

114TH CONGRESS
1ST SESSION

H. R. 789

To provide for research with respect to Lyme disease and other tick-borne diseases, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 5, 2015

Mr. GIBSON (for himself, Mr. SEAN PATRICK MALONEY of New York, Mr. WITTMAN, Mr. SMITH of New Jersey, Mr. ZELDIN, Mr. KATKO, Mr. COURTNEY, Mr. WELCH, Mr. BARLETTA, and Ms. STEFANIK) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To provide for research with respect to Lyme disease and other tick-borne diseases, 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 “Tick-Borne Disease
5 Research Accountability and Transparency Act of 2015”.

6 **SEC. 2. LYME DISEASE AND OTHER TICK-BORNE DISEASES.**

7 Title III of the Public Health Service Act (42 U.S.C.
8 241 et seq.) is amended by adding at the end the following
9 new part:

1 **“PART W—LYME DISEASE AND OTHER TICK-**
2 **BORNE DISEASES**

3 **“SEC. 39900. RESEARCH.**

4 “(a) IN GENERAL.—The Secretary shall conduct or
5 support epidemiological, basic, translational, and clinical
6 research regarding Lyme disease and other tick-borne dis-
7 eases.

8 “(b) BIENNIAL REPORTS.—The Secretary shall en-
9 sure that each biennial report under section 403 includes
10 information on actions undertaken by the National Insti-
11 tutes of Health to carry out subsection (a) with respect
12 to Lyme disease and other tick-borne diseases, including
13 an assessment of the progress made in improving the out-
14 comes of Lyme disease and such other tick-borne diseases.

15 **“SEC. 39900–1. WORKING GROUP.**

16 “(a) ESTABLISHMENT.—The Secretary shall estab-
17 lish a permanent working group, to be known as the Inter-
18 agency Lyme and Tick-Borne Disease Working Group (in
19 this section and section 39900–2 referred to as the
20 ‘Working Group’), to review all efforts within the Depart-
21 ment of Health and Human Services concerning Lyme dis-
22 ease and other tick-borne diseases to ensure interagency
23 coordination, minimize overlap, and examine research pri-
24 orities.

25 “(b) RESPONSIBILITIES.—The Working Group
26 shall—

1 “(1) not later than 24 months after the date of
2 enactment of this part, and every 24 months there-
3 after, develop or update a summary of—

4 “(A) ongoing Lyme disease and other tick-
5 borne disease research related to causes, pre-
6 vention, treatment, surveillance, diagnosis,
7 diagnostics, duration of illness, intervention,
8 and access to services and supports for individ-
9 uals with Lyme disease or other tick-borne dis-
10 eases;

11 “(B) advances made pursuant to such re-
12 search;

13 “(C) the engagement of the Department of
14 Health and Human Services with persons that
15 participate at the public meetings required by
16 paragraph (5); and

17 “(D) the comments received by the Work-
18 ing Group at such public meetings and the Sec-
19 retary’s response to such comments;

20 “(2) ensure that a broad spectrum of scientific
21 viewpoints is represented in each such summary;

22 “(3) monitor Federal activities with respect to
23 Lyme disease and other tick-borne diseases;

1 “(4) make recommendations to the Secretary
2 regarding any appropriate changes to such activities;
3 and

4 “(5) ensure public input by holding annual pub-
5 lic meetings that address scientific advances, re-
6 search questions, surveillance activities, and emerg-
7 ing strains in species of pathogenic organisms.

8 “(c) MEMBERSHIP.—

9 “(1) IN GENERAL.—The Working Group shall
10 be composed of a total of 14 members as follows:

11 “(A) FEDERAL MEMBERS.—Seven Federal
12 members, consisting of one or more representa-
13 tives of each of—

14 “(i) the Office of the Assistant Sec-
15 retary for Health;

16 “(ii) the Food and Drug Administra-
17 tion;

18 “(iii) the Centers for Disease Control
19 and Prevention;

20 “(iv) the National Institutes of
21 Health; and

22 “(v) such other agencies and offices of
23 the Department of Health and Human
24 Services as the Secretary determines ap-
25 propriate.

