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S. 1905

To establish a program to provide for a reduction in the incidence and prevalence of Lyme disease.

IN THE SENATE OF THE UNITED STATES

NOVEMBER 10, 1999

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

A BILL

To establish a program to provide for a reduction in the incidence and prevalence of Lyme disease.

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 Disease Initia-
5 tive of 1999”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) The incidence of Lyme disease in the
9 United States is increasing rapidly. The Centers for

1 Disease Control and Prevention (referred to in this
2 Act as the “CDC”) has determined that, since 1982,
3 there has been a 32-fold increase in reported cases.

4 (2) In 1998, a total of 15,934 cases of Lyme
5 disease were reported to CDC by 50 States and the
6 District of Columbia (the overall incidence was 6.06
7 per 100,000), representing a 24 percent increase
8 from the 12,807 cases reported in 1997.

9 (3) There is no reliable standardized diagnostic
10 test for chronic Lyme disease, and the test for acute
11 Lyme disease should be improved. As a result, the
12 disease is underreported or misreported by as much
13 as 10 or 12 fold, according to some studies, because
14 the symptoms of Lyme disease mimic other health
15 conditions. Thus, precise figures on the incidence of
16 Lyme disease are difficult to develop.

17 (4) Lyme disease costs our Nation between
18 \$1,000,000,000 and \$2,000,000,000 in medical
19 costs annually, according to studies. Lost produc-
20 tivity annually per person from Lyme disease has
21 been estimated at 5 to 37 days.

22 (5) Many health care providers lack the nec-
23 essary knowledge and expertise—particularly in non-
24 endemic areas—to accurately diagnose and prevent
25 Lyme disease. As a result, patients often visit mul-

1 tiple doctors before obtaining a diagnosis of the dis-
2 ease, resulting in prolonged pain and suffering, un-
3 necessary tests, and costly, delayed, or futile treat-
4 ments.

5 (6) Due to scientific uncertainties about the di-
6 agnosis of acute and chronic Lyme disease, and the
7 proper course and length of treatment, many pa-
8 tients have encountered difficulties in obtaining
9 needed insurance coverage for Lyme disease.

10 (7) Most Lyme disease infections are thought to
11 result from peri-residential exposure to infected ticks
12 during property maintenance, recreation, and leisure
13 activities. Thus, individuals who live or work in resi-
14 dential areas surrounded by woods or overgrown
15 brush infested by vector ticks are at risk of Lyme
16 disease. In addition, persons who participate in rec-
17 reational activities away from home (such as hiking,
18 camping, fishing and hunting in tick habitat) and
19 persons who engage in outdoor occupations (such as
20 landscaping, brush clearing, forestry, military serv-
21 ice, and wildlife and parks management in endemic
22 areas) may also be at risk of Lyme disease. Some
23 estimates indicate outdoor workers have a 4-to-4
24 fold elevation in risk of Lyme disease.

1 **SEC. 3. PUBLIC HEALTH GOALS; 5-YEAR PLAN.**

2 (a) IN GENERAL.—The Secretary of Health and
3 Human Services (acting as appropriate through the Direc-
4 tor of the Centers for Disease Control and Prevention, the
5 Director of the National Institutes of Health, and the
6 Commissioner of Food and Drugs), the Secretary of Agri-
7 culture, the Secretary of the Interior, and the Secretary
8 of Defense (in this Act referred to collectively as the “Sec-
9 retaries”) shall collaborate to carry out the following:

10 (1) The Secretaries shall establish the goals de-
11 scribed in subsections (c) through (g) relating to ac-
12 tivities to provide for a reduction in the incidence
13 and prevalence of Lyme disease and related tick-
14 borne infectious diseases.

15 (2) The Secretaries shall carry out activities to-
16 ward achieving the goals, which may include activi-
17 ties carried out directly by the Secretaries and ac-
18 tivities carried out through awards of grants or con-
19 tracts to public or nonprofit private entities.

20 (3) In carrying out paragraph (2), the Secre-
21 taries shall give priority—

22 (A) first, to achieving the goal under sub-
23 section (c);

24 (B) second, to achieving the goal under
25 subsection (d);

1 (C) third, to achieving the goal under sub-
2 section (e);

3 (D) fourth, to achieving the goal under
4 subsection (f); and

5 (E) fifth, to achieving the goal under sub-
6 section (g).

