

107TH CONGRESS
1ST SESSION

H. R. 2118

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

IN THE HOUSE OF REPRESENTATIVES

JUNE 8, 2001

Mr. GREENWOOD (for himself, Mrs. LOWEY, Mr. SIMMONS, Mr. BALDACCI, Mr. MALONEY of Connecticut, Mr. KIRK, and Mr. LARSON of Connecticut) 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 “Lyme and Infectious
5 Disease Information and Fairness in Treatment (LIIFT)
6 Act”.

7 **SEC. 2. FINDINGS.**

8 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.

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

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

22 (6) According to the Centers for Disease Con-
23 trol and Prevention, cases of this tick-borne disease
24 have increased 25-fold since national surveillance of
25 it began in 1982. Although tick-borne disease cases

1 have been reported in 49 States and the District of
2 Columbia, about 90 percent of the 15,000 cases have
3 been reported in the following 10 States: Con-
4 necticut, Pennsylvania, New York, New Jersey,
5 Rhode Island, Maryland, Massachusetts, Minnesota,
6 Delaware, and Wisconsin. Studies have shown that
7 the actual number of tick-borne disease cases are
8 approximately 10 times the amount reported due to
9 poor surveillance of the disease.

10 (7) According to studies, Lyme disease costs
11 our Nation between \$1,000,000,000 to
12 \$2,000,000,000 each year in increased medical
13 costs, lost productivity, prolonged pain and suf-
14 fering, unnecessary testing, and costly delays in di-
15 agnosis and inappropriate treatment.

16 (8) Patients with Lyme disease are increasingly
17 having difficulty obtaining diagnosis and treatment
18 for the disease, and being restored to health. Be-
19 cause of differences in medical and scientific opinion,
20 clinicians fear retaliation from insurance companies
21 and medical licensure boards based on their diag-
22 nosis and treatment of patients.

23 (9) A number of patients have difficulties in ob-
24 taining insurance coverage for treatment of Lyme
25 disease.

1 (10) Despite 14 years of Federal funding, there
2 is still no test that can accurately determine infec-
3 tion so that proper treatment is adequately achieved.
4 Persistence of symptomatology in many patients
5 without reliable testing makes treatment of patients
6 more difficult.

7 (11) According to the General Accounting Of-
8 fice, over the past 10 years, the Centers for Disease
9 Control and Prevention has only increased its alloca-
10 tion for tick-borne research and education by 7 per-
11 cent, from \$6,900,000 to \$7,400,000. Over that
12 same period, the Centers for Disease Control and
13 Prevention's expenditures for infectious diseases rose
14 318 percent, from \$70,800,000 to \$296,000,000.

15 (12) According to the General Accounting Of-
16 fice, over the past 10 years, the National Institutes
17 of Health have increased expenditures almost every
18 year, from \$13,100,000 in fiscal year 1991 to
19 \$26,000,000 in fiscal year 2000.

20 (13) The Lyme disease vaccine gained approval
21 from the Food and Drug Administration in 1998.
22 Since that time, the Food and Drug Administration
23 has received over 1,000 adverse event reports on the
24 vaccine, including reports of severe arthritic symp-
25 toms and even Lyme disease.

1 **SEC. 3. PURPOSE.**

2 The purpose of this Act is to establish a Tick-Borne
3 Disorders Advisory Committee that will—

4 (1) provide a public voice regarding the direc-
5 tion and activities of the governmental agencies that
6 deal with Lyme disease in order to create a better
7 understanding and response by the government to
8 the public need regarding the disease;

9 (2) assure communication and coordination re-
10 garding tick-borne disorder issues between agencies
11 of the Department of Health and Human Services,
12 the biomedical community, and voluntary organiza-
13 tions concerned; and

14 (3) promote coordination of activities with the
15 Social Security Administration and Department of
16 Defense.

17 **SEC. 4. TICK-BORNE DISORDERS ADVISORY COMMITTEE.**

18 (a) ESTABLISHMENT OF COMMITTEE.—Not later
19 than 180 days after the date of enactment of this Act,
20 there shall be established an advisory committee to be
21 known as the Tick-Borne Disorders Advisory Committee
22 (referred to in this Act as the “Committee”) organized
23 in the Office of the Secretary of Health and Human Serv-
24 ices.

1 (b) DUTIES.—The Committee shall advise the Sec-
2 retary of Health and Human Services (in this Act referred
3 to as the “Secretary”) regarding how to—

4 (1) provide public input on the public’s needs
5 regarding tick-borne disorders, so that government
6 agencies can more effectively plan and execute their
7 activities, thus improving the response to public
8 need;

9 (2) assure interagency coordination and com-
10 munication and minimize overlap regarding tick-
11 borne disorder issues;

12 (3) identify opportunities to coordinate efforts
13 with other Federal agencies and tick-borne disorder
14 national nonprofits; and

15 (4) develop informed responses to constituency
16 groups regarding the efforts and progress of the De-
17 partment of Health and Human Services.

