

110TH CONGRESS  
1ST SESSION

# H. R. 741

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

JANUARY 31, 2007

Mr. SMITH of New Jersey (for himself, Mr. STUPAK, Mr. HOLDEN, Mr. GILCHREST, Mr. SHAYS, Mrs. LOWEY, Ms. DELAURO, Ms. BEAN, Mr. LANGEVIN, Mr. BAIRD, Mr. KIRK, Mr. ACKERMAN, Mr. GRIJALVA, and Mr. MCHUGH) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## 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 Disease Prevention, Education, and Research Act of  
6 2007”.

1 **SEC. 2. FINDINGS.**

2 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 a bacterial infection that is  
7 transmitted by a tick bite. Early signs of infection  
8 may include a rash and flu-like symptoms such as  
9 fever, muscle aches, headaches, and fatigue.

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

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

20 (5) Although Lyme disease accounts for 90 per-  
21 cent of all vector-borne infections in the United  
22 States, the ticks that spread Lyme disease also  
23 spread other diseases, such as ehrlichiosis,  
24 babesiosis, and other strains of *Borrelia*. All of these  
25 diseases in 1 patient makes diagnosis and treatment  
26 more difficult.

1           (6) Studies indicate that the actual number of  
2 tick-borne disease cases are approximately 10 times  
3 the amount reported.

4           (7) Persistence of symptomatology in many pa-  
5 tients without reliable testing makes treatment of  
6 patients more difficult.

7 **SEC. 3. ESTABLISHMENT OF A TICK-BORNE DISEASES ADVI-**  
8 **SORY COMMITTEE.**

9           (a) ESTABLISHMENT.—Not later than 180 days after  
10 the date of the enactment of this Act, the Secretary of  
11 Health and Human Services (referred to in this Act as  
12 the “Secretary”) shall establish within the Office of the  
13 Secretary an advisory committee to be known as the Tick-  
14 Borne Diseases Advisory Committee (referred to in this  
15 section as the “Committee”).

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

19           (1) ensure interagency coordination and com-  
20 munication and minimize overlap regarding efforts  
21 to address tick-borne diseases;

22           (2) identify opportunities to coordinate efforts  
23 with other Federal agencies and private organiza-  
24 tions addressing such diseases;

1           (3) ensure interagency coordination and com-  
2           munication with constituency groups;

3           (4) ensure that a broad spectrum of scientific  
4           viewpoints are represented in public health policy de-  
5           cisions and that information disseminated to the  
6           public and physicians is balanced; and

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

9           (c) MEMBERSHIP.—

10           (1) APPOINTED MEMBERS.—

11           (A) IN GENERAL.—From among individ-  
12           uals who are not officers or employees of the  
13           Federal Government, the Secretary shall ap-  
14           point to the Committee, as voting members, an  
15           equal number of individuals from each of the  
16           groups described in clauses (i) through (v) of  
17           subparagraph (B).

18           (B) GROUPS.—The groups described in  
19           this subparagraph include the following:

20           (i) Scientific community members rep-  
21           resenting the broad spectrum of viewpoints  
22           held within the scientific community re-  
23           lated to Lyme and other tick-borne dis-  
24           eases.

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

3 (iii) Health care providers, including  
4 at least 1 full-time practicing physician,  
5 with relevant experience providing care for  
6 individuals with a broad range of acute  
7 and chronic tick-borne diseases.

8 (iv) Patient representatives who are  
9 individuals who have been diagnosed with a  
10 tick-borne disease or who have had an im-  
11 mediate family member diagnosed with  
12 such a disease.

13 (v) Representatives of State and local  
14 health departments and national organiza-  
15 tions that represent State and local health  
16 professionals.

17 (C) DIVERSITY.—In appointing members  
18 under this paragraph, the Secretary shall en-  
19 sure that such members, as a group, represent  
20 a diversity of scientific perspectives relevant to  
21 the duties of the Committee.

22 (2) EX OFFICIO MEMBERS.—The Secretary  
23 shall designate, as nonvoting, ex officio members of  
24 the Committee, representatives overseeing tick-borne

1 disease activities from each of the following Federal  
2 agencies:

3 (A) The Centers for Disease Control and  
4 Prevention.

5 (B) The National Institutes of Health.

6 (C) The Agency for Healthcare Research  
7 and Quality.

8 (D) The Food and Drug Administration.

9 (E) The Office of the Assistant Secretary  
10 for Health.

11 (F) Such additional Federal agencies as  
12 the Secretary determines to be appropriate.

13 (3) CO-CHAIRPERSONS.—The Secretary shall  
14 designate the Assistant Secretary of Health as the  
15 co-chairperson of the Committee. The appointed  
16 members of the Committee shall also elect a public  
17 co-chairperson. The public co-chairperson shall serve  
18 a 2-year term.

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

22 (5) VACANCY.—A vacancy in the membership of  
23 the Committee shall be filled in the same manner as  
24 the original appointment. Any member appointed to  
25 fill a vacancy for an unexpired term shall be ap-

1 pointed for the remainder of that term. Members  
2 may serve after the expiration of their terms until  
3 their successors have taken office.