7 (b) FIVE-YEAR PLAN.—In carrying out subsection
8 (a), the Secretaries shall establish a plan that, for the 5
9 fiscal years following the date of the enactment of this
10 Act, provides for the activities to be carried out during
11 such fiscal years toward achieving the goals under sub-
12 sections (c) through (g). The plan shall, as appropriate
13 to such goals, provide for the coordination of programs
14 and activities regarding Lyme disease that are conducted
15 or supported by the Federal Government.

16 (c) FIRST GOAL: DETECTION TEST.—For purposes
17 of subsection (a), the goal described in this subsection is
18 the development of novel and more sensitive, specific, and
19 reproducible diagnostic tests and procedures (or the im-
20 provement or refinement of existing tests) that—

21 (1) can accurately determine whether an indi-
22 vidual has acute or chronic Lyme disease;

23 (2) can accurately determine the activity of
24 acute or chronic Lyme disease infection or both;

1 (3) can accurately distinguish acute or chronic
2 Lyme disease or both from other related, tick-borne,
3 coinfectious diseases; and

4 (4) can accurately measure the responsiveness
5 of acute or chronic Lyme disease infection or both
6 to treatment.

7 (d) SECOND GOAL: IMPROVED SURVEILLANCE AND
8 REPORTING SYSTEM.—

9 (1) IN GENERAL.—For purposes of subsection
10 (a), the goal described in this subsection is to assess
11 the medical, social, and economic burden of Lyme
12 disease in the United States. This assessment shall
13 include a review of the system in the United States
14 for surveillance and reporting with respect to Lyme
15 disease and a determination of whether and in what
16 manner the system can be improved.

17 (2) CERTAIN ACTIVITIES.—In carrying out ac-
18 tivities toward the goal described in paragraph (1),
19 the Secretaries shall—

20 (A) consult with the States, the Conference
21 of State and Territorial Epidemiologists, units
22 of local government, physicians and health pro-
23 viders, patients with Lyme disease, and organi-
24 zations representing such patients;

1 (B) consider whether uniform formats
2 should be developed for the reporting by physi-
3 cians and laboratories of cases of Lyme disease
4 to public health officials; and

5 (C) with respect to health conditions that
6 are reported by physicians as cases of Lyme
7 disease but do not meet the surveillance criteria
8 established by the Director of the Centers for
9 Disease Control and Prevention to be counted
10 as such cases, consider whether data on such
11 health conditions should be maintained and
12 analyzed to assist in understanding the cir-
13 cumstances in which Lyme disease is being di-
14 agnosed and the manner in which it is being
15 treated.

16 (e) **THIRD GOAL: LYME DISEASE PREVENTION; DE-**
17 **VELOPMENT OF INDICATORS.**—For purposes of subsection
18 (a), the goal described in this subsection is to reduce,
19 through the use of effective public health education, pre-
20 vention, and tick population reduction techniques, the inci-
21 dence of Lyme disease in the 10 highest endemic States
22 by 33 percent by the date that is 5 years after the date
23 of the enactment of this Act. In carrying out activities to-
24 ward such goal, the Secretaries shall carry out each of
25 the following:

1 (1) Establish a baseline incidence rate of Lyme
2 disease in the 10 highest endemic States. The estab-
3 lishment of this baseline must take into consider-
4 ation the surveillance criteria review specified in sub-
5 section (d).

6 (2) Encourage the use of natural and nonpes-
7 ticial methods to control and reduce tick popu-
8 lations, where appropriate.

9 (3) Reduce the risks of Lyme disease at all fed-
10 erally owned lands located in endemic States and re-
11 gions, as well as at locations known or suspected to
12 pose a risk of Lyme disease to patrons and employ-
13 ees, through the following:

14 (A) The development of standardized, peri-
15 odic (not less than 1 per year) Lyme disease
16 risk assessments that test and then categorize
17 the overall level of risk of Lyme disease at fed-
18 erally owned lands in endemic States and re-
19 gions. The Lyme disease risk assessments shall
20 be made available to the public in appropriate
21 forms, and may include such factors as—

22 (i) whether any human cases of Lyme
23 disease have been diagnosed and treated
24 on, or in areas adjacent to, the federally
25 owned lands;

1 (ii) whether vectors capable of trans-
2 mitting Lyme disease to humans are
3 known to inhabit the federally owned land;

4 (iii) whether any such vectors present
5 on the federally owned land are known to
6 actually be infected with Lyme disease;
7 and

8 (iv) the geographic distribution of
9 Lyme disease risk within the federally
10 owned land.

