

**AMENDMENT IN THE NATURE OF A SUBSTITUTE
TO H.R. 4701
OFFERED BY M . _____**

Strike all after the enacting clause and insert the following:

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 DIS-**
5 **EASES.**

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

9 **[“PART W—LYME DISEASE AND OTHER TICK-**
10 **BORNE DISEASES]**

11 **[“SEC. 3990O. RESEARCH.**

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

16 **[“(b) BIENNIAL REPORTS.—**The Secretary shall en-
17 sure that each biennial report under section 403 includes
18 information on actions undertaken by the National Insti-

1 tutes of Health to carry out subsection (a) with respect
2 to Lyme disease and other tick-borne diseases, including
3 an assessment of the progress made in improving the out-
4 comes of Lyme disease and such other tick-borne dis-
5 eases.]

6 **["SEC. 39900-1. WORKING GROUP.**

7 **["(a) ESTABLISHMENT.—**The Secretary shall estab-
8 lish a permanent working group, to be known as the Inter-
9 agency Lyme and Tick-Borne Disease Working Group (in
10 this section and section 39900-2 referred to as the
11 ‘Working Group’), to review all efforts within the Depart-
12 ment of Health and Human Services concerning Lyme dis-
13 ease and other tick-borne diseases to ensure interagency
14 coordination, minimize overlap, and examine research pri-
15 orities.]

16 **["(b) RESPONSIBILITIES.—**The Working Group
17 shall—]

18 **["(1) not later than 24 months after the date**
19 **of enactment of this part, and every 24 months**
20 **thereafter, develop or update a summary of—]**

21 **["(A) ongoing Lyme disease and other**
22 **tick-borne disease research related to causes,**
23 **prevention, treatment, surveillance, diagnosis,**
24 **duration of illness, intervention, and access to**

1 services and supports for individuals with Lyme
2 disease or other tick-borne diseases;】

3 【“(B) advances made pursuant to such re-
4 search;】

5 【“(C) the engagement of the Department
6 of Health and Human Services with persons
7 that participate at the public meetings required
8 by paragraph (5); and】

9 【“(D) the comments received by the Work-
10 ing Group at such public meetings and the Sec-
11 retary’s response to such comments;】

12 【“(2) ensure that a broad spectrum of scientific
13 viewpoints is represented in each such summary;】

14 【“(3) monitor Federal activities with respect to
15 Lyme disease and other tick-borne diseases;】

16 【“(4) make recommendations to the Secretary
17 regarding any appropriate changes to such activities;
18 and】

19 【“(5) ensure public input by holding annual
20 public meetings that address scientific advances, re-
21 search questions, surveillance activities, and emerg-
22 ing strains in species of pathogenic organisms.】

23 【“(c) MEMBERSHIP.—】

24 【“(1) IN GENERAL.—The Working Group shall
25 be composed of a total of 14 members as follows:】

1 【“(A) FEDERAL MEMBERS.—Seven Fed-
2 eral members, consisting of one or more rep-
3 resentatives of each of—】

4 【“(i) the Office of the Assistant Sec-
5 retary for Health;】

6 【“(ii) the Food and Drug Administra-
7 tion;】

8 【“(iii) the Centers for Disease Con-
9 trol and Prevention;】

10 【“(iv) the National Institutes of
11 Health; and】

12 【“(v) such other agencies and offices
13 of the Department of Health and Human
14 Services as the Secretary determines ap-
15 propriate.】

16 【“(B) NON-FEDERAL PUBLIC MEMBERS.—
17 Seven non-Federal public members, consisting
18 of representatives of the following categories:】

19 【“(i) Physicians and other medical
20 providers with experience in diagnosing
21 and treating Lyme disease and other tick-
22 borne diseases.】

23 【“(ii) Scientists or researchers with
24 expertise.】

1 【“(iii) Patients and their family mem-
2 bers.】

3 【“(iv) Nonprofit organizations that
4 advocate for patients with respect to Lyme
5 disease and other tick-borne diseases.】

6 【“(v) Other individuals whose exper-
7 tise is determined by the Secretary to be
8 beneficial to the functioning of the Work-
9 ing Group.】

10 【“(2) APPOINTMENT.—The members of the
11 Working Group shall be appointed by the Secretary,
12 except that of the non-Federal public members
13 under paragraph (1)(B)—】

14 【“(A) one shall be appointed by the Speak-
15 er of the House of Representatives; and】

16 【“(B) one shall be appointed by the Ma-
17 jority Leader of the Senate.】

18 “(3) DIVERSITY OF SCIENTIFIC PERSPEC-
19 TIVES.—In making appointments under paragraph
20 (2), the Secretary, the Speaker of the House of Rep-
21 resentatives, and the Majority Leader of the Senate
22 shall ensure that the non-Federal public members of
23 the Working Group represent a diversity of scientific
24 perspectives.

1 【“(4) TERMS.—The non-Federal public mem-
2 bers of the Working Group shall each be appointed
3 to serve a 4-year term and may be reappointed at
4 the end of such term.】

5 【“(d) MEETINGS.—The Working Group shall meet
6 as often as necessary, as determined by the Secretary, but
7 not less than twice each year.】

8 【“(e) REPORTING.—Not later than 24 months after
9 the date of enactment of this part, and every 24 months
10 thereafter, the Working Group—】

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

18 【“(2) shall make each such report publicly
19 available on the website of the Department of
20 Health and Human Services; and】

21 【“(3) shall allow any member of the Working
22 Group to include in any such report minority views.】

23 **【“SEC. 39900-2. STRATEGIC PLAN.**

24 “Not later than 3 years after the date of enactment
25 of this section, and every 5 years thereafter, the Secretary

1 shall submit to the Congress a strategic plan, informed
2 by the most recent summary under section 39900–
3 1(b)(1), for the conduct and support of Lyme disease and
4 tick-borne disease research, including—】

5 【“(1) proposed budgetary requirements;】

6 【“(2) a plan for improving outcomes of Lyme
7 disease and other tick-borne diseases, including
8 progress related to chronic or persistent symptoms
9 and chronic or persistent infection and co-infec-
10 tions;】

11 【“(3) a plan for improving diagnosis, treat-
12 ment, and prevention;】

13 【“(4) appropriate benchmarks to measure
14 progress on achieving the improvements described in
15 paragraphs (2) and (3); and】

16 【“(5) a plan to disseminate each summary
17 under section 39900–1(b)(1) and other relevant in-
18 formation developed by the Working Group to the
19 public, including health care providers, public health
20 departments, 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.”.

