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113TH CONGRESS
2D 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

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A BILL

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

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 ''Vector-Borne Disease Research Accountability and Transparency Act of 2014''.

SEC. 2. SCIENTIFIC FRAMEWORK FOR VECTOR-BORNE DISEASES.

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

"SEC. 447D. SCIENTIFIC FRAMEWORK FOR VECTOR-BORNE DISEASES.

"(a) DEVELOPMENT OF SCIENTIFIC FRAMEWORK FOR VECTOR-BORNE DISEASES.—

"(1) IN GENERAL.—For each vector-borne disease identified under subsection (b), the Directors shall develop a scientific framework for the conduct or support of research on such vector-borne disease.

"(2) CONTENTS.—The scientific framework with respect to a vector-borne disease shall include the following:

"(A) CURRENT STATUS.—

"(i) COMPREHENSIVE REVIEW OF THE LITERATURE.—A summary of findings from the current literature in the areas of—

"(I) the prevention, diagnosis, and treatment of acute and chronic vector-borne disease;

"(II) the fundamental environmental and biologic process that regulate acute and chronic vector-borne disease; and

"(III) the epidemiology of acute and chronic vector-borne disease.

''(ii) NUMBER OF INCIDENCES INTERNATIONALLY.—An assessment of the incidence of acute and chronic vector-borne disease reported internationally.

''(iii) SCIENTIFIC ADVANCES.—The identification of relevant and diverse emerging scientific areas, and promising scientific advances, in basic, translational, and clinical science relating to the areas described in subclauses (I) and (II) of clause (i).

''(iv) RESEARCHERS.—A description of the availability of individuals who—

''(I) conduct scientific research in the areas described in clause (i); and

''(II) represent a diversity of scientific perspectives relevant to such areas.

''(v) COORDINATED RESEARCH INITIATIVES.—The identification of the types of initiatives and partnerships for the coordination of intramural and extramural research of the National Institutes of Health and the Centers for Disease Control and Prevention in the areas described in clause

(i) with research of the relevant national research institutes, Federal agencies, and non-Federal public and private entities in such areas.

''(vi) RESEARCH RESOURCES.—The identification of public and private resources, such as patient registries, that are available to facilitate research relating to each of the areas described in clause (i).

''(B) IDENTIFICATION OF RESEARCH QUESTIONS.—The identification of research questions relating to basic, translational, and clinical science in the areas described in subclauses (I) and (II) of subparagraph (A)(i) that have not been adequately addressed with respect to acute or chronic vector-borne disease.

''(C) RECOMMENDATIONS.—Recommendations for appropriate actions that should be taken to advance research in the areas described in subparagraph (A)(i) and to address the research questions identified in subparagraph (B), as well as for appropriate benchmarks to measure progress on achieving such action, including the following:

"(i) RESEARCHERS.—Ensuring adequate availability of individuals described in subparagraph (A)(iv).

"(ii) COORDINATED RESEARCH INITIATIVES.—Promoting and developing initiatives and partnerships described in subparagraph (A)(v).

"(iii) RESEARCH RESOURCES.—Developing additional public and private resources described in subparagraph (A)(vi) and strengthening existing resources.

"(3) TIMING.—

"(A) INITIAL DEVELOPMENT AND SUBSEQUENT UPDATE.—For each vector-borne disease identified under subsection (b)(1), the Directors shall—

"(i) develop a scientific framework under this subsection not later than 18 months after the date of the enactment of this section; and

"(ii) review and update the scientific framework not later than 5 years after its initial development.

"(B) OTHER UPDATES.—The Directors may review and update each scientific frame-

work developed under this subsection as necessary.

''(4) PUBLIC NOTICE.—With respect to each scientific framework developed under this subsection, not later than 30 days after the date of completion of the framework, the Directors shall—

''(A) submit such framework to the Committee on Energy and Commerce and the Committee on Appropriations of the House of Representatives, and the Committee on Health, Education, Labor, and Pensions and the Committee on Appropriations of the Senate; and

''(B) make such framework publicly available on the Internet Web site of the Department of Health and Human Services.

''(b) IDENTIFICATION OF VECTOR-BORNE DISEASES.—

''(1) IN GENERAL.—Not later than 6 months after the date of the enactment of this section, the Directors shall identify 2 or more bacterial or parasitic vector-borne diseases that each have a high incidence domestically.

