

Strength in numbers



New estimates of 1 million people living with MS in the U.S. could increase awareness, treatment and services.

by Aviva Patz

New research has shown that nearly 1 million people are living with multiple sclerosis in the United States—more than twice the last official estimate in 1976—and it may be a game-changer for the MS community.

“This study tells us many things, but one in particular is that twice as many people need a cure,” says Cyndi Zagieboylo, CEO of the National Multiple Sclerosis Society, which funded the study published in the February 2019 online issue of *Neurology*. “We’ve suspected for years that the previous estimate—400,000 people in the U.S. living with MS—was too low, but we needed a scientifically sound study to prove it.”

The MS community is just beginning to explore the impact of these new numbers, including how they will affect public awareness of the disease, rate of diagnosis, healthcare options, and funding for research and development of new treatments.

Here’s what might be next, according to MS experts and the people who are living with the disease.

About the research

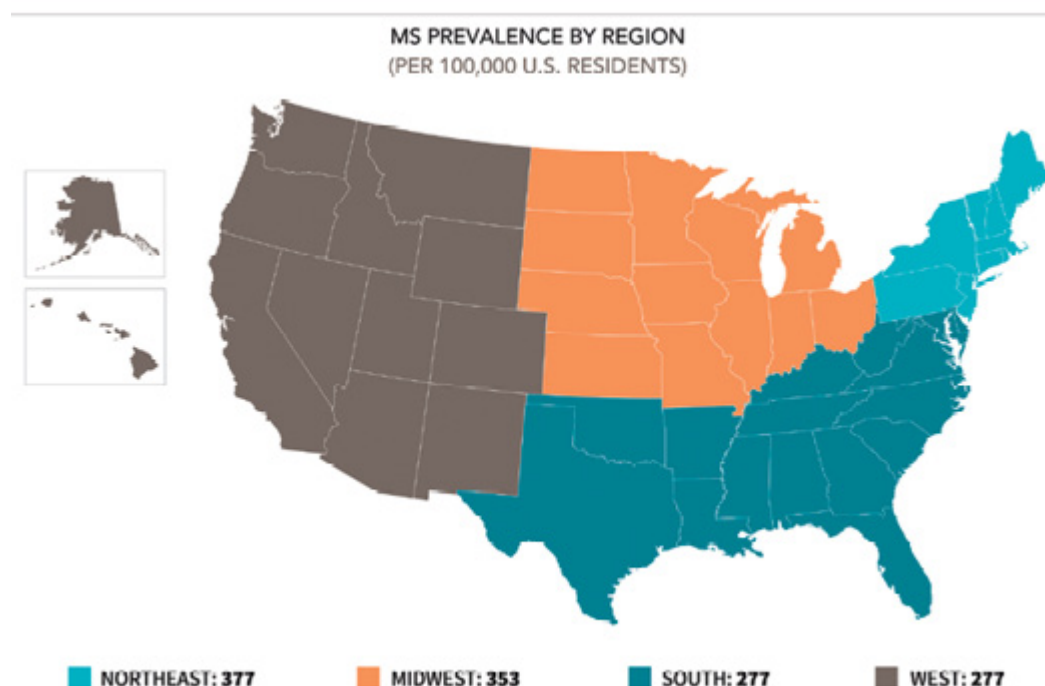
To address the gap in knowledge of how many people have MS (since the government does not require healthcare providers to report or track it), the Society brought together an international team of epidemiologists and other experts who looked at data on health care

claims to identify MS cases.

Their findings were dramatic but not unexpected: 362 per 100,000 people had MS in 2017, a steady climb from 309 per 100,000 in 2010, 85 per 100,000 in 1994, and 58 per 100,000 in 1976. Nearly three-quarters of the population living with MS are women, a more than 10 percent increase over data from 1976. The demographic with the highest prevalence (the number of people living with the diagnosis within a given period of time), according to the research, is women aged 45 to 54 in the Northeast United States; the group with the lowest prevalence is men aged 18 to 24 in the Southwest.

Why the big increase?

Since the last scientific study of prevalence is over 40 years old, it's no surprise that it's out of date. But have the numbers really more than doubled? "While the exact reason for this increase is unknown, we suspect it has more to do with developing a more accurate way to count people living with MS," explains Bari Talente, executive vice president of advocacy for the Society. She suggests the availability of disease-modifying treatments and improved diagnosis may also be factors. "There is evidence from other countries that the rate of MS may be increasing slightly. This is something that needs to be explored in more detail," she says.



Source: Wallin, Mitchell T.

What it means for people living with MS

The news is bittersweet. "I feel bad that there are now 500,000 more people fighting this frustrating, unpredictable disease," says Tim Hilton, of Lombard, Illinois, who has MS. "It also means there are even more of us fighting this battle than we thought, and the bigger

numbers give us more strength to beat MS.”

