National Neurological Conditions Surveillance System

Request: Support $5 million for the National Neurological Conditions Surveillance System at the Centers for Disease Control and Prevention in the final FY19 LHHS Appropriations bill.

Congress must keep the promise of the 21st Century Cures Act.

- Currently, MS incidence and prevalence are not consistently reported or tracked by the U.S. government.
- The 21st Century Cures Act (P.L. No. 114-255) authorized the creation of the National Neurological Conditions Surveillance System (System) at the Centers for Disease Control and Prevention (CDC) in 2016.
- The law authorized $5 million a year for the System FY2018-FY2022, but did not provide the funding for it.
- The CDC cannot implement the System without dedicated funding from Congress.

The Society estimates that nearly 1 million people live with MS in the United States.

- Current data on how widespread MS is (prevalence) and the risk of developing MS (incidence) are critical for researchers and the health care community.
- Current, accurate and complete data on all neurologic conditions will expedite novel treatments, and allow for better anticipation of health care needs and more efficient utilization of resources.
- The CDC can utilize the Society's new data on MS prevalence to accelerate implementation of the System.
- The System could provide additional information to help researchers refine and target research questions, including:
  - Geographic clusters of conditions;
  - Demographic and genetic information (age, sex, race);
  - Outcome measures; and
  - Health care practices and utilization.

Wallin et al. The Prevalence of Multiple Sclerosis in the United States: A Population-Based Healthcare Database Approach. Poster presented at: European Committee For Treatment and Research In Multiple Sclerosis; 2017 October 25-18; Paris, France.

What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- MS interrupts the flow of information within the brain, and between the brain and body.
- Symptoms range from numbness and tingling to blindness and paralysis.
- The progress, severity and specific symptoms of MS in any one person cannot yet be predicted.

MS prevalence in the U.S.

- The National MS Society views research as a public/private partnership between our organization, academia and the federal government.
- The new Society estimate shows that MS prevalence is more than double the previous estimate.
- Previous MS prevalence estimates of 400,000 Americans living with MS were based on a 1975 study that was updated using population data.
- The Society launched the MS Prevalence Initiative to determine an estimate of the number of people in the U.S. who have MS. Publication of this estimate is expected in 2018.
Weyman, Georgia

“It’s a coincidence.”

Those are the words the Johnson family heard when yet another family member got diagnosed with multiple sclerosis back in the 1960s. Weyman Johnson’s father, aunt and sister were all living with the disease when he himself was diagnosed in 1990.

“We were told it was a coincidence my father and his older sister had MS,” recalls Weyman. “It just didn’t sound right.”

Because of his family history with the disease, Weyman has been particularly interested in genetic research. Current research suggests there may be many genes that contribute to MS susceptibility. But in order to fully understand how genetics plays a role in developing MS, researchers first need to understand how many people live with the disease.

How many families are like Weyman’s? How does geography, gender and ethnicity affect MS prevalence and progression?

With no concrete, current data to even begin answering these questions, MS researchers have difficulty identifying and pursuing potential leads of environmental, viral or genetic triggers that may influence the presence of MS.

And that’s why Weyman and his family support Congress providing $5 million to the Centers for Disease Control and Prevention (CDC) to implement the National Neurological Conditions Surveillance System, authorized by the 21st Century Cures Act.

“There are a lot of other families who are facing challenges like mine,” he shares. “The primary benefit this bill would have for all of us is that it would enable the research community to understand the disease better.”

With a better understanding of the disease, families may one day never have to face the initial onset of worry that flooded Weyman’s mind. Weyman knows that his own two daughters may have a predisposition to MS. Providing the funding to implement the National Neurological Conditions Surveillance System will help researchers take a tangible first and necessary step to unlock the possible causes and treatments for MS so that the next generation will never be affected by the disease.

“MS is a family disease. It affects everyone – family and friends,” he says. “I don’t want someone to ever see someone they care about have this kind of illness.”