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(Original Signature of Member)

111TH CONGRESS  
1ST SESSION

**H. R.** \_\_\_\_\_

To provide for the expansion of Federal efforts concerning the prevention, education, treatment, and research activities related to Lyme and other tick-borne diseases, including the establishment of a Tick-Borne Diseases Advisory Committee.

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IN THE HOUSE OF REPRESENTATIVES

Mr. SMITH of New Jersey introduced the following bill; which was referred to the Committee on \_\_\_\_\_

\_\_\_\_\_  
**A BILL**

To provide for the expansion of Federal efforts concerning the prevention, education, treatment, and research activities related to Lyme and other tick-borne diseases, including the establishment of a Tick-Borne Diseases Advisory Committee.

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 “Lyme and Tick-Borne  
5 Diseases Prevention, Education, and Research Act of  
6 2009”.

1 **SEC. 2. FINDINGS.**

2 The Congress makes the following findings:

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

6 (2) Lyme disease is caused by the bacterium  
7 *Borrelia burgdorferi*, which belongs to the class of  
8 spirochetes, and is transmitted to humans by the  
9 bite of infected black-legged ticks. Early signs of in-  
10 fection may include a rash and flu-like symptoms  
11 such as fever, muscle aches, headaches, and fatigue.

12 (3) Although Lyme disease can be treated with  
13 antibiotics if caught early, the disease often goes un-  
14 detected because it mimics other illnesses or may be  
15 misdiagnosed.

16 (4) If an individual with Lyme disease does not  
17 receive treatment, such individual can develop severe  
18 heart, neurological, eye, and joint problems.

19 (5) Although Lyme disease accounts for 90 per-  
20 cent of all vector-borne infections in the United  
21 States, the ticks that spread Lyme disease also  
22 spread other diseases, such as anaplasmosis,  
23 babesiosis, and tularemia, and carry *Bartonella* and  
24 other strains of *Borrelia*. Other tick species, such as  
25 the aggressive lone star, spread ehrlichiosis, Rocky  
26 Mountain spotted fever, and southern tick-associated

1 rash illness (STARI). Multiple diseases in 1 patient  
2 make diagnosis and treatment more difficult.

3 (6) The Centers for Disease Control and Pre-  
4 vention reported 27,444 new cases of Lyme disease  
5 in 2007, a 38 percent increase nationally from 2006.  
6 Studies indicate that the actual number of tick-  
7 borne disease cases is approximately 10 times the  
8 amount reported.

9 (7) According to the Centers for Disease Con-  
10 trol and Prevention, from 1992 to 2006, the inci-  
11 dence of Lyme disease was highest among children  
12 aged 5 to 14 years of age.

13 (8) Persistence of symptomatology in many pa-  
14 tients without reliable testing makes treatment of  
15 patients more difficult.

16 **SEC. 3. ESTABLISHMENT OF A TICK-BORNE DISEASES ADVI-**  
17 **SORY COMMITTEE.**

18 (a) ESTABLISHMENT.—Not later than 180 days after  
19 the date of the enactment of this Act, the Secretary of  
20 Health and Human Services (referred to in this Act as  
21 the “Secretary”) shall establish within the Office of the  
22 Secretary an advisory committee to be known as the Tick-  
23 Borne Diseases Advisory Committee (referred to in this  
24 section as the “Committee”).

1 (b) DUTIES.—The Committee shall advise the Sec-  
2 retary and the Assistant Secretary for Health regarding  
3 the manner in which such officials can—

4 (1) ensure interagency coordination and com-  
5 munication and minimize overlap regarding efforts  
6 to address tick-borne diseases;

7 (2) identify opportunities to coordinate efforts  
8 with other Federal agencies and private organiza-  
9 tions addressing such diseases;

10 (3) ensure interagency coordination and com-  
11 munication with constituency groups;

12 (4) ensure that a broad spectrum of scientific  
13 viewpoints is represented in public health policy deci-  
14 sions and that information disseminated to the pub-  
15 lic and physicians is balanced; and

16 (5) advise relevant Federal agencies on prior-  
17 ities related to the Lyme and tick-borne diseases.

18 (c) MEMBERSHIP.—

19 (1) APPOINTED MEMBERS.—

20 (A) IN GENERAL.—The Secretary shall ap-  
21 point the voting members of the Committee  
22 from among individuals who are not officers or  
23 employees of the Federal Government.

24 (B) GROUPS.—The voting members of the  
25 Committee shall include the following::

1 (i) At least 4 members from the sci-  
2 entific community representing the broad  
3 spectrum of viewpoints held within the sci-  
4 entific community related to Lyme and  
5 other tick-borne diseases.

6 (ii) At least 2 representatives of tick-  
7 borne disease voluntary organizations.

