services, advocacy, research and awareness so that people affected by MS can live their best lives as we seek a cure for this disease. You have played an important role—thank you!

Now, we've discovered that nearly 1 million people are living with MS in the United States, twice as many as originally thought.

We have long suspected that MS was under recognized in the United States, that it is a much bigger health concern for the country. Previous studies of MS prevalence estimated the number of people affected to be 400,000, but our new study, recently published in the prestigious medical journal **Neurology**, shows that **this number is almost 1 million**.

The results of this study mean that there are twice as many people in the U.S. today who need a cure for multiple sclerosis, twice as many people who need to know that their National MS Society can be a supportive partner in overcoming the challenges of MS. These people, and their families, are fortunate to have supporters like you who are actively investing in work that will create more breakthroughs. Thank you for contributing to our Breakthrough MS campaign!

Having an up-to-date, scientifically-sound estimate of how many people are living with MS helps us better understand and describe the extent of the burden MS puts on families and the scope of what is needed for people to live their best lives. It provides us with a benchmark for awareness—how many people have not yet connected with their National MS Society? This data also gives researchers insight into whether MS is increasing. We must raise more money to fund the research, programs and services that will change the lives of the nearly 1 million people with this unpredictable disease and their families.

We are always stronger together! Each of us have something important to contribute to this campaign, which is why I am so proud we have you by our side. We must continue to move forward to reach our \$1 billion goal and break through MS. From the bottom of my heart, thank you so much for being such a vital part of this movement.

With gratitude,

Cyndi Zagieboylo, President & CEO  
National MS Society



# 2x

AS MANY PEOPLE  
NEED OUR HELP TO  
**FIND A CURE**

#TWICEASMANY



"This new number will hopefully add to the sense of urgency to help find that cure. I believe that we are stronger in numbers — the more sisters and brothers I have fighting with me, the better my chances of winning!"

— Rita Joubran, diagnosed  
with MS in 2009

# TWICE AS MANY PEOPLE NOW NEED SOLUTIONS AND A CURE

Until we end this disease forever, we will do whatever it takes to accelerate breakthroughs and we can't do this without your ongoing, generous support. Whether you are one of the nearly one million people living with MS or want to make a difference for someone who is, we need you to help us grow the movement.

## This movement, by and for people living with multiple sclerosis, wouldn't exist without you.

You and thousands of people affected by MS shared their motivations and passions around who, as a movement, we aspire to be for people affected by MS. Watch this video, starring 14 people living with MS and their support systems, who share the power and resilience of this movement of which you are such a critical part.



<https://youtu.be/fEbf8RUA2og>

**We believe** that we all have something to contribute—whether it's time, money, connections or sheer passion. There is strength in numbers.

We are calling on you to help us expand the movement and continue providing the support needed to breakthrough MS. We need you. Give your best gift today so that together, we will create a world free of MS. ■

## QUESTIONS ABOUT #TWICEASMANY

### What is prevalence?

The number of people currently living with a disease.

### Why is this information important?

It leads to better understanding of the needs of people with MS and provides new clues for researchers.

### Where did the earlier MS prevalence number of 400,000 come from?

It was an estimate calculated from a population-based national study of MS prevalence published in 1981.

### What exactly is the updated MS prevalence number in the U.S.?

913,925

### Does this mean more people are getting MS?

This is yet to be determined.

### Will MS prevalence continue to be tracked?

Yes, through a new National Neurological Conditions Surveillance System being developed by the Centers of Disease Control.

### Where can I learn more?

[nationalMSSociety.org/Prevalence](http://nationalMSSociety.org/Prevalence)

## AN INSPIRING MS DONOR: BRINGING DIGNITY IN HIS MOTHER'S HONOR

Kevin Goetz's support of the National MS Society began shortly after his mother, Rhoda, was diagnosed with primary progressive multiple sclerosis at age 48. Rhoda, like many others across the country, was faced with the reality of losing abilities she once had, having to use a wheelchair and being forced to stop working. Fortunately, the Society was there to put Kevin and his family in touch with the programs and services that would help Rhoda cope with the many effects of her disease, including her diminished income.

Eleven years after being diagnosed, Rhoda passed away from a sudden and catastrophic embolism. It was during this time of loss that Kevin's fundraising for the Society—which had already included participating in Walk MS® annually—gathered significant momentum. He resolved to do all he could to help others with MS, and he would do it in memory of his dear mother.

"My heart breaks for those people around the country who have to go through what my mother went through early on," says Kevin. "There was a time she had to call the police just to help her get off the toilet. People who have this disease need help to retain their dignity and independence. They need to know they can pick up the phone and call the National MS Society."