Zagieboylo says the new prevalence estimates have already prompted an increased interest in fundraising for the Society, to help finance more programs and services. “People are hoping that increased MS awareness will lead to more financial support, which will lead to breakthroughs of all kinds and, ultimately, a cure,” she says.

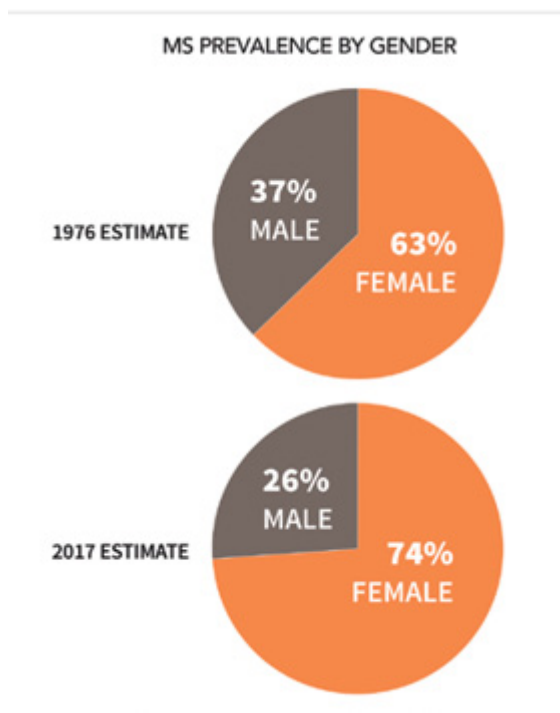
The findings also will help researchers and healthcare providers better meet the needs of the MS population.

“Understanding the community—knowing more about who is seeking treatment and where—is important so we can best serve that community and get them the resources they need,” Talente says. “And from an advocacy perspective, it’s important to show both the experience of individuals with MS and the impact of MS on the country—from the financial burden to effects on the health system and on other resources and services, because that paints a fuller picture of MS and allows us to advocate more effectively for what people with MS truly need.”

Not surprised by numbers

The news about the higher prevalence was encouraging for many. “We sang ‘hallelujah’ because as the MS community, we knew there had to be more people out there with this disease, but we couldn’t prove it,” says Nicole Ramirez-Hermann, of Sugar Land, Texas, who was diagnosed with MS in 2011. “Now we have proof.”

Talente says she doesn’t know a single person with MS who was surprised by the findings. “Most people encounter connections to MS as they’re living their daily lives. They tell someone they’re doing a Walk MS event and they hear that an aunt or a favorite teacher had MS,” she says. “People with MS have long had a sense that it’s been bigger than previously thought.”



Source: Wallin, Mitchell T.

Alisa Loucado, who was diagnosed with MS in 2005, believes the results are long overdue. “It seems like everywhere I turn, someone else is being diagnosed,” says the West Sunrise, Florida, resident. “It’s very frustrating but hopeful at the same time, as multiple sclerosis is becoming less of an enigma.”

What it means for awareness and perception

The study in *Neurology*, a highly respected medical journal, has already helped put MS on the active radar of the *New York Times*, the *Los Angeles Times* and other news outlets that covered the findings. It didn’t hurt that around the same time the study was released, actress Selma Blair went public with her MS—telling “*Good Morning America*” that she’d been suffering since 2011 with intense fatigue, emotional distress, and difficulties with speech and walking. It was also MS Awareness Week. “Those three things all at once created a lot of awareness in a short amount of time,” says Talente, who saw an uptick in the Society’s social media engagement, followers and website visits as a result.

Some people with MS, including Rita Joubran of Houston, Texas, hope the increased awareness will continue to attract talent to research and development. “The amount of awareness that has been raised in just the past 10 years has drawn so many bright, brilliant, and innovative minds to the professional field,” she says. When Joubran was first diagnosed with MS more than 10 years ago, she didn’t know anyone else who had MS or even what it was. “Now, as a family, we are doing everything in our power to ensure that MS is eradicated, so that no one will have to hear the words, ‘You have MS,’ ever again.”

People with MS are also eager to see the world learn more about the disease. “There are so

many misconceptions about MS, like it's a disease that puts you in a wheelchair," Loucado says. "I am not in a wheelchair and I have had this disease for at least 21 years."

For Ramirez-Hermann, it's about finally recognizing the severity of a disease that can often seem invisible. "In my opinion, the effect that this study has on the future of the disease is that it is bringing MS to the forefront and letting the world know that we are not going to lie down and be ignored anymore when, even though we may 'look good,' we have this debilitating disease."

