

SUPPORT \$5 MILLION FOR NATIONAL NEUROLOGICAL CONDITIONS SURVEILLANCE SYSTEM AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION

***** One in six Americans suffers from a neurologic condition, yet the U.S. lacks a coordinated system to collect and analyze data on these conditions. *****

**** THE REQUEST WILL BE CONSIDERED PROGRAMMATIC ****

Deadline: COB Tuesday, March 26, 2019

Dear Colleague:

Please join us in supporting a \$5 million line-item for the Centers for Disease Control and Prevention (CDC) in the FY 2020 Labor, Health, and Human Services Appropriations bill to implement a national neurological conditions surveillance system. This system was authorized by the 21st Century Cures Act, which was signed into law in December 2016 (Public Law 114-255). The underlying bill—the Advancing Research for Neurological Diseases Act (H.R. 292/S. 849 in the 114th Congress)—was cosponsored by 129 bipartisan Representatives and 27 bipartisan Senators. But money was never appropriated.

It is thought that one in six Americans suffers from a neurologic condition. However, many condition-specific figures are severely outdated. For instance, the last national study of prevalence and incidence of MS was done in 1975. Currently, the U.S. lacks a coordinated system to collect and analyze data on these conditions. Giving the CDC the ability to track the incidence and prevalence of neurological conditions is critical to understanding the epidemiological pathways of these conditions. The data collected by this system will significantly accelerate neurologic research by allowing more informed analysis of genetic and environmental risk factors. It also will provide a foundation for evaluating and understanding aspects of these conditions that we currently do not have a good grasp of, such as the geography and demographics of diagnoses, variances in gender, disease burden, and changes in health care practices and utilization among patients.

Ultimately, this data will increase the likelihood of discovering and developing new treatments and cures for neurological conditions.

We ask that you support our request of \$5 million line-item for the Centers for Disease Control and Prevention Research Programs in the FY 2020 Labor Health and Human Services Appropriations bill. Please contact Nancy.Perry@mail.house.gov in Congressman Larson's office or Shayne.Woods@mail.house.gov in Congressman Bilirakis's office by **COB, March 26th** to sign onto the attached letter.

Sincerely,

John B. Larson
Member of Congress

Gus M. Bilirakis
Member of Congress

Congress of the United States
Washington, DC 20515

March 28, 2019

The Honorable Rosa DeLauro
Chairwoman
Subcommittee on Labor, Health and
Human Services, Education and Related Agencies
House Committee on Appropriations
2358-B Rayburn House Office Building
Washington, D.C. 20515

The Honorable Tom Cole
Ranking Member
Subcommittee on Labor, Health and
Human Services and Related Agencies
House Committee on Appropriations
1016 Longworth House Office Building
Washington, D.C. 20515

Dear Chairwoman DeLauro and Ranking Member Cole:

On behalf of the millions of Americans living with neurological conditions and diseases, we urge you to continue Congress' \$5 million investment in the National Neurological Conditions Surveillance System (NNCSS) at the Centers for Disease Control and Prevention (CDC). This system was authorized by the 21st Century Cures Act, which was signed into law in December 2016, (Public Law 114-255) and received its first appropriation in FY19.

Estimates indicated that one in six Americans suffers from a neurologic condition. However, the U.S. lacks a coordinated system to collect and analyze data on neurologic conditions. Last year's appropriation allowed CDC to begin its developmental and implementation work, ensuring that the NNCSS is an effective tool for all stakeholders- patients, researchers, Congress and the public. The CDC is in the process of setting up demonstrations of the NNCSS, using two neurologic conditions- multiple sclerosis and Parkinson's disease, - in order to determine best practices in utilizing innovative methods and data sources. These demonstrations will help efficiently extend the NNCSS to other neurologic conditions.

Further appropriations will allow the NNCSS to expand to other neurologic conditions and collect data to help increase understanding of neurological disorders. This data will provide a foundation for evaluating and understanding aspects of these conditions that we currently do not have a good grasp of, such as the geography and demographics of diagnoses, variances in gender, disease burden, and changes in health care practices and utilization among patients. For the health care system, the data will allow for future planning of health care as the needs of those with neurological diseases can be assessed on a deeper level.

The data from the NNCSS will drive innovative research and expedite the development of novel therapies that are desperately needed by those who live with these conditions. We ask that you continue Congress' investment in the NNCSS and include a \$5 million line-item for the NNCSS at the CDC in the FY 2020 Labor, Health, and Human Services Appropriations bill.

Sincerely,

John B. Larson
Member of Congress

Gus M. Bilirakis
Member of Congress