

107TH CONGRESS  
1ST SESSION

# S. 969

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

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IN THE SENATE OF THE UNITED STATES

MAY 25, 2001

Mr. DODD (for himself and Mr. SANTORUM) introduced the following bill;  
which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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## 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 (LIFT)  
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. Untreated, Lyme disease can lead to  
12          severe heart, neurological, eye, and joint problems  
13          because the bacteria can invade any system of the  
14          body.

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

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

1           (6) According to the Centers for Disease Con-  
2           trol and Prevention, cases of this tick-borne disease  
3           have increased 25-fold since national surveillance of  
4           it began in 1982. Although tick-borne disease cases  
5           have been reported in 49 States and the District of  
6           Columbia, about 90 percent of the 15,000 cases have  
7           been reported in the following 10 States: Con-  
8           necticut, Pennsylvania, New York, New Jersey,  
9           Rhode Island, Maryland, Massachusetts, Minnesota,  
10          Delaware, and Wisconsin. Studies have shown that  
11          the actual number of tick-borne disease cases are  
12          approximately 10 times the amount reported due to  
13          poor surveillance of the disease.

14          (7) According to studies, Lyme disease costs  
15          our Nation between \$1,000,000,000 to  
16          \$2,000,000,000 each year in increased medical  
17          costs, lost productivity, prolonged pain and suf-  
18          fering, unnecessary testing, and costly delays in di-  
19          agnosis and inappropriate treatment.

20          (8) Patients with Lyme disease are increasingly  
21          having difficulty obtaining diagnosis and treatment  
22          for the disease, and being restored to health. Be-  
23          cause of differences in medical and scientific opinion,  
24          clinicians fear retaliation from insurance companies

1 and medical licensure boards based on their diag-  
2 nosis and treatment of patients.

3 (9) A number of patients have difficulties in ob-  
4 taining insurance coverage for treatment of Lyme  
5 disease.

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

12 (11) According to the General Accounting Of-  
13 fice, over the past 10 years, the Centers for Disease  
14 Control and Prevention has only increased its alloca-  
15 tion for tick-borne research and education by 7 per-  
16 cent, from \$6,900,000 to \$7,400,000. Over that  
17 same period, the Centers for Disease Control and  
18 Prevention's expenditures for infectious diseases rose  
19 318 percent, from \$70,800,000 to \$296,000,000.

20 (12) According to the General Accounting Of-  
21 fice, over the past 10 years, the National Institutes  
22 of Health have increased expenditures almost every  
23 year, from \$13,100,000 in fiscal year 1991 to  
24 \$26,000,000 in fiscal year 2000.

1           (13) The Lyme disease vaccine gained approval  
2           from the Food and Drug Administration in 1998.  
3           Since that time, the Food and Drug Administration  
4           has received over 1,000 adverse event reports on the  
5           vaccine, including reports of severe arthritic symp-  
6           toms and even Lyme disease.

7   **SEC. 3. PURPOSE.**

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

10           (1) provide a public voice regarding the direc-  
11           tion and activities of the governmental agencies that  
12           deal with Lyme disease in order to create a better  
13           understanding and response by the government to  
14           the public need regarding the disease;

15           (2) assure communication and coordination re-  
16           garding tick-borne disorder issues between agencies  
17           of the Department of Health and Human Services,  
18           the biomedical community, and voluntary organiza-  
19           tions concerned; and

20           (3) promote coordination of activities with the  
21           Social Security Administration and Department of  
22           Defense.

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

24           (a) ESTABLISHMENT OF COMMITTEE.—Not later  
25   than 180 days after the date of enactment of this Act,

1 there shall be established an advisory committee to be  
2 known as the Tick-Borne Disorders Advisory Committee  
3 (referred to in this Act as the “Committee”) organized  
4 in the Office of the Secretary.

5 (b) DUTIES.—The Committee shall advise the Sec-  
6 retary and Assistant Secretary of Health and Human  
7 Services and the Social Security Administration Commis-  
8 sioner regarding how to—

9 (1) provide public input on the public’s needs  
10 regarding tick-borne disorders, so that government  
11 agencies can more effectively plan and execute their  
12 activities, thus improving the response to public  
13 need;

14 (2) assure interagency coordination and com-  
15 munication and minimize overlap regarding tick-  
16 borne disorder issues;

17 (3) identify opportunities to coordinate efforts  
18 with other Federal agencies and tick-borne disorder  
19 national nonprofits; and

20 (4) develop informed responses to constituency  
21 groups regarding the Department of Health and  
22 Human Services and Social Security Administra-  
23 tion’s efforts and progress.

24 (c) MEMBERSHIP.—

1           (1) IN GENERAL.—The Secretary of Health and  
2       Human Services shall appoint 11 voting members to  
3       the Committee of which—

4           (A) 3 shall be scientific community mem-  
5       bers, including a researcher or public health of-  
6       ficial, with demonstrated achievement in tick-  
7       borne education, research, or advocacy, and ex-  
8       tensive experience in working with a diverse  
9       range of patients, patient groups, and tick-  
10      borne non-profits;

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

16          (C) 3 shall be clinicians with extensive ex-  
17      perience in the diagnoses and treatment of tick-  
18      borne diseases and with long-term experience,  
19      independent of an individual practice or re-  
20      search, in working with patients, patient  
21      groups, and tick-borne non-profits; and

22          (D) 2 shall be patient representatives who  
23      are individuals who have been diagnosed with  
24      tick-borne illnesses or who have had an imme-

1           diate family member diagnosed with such ill-  
2           ness.