8 (iii) At least 2 health care providers,  
9 including at least 1 full-time practicing  
10 physician, with relevant experience pro-  
11 viding care for individuals with a broad  
12 range of acute and chronic tick-borne dis-  
13 eases.

14 (iv) At least 2 patient representatives  
15 who are individuals who have been diag-  
16 nosed with a tick-borne disease or who  
17 have had an immediate family member di-  
18 agnosed with such a disease.

19 (v) At least 2 representatives of State  
20 and local health departments and national  
21 organizations that represent State and  
22 local health professionals.

23 (C) DIVERSITY.—In appointing members  
24 under this paragraph, the Secretary shall en-  
25 sure that such members, as a group, represent

1 a diversity of scientific perspectives relevant to  
2 the duties of the Committee.

3 (2) EX OFFICIO MEMBERS.—The Secretary  
4 shall designate, as nonvoting, ex officio members of  
5 the Committee, representatives overseeing tick-borne  
6 disease activities from each of the following Federal  
7 agencies:

8 (A) The Centers for Disease Control and  
9 Prevention.

10 (B) The National Institutes of Health.

11 (C) The Agency for Healthcare Research  
12 and Quality.

13 (D) The Food and Drug Administration.

14 (E) The Office of the Assistant Secretary  
15 for Health.

16 (F) Such additional Federal agencies as  
17 the Secretary determines to be appropriate.

18 (3) CO-CHAIRPERSONS.—The Secretary shall  
19 designate the Assistant Secretary of Health as the  
20 co-chairperson of the Committee. The appointed  
21 members of the Committee shall also elect a public  
22 co-chairperson. The public co-chairperson shall serve  
23 a 2-year term.

1           (4) TERM OF APPOINTMENT.—The term of  
2           service for each member of the Committee appointed  
3           under paragraph (1) shall be 4 years.

4           (5) VACANCY.—A vacancy in the membership of  
5           the Committee shall be filled in the same manner as  
6           the original appointment. Any member appointed to  
7           fill a vacancy for an unexpired term shall be ap-  
8           pointed for the remainder of that term. Members  
9           may serve after the expiration of their terms until  
10          their successors have taken office.

11          (d) MEETINGS.—The Committee shall hold public  
12          meetings, except as otherwise determined by the Sec-  
13          retary, after providing notice to the public of such meet-  
14          ings, and shall meet at least twice a year with additional  
15          meetings subject to the call of the co-chairpersons. Agenda  
16          items with respect to such meetings may be added at the  
17          request of the members of the Committee, including the  
18          co-chairpersons. Meetings shall be conducted, and records  
19          of the proceedings shall be maintained, as required by ap-  
20          plicable law and by regulations of the Secretary.

21          (e) REPORT.—Not later than 1 year after the date  
22          of the enactment of this Act, and annually thereafter, the  
23          Committee, through the Director of the Centers for Dis-  
24          ease Control and Prevention and the Director of the Na-  
25          tional Institutes of Health, shall submit a report to the

1 Secretary. Each such report shall contain, at a min-  
2 imum—

3 (1) a description of the Committee's functions;

4 (2) a list of the Committee's members and their  
5 affiliations; and

6 (3) a summary of the Committee's activities  
7 and recommendations during the previous year, in-  
8 cluding any significant issues regarding the func-  
9 tioning of the Committee.

10 (f) AUTHORIZATION OF APPROPRIATIONS.—For the  
11 purpose of carrying out this section, there is authorized  
12 to be appropriated \$250,000 for each of fiscal years 2010  
13 through 2014. Amounts appropriated under the preceding  
14 sentence shall be used for the expenses and per diem costs  
15 incurred by the Committee under this section in accord-  
16 ance with the Federal Advisory Committee Act, except  
17 that no voting member of the Committee shall be a perma-  
18 nent salaried employee.

19 **SEC. 4. FEDERAL ACTIVITIES RELATED TO THE DIAGNOSIS,**  
20 **SURVEILLANCE, PREVENTION, AND RE-**  
21 **SEARCH OF LYME AND OTHER TICK-BORNE**  
22 **DISEASES.**

23 (a) IN GENERAL.—The Secretary, acting as appro-  
24 priate through the Director of the Centers for Disease  
25 Control and Prevention, the Director of the National Insti-



1 tutes of Health, the Commissioner of Food and Drugs,  
2 and the Director of the Agency for Healthcare Research  
3 and Quality, as well as additional Federal agencies as the  
4 Secretary determines to be appropriate, and in consulta-  
5 tion with the Tick-Borne Diseases Advisory Committee,  
6 shall provide for—

7 (1) the conduct or support of activities de-  
8 scribed in paragraphs (1) through (4) of subsection  
9 (b); and

10 (2) the coordination of all Federal programs  
11 and activities related to Lyme disease and other  
12 tick-borne diseases.

