

Pulmonary Fibrosis Research Enhancement Act of 2008 Introduced in U.S. Congress (marketwatch.com)

WASHINGTON, July 23, 2008 /PRNewswire-USNewswire via COMTEX/ -- Landmark Bill Would Create National Patient Registry, Increase Public Awareness of Deadly Lung Disease

Not much is known about Pulmonary Fibrosis (PF), a progressive and ultimately fatal lung disease that claims the lives of 40,000 Americans each year and kills an estimated two-thirds of patients within their first five years of diagnosis. As two members of the House of Representatives who have been personally impacted by PF, Congressmen Brian Baird (WA-03) and Mike Castle (DE-at large) today introduced the Pulmonary Fibrosis Research Enhancement of 2008, which will fund the creation of a national PF patient registry, and call on the National Institutes of Health (NIH) to expand and intensify PF research efforts.

Reps. Baird and Castle have been working closely with the Coalition for Pulmonary Fibrosis (CPF) since early 2007 to author legislation that is the first of its kind to improve research and awareness of this deadly disease. There is known cause, no FDA approved treatment and no cure for PF. For more information on PF, visit www.coalitionforpf.org.

"I am pleased to have worked with my colleague and the CPF to bring about this important legislation," said Rep. Castle. "PF is an ultimately debilitating and fatal disease, and one that has taken people close to me. I remain dedicated to supporting research efforts to eradicate this disease."

The Act would also mandate the creation of a National PF Action Plan, in conjunction with the National Institutes of Health (NIH) and Centers for Disease Control (CDC), which would focus on strategies to improve public awareness of PF, and accelerate patient and medical education strategies. The Action Plan would be provided to the Director of the NIH within one year of the Act's passage.

The Act also calls for establishment of National PF Advisory Board, which would make recommendations to the NIH and CDC concerning the structure and management of a PF patient registry. The goal of the registry would be to improve understanding of the cause and progression of PF, standards of care can be improved, research can be accelerated, and new therapies can be developed sooner.

Lastly, the Act mandates the establishment of a National Summit on PF, to foster collaboration between Federal Agencies, researchers, patients and advocates to identify new approaches to research and treat PF. The Summit would be held every three years.

"Neither my dad nor I had ever heard of PF prior to the day that he was diagnosed. That's when the doctor informed us it was a death sentence," said Congressman Brian Baird (D-WA-03). "Every 13 minutes, some family somewhere experiences the suffering that my father went through. We must stop that. This legislation takes an important step in searching for the cause of, and the cure for this dreaded disease."

Since 2002, the CPF has been leading a national advocacy effort toward the NIH & CDC to increase research funding for PF and accelerate efforts to find a cure for this devastating lung disorder. This has included a close collaboration with the late Congressman Charlie Norwood, who lost his battle with IPF in 2007. The CPF worked closely with Rep. Norwood to secure passage of H.R. 182 in 2007, which was the first-ever Congressional recognition of the need for increased research funding and improved public awareness of PF in the United States. This resolution laid the groundwork for the PF Research Enhancement Act to become a reality.

"The PF Research Enhancement Act is an important first step for the fight against PF and it is compelling to see these strong leaders come together to fight for a disease that knows no boundaries and can attack anyone," said Mishka Michon, Chief Executive Officer for the CPF. "We are inspired by their leadership in this effort. Our membership will be mobilized to contact their Congressional representatives to urgently request their support in the effort to find answers to Pulmonary Fibrosis. We look forward to the successful passage of this legislation."

About Idiopathic Pulmonary Fibrosis (IPF)

IPF is a lung disorder characterized by a progressive scarring - known as fibrosis - and deterioration of the lungs, which slowly robs its victims of their ability to breathe. Approximately 128,000 Americans suffer from IPF, which is the most prevalent of a classification of lung disorders known as interstitial lung diseases (ILD's). There is currently no known cause or cure for IPF, nor is there an FDA-approved treatment. An estimated 48,000 new cases are diagnosed each year. IPF is difficult to diagnose, and an estimated two-thirds of patients die within five years of diagnosis.

About the Coalition for Pulmonary Fibrosis

The Coalition for Pulmonary Fibrosis (CPF) is a 501(c)(3) nonprofit organization, founded in 2001 to accelerate research efforts leading to a cure for idiopathic pulmonary fibrosis (IPF), while educating, supporting, and advocating for the community of patients, families, and medical professionals fighting this disease. The CPF funds promising research into new approaches to treat and cure pulmonary fibrosis; provides patients and families with comprehensive education materials, resources, and hope; serves as a voice for national advocacy of IPF issues; and works to improve awareness of IPF in the medical community as well as the general public. The CPF's nonprofit partners include many of the most respected medical centers and healthcare organizations in the U.S. With more than 16,000 members nationwide, the CPF is the largest nonprofit organization in the U.S. dedicated to advocating for those with pulmonary fibrosis. For more information please visit www.coalitionforpf.org or call (888) 222-8541.

SOURCE Coalition for Pulmonary Fibrosis