

September 13, 2017

The Honorable Mitch McConnell
Majority Leader
U.S. Senate

The Honorable Charles E. Schumer
Democratic Leader
U.S. Senate

The Honorable Thad Cochran
Chair
Committee on Appropriations
U.S. Senate

The Honorable Patrick Leahy
Vice Chairman
Committee on Appropriations
U.S. Senate

Dear Majority Leader McConnell, Leader Schumer, Chairman Cochran and Vice Chairman Leahy:

We, the undersigned groups, representing those living with neurological diseases and conditions, write to urge Congress to work in a bipartisan manner to pass a budget that adequately funds all national priorities, including both defense and non-defense discretionary (NDD) programs.

NDD programs play a vital role in the health and well-being of the lives and communities of people with neurological conditions. Because of the Budget Control Act of 2011 (BCA) and the lowered budget caps caused by sequestration, NDD programs have been cut to their lowest levels in over 50 years. These cuts impact investment in scientific discovery, and erode the public health infrastructure across the United States. Without changes, by the time the BCA expires in 2021, NDD programs will represent just 2 ½ percent of gross domestic product. Continued cuts to NDD programs hurt millions of Americans but do nothing to address the actual drivers of federal debt.

Last year, the 21st Century Cures Act (Public Law No: 114-255) was signed into law to create programs that invigorate medical research, promote innovation, and speed the development of new treatments for chronic diseases. While many of these programs have been funded, many others that are necessary to accomplish the goals of the 21st Century Cures Act, such as programs for mentally ill adults and systems that will provide basic information on chronic conditions, remain unfunded. Unfortunately, the current BCA mandated budget caps are too low to allow funding through the traditional appropriations process. Without an increased allocation, important programs that received broad bipartisan support will not be implemented.

Neurological Disease Surveillance System – Providing Data for the Public Health Sector

The 21st Century Cures Act authorized \$5 million for the creation of a system to track the incidence and prevalence of neurological conditions at the Centers for Disease Control and Prevention (CDC). Knowing basic data about the impacted population is critical to understanding the epidemiological pathways of these conditions. Estimates indicate that one in six Americans lives with a neurological condition; however, many condition-specific figures are severely outdated. For instance, the last national study of prevalence and incidence of multiple sclerosis (MS) was done in 1975, and data on the prevalence of Parkinson's disease is based on a

very limited 1985 study. Currently, the U.S. lacks a coordinated system to collect and analyze this data.

The data collected by this system 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 as the needs of those with neurological diseases can be assessed on a deeper level.

Ultimately, this data will increase the likelihood of discovering and developing new treatments and cures for neurological conditions, which will in turn save money in health care costs through decreased need for mandatory health-care funding like Medicare and Medicaid. The CDC's core discretionary budget has been cut approximately 20% over the past decade and almost 70% of their budget goes directly to state and local health departments and other external partners. This prevents the agency from being able to implement the system without dedicated funding. A small investment now has the potential to save billions of dollars in the future.

We urge Congress and the President to work together to find a balanced solution that puts an end to the destructive cycle of crisis-budgeting, eliminates sequestration, and stops cutting programs that Americans rely on every day to live their best lives.

Sincerely,

The Michael J. Fox Foundation
National Multiple Sclerosis Society
Accelerated Cure Project for Multiple Sclerosis
American Academy of Neurology
American Association of Chairs of Departments of Psychiatry
American Brain Coalition
American Society of Clinical Psychopharmacology
The Association for Frontotemporal Degeneration
Brain Injury Association of America
Brian Grant Foundation
Can Do MS
Consortium of Multiple Sclerosis Centers
Davis Phinney Foundation
Dementia Society of America
Epilepsy Foundation
Federation of Associations in Behavioral and Brain Sciences
Hawai'i Parkinson's Association
Houston Area Parkinson Society
Huntington's Disease Society of America
The Hydrocephalus Association
International Essential Tremor Foundation

International Organization of Multiple Sclerosis Nurses
MS Coalition
National Alliance on Mental Illness
MS Views and News
The Parkinson Alliance
The Parkinson's Unity Walk
Parkinson's Resources of Oregon
Power for Parkinson's
Tourette Association of America
Tuberous Sclerosis Alliance
United Spinal Association

cc:

Members of the Senate Appropriations Committee
Senator Johnny Isakson
Senator Richard Blumenthal
Senator Cory Booker
Senator Kristen Gillibrand
Senator Edward Markey