To establish a National Commission on Fibrotic Diseases.

IN THE HOUSE OF REPRESENTATIVES

JUNE 24, 2019

Mr. King of New York (for himself, Mr. Engel, Mr. Thompson of Mississippi, Mr. Fitzpatrick, Ms. Jayapal, Miss Rice of New York, Mr. Clay, Mr. Levin of Michigan, and Mrs. Beatty) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To establish a National Commission on Fibrotic 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 “National Commission on Scleroderma and Fibrotic Diseases Act of 2019”.

SEC. 2. NATIONAL COMMISSION ON FIBROTIC DISEASES RESEARCH.

(a) ESTABLISHMENT.—There is hereby established, within the National Institutes of Health (in this section referred to as “NIH”), a National Commission on Fibrotic
Diseases (in this section referred to as the “Commission”) to evaluate and make recommendations regarding improvements to the coordination and advancement of NIH-supported research activities related to fibrosis and fibrotic diseases, which may include scleroderma as a prototypical condition that can cause fibrosis in various organs.

(b) Membership.—

(1) In general.—The Commission shall be composed of the following voting members:

(A) The Director of NIH, or the designee of such director.

(B) The Directors of the following Institutes, or the designees of such directors:

(i) National Institute of Arthritis and Musculoskeletal and Skin Diseases.

(ii) National Heart, Lung, and Blood Institute.

(iii) National Institute of Diabetes and Digestive, and Kidney Diseases.

(iv) National Human Genome Research Institute.

(v) Any other Institutes or Centers with an active fibrotic disease research portfolio.
(vi) Twelve additional voting members appointed under paragraph (2).

(2) ADDITIONAL MEMBERS.—The Commission shall include additional voting members, as may be appointed by the Director of NIH, with expertise in the prevention, care, and epidemiology of any of the diseases and complications described in subsection (a), including one or more such members from each of the following categories:

(A) Leading scientists or physicians with research expertise in the conditions described in subsection (a).

(B) Patient and advocates with a perspective on the conditions described in subsection (a).

(3) CHAIRPERSON.—The members of the Commission shall select a chairperson from the members appointed under paragraph (2).

(4) MEETINGS.—The Commission shall meet at least three times a year, with the first meeting occurring not later than April 1, 2021.

(5) VACANCIES.—A vacancy on the Commission shall be filled in the same manner as the original appointments.
(c) RESPONSIBILITIES.—The duties of the Commission are the following:

(1) To study the incidence, duration, and mortality rates of fibrotic diseases as described in subsection (a).

(2) To evaluate facilities and resources for the diagnosis, prevision, and treatment of fibrotic diseases described in subsection (a).

(3) To develop a long-range plan for the use and organization of national resources to effectively advance research and effectively deal with fibrotic diseases as described in subsection (a), including—

(A) a comprehensive research plan, which prioritizes fibrosis opportunities that have cross-cutting value and require coordination across multiple Institutes and Centers;

(B) topic-specific research recommendations for each organ or system as impacted by fibrotic diseases described in subsection (a); and

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

(4) To make recommendations, as appropriate, to the Director of NIH and Congress with respect to the study, evaluation, and long-range plan de-
scribed in the preceding paragraphs of this subsection.

(d) OPERATING PLAN.—Not later than 90 days after its first meeting, the Commission shall submit to the Director of NIH and the Congress an operating plan for carrying out the duties of the Commission as described in subsection (c). Such operating plan may include—

(1) a list of specific activities that the Commission plans to conduct for purposes of carrying out the duties described in each of the paragraphs in subsection (c);

(2) a plan for completing the activities;

(3) a list of members of the Commission and other individuals who are not members of the Commission who will need to be involved to conduct such activities;

(4) an explanation of NIH Institute and Center involvement and coordination needed to conduct such activities;

(5) a budget for conducting such activities; and

(6) other information that the Commission deems appropriate.

(e) FINAL REPORT.—Not later than 2 years after the date of the Commission’s first meeting, the Commission shall submit to the Director of NIH and the Congress a
final report containing all of the findings and recommendation required by subsection (e).

(f) SUNSET.—The Commission shall terminate 60 days after submitting its final report, but not later than September 30, 2023.