

May 13, 2016

The Honorable Michael Burgess  
U.S. House of Representatives  
2336 Rayburn House Office Building  
Washington, DC 20515

The Honorable Johnny Isakson  
U.S. Senate  
131 Russell Senate Office Building  
Washington, DC 20510

The Honorable Chris Van Hollen  
U.S. House of Representatives  
1707 Longworth House Office Building  
Washington, DC 20515

The Honorable Chris Murphy  
U.S. Senate  
136 Hart Senate Office Building  
Washington, DC 20510

CC: Energy and Commerce Committee

CC: Health, Education, Labor and  
Pensions Committee

Re: Conferencing the Advancing Research for Neurological Diseases Act

Representatives Burgess and Van Hollen, and Senators Isakson and Murphy,

On behalf of the undersigned organizations representing the needs of people with neurological conditions, we applaud you for your passionate leadership of the Advancing Research for Neurological Diseases Act (H.R. 292 / S. 849). We could not have made this much progress without your tireless dedication to improving the lives of people affected by neurological diseases. Thank you for including us in this process and keeping us apprised of ongoing developments concerning this legislation.

By establishing a data collection system to track the incidence and prevalence of neurological diseases, this bill will provide a foundation for evaluating and understanding aspects of neurological diseases on which we currently do not have a good grasp—such as the geography of diagnoses, variances in gender and disease burden. In February, changes were made to the Advancing Research for Neurological Diseases Act to secure its approval by the Senate Health, Education, Labor, and Pensions Committee. As the bill continues to advance, we wanted to stress the importance of certain provisions in the Advancing Research for Neurological Diseases Act. If, for instance, the bill is ultimately conferenced with the House-passed 21<sup>st</sup> Century Cures Act, we believe the conferencing process is a good opportunity to reach middle ground and ensure that the bill's final language is as strong as possible in order to achieve a successful data collection system that will prove beneficial to researchers.

As Congress continues to advance the Advancing Research for Neurological Diseases Act, we urge the following changes to the final conferenced version:

- Reinstating the \$25 million authorized appropriations so that the Centers for Disease Control and Prevention has adequate funds to develop the data collection system without compromising funds for other very important public health programs and services;
- Coupled with providing adequate funds, making the Secretary's establishment of the data collection system mandatory instead of permissive; and

- Give the Secretary of Health and Human Services, acting through the Director of the CDC, and in consultation with specified individuals and entities, the discretion to decide which neurological diseases and conditions will be tracked. Additionally, eliminate the restriction on the number of diseases and conditions to be tracked.

Thank you for your close attention to this matter. We believe that these changes are necessary to creating the most effective data collection system possible. We are incredibly grateful to have partnered with you in this endeavor. With our combined efforts, we are one step closer to better understanding, treating and finding cures for neurological diseases.

If you have any questions, please contact John Wylam at [john.wylam@nmss.org](mailto:john.wylam@nmss.org).

Thank you,

American Academy of Neurology  
American Brain Coalition  
Brain Injury Association of America  
Epilepsy Foundation  
EveryLife Foundation for Rare Diseases  
Hydrocephalus Association  
International Essential Tremor Foundation  
Michael J. Fox Foundation for Parkinson's Research  
National Multiple Sclerosis Society  
National Organization for Rare Disorders  
National Stroke Association  
Research!America  
Tourette Association  
United Spinal Association