113TH CONGRESS
1ST SESSION

S. 1453

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 SENATE OF THE UNITED STATES

AUGUST 1, 2013

Mr. CASEY 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 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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Pulmonary Hypertension Research and Diagnosis Act of 2013''.

SEC. 2. FINDINGS.

The Congress finds as follows:

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

(2) In advanced stages of pulmonary hypertension, the patient is able to perform only minimal activity and has symptoms even when resting, resulting in considerable disability. The disease may worsen to the point where the patient is completely bedridden. In a matter of months, many pulmonary hypertension patients have become so functionally deteriorated that they have lost their jobs and are dependent on family and disability benefits.

(3) Despite the importance of early diagnosis on prognosis, pulmonary hypertension is rarely picked up in a routine medical exam. Even in its later stages, the signs of the disease are frequently confused with more common conditions that affect the heart and lungs. Due to the fact that the average length of time between the onset of symptoms

and an accurate diagnosis is presently 2.8 years, nearly three out of four patients have advanced pulmonary hypertension by the time they are accurately diagnosed.

(4) While pulmonary hypertension remains an incurable condition, progress in our scientific understanding of the disease has led to the development and Food and Drug Administration approval of nine innovative therapies indicated to treat pulmonary hypertension.

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

SEC. 3. INTERAGENCY PULMONARY HYPERTENSION COORDINATING COMMITTEE.

(a) ESTABLISHMENT.—The Secretary of Health and Human Services (in this Act referred to as the ''Sec-

retary'') shall establish a committee, to be known as the ''Interagency Pulmonary Hypertension Coordinating Committee'' (in this Act referred to as the ''Committee''), to make recommendations on, and coordinate, all efforts within the Department of Health and Human Services concerning pulmonary hypertension.

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

(1) develop and annually update a summary of pulmonary hypertension advances in medical research and treatment development and improvement, early and accurate diagnosis, appropriate and timely intervention, transplantation, and access to care and therapies for patients;

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

(3) make recommendations to the Secretary regarding appropriate changes to such activities, including recommendations with respect to the strategic plan developed under paragraph (5);

(4) make recommendations to the Secretary regarding stakeholder participation in decisions relating to pulmonary hypertension;

(5) develop and annually update a comprehensive strategic plan to cooperatively improve health

outcomes for pulmonary hypertension patients which includes—

(A) recommendations to improve professional education concerning accurate diagnosis and appropriate intervention for health care providers;

(B) recommendations to improve the transplantation criteria and process concerning lung and heart-lung transplants for pulmonary hypertension patients;

(C) recommendations to improve public awareness and recognition of pulmonary hypertension;

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

(E) recommendations to systematically advance the full spectrum of biomedical research, including specific recommendations for basic, translational, clinical, and pediatric research, and research training and career development; and

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

(c) MEMBERSHIP.—

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

(A) the Administrator of the Health Resources and Services Administration;

(B) the Director of the Centers for Disease Control and Prevention and the directors of such centers at the Centers for Disease Control and Prevention as the Secretary determines appropriate;

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

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

(E) the Commissioner of Food and Drugs and the directors of such centers and offices at the Food and Drug Administration as the Secretary determines appropriate;

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

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

(2) ADDITIONAL MEMBERS.—Not fewer than 6 members of the Committee or ⅓ of the total membership of the Committee, whichever is greater, shall be composed of non-Federal public members to be appointed by the Secretary, of which—

(A) at least one such member shall be an individual with a diagnosis of pulmonary hypertension;

(B) at least one such member shall be the primary caregiver for an individual with a diagnosis of pulmonary hypertension; and

(C) at least one such member shall be a representative of a leading research, advocacy, and support organization primarily serving individuals with a diagnosis of pulmonary hypertension.

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

(1) The Committee shall receive necessary and appropriate administrative support from the Secretary.

(2) Members of the Committee appointed under subsection (c)(2) shall serve for a term of 4 years, and may be appointed for one or more additional 4-

year terms. Any member appointed to fill a vacancy for an unexpired term shall be appointed for the remainder of such term. A member may serve after the expiration of the member's term until a successor has taken office.

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

(4) All meetings of the Committee shall be public and shall include appropriate time periods for questions and presentations by the public.

(e) SUBCOMMITTEES; ESTABLISHMENT AND MEMBERSHIP.—In carrying out its functions, the Committee may establish subcommittees and convene workshops and conferences. Such subcommittees shall be composed of Committee members and may hold such meetings as are necessary to enable the subcommittees to carry out their duties.

SEC. 4. REPORT TO CONGRESS.

(a) IN GENERAL.—Not later than one year after the date of enactment of this Act, and biennially thereafter, the Secretary, in coordination with the Committee, shall prepare and submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Com-

mittee on Energy and Commerce Committee of the House of Representatives a progress report on activities related to improving health outcomes for pulmonary hypertension patients.

(b) CONTENTS.—The report submitted under subsection (a) shall contain—

(1) information on the incidence of pulmonary hypertension and trend data of such incidence since the date of enactment of the Pulmonary Hypertension Research and Diagnosis Act of 2013;

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

(3) information on the effectiveness and outcomes of interventions for individuals diagnosed with pulmonary hypertension, including—

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

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

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

(5) information on activity to facilitate the development of innovative treatment options and diagnostic tools; and

(6) information on services and supports provided to individuals with a diagnosis of pulmonary hypertension.

SEC. 5. SUNSET.

This Act shall not apply after September 30, 2018, and the Interagency Pulmonary Hypertension Coordinating Committee shall be terminated on such date.

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