

My Turn: A new cause with every breath he takes

A diagnosis of idiopathic pulmonary fibrosis, a scarring of the lungs, carries with it a sobering reality. But also new challenges.

I was 68 and had enjoyed a lifetime of good health, but at Yellowstone I discovered that I was short of breath when I walked any distance or went up stairs. I blamed the elevation but upon my return decided to see my primary care physician, which led to a cardiologist, which led to a pulmonologist.

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By Bob O'Rourke, Special to the Los Angeles Times
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For many, Yellowstone National Park is a place where nature gives a lifetime of memories — the beauty of the landscape, the wildlife and the geysers. For me, Yellowstone is a reminder of a turning point in my life, one that resulted in a death sentence. It's a memory I'd rather forget.

I was the vice president for public relations at the California Institute of Technology in the fall of 2006 when I took a vacation to Yellowstone. I normally didn't like to take vacations. I did conference calls from cruise ships and wrote e-mails from beach houses. There's no challenge in relaxation.

They said it was pulmonary hypertension ... a common misdiagnosis for what I had.

After a breathing test and CT scan, I was correctly diagnosed with idiopathic pulmonary fibrosis, a scarring of the lungs. The doctor didn't explain the severity, but when I asked my wife, Sandy, "Why the tears?" she reminded me that we had lost a dear friend to pulmonary fibrosis only three months earlier.

This disease affects those who worked at ground zero in New York City after 9/11 and those exposed to Agent Orange. But most don't know why they have it, and it can go undiagnosed for years because a patient may have only a dry cough.

It's a stealth disease. It creeps up on people, as it did with Robert Goulet, Evel Knievel and Marlon Brando.

At the time, I didn't know that the same number of people die of PF every year as die of breast cancer (40,000).

... or that the only hope for survival is a lung transplant (only 1% of patients get one).

... or that from the point of diagnosis, most patients live only three years.

I only knew I had to find the best doctors.

I joined a clinical trial at UCLA to test the drug pirfenidone, which is a treatment but not a cure. Maybe it's because of that trial that I'm still alive 3.5 years later. Or maybe it's the luck of the Irish (after all, I am a card-carrying member of the Los Angeles Chapter of the Friendly Sons of St. Patrick).

Until this April, my breathing was only slightly affected, but I am now on oxygen 24 hours a day.

I have been through a barrage of tests that qualified me for a lung transplant, and now I wait. I could get the OK that a lung is available in the next 10 minutes. Or it might take months. It's strange to live moment to moment in this way.

I recently discovered the Coalition for Pulmonary Fibrosis, a nonprofit that seeks awareness, research funding and FDA-approved treatments. My communication role is to raise awareness of PF and help raise funds for research.

Next to fighting this disease, speaking on camera is the most difficult thing I've had to do in my life. I've always been the man behind the man speaking on camera, but I'm doing this because, if I can make headway in bringing awareness to this disease, the payoff could be tremendous.

And anyway, there's no challenge in merely waiting.

O'Rourke had been vice president for public relations at Caltech since 1986; he stepped down in September and is now senior advisor to the president for external relations.

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