October 2, 2018

The Honorable Mitch McConnell
Majority Leader
United States Senate

The Honorable Charles Schumer
Minority Leader
United States Senate

The Honorable Paul Ryan
Speaker
United States House of Representatives

The Honorable Nancy Pelosi
Minority Leader
United States House of Representatives

Dear Majority Leader McConnell, Minority Leader Schumer, Speaker Ryan, and Minority Leader Pelosi:

On behalf of the entire neurological community, thank you for providing funding for the National Neurological Conditions Surveillance System within the joint FY2019 Defense and Labor, Health and Human Services and Education appropriations bills. The $5 million appropriation is an important next step in ultimately implementing a system to ensure that research on neurologic conditions is based on current data. Coupled with research, this modest program has the potential to benefit all Americans.

More than 100 million Americans live with one or more neurologic conditions; totaling almost one-third of the U.S. population. The data collected by the program will significantly accelerate research by allowing more informed analysis of genetic and environmental risk factors. It will provide a foundation for evaluating and understanding aspects of these conditions 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 services as the needs of those with neurological diseases can be assessed on a deeper level.

Again, thank you for ensuring this priority was funded and for your commitment to biomedical research.

Sincerely,
American Academy of Neurology
American Brain Coalition
American Neurological Association
American Parkinson Disease Association
Brain Injury Association of America
Brian Grant Foundation
Bridge the Gap - SYNGAP Education and Research Foundation
Consortium of Multiple Sclerosis Centers
Davis Phinney Foundation
Epilepsy Foundation
FND Hope
Friends of Parkinson’s, Inc.
Hawai‘i Parkinson’s Association
Houston Area Parkinson Society
Hydrocephalus Association
MS Views and News
Multiple Sclerosis Coalition
Multiple Sclerosis Foundation
National Alliance on Mental Illness
National Multiple Sclerosis Society
National Organization for Rare Disorders (NORD)
Northwest Parkinson's Foundation
Parkinson Association of the Rockies
Parkinson Voice Project
Parkinson's Foundation
Parkinson's Resources of Oregon
Patrick Risha CTE Awareness Foundation
Research!America
The Association for Frontotemporal Degeneration
The Michael J. Fox Foundation for Parkinson’s Research
The Parkinson Alliance
Tourette Association of America
Tuberous Sclerosis Alliance
United Spinal Association

Cc: United States Senate Committee on Appropriations Chairman Cochran
United States Senate Committee on Appropriations Vice Chairman Leahy
United States House of Representatives Committee on Appropriations Chairman Frelinghuysen
United States House of Representatives Committee on Appropriations Ranking Member Lowey
Conferees to the Department of Defense and Labor, Health and Human Services, and
Education Appropriations Act, 2019 and Continuing Appropriations Act, 2019