1 “(B) NON-FEDERAL PUBLIC MEMBERS.—
2 Seven non-Federal public members, consisting
3 of representatives of the following categories:

4 “(i) Physicians and other medical pro-
5 viders with experience in diagnosing and
6 treating Lyme disease and other tick-borne
7 diseases.

8 “(ii) Scientists or researchers with ex-
9 pertise.

10 “(iii) Patients and their family mem-
11 bers.

12 “(iv) Nonprofit organizations that ad-
13 vocate for patients with respect to Lyme
14 disease and other tick-borne diseases.

15 “(v) Other individuals whose expertise
16 is determined by the Secretary to be bene-
17 ficial to the functioning of the Working
18 Group.

19 “(2) APPOINTMENT.—The members of the
20 Working Group shall be appointed by the Secretary,
21 except that of the non-Federal public members
22 under paragraph (1)(B)—

23 “(A) one shall be appointed by the Speaker
24 of the House of Representatives; and

1 “(B) one shall be appointed by the Major-
2 ity Leader of the Senate.

3 “(3) DIVERSITY OF SCIENTIFIC PERSPEC-
4 TIVES.—In making appointments under paragraph
5 (2), the Secretary, the Speaker of the House of Rep-
6 resentatives, and the Majority Leader of the Senate
7 shall ensure that the non-Federal public members of
8 the Working Group represent a diversity of scientific
9 perspectives.

10 “(4) TERMS.—The non-Federal public members
11 of the Working Group shall each be appointed to
12 serve a 4-year term and may be reappointed at the
13 end of such term.

14 “(d) MEETINGS.—The Working Group shall meet as
15 often as necessary, as determined by the Secretary, but
16 not less than twice each year.

17 “(e) APPLICABILITY OF FACCA.—The Working Group
18 shall be treated as an advisory committee subject to the
19 Federal Advisory Committee Act.

20 “(f) REPORTING.—Not later than 24 months after
21 the date of enactment of this part, and every 24 months
22 thereafter, the Working Group—

23 “(1) shall submit a report on its activities, in-
24 cluding an up-to-date summary under subsection
25 (b)(1) and any recommendations under subsection

1 (b)(4), to the Secretary, the Committee on Energy
2 and Commerce of the House of Representatives, and
3 the Committee on Health, Education, Labor and
4 Pensions of the Senate;

5 “(2) shall make each such report publicly avail-
6 able on the website of the Department of Health and
7 Human Services; and

8 “(3) shall allow any member of the Working
9 Group to include in any such report minority views.

10 **“SEC. 39900-2. STRATEGIC PLAN.**

11 “Not later than 3 years after the date of enactment
12 of this section, and every 5 years thereafter, the Secretary
13 shall submit to the Congress a strategic plan, informed
14 by the most recent summary under section 39900-
15 1(b)(1), for the conduct and support of Lyme disease and
16 tick-borne disease research, including—

17 “(1) proposed budgetary requirements;

18 “(2) a plan for improving outcomes of Lyme
19 disease and other tick-borne diseases, including
20 progress related to chronic or persistent symptoms
21 and chronic or persistent infection and co-infections;

22 “(3) a plan for improving diagnosis, treatment,
23 and prevention;

1 “(4) appropriate benchmarks to measure
2 progress on achieving the improvements described in
3 paragraphs (2) and (3); and

4 “(5) a plan to disseminate each summary under
5 section 39900–1(b)(1) and other relevant informa-
6 tion developed by the Working Group to the public,
7 including health care providers, public health depart-
8 ments, and other relevant medical groups.”.

9 **SEC. 3. NO ADDITIONAL AUTHORIZATION OF APPROPRIA-**
10 **TIONS.**

11 No additional funds are authorized to be appro-
12 priated to carry out this Act and the amendment made
13 by this Act, and this Act and such amendment shall be
14 carried out using amounts otherwise available for such
15 purpose.

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