

Suspend the Rules And Pass the Bill, H.R. 4701, with Amendments

(The amendments strike all after the enacting clause and insert a new text and a new title)

113TH CONGRESS
2^D SESSION

H. R. 4701

To provide for scientific frameworks with respect to vector-borne diseases.

IN THE HOUSE OF REPRESENTATIVES

MAY 21, 2014

Mr. GIBSON (for himself, Mr. COURTNEY, Mr. PETERSON, Mr. SMITH of New Jersey, Mr. WOLF, and Mr. BARLETTA) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To provide for scientific frameworks with respect to vector-borne diseases.

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 2014”.

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

2 Title III of the Public Health Service Act (42 U.S.C.
3 241 et seq.) is amended by adding at the end the following
4 new part:

5 **“PART W—LYME DISEASE AND OTHER TICK-**
6 **BORNE DISEASES**

7 **“SEC. 3990O. RESEARCH.**

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

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

19 **“SEC. 3990O-1. WORKING GROUP.**

20 “(a) ESTABLISHMENT.—The Secretary shall estab-
21 lish a permanent working group, to be known as the Inter-
22 agency Lyme and Tick-Borne Disease Working Group (in
23 this section and section 3990O-2 referred to as the
24 ‘Working Group’), to review all efforts within the Depart-
25 ment of Health and Human Services concerning Lyme dis-
26 ease and other tick-borne diseases to ensure interagency

1 coordination, minimize overlap, and examine research pri-
2 orities.

3 “(b) RESPONSIBILITIES.—The Working Group
4 shall—

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

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

15 “(B) advances made pursuant to such re-
16 search;

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

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

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

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

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

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

10 “(c) MEMBERSHIP.—

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

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

16 “(i) the Office of the Assistant Sec-
17 retary for Health;

18 “(ii) the Food and Drug Administra-
19 tion;

20 “(iii) the Centers for Disease Control
21 and Prevention;

22 “(iv) the National Institutes of
23 Health; and

24 “(v) such other agencies and offices of
25 the Department of Health and Human

1 Services as the Secretary determines ap-
2 propriate.

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

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

10 “(ii) Scientists or researchers with ex-
11 pertise.

12 “(iii) Patients and their family mem-
13 bers.

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

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

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

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

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

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

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

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

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

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

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

8 “(2) shall make each such report publicly avail-
9 able on the website of the Department of Health and
10 Human Services; and

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

13 **“SEC. 39900-2. STRATEGIC PLAN.**

14 “Not later than 3 years after the date of enactment
15 of this section, and every 5 years thereafter, the Secretary
16 shall submit to the Congress a strategic plan, informed
17 by the most recent summary under section 39900-
18 1(b)(1), for the conduct and support of Lyme disease and
19 tick-borne disease research, including—

20 “(1) proposed budgetary requirements;

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

1 “(3) a plan for improving diagnosis, treatment,
2 and prevention;

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

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

11 **SEC. 3. NO ADDITIONAL AUTHORIZATION OF APPROPRIA-**
12 **TIONS.**

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

 Amend the title so as to read: “A bill to provide for
research with respect to Lyme disease and other tick-
borne diseases, and for other purposes.”.