

116TH CONGRESS
1ST SESSION

H. R. 3446

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.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “National Commission
5 on Scleroderma and Fibrotic Diseases Act of 2019”.

6 **SEC. 2. NATIONAL COMMISSION ON FIBROTIC DISEASES**

7 **RESEARCH.**

8 (a) **ESTABLISHMENT.**—There is hereby established,
9 within the National Institutes of Health (in this section
10 referred to as “NIH”), a National Commission on Fibrotic

1 Diseases (in this section referred to as the “Commission”)
2 to evaluate and make recommendations regarding im-
3 provements to the coordination and advancement of NIH-
4 supported research activities related to fibrosis and fi-
5 brotic diseases, which may include scleroderma as a
6 prototypical condition that can cause fibrosis in various
7 organs.

8 (b) MEMBERSHIP.—

9 (1) IN GENERAL.—The Commission shall be
10 composed of the following voting members:

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

13 (B) The Directors of the following Insti-
14 tutes, or the designees of such directors:

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

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

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

21 (iv) National Human Genome Re-
22 search Institute.

23 (v) Any other Institutes or Centers
24 with an active fibrotic disease research
25 portfolio.

1 (vi) Twelve additional voting members
2 appointed under paragraph (2).

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

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

13 (B) Patient and advocates with a perspec-
14 tive on the conditions described in subsection
15 (a).

16 (3) CHAIRPERSON.—The members of the Com-
17 mission shall select a chairperson from the members
18 appointed under paragraph (2).

19 (4) MEETINGS.—The Commission shall meet at
20 least three times a year, with the first meeting oc-
21 ccurring not later than April 1, 2021.

22 (5) VACANCIES.—A vacancy on the Commission
23 shall be filled in the same manner as the original ap-
24 pointments.

1 (c) RESPONSIBILITIES.—The duties of the Commis-
2 sion are the following:

3 (1) To study the incidence, duration, and mor-
4 tality rates of fibrotic diseases as described in sub-
5 section (a).

6 (2) To evaluate facilities and resources for the
7 diagnosis, prevision, and treatment of fibrotic dis-
8 eases described in subsection (a).

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

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

17 (B) topic-specific research recommenda-
18 tions for each organ or system as impacted by
19 fibrotic diseases described in subsection (a); and

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

22 (4) To make recommendations, as appropriate,
23 to the Director of NIH and Congress with respect
24 to the study, evaluation, and long-range plan de-

1 scribed in the preceding paragraphs of this sub-
2 section.

3 (d) OPERATING PLAN.—Not later than 90 days after
4 its first meeting, the Commission shall submit to the Di-
5 rector of NIH and the Congress an operating plan for car-
6 rying out the duties of the Commission as described in
7 subsection (c). Such operating plan may include—

8 (1) a list of specific activities that the Commis-
9 sion plans to conduct for purposes of carrying out
10 the duties described in each of the paragraphs in
11 subsection (c);

12 (2) a plan for completing the activities;

13 (3) a list of members of the Commission and
14 other individuals who are not members of the Com-
15 mission who will need to be involved to conduct such
16 activities;

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

20 (5) a budget for conducting such activities; and

21 (6) other information that the Commission
22 deems appropriate.

23 (e) FINAL REPORT.—Not later than 2 years after the
24 date of the Commission's first meeting, the Commission
25 shall submit to the Director of NIH and the Congress a

1 final report containing all of the findings and rec-
2 ommendation required by subsection (c).

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

○