

# Union Calendar No. 376

111<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 1362

[Report No. 111-636]

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.

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## IN THE HOUSE OF REPRESENTATIVES

MARCH 5, 2009

Mr. VAN HOLLEN (for himself, Mr. BURGESS, Mrs. MALONEY, Mr. UPTON, Mr. CARNAHAN, and Mr. KING of New York) introduced the following bill; which was referred to the Committee on Energy and Commerce

SEPTEMBER 28, 2010

Additional sponsors: Ms. LEE of California, Mr. TAYLOR, Mr. BISHOP of Georgia, Mrs. LUMMIS, Mrs. EMERSON, Mr. ANDREWS, Mr. BOUCHER, Mr. MORAN of Virginia, Ms. BORDALLO, Ms. HIRONO, Mr. MCGOVERN, Mr. FARR, Mr. DEFazio, Mr. SIRES, Mr. KUCINICH, Mr. GORDON of Tennessee, Mr. MCDERMOTT, Mr. WELCH, Mr. CONNOLLY of Virginia, Mr. OBERSTAR, Mr. LEWIS of Georgia, Mr. WOLF, Ms. KILPATRICK of Michigan, Mr. HINOJOSA, Ms. ESHOO, Mr. WALDEN, Mr. JONES, Mr. BOSWELL, Mr. SPRATT, Mr. JOHNSON of Georgia, Mr. PATRICK J. MURPHY of Pennsylvania, Ms. KAPTUR, Mr. YARMUTH, Mr. ROGERS of Alabama, Mr. CARSON of Indiana, Mr. HOLDEN, Mr. SERRANO, Mr. WITTMAN, Mr. ROTHMAN of New Jersey, Ms. BALDWIN, Mr. RUPPERSBERGER, Ms. SCHAKOWSKY, Mr. BUCHANAN, Mr. TERRY, Mr. CULBERSON, Mr. YOUNG of Alaska, Mr. MORAN of Kansas, Mr. BACHUS, Mr. GEORGE MILLER of California, Ms. LINDA T. SÁNCHEZ of California, Mr. SESTAK, Mr. RUSH, Mr. SPACE, Ms. SCHWARTZ, Mr. DAVIS of Alabama, Mrs. SCHMIDT, Mr. GERLACH, Mr. CLEAVER, Mr. HARE, Mr. LEE of New York, Ms. FUDGE, Mr. PUTNAM, Ms. CASTOR of Florida, Mr. LEVIN, Mr. FORTENBERRY, Ms. WOOLSEY, Mr. MCCARTHY of California, Mr. MITCHELL, Mr. BOYD, Mr. LATHAM, Ms. DEGETTE, Mr. SOUDER, Mr. DONNELLY of Indiana, Mr. PLATTS, Mr. ROSS, Mrs. BLACKBURN, Mr. COHEN, Mrs. CAPPS, Mr. ABERCROMBIE, Mr. ALTMIRE, Mr. FILNER, Mr. ELLISON, Mr. COBLE, Mr. FORBES, Ms.

