



Bob Casey

United States Senator for Pennsylvania



The Pulmonary Hypertension Research and Diagnosis Act of 2016

The *Pulmonary Hypertension Research and Diagnosis Act* seeks to improve health outcomes for pulmonary hypertension (PH) patients by establishing a timely dialogue between the various health agencies currently working to address PH.

This innovative coordination will leverage emerging and ongoing federal activities to effectively and efficiently advance medical research and improve care for PH patients. By taking a results-based approach to combating PH, we can ensure that the federal investment in research is directly leading to prolonged life and improved quality of life for PH patients, while potentially lowering health care expenses traditionally associated with PH, such as disability and organ transplantation.

The *Pulmonary Hypertension Research and Diagnosis Act* establishes an Interagency Pulmonary Hypertension Coordinating Committee for a period of five years. This Committee, which will consist of representatives from federal agencies, the patient community, the caregiver community and the advocacy community, will be responsible for coordinating activities relating to PH. The Committee will: 1) develop a summary of advances in medical research relevant to PH, including diagnosis and treatment advances; 2) monitor federal activities related to PH; 3) make recommendations regarding federal activities and ways to engage stakeholders; and 5) develop a strategic plan to improve the health outcomes for PH patients.

The bill also requires a series of reports to Congress on pulmonary hypertension and progress being made to address the impact of this disease.

About Pulmonary Hypertension (PH)

PH is a debilitating and often fatal progressive condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, blood flow between the heart and lungs is blocked or constricted. As a result, the heart must pump harder, causing it to enlarge and ultimately fail. PH can be idiopathic, and occur without a known cause, or be secondary to other conditions, such as scleroderma, lupus, blood clots, and sickle cell disease. PH impacts individuals of all races and ages.

Meaningful advancements have been made in PH treatment, but more needs to be done:

- Since 1996, the FDA has approved fourteen therapies for the treatment of PH.
- The median survival rate without treatment is approximately 2.8 years, and the average duration from symptom onset to a confirmed diagnosis is also 2.8 years.
- Nearly 75 percent of patients have advanced PH by the time they are diagnosed, which significantly reduces the effectiveness of current therapies, drastically lowers life expectancy, and requires patients to consider serious medical interventions like heart-lung transplantation.

To cosponsor this legislation, please contact Doug Hartman in Senator Casey's office, at Doug_Hartman@casey.senate.gov.