

115TH CONGRESS
2D SESSION

S. 3267

To establish a National Commission on Fibrotic Diseases.

IN THE SENATE OF THE UNITED STATES

JULY 25, 2018

Mrs. GILLIBRAND (for herself and Mr. SCHUMER) 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 2018”.

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

7 (a) ESTABLISHMENT.—There is established, within
8 the National Institutes of Health, a National Commission
9 on Fibrotic Diseases (referred to in this section as the
10 “Commission”) to evaluate and make recommendations
11 regarding improvements to the coordination and advance-

1 ment of research activities related to fibrosis and fibrotic
 2 diseases, which may include scleroderma as a prototypical
 3 condition that can cause fibrosis in various organs, sup-
 4 ported by the National Institutes of Health.

5 (b) MEMBERSHIP.—

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

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

10 (B) The Directors of the following Insti-
 11 tutes, or their designees:

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

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

16 (iii) The National Institute of Diabe-
 17 tes and Digestive and Kidney Diseases.

18 (iv) The National Human Genome
 19 Research Institute.

20 (v) Any other national research insti-
 21 tute or center with an active fibrotic dis-
 22 ease research portfolio.

23 (C) Twelve additional voting members ap-
 24 pointed under paragraph (2).

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

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

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

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

16 (4) MEETINGS.—The Commission shall meet 3
17 times per year.

18 (5) VACANCIES.—A vacancy on the Commission
19 shall be filled in the same manner as the original ap-
20 pointments.

21 (c) RESPONSIBILITIES.—The Commission shall
22 evaluate and make recommendations, as appropriate, to
23 the Director of NIH and Congress regarding—

24 (1) the incidence, duration, and mortality rates
25 of fibrotic diseases as described in subsection (a);

1 (2) facilities and resources for the diagnosis,
 2 prevision, and treatment of fibrotic diseases de-
 3 scribed in subsection (a); and

4 (3) a long-range plan for the use and organiza-
 5 tion of national resources to effectively advance re-
 6 search and effectively deal with fibrotic diseases as
 7 described in subsection (a), including—

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

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

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

18 (d) OPERATING PLAN.—Not later than 90 days after
 19 its first meeting the Commission shall—

20 (1) submit to the Director of NIH and Con-
 21 gress an operating plan for carrying out the activi-
 22 ties of the Commission as described in subsection
 23 (c). Such operating plan may include—

24 (A) a list of specific activities that the
 25 Commission plans to conduct for purposes of

1 carrying out the duties described in each of
2 paragraphs (1) through (3) of subsection (c);

3 (B) a plan for completing such activities;

4 (C) a list of members of the Commission
5 and other individuals who are not members of
6 the Commission who will need to be involved to
7 conduct such activities;

8 (D) an explanation of involvement and co-
9 ordination among the institutes and centers of
10 the National Institutes of Health that is needed
11 to conduct such activities;

12 (E) a budget for conducting such activities;

13 and

14 (F) other information that the Commission
15 determines appropriate.

16 (e) FINAL REPORT.—Not later than 2 years after the
17 date of the Commission’s first meeting, the Commission
18 shall submit to the Director of NIH and Congress a final
19 report containing all of the findings and recommendations
20 required under subsection (c).

21 (f) SUNSET.—The Commission shall terminate 60
22 days after submitting its final report, and not later than
23 the end of fiscal year 2022.

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