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 (NCCSS) 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 NCCSS 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 NCCSS, 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 NCCSS to other neurologic conditions.

Further appropriations will allow the NCCSS 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 NCCSS 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 NCCSS and include a $5 million line-item for the NCCSS 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
Lisa Blunt Rochester
Member of Congress