The future of MS

What does the study mean going forward? "We still have a lot to do—there are twice as many people counting on us," Zagieboylo says. "Twice as many people means we are twice as powerful." She says advocates are amply justified in asking for increased funding for MS research.

The new studies, which put the number of Americans living with MS at anywhere from 851,749 to 913,925 people, may themselves offer a treasure trove of insights. "We're going to keep trying to understand what those numbers tell us," Talente says. "That's what prevalence gets us—it provides information for researchers to build new questions around."

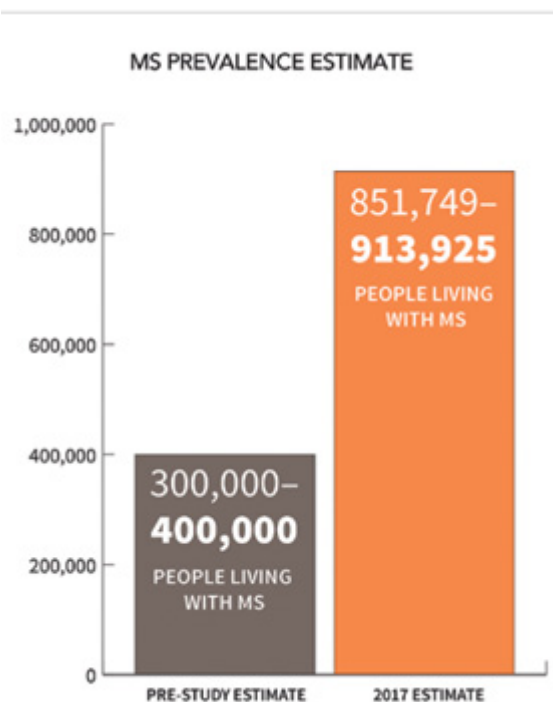
For example, she explains, researchers could look at smaller sections of the country and contrast data across periods of time to ask: "Are we seeing more cases of MS or is the number increased because people are living longer with MS?" It can also help identify geographic themes. "If you know there's a higher prevalence of MS in Michigan compared to Oklahoma, then you can look at what's different in those two places," she says.

The newest data show that people living in the Northeast, in states including Maine, New Hampshire, Vermont, Rhode Island, Massachusetts, New York, New Jersey and Pennsylvania, have a higher prevalence of MS (377 per 100,000) than people who live in the South and in the West (277 per 100,000).

Greater awareness will also ideally lead to more people getting accurate diagnoses. "I have had a front-row seat to the advancements that are being made, thanks to the leadership of the Society," Joubran says. "So much awareness has been raised, which I believe has contributed to better and earlier diagnosis."

Boosts to medical and other healthcare treatment

In simple terms, more people with MS means greater demand for quality treatment, which could lead to broader availability of care, a larger supply of healthcare providers with interest, experience and continuing education in MS care, and lower prices for medications and disease-modifying therapies (DMTs). With proof of higher prevalence, Zagieboylo says, "our fight for access to quality affordable healthcare and demand for affordable and accessible medication for people with MS is twice as important."



Source: Wallin, Mitchell T.

Bardia Nourbakhsh, MD, assistant professor of neurology at Johns Hopkins University, says while it's difficult to predict specific details on how the new numbers will affect care of people with MS, "based on these numbers, it is clear that we need more MS specialists to provide high-quality care for people with MS. We already knew that we had to spend more time and energy on answering difficult questions facing the MS community, such as how to slow down and stop disability worsening in people with progressive types of MS and how to restore functions that are lost.

These new prevalence numbers make those issues more urgent and pressing. The numbers show that MS is not a rare disease and affects millions of Americans directly or indirectly, and the resources needed for research, treatment and rehabilitation should be allocated accordingly."

Ideally, the new numbers open doors for more funding. Says Talente, "For researchers and industries looking into healthcare solutions for people with MS, we now have documentation that there's a robust population of people who need those services, whether medications or other services. There's a greater potential market, which is one factor companies may look at it when deciding how to invest their research and development dollars."

Hilton, for one, hopes that the numbers will lead to greater drug development and ultimately, lower drug prices.

Greater awareness of MS also is likely to inspire more people to seek a diagnosis. "We believe the study and the awareness it raises will prompt more people who are having symptoms to go and get checked out to see if they do in fact have MS," Zagieboylo says. "It's

an unpredictable disease and many people, like actress Selma Blair, live with the symptoms for years before being diagnosed. We hope the awareness around our study will encourage more people to seek answers. We know that early treatment is important.”

There is one possible downside to that. Ramirez-Hermann notes, “As more doctors might look for MS-type symptoms, I am afraid they will be too quick to say, ‘Oh, you’re having balance issues? Then you have MS,’” she says. “Because MS is what I like to call a ‘snowflake’ disease, meaning that there are no two people with MS that are affected the same way.”

