

109TH CONGRESS
1ST SESSION

H. R. 2526

To establish a Tick-Borne Disorders Advisory Committee, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MAY 23, 2005

Mrs. KELLY (for herself, Mr. HINCHEY, Mr. KILDEE, Mr. McNULTY, Mr. BRADLEY of New Hampshire, Mr. WOLF, Mr. PAYNE, Mr. ENGLISH of Pennsylvania, Mr. SWEENEY, Mr. GILCREST, Mr. HASTINGS of Florida, and Mr. FRANK of Massachusetts) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To establish a Tick-Borne Disorders Advisory Committee,
and for other purposes.

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 “Tick-Borne Disorders
5 Advisory Committee Act of 2005”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

1 (1) Lyme disease is a common but frequently
2 misunderstood illness that, if not caught early and
3 treated properly, can cause serious health problems.

4 (2) Lyme disease is a bacterial infection that is
5 transmitted by a tick bite. Early signs of infection
6 may include a rash and flu-like symptoms such as
7 fever, muscle aches, headaches, and fatigue.

8 (3) Although Lyme disease can be treated with
9 antibiotics if caught early, the disease often goes un-
10 detected because it mimics other illnesses or may be
11 misdiagnosed. Untreated, Lyme disease can lead to
12 severe heart, neurological, eye, and joint problems
13 because the bacteria can affect many different or-
14 gans and organ systems.

15 (4) Despite 17 years of Federal funding, there
16 is still no test that can accurately determine infec-
17 tion and then prove bactericidal cure so that proper
18 treatment is adequately achieved. Persistence of
19 symptomatology in many patients without reliable
20 testing makes treatment of patients more difficult.

21 (5) If an individual with Lyme disease does not
22 receive treatment, such individual can develop severe
23 heart, neurological, eye, and joint problems.

24 (6) Although Lyme disease accounts for 90 per-
25 cent of all vector-borne infections in the United

1 States, the ticks that spread Lyme disease also
2 spread other disorders, such as ehrlichiosis,
3 babesiosis, and other strains of Borrelia. All of these
4 diseases in 1 patient makes diagnosis and treatment
5 more difficult.

6 (7) Although tick-borne disease cases have been
7 reported in 49 States and the District of Columbia,
8 about 90 percent of the 20,000 cases have been re-
9 ported in the following 10 States: Connecticut,
10 Pennsylvania, New York, New Jersey, Rhode Island,
11 Maryland, Massachusetts, Minnesota, Delaware, and
12 Wisconsin. Studies have shown that the actual num-
13 ber of tick-borne disease cases are approximately 10
14 times the amount reported due to poor surveillance
15 of the disease.

16 (8) Persistence of symptomatology in many pa-
17 tients without reliable testing makes treatment of
18 patients more difficult.

19 (9) According to studies, Lyme disease costs
20 the Nation between \$1,000,000,000 to
21 \$2,000,000,000 each year in increased medical
22 costs, lost productivity, prolonged pain and suf-
23 fering, and costly delays in diagnosis and inappro-
24 priate treatment.

1 **SEC. 3. ESTABLISHMENT OF A TICK-BORNE DISORDERS AD-**
2 **VISORY COMMITTEE.**

3 (a) ESTABLISHMENT OF COMMITTEE.—Not later
4 than 180 days after the date of enactment of this Act,
5 there shall be established an advisory committee to be
6 known as the Tick-Borne Disorders Advisory Committee
7 organized in the Office of the Secretary.

8 (b) DUTIES.—The Committee shall advise the Sec-
9 retary of Health and Human Services and the Assistant
10 Secretary for Health regarding how to—

11 (1) assure interagency coordination and com-
12 munication and minimize overlap regarding efforts
13 to address tick-borne disorders;

14 (2) identify opportunities to coordinate efforts
15 with other Federal agencies and private organiza-
16 tions addressing tick-borne disorders; and

17 (3) develop informed responses to constituency
18 groups regarding the Department of Health and
19 Human Services' efforts and progress.

20 (c) MEMBERSHIP.—

21 (1) APPOINTED MEMBERS.—

22 (A) IN GENERAL.—The Secretary shall ap-
23 point voting members to the Committee from
24 among the following member groups:

25 (i) Scientific community members.

1 (ii) Representatives of tick-borne dis-
2 order voluntary organizations.

3 (iii) Health care providers.

4 (iv) Patient representatives who are
5 individuals who have been diagnosed with
6 tick-borne illnesses or who have had an im-
7 mediate family member diagnosed with
8 such illness.

9 (v) Representatives of State and local
10 health departments and national organiza-
11 tions who represent State and local health
12 professionals.

13 (B) REQUIREMENT.—The Secretary shall
14 ensure that an equal number of individuals are
15 appointed to the Committee from each of the
16 member groups described in clauses (i) through
17 (v) of subparagraph (A).

18 (2) EX OFFICIO MEMBERS.—The Committee
19 shall have nonvoting ex officio members determined
20 appropriate by the Secretary.

