



(Original Signature of Member)

112TH CONGRESS
1ST SESSION

H. R.

To amend the Public Health Service Act to provide for the establishment of permanent national surveillance systems for multiple sclerosis, Parkinson's disease, and other neurological diseases and disorders.

IN THE HOUSE OF REPRESENTATIVES

Mr. VAN HOLLEN (for himself and Mr. BURGESS) introduced the following bill; which was referred to the Committee on

A BILL

To amend the Public Health Service Act to provide for the establishment of permanent national surveillance systems for multiple sclerosis, Parkinson's disease, and other neurological diseases and disorders.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the "National Neurological
5 Diseases Surveillance System Act of 2011".

1 **SEC. 2. NATIONAL NEUROLOGICAL DISEASES SURVEIL-**
2 **LANCE SYSTEM.**

3 Part P of title III of the Public Health Service Act
4 (42 U.S.C. 280g et seq.) is amended by adding at the end
5 the following:

6 **“SEC. 399V-6. SURVEILLANCE OF NEUROLOGICAL DIS-**
7 **EASES.**

8 “(a) IN GENERAL.—The Secretary, acting through
9 the Director of the Centers for Disease Control and Pre-
10 vention, shall—

11 “(1) enhance and expand infrastructure and ac-
12 tivities to track the epidemiology of neurological dis-
13 eases, including multiple sclerosis and Parkinson’s
14 disease; and

15 “(2) incorporate information obtained through
16 such activities into a statistically-sound, scientif-
17 ically-credible, integrated surveillance system, to be
18 known as the National Neurological Diseases Sur-
19 veillance System.

20 “(b) RESEARCH.—The Secretary shall ensure that
21 the National Neurological Diseases Surveillance System is
22 designed in a manner that facilitates further research on
23 neurological diseases.

24 “(c) CONTENT.—In carrying out subsection (a), the
25 Secretary—

1 “(1) shall provide for the collection and storage
2 of information on the incidence and prevalence of
3 neurological diseases in the United States;

4 “(2) to the extent practicable, shall provide for
5 the collection and storage of other available informa-
6 tion on neurological diseases, such as information
7 concerning—

8 “(A) demographics and other information
9 associated or possibly associated with neuro-
10 logical diseases, such as age, race, ethnicity,
11 sex, geographic location, and family history;

12 “(B) risk factors associated or possibly as-
13 sociated with neurological diseases, including
14 genetic and environmental risk factors; and

15 “(C) diagnosis and progression markers;

16 “(3) may provide for the collection and storage
17 of information relevant to analysis on neurological
18 diseases, such as information concerning—

19 “(A) the epidemiology of the diseases;

20 “(B) the natural history of the diseases;

21 “(C) the prevention of the diseases;

22 “(D) the detection, management, and
23 treatment approaches for the diseases; and

24 “(E) the development of outcomes meas-
25 ures; and

1 “(4) may address issues identified during the
2 consultation process under subsection (d).

3 “(d) CONSULTATION.—In carrying out this section,
4 the Secretary shall consult with individuals with appro-
5 priate expertise, including—

6 “(1) epidemiologists with experience in disease
7 surveillance or registries;

8 “(2) representatives of national voluntary
9 health associations that—

10 “(A) focus on neurological diseases, includ-
11 ing multiple sclerosis and Parkinson’s disease;
12 and

13 “(B) have demonstrated experience in re-
14 search, care, or patient services;

15 “(3) health information technology experts or
16 other information management specialists;

17 “(4) clinicians with expertise in neurological
18 diseases; and

19 “(5) research scientists with experience con-
20 ducting translational research or utilizing surveil-
21 lance systems for scientific research purposes.

22 “(e) GRANTS.—The Secretary may award grants to,
23 or enter into contracts or cooperative agreements with,
24 public or private nonprofit entities to carry out activities
25 under this section.

1 “(f) COORDINATION WITH OTHER FEDERAL AGEN-
2 CIES.—Subject to subsection (h), the Secretary shall make
3 information and analysis in the National Neurological Dis-
4 eases Surveillance System available, as appropriate, to
5 Federal departments and agencies, such as the National
6 Institutes of Health, the Food and Drug Administration,
7 the Centers for Medicare & Medicaid Services, the Agency
8 for Healthcare Research and Quality, the Department of
9 Veterans Affairs, and the Department of Defense.

10 “(g) PUBLIC ACCESS.—Subject to subsection (h), the
11 Secretary shall make information and analysis in the Na-
12 tional Neurological Diseases Surveillance System avail-
13 able, as appropriate, to the public, including researchers.

14 “(h) PRIVACY.—The Secretary shall ensure that pri-
15 vacy and security protections applicable to the National
16 Neurological Diseases Surveillance System are at least as
17 stringent as the privacy and security protections under
18 HIPAA privacy and security law (as defined in section
19 3009(a)(2)).

20 “(i) REPORT.—Not later than 4 years after the date
21 of the enactment of this section, the Secretary shall sub-
22 mit a report to the Congress concerning the implementa-
23 tion of this section. Such report shall include information
24 on—

1 “(1) the development and maintenance of the
2 National Neurological Diseases Surveillance System;

3 “(2) the type of information collected and
4 stored in the System;

5 “(3) the use and availability of such informa-
6 tion, including guidelines for such use; and

7 “(4) the use and coordination of databases that
8 collect or maintain information on neurological dis-
9 eases.

10 “(j) DEFINITION.—In this section, the term ‘national
11 voluntary health association’ means a national nonprofit
12 organization with chapters, other affiliated organizations,
13 or networks in States throughout the United States.

14 “(k) AUTHORIZATION OF APPROPRIATIONS.—To
15 carry out this section, there is authorized to be appro-
16 priated \$5,000,000 for each of fiscal years 2012 through
17 2016.”.