

[Advancing Research for Neurological Diseases Act of 2015 \(S 849, 114th Congress\)](#)

Establishes a neurological disease surveillance system to facilitate research.

Updated last **April 1, 2016**
for the 3/24/2015 version of S 849.

WHAT IT DOES

In an effort to facilitate further research, surveillance and reporting on the epidemiology and progression of neurological diseases such as Multiple Sclerosis and Parkinson's disease, [S 849](#) will amend the [Public Health Service Act](#) to establish a National Neurological Diseases Surveillance System. The system will:

- Enhance and expand the current infrastructure and activities within the [Centers for Disease Control and Prevention](#) (CDC) to track neurological disease, create an integrated surveillance system and facilitate further research.
- Be created through consultation with 1) epidemiologists who have experience with disease surveillance or registries, 2) national voluntary health associations, 3) health information technology experts, 4) clinicians, and 5) research scientists who have experience in translational research or use of surveillance systems.
- Ensure privacy protections meeting Health Insurance Portability and Accountability Act standards and be accessible to the public.
- Require periodic reporting to the Secretary of Health and Human Services.

Data collected will provide a foundation for understanding and evaluating basic epidemiology and progression of these diseases, resulting in better and more targeted treatments.

A total of \$25 million dollars over five fiscal years will be appropriated for this purpose (five million dollars per fiscal year between FY 2015 and FY 2019).

RELEVANT SCIENCE

[Neurological Disease](#): There are more than 600 neurological diseases. These diseases affect your central nervous system, including your brain and spinal cord, and/ or your peripheral nervous system, including your nerves and connections between your nerves and your muscles. Neurological diseases can interfere with your ability to move, to speak, to eat, and to breathe. They can also interfere with your ability to learn new information, your memory, your senses, and your emotions.

The neurological diseases mentioned by name in the bill are:

[Parkinson's Disease](#)

- A chronic and progressive movement disorder, characterized by the loss of dopamine-producing neurons.
- Symptoms include tremors, rigid muscles, slowed movement, and difficulty with posture, balance, walking and speech.
- Affects nearly [1 million](#) in the U.S.
- Cause is unknown and there is no cure.

[Multiple Sclerosis](#)

- A neuroinflammatory disease where the body's immune system attacks its own tissues. This immune system malfunction destroys myelin (the fatty substance that coats and protects nerve fibers in the brain and spinal cord). This disease can be

progressive, or can occur in isolated attacks with periods of remission between attacks.

- Symptoms can include problems with vision, muscle weakness, muscle spasms and difficult coordinating movements, problems with thinking, and emotional difficulties like depression.
- Prevalence in the U.S. is estimated between 250,000 - 350,000.

The cause is considered to be a combination of genetics and environmental factors, but the precise mechanism is unknown. There is no cure.

ENDORSEMENTS & OPPOSITION

Endorsements:

- S 849 has been endorsed by numerous neurological disease advocacy groups including the [National Multiple Sclerosis Society](#), [Parkinson's Action Network](#), and the [American Neurological Association](#). A [brief](#) released by the Parkinson's Action Network includes the endorsements of twelve advocacy groups and states, "Without basic data concerning the size and makeup of people with neurological diseases, our researchers are working at a distinct disadvantage. Additional information could lead to new treatment targets, better understanding of diseases, and ultimately their cures."

Opposition:

- As of February 11, 2016, there have not been any public statements opposing the bill.

STATUS

Introduced and referred to the Senate Committee on [Health, Education, Labor and Pensions](#) on March 24th, 2015. The bill was reported by the committee on February 9th, 2016, and will go to the full Senate chamber for consideration.

RELATED POLICIES

[HR 292](#) with the same title was introduced on January 13th, 2015 by Rep. [Michael C Burgess](#) (R-TX-26) and was initially referred to the House Committee on [Energy and Commerce](#) Subcommittee on [Health](#). Rep. [Chris Van Hollen](#) (D-MD-8), Rep. [Carolyn Maloney](#) (D-NY-12), Rep. [Peter King](#) (R-NY-2), and Rep. [Gus Bilirakis](#) (R-FL-12) were original co-sponsors.

HR 292 was included as a provision in [21st Century Cures Act](#), which passed the House on July 10th. Portions of that bill, but not the bill in its entirety, are now under consideration in the Senate.

POLICY HISTORY

The same bill was introduced in both the House and Senate in the 112th Congress under the title of the [National Neurological Diseases Surveillance System Act of 2011](#) (HR 2595), but never made it past committee in either chamber.

SPONSORS

S 849 is sponsored by Sen. [John "Johnny" Isakson](#) (R-GA), [Robert "Bob" Casey](#) (D-PA), [Christopher Murphy](#) (D-CT), [David Vitter \(R-LA\)](#) and [Roger Wicker \(R-MS\)](#) are original cosponsors.

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RECOMMENDED CITATION

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