

**H.R.789 -- Tick-Borne Disease Research Accountability and Transparency
Act of 2015 (Introduced in House - IH)**

HR 789 IH

114th CONGRESS
1st Session
H. R. 789

To provide for research with respect to Lyme disease and other tick-borne diseases, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

February 5, 2015

Mr. GIBSON (for himself, Mr. SEAN PATRICK MALONEY of New York, Mr. WITTMAN, Mr. SMITH of New Jersey, Mr. ZELDIN, Mr. KATKO, Mr. COURTNEY, Mr. WELCH, Mr. BARLETTA, and Ms. STEFANIK) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To provide for research with respect to Lyme disease and other tick-borne diseases, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the 'Tick-Borne Disease Research Accountability and Transparency Act of 2015'.

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

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

PART W--LYME DISEASE AND OTHER TICK-BORNE DISEASES

SEC. 39900. RESEARCH.

(a) In General- The Secretary shall conduct or support epidemiological, basic, translational, and clinical research regarding Lyme disease and other tick-borne diseases.

(b) Biennial Reports- The Secretary shall ensure that each biennial report under section 403 includes information on actions undertaken by the National Institutes of Health to carry out subsection (a) with respect to Lyme disease and other tick-borne diseases, including an assessment of the progress made in improving the outcomes of Lyme disease and such other tick-borne diseases.

SEC. 39900-1. WORKING GROUP.

(a) Establishment- The Secretary shall establish a permanent working group, to be known as the Interagency Lyme and Tick-Borne Disease Working Group (in this section and section 39900-2 referred to as the 'Working Group'), to review all efforts within the Department of Health and Human Services concerning Lyme disease and other tick-borne diseases to ensure interagency coordination, minimize overlap, and examine research priorities.

(b) Responsibilities- The Working Group shall--

(1) not later than 24 months after the date of enactment of this part, and every 24 months thereafter, develop or update a summary of--

(A) ongoing Lyme disease and other tick-borne disease research related to causes, prevention, treatment, surveillance, diagnosis, diagnostics, duration of illness, intervention, and access to services and supports for individuals with Lyme disease or other tick-borne diseases;

(B) advances made pursuant to such research;

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

`(D) the comments received by the Working Group at such public meetings and the Secretary's response to such comments;

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

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

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

`(5) ensure public input by holding annual public meetings that address scientific advances, research questions, surveillance activities, and emerging strains in species of pathogenic organisms.

`(c) Membership-

`(1) IN GENERAL- The Working Group shall be composed of a total of 14 members as follows:

`(A) FEDERAL MEMBERS- Seven Federal members, consisting of one or more representatives of each of--

`(i) the Office of the Assistant Secretary for Health;

`(ii) the Food and Drug Administration;

`(iii) the Centers for Disease Control and Prevention;

`(iv) the National Institutes of Health; and

`(v) such other agencies and offices of the Department of Health and Human Services as the Secretary determines appropriate.

`(B) NON-FEDERAL PUBLIC MEMBERS- Seven non-Federal public members, consisting of representatives of the following categories:

`(i) Physicians and other medical providers with experience in diagnosing and treating Lyme disease and other tick-borne diseases.

`(ii) Scientists or researchers with expertise.

`(iii) Patients and their family members.

`(iv) Nonprofit organizations that advocate for patients with respect to Lyme disease and other tick-borne diseases.

`(v) Other individuals whose expertise is determined by the Secretary to be beneficial to the functioning of the Working Group.

`(2) APPOINTMENT- The members of the Working Group shall be appointed by the Secretary, except that of the non-Federal public members under paragraph (1)(B)--

`(A) one shall be appointed by the Speaker of the House of Representatives; and

`(B) one shall be appointed by the Majority Leader of the Senate.

`(3) DIVERSITY OF SCIENTIFIC PERSPECTIVES- In making appointments under paragraph (2), the Secretary, the Speaker of the House of Representatives, and the Majority Leader of the Senate shall ensure that the non-Federal public members of the Working Group represent a diversity of scientific perspectives.

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

`(d) Meetings- The Working Group shall meet as often as necessary, as determined by the Secretary, but not less than twice each year.

`(e) Applicability of FACA- The Working Group shall be treated as an advisory committee subject to the Federal Advisory Committee Act.

`(f) Reporting- Not later than 24 months after the date of enactment of this part, and every 24 months thereafter, the Working Group--

`(1) shall submit a report on its activities, including an up-to-date summary under subsection (b)(1) and any recommendations under subsection (b)(4), to the Secretary, the Committee on Energy and Commerce of the House of Representatives, and the Committee on Health, Education, Labor and Pensions of the Senate;

`(2) shall make each such report publicly available on the website of the Department of Health and Human Services; and

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

SEC. 39900-2. STRATEGIC PLAN.

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

- (1) proposed budgetary requirements;
- (2) a plan for improving outcomes of Lyme disease and other tick-borne diseases, including progress related to chronic or persistent symptoms and chronic or persistent infection and co-infections;
- (3) a plan for improving diagnosis, treatment, and prevention;
- (4) appropriate benchmarks to measure progress on achieving the improvements described in paragraphs (2) and (3); and
- (5) a plan to disseminate each summary under section 39900-1(b)(1) and other relevant information developed by the Working Group to the public, including health care providers, public health departments, and other relevant medical groups.'

SEC. 3. NO ADDITIONAL AUTHORIZATION OF APPROPRIATIONS.

No additional funds are authorized to be appropriated to carry out this Act and the amendment made by this Act, and this Act and such amendment shall be carried out using amounts otherwise available for such purpose.