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114TH CONGRESS
1ST SESSION

H. R. 3666

To coordinate and advance fibrosis research activities at the National Institutes of Health, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

OCTOBER 1, 2015

Mr. KING of New York (for himself, Mrs. CAPPS, Mr. RANGEL, Ms. NORTON, and Mr. CROWLEY) introduced the following bill; which was referred to the Committee on Energy and Commerce

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A BILL

To coordinate and advance fibrosis research activities at the National Institutes of Health, 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 ''Scleroderma and Fibrosis Research Enhancement Act of 2015''.

SEC. 2. FINDINGS.

Congress finds as follows:

(1) Scleroderma, or systemic sclerosis, is a chronic and potentially fatal rheumatic autoimmune disease of the connective tissue.

(2) About 100,000 Americans have systemic sclerosis, which causes fibrosis (very similar to scarring where excess connective tissue is created). The symptoms of scleroderma vary greatly for each person, and the effects of scleroderma can range from very mild to life-threatening. The seriousness of scleroderma depends on the parts of the body that are affected and the extent to which they are affected.

(3) Nearly 45 percent of all deaths in the developed world are attributed to some type of chronic fibroproliferative disease. As scleroderma impacts multiple organ systems, systemic sclerosis can be considered as a prototypical disease for study, and any insights into its causes are likely to be applicable more broadly to other forms of organ fibrosis and fibrotic illnesses (such as pulmonary fibrosis and liver fibrosis).

(4) Various institutes and centers of the National Institutes of Health currently support research into forms of fibrotic illness, but there is little coordination and limited cross-cutting opportunity between these research portfolios. Much scientific progress will be gained by taking a broad, collaborative, and systematic approach to studying fibrosis.

SEC. 3. NATIONAL COMMISSION ON SCLERODERMA AND FIBROSIS RESEARCH.

(a) ESTABLISHMENT.—Not later than 1 year after the date of enactment of this Act, the Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, acting jointly with the Director of the National Institutes of Health, shall establish a National Commission on Scleroderma and Fibrosis Research (in this section referred to as the ''Commission'') to develop the long-term plan under subsection (b).

(b) LONG-TERM PLAN.—

(1) IN GENERAL.—Not later than 18 months after the date of establishment of the Commission, the Commission shall develop and submit to the Congress a long-term plan on opportunities and challenges in scleroderma and fibrosis research.

(2) RECOMMENDATIONS ON RESEARCH OPPORTUNITIES.—The plan under paragraph (1) shall include recommendations on relevant research opportunities over the next decade, including—

(A) a comprehensive research plan which prioritizes fibrosis research opportunities that have cross-cutting value and require coordination across multiple institutes and centers of the National Institutes of Health;

(B) topic-specific research recommendations for each organ or system; and

(C) an overview of common themes and specific steps for implementation of scleroderma and fibrosis research.

(c) WORKING GROUPS.—The Commission shall establish working groups—

(1) to consider the various organs and systems impacted by fibrotic illness; and

(2) to formulate the topic-specific research recommendations under subsection (b)(2)(B).

(d) MEMBERSHIP.—The Commission shall be composed of—

(1) the Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (or the Director's representative);

(2) a representative of the Office of the Director of the National Institutes of Health who can provide input on program coordination across the institutes and centers of the National Institutes of Health;

(3) staff from institutes and centers of the National Institutes of Health, as determined appropriate; and

(4) non-Federal medical experts and patient advocates representing the various manifestations of scleroderma and fibrosis, as determined necessary to form effective working groups under subsection (c).

(e) TERMINATION.—The Commission shall terminate not later than 2 years after the date of its establishment.

SEC. 4. SCLERODERMA AND FIBROSIS WORKING GROUP.

(a) ESTABLISHMENT.—Not later than 180 days after the development and dissemination of the long-term plan under section 3(b), the Director of the National Institute of Arthritis and Musculoskeletal and Skins Diseases shall create a working group, to be known as the Scleroderma and Fibrosis Working Group (in this section referred to as the ''Working Group'').

(b) RESPONSIBILITIES.—The Working Group shall—

(1) oversee and assist with the implementation of the recommendations and research opportunities identified in the long-term plan under section 3(b);

(2) coordinate with the Office of the Director of the National Institutes of Health and the various institutes and centers of the National Institutes of Health as appropriate to oversee and assist with such implementation; and

(3) report, as needed, to the advisory council of the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

(c) MEMBERSHIP.—The Working Group shall be composed of—

(1) representatives of the institutes and centers at the National Institutes of Health with active or planned research projects in scleroderma or fibrosis, particularly staff who are serving or have served on the National Commission on Scleroderma and Fibrosis Research under section 3; and

(2) patient advocates and extramural researchers who can provide meaningful input on the recommendations and research opportunities identified in the long-range plan under section 3(b), particularly individuals who are serving or have served on the National Commission on Scleroderma and Fibrosis Research under section 3.

(d) MEETINGS.—The Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases shall convene the Working Group for a meeting at least 3 times each year.

SEC. 5. REPORT TO CONGRESS.

Not later than 2 years after the date of establishment of the National Commission on Scleroderma and Fibrosis

Research under section 3, the Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases shall submit to the Congress a report on implementation of the long-range plan under section 3(b).

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