ROYBAL-ALLARD, Mr. PETERSON, Mr. GENE GREEN of Texas, Mr. DAVIS of Illinois, Mr. DICKS, Mr. HOLT, Mr. HIMES, Mr. KENNEDY, Mr. KLEIN of Florida, Mr. PASCRELL, Mr. GALLEGLY, Mr. REICHERT, Mr. SESSIONS, Mr. HARPER, Mr. INSLEE, Ms. WASSERMAN SCHULTZ, Mr. SNYDER, Mr. REHBERG, Mrs. BIGGERT, Mr. MILLER of North Carolina, Mr. YOUNG of Florida, Mr. CAO, Mr. HODES, Mr. MCCOTTER, Mr. TURNER, Mr. CRENSHAW, Ms. BERKLEY, Ms. MATSUI, Mr. DRIEHAUS, Mr. POSEY, Mr. BISHOP of New York, Ms. DELAURO, Mr. BAIRD, Mr. LANGEVIN, Mr. LIPINSKI, Mr. LINCOLN DIAZ-BALART of Florida, Mr. EHLERS, Mr. BERMAN, Mr. MURPHY of Connecticut, Mr. WILSON of South Carolina, Mr. BRALEY of Iowa, Mr. WU, Mr. LOBIONDO, Mr. MOORE of Kansas, Mr. HONDA, Mr. MANZULLO, Mr. LATOURETTE, Mr. GONZALEZ, Mr. BOCCIERI, Mr. MCNERNEY, Mr. OLVER, Mr. PRICE of North Carolina, Mr. BOOZMAN, Mr. SCHIFF, Mr. KIRK, Mr. ROE of Tennessee, Mrs. DAVIS of California, Mr. TIBERI, Mr. THOMPSON of California, Mr. HINCHEY, Ms. MCCOLLUM, Mr. CALVERT, Mr. STARK, Mr. MASSA, Mr. FRANK of Massachusetts, Mr. HALL of New York, Mr. THORNBERRY, Ms. KOSMAS, Mr. SCOTT of Virginia, Mr. MILLER of Florida, Mr. AUSTRIA, Mr. BLUNT, Mr. MARKEY of Massachusetts, Mr. MICHAUD, Mr. MARSHALL, Mr. GINGREY of Georgia, Mr. BOREN, Mr. TOWNS, Mr. CASTLE, Mr. CHAFFETZ, Mr. WEINER, Ms. NORTON, Mr. PITTS, Mr. KLINE of Minnesota, Ms. LORETTA SANCHEZ of California, Mr. MELANCON, Mr. FRELINGHUYSEN, Mr. MATHESON, Ms. SUTTON, Ms. MOORE of Wisconsin, Mr. NYE, Mr. HEINRICH, Mr. DEUTCH, Mr. BLUMENAUER, Mr. GUTHRIE, Mr. TIAHRT, Mr. NADLER of New York, Mrs. MCMORRIS RODGERS, Mr. SCHOCK, Ms. PINGREE of Maine, Mr. COSTA, Mr. FATTAH, Ms. EDWARDS of Maryland, Ms. CLARKE, Mrs. DAHLKEMPER, Mr. HIGGINS, Mrs. CHRISTENSEN, Mr. THOMPSON of Mississippi, Mrs. NAPOLITANO, Mr. LARSEN of Washington, Mr. LUETKEMEYER, Mr. COSTELLO, Mr. WILSON of Ohio, Mr. GRAVES of Missouri, Mr. KISSELL, Ms. SPEIER, and Mr. DENT

SEPTEMBER 28, 2010

Reported with an amendment, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in *italie*]

[For text of introduced bill, see copy of bill as introduced on March 5, 2009]

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## 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 2010”.*

6 **SEC. 2. NATIONAL NEUROLOGICAL DISEASES SURVEIL-**  
7 **LANCE SYSTEM.**

8 *Part P of title III of the Public Health Service Act*  
9 *(42 U.S.C. 280g et seq.) is amended by adding at the end*  
10 *the following:*

11 **“SEC. 399V-5 SURVEILLANCE OF NEUROLOGICAL DISEASES.**

12 *“(a) IN GENERAL.—The Secretary, acting through the*  
13 *Director of the Centers for Disease Control and Prevention,*  
14 *shall—*

15 *“(1) enhance and expand infrastructure and ac-*  
16 *tivities to track the epidemiology of neurological dis-*  
17 *eases, including multiple sclerosis and Parkinson’s*  
18 *disease; and*

19 *“(2) incorporate information obtained through*  
20 *such activities into a statistically-sound, scientif-*  
21 *ically-credible, integrated surveillance system, to be*  
22 *known as the National Neurological Diseases Surveil-*  
23 *lance System.*

24 *“(b) RESEARCH.—The Secretary shall ensure that the*  
25 *National Neurological Diseases Surveillance System is de-*

1 *signed in a manner that facilitates further research on neu-*  
2 *rological diseases.*