21 (d) CO-CHAIRPERSONS.—The Assistant Secretary for
22 Health shall serve as the co-chairperson of the Committee
23 with a public co-chairperson chosen by the members de-
24 scribed under subsection (c). The public co-chairperson
25 shall serve a 2-year term and retain all voting rights.

1 (e) TERM OF APPOINTMENT.—All members shall be
2 appointed to serve on the Committee for 4 year terms.

3 (f) VACANCY.—If there is a vacancy on the Com-
4 mittee, such position shall be filled in the same manner
5 as the original appointment. Any member appointed to fill
6 a vacancy for an unexpired term shall be appointed for
7 the remainder of that term. Members may serve after the
8 expiration of their terms until their successors have taken
9 office.

10 (g) MEETINGS.—The Committee shall hold public
11 meetings, except as otherwise determined by the Sec-
12 retary, giving notice to the public of such, and meet at
13 least twice a year with additional meetings subject to the
14 call of the co-chairpersons. Agenda items can be added
15 at the request of the Committee members, as well as the
16 co-chairpersons. Meetings shall be conducted, and records
17 of the proceedings kept as required by applicable laws and
18 departmental regulations.

19 (h) REPORTS.—

20 (1) IN GENERAL.—Not later than 24 months
21 after the date of enactment of this Act, and annually
22 thereafter, the Secretary shall submit to Congress a
23 report on the activities carried out under this Act.

24 (2) CONTENT.—Such reports shall describe—

1 (A) progress in the development of accu-
2 rate diagnostic tools that are more useful in the
3 clinical setting; and

4 (B) the promotion of public awareness and
5 physician education initiatives to improve the
6 knowledge of health care providers and the pub-
7 lic regarding clinical and surveillance practices
8 for Lyme disease and other tick-borne dis-
9 orders.

10 (i) **AUTHORIZATION OF APPROPRIATIONS.**—There is
11 authorized to be appropriated to carry out this Act,
12 \$250,000 for each of fiscal years 2006 and 2007.
13 Amounts appropriated under this subsection shall be used
14 for the expenses and per diem costs incurred by the Com-
15 mittee under this section in accordance with the Federal
16 Advisory Committee Act (5 U.S.C. App.), except that no
17 voting member of the Committee shall be a permanent sal-
18 aried employee.

19 **SEC. 4. AUTHORIZATION FOR RESEARCH FUNDING.**

20 There is authorized to be appropriated \$10,000,000
21 for each of fiscal years 2006 through 2010 to provide for
22 research and educational activities concerning Lyme dis-
23 ease and other tick-borne disorders, and to carry out ef-
24 forts to prevent Lyme disease and other tick-borne dis-
25 orders.

1 **SEC. 5. GOALS.**

2 It is the sense of the Congress that, in carrying out
3 this Act, the Secretary of Health and Human Services,
4 acting as appropriate in consultation with the Director of
5 the Centers for Disease Control and Prevention, the Direc-
6 tor of the National Institutes of Health, the Committee,
7 and other agencies, should consider carrying out the fol-
8 lowing:

9 (1) FIVE-YEAR PLAN.—It is the sense of the
10 Congress that the Secretary should consider the es-
11 tablishment of a plan that, for the five fiscal years
12 following the date of the enactment of this Act, pro-
13 vides for the activities to be carried out during such
14 fiscal years toward achieving the goals under para-
15 graphs (2) through (4). The plan should, as appro-
16 priate to such goals, provide for the coordination of
17 programs and activities regarding Lyme disease and
18 other tick-borne disorders that are conducted or sup-
19 ported by the Federal Government.

20 (2) FIRST GOAL: DIAGNOSTIC TEST.—The goal
21 described in this paragraph is to develop a diag-
22 nostic test for Lyme disease and other tick-borne
23 disorders for use in clinical testing.

24 (3) SECOND GOAL: SURVEILLANCE AND RE-
25 PORTING OF LYME DISEASE AND OTHER TICK-
26 BORNE DISORDERS.—The goal described in this

1 paragraph is to accurately determine the prevalence
2 of Lyme disease and other tick-borne disorders in
3 the United States.

4 (4) **THIRD GOAL: PREVENTION OF LYME DIS-**
5 **EASE AND OTHER TICK-BORNE DISORDERS.**—The
6 goal described in this paragraph is to develop the ca-
7 pabilities at the Department of Health and Human
8 Services to design and implement improved strate-
9 gies for the prevention and control of Lyme disease
10 and other tick-borne diseases. Such diseases may in-
11 clude Southern Tick Associated Rash Illness,
12 ehrlichiosis, babesiosis, and other bacterial, viral,
13 and rickettsial diseases such as tularemia, tick-borne
14 encephalitis, Rocky Mountain Spotted Fever, and
15 bartonella, respectively.

16 **SEC. 6. DEFINITIONS.**

17 In this Act:

18 (1) The term “Committee” means the Tick-
19 Borne Disorders Advisory Committee established by
20 section 2.

21 (2) The term “Secretary” means the Secretary
22 of Health and Human Services.

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