

**AMENDMENT IN THE NATURE OF A SUBSTITUTE  
TO H.R. 1362  
OFFERED BY M . \_\_\_\_\_**

Strike all after the enacting clause and insert the following:

**1 SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “National Neurological  
3 Diseases Surveillance System Act of 2010”.

**4 SEC. 2. NATIONAL NEUROLOGICAL DISEASES SURVEIL-  
5 LANCE SYSTEM.**

6 Part P of title III of the Public Health Service Act  
7 (42 U.S.C. 280g et seq.) is amended by adding at the end  
8 the following:

**9 “SEC. 399V-5. SURVEILLANCE OF NEUROLOGICAL DIS-  
10 EASES.**

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

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

1           “(2) incorporate information obtained through  
2           such activities into a statistically-sound, scientifi-  
3           cally-credible, integrated surveillance system, to be  
4           known as the National Neurological Diseases Sur-  
5           veillance System.

6           “(b) RESEARCH.—The Secretary shall ensure that  
7           the National Neurological Diseases Surveillance System is  
8           designed in a manner that facilitates further research on  
9           neurological diseases.

10          “(c) CONTENT.—In carrying out subsection (a), the  
11          Secretary—

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

15                 “(2) to the extent practicable, shall provide for  
16                 the collection and storage of other available informa-  
17                 tion on neurological diseases, such as information  
18                 concerning—

19                         “(A) demographics and other information  
20                         associated or possibly associated with neuro-  
21                         logical diseases, such as age, race, ethnicity,  
22                         sex, geographic location, and family history;

23                         “(B) risk factors associated or possibly as-  
24                         sociated with neurological diseases, including  
25                         genetic and environmental risk factors; and

1 “(C) diagnosis and progression markers;

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

5 “(A) the epidemiology of the diseases;

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

7 “(C) the prevention of the diseases;

8 “(D) the detection, management, and  
9 treatment approaches for the diseases; and

10 “(E) the development of outcomes meas-  
11 ures; and

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

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

17 “(1) epidemiologists with experience in disease  
18 surveillance or registries;

19 “(2) representatives of national voluntary  
20 health associations that—

21 “(A) focus on neurological diseases, includ-  
22 ing multiple sclerosis and Parkinson’s disease;  
23 and

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

1           “(3) health information technology experts or  
2           other information management specialists;

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

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

8           “(e) GRANTS.—The Secretary may award grants to,  
9           or enter into contracts or cooperative agreements with,  
10          public or private nonprofit entities to carry out activities  
11          under this section.

12          “(f) COORDINATION WITH OTHER FEDERAL AGEN-  
13          CIES.—Subject to subsection (h), the Secretary shall make  
14          information and analysis in the National Neurological Dis-  
15          eases Surveillance System available, as appropriate, to  
16          Federal departments and agencies, such as the National  
17          Institutes of Health, the Food and Drug Administration,  
18          the Centers for Medicare & Medicaid Services, the Agency  
19          for Healthcare Research and Quality, the Department of  
20          Veterans Affairs, and the Department of Defense.

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

1       “(h) PRIVACY.—The Secretary shall ensure that pri-  
2 vacy and security protections applicable to the National  
3 Neurological Diseases Surveillance System are at least as  
4 stringent as the privacy and security protections under  
5 HIPAA privacy and security law (as defined in section  
6 3009(a)(2)).

7       “(i) REPORT.—Not later than 4 years after the date  
8 of the enactment of this section, the Secretary shall sub-  
9 mit a report to the Congress concerning the implementa-  
10 tion of this section. Such report shall include information  
11 on—

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

14               “(2) the type of information collected and  
15 stored in the System;

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

18               “(4) the use and coordination of databases that  
19 collect or maintain information on neurological dis-  
20 eases.

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

1       “(k) AUTHORIZATION OF APPROPRIATIONS.—To  
2 carry out this section, there is authorized to be appro-  
3 priated \$5,000,000 for each of fiscal years 2012 through  
4 2016.”.

