

Search our website

> About the Society > MS Prevalence

### **MS** Prevalence

Worldwide prevalence

Worldwide, MS organizations have estimated that 2.3 million individuals are living with MS.

Improving reporting

You can help improve the accuracy of MS prevalence reporting by joining the Society in our collective efforts to advocate for the establishment of a national registry that would track MS prevalence in the US by joining the Society's <u>activist network</u>.

# MS prevalence

➤ Worldwide Prevalence: MS organizations have estimated that 2.3 million people are living with MS worldwide. However, in the U.S., there has not been a scientifically sound, national study of prevalence since 1975. Additionally, MS incidence and prevalence are not consistently reported or tracked in the U.S., and there is no government requirement to do so. In the absence of government-reported data, the National MS Society relies on scientifically-sound estimates of prevalence while we advocate for better and more systematic reporting and tracking at a nationwide level.

# National MS Society study to develop a new prevalence estimate

- ➤ To address the gap in prevalence estimates the Society launched the MS Prevalence Initiative with the goal of determining the best way to develop a scientifically sound and economically feasible estimate of the number of people in the U.S. who have MS. This initiative included leading experts in MS prevalence, who utilized administrative datasets from a variety of sources including Medicare, Medicaid, Veteran's Health Administration, and private insurers. This scientifically rigorous approach was necessary to ensure an accurate prevalence estimate.
- ▶ The Society's progress in updating the estimate of multiple sclerosis prevalence in the U.S. is vital to the MS movement both here and globally. Our increased understanding of the impact of MS on people's lives, including the individual and collective financial impact of managing MS, along with the healthcare and services people with MS need, is essential. A scientifically sound prevalence estimate will help researchers understand if MS is increasing, or if there are MS clusters that may hold clues to factors that may trigger MS. Additionally, it will ensure the continued acceleration of crucial research to ultimately find treatments and solutions for each person living with MS.
- ▶ Preliminary results of the study estimate that nearly 1 million people are living with MS in the U.S., which is more than twice the previously reported number. The results were presented in October 2017 at ECTRIMS the world's largest MS research meeting.
- An important next step in confirming this prevalence number includes anticipated publication in a prominent medical journal. Publication is expected in 2018, The final results will be broadly communicated as another



# Other related National MS Society work

- ➤ A National Neurological Conditions Surveillance System through the Centers for Disease Control and Prevention (CDC) was authorized through the 21<sup>st</sup> Century Cures Act.
- ▶ The Society, and MS advocates nationwide, advocated for the inclusion of the System in the 21<sup>st</sup>Century Cures Act to track and collect data on the epidemiology of neurological conditions. It is authorized for \$5 million a year from 2018-2022.
- Now that the System is authorized, MS activists and others with neurological conditions must advocate for funding for the CDC to create and manage the System.
- Learn more about this <u>issue</u>.
- ➤ To ensure that the voices of people with MS are heard, and that to advocate for funding for the System and for other issues important to people with MS, please join the <u>Society's activist network</u>.

#### **Definitions**

- **Prevalence** = the number of people living with a diagnosis of MS within a given period of time.
- **Incidence** = the number of people NEWLY diagnosed with MS within a given period of time.