18 (c) MEMBERSHIP.—

19 (1) IN GENERAL.—The Secretary shall appoint
20 11 voting members to the Committee of which—

21 (A) 3 shall be scientific community mem-
22 bers, including a researcher or public health of-
23 ficial, with demonstrated achievement in tick-
24 borne education, research, or advocacy, and ex-
25 tensive experience in working with a diverse

1 range of patients, patient groups, and tick-
2 borne non-profits;

3 (B) 3 shall be representatives of national
4 tick-borne disorder voluntary organizations that
5 advocate for the public, as well as those suf-
6 fering from or providing medical care to pa-
7 tients with tick-borne disorders;

8 (C) 3 shall be clinicians with extensive ex-
9 perience in the diagnoses and treatment of tick-
10 borne diseases and with long-term experience,
11 independent of an individual practice or re-
12 search, in working with patients, patient
13 groups, and tick-borne non-profits; and

14 (D) 2 shall be patient representatives who
15 are individuals who have been diagnosed with
16 tick-borne illnesses or who have had an imme-
17 diate family member diagnosed with such ill-
18 ness.

19 (2) EX-OFFICIO REPRESENTATIVES.—The Com-
20 mittee shall have nonvoting ex-officio members of
21 which—

22 (A) 2 shall be from the Centers for Disease
23 Control and Prevention, 1 of which shall be
24 from the Viral and Rickettsial Diseases Division
25 of the Viral and Rickettsial Zoonoses Branch;

1 (B) 1 shall be from the Food and Drug
2 Administration, Office of Special Health Issues,
3 in the Office of the Commissioner;

4 (C) 3 shall be from the National Institutes
5 of Health—

6 (i) 1 of which shall be from the Rocky
7 Mountain Laboratories Microscopy
8 Branch; and

9 (ii) 1 of which shall be a pathologist
10 with the National Institutes of Health who
11 has extensive experience in Lyme disease
12 research and a demonstrated ability to
13 work well with diverse groups in the pa-
14 tient, public, and health care provider com-
15 munities;

16 (D) 1 shall be from the Health Resources
17 and Services Administration;

18 (E) 1 shall be from the Social Security Ad-
19 ministration;

20 (F) 1 shall be from the Department of De-
21 fense, United States Army Center for Health
22 Promotion and Preventive Medicine;

23 (G) 1 shall be from the Health Care Fi-
24 nancing Administration; and

1 (H) any additional members shall be added
2 from other Departments if necessary to aid the
3 Committee in its overall goals.

4 (d) CHAIRPERSON.—The Assistant Secretary for
5 Health (Department of Health and Human Services) shall
6 serve as the co-chairperson of the Committee with a public
7 co-chairperson chosen by the members described under
8 subsection (c)(1). The public co-chairperson shall serve a
9 2-year term and retain all voting rights.

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

12 (f) VACANCY.—If there is a vacancy on the Com-
13 mittee, such position shall be filled in the same manner
14 as the original appointment. Any member appointed to fill
15 a vacancy for an unexpired term shall be appointed for
16 the remainder of that term. Members may serve after the
17 expiration of their terms until their successors have taken
18 office.

19 (g) MEETINGS.—The Committee shall hold public
20 meetings, except as otherwise determined by the Sec-
21 retary, giving notice to the public of such, and meet at
22 least twice a year with additional meetings subject to the
23 call of the Chairperson. Agenda items can be added at the
24 request of the Committee members, as well as the Chair-
25 person. Meetings shall be conducted, and records of the

1 proceedings kept as required by applicable laws and De-
2 partmental regulations.

3 (h) REPORTS.—

4 (1) IN GENERAL.—Not later than 18 months
5 after the date of enactment of this Act, and annually
6 thereafter, the Secretary shall submit to Congress a
7 report on the activities carried out under this Act.

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

9 (A) progress in the development of more
10 accurate diagnostic tools and tests;

11 (B) the development of the other seven
12 categories of case definitions;

13 (C) the promotion of public awareness and
14 physician education initiatives to improve the
15 knowledge of health care providers and the pub-
16 lic regarding the best and most effective meth-
17 ods to prevent, diagnose and treat tick-borne
18 disorders;

19 (D) the improved access to disability bene-
20 fits policies for people living with tick-borne dis-
21 orders; and

22 (E) recommendations for resolving dif-
23 ferences in medical and scientific opinion that
24 have resulted in the exceptional number of re-

1 views of Lyme disease clinicians by insurance
2 companies and State medical licensure boards.

3 (i) AUTHORIZATION OF APPROPRIATIONS.—There is
4 authorized to be appropriated to carry out this Act,
5 \$250,000 for each of the fiscal years 2002 and 2003.

6 **SEC. 5. CENTERS FOR DISEASE CONTROL AND PREVEN-**
7 **TION.**

8 There are authorized to be appropriated for the Cen-
9 ters for Disease Control and Prevention—

10 (1) \$14,500,000 for each of the fiscal years
11 2002 and 2003 to enable such Centers to focus on
12 developing better diagnostic tools and tests, expand-
13 ing educational efforts regarding other tick-borne
14 disorders beyond Lyme disease, and re-educating cli-
15 nicians, medical licensure boards, and health care in-
16 surers about the inappropriate uses of the Lyme dis-
17 ease case surveillance definition in the diagnosis and
18 treatment of patients; and

19 (2) \$7,000,000 for each of the fiscal years 2002
20 and 2003 to collaborate with the National Institutes
21 of Health, the Department of Defense, and other ap-
22 propriate agencies for further research on tick-borne
23 disorders, including the study of preventive methods
24 to decrease exposure to such disorders.

1 **SEC. 6. NATIONAL INSTITUTES OF HEALTH.**

2 The Director of the National Institutes of Health, in
3 working with the Tick-Borne Disorders Advisory Com-
4 mittee established under this Act, and recognizing that
5 tick-borne disorders affect multiple systems of the body,
6 shall coordinate activities and research regarding tick-
7 borne diseases across Institutes to encourage collaborative
8 research.

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