

116TH CONGRESS
1ST SESSION

S. 2477

To establish a National Commission on Fibrotic Diseases.

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 12, 2019

Mrs. GILLIBRAND introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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 (referred to in
10 this section as “NIH”), a National Commission on Fi-
11 brotic Diseases (referred to in this section as the “Com-
12 mission”) to evaluate and make recommendations regard-

1 ing improvements to the coordination and advancement of
 2 NIH-supported research activities related to fibrosis and
 3 fibrotic diseases, which may include scleroderma as a
 4 prototypical condition that can cause fibrosis in various
 5 organs.

6 (b) MEMBERSHIP.—

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

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

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

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

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

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

19 (iv) National Human Genome Re-
 20 search Institute.

21 (v) Any other national research insti-
 22 tutes or national centers with an active fi-
 23 brotic disease research portfolio.

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

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

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

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

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

17 (4) MEETINGS.—The Commission shall meet at
18 least 3 times a year, with the first meeting occurring
19 not later than April 1, 2021.

20 (5) VACANCIES.—A vacancy on the Commission
21 shall be filled in the same manner as the original ap-
22 pointment.

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

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

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

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

11 (A) a comprehensive research plan, which
12 prioritizes fibrosis opportunities that have
13 cross-cutting value and require coordination
14 across multiple national research institutes and
15 national centers;

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

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

21 (4) To make recommendations, as appropriate,
22 to the Director of NIH and Congress with respect
23 to the study, evaluation, and long-range plan de-
24 scribed in the preceding paragraphs of this sub-
25 section.

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

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

10 (2) a plan for completing the activities;

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

15 (4) an explanation of involvement and coordina-
16 tion of national research institutes and national cen-
17 ters needed to conduct such activities;

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

19 (6) other information that the Commission de-
20 termines appropriate.

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

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

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