



Bob O'Rourke

Every breath counts

Caltech's bob o'rourke waits for a lung that will save his life

By [Andy Lee](#) , [Kevin Uhrich](#) 07/15/2010

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Taking things for granted is a luxury Bob O'Rourke can no longer afford. Now suffering from a mysterious lung disease — one that is always fatal — the longtime Caltech community and media relations executive knows all too well that some day soon something as simple as taking a breath will be impossible.

"When one gets diagnosed with it, it's a death sentence," O'Rourke said of idiopathic pulmonary fibrosis, a disease which he was diagnosed with three-and-a-half years ago. Pulmonary fibrosis kills 40,000 people a year — roughly the same number of annual deaths related to breast cancer. For reasons still unknown, the disease ultimately causes a person's lungs to fill with scar tissue, which gradually forces the organs to stop functioning.

"You have three to five years before you die," O'Rourke noted matter-of-factly during an interview at his home. "No chemo, no pills; there's nothing."

Today, O'Rourke suffers sporadic episodes in which it is difficult for him to breathe without the help of an oxygen tank. He appears to be healthy, but has difficulty walking very far without having to rest for several minutes and catch his breath. The only thing that can save his life, he and his family members know, is a lung transplant, which is rare and expensive, costing upward of \$450,000 to perform.

To that end, the 71-year-old is currently on an organ donor waiting list, and he's gone public with his plight, both to give hope to those suffering as he is and to put another well-known face on a disease that caused the deaths of such celebrities as actor Marlon Brando, singer Robert Goulet and daredevil Evel Knievel.

Since being diagnosed, O'Rourke has made it his mission to spread the word by sharing accounts of the struggles that he's faced, most recently speaking about his condition on NBC's "Today" show.

"The issue that we're fighting right now is that no one knows anything about this disease, because we don't have a champion," said O'Rourke. "We need a champion; it has to be someone with an identity with pulmonary fibrosis."

O'Rourke, who lives in a well-appointed condo on Orange Grove Boulevard in Pasadena with his wife Sandy, has six grown children and seven grandchildren, many of whom he sees often. Currently, O'Rourke works part time as the senior adviser for external affairs to Caltech President Jean-Lou Chameau, who upon hearing in August of his retirement described O'Rourke as "an integral part of the Caltech community and an extraordinarily effective ambassador for the institute," according to Caltech's online newsletter.

A 1962 graduate of the University of Arizona, O'Rourke came to Caltech from Boston University, where he was assistant vice president for public relations and press secretary to the president from 1980 to 1986. From 1977 to 1980, he was vice president for institutional relations at the Medical College of Pennsylvania in Philadelphia, and before that he served as director of public affairs and community health education at the University of Wisconsin Center for Health Sciences in Madison. In 1996, O'Rourke became associate vice president for institute relations at Caltech.

It's a tragic irony that O'Rourke, who has worked nearly 25 years for an institution devoted to unlocking the mysteries of science and nature, would be stricken by a disease about which so little is known. In fact, the word "idiopathic" denotes the fact that the medical community simply doesn't understand what causes pulmonary fibrosis, how it behaves or — most importantly — how to combat it.

"I think one of the issues that I've got is that the medical profession really doesn't know much about this disease," which approximately 128,000 Americans suffer from, with an estimated 48,000 new cases diagnosed annually. "So, consequently," said O'Rourke, "they get a patient who's diagnosed, confirm that he or she has pulmonary fibrosis and the poor patient and the family and the caregiver don't know what to do with this."

O'Rourke said he has found hope in working with the Coalition for Pulmonary Fibrosis. Founded in 2001, the Culver City-based nonprofit organization aims to alleviate confusion, anxiety and stress experienced by the afflicted and caregivers by providing information about the disease and offering a support network for those who are diagnosed with it.

O'Rourke remembers walking and carrying out daily functions without much trouble soon after being diagnosed, explaining that the impacts of the disease are quite mild during its initial stages. But during an April morning just this year, O'Rourke woke up feeling winded, and he was rushed to the hospital. He has since been forced to use an oxygen tank.

"We went along for several years at a pretty normal lifestyle, and then he would have a problem," said Sandy. In May, O'Rourke told the Pasadena Star-News that he first noticed something was wrong a few years ago, when he became short of breath while hiking in Yellowstone National Park.

"He would get a little worse and then we would go on again and have another problem, and then we got to the point when we know we were in trouble and that the disease was taking its toll and we wouldn't have that much longer," said Sandy. Today, O'Rourke admits that after just a short walk he needs to rest for 10 minutes just to catch his breath. "It's like breathing through a straw," he said.

O'Rourke knows he will not live long without a new lung, just as he knows the chances of that happening are slim.

"Out of the 40,000 that die, very few will get the transplant. And here I am sitting at 71 years old, waiting for the phone to ring," he said. "You don't just go to Home Depot to buy a lung."

In order to receive a lung transplant, one must first gain admittance to the national organ waiting list. From there, a lung allocation score is determined by factors, such as blood type, height, age, immediate need and geographic distance (donated lungs can only survive up to 6 hours once they leave their host).

O'Rourke was recently placed on the waiting list at the Ronald Reagan UCLA Medical Center. Officials there must be able to get

in touch with O'Rourke at any given moment when a compatible lung is obtained. With that in mind, O'Rourke has a separate bag filled with his belongings and oxygen tank ready to go.

"Every time the phone rings, we hope they found a lung," he said.

"We are among the lucky ones to have the option of getting a lung, but there's still the unknown of ... can we beat the odds and get the lung before he gets too sick," said Sandy.

If O'Rourke were to receive a lung, he would still have to face the obstacles that arise after the operation: possible rejection and infection. When a foreign organ is first introduced, the receiving party's immune system automatically classifies it as a threat. Thus, patients are given immunosuppressive drugs in order to aid the body in accepting the new lung. However, the drugs also weaken the immune system, lessening a patient's ability to fight off disease and infection.

"You never realize how important your lungs are. I see people walking on Orange Grove and I can't wait to do that again because that was never a chore," he said. "It's the everyday little things that we tend not to appreciate ... and all of a sudden it's taken away from you," said O'Rourke. "Really appreciate every day, from the moment you get up till you go to sleep. Appreciate your partner, appreciate your family and appreciate your friends. Don't miss out on opportunities to do something that you would postpone — do it now, because there may not be a later."