

Union Calendar No. 424

113TH CONGRESS
2^D SESSION

H. R. 4701

[Report No. 113–573]

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

SEPTEMBER 8, 2014

Additional sponsors: Mr. WELCH, Mr. SEAN PATRICK MALONEY of New York, Mr. POSEY, Mr. WITTMAN, Ms. SCHAKOWSKY, Ms. ESTY, Mr. LANCE, Mr. SHIMKUS, Mr. TONKO, Mr. BARROW of Georgia, Mr. KEATING, Mr. CONNOLLY, Ms. SHEA-PORTER, and Mr. MAFFEI

SEPTEMBER 8, 2014

Reported with amendments, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in *italic*]

[For text of introduced bill, see copy of bill as introduced on May 21, 2014]

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 Re-*
5 *search Accountability and Transparency Act of 2014”.*

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:*

10 **“PART W—LYME DISEASE AND OTHER TICK-**
11 **BORNE DISEASES**

12 **“SEC. 3990O. RESEARCH.**

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

17 *“(b) BIENNIAL REPORTS.—The Secretary shall ensure*
18 *that each biennial report under section 403 includes infor-*
19 *mation on actions undertaken by the National Institutes*
20 *of Health to carry out subsection (a) with respect to Lyme*
21 *disease and other tick-borne diseases, including an assess-*
22 *ment of the progress made in improving the outcomes of*
23 *Lyme disease and such other tick-borne diseases.*

1 **“SEC. 39900–1. WORKING GROUP.**

2 “(a) *ESTABLISHMENT.*—*The Secretary shall establish*
3 *a permanent working group, to be known as the Interagency*
4 *Lyme and Tick-Borne Disease Working Group (in this sec-*
5 *tion and section 39900–2 referred to as the ‘Working*
6 *Group’), to review all efforts within the Department of*
7 *Health and Human Services concerning Lyme disease and*
8 *other tick-borne diseases to ensure interagency coordination,*
9 *minimize overlap, and examine research priorities.*

10 “(b) *RESPONSIBILITIES.*—*The Working Group shall—*

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

14 “(A) *ongoing Lyme disease and other tick-*
15 *borne disease research related to causes, preven-*
16 *tion, treatment, surveillance, diagnosis, duration*
17 *of illness, intervention, and access to services and*
18 *supports for individuals with Lyme disease or*
19 *other tick-borne diseases;*

20 “(B) *advances made pursuant to such re-*
21 *search;*

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

1 “(D) the comments received by the Working
2 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 re-
9 garding any appropriate changes to such activities;
10 and

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

15 “(c) MEMBERSHIP.—

16 “(1) IN GENERAL.—The Working Group shall be
17 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 Health;
4 and

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

9 “(B) NON-FEDERAL PUBLIC MEMBERS.—
10 Seven non-Federal public members, consisting of
11 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 Work-*
4 *ing Group shall be appointed by the Secretary, except*
5 *that of the non-Federal public members under para-*
6 *graph (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 Majority*
10 *Leader of the Senate.*

11 “(3) *DIVERSITY OF SCIENTIFIC PERSPECTIVES.—*
12 *In making appointments under paragraph (2), the*
13 *Secretary, the Speaker of the House of Representa-*
14 *tives, and the Majority Leader of the Senate shall en-*
15 *sure that the non-Federal public members of the*
16 *Working Group represent a diversity of scientific per-*
17 *spectives.*

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

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

1 “(e) *REPORTING.*—Not later than 24 months after the
 2 date of enactment of this part, and every 24 months there-
 3 after, the Working Group—

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

11 “(2) shall make each such report publicly avail-
 12 able on the website of the Department of Health and
 13 Human Services; and

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

16 **“SEC. 39900–2. STRATEGIC PLAN.**

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

23 “(1) proposed budgetary requirements;

24 “(2) a plan for improving outcomes of Lyme dis-
 25 ease and other tick-borne diseases, including progress

1 *related to chronic or persistent symptoms and chronic*
2 *or persistent infection and co-infections;*

3 *“(3) a plan for improving diagnosis, treatment,*
4 *and prevention;*

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

8 *“(5) a plan to disseminate each summary under*
9 *section 399OO–1(b)(1) and other relevant information*
10 *developed by the Working Group to the public, includ-*
11 *ing health care providers, public health departments,*
12 *and other relevant medical groups.”.*

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.”.

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