

114TH CONGRESS  
1ST SESSION

# H. R. 3520

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

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## IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 16, 2015

Mr. BRADY of Texas (for himself and Mrs. CAPPs) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## 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”.

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

8 Part P of title III of the Public Health Service Act  
9 (42 U.S.C. 280g et seq.) is amended by adding at the end  
10 the following new section:

1 **“SEC. 399V-6. INTERAGENCY PULMONARY HYPERTENSION**  
2 **COORDINATING COMMITTEE.**

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

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

10 “(1) develop and annually update a summary of  
11 the advances made in research on, and treatment  
12 and diagnosis of, pulmonary hypertension;

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

16 “(3) monitor pulmonary hypertension research,  
17 services, and support activities across the Federal  
18 Government, including coordination of Federal ac-  
19 tivities and programs with respect to pulmonary hy-  
20 pertension;

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

1           “(5) develop and annually update the progress  
2           made in implementing such comprehensive strategic  
3           plan.

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

11           “(1) Recommendations to advance research on  
12          pulmonary hypertension.

13           “(2) Recommendations to improve the trans-  
14          plantation criteria and process concerning lung and  
15          heart-lung transplants for individuals with a diag-  
16          nosis of pulmonary hypertension.

17           “(3) Recommendations to improve public  
18          awareness and recognition of pulmonary hyper-  
19          tension.

20           “(4) Recommendations to improve health care  
21          delivery for individuals with a diagnosis of pul-  
22          monary hypertension.

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

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

4           “(d) MEMBERSHIP.—

5           “(1) IN GENERAL.—The Committee shall be  
6           composed of—

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

9           “(B) the non-Federal members appointed  
10          under paragraph (3).

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

13          “(A) The Department of Defense.

14          “(B) The Food and Drug Administration.

15          “(C) The National Institutes of Health.

16          “(D) The Agency for Healthcare Research  
17          and Quality.

18          “(E) The Administration for Children and  
19          Families.

20          “(F) The Centers for Disease Control and  
21          Prevention.

22          “(G) The Centers for Medicare & Medicaid  
23          Services.

24          “(H) The Health Resources and Services  
25          Administration.

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

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

8           “(B) at least one shall be the parent or  
9 guardian of an individual with a diagnosis of  
10 pulmonary hypertension;

11           “(C) at least one shall be a representative  
12 of a pharmaceutical company that manufac-  
13 tures a drug or device for detecting, preventing,  
14 or treating pulmonary hypertension; and

15           “(D) at least one shall be a representative  
16 of a leading research, advocacy, or support or-  
17 ganization primarily serving individuals with a  
18 diagnosis of pulmonary hypertension.

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

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

1 **SEC. 3. REPORT TO CONGRESS.**

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

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

14 (1) information on the incidence of pulmonary  
15 hypertension, including such incidence since the date  
16 of the enactment of this Act;

17 (2) information on the prevalence of pulmonary  
18 hypertension in children and adults;

19 (3) information on the average time between  
20 the initial screening and the accurate diagnosis of  
21 pulmonary hypertension;

22 (4) information on the average stage of pul-  
23 monary hypertension when appropriate intervention  
24 begins;

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

4                   (A) mortality rate; and

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

7           (6) information on new developments in re-  
8 search activities;

9           (7) information on innovative treatment options  
10 and diagnostic tools; and

11           (8) information on services and supports avail-  
12 able to individuals with a diagnosis of pulmonary hy-  
13 pertension.

14       (c) PUBLICATION.—The Secretary of Health and  
15 Human Services shall make the report submitted under  
16 subsection (a) available on the public website of the De-  
17 partment of Health and Human Services.

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