

**THE**  
MAGAZINE  
PASADENA FOOTHILLS REGION  
WORLD CLASS LIVING

# THE FALL CHARITY EVENTS

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HAIRSTYLE

## INSIDE STORY

BOB O'ROURKE: GASPING FOR AIR



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HONORING  
PAUL RUSNAK

# My Friend Is Gasping For Air...

Bob O'Rourke waits for his lung transplant.

By Steve Tobia

**M**y dear friend and long-time mentor, Bob O'Rourke, former vice president of external affairs for Caltech and a major personal pillar of our community, is in a fight for his life as he awaits a lung transplant. But this "Fighting Irishman" isn't taking the biggest challenge of his life sitting down.

Bob was diagnosed with Idiopathic Pulmonary Fibrosis in the Fall of 2006, a disease for which so little is known that no cure has been developed, yet it currently affects about 128,000 people in the United States. The debilitating disease is characterized by irreversible scarring of the lungs that interferes with a person's ability to breathe and is ultimately fatal. More than 40,000 people die each year from this slow debilitating disease which takes the same number of lives as breast cancer.



Bob O'Rourke anxiously waits to hear the voices of his doctors from UCLA each time the phone rings. His hope is that there is a match for his lung transplant- the only hope he has to breathe again without his oxygen machine.

## **Pulmonary Fibrosis:** Kills The Same Number of Americans As Breast Cancer

(Continue on page 72)

## A Personal Journey

### *Raise Awareness Find A Cure*

When Bob was diagnosed there was no information provided to him and his wife, Sandy, to help them understand and cope with the severity of this disease. Not the type to wallow in self-pity, he took this personal challenge to help others. For the last several months, he has been working with friends across the US to raise the awareness of Pulmonary Fibrosis. In a recent meeting in Bob and Sandy's living room on Orange Grove a few of us in the media met the staff from the Coalition for Pulmonary Fibrosis to learn more about the disease and what we could do to help Bob's cause. This national organization advocates for funds for research and educates patients, families and caregivers about Pulmonary Fibrosis. Since that time, Bob's story and the deadly disease have been featured on national and local television programs as well as national and local newspapers and magazines.

Through these public education efforts not only is the general public becoming aware of PF but our political and government leaders are becoming educated. Both Congressman Adam Schiff [D-Pasadena] and Congressman David Dreier [R-San Dimas] are co-sponsors of H.R. 1079 [The Pulmonary Fibrosis Research Enhancement Act.]

Despite our local congressional support, I asked the staff of the PF Coalition why the FDA has not approved drug treatments in the US that are available in foreign countries and why drug companies are not allocating more research funds to find a treatment or cure. The answers were as troublesome as the first day I learned from Bob of his diagnosis.

### **The Federal Bureaucracy.**

Although PF patients have access to a drug in Japan that can extend patients' lives for many months (not approved in Europe yet), there is no long-term treatment or cure. The drug, Pirfenidone, was not approved by the FDA this past May and despite a recommendation for approval by the FDA Advisory Committee last March they have asked for further study of the drug. In response to the FDA ruling, the Coalition responded by stating, "Although the drug is not seen as a cure, it offers the first-ever option for treatment and some hope for these dying patients. This is a setback for those patients who are anxious to gain access to this treatment now. The need is profound and urgent." The FDA and InterMune, the producer of Pirfenidone, will be meeting this summer to discuss any further research required to ultimately move the drug to approval.

Since 2002, the Coalition has been leading a national advocacy effort toward the National Institutes of Health (NIH) and the Centers for Disease Control (CDC) to increase research funding for PF and accelerate efforts to find a cure for this devastating lung disorder. The Pulmonary Fibrosis Research Enhancement Act (H.R. 1079) was first introduced in Congress in 2008 and currently sits in committee awaiting review and a vote. The Coalition is hopeful for a possible vote this fall and will be on Capitol Hill in September meeting with legislators around the effort.



Without Federal funding to build a patient registry, researchers and physicians have limited information about the PF patient base – their common traits, ages, disease progression and other critical details that inform the research process as well as assist the government in determining patient needs for care and support. That registry will improve understanding of the cause and progression of PF, improve standards of care, accelerate research and find ways for new therapies to be developed sooner.

Long-term research success for both pharmaceutical companies and independent researchers rests on securing critical data on the national patient base, and the success of the registry itself will depend on how the process is managed. The current bill requires establishment of a National PF Advisory Board to oversee the process nationally,



*Pulmonary Fibrosis belongs to a family of 100 related diseases called interstitial lung diseases, which have similar characteristics and it can sometimes be linked to a particular cause. In many instances though, there is no known cause for this disease. Hence the name: Idiopathic Pulmonary Fibrosis. Pulmonary Fibrosis results in chronic inflammation and uncontrolled and exaggerated tissue repair, which cause collagen accumulation and scarring on the lungs. This reduces the elasticity of the lungs and inhibits their ability to transfer oxygen to the bloodstream.*

## **What You Can Do To Help.**

*Being informed is the first step. Asking and persuading ALL congressional representatives and US Senators is the next step. To learn more about PF and how you can help bring this debilitating disease to the forefront of Federal Government Health Officials log onto to [www.coalitionforpf.org](http://www.coalitionforpf.org).*