

113TH CONGRESS
1ST SESSION

H. R. 611

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.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 12, 2013

Mr. SMITH of New Jersey (for himself, Mr. WOLF, Mr. GIBSON, and Mr. PETERSON) introduced the following bill; which was referred to the Committee on Energy and Commerce

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 2013”.

1 **SEC. 2. ESTABLISHMENT OF A TICK-BORNE DISEASES ADVI-**
2 **SORY COMMITTEE.**

3 (a) ESTABLISHMENT.—Not later than 180 days after
4 the date of the enactment of this Act, the Secretary of
5 Health and Human Services (referred to in this Act as
6 the “Secretary”) shall establish within the Office of the
7 Secretary an advisory committee to be known as the Tick-
8 Borne Diseases Advisory Committee (referred to in this
9 section as the “Committee”).

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

13 (1) ensure interagency coordination and com-
14 munication and minimize overlap regarding efforts
15 to address tick-borne diseases;

16 (2) identify opportunities to coordinate efforts
17 with other Federal agencies and private organiza-
18 tions addressing such diseases;

19 (3) ensure interagency coordination and com-
20 munication with constituency groups;

21 (4) ensure that a broad spectrum of scientific
22 viewpoints is represented in public health policy deci-
23 sions and that information disseminated to the pub-
24 lic and physicians is balanced; and

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

1 (c) MEMBERSHIP.—

2 (1) APPOINTED MEMBERS.—

3 (A) IN GENERAL.—The Secretary shall ap-
4 point the voting members of the Committee
5 from among individuals who are not officers or
6 employees of the Federal Government.

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

9 (i) At least 4 members from the sci-
10 entific community representing the broad
11 spectrum of viewpoints held within the sci-
12 entific community related to Lyme and
13 other tick-borne diseases.

14 (ii) At least 2 representatives of tick-
15 borne disease voluntary organizations.

16 (iii) At least 2 health care providers,
17 including at least 1 full-time practicing
18 physician, with relevant experience pro-
19 viding care for individuals with a broad
20 range of acute and chronic tick-borne dis-
21 eases.

22 (iv) At least 2 patient representatives
23 who are individuals who have been diag-
24 nosed with a tick-borne disease or who

1 have had an immediate family member di-
2 agnosed with such a disease.

3 (v) At least 2 representatives of State
4 and local health departments and national
5 organizations that represent State and
6 local health professionals.

7 (C) DIVERSITY.—In appointing members
8 under this paragraph, the Secretary shall en-
9 sure that such members, as a group, represent
10 a diversity of scientific perspectives relevant to
11 the duties of the Committee.

12 (2) EX OFFICIO MEMBERS.—The Secretary
13 shall designate, as nonvoting, ex officio members of
14 the Committee, representatives overseeing tick-borne
15 disease activities from each of the following Federal
16 agencies:

17 (A) The Centers for Disease Control and
18 Prevention.

19 (B) The National Institutes of Health.

20 (C) The Agency for Healthcare Research
21 and Quality.

22 (D) The Food and Drug Administration.

23 (E) The Office of the Assistant Secretary
24 for Health.

1 (F) Such additional Federal agencies as
2 the Secretary determines to be appropriate.

3 (3) CO-CHAIRPERSONS.—The Secretary shall
4 designate the Assistant Secretary of Health as the
5 co-chairperson of the Committee. The appointed
6 members of the Committee shall also elect a public
7 co-chairperson. The public co-chairperson shall serve
8 a 2-year term.

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

12 (5) VACANCY.—A vacancy in the membership of
13 the Committee shall be filled in the same manner as
14 the original appointment. Any member appointed to
15 fill a vacancy for an unexpired term shall be ap-
16 pointed for the remainder of that term. Members
17 may serve after the expiration of their terms until
18 their successors have taken office.

19 (d) MEETINGS.—The Committee shall hold public
20 meetings, except as otherwise determined by the Sec-
21 retary, after providing notice to the public of such meet-
22 ings, and shall meet at least twice a year with additional
23 meetings subject to the call of the co-chairpersons. Agenda
24 items with respect to such meetings may be added at the
25 request of the members of the Committee, including the

1 co-chairpersons. Meetings shall be conducted, and records
2 of the proceedings shall be maintained, as required by ap-
3 plicable law and by regulations of the Secretary.

4 (e) REPORT.—Not later than 1 year after the date
5 of the enactment of this Act, and annually thereafter, the
6 Committee, through the Director of the Centers for Dis-
7 ease Control and Prevention and the Director of the Na-
8 tional Institutes of Health, shall submit a report to the
9 Secretary. Each such report shall contain, at a min-
10 imum—

11 (1) a description of the Committee’s functions;

12 (2) a list of the Committee’s members and their
13 affiliations; and

14 (3) a summary of the Committee’s activities
15 and recommendations during the previous year, in-
16 cluding any significant issues regarding the func-
17 tioning of the Committee.