11 (B) The development and coordination of
12 public awareness programs to educate patrons,
13 employees, and health professionals at federally
14 owned lands about the risks of Lyme disease,
15 all appropriate prevention methods that can be
16 used to reduce these risks, and information
17 about the symptoms and nature of the disease.

18 (C) The use of appropriate habitat man-
19 agement and integrated pest-control techniques
20 to reduce the number of tick-borne Lyme dis-
21 ease vectors in areas where humans work or
22 recreate.

23 (f) **FOURTH GOAL: PREVENTION OF TICK-BORNE**
24 **DISEASES OTHER THAN LYME.**—For purposes of sub-
25 section (a), the goal described in this subsection is to de-

1 velop the capabilities at the Centers for Disease Control
2 and Prevention, within the Department of Defense, and
3 in State and local health departments to implement ade-
4 quate surveillance, improved diagnosis, and effective strat-
5 egies for the prevention and control of tick-borne diseases
6 other than Lyme disease. Such diseases may include
7 Lyme-like illness, ehrlichiosis, babesiosis, other bacterial,
8 viral and rickettsial diseases such as tularemia, tick-borne
9 encephalitis, and Rocky Mountain Spotted Fever, respec-
10 tively.

11 (g) FIFTH GOAL: IMPROVED PUBLIC AND PHYSICIAN
12 EDUCATION.—For purposes of subsection (a), the goal de-
13 scribed in this subsection is to improve the knowledge of
14 physicians, health care providers, and the public regarding
15 the best and most effective methods to prevent, diagnose,
16 and treat Lyme disease and related tick-borne diseases.

17 **SEC. 4. LYME DISEASE TASKFORCE.**

18 (a) IN GENERAL.—Not later than 120 days after the
19 date of enactment of this Act, there shall be established
20 in accordance with this section an advisory committee to
21 be known as the Lyme Disease Taskforce (in this section
22 referred to as the “Task Force”).

23 (b) DUTIES.—The Task Force shall provide advice
24 to the Secretaries with respect to achieving the goals
25 under section 3, including advice on the plan under sub-

1 section (b) of such section. Nothing in this section may
2 be construed as interfering with or undermining the peer
3 review process for research programs and grants, and the
4 Task Force shall take care that its activities complement
5 existing interagency relationships and interdepartmental
6 working groups to the maximum extent practicable.

7 (c) MEMBERSHIP.—

8 (1) EX OFFICIO MEMBERS.—The following offi-
9 cials (or their designees) shall serve as ex officio
10 members of the Task Force:

11 (A) The Director of the National Institute
12 of Allergy and Infectious Diseases.

13 (B) The Director of the National Institute
14 of Arthritis and Musculoskeletal and Skin Dis-
15 eases.

16 (C) The Director of the National Institute
17 of Neurological Disorders and Stroke.

18 (D) The Director of the National Center
19 for Infectious Diseases.

20 (E) The Director of the Epidemiology Pro-
21 gram Office.

22 (F) The Director of the Public Health
23 Practice Program Office.

24 (G) The Commander of the United States
25 Army Medical Command.

1 (H) The Commander of the United States
2 Army Center for Health Promotion and Pre-
3 ventative Medicine.

4 (I) The Director of the Center for Bio-
5 logics Evaluation and Research.

6 (J) The Administrator of the Agricultural
7 Research Service.

8 (K) The Director of the National Park
9 Service.

10 (L) The Director of the Fish and Wildlife
11 Service.

12 (M) The Director of the Indian Health
13 Service.

14 (N) The Chief Biologist of the Biological
15 Resources Division, United States Geological
16 Survey.

17 (2) APPOINTED MEMBERS.—Appointments to
18 the Task Force shall be made in accordance with the
19 following:

20 (A) Two members shall be research sci-
21 entists with demonstrated achievements in re-
22 search related to Lyme disease and related tick-
23 borne diseases. The scientists shall be appointed
24 by the Secretary of Health and Human Services
25 (in this paragraph referred to as the “Sec-

1 retary’’) in consultation with the National
2 Academy of Sciences.

3 (B) Four members shall be representatives
4 of organizations whose primary emphasis is on
5 research and public education into Lyme dis-
6 ease and related tick-borne diseases. One rep-
7 resentative from each of such organizations
8 shall be appointed by the Secretary in consulta-
9 tion with the National Academy of Sciences.

