

# Parkinson's Action Network Applauds Advancing Research for Neurological Diseases Act of 2015

January 13, 2015 [Statements & Press Releases](#)

*Bill would create a national data collection system for Parkinson's disease and other neurological diseases; Better data would lead to better research and services*

(WASHINGTON, January 13, 2015) – The Parkinson's Action Network (PAN) applauds the *Advancing Research for Neurological Diseases Act of 2015* introduced today by Rep. Michael C. Burgess (R-TX) and Rep. Chris Van Hollen (D-MD).

The *Advancing Research for Neurological Diseases Act of 2015* (H.R. 292) would create a national data collection system for neurological diseases, including Parkinson's disease. A national data collection system at the Centers for Disease Control will provide data on the epidemiology, incidence, and prevalence of Parkinson's, a progressive, neurodegenerative disease that affects an estimated 500,000 to 1.5 million Americans today. Better data would allow for future planning of health care needs, detect changes in health practices, assess disease burden, promote education about neurological diseases, and support a wide range of research initiatives.

"Having a national data collection system gathering critical information on Parkinson's disease would be a game changer," said Ted Thompson, CEO of the Parkinson's Action Network. "We have advocated for the federal government to engage in this area because researchers have long said that such a system will help ensure better and more effective research, better treatments, and better services for people living with Parkinson's disease and other neurological disorders. Our hope is that it would one day help contribute to ultimately finding a cure for Parkinson's."

This legislation, formally known as the *National Neurological Surveillance System Act*, passed the House of Representatives by voice vote in the 111th Congress and represents an opportunity to move neurological disease research in a meaningful way that aims to improve the lives of all Americans suffering from Parkinson's, multiple sclerosis, or other neurological diseases.

## Ask Congress to Support Data Collection for Parkinson's Disease!

How many Americans have Parkinson's? We don't know the exact answer to that question, but you can help us find out!

**TAKE ACTION!**

**Tell Congress that a National  
Data Collection System is  
Critical for Parkinson's  
Research**

Contact your Senators today and ask them to support the *Advancing Research for Neurological Diseases Act* (H.R. 292/S.849).

Last week, the House of Representative's Energy and Commerce Committee released a second draft of the *21st Century Cures Act*, a broad piece of legislation focused on accelerating the pace of cures in America through medical innovation. Thanks to your advocacy, H.R. 292 was included!

The *Advancing Research for Neurological Diseases Act* will create a nationwide system to track the incidence and prevalence of neurological diseases, including Parkinson's disease. Information collected will provide a foundation for evaluating and understanding aspects of these diseases on which we currently do not have a good grasp – such as the geography of diagnoses, variances in gender, disease burden and changes in healthcare practices among patients.

The House is expected to bring the *21st Century Cures Act* to a vote this summer. After that vote, the Senate will debate their version. Help ensure the same success in the Senate!

Please ask your Senators to show their support for this important priority by co-sponsoring the *Advancing Research for Neurological Disease Act* TODAY!

January 12, 2015

Dear Representatives Burgess and Van Hollen,

On behalf of the entire Parkinson's community, the Parkinson's Action Network (PAN) strongly supports the Advancing Research for Neurological Diseases Act of 2015. We applaud this important legislation to create a National Neurological Diseases Surveillance System at the Centers for Disease Control (CDC), which will collect data on neurological diseases, including Parkinson's disease. PAN is the unified voice of the Parkinson's community advocating for better treatments and a cure. In partnership with other Parkinson's organizations and our powerful grassroots network, we educate the public and government leaders on better policies for research and an improved quality of life for people living with Parkinson's. We estimate that between 500,000 to 1.5 million Americans are

living with Parkinson's disease but we do not have accurate information on how many are actually battling Parkinson's, and what causes the disease. This lack of core knowledge inhibits Parkinson's research, treatments, programs, and services. A national neurological surveillance system at the CDC will provide data on the epidemiology, incidence, and prevalence of this progressive, neurodegenerative disease. Better data would allow for future planning of health care needs, detect changes in health practices, assess disease burden, promote education about neurological diseases, and support a wide range of research initiatives. We thank you for introducing the bill in the 114th Congress and encourage Members of Congress to include this important legislation in the 21st Century Cures Initiative. It is our hope that a national data collection system focused on neurological diseases will facilitate research that may lead to discovery of breakthrough treatments, and, one day, a cure for Parkinson's, Multiple Sclerosis, and many other neurological diseases. Thank you for your continued commitment to the Parkinson's disease community. Please contact me at [tthompson@parkinsonaction.org](mailto:tthompson@parkinsonaction.org) or 202-638-4101 ext. 106 or Jennifer Sheridan Palute, director of policy, at [jpalute@parkinsonsaction.org](mailto:jpalute@parkinsonsaction.org) or 202-638-4101 ext. 112 if we can be helpful.

Sincerely, Ted Thompson, J.D. Chief Executive Officer