

113TH CONGRESS
1ST SESSION

H. R. 2073

To direct the Secretary of Health and Human Services to establish an interagency coordinating committee on pulmonary hypertension to develop recommendations to advance research, increase awareness and education, and improve health and health care, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MAY 21, 2013

Mr. BRADY of Texas (for himself, Mrs. CAPPS, Mr. KING of New York, Ms. NORTON, Mr. ROSKAM, Mr. COSTA, and Mr. BISHOP of New York) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To direct the Secretary of Health and Human Services to establish an interagency coordinating committee on pulmonary hypertension to develop recommendations to advance research, increase awareness and education, and improve health and health care, 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 Hyper-
5 tension Research and Diagnosis Act of 2013”.

1 **SEC. 2. FINDINGS.**

2 The Congress finds as follows:

3 (1) Pulmonary hypertension is a serious, debili-
4 tating, and often fatal progressive condition where
5 the blood pressure in the lungs rises to dangerously
6 high levels. In pulmonary hypertension patients, the
7 walls of the arteries that take blood from the right
8 side of the heart to the lungs thicken and constrict.
9 As a result, the right side of the heart has to pump
10 harder to move blood into the lungs, causing it to
11 enlarge and ultimately fail.

12 (2) In advanced stages of pulmonary hyper-
13 tension, the patient is able to perform only minimal
14 activity and has symptoms even when resting, result-
15 ing in considerable disability. The disease may wors-
16 en to the point where the patient is completely bed-
17 ridden. In a matter of months, many pulmonary hy-
18 pertension patients have become so functionally dete-
19 riorated that they have lost their jobs and are de-
20 pendent on family and disability benefits.

21 (3) Despite the importance of early diagnosis
22 on prognosis, pulmonary hypertension is rarely
23 picked up in a routine medical exam. Even in its
24 later stages, the signs of the disease are frequently
25 confused with more common conditions that affect
26 the heart and lungs. Due to the fact that the aver-

1 age length of time between the onset of symptoms
2 and an accurate diagnosis is presently 2.8 years,
3 nearly three out of four patients have advanced pul-
4 monary hypertension by the time they are accurately
5 diagnosed.

6 (4) While pulmonary hypertension remains an
7 incurable condition, progress in our scientific under-
8 standing of the disease has led to the development
9 and Food and Drug Administration approval of nine
10 innovative therapies indicated to treat pulmonary
11 hypertension.

12 (5) Existing treatment options can significantly
13 extend life and improve quality of life for patients
14 with pulmonary hypertension. The effectiveness of
15 pulmonary hypertension treatment options is directly
16 tied to how early in the progression of the condition
17 a patient can be accurately diagnosed and begin the
18 correct regimen of therapies. Improved early inter-
19 vention will improve health outcomes for pulmonary
20 hypertension patients while reducing the necessity
21 for more drastic and costly treatment options, such
22 as a lung or heart-lung transplant.

1 **SEC. 3. INTERAGENCY PULMONARY HYPERTENSION CO-**
2 **ORDINATING COMMITTEE.**

3 (a) ESTABLISHMENT.—The Secretary of Health and
4 Human Services (in this Act referred to as the “Sec-
5 retary”) shall establish a committee, to be known as the
6 “Interagency Pulmonary Hypertension Coordinating Com-
7 mittee” (in this Act referred to as the “Committee”), to
8 make recommendations on, and coordinate, all efforts
9 within the Department of Health and Human Services
10 concerning pulmonary hypertension.

11 (b) RESPONSIBILITIES.—In carrying out its duties
12 under this section, the Committee shall—

13 (1) develop and annually update a summary of
14 pulmonary hypertension advances in medical re-
15 search and treatment development and improvement,
16 early and accurate diagnosis, appropriate and timely
17 intervention, transplantation, and access to care and
18 therapies for patients;

19 (2) monitor Federal activities with respect to
20 pulmonary hypertension;

21 (3) make recommendations to the Secretary re-
22 garding appropriate changes to such activities, in-
23 cluding recommendations with respect to the stra-
24 tegic plan developed under paragraph (5);

1 (4) make recommendations to the Secretary re-
2 garding stakeholder participation in decisions relat-
3 ing to pulmonary hypertension;

4 (5) develop and annually update a comprehen-
5 sive strategic plan to cooperatively improve health
6 outcomes for pulmonary hypertension patients which
7 includes—

8 (A) recommendations to improve profes-
9 sional education concerning accurate diagnosis
10 and appropriate intervention for health care
11 providers;

12 (B) recommendations to improve the trans-
13 plantation criteria and process concerning lung
14 and heart-lung transplants for pulmonary hy-
15 pertension patients;

16 (C) recommendations to improve public
17 awareness and recognition of pulmonary hyper-
18 tension;

19 (D) recommendations to improve health
20 care delivery and promote early and accurate
21 diagnosis for pulmonary hypertension patients;
22 and

23 (E) recommendations to systematically ad-
24 vance the full spectrum of biomedical research,
25 including specific recommendations for basic,

1 translational, clinical, and pediatric research,
2 and research training and career development;
3 and

4 (6) submit to the Congress the strategic plan
5 under paragraph (5) and any updates to such plan.

