

In A Nutshell  
January 2020



## The Year 2019 in Review

It has long been 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 a new study, recently published in the prestigious medical journal **Neurology**, shows that **this number is almost 1 million**. Having an up-to-date, scientifically-sound estimate of how many people are living with MS helps to 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.

At the end of 2019 the NMSS held their Society Leadership Conference which brought together volunteer and staff leaders from across the country to set the course for the year and build momentum. Also, almost 100 research and clinical fellows came together for the Tykeson Fellows Conference which happens every other year in conjunction with our Leadership Conference. Bringing together both conferences provides early career researchers and budding MS specialists an opportunity to connect with those living with MS, passionate leaders in the MS Movement and funders of their research and training grants, and in turn provides other attendees a chance to learn about cutting-edge research happening right now by the next generation of MS researchers.

The NMSS has reached a profound new moment in the history of MS. They have the right priorities, partners, process, and track record to deliver the next generation of breakthroughs. The only question now, is how fast will it move. It is quite possible that the next chapter of the story could be the final chapter for MS.

Exciting breakthroughs to improve the lives of people affected by MS are being achieved. Recent progress includes the approval of two new treatments for MS. These two medications—siponimod (Mayzent®) and cladribine (Mavenclad®)—have been approved by the FDA for people with relapsing forms of MS, including active secondary progressive MS. People with active secondary progressive MS have had progression of disability but still experience acute relapses or new MRI activity.

The NMSS 2019-2021 Strategic Plan specifies the importance of gaining international consensus on pathways to a cure on the way to delivering breakthroughs to a cure.

The NMSS is funding a clinical trial to use people's own stem cells to treat progressive MS. Stem cells have the potential to decrease or even halt the progression of MS by slowing or repairing damage to the nervous system. Clinical trials help scientists study the optimal cells, delivery method, and safety of stem cell treatment. These trials are critically important in identifying breakthrough therapies.

There have been 14 new pilot research grants this year to test novel, high-risk/high-reward ideas. One of these pilot projects focuses on the way that probiotics combat changes in the gut microbiome during MS. Results of the study, if confirmed by larger trials, could potentially identify a dietary supplement to reduce MS symptoms. On-going wellness research like this helps to provide people with MS more options to proactively manage their disease through lifestyle choices. This investment is part of the most recent round of research grants, totaling \$24.4 million.

Escalating drug prices are creating significant barriers to MS treatment. Because of rising drug prices and the design of most insurance plans, a greater financial burden is being put on patients, putting some life-changing treatments out of reach. New treatments for MS cannot make a difference in people's lives if they're not accessible. With drugs coming to market at prices as high as \$99,500 per year, it's important that the NMSS continues to help combat high drug prices.

The Society's advocacy efforts were highlighted at this year's Public Policy Conference. The conference brings together nearly 300 MS activists from across the country to educate elected officials in Washington DC about the needs of people living with MS. By supporting the Society, you are helping to ensure that those diagnosed with MS have access to the treatments that will help them live their best lives possible.

Ending this disease forever will take dedicated investments into exploring all possible pathways to a cure – whether it's stopping MS progression, reversing damage and restoring lost function, or preventing the disease from occurring in the first place.

People affected by MS can count on the National MS Society as a lifetime supportive partner in living their best lives.

<https://www.nationalmssociety.org/Breakthrough-MS/Quarterly-Updates/Winter-2019-2020>

## Just for Fun

The NMSS has a twitter account named for the recent revelation that there are twice as many people living with MS than was previously thought. So, I decided to check it out.

1. Go to the app store and install twitter on your phone
2. Set up an account with an ID and password
3. Go to #twiceasmany and check out what one million people with MS are tweeting about.