18 (f) AUTHORIZATION OF APPROPRIATIONS.—For the
19 purpose of carrying out this section, there is authorized
20 to be appropriated \$250,000 for each of fiscal years 2014
21 through 2018. Amounts appropriated under the preceding
22 sentence shall be used for the expenses and per diem costs
23 incurred by the Committee under this section in accord-
24 ance with the Federal Advisory Committee Act, except

1 that no voting member of the Committee shall be a perma-
2 nent salaried employee.

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

7 (a) IN GENERAL.—The Secretary, acting as appro-
8 priate through the Director of the Centers for Disease
9 Control and Prevention, the Director of the National Insti-
10 tutes of Health, the Commissioner of Food and Drugs,
11 and the Director of the Agency for Healthcare Research
12 and Quality, as well as additional Federal agencies as the
13 Secretary determines to be appropriate, and in consulta-
14 tion with the Tick-Borne Diseases Advisory Committee,
15 shall provide for—

16 (1) the conduct or support of activities de-
17 scribed in paragraphs (1) through (4) of subsection
18 (b); and

19 (2) the coordination of all Federal programs
20 and activities related to Lyme disease and other
21 tick-borne diseases.

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

24 (1) DEVELOPMENT OF DIAGNOSTIC TESTS.—

1 (A) The development of sensitive and more
2 accurate diagnostic tools and tests, including a
3 direct detection test for Lyme disease capable
4 of distinguishing active infection from past in-
5 fection.

6 (B) Improving the efficient utilization of
7 diagnostic testing currently available to account
8 for the multiple clinical manifestations of both
9 acute and chronic Lyme disease.

10 (C) Providing for the timely evaluation of
11 promising emerging diagnostic methods.

12 (2) SURVEILLANCE AND REPORTING.—

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

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

22 (C) Evaluating the feasibility of creating a
23 national uniform reporting system including re-
24 quired reporting by laboratories in each State.

25 (3) PREVENTION.—

1 (A) The provision and promotion of access
2 to a comprehensive, up-to-date clearinghouse of
3 peer-reviewed information on Lyme and other
4 tick-borne disease.

5 (B) Increased public education related to
6 Lyme and other tick-borne diseases through the
7 expansion of the community-based education
8 programs of the Centers for Disease Control
9 and Prevention to include expansion of informa-
10 tion access points to the public.

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

15 (D) The sponsoring of scientific con-
16 ferences on Lyme and other tick-borne diseases,
17 including reporting and consideration of the full
18 spectrum of clinically based knowledge, with the
19 first of such conferences to be held not later
20 than 24 months after the date of the enactment
21 of this Act.

22 (4) CLINICAL OUTCOMES RESEARCH.—

23 (A) The establishment of epidemiological
24 research objectives to determine the long-term
25 course of illness for Lyme disease.

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 providing for ad-
6 ditional research, prevention, and educational activities for
7 Lyme and other tick-borne diseases, there is authorized
8 to be appropriated \$20,000,000 for each of fiscal years
9 2014 through 2018. Such authorization of appropriations
10 is in addition to any other authorization of appropriations
11 available for such purpose. Of the amounts authorized to
12 be appropriated under this subsection—

13 (1) for fiscal year 2014, at least \$7,500,000
14 shall be for activities of the Centers for Disease Con-
15 trol and Prevention; and

16 (2) for each of fiscal years 2015 through 2018,
17 at least \$5,000,000 shall be for activities of the Cen-
18 ters for Disease Control and Prevention.

19 **SEC. 4. REPORTS ON LYME AND OTHER TICK-BORNE DIS-**
20 **EASES.**

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

1 (b) CONTENT.—Reports under subsection (a) shall
2 contain—

3 (1) a description of significant activities or de-
4 velopments related to the surveillance, diagnosis,
5 treatment, education, or prevention of Lyme or other
6 tick-borne diseases, including suggestions for further
7 research and education;

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

17 (3) a description of progress in the development
18 of accurate diagnostic tools that are more useful in
19 the clinical setting for both acute and chronic dis-
20 ease;

21 (4) a description of activities for the promotion
22 of public awareness and physician education initia-
23 tives to improve the knowledge of health care pro-
24 viders and the public regarding clinical and surveil-

1 lance practices for Lyme disease and other tick-
2 borne diseases; and
3 (5) a copy of the most recent annual report
4 issued by the Tick-Borne Diseases Advisory Com-
5 mittee established in section 2 and an assessment of
6 progress in achieving recommendations of that Com-
7 mittee.

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