Richard Blumenthal
United States Senator

Christopher A. Coons
United States Senator

Kirsten Gillibrand
United States Senator

Amy Klobuchar
United States Senator

Jack Reed
United States Senator

Chris Van Hollen
United States Senator

Cory A. Booker
United States Senator

Dianne Feinstein
United States Senator

Angus S. King, Jr.
United States Senator

Edward J. Markey
United States Senator

Kyrsten Sinema
United States Senator
The Honorable Roy Blunt  
Chairman, Subcommittee on Labor,  
Health, and Human Services, Education  
United States Senate  
Washington, D.C. 20510

The Honorable Patty Murray  
Ranking Member, Subcommittee on Labor,  
Health and Human Services, Education  
United States Senate  
Washington, D.C. 20510

Dear Chairman Blunt and Ranking Member Murray:

On behalf of the millions of Americans living with neurological conditions and diseases, we urge you to continue Congress’ full 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 fiscal year (FY) 2019.

Estimates indicate that one in six Americans suffers from a neurologic condition. However, figures for specific disorders may be outdated since the U.S. lacks a coordinated system to collect and analyze data on neurologic conditions. Fortunately, 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. The focus on these two demonstrations will help determine best practices in utilizing innovative methods and data sources to guide future application use of the NNCSS to other neurologic conditions.

Continued appropriations will ensure the success of the NNCSS expansion to other neurologic conditions. Additional opportunities to collect data will provide a foundation for evaluating aspects of neurological conditions that currently lack an adequate clinical understanding. For example, expansion of the NNCSS could yield information about the geography and demographics of diagnoses, variances in gender, disease burden, and changes in health care practices and utilization among patients with various neurological conditions. The data collected by the NNCSS will also help accelerate neurologic research by facilitating a more informed analysis of genetic and environmental risk factors. For the health care system, this information 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 line-item for the NNCSS at the CDC in the FY 2020 Labor, Health, and Human Services Appropriations bill.

Sincerely,

Christopher Murphy  
United States Senator

Johnny Isakson  
United States Senator