

111TH CONGRESS
2^D SESSION

S. 3703

To expand the research, prevention, and awareness activities of the Centers for Disease Control and Prevention and the National Institutes of Health with respect to pulmonary fibrosis, and for other purposes.

IN THE SENATE OF THE UNITED STATES

AUGUST 4, 2010

Mrs. MURRAY (for herself and Mr. CRAPO) 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, prevention, and awareness activities of the Centers for Disease Control and Prevention and the National Institutes of Health with respect to pulmonary fibrosis, 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 “Pulmonary Fibrosis
5 Research Enhancement Act”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

1 (1) Pulmonary fibrosis (in this section referred
2 to as “PF”) is a relentlessly progressive, ultimately
3 fatal disease that affects the lungs, gradually rob-
4 bing a person of the ability to breathe.

5 (2) More than 200,000 individuals may be liv-
6 ing with PF in the United States; 48,000 individuals
7 in the United States are diagnosed with PF annu-
8 ally; and as many as 40,000 die annually.

9 (3) Prevalence of PF has increased more than
10 150 percent since 2001, and is expected to continue
11 rising.

12 (4) The median survival rate for a person with
13 PF is 2.8 years.

14 (5) More than 50 percent of PF cases are ini-
15 tially misdiagnosed as other forms of respiratory ill-
16 ness before being correctly diagnosed as PF, and
17 more than 58 percent of patients go more than a
18 year with symptoms before being diagnosed cor-
19 rectly.

20 (6) The cause of PF is not well understood, and
21 in most cases is unknown, though there is growing
22 evidence that one cause of PF may be environmental
23 or occupational exposure to pollutants.

24 (7) There is no Food and Drug Administration-
25 approved treatment or cure for PF.

1 (8) Public awareness of PF remains low com-
2 pared to rare diseases of lesser prevalence, despite
3 PF's increasing prevalence.

4 (9) There has been no federally funded national
5 awareness or educational effort to improve under-
6 standing of PF in the public or medical commu-
7 nities, though nonprofit patient education and re-
8 search groups have begun to increase awareness.
9 The first Federal legislation expressing Congress's
10 support for PF research, H. Con. Res. 182, was
11 agreed to by both Houses of Congress in 2007.

12 **SEC. 3. PULMONARY FIBROSIS ADVISORY BOARD AND REG-**
13 **ISTRY.**

14 Part B of title III of the Public Health Service Act
15 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
16 tion 317T the following:

17 **"SEC. 317U. PULMONARY FIBROSIS ADVISORY BOARD AND**
18 **REGISTRY.**

19 “(a) ADVISORY BOARD.—

20 “(1) ESTABLISHMENT.—Not later than 90 days
21 after the date of the enactment of this section, the
22 Secretary, acting through the Director of the Cen-
23 ters for Disease Control and Prevention, shall estab-
24 lish a board to be known as the National Pulmonary
25 Fibrosis Advisory Board (in this section referred to

1 as the ‘Advisory Board’). The Advisory Board shall
2 be composed of at least one member, to be appointed
3 by the Secretary, acting through the Director of the
4 Centers for Disease Control and Prevention, rep-
5 resenting each of the following:

6 “(A) The National Institutes of Health.

7 “(B) The National Institute of Environ-
8 mental Health Sciences.

9 “(C) The Department of Veterans Affairs.

10 “(D) The Agency for Toxic Substances
11 and Disease Registry.

12 “(E) The Centers for Disease Control and
13 Prevention.

14 “(F) Patients with PF or their family
15 members and other individuals with an interest
16 in developing and maintaining the National PF
17 Registry.

18 “(G) Patient advocates, including organi-
19 zation representing such advocates.

20 “(H) Clinicians with expertise on PF and
21 related diseases.

22 “(I) Epidemiologists with experience work-
23 ing with data registries.

1 “(J) Geneticists or experts in genetics who
2 have experience with the genetics of PF or
3 other interstitial lung diseases.

4 “(2) DUTIES.—The Advisory Board shall—

5 “(A) review information and make rec-
6 ommendations to the Secretary concerning—

7 “(i) the development and maintenance
8 of the National PF Registry;

9 “(ii) the type of information to be col-
10 lected and stored in the National PF Reg-
11 istry;

12 “(iii) the manner in which such data
13 is to be collected;

14 “(iv) the use and availability of such
15 data, including guidelines for such use; and

16 “(v) the collection of information
17 about diseases and disorders that primarily
18 affect the lungs that are considered essen-
19 tial to furthering the study and cure of
20 PF; and

21 “(B) consult with the Director of the Cen-
22 ters for Disease Control and Prevention regard-
23 ing preparation of the National Pulmonary Fi-
24 brosis Education and Awareness Plan under

1 section 4(a) of the Pulmonary Fibrosis Re-
2 search Enhancement Act.

3 “(3) REPORT.—Not later than 1 year after the
4 date of enactment of this section, the Advisory
5 Board shall submit to the Secretary, the Committee
6 on Energy and Commerce of the House of Rep-
7 resentatives, and the Health, Education, Labor, and
8 Pensions Committee of the Senate a report on the
9 review conducted under paragraph (2), including the
10 recommendations of the Advisory Board resulting
11 from such review.