10 (C) Two members shall be clinicians with
11 extensive experience in the treatment of individ-
12 uals with chronic Lyme disease and related
13 tick-borne diseases. The clinicians shall be ap-
14 pointed by the Secretary in consultation with
15 the Institute of Medicine and the National
16 Academy of Sciences.

17 (D) Two members shall be individuals who
18 are the parents, spouse, or legal guardians of a
19 person or persons that have contracted Lyme
20 disease or a related tick-borne disease. The in-
21 dividuals shall be appointed by the Secretary in
22 consultation with the ex officio members under
23 paragraph (1) and the four organizations re-
24 ferred to in subparagraph (B).

1 (E) One member shall be a representative
2 of the Council of State and Territorial Epi-
3 demologists.

4 (F) One member shall be a representative
5 of the National Association of County and City
6 Health Officials.

7 (G) One member shall be an epidemiologist
8 of demonstrated achievements in the field of ep-
9 idemiology. The epidemiologist shall be ap-
10 pointed by the Secretary in consultation with
11 the National Academy of Sciences.

12 (d) ADMINISTRATIVE SUPPORT; TERMS OF SERVICE;
13 OTHER PROVISIONS.—The following apply with respect to
14 the Task Force:

15 (1) The Task Force shall receive necessary and
16 appropriate administrative support from the Depart-
17 ment of Health and Human Services.

18 (2) Members of the Task Force shall be ap-
19 pointed for the duration of the Task Force.

20 (3) From among the members appointed under
21 subsection (c)(2), the Task Force shall designate an
22 individual to serve as the chairperson of the Task
23 Force.

24 (4) The Task Force shall meet no less than 2
25 times per year.

1 (5) Members of the Task Force shall not re-
2 ceive additional compensation for their service. Such
3 members may receive reimbursement for appropriate
4 and additional expenses that are incurred through
5 service on the Task Force which would not have in-
6 curred had they not been a member of the Task
7 Force.

8 (6) Any vacancy in the membership of the Task
9 Force shall be filled in the manner in which the
10 original appointment was made and does not affect
11 the power of the remaining members to carry out
12 the duties of the Task Force.

13 **SEC. 5. ANNUAL REPORTS.**

14 The Secretaries shall submit to the Congress periodic
15 reports on the activities carried out under this Act and
16 the extent of progress being made toward the goals estab-
17 lished under section 3. The first such report shall be sub-
18 mitted not later than 18 months after the date of the en-
19 actment of this Act, and subsequent reports shall be sub-
20 mitted annually thereafter until the goals are met.

21 **SEC. 6. AUTHORIZATION OF APPROPRIATIONS.**

22 (a) NATIONAL INSTITUTES OF HEALTH.—In addi-
23 tion to other authorizations of appropriations that are
24 available for carrying out the purposes described in this
25 Act and that are established for the National Institutes

1 of Health, there are authorized to be appropriated to the
2 Director of such Institutes for such purposes \$8,000,000
3 for each of the fiscal years 2000 through 2004.

4 (b) CENTERS FOR DISEASE CONTROL AND PREVEN-
5 TION.—In addition to other authorizations of appropria-
6 tions that are available for carrying out the purposes de-
7 scribed in this Act and that are established for the Centers
8 for Disease Control and Prevention, there are authorized
9 to be appropriated to the Director of such Centers for such
10 purposes \$8,000,000 for each of the fiscal years 2000
11 through 2004.

12 (c) DEPARTMENT OF DEFENSE.—In addition to
13 other authorizations of appropriations that are available
14 for carrying out the purposes described in this Act and
15 that are established for the Department of Defense, there
16 are authorized to be appropriated to the Secretary of De-
17 fense for such purposes \$6,000,000 for each of the fiscal
18 years 2000 through 2004.

19 (d) DEPARTMENT OF AGRICULTURE.—In addition to
20 other authorizations of appropriations that are available
21 for carrying out the purposes described in this Act and
22 that are established for the Department of Agriculture,
23 there are authorized to be appropriated to the Secretary
24 of Agriculture for such purposes \$1,500,000 for each of
25 the fiscal years 2000 through 2004.

1 (e) DEPARTMENT OF INTERIOR.—In addition to
2 other authorizations of appropriations that are available
3 for carrying out the purposes described in this Act and
4 that are established for the Department of Interior, there
5 are authorized to be appropriated to the Secretary of Inte-
6 rior for such purposes \$1,500,000 million for each of the
7 fiscal years 2000 through 2004.

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