6 (c) MEMBERSHIP.—

7 (1) IN GENERAL.—The Committee shall be
8 composed of—

9 (A) the Administrator of the Health Re-
10 sources and Services Administration;

11 (B) the Director of the Centers for Disease
12 Control and Prevention and the directors of
13 such centers at the Centers for Disease Control
14 and Prevention as the Secretary determines ap-
15 propriate;

16 (C) the Director of the National Institutes
17 of Health and the directors of such institutes,
18 centers, and offices at the National Institutes of
19 Health as the Secretary determines appropriate;

20 (D) the Director of the Agency for
21 Healthcare Research and Quality;

22 (E) the Commissioner of Food and Drugs
23 and the directors of such centers and offices at
24 the Food and Drug Administration as the Sec-
25 retary determines appropriate;

1 (F) the heads of other relevant agencies as
2 the Secretary deems appropriate; and

3 (G) the additional members appointed
4 under paragraph (2).

5 (2) ADDITIONAL MEMBERS.—Not fewer than 6
6 members of the Committee or $\frac{1}{3}$ of the total mem-
7 bership of the Committee, whichever is greater, shall
8 be composed of non-Federal public members to be
9 appointed by the Secretary, of which—

10 (A) at least one such member shall be an
11 individual with a diagnosis of pulmonary hyper-
12 tension;

13 (B) at least one such member shall be the
14 primary caregiver for an individual with a diag-
15 nosis of pulmonary hypertension; and

16 (C) at least one such member shall be a
17 representative of a leading research, advocacy,
18 and support organization primarily serving indi-
19 viduals with a diagnosis of pulmonary hyper-
20 tension.

21 (d) ADMINISTRATIVE SUPPORT; TERMS OF SERVICE;
22 OTHER PROVISIONS.—The following provisions shall apply
23 with respect to the Committee:

1 (1) The Committee shall receive necessary and
2 appropriate administrative support from the Sec-
3 retary.

4 (2) Members of the Committee appointed under
5 subsection (c)(2) shall serve for a term of 4 years,
6 and may be appointed for one or more additional 4-
7 year terms. Any member appointed to fill a vacancy
8 for an unexpired term shall be appointed for the re-
9 mainder of such term. A member may serve after
10 the expiration of the member's term until a suc-
11 cessor has taken office.

12 (3) The Committee shall meet at the call of the
13 chairperson or upon the request of the Secretary.
14 The Committee shall meet not fewer than two times
15 each year.

16 (4) All meetings of the Committee shall be pub-
17 lic and shall include appropriate time periods for
18 questions and presentations by the public.

19 (e) SUBCOMMITTEES; ESTABLISHMENT AND MEM-
20 BERSHIP.—In carrying out its functions, the Committee
21 may establish subcommittees and convene workshops and
22 conferences. Such subcommittees shall be composed of
23 Committee members and may hold such meetings as are
24 necessary to enable the subcommittees to carry out their
25 duties.

1 (f) SUNSET.—This section shall not apply after Sep-
2 tember 30, 2019, and the Committee shall be terminated
3 on such date.

4 **SEC. 4. REPORT TO CONGRESS.**

5 (a) IN GENERAL.—On a biennial basis after the date
6 of enactment of this Act, the Secretary, in coordination
7 with the Committee, shall prepare and submit to the Com-
8 mittee on Health, Education, Labor, and Pensions of the
9 Senate and the Committee on Energy and Commerce
10 Committee of the House of Representatives a progress re-
11 port on activities related to improving health outcomes for
12 pulmonary hypertension patients.

13 (b) CONTENTS.—The report submitted under sub-
14 section (a) shall contain—

15 (1) information on the incidence of pulmonary
16 hypertension and trend data of such incidence since
17 the date of enactment of the Pulmonary Hyper-
18 tension Research and Diagnosis Act of 2013;

19 (2) information on the average time between
20 initial screening and accurate diagnosis as well as
21 the average stage of pulmonary hypertension when
22 appropriate intervention begins and up-to-date, re-
23 lated trend data;

1 (3) information on the effectiveness and out-
2 comes of interventions for individuals diagnosed with
3 pulmonary hypertension, including—

4 (A) mortality rate, as well as the frequency
5 of drastic treatment options like lung and
6 heart-lung transplants; and

7 (B) up-to-date, related trend data;

8 (4) information on breakthroughs in basic
9 science as well as translational and clinical research
10 activities;

11 (5) information on activity to facilitate the de-
12 velopment of innovative treatment options and diag-
13 nostic tools; and

14 (6) information on services and supports pro-
15 vided to individuals with a diagnosis of pulmonary
16 hypertension.

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