

110TH CONGRESS
2D SESSION

H. R. 5874

To amend the Public Health Service Act to provide for the establishment of a permanent Multiple Sclerosis National Surveillance System.

IN THE HOUSE OF REPRESENTATIVES

APRIL 22, 2008

Mr. BURGESS (for himself and Mr. CARNAHAN) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to provide for the establishment of a permanent Multiple Sclerosis National Surveillance System.

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 MS Disease
5 Registry Act”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) Multiple sclerosis (referred to in this section
9 as “MS”) is a progressive, disabling disease that af-

1 fects the brain and the spinal cord causing loss of
2 myelin, damage to axons, and cerebral atrophy.

3 (2) MS is a prime-of-life disease with an aver-
4 age age of onset at 30 to 35 years of age.

5 (3) The causes of MS are not well understood.

6 (4) There is no known cure for MS.

7 (5) There are several drugs currently approved
8 by the Food and Drug Administration for the treat-
9 ment of MS, which have shown modest success in re-
10 ducing relapses, slowing progression of disability,
11 and limiting the accumulation of brain lesions.

12 (6) More than 10,000 individuals in the United
13 States are diagnosed with MS annually, and it is
14 thought that more than 400,000 individuals in the
15 United States have MS.

16 (7) Studies have found relationships between
17 MS and environmental and genetic factors, but those
18 relationships are not well understood.

19 (8) Several small and uncoordinated MS reg-
20 istries and databases exist in the United States and
21 throughout the world.

22 (9) A single national system to collect and store
23 information on the incidence and prevalence of MS
24 in the United States does not exist.

1 (10) The Agency for Toxic Substances and Dis-
2 ease Registry has established a series of small pilot
3 studies, beginning in fiscal year 2006, to evaluate
4 the feasibility of various methodologies that might be
5 used to create a MS surveillance system at the na-
6 tional level.

7 (11) The establishment of a national surveil-
8 lance system will help—

9 (A) to identify the incidence and preva-
10 lence of MS in the United States;

11 (B) to collect data important to the study
12 of MS;

13 (C) to produce epidemiologically sound
14 data that can be used to compare with MS clus-
15 ter information, data sets of the Department of
16 Veterans Affairs data sets, and other informa-
17 tion;

18 (D) to promote a better understanding of
19 MS;

20 (E) to better understand public and pri-
21 vate resource impact;

22 (F) to collect information that is important
23 for research into genetic and environmental risk
24 factors for MS;

1 (G) to enhance biomedical and clinical re-
2 search by providing a basis for population com-
3 parisons; and

4 (H) to enhance efforts to find treatments
5 and a cure for MS.

6 **SEC. 3. AMENDMENT TO THE PUBLIC HEALTH SERVICE**
7 **ACT.**

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. 399R. MULTIPLE SCLEROSIS NATIONAL SURVEIL-**
12 **LANCE SYSTEM.**

13 “(a) ESTABLISHMENT.—

14 “(1) IN GENERAL.—Not later than 1 year after
15 the receipt of the report described in subsection
16 (b)(3), the Secretary, acting through the Director of
17 the Agency for Toxic Substances and Disease Reg-
18 istry and in consultation with a national voluntary
19 health organization with experience serving the pop-
20 ulation of individuals with multiple sclerosis (re-
21 ferred to in this section as ‘MS’), shall—

22 “(A) develop a system to collect data on
23 MS including information with respect to the
24 incidence and prevalence of the disease in the
25 United States; and

1 “(B) establish a national surveillance sys-
2 tem for the collection and storage of such data
3 to include a population-based registry of cases
4 of MS in the United States.

5 “(2) PURPOSE.—It is the purpose of the reg-
6 istry established under paragraph (1)(B) to gather
7 available data concerning—

8 “(A) MS, including the incidence and prev-
9 alence of MS in the United States;

10 “(B) the age, race or ethnicity, gender,
11 and family history of individuals who are diag-
12 nosed with the disease; and

13 “(C) other matters as recommended by the
14 Advisory Committee established pursuant to
15 subsection (b).

16 “(b) ADVISORY COMMITTEE.—

17 “(1) ESTABLISHMENT.—Not later than 180
18 days after the date of the enactment of this section,
19 the Secretary, acting through the Director of the
20 Agency for Toxic Substances and Disease Registry
21 shall establish a committee to be known as the Advi-
22 sory Committee on the MS National Surveillance
23 System (referred to in this section as the ‘Advisory
24 Committee’). The Advisory Committee shall be com-
25 posed of at least one member, to be appointed by the

1 Secretary, acting through the Director of the Agency
2 for Toxic Substances and Disease Registry, rep-
3 resenting each of the following:

4 “(A) National voluntary health associa-
5 tions that focus solely on MS and have dem-
6 onstrated experience in MS research, care, or
7 patient services.

