

114TH CONGRESS  
2D SESSION

# S. 3361

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 SENATE OF THE UNITED STATES

SEPTEMBER 20, 2016

Mr. CASEY (for himself and Mr. KING) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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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 2016”.

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-7. 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 2016 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) the Director of the Agency for  
13 Healthcare Research and Quality;

14           “(B) the Assistant Secretary of the Admin-  
15 istration for Children and Families;

16           “(C) the Director of the Centers for Dis-  
17 ease Control and Prevention;

18           “(D) the Administrator of the Centers for  
19 Medicare & Medicaid Services;

20           “(E) the Secretary of Defense;

21           “(F) the Commissioner of Food and  
22 Drugs;

23           “(G) the Administrator of the Health Re-  
24 sources and Services Administration;

1           “(H) the Director of the National Insti-  
2           tutes of Health; and

3           “(I) the non-Federal members appointed  
4           under paragraph (2).

5           “(2) NON-FEDERAL MEMBERS.—Not fewer  
6           than 6 members of the Committee or one-third of  
7           the total membership of the Committee, whichever is  
8           greater, shall be composed of non-Federal members  
9           to be appointed by the Secretary, of which—

10           “(A) at least 2 shall be individuals with a  
11           diagnosis of pulmonary hypertension;

12           “(B) at least 1 shall be the parent or  
13           guardian of an individual with a diagnosis of  
14           pulmonary hypertension;

15           “(C) at least 1 shall be a representative of  
16           a pharmaceutical company that manufactures a  
17           drug or device for detecting, preventing, or  
18           treating pulmonary hypertension; and

19           “(D) at least 1 shall be a representative of  
20           a leading research, advocacy, or support organi-  
21           zation primarily serving individuals with a diag-  
22           nosis of pulmonary hypertension.

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

1           “(f) **TERMINATION DATE.**—The Committee shall ter-  
2       minate on the date that is 5 years after the date of the  
3       enactment of the Pulmonary Hypertension Research and  
4       Diagnosis Act of 2016.”.

5       **SEC. 3. REPORT TO CONGRESS.**

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

16          (b) **CONTENTS OF REPORT.**—The report submitted  
17      under subsection (a) shall contain—

18              (1) information on the incidence of pulmonary  
19      hypertension including such incidence since the date  
20      of the enactment of this Act;

21              (2) information on the prevalence of pulmonary  
22      hypertension in children and adults;

23              (3) information on the average time between  
24      the initial screening and the accurate diagnosis of  
25      pulmonary hypertension;

1           (4) information on the average stage of pul-  
2           monary hypertension when appropriate intervention  
3           begins;

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

7                   (A) mortality rate; and

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

10          (6) information on new developments in re-  
11          search activities;

12          (7) information on innovative treatment options  
13          and diagnostic tools; and

14          (8) information on services and supports avail-  
15          able to individuals with a diagnosis of pulmonary hy-  
16          pertension.

17          (c) PUBLICATION.—The Secretary of Health and  
18          Human Services shall make the report submitted under  
19          subsection (a) available on the public Internet Web site  
20          of the Department of Health and Human Services.

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