

108TH CONGRESS  
1ST SESSION

# S. 1527

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

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## IN THE SENATE OF THE UNITED STATES

JULY 31 (legislative day, JULY 21), 2003

Mr. SANTORUM (for himself, Mr. DODD, Mr. CHAFEE, Ms. COLLINS, Mr. KERRY, Mr. SCHUMER, Mr. REED, and Mr. LIEBERMAN) 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. FINDINGS.**

4       Congress makes the following findings:

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

8               (2) Lyme disease is a bacterial infection that is  
9       transmitted by a tick bite. Early signs of infection

1 may include a rash and flu-like symptoms such as  
2 fever, muscle aches, headaches, and fatigue.

3 (3) Although Lyme disease can be treated with  
4 antibiotics if caught early, the disease often goes un-  
5 detected because it mimics other illnesses or may be  
6 misdiagnosed. Untreated, Lyme disease can lead to  
7 severe heart, neurological, eye, and joint problems  
8 because the bacteria can affect many different or-  
9 gans and organ systems.

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

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

20 (6) Although tick-borne disease cases have been  
21 reported in 49 States and the District of Columbia,  
22 about 90 percent of the 15,000 cases have been re-  
23 ported in the following 10 States: Connecticut,  
24 Pennsylvania, New York, New Jersey, Rhode Island,  
25 Maryland, Massachusetts, Minnesota, Delaware, and

1 Wisconsin. Studies have shown that the actual num-  
2 ber of tick-borne disease cases are approximately 10  
3 times the amount reported due to poor surveillance  
4 of the disease.

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

8 **SEC. 2. ESTABLISHMENT OF A TICK-BORNE DISORDERS AD-**  
9 **VISORY COMMITTEE.**

10 (a) ESTABLISHMENT OF COMMITTEE.—Not later  
11 than 180 days after the date of enactment of this Act,  
12 there shall be established an advisory committee to be  
13 known as the Tick-Borne Disorders Advisory Committee  
14 (referred to in this Act as the “Committee”) organized  
15 in the Office of the Secretary.

16 (b) DUTIES.—The Committee shall advise the Sec-  
17 retary and Assistant Secretary of Health regarding how  
18 to—

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

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

1           (3) develop informed responses to constituency  
2 groups regarding the Department of Health and  
3 Human Services' efforts and progress.

4       (c) MEMBERSHIP.—

5           (1) APPOINTED MEMBERS.—

6           (A) IN GENERAL.—The Secretary of  
7 Health and Human Services shall appoint vot-  
8 ing members to the Committee from among the  
9 following member groups:

10           (i) Scientific community members.

11           (ii) Representatives of tick-borne dis-  
12 order voluntary organizations.

13           (iii) Health care providers.

14           (iv) Patient representatives who are  
15 individuals who have been diagnosed with  
16 tick-borne illnesses or who have had an im-  
17 mediate family member diagnosed with  
18 such illness.

19           (v) Representatives of State and local  
20 health departments and national organiza-  
21 tions who represent State and local health  
22 professionals.

23           (B) REQUIREMENT.—The Secretary shall  
24 ensure that an equal number of individuals are  
25 appointed to the Committee from each of the

1 member groups described in clauses (i) through  
2 (v) of subparagraph (A).

3 (2) EX OFFICIO MEMBERS.—The Committee  
4 shall have nonvoting ex officio members determined  
5 appropriate by the Secretary.

6 (d) CO-CHAIRPERSONS.—The Assistant Secretary of  
7 Health shall serve as the co-chairperson of the Committee  
8 with a public co-chairperson chosen by the members de-  
9 scribed under subsection (c). The public co-chairperson  
10 shall serve a 2-year term and retain all voting rights.

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

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

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

1 co-chairpersons. Meetings shall be conducted, and records  
2 of the proceedings kept as required by applicable laws and  
3 Departmental regulations.

4 (h) REPORTS.—

5 (1) IN GENERAL.—Not later than 24 months  
6 after the date of enactment of this Act, and annually  
7 thereafter, the Secretary shall submit to Congress a  
8 report on the activities carried out under this Act.

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

10 (A) progress in the development of accu-  
11 rate diagnostic tools that are more useful in the  
12 clinical setting; and

13 (B) 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 clinical and surveillance practices  
17 for Lyme disease and other tick-borne dis-  
18 orders.

19 (i) AUTHORIZATION OF APPROPRIATIONS.—There is  
20 authorized to be appropriated to carry out this Act,  
21 \$250,000 for each of fiscal years 2004 and 2005.  
22 Amounts appropriated under this subsection shall be used  
23 for the expenses and per diem costs incurred by the Com-  
24 mittee under this section in accordance with the Federal  
25 Advisory Committee Act (5 U.S.C. App.), except that no

1 voting member of the Committee shall be a permanent sal-  
2 aried employee.

3 **SEC. 3. AUTHORIZATION FOR RESEARCH FUNDING.**

4       There are authorized to be appropriated \$10,000,000  
5 for each of fiscal years 2004 through 2008 to provide for  
6 research and educational activities concerning Lyme dis-  
7 ease and other tick-borne disorders, and to carry out ef-  
8 forts to prevent Lyme disease and other tick-borne dis-  
9 orders.

10 **SEC. 4. GOALS.**

11       It is the sense of the Senate that, in carrying out  
12 this Act, the Secretary of Health and Human Services (re-  
13 ferred to in this section as the “Secretary”), acting as ap-  
14 propriate in consultation with the Director of the Centers  
15 for Disease Control and Prevention, the Director of the  
16 National Institutes of Health, the Committee, and other  
17 agencies, should consider carrying out the following:

18           (1) FIVE-YEAR PLAN.—It is the sense of the  
19 Senate that the Secretary should consider the estab-  
20 lishment of a plan that, for the five fiscal years fol-  
21 lowing the date of the enactment of this Act, pro-  
22 vides for the activities to be carried out during such  
23 fiscal years toward achieving the goals under para-  
24 graphs (2) through (4). The plan should, as appro-  
25 priate to such goals, provide for the coordination of

1 programs and activities regarding Lyme disease and  
2 other tick-borne disorders that are conducted or sup-  
3 ported by the Federal Government.

4 (2) FIRST GOAL: DIAGNOSTIC TEST.—The goal  
5 described in this paragraph is to develop a diag-  
6 nostic test for Lyme disease and other tick-borne  
7 disorders for use in clinical testing.

8 (3) SECOND GOAL: SURVEILLANCE AND RE-  
9 PORTING OF LYME DISEASE AND OTHER TICK-  
10 BORNE DISORDERS.—The goal described in this  
11 paragraph is to accurately determine the prevalence  
12 of Lyme disease and other tick-borne disorders in  
13 the United States.

14 (4) THIRD GOAL: PREVENTION OF LYME DIS-  
15 EASE AND OTHER TICK-BORNE DISORDERS.—The  
16 goal described in this paragraph is to develop the ca-  
17 pabilities at the Department of Health and Human  
18 Services to design and implement improved strate-  
19 gies for the prevention and control of Lyme disease  
20 and other tick-borne diseases. Such diseases may in-  
21 clude Masters' disease, ehrlichiosis, babesiosis, other  
22 bacterial, viral and rickettsial diseases such as tula-  
23 remia, tick-borne encephalitis, Rocky Mountain  
24 Spotted Fever, and bartonella, respectively.

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