107th CONGRESS 2D Session **S. 969**

AN ACT

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,

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

(7) Persistence of symptomatology in many patients without reliable testing makes treatment of
patients more difficult.

14 SEC. 2. ESTABLISHMENT OF A TICK-BORNE DISORDERS AD-

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VISORY COMMITTEE.

16 (a) ESTABLISHMENT OF COMMITTEE.—Not later 17 than 180 days after the date of enactment of this Act, 18 there shall be established an advisory committee to be 19 known as the Tick-Borne Disorders Advisory Committee 20 (referred to in this Act as the "Committee") organized 21 in the Office of the Secretary.

(b) DUTIES.—The Committee shall advise the Secretary and Assistant Secretary of Health regarding how
to—

1	(1) assure interagency coordination and com-
2	munication and minimize overlap regarding efforts
3	to address tick-borne disorders;
4	(2) identify opportunities to coordinate efforts
5	with other Federal agencies and private organiza-
6	tions addressing tick-borne disorders; and
7	(3) develop informed responses to constituency
8	groups regarding the Department of Health and
9	Human Services' efforts and progress.
10	(c) Membership.—
11	(1) Appointed members.—
12	(A) IN GENERAL.—The Secretary of
13	Health and Human Services shall appoint vot-
14	ing members to the Committee from among the
15	following member groups:
16	(i) Scientific community members.
17	(ii) Representatives of tick-borne dis-
18	order voluntary organizations.
19	(iii) Health care providers.
20	(iv) Patient representatives who are
21	individuals who have been diagnosed with
22	tick-borne illnesses or who have had an im-
23	mediate family member diagnosed with
24	such illness.

1	(v) Representatives of State and local
2	health departments and national organiza-
3	tions who represent State and local health
4	professionals.
5	(B) REQUIREMENT.—The Secretary shall
6	ensure that an equal number of individuals are
7	appointed to the Committee from each of the
8	member groups described in clauses (i) through
9	(v) of subparagraph (A).
10	(2) Ex officio members.—The Committee
11	shall have nonvoting ex officio members determined
12	appropriate by the Secretary.
13	(d) CO-CHAIRPERSONS.—The Assistant Secretary of
14	Health shall serve as the co-chairperson of the Committee
15	with a public co-chairperson chosen by the members de-
16	scribed under subsection (c). The public co-chairperson
17	shall serve a 2-year term and retain all voting rights.
18	(e) TERM OF APPOINTMENT.—All members shall be
19	appointed to serve on the Committee for 4 year terms.
20	(f) VACANCY.—If there is a vacancy on the Com-
21	mittee, such position shall be filled in the same manner
22	as the original appointment. Any member appointed to fill
23	a vacancy for an unexpired term shall be appointed for
24	the remainder of that term. Members may serve after the

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expiration of their terms until their successors have taken
 office.

3 (g) MEETINGS.—The Committee shall hold public 4 meetings, except as otherwise determined by the Sec-5 retary, giving notice to the public of such, and meet at least twice a year with additional meetings subject to the 6 7 call of the co-chairpersons. Agenda items can be added 8 at the request of the Committee members, as well as the 9 co-chairpersons. Meetings shall be conducted, and records 10 of the proceedings kept as required by applicable laws and Departmental regulations. 11

- 12 (h) REPORTS.—
- 13 (1) IN GENERAL.—Not later than 24 months 14 after the date of enactment of this Act, and annually 15 thereafter, the Secretary shall submit to Congress a 16 report on the activities carried out under this Act. 17 (2) CONTENT.—Such reports shall describe— 18 (A) progress in the development of accu-19 rate diagnostic tools that are more useful in the 20 clinical setting; and 21 (B) the promotion of public awareness and 22 physician education initiatives to improve the 23
 - knowledge of health care providers and the public regarding clinical and surveillance practices

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for Lyme disease and other tick-borne dis orders.

3 (i) AUTHORIZATION OF APPROPRIATIONS.—There is 4 authorized to be appropriated to carry out this Act, 5 \$250,000 for each of fiscal years 2003 and 2004. Amounts appropriated under this subsection shall be used 6 7 for the expenses and per diem costs incurred by the Com-8 mittee under this section in accordance with the Federal 9 Advisory Committee Act (5 U.S.C. App.), except that no 10 voting member of the Committee shall be a permanent sal-11 aried employee.

12 SEC. 3. AUTHORIZATION FOR RESEARCH FUNDING.

There are authorized to be appropriated \$10,000,000 for each of fiscal years 2003 through 2007 to provide for research and educational activities concerning Lyme disease and other tick-borne disorders, and to carry out efforts to prevent Lyme disease and other tick-borne disorders.

19 SEC. 4. GOALS.

It is the sense of the Senate that, in carrying out this Act, the Secretary of Health and Human Services (referred to in this section as the "Secretary"), acting as appropriate in consultation with the Director of the Centers for Disease Control and Prevention, the Director of the National Institutes of Health, the Committee, and other
 agencies, should consider carrying out the following:

3 (1) FIVE-YEAR PLAN.—It is the sense of the 4 Senate that the Secretary should consider the estab-5 lishment of a plan that, for the five fiscal years fol-6 lowing the date of the enactment of this Act, pro-7 vides for the activities to be carried out during such 8 fiscal years toward achieving the goals under para-9 graphs (2) through (4). The plan should, as appro-10 priate to such goals, provide for the coordination of 11 programs and activities regarding Lyme disease and 12 other tick-borne disorders that are conducted or sup-13 ported by the Federal Government.

14 (2) FIRST GOAL: DIAGNOSTIC TEST.—The goal
15 described in this paragraph is to develop a diag16 nostic test for Lyme disease and other tick-borne
17 disorders for use in clinical testing.

18 (3) SECOND GOAL: SURVEILLANCE AND RE19 PORTING OF LYME DISEASE AND OTHER TICK20 BORNE DISORDERS.—The goal described in this
21 paragraph is to accurately determine the prevalence
22 of Lyme disease and other tick-borne disorders in
23 the United States.

24 (4) THIRD GOAL: PREVENTION OF LYME DIS25 EASE AND OTHER TICK-BORNE DISORDERS.—The

goal described in this paragraph is to develop the ca-1 2 pabilities at the Department of Health and Human 3 Services to design and implement improved strategies for the prevention and control of Lyme disease 4 5 and other tick-borne diseases. Such diseases may include Masters' disease, ehrlichiosis, babesiosis, other 6 7 bacterial, viral and rickettsial diseases such as tulatick-borne encephalitis, 8 remia, Rocky Mountain Spotted Fever, and bartonella, respectively. 9 Passed the Senate October 17, 2002.

Attest:

Secretary.



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