3           (2) EX-OFFICIO REPRESENTATIVES.—The Com-  
4           mittee shall have nonvoting ex-officio members of  
5           which—

6                   (A) 2 shall be from the Centers for Disease  
7           Control and Prevention, 1 of which shall be  
8           from the Viral and Rickettsial Diseases Division  
9           of the Viral and Rickettsial Zoonoses Branch;

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

13                  (C) 3 shall be from the National Institutes  
14           of Health—

15                   (i) 1 of which shall be from the Rocky  
16           Mountain       Laboratories       Microscopy  
17           Branch; and

18                   (ii) 1 of which shall be a pathologist  
19           with the National Institutes of Health who  
20           has extensive experience in Lyme disease  
21           research and a demonstrated ability to  
22           work well with diverse groups in the pa-  
23           tient, public, and health care provider com-  
24           munities;

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

3 (E) 1 shall be from the Social Security Ad-  
4 ministration, preferably from the Office of the  
5 Deputy Commissioner, Disability and Income  
6 Security or Office of the Deputy Commissioner,  
7 Policy;

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

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

13 (H) any additional members shall be added  
14 from other Departments if necessary to aid the  
15 Committee in its overall goals.

16 (d) CHAIRPERSON.—The Assistant Secretary of  
17 Health and Human Services shall serve as the co-chair-  
18 person of the Committee with a public co-chairperson cho-  
19 sen by the members described under subsection (c)(1).  
20 The public co-chairperson shall serve a 2-year term and  
21 retain all voting rights.

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

24 (f) VACANCY.—If there is a vacancy on the Com-  
25 mittee, such position shall be filled in the same manner

1 as the original appointment. Any member appointed to fill  
2 a vacancy for an unexpired term shall be appointed for  
3 the remainder of that term. Members may serve after the  
4 expiration of their terms until their successors have taken  
5 office.

6 (g) MEETINGS.—The Committee shall hold public  
7 meetings, except as otherwise determined by the Sec-  
8 retary, giving notice to the public of such, and meet at  
9 least twice a year with additional meetings subject to the  
10 call of the Chairperson. Agenda items can be added at the  
11 request of the Committee members, as well as the Chair-  
12 person. Meetings shall be conducted, and records of the  
13 proceedings kept as required by applicable laws and De-  
14 partmental regulations.

15 (h) REPORTS.—

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

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

21 (A) progress in the development of more  
22 accurate diagnostic tools and tests;

23 (B) the expansion and improvement of the  
24 Lyme disease surveillance case definition;

1 (C) the promotion of public awareness and  
2 physician education initiatives to improve the  
3 knowledge of health care providers and the pub-  
4 lic regarding the best and most effective meth-  
5 ods to prevent, diagnose and treat tick-borne  
6 disorders;

7 (D) the improved access to disability bene-  
8 fits policies for people living with tick-borne dis-  
9 orders; and

10 (E) recommendations for resolving dif-  
11 ferences in medical and scientific opinion that  
12 have resulted in the exceptional number of re-  
13 views of Lyme disease clinicians by insurance  
14 companies and State medical licensure boards.

15 (i) AUTHORIZATION OF APPROPRIATIONS.—There is  
16 authorized to be appropriated to carry out this Act,  
17 \$250,000 for each of the fiscal years 2002 and 2003.

18 **SEC. 5. CENTERS FOR DISEASE CONTROL AND PREVEN-**  
19 **TION.**

20 There is authorized to be appropriated for the Cen-  
21 ters for Disease Control and Prevention, \$14,500,000 for  
22 each of the fiscal years 2002 and 2003 to enable such Cen-  
23 ters to focus on developing better diagnostic tools and  
24 tests, expanding educational efforts regarding other tick-  
25 borne disorders beyond Lyme disease, and re-educating

1 clinicians, medical licensure boards, and health care insur-  
2 ers about the inappropriate uses of the Lyme disease case  
3 surveillance definition in the diagnosis and treatment of  
4 patients.

5 **SEC. 6. DEPARTMENT OF DEFENSE.**

6       There are authorized to be appropriated for the  
7 United States Army Center for Health Promotion and  
8 Preventive Medicine, \$7,000,000 for each of the fiscal  
9 years 2002 and 2003 to increase risk assessment evalua-  
10 tions of United States military bases in the United States  
11 for all tick-borne disorders, to continue the study of pre-  
12 ventive methods to decrease troop exposure to tick-borne  
13 disorders and to promote collaboration in promising areas  
14 of research with the Centers for Disease Control and Pre-  
15 vention and the National Institutes of Health.

16 **SEC. 7. THE NATIONAL INSTITUTES OF HEALTH.**

17       The Director of the National Institutes of Health, in  
18 working with the Tick-Borne Disorders Advisory Com-  
19 mittee established under this Act, and recognizing that  
20 tick-borne disorders affect multiple systems of the body,  
21 shall coordinate activities and research regarding tick-  
22 borne diseases across Institutes to encourage collaborative  
23 research.