''(2) TREATING TICK-BORNE DISEASES AS A SINGLE VECTOR-BORNE DISEASE.—For purposes of identifying vector-borne diseases under this sub-

section and developing scientific frameworks for such diseases under subsection (a), tick-borne diseases, including Lyme disease and other tick-borne diseases that are known to be transmitted by ticks to humans in the United States, shall be treated as a single vector-borne disease.

''(3) ADDITIONAL VECTOR-BORNE DISEASES.—Subject to paragraph (2), the Directors may, at any time, identify other vector-borne diseases for purposes of this section. In identifying a vector-borne disease pursuant to the previous sentence, the Directors may consider additional metrics of progress against such type of vector-borne disease.

''(c) WORKING GROUPS.—

''(1) IN GENERAL.—For each vector-borne disease identified under subsection (b), the Directors shall convene a working group in accordance with the Federal Advisory Committee Act. The Directors (or their designees) shall participate in the meetings of each such working group.

''(2) MEMBERS.—Each working group convened under this subsection shall be comprised of the following members:

''(A) One or more representatives of each of the following:

"(i) The National Institutes of Health.

"(ii) The Centers for Disease Control and Prevention.

"(iii) Other agencies or offices of the Department of Health and Human Services, as determined appropriate by the Directors.

"(iv) Other Federal agencies, as determined appropriate by the Directors.

"(B) One or more representatives of each of the following categories:

"(i) Physicians with experience in diagnosing and treating stages or manifestations of the relevant vector-borne disease.

"(ii) Non-Federal scientists or researchers with expertise, and representing a diversity of perspectives, regarding the science pertaining to vector-borne diseases.

"(iii) Patients and their family members.

"(iv) Nonprofit organizations that advocate for patients by promoting education, services, or research.

''(v) Other individuals whose expertise is determined by the Directors to be beneficial to the functioning of the working group.

''(C) One individual appointed by the Speaker of the House of Representatives.

''(D) One individual appointed by the Majority Leader of the Senate.

''(3) FACA SUNSET INAPPLICABLE.—Section 14(a) of the Federal Advisory Committee Act (5 U.S.C. App.; relating to termination of advisory committees) shall not apply to a working group convened under paragraph (1).

''(4) OTHER WORKING GROUPS.—If the Directors, in addition to convening the working groups required by this subsection, choose to continue any working group on any vector-borne disease in existence on the date of enactment of the Vector-Borne Disease Research Accountability and Transparency Act of 2014, any such working group is deemed to be an advisory committee subject to the Federal Advisory Committee Act.

''(d) PUBLIC HEARINGS.—

''(1) IN GENERAL.—The Directors shall, within 60 days after identifying a vector-borne disease

under section (b), and annually thereafter, convene public forums—

''(A) to seek public input on the development of the scientific framework for such vector-borne disease under this section and progress in addressing related chronic conditions; and

''(B) to identify, and seek public input on, potential emerging strains in species of pathogenic organisms.

''(2) PARTICIPANTS.—The participants at the forums convened under this subsection shall be researchers, physicians, patients, and other members of the public.

''(e) REPORTING.—

''(1) BIENNIAL REPORTS.—The Directors shall ensure that each biennial report under section 403 includes information on actions undertaken to carry out each scientific framework developed under subsection (a) with respect to a vector-borne disease, including the following:

''(A) Information on research grants awarded by the National Institutes of Health and the Centers for Disease Control and Pre-

vention for research relating to such vector-borne disease.

"(B) An assessment of the progress made in improving outcomes.

"(2) ADDITIONAL ONE-TIME REPORTS.—

"(A) FRAMEWORKS.—For each vector-borne disease identified under subsection (b)(1), the Directors shall, not later than 6 years after the initial development of a scientific framework for such disease under subsection (a), submit a report to the Congress on the effectiveness of the framework (including the update required by subsection (a)(3)(A)(ii)) in improving the prevention, detection, diagnosis, and treatment of such disease.

"(B) TOTAL NUMBER OF WORKING GROUPS.—Not later than 1 year after the date of enactment of this section, the Directors shall submit a report to the Congress identifying the total number of working groups convened under this section.

"(f) RECOMMENDATIONS FOR EXCEPTION FUNDING.—The Directors shall consider each relevant scientific framework developed under subsection (a) when making

recommendations for exception funding for grant applications.

''(g) DEFINITION.—In this section:

''(1) The term 'Directors' means the Director of NIH and the Director of the Centers for Disease Control and Prevention acting jointly.

''(2) The term 'vector-borne disease' means an infection transmitted to humans or other animals by ticks, mosquitoes, or fleas, such as Lyme disease.''.

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