3 “(c) *CONTENT.*—*In carrying out subsection (a), the*  
4 *Secretary—*

5 “(1) *shall provide for the collection and storage*  
6 *of information on the incidence and prevalence of*  
7 *neurological diseases in the United States;*

8 “(2) *to the extent practicable, shall provide for*  
9 *the collection and storage of other available informa-*  
10 *tion on neurological diseases, such as information*  
11 *concerning—*

12 “(A) *demographics and other information*  
13 *associated or possibly associated with neuro-*  
14 *logical diseases, such as age, race, ethnicity, sex,*  
15 *geographic location, and family history;*

16 “(B) *risk factors associated or possibly asso-*  
17 *ciated with neurological diseases, including ge-*  
18 *netic and environmental risk factors; and*

19 “(C) *diagnosis and progression markers;*

20 “(3) *may provide for the collection and storage*  
21 *of information relevant to analysis on neurological*  
22 *diseases, such as information concerning—*

23 “(A) *the epidemiology of the diseases;*

24 “(B) *the natural history of the diseases;*

25 “(C) *the prevention of the diseases;*

1           “(D) the detection, management, and treat-  
2           ment approaches for the diseases; and

3           “(E) the development of outcomes measures;  
4           and

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

7           “(d) CONSULTATION.—In carrying out this section, the  
8           Secretary shall consult with individuals with appropriate  
9           expertise, including—

10           “(1) epidemiologists with experience in disease  
11           surveillance or registries;

12           “(2) representatives of national voluntary health  
13           associations that—

14           “(A) focus on neurological diseases, includ-  
15           ing multiple sclerosis and Parkinson’s disease;  
16           and

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

19           “(3) health information technology experts or  
20           other information management specialists;

21           “(4) clinicians with expertise in neurological  
22           diseases; and

23           “(5) research scientists with experience con-  
24           ducting translational research or utilizing surveil-  
25           lance systems for scientific research purposes.

1       “(e) *GRANTS.*—*The Secretary may award grants to,*  
2 *or enter into contracts or cooperative agreements with, pub-*  
3 *lic or private nonprofit entities to carry out activities under*  
4 *this section.*

5       “(f) *COORDINATION WITH OTHER FEDERAL AGEN-*  
6 *CIES.*—*Subject to subsection (h), the Secretary shall make*  
7 *information and analysis in the National Neurological Dis-*  
8 *eases Surveillance System available, as appropriate, to Fed-*  
9 *eral departments and agencies, such as the National Insti-*  
10 *tutes of Health, the Food and Drug Administration, the*  
11 *Centers for Medicare & Medicaid Services, the Agency for*  
12 *Healthcare Research and Quality, the Department of Vet-*  
13 *erans Affairs, and the Department of Defense.*

14       “(g) *PUBLIC ACCESS.*—*Subject to subsection (h), the*  
15 *Secretary shall make information and analysis in the Na-*  
16 *tional Neurological Diseases Surveillance System available,*  
17 *as appropriate, to the public, including researchers.*

18       “(h) *PRIVACY.*—*The Secretary shall ensure that pri-*  
19 *vacy and security protections applicable to the National*  
20 *Neurological Diseases Surveillance System are at least as*  
21 *stringent as the privacy and security protections under*  
22 *HIPAA privacy and security law (as defined in section*  
23 *3009(a)(2)).*

24       “(i) *REPORT.*—*Not later than 4 years after the date*  
25 *of the enactment of this section, the Secretary shall submit*

1 *a report to the Congress concerning the implementation of*  
2 *this section. Such report shall include information on—*

3 *“(1) the development and maintenance of the*  
4 *National Neurological Diseases Surveillance System;*

5 *“(2) the type of information collected and stored*  
6 *in the System;*

7 *“(3) the use and availability of such informa-*  
8 *tion, including guidelines for such use; and*

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

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

16 *“(k) AUTHORIZATION OF APPROPRIATIONS.—To carry*  
17 *out this section, there is authorized to be appropriated*  
18 *\$5,000,000 for each of fiscal years 2012 through 2016.”.*

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11<sup>TH</sup> CONGRESS  
2<sup>D</sup> Session

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