8 “(B) The National Institutes of Health, to
9 include, upon the recommendation of the Direc-
10 tor of the National Institutes of Health, rep-
11 resentatives from the National Institute of Neu-
12 rological Disorders and Stroke, the National In-
13 stitute of Environmental Health Sciences, and
14 the National Institute of Allergy and Infectious
15 Diseases.

16 “(C) The Department of Veterans Affairs.

17 “(D) The Department of Defense.

18 “(E) The Agency for Toxic Substances and
19 Disease Registry.

20 “(F) The Centers for Disease Control and
21 Prevention.

22 “(G) Patients with MS or their family
23 members.

24 “(H) Clinicians with expertise on MS and
25 related diseases.

1 “(I) Epidemiologists with experience in
2 data registries.

3 “(J) Geneticists or experts in genetics who
4 have experience with the genetics of MS.

5 “(K) Statisticians.

6 “(L) Ethicists.

7 “(M) Attorneys.

8 “(N) Other individuals, organizations, or
9 agencies with an interest in developing and
10 maintaining the MS National Surveillance Sys-
11 tem.

12 “(2) DUTIES.—The Advisory Committee shall
13 review information and make recommendations to
14 the Secretary concerning—

15 “(A) the development and maintenance of
16 the MS National Surveillance System;

17 “(B) the type of information to be col-
18 lected and stored in the System;

19 “(C) the manner in which such data is to
20 be collected; and

21 “(D) the use and availability of such data
22 including guidelines for such use.

23 “(3) REPORT.—Not later than 1 year after the
24 date on which the Advisory Committee is estab-
25 lished, the Advisory Committee shall submit a report

1 concerning the review conducted under paragraph
2 (2) that contains the recommendations of the Advi-
3 sory Committee with respect to the results of such
4 review.

5 “(c) GRANTS.—Notwithstanding the recommenda-
6 tions of the Advisory Committee under subsection (b), the
7 Secretary, acting through the Director of the Agency for
8 Toxic Substances and Disease Registry, may award grants
9 to, and enter into contracts and cooperative agreements
10 with, public or private nonprofit entities for the collection,
11 analysis, and reporting of data on MS.

12 “(d) COORDINATION WITH STATE, LOCAL, AND FED-
13 ERAL REGISTRIES.—

14 “(1) IN GENERAL.—In establishing the MS Na-
15 tional Surveillance System under subsection (a), the
16 Secretary, acting through the Director of the Agency
17 for Toxic Substances and Disease Registry, shall—

18 “(A) identify, build upon, expand, and co-
19 ordinate existing data and surveillance systems,
20 surveys, registries, and other Federal public
21 health and environmental infrastructure wher-
22 ever possible, including—

23 “(i) the 2 MS surveillance pilot stud-
24 ies initiated in fiscal year 2006 by the Cen-
25 ters for Disease Control and Prevention

1 and the Agency for Toxic Substances and
2 Disease Registry;

3 “(ii) the MS database of the Depart-
4 ment of Veterans Affairs;

5 “(iii) current MS registries, including
6 the New York State MS Registry and the
7 North American Research Committee on
8 MS (NARCOMS) Registry; and

9 “(iv) any other existing or relevant
10 databases that collect or maintain informa-
11 tion on neurological diseases identified by
12 researchers or recommended by the Advi-
13 sory Committee established in subsection
14 (b); and

15 “(B) provide for research access to MS
16 data as recommended by the Advisory Com-
17 mittee established pursuant to subsection (b) to
18 the extent permitted by applicable statutes and
19 regulations and in a manner that protects per-
20 sonal privacy consistent with applicable privacy
21 statutes and regulations.

22 “(2) COORDINATION WITH OTHER FEDERAL
23 AGENCIES.—Notwithstanding the recommendations
24 of the Advisory Committee established pursuant to
25 subsection (b), and consistent with applicable pri-

1 vacy statutes and regulations, the Secretary shall en-
2 sure that epidemiological and other types of informa-
3 tion obtained under subsection (a) are made avail-
4 able to agencies such as the National Institutes of
5 Health, the Department of Veterans Affairs, and the
6 Department of Defense.

7 “(e) DEFINITION.—For the purposes of this section,
8 the term ‘national voluntary health association’ means a
9 national nonprofit organization with chapters or other af-
10 filiated organizations in States throughout the United
11 States.

12 “(f) AUTHORIZATION OF APPROPRIATIONS.—There
13 are authorized to be appropriated to carry out this section
14 \$5,000,000 for each of fiscal years 2009 through 2013.”.

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