Increased services for people with MS

Greater numbers may lead to more services. “With the results saying that now there are twice as many of us out here with this disease, hopefully there will be more of an avenue for all sorts of services to become available,” Ramirez-Hermann says.

MS researchers and advocates are looking forward to parsing the data further to reveal which services would be most helpful to the specific demographics of the people who are living with MS. “The next wave is being able to break down the numbers to the extent that we can understand these people,” Talente says, noting that for starters, the data confirms that MS affects three times as many women as men. “All of these things can help us plan services to make sure we can better reach the audiences that are out there.”

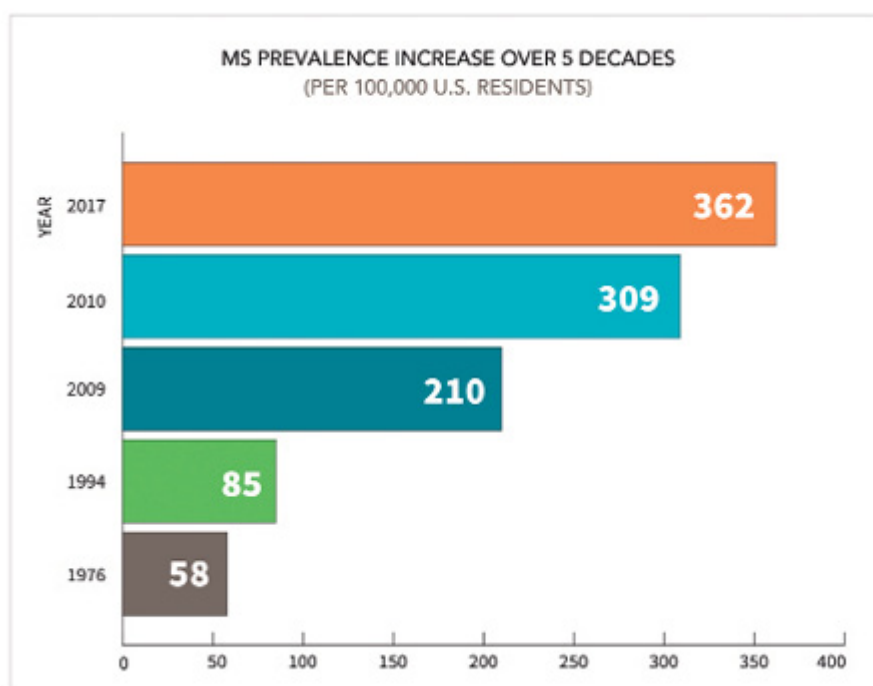
That path, according to Zagieboylo, begins with finding a way to connect with more people with MS. “They are out there, and we need to find them to make sure they have the information and resources they need to live their best lives,” she says, noting that the MS Navigator program is a prime resource to know about. The program connects people to resources in their own communities, and provides them with a lifelong supportive partner to navigate the challenges of living with MS. “We keep developing and improving our services so we can connect with everyone in the ways they want to connect. Technology and social media are massive accelerators. The breakneck pace of change in these areas is mind boggling, and also so exciting. We know we can do more. We have to do more. Connected people live happier lives—everyone needs connections,” she adds.

Advocacy and funding efforts

Ramirez-Hermann, who is an MS Ambassador in her area, believes the new numbers may inspire greater advocacy as well as bigger fundraising dollars.

“I am ever so hopeful that more major companies and corporations will get more involved and sponsor people who have this disease in their fundraising efforts.”

Two popular events to get involved in are Walk MS and Bike MS.



Source: Wallin, Mitchell T.

“The study has already had a significant effect on our advocacy efforts, and we hope it will have an effect on MS research funding,” Zagieboylo says. She recalls that the study came out in the printed version of *Neurology* on March 5, 2019, which also happened to be “Hill Day” in Washington, D.C., where hundreds of MS activists wearing MS orange descended on Capitol Hill to meet with members of Congress. “Armed with the study, they asked for increased funding for both the National Institutes of Health and the MS Research Program at the Department of Defense,” Zagieboylo says. “I was in a number of those meetings, and when we said there are twice as many people living with MS, members of Congress and their staff took notice. They asked follow-up questions and took notes. We were heard.”

Since MS is an expensive disease for people to live with and for the healthcare system to treat, Zagieboylo adds, being able to paint a realistic picture of what that looks like, based on the new prevalence findings, helps bring MS activists to the table in conversations about access to medications and health care. “It really is a profound report, and we hope it spurs action on both the state and federal levels. We have twice as many voices that need to be heard,” she says.

Aviva Patz is a writer in Montclair, New Jersey.

Contact an [MS Navigator](#) by calling 1-800-344-4867 or emailing ContactUsNMSS@nmss.org.

Learn more about the [MS prevalence study](#).