13 (b) ACTIVITIES.—The activities to be conducted or  
14 supported under subsection (a) include the following:

15 (1) DEVELOPMENT OF DIAGNOSTIC TESTS.—

16 (A) The development of sensitive and more  
17 accurate diagnostic tools and tests, including a  
18 direct detection test for Lyme disease capable  
19 of distinguishing active infection from past in-  
20 fection.

21 (B) Improving the efficient utilization of  
22 diagnostic testing currently available to account  
23 for the multiple clinical manifestations of both  
24 acute and chronic Lyme disease.

1 (C) Providing for the timely evaluation of  
2 promising emerging diagnostic methods.

3 (2) SURVEILLANCE AND REPORTING.—

4 (A) Accurately determining the prevalence  
5 of Lyme and other tick-borne disease.

6 (B) Evaluating the feasibility of developing  
7 a reporting system for the collection of data on  
8 physician-diagnosed cases of Lyme disease that  
9 do not meet the surveillance criteria of the Cen-  
10 ters for Disease Control and Prevention in  
11 order to more accurately gauge disease inci-  
12 dence.

13 (C) Evaluating the feasibility of creating a  
14 national uniform reporting system including re-  
15 quired reporting by laboratories in each State.

16 (3) PREVENTION.—

17 (A) The provision and promotion of access  
18 to a comprehensive, up-to-date clearinghouse of  
19 peer-reviewed information on Lyme and other  
20 tick-borne disease.

21 (B) Increased public education related to  
22 Lyme and other tick-borne diseases through the  
23 expansion of the community-based education  
24 programs of the Centers for Disease Control

1 and Prevention to include expansion of informa-  
2 tion access points to the public.

3 (C) The creation of a physician education  
4 program that includes the full spectrum of sci-  
5 entific research related to Lyme and other tick-  
6 borne diseases.

7 (D) The sponsoring of scientific con-  
8 ferences on Lyme and other tick-borne diseases,  
9 including reporting and consideration of the full  
10 spectrum of clinically based knowledge, with the  
11 first of such conferences to be held not later  
12 than 24 months after the date of the enactment  
13 of this Act.

14 (4) CLINICAL OUTCOMES RESEARCH.—

15 (A) The establishment of epidemiological  
16 research objectives to determine the long-term  
17 course of illness for Lyme disease.

18 (B) Determination of the effectiveness of  
19 different treatment modalities by establishing  
20 treatment outcome objectives.

21 (c) AUTHORIZATION OF APPROPRIATIONS.—For the  
22 purposes of carrying out this section and providing for ad-  
23 ditional research, prevention, and educational activities for  
24 Lyme and other tick-borne diseases, there is authorized  
25 to be appropriated \$20,000,000 for each of fiscal years

1 2010 through 2014. Such authorization of appropriations  
2 is in addition to any other authorization of appropriations  
3 available for such purpose. Of the amounts authorized to  
4 be appropriated under this subsection—

5 (1) for fiscal year 2010, at least \$7,500,000  
6 shall be for activities of the Centers for Disease Con-  
7 trol and Prevention; and

8 (2) for each of fiscal years 2011 through 2014,  
9 at least \$5,000,000 shall be for activities of the Cen-  
10 ters for Disease Control and Prevention.

11 **SEC. 5. REPORTS ON LYME AND OTHER TICK-BORNE DIS-**  
12 **EASES.**

13 (a) IN GENERAL.—Not later than 18 months after  
14 the date of the enactment of this Act, and annually there-  
15 after, the Secretary shall submit to the Congress a report  
16 on the activities carried out under this Act.

17 (b) CONTENT.—Reports under subsection (a) shall  
18 contain—

19 (1) a description of significant activities or de-  
20 velopments related to the surveillance, diagnosis,  
21 treatment, education, or prevention of Lyme or other  
22 tick-borne diseases, including suggestions for further  
23 research and education;

24 (2) a scientifically qualified assessment of Lyme  
25 and other tick-borne diseases, including both acute

1 and chronic instances, related to the broad spectrum  
2 of empirical evidence of treating physicians, as well  
3 as published peer-reviewed data, that shall include  
4 recommendations for addressing research gaps in di-  
5 agnosis and treatment of Lyme and other tick-borne  
6 diseases and an evaluation of treatment guidelines  
7 and their utilization;

8 (3) a description of progress in the development  
9 of accurate diagnostic tools that are more useful in  
10 the clinical setting for both acute and chronic dis-  
11 ease;

12 (4) a description of activities for the promotion  
13 of public awareness and physician education initia-  
14 tives to improve the knowledge of health care pro-  
15 viders and the public regarding clinical and surveil-  
16 lance practices for Lyme disease and other tick-  
17 borne diseases; and

18 (5) a copy of the most recent annual report  
19 issued by the Tick-Borne Diseases Advisory Com-  
20 mittee established in section 3 and an assessment of  
21 progress in achieving recommendations of that Com-  
22 mittee.