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(Original Signature of Member)

114TH CONGRESS
1ST SESSION

H. R. _____

To amend the Public Health Service Act to establish an interagency coordinating committee on pulmonary hypertension, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

Mr. BRADY of Texas introduced the following bill; which was referred to the Committee on _____

A BILL

To amend the Public Health Service Act to establish an interagency coordinating committee on pulmonary hypertension, 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 2015”.

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

3 Part P of title III of the Public Health Service Act
4 (42 U.S.C. 280g et seq.) is amended by adding at the end
5 the following new section:

6 **“SEC. 399V–6. INTERAGENCY PULMONARY HYPERTENSION**
7 **COORDINATING COMMITTEE.**

8 “(a) COMMITTEE ESTABLISHED.—The Secretary
9 shall establish a committee, to be known as the Inter-
10 agency Pulmonary Hypertension Coordinating Committee
11 (in this section referred to as the ‘Committee’), to coordi-
12 nate all efforts within the Department of Health and
13 Human Services concerning pulmonary hypertension.

14 “(b) RESPONSIBILITIES.—The Committee shall—

15 “(1) develop and annually update a summary of
16 the advances made in research on, and treatment
17 and diagnosis of, pulmonary hypertension;

18 “(2) develop and annually update a summary of
19 the advances made in access to care for individuals
20 with a diagnosis of pulmonary hypertension;

21 “(3) monitor pulmonary hypertension research,
22 services, and support activities across the Federal
23 Government, including coordination of Federal ac-
24 tivities and programs with respect to pulmonary hy-
25 pertension;

1 “(4) develop and annually update a comprehen-
2 sive strategic plan under subsection (c) to improve
3 health outcomes for individuals with a diagnosis of
4 pulmonary hypertension; and

5 “(5) develop and annually update the progress
6 made in implementing such comprehensive strategic
7 plan.

8 “(c) STRATEGY.—Not later than one year after the
9 date of the enactment of the Pulmonary Hypertension Re-
10 search and Diagnosis Act of 2015 and annually thereafter,
11 the Committee shall submit to Congress and the Secretary
12 a strategy to improve health outcomes for individuals with
13 a diagnosis of pulmonary hypertension. Such strategy
14 shall include the following:

15 “(1) Recommendations to advance research on
16 pulmonary hypertension.

17 “(2) Recommendations to improve the trans-
18 plantation criteria and process concerning lung and
19 heart-lung transplants for individuals with a diag-
20 nosis of pulmonary hypertension.

21 “(3) Recommendations to improve public
22 awareness and recognition of pulmonary hyper-
23 tension.

1 “(4) Recommendations to improve health care
2 delivery for individuals with a diagnosis of pul-
3 monary hypertension.

4 “(5) Recommendations to improve the early and
5 accurate diagnosis of pulmonary hypertension.

6 “(6) Recommendations to systematically ad-
7 vance the full spectrum of biomedical research on
8 pulmonary hypertension.

9 “(d) MEMBERSHIP.—

10 “(1) IN GENERAL.—The Committee shall be
11 composed of—

12 “(A) a representative from each of the en-
13 tities listed in paragraph (2); and

14 “(B) the non-Federal members appointed
15 under paragraph (3).

16 “(2) FEDERAL MEMBERS.—The entities listed
17 in this paragraph are the following:

18 “(A) The Department of Defense.

19 “(B) The Food and Drug Administration.

20 “(C) The National Institutes of Health.

21 “(D) The Agency for Healthcare Research
22 and Quality.

23 “(E) The Administration for Children and
24 Families.

1 “(F) The Centers for Disease Control and
2 Prevention.

3 “(G) The Centers for Medicare & Medicaid
4 Services.

5 “(H) The Health Resources and Services
6 Administration.

7 “(3) NON-FEDERAL MEMBERS.—Not fewer
8 than six members of the Committee or one-third of
9 the total membership of the Committee, whichever is
10 greater, shall be composed of non-Federal members
11 to be appointed by the Secretary, of which—

12 “(A) at least two shall be individuals with
13 a diagnosis of pulmonary hypertension;

14 “(B) at least one shall be the parent or
15 guardian of an individual with a diagnosis of
16 pulmonary hypertension;

17 “(C) at least one shall be a representative
18 of a pharmaceutical company that manufac-
19 tures a drug or device for detecting, preventing,
20 or treating pulmonary hypertension; and

21 “(D) at least one shall be a representative
22 of a leading research, advocacy, or support or-
23 ganization primarily serving individuals with a
24 diagnosis of pulmonary hypertension.

1 “(e) MEETINGS.—The Committee shall meet not
2 fewer than two times each year. All meetings shall be open
3 to the public.

4 “(f) TERMINATION DATE.—The Committee shall ter-
5minate on the date that is five years after the date of the
6 enactment of the Pulmonary Hypertension Research and
7 Diagnosis Act of 2015.”.

8 **SEC. 3. REPORT TO CONGRESS.**

9 (a) REPORT REQUIRED.—Not later than two years
10 after the date of the enactment of this Act, the Secretary
11 of Health and Human Services, in coordination with the
12 Interagency Pulmonary Hypertension Coordinating Com-
13 mittee, shall prepare and submit to the Committee on
14 Health, Education, Labor and Pensions of the Senate and
15 the Committee on Energy and Commerce of the House
16 of Representatives a progress report on activities related
17 to improving health outcomes for individuals with a diag-
18 nosis of pulmonary hypertension.

19 (b) CONTENTS OF REPORT.—The report submitted
20 under subsection (a) shall contain—

21 (1) information on the incidence of pulmonary
22 hypertension, including such incidence since the date
23 of the enactment of this Act;

24 (2) information on the prevalence of pulmonary
25 hypertension in children and adults;

1 (3) information on the average time between
2 the initial screening and the accurate diagnosis of
3 pulmonary hypertension;

4 (4) information on the average stage of pul-
5 monary hypertension when appropriate intervention
6 begins;

7 (5) information on the effectiveness and out-
8 comes of interventions for individuals with a diag-
9 nosis of pulmonary hypertension, including—

10 (A) mortality rate; and

11 (B) the frequency of drastic treatment op-
12 tions such as lung and heart-lung transplants;

13 (6) information on new developments in re-
14 search activities;

15 (7) information on innovative treatment options
16 and diagnostic tools; and

17 (8) information on services and supports avail-
18 able to individuals with a diagnosis of pulmonary hy-
19 pertension.

20 (c) PUBLICATION.—The Secretary of Health and
21 Human Services shall make the report submitted under
22 subsection (a) available on the public website of the De-
23 partment of Health and Human Services.