



The Pulmonary Fibrosis Research Enhancement Act of 2011

Senator Chris Coons (D-Del.), Senator Mike Crapo (R-Idaho), Senator Patty Murray (D-Wash.), and Senator Mark Kirk (R-Ill.)

Pulmonary Fibrosis (PF) is a relentlessly progressive, and ultimately fatal, condition in which the lung tissue becomes thickened, stiff, and scarred. As the condition worsens, the lungs lose their ability to transfer oxygen into the bloodstream, resulting in less oxygen for the brain and other organs. **There is no known cause of PF, it has no cure, and there are currently no FDA-approved treatments.**

Most patients with PF live only 3 to 5 years after diagnosis. In the United States, more than 200,000 people are living with PF; 48,000 individuals are diagnosed with PF annually; and as many as 40,000 die each year. As the prevalence of PF is on the rise, up at least 150% since 2001, it is becoming increasingly important to understand better the origin, incidence, and effectiveness of therapies as they relate to PF. **The Pulmonary Fibrosis Research Enhancement Act (PFREA) is a crucial first step in combatting this debilitating disease.**

The PFREA would provide for the creation of a national PF Registry and a PF Action Plan as well as encourage the expansion of PF research efforts at the NIH.

Creates a PF Registry and Advisory Board. The PFREA would establish the first National PF Registry to collect and store data related to the incidence and prevalence of PF in the United States. The Registry will also include relevant data about environmental and occupational factors; age, race or ethnicity, gender, and family history; pathogenesis of PF; and any other appropriate information. The Registry is a critical component to improving data collection and information sharing about the disease.

A National Pulmonary Fibrosis Advisory Board will be created to develop the Registry. The Advisory Board's members would include representatives from various federal agencies, such as the National Institutes of Health and the Centers for Disease Control and Prevention, as well patients with PF, patient advocates, and clinicians and geneticists with expertise on PF.

Establishes a National PF Action Plan. The PFREA would require the Director of the Centers for Disease Control, in consultation with the National Pulmonary Fibrosis Advisory Board, to prepare a comprehensive education and awareness plan for PF.

Encourages Federal Research on PF. The PFREA would encourage the National Institutes of Health to expand, intensify, and coordinate the activities of the Institute to help improve the understanding and treatment of PF.

Legislative Background

Prior to its reintroduction by Senators Coons, Crapo, Murray, and Kirk during the 112th Congress, the PFREA received strong bipartisan support during both the 110th and 111th Congress. Originally introduced in the U.S. House of Representatives by former Representatives Mike Castle and Brian Baird in 2008, its reintroduction in the House during the 111th Congress included 147 bipartisan cosponsors. Senators Mike Crapo and Patty Murray first introduced the Senate version of the PFREA in 2010, and it received bipartisan support from six additional cosponsors by the end of the 111th Congress. The continued support from members on both sides of the aisle demonstrates the critical need to address this terrible disease and that the time has finally come for Congress to pass this bill and take a significant step forward to address PF.