

111TH CONGRESS
1ST SESSION

S. 1545

To expand the research and awareness activities of the National Institute of Arthritis and Musculoskeletal and Skin Diseases and the Centers for Disease Control and Prevention with respect to scleroderma, and for other purposes.

IN THE SENATE OF THE UNITED STATES

JULY 30, 2009

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

A BILL

To expand the research and awareness activities of the National Institute of Arthritis and Musculoskeletal and Skin Diseases and the Centers for Disease Control and Prevention with respect to scleroderma, and for other purposes.

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 “Scleroderma Research
5 and Awareness Act”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds as follows:

1 (1) Scleroderma is a chronic, disabling and
2 often fatal autoimmune disease in which the body's
3 soft tissues contract and harden due to an over-
4 production of collagen.

5 (2) Scleroderma causes damage to one or more
6 of the body's organ systems, including the skin,
7 heart, lungs, kidneys, gastrointestinal tract, and
8 blood vessels.

9 (3) It is estimated that 300,000 people in the
10 United States suffer from scleroderma, 80 percent of
11 whom are women often diagnosed during their child
12 bearing years.

13 (4) Choctaw Native Americans, African-Ameri-
14 cans, and Hispanics are disproportionately affected
15 by scleroderma and tend to exhibit more rapidly pro-
16 gressing and severe cases of the disease.

17 (5) The causes of scleroderma are unknown.

18 (6) Scleroderma is associated with many other
19 conditions including pulmonary hypertension,
20 gastroparesis, Raynaud's phenomenon, Sjögren's
21 Syndrome and lupus.

22 (7) The estimated total annual economic impact
23 of scleroderma in the United States is in excess of
24 \$1,500,000,000.

1 (8) Annual Federal support for scleroderma re-
2 search at the National Institutes of Health is cur-
3 rently estimated at \$20,000,000.

4 **SEC. 3. NATIONAL INSTITUTE OF ARTHRITIS AND MUS-**
5 **CULOSKELETAL AND SKIN DISEASES;**
6 **SCLERODERMA RESEARCH EXPANSION.**

7 (a) IN GENERAL.—The Director of The National In-
8 stitute of Arthritis and Musculoskeletal and Skin Diseases
9 shall expand, intensify, and coordinate the activities of the
10 Institute with respect to scleroderma, with particular em-
11 phasis on the following areas:

12 (1) Research focused on the etiology of
13 scleroderma and the development of new treatment
14 options.

15 (2) Clinical research to evaluate new treatments
16 options.

17 (3) Basic research on the relationship between
18 scleroderma and secondary conditions such as pul-
19 monary hypertension, gastroparesis, Raynaud's phe-
20 nomenon, Sjögren's Syndrome (and other diseases as
21 determined by the Director).

22 (4) Establishment of scleroderma patient reg-
23 istries, including family and childhood onset reg-
24 istries.

1 (5) Support for training of new clinicians and
2 investigators with expertise in scleroderma.

3 (b) BIENNIAL REPORTS.—As a part of the biennial
4 report made under section 403 of the Public Health Serv-
5 ice Act (42 U.S.C. 283), the Secretary shall include infor-
6 mation on the status of scleroderma research at the Na-
7 tional Institutes of Health.

8 (c) AUTHORIZATION OF APPROPRIATIONS.—

9 (1) IN GENERAL.—For the purpose of carrying
10 out subsection (a), there are authorized to be appro-
11 priated \$25,000,000 in fiscal year 2010,
12 \$30,000,000 in fiscal year 2011, and \$35,000,000 in
13 fiscal year 2012.

14 (2) RESERVATIONS.—Of the amounts author-
15 ized to be appropriated under paragraph (1), not
16 more than 15 percent shall be reserved for the train-
17 ing of qualified health professionals in biomedical re-
18 search focused on scleroderma.

19 **SEC. 4. PROMOTING PUBLIC AWARENESS OF**
20 **SCLERODERMA.**

21 (a) IN GENERAL.—The Secretary, acting through the
22 Director of the Centers for Disease Control and Preven-
23 tion, shall carry out an educational campaign to increase
24 public awareness of scleroderma. Print, video, and Web-

1 based materials distributed under this program may in-
2 clude—

3 (1) basic information on scleroderma and its
4 symptoms;

5 (2) information on the incidence and prevalence
6 of scleroderma;

7 (3) diseases and conditions affiliated with
8 scleroderma; or

9 (4) the importance of early diagnosis and treat-
10 ment.

11 (b) DISSEMINATION OF INFORMATION.—The Sec-
12 retary is encouraged to disseminate information under
13 subsection (a) through a cooperative agreement with a na-
14 tional nonprofit entity with expertise in scleroderma.

15 (c) REPORT TO CONGRESS.—Not later than Sep-
16 tember 30, 2010, the Secretary shall report to the Com-
17 mittee on Energy and Commerce of the House of Rep-
18 resentatives, the Committee on Health, Education, Labor,
19 and Pensions of the Senate, and the Committee on Appro-
20 priations of the House of Representatives and the Senate
21 on the status of activities under this section.

22 (d) AUTHORIZATION OF APPROPRIATIONS.—For the
23 purpose of carrying out this section, there is authorized

- 1 to be appropriated \$2,500,000 for each of fiscal years
- 2 2010, 2011, and 2012.