Kevin speaks very fondly of his mother as an active woman who loved to cook, shop, and take good care of herself. While coping with the effects of MS, Rhoda looked forward to her weekly trips to the beauty parlor where she would have her nails painted and hair done. It was at those times that Kevin's mother saw a glimpse of her old self in the mirror and perked up with pride. This memory of his mother is what made Kevin decide to establish the Rhoda Goetz Foundation and work with the Society to start a personal care program for people with MS in 2005.

"I've heard so many stories of individuals we have helped through this program over the years and it's so beautiful," says Kevin.



"It's not out of the realm of possibility to think that we could eliminate this disease within our lifetime. Until then, we must open our hearts to help those who are having trouble helping themselves."

— Kevin Goetz, National MS Society Supporter

It's because of exemplary donors like Kevin Goetz that the National MS Society can be a supportive partner to people affected by MS whenever and wherever they need it, as well as provide backing to researchers who are uncovering insights that could lead to new treatments. Kevin feels strongly about supporting MS research and believes that we could be on the edge of eliminating this disease forever. His personal commitment to solving MS is an important part of what allows the Society to continue its work. You are also part of this caring community of donors, and together, we are gaining the momentum needed to achieve our vision—a world free of MS. ■

Eager to further expand the impact of his giving, **Kevin recently pledged \$100,000** to help all people with MS retain their dignity and independence through customized support from a Society MS Navigator.



# 2018 BARANCIK PRIZE WINNER UNLOCKS CLUE TO MS

## 2018 BARANCIK PRIZE WINNER



**Name:** Dr. Katerina Akassoglou

**Roles:** Senior Investigator at the Gladstone Institutes of Neurological Disease; Professor of Neurology at the University of California, San Francisco

**Research Focus:** The blood brain barrier during multiple sclerosis

**Goal:** Find new treatments for MS!

The Barancik Prize for Innovation in MS Research is made possible through the generous support of The Charles and Margery Barancik Foundation who, like you, are committed to finding new treatments and a cure for MS. Each year, the award honors an individual who has made a significant scientific contribution that holds great promise to impact the lives of people living with this disease.

Dr. Akassoglou, our 2018 award winner, has led a series of cutting-edge studies that could lead to a novel solution for people experiencing MS disability and progression.

Dr. Akassoglou has long been interested in the ways that the immune system is connected to multiple sclerosis. After discovering how little was known about the link between the immune system, the brain, and other vascular functions, she made a commitment to uncovering new connections between these disciplines. This has led her to begin researching how the blood brain barrier can contribute to MS symptoms, while trying to answer existing questions about how the blood affects the brain in MS.

To date, her team has uncovered the role of protein called fibrin, which hinders the body's natural repair abilities and triggers inflammation and nerve damage. Using an antibody that inhibits fibrin, her team has been able to decrease damage and actually protect the nervous system in both early and late phases of MS.

"I am curious to understand the mechanism of communication between the brain and the immune system and how they work together to induce pathology in the brain," said Dr. Akassoglou after her 2018 award win. "I'm inspired by the impact that new discoveries could make in the lives of MS patients. I've seen how much this

research means to people living with MS. They put hope in our hands to be able to develop a cure."

Dr. Akassoglou's lab has received vital support from donors like you over the years. She has received numerous Society grants to further her research, and the young investigators who work with her have received critical career support through Society fellowships. Her collaborative work has been essential to solving fundamental questions that will have a significant impact on understanding multiple sclerosis and improving the lives of people with the disease.

Dr. Akassoglou is one of many researchers who are helping innovation to flourish in MS research. Her contributions are leading us closer to developing new treatments that will change lives around the world. Your support of the pioneering work of our all our Barancik Prize winners is allowing for scientific discovery that could get us closer to ending MS forever. ■

**Congratulations to Dr. Akassoglou on winning the Barancik Prize in 2018. We stand behind her quest to find new treatments for MS.**

### **This year's winner nominated by . . . Dr. Daniel Reich, 2016 Barancik Prize Recipient**

"Winning the Barancik Prize two years ago helped me raise my credibility as a researcher and engage with a wider community of scientists and forward-thinking pharmaceutical companies. The recognition also brought my own science to a new level and helped me attract outstanding junior scientists and young doctors into my lab who can help push this field forward."



Dr. Daniel Reich

I nominated Katerina Akassoglou for the award in 2018 because her work is innovative, creative and significant. This prize asks people to think outside the box and take risks that may not otherwise be taken, in order to get more interesting and important results. The work that Katerina is doing will help us understand MS and also help us to fill unmet needs that patients have."