

**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 “Vector-Borne Disease
3 Research Accountability and Transparency Act of 2014”.

**4 SEC. 2. RESEARCH REGARDING LYME DISEASE AND OTHER
5 VECTOR-BORNE DISEASES.**

6 Subpart 6 of part C of title IV of the Public Health
7 Service Act (42 U.S.C. 285f et seq.) is amended by adding
8 at the end the following:

**9 “SEC. 447D. RESEARCH REGARDING LYME DISEASE AND
10 OTHER VECTOR-BORNE DISEASES.**

11 “(a) IN GENERAL.—In carrying out section 446, the
12 Director of the Institute shall conduct or support basic,
13 translational, and clinical research regarding Lyme Dis-
14 ease and other vector-borne diseases.

15 “(b) BIENNIAL REPORTS.—The Director of NIH
16 shall ensure that each biennial report under section 403
17 includes information on actions undertaken to carry out
18 subsection (a) with respect to Lyme Disease and other

1 tick-borne diseases, including an assessment of the
2 progress made in improving the outcomes of Lyme Disease
3 and such other tick-borne diseases.”.

4 **SEC. 3. LYME AND TICK-BORNE DISEASES WORKING**
5 **GROUP.**

6 Part P of title III of the Public Health Service Act
7 (42 U.S.C. 280g et seq.) is amended by adding at the end
8 the following:

9 **“SEC. 399V-6. LYME AND TICK-BORNE DISEASES WORKING**
10 **GROUP.**

11 “(a) IN GENERAL.—For the purpose described in
12 subsection (b), the Secretary shall continue to maintain,
13 as a permanent working group, the Department of Health
14 and Human Services Lyme and Tick-borne Diseases
15 Working Group (in this section referred to as the ‘Work-
16 ing Group’).

17 “(b) PURPOSE.—The purpose of the Working Group
18 shall be to review programs and activities (including re-
19 search and surveillance, policy updates, and events) relat-
20 ing to Lyme Disease and other tick-borne diseases across
21 all agencies and offices of the Department of Health and
22 Human Services to ensure coordination and collaboration
23 of such programs and activities.

24 “(c) MEMBERSHIP.—The members of the Working
25 Group shall consist of—

1 “(1) the Commissioner of Food and Drugs (or
2 the Commissioner’s designee);

3 “(2) the Director of the Centers of Disease
4 Control and Prevention (or the Director’s designee);

5 “(3) the Director of the National Institutes of
6 Health (or the Director’s designee); and

7 “(4) such other officials and employees of the
8 Department of Health and Human Services as the
9 Secretary determines appropriate.

10 “(d) CONSULTATION.—In carrying out the purpose
11 described in subsection (b), the Working Group shall—

12 “(1) consult with one or more representatives of
13 each of the categories of—

14 “(A) physicians and other clinicians with
15 experience in diagnosing and treating Lyme
16 Disease and other tick-borne diseases;

17 “(B) non-Federal scientists or researchers
18 with appropriate expertise;

19 “(C) patients and their family members;

20 “(D) nonprofit organizations that advocate
21 for patients by promoting education, services,
22 or research; and

23 “(E) other individuals whose expertise is
24 determined by the Secretary to be beneficial;
25 and

1 “(2) hold a public meeting before the issuance
2 of each report under subsection (e) and in each such
3 meeting address, with respect to Lyme Disease and
4 other tick-borne diseases—

5 “(A) scientific advances;

6 “(B) research questions on basic,
7 translational, and clinical research;

8 “(C) surveillance activities; and

9 “(D) emerging strains.

10 “(e) PROGRESS REPORT AND PLAN.—

11 “(1) INITIAL REPORT.—Not later than 24
12 months after the date of enactment of the Vector-
13 Borne Disease Research Accountability and Trans-
14 parency Act of 2014, the Secretary shall, with re-
15 spect to Lyme Disease and other tick-borne diseases,
16 prepare and submit to the Committee on Energy
17 and Commerce of the House of Representatives and
18 the Committee on Health, Education, Labor, and
19 Pensions of the Senate a progress report including
20 the following:

21 “(A) A description of the activities of the
22 Working Group.

23 “(B) A description of scientific advances
24 related to Lyme Disease and other tick-borne
25 diseases, including new scientific findings in the

1 areas of prevention, diagnosis, and treatment of
2 Lyme Disease and other tick-borne diseases.

3 “(C) Research questions relating to basic,
4 translational, and clinical science on prevention,
5 diagnosis, and treatment.

6 “(D) An assessment of the progress made
7 in improving outcomes of Lyme Disease and
8 other tick-borne diseases.

9 “(E) A summary of current surveillance
10 activities.

11 “(F) A description of engagement by the
12 Department of Health and Human Services
13 with the categories of people listed in subsection
14 (d)(1).

15 “(G) A summary of the comments received
16 at, and of the Department’s response to, the
17 public meetings required by subsection (d)(2).

18 “(H) Recommendations for appropriate ac-
19 tions to advance research questions, improve
20 surveillance, and identify appropriate bench-
21 marks to measure progress on achieving such
22 actions.

23 “(I) A strategic plan for implementing
24 such recommendations.

1 “(2) UPDATES.—Every 5 years after the sub-
2 mission of the initial progress report under para-
3 graph (1), the Secretary shall submit an updated
4 version of such report to the committees referred to
5 in such paragraph.”.

Amend the long title to read as follows: “A bill to
provide for research with respect to Lyme Disease and
other vector-borne diseases, and for other purposes.”.

