



National Neurological Conditions Surveillance System

Request: Provide \$5 million for the Centers for Disease Control and Prevention's National Neurological Conditions Surveillance System in FY 2018.

Legislative Background

- Introduced in the 114th Congress as the Advancing Research for Neurological Diseases Act of 2015 (H.R. 292/S. 849) and garnered 129 bipartisan cosponsors in the House and 27 bipartisan cosponsors in the Senate.
- Included in the 21st Century Cure Act (Public Law No. 114-255):
 - The National Neurological Conditions Surveillance System (System) at the Centers for Disease Control and Prevention (CDC) will collect data to improve neurologic research.
 - 21st Century Cures authorized \$5 million a year for the the System from 2018-2022.
 - Congress must separately appropriate that money to the CDC for the System.

Accurate and Comprehensive Data Is Critical to Improving Research and Care

- Information collected will provide a foundation for the evaluation and understanding of neurological conditions, such as:
 - Incidence and prevalence;
 - Geographic clusters of conditions;
 - Demographic (age, sex, race) variability;
 - Outcome measures; and
 - Healthcare practices and utilization.
- The System will pull information from existing databases and sources such as Medicare, Medicaid and Veterans Affairs, as well as state and local MS registries.
- This data will:
 - Refine and target research, which will lead to novel treatments and cures.
 - Allow for better anticipation of healthcare needs and more efficient utilization of resources.

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.

How would the National Neurological Surveillance System help MS?

- The System will track and collect data on the epidemiology of neurological conditions, which may include MS.
- The last national study on the incidence and prevalence of MS was conducted in 1975.
- At the present time, MS incidence and prevalence are not consistently reported and tracked in the U.S.
- The absence of this data also slows MS research and drug development and makes it difficult to properly allocate health care services.



National
Multiple Sclerosis
Society

“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.”