12 “(b) ESTABLISHMENT OF REGISTRY.—

13 “(1) IN GENERAL.—Not later than 1 year after
14 the receipt of the report required by subsection
15 (a)(3), the Secretary, acting through the Director of
16 the Centers for Disease Control and Prevention and
17 in consultation with patients, patient advocates, and
18 others with expertise in research and care of pul-
19 monary fibrosis (referred to in this section as ‘PF’),
20 shall—

21 “(A) develop a system to collect data on
22 PF and other interstitial lung diseases that are
23 related to PF, including information with re-
24 spect to the incidence and prevalence of the dis-
25 ease in the United States; and

1 “(B) establish a national registry (in this
2 section referred to as the ‘National PF Reg-
3 istry’) that—

4 “(i) is used for the collection and stor-
5 age of data described in subparagraph (A);
6 and

7 “(ii) includes a population-based reg-
8 istry of cases in the United States of PF
9 and other interstitial lung diseases that are
10 related to PF.

11 “(2) PURPOSE.—The purpose of the National
12 PF Registry shall be to gather available data con-
13 cerning—

14 “(A) PF, including the incidence and prev-
15 alence of PF in the United States;

16 “(B) environmental and occupational fac-
17 tors that may be associated with the disease;

18 “(C) age, race or ethnicity, gender, and
19 family history of individuals who are diagnosed
20 with the disease;

21 “(D) pathogenesis of PF; and

22 “(E) other matters as determined appro-
23 priate by the Secretary.

24 “(c) COORDINATION WITH STATE, LOCAL, AND FED-
25 ERAL REGISTRIES.—

1 “(1) IN GENERAL.—In establishing the Na-
2 tional PF Registry under subsection (b), the Sec-
3 retary shall—

4 “(A) identify, build upon, expand, and co-
5 ordinate among existing data and surveillance
6 systems, surveys, registries, and other Federal
7 public health and environmental infrastructure
8 wherever possible, including—

9 “(i) existing systems in place at uni-
10 versities, medical centers, and government
11 agencies;

12 “(ii) State-based PF registries, Na-
13 tional Institutes of Health registries, and
14 Department of Veterans Affairs registries,
15 as available; and

16 “(iii) any other relevant databases
17 that collect or maintain information on in-
18 terstitial lung diseases; and

19 “(B) provide for research access to PF
20 data in accordance with applicable statutes and
21 regulations, including those protecting personal
22 privacy.

23 “(2) COORDINATION WITH NIH AND DEPART-
24 MENT OF VETERANS AFFAIRS.—Consistent with ap-
25 plicable privacy statutes and regulations, the Sec-

1 retary shall ensure that epidemiological and other
2 types of information obtained under subsection (b) is
3 made available to the National Institutes of Health
4 and the Department of Veterans Affairs.

5 “(d) AUTHORIZATION OF APPROPRIATIONS.—There
6 are authorized to be appropriated to carry out this section
7 \$5,000,000 for fiscal year 2010 and \$2,500,000 for each
8 of the fiscal years 2011 through 2014.”.

9 **SEC. 4. NATIONAL PULMONARY FIBROSIS EDUCATION AND**
10 **AWARENESS PLAN.**

11 (a) IN GENERAL.—

12 (1) PREPARATION OF PLAN.—The Director of
13 the Centers for Disease Control and Prevention, in
14 consultation with the National Pulmonary Fibrosis
15 Advisory Board established under section 317U of
16 the Public Health Service Act, as added by section
17 3 of this Act, shall prepare a comprehensive plan (in
18 this section referred to as the “National Pulmonary
19 Fibrosis Education and Awareness Plan”).

20 (2) REPORT TO CONGRESS.—Not later than one
21 year after the date of the enactment of this Act, and
22 at the same time as the report is submitted under
23 section 317U(a)(3) of the Public Health Service Act,
24 the Director of the Centers for Disease Control and
25 Prevention shall submit the National Pulmonary Fi-

1 brosis Education and Awareness Plan to the Com-
2 mittee on Energy and Commerce and the Committee
3 on Appropriations of the House of Representatives
4 and to the Committee on Health, Education, Labor,
5 and Pensions and the Committee on Appropriations
6 of the Senate.

7 (b) CONTENT.—The National Pulmonary Fibrosis
8 Education and Awareness Plan shall—

9 (1) focus on strategies to increase public edu-
10 cation and awareness of pulmonary fibrosis;

11 (2) accelerate patient education strategies, with
12 respect to pulmonary fibrosis, nationwide;

13 (3) address the need for new physician edu-
14 cation strategies to improve diagnosis and treatment
15 standards with respect to pulmonary fibrosis;

16 (4) assess and monitor the costs of pulmonary
17 fibrosis and its burden on patients and families; and

18 (5) develop such strategies in partnership with
19 patients, patient advocates, and others with exper-
20 tise in research and care of pulmonary fibrosis.

21 (c) AUTHORIZATION OF APPROPRIATIONS.—There
22 are authorized to be appropriated to carry out this section
23 \$1,000,000 for fiscal year 2010.

1 **SEC. 5. PULMONARY FIBROSIS RESEARCH EXPANSION.**

2 Subpart 2 of part C of title IV of the Public Health
3 Service Act (42 U.S.C. 285b et seq.) is amended by adding
4 at the end the following:

5 **“SEC. 424D. PULMONARY FIBROSIS RESEARCH EXPANSION.**

6 “The Director of the Institute is encouraged to ex-
7 pand, intensify, and coordinate the activities of the Insti-
8 tute with respect to research on pulmonary fibrosis, as ap-
9 propriate.”.

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