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

14 (e) AUTHORIZATION OF APPROPRIATIONS.—For the  
15 purpose of carrying out this section, there is authorized  
16 to be appropriated \$250,000 for each of the fiscal years  
17 2008 through 2011. Amounts appropriated under the pre-  
18 ceding sentence shall be used for the expenses and per  
19 diem costs incurred by the Committee under this section  
20 in accordance with the Federal Advisory Committee Act,  
21 except that no voting member of the Committee shall be  
22 a permanent salaried employee.

1 **SEC. 4. FEDERAL ACTIVITIES RELATED TO THE DIAGNOSIS,**  
2 **SURVEILLANCE, PREVENTION, AND RE-**  
3 **SEARCH OF LYME AND OTHER TICK-BORNE**  
4 **DISEASES.**

5 (a) IN GENERAL.—The Secretary, acting as appro-  
6 priate through the Director of the Centers for Disease  
7 Control and Prevention, the Director of the National Insti-  
8 tutes of Health, the Commissioner of Food and Drugs,  
9 and the Director of the Agency for Healthcare Research  
10 and Quality, as well as additional Federal agencies as the  
11 Secretary determines to be appropriate, and in consulta-  
12 tion with the Tick-Borne Diseases Advisory Committee,  
13 shall provide for the coordination of all Federal programs  
14 and activities related to Lyme and other tick-borne dis-  
15 eases, including the activities described in paragraphs (1)  
16 through (4) of subsection (b).

17 (b) ACTIVITIES.—The activities described in this sub-  
18 section are the following:

19 (1) DEVELOPMENT OF DIAGNOSTIC TESTS.—

20 Such activities include—

21 (A) the development of sensitive and more  
22 accurate diagnostic tools and tests, including a  
23 direct detection test for Lyme disease capable  
24 of distinguishing active infection from past in-  
25 fection;



1 (B) improving the efficient utilization of  
2 diagnostic testing currently available to account  
3 for the multiple clinical manifestations of both  
4 acute and chronic Lyme disease; and

5 (C) providing for the timely evaluation of  
6 promising emerging diagnostic methods.

7 (2) SURVEILLANCE AND REPORTING.—Such ac-  
8 tivities include surveillance and reporting of Lyme  
9 and other tick-borne diseases—

10 (A) to accurately determine the prevalence  
11 of Lyme and other tick-borne disease;

12 (B) to evaluate the feasibility of developing  
13 a reporting system for the collection of data on  
14 physician-diagnosed cases of Lyme disease that  
15 do not meet the surveillance criteria of the Cen-  
16 ters for Disease Control and Prevention in  
17 order to more accurately gauge disease inci-  
18 dence; and

19 (C) to evaluate the feasibility of creating a  
20 national uniform reporting system including re-  
21 quired reporting by laboratories in each State.

22 (3) PREVENTION.—Such activities include—

23 (A) the provision and promotion of access  
24 to a comprehensive, up-to-date clearinghouse of

1 peer-reviewed information on Lyme and other  
2 tick-borne disease;

3 (B) increased public education related to  
4 Lyme and other tick-borne diseases through the  
5 expansion of the Community Based Education  
6 Programs of the Centers for Disease Control  
7 and Prevention to include expansion of informa-  
8 tion access points to the public;

9 (C) the creation of a physician education  
10 program that includes the full spectrum of sci-  
11 entific research related to Lyme and other tick-  
12 borne diseases; and

13 (D) the sponsoring of scientific conferences  
14 on Lyme and other tick-borne diseases, includ-  
15 ing reporting and consideration of the full spec-  
16 trum of clinically-based knowledge, with the  
17 first of such conferences to be held not later  
18 than 24 months after the date of enactment of  
19 this Act.

20 (4) CLINICAL OUTCOMES RESEARCH.—Such ac-  
21 tivities include—

22 (A) the establishment of epidemiological  
23 research objectives to determine the long term  
24 course of illness for Lyme disease; and

1 (B) determination of the effectiveness of  
2 different treatment modalities by establishing  
3 treatment outcome objectives.

4 (c) AUTHORIZATION OF APPROPRIATIONS.—For the  
5 purposes of carrying out this section, and for the purposes  
6 of providing for additional research, prevention, and edu-  
7 cational activities for Lyme and other tick-borne diseases,  
8 there is authorized to be appropriated \$20,000,000 for  
9 each of the fiscal years 2008 through 2012. Such author-  
10 ization is in addition to any other authorization of appro-  
11 priations available for such purpose.

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

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

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

20 (1) significant activities or developments related  
21 to the surveillance, diagnosis, treatment, education,  
22 or prevention of Lyme or other tick-borne diseases,  
23 including suggestions for further research and edu-  
24 cation;

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

10           (3) progress in the development of accurate di-  
11           agnostic tools that are more useful in the clinical  
12           setting for both acute and chronic disease; and

13           (4) the promotion of public awareness and phy-  
14           sician education initiatives to improve the knowledge  
15           of health care providers and the public regarding  
16           clinical and surveillance practices for Lyme disease  
17           and other tick-borne diseases.

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