

113TH CONGRESS
2^D SESSION

H. R. 4701

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 10, 2014

Received; read twice and referred to the Committee on Health, Education,
Labor, and Pensions

AN ACT

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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Tick-Borne Disease
3 Research Accountability and Transparency Act of 2014”.

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

5 Title III of the Public Health Service Act (42 U.S.C.
6 241 et seq.) is amended by adding at the end the following
7 new part:

8 **“PART W—LYME DISEASE AND OTHER TICK-**
9 **BORNE DISEASES**

10 **“SEC. 39900. RESEARCH.**

11 “(a) IN GENERAL.—The Secretary shall conduct or
12 support epidemiological, basic, translational, and clinical
13 research regarding Lyme disease and other tick-borne dis-
14 eases.

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

22 **“SEC. 39900–1. WORKING GROUP.**

23 “(a) ESTABLISHMENT.—The Secretary shall estab-
24 lish a permanent working group, to be known as the Inter-
25 agency Lyme and Tick-Borne Disease Working Group (in
26 this section and section 39900–2 referred to as the

1 ‘Working Group’), to review all efforts within the Depart-
2 ment of Health and Human Services concerning Lyme dis-
3 ease and other tick-borne diseases to ensure interagency
4 coordination, minimize overlap, and examine research pri-
5 orities.

6 “(b) RESPONSIBILITIES.—The Working Group
7 shall—

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

11 “(A) ongoing Lyme disease and other tick-
12 borne disease research related to causes, pre-
13 vention, treatment, surveillance, diagnosis,
14 diagnostics, duration of illness, intervention,
15 and access to services and supports for individ-
16 uals with Lyme disease or other tick-borne dis-
17 eases;

18 “(B) advances made pursuant to such re-
19 search;

20 “(C) the engagement of the Department of
21 Health and Human Services with persons that
22 participate at the public meetings required by
23 paragraph (5); and

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

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

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

8 “(4) make recommendations to the Secretary
9 regarding any appropriate changes to such activities;
10 and

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

15 “(c) MEMBERSHIP.—

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

18 “(A) FEDERAL MEMBERS.—Seven Federal
19 members, consisting of one or more representa-
20 tives of each of—

21 “(i) the Office of the Assistant Sec-
22 retary for Health;

23 “(ii) the Food and Drug Administra-
24 tion;

1 “(iii) the Centers for Disease Control
2 and Prevention;

3 “(iv) the National Institutes of
4 Health; and

5 “(v) such other agencies and offices of
6 the Department of Health and Human
7 Services as the Secretary determines ap-
8 propriate.

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

12 “(i) Physicians and other medical pro-
13 viders with experience in diagnosing and
14 treating Lyme disease and other tick-borne
15 diseases.

16 “(ii) Scientists or researchers with ex-
17 pertise.

18 “(iii) Patients and their family mem-
19 bers.

20 “(iv) Nonprofit organizations that ad-
21 vocate for patients with respect to Lyme
22 disease and other tick-borne diseases.

23 “(v) Other individuals whose expertise
24 is determined by the Secretary to be bene-

1 ficial to the functioning of the Working
2 Group.

3 “(2) APPOINTMENT.—The members of the
4 Working Group shall be appointed by the Secretary,
5 except that of the non-Federal public members
6 under paragraph (1)(B)—

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

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

11 “(3) DIVERSITY OF SCIENTIFIC PERSPEC-
12 TIVES.—In making appointments under paragraph
13 (2), the Secretary, the Speaker of the House of Rep-
14 resentatives, and the Majority Leader of the Senate
15 shall ensure that the non-Federal public members of
16 the Working Group represent a diversity of scientific
17 perspectives.

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

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

1 “(e) APPLICABILITY OF FACA.—The Working Group
2 shall be treated as an advisory committee subject to the
3 Federal Advisory Committee Act.

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

7 “(1) shall submit a report on its activities, in-
8 cluding an up-to-date summary under subsection
9 (b)(1) and any recommendations under subsection
10 (b)(4), to the Secretary, the Committee on Energy
11 and Commerce of the House of Representatives, and
12 the Committee on Health, Education, Labor and
13 Pensions of the Senate;

14 “(2) shall make each such report publicly avail-
15 able on the website of the Department of Health and
16 Human Services; and

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

19 **“SEC. 39900-2. STRATEGIC PLAN.**

20 “Not later than 3 years after the date of enactment
21 of this section, and every 5 years thereafter, the Secretary
22 shall submit to the Congress a strategic plan, informed
23 by the most recent summary under section 39900-
24 1(b)(1), for the conduct and support of Lyme disease and
25 tick-borne disease research, including—

1 “(1) proposed budgetary requirements;

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

6 “(3) a plan for improving diagnosis, treatment,
7 and prevention;

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

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

16 **SEC. 3. NO ADDITIONAL AUTHORIZATION OF APPROPRIA-**
17 **TIONS.**

18 No additional funds are authorized to be appro-
19 priated to carry out this Act and the amendment made
20 by this Act, and this Act and such amendment shall be

1 carried out using amounts otherwise available for such
2 purpose.

Passed the House of Representatives September 9,
2014.

Attest:

KAREN L. HAAS,

Clerk.