THE ONLY PICTURE ON THE DESK OF DICK SIMMONS, the retired chair of Allegheny Technologies who once marshaled a gutsy $195 million buyout of a steel manufacturer during the industry’s darker days, shows him with his wife of 42 years, Dorothy, and two grandchildren. No clouds muddle the turquoise sky in the background. It is an image of a pleasant vacation, a simple moment last January in Boca Grande, Florida, for a family in which, says Simmons, “the men go out into the world and do battle, and the women stay home and do their own battle.”

It is difficult to guess that the photograph was taken weeks before Dorothy Simmons would lose her toughest battle—with an incurable disease—because to look at the picture is to gaze upon a family seemingly in control of life. One recent day as Simmons looks above the photograph, out the window of his Pittsburgh office, tears welling up in his eyes, that false impression fades as quickly as the fragile veil of good health sometimes does.

Dorothy Simmons was diagnosed in 1995 with idiopathic pulmonary fibrosis (IPF), a degenerative lung disease in which the interstitium, the air sacs of the lung, become scarred and unable to process oxygen. For the next six years she and her husband hunted for answers. What is the cause? What are the effective treatments? Inevitably the question became, How much time is left?

“We don’t know,” the doctors would say, again and again, in a refrain familiar to the estimated four to 10 people in every 100,000 who get this disease. The questions outnumbered the answers, and shortly before Dorothy Simmons died the couple pledged a total of $5 million to the University of Pittsburgh. The gift created the Dorothy P. and Richard P. Simmons Center for Research and Education in Interstitial Lung Disease and an endowed chair for pulmonary research.

Typically IPF affects the elderly, but it is not unheard of for someone to be diagnosed in his or her 30s. It was once thought IPF’s cause could be related to environmental and occupational conditions that perhaps trigger the disease. That might be so, and it might not. “We don’t think there’s a clear relationship,” says Kevin Gibson, an associate professor of medicine investigating the disease. “You’ll see IPF all over the country, in areas where there’s no industry.”

Often people will develop a cough prior to diagnosis. Sometimes they’re misdiagnosed with pneumonia, tuberculosis, or chronic obstructive pulmonary disease. Among those diagnosed correctly, usually following an open lung biopsy, some lose ground gradually, others quickly. Some become sick and get better, then become sick and get better again. The sickest patients are told they have four to seven years to live. The only known cure is lung transplantation.

Treatments vary. Many people with IPF need a constant influx of tanked oxygen. Most receive steroids, because doctors have thought of the disease as an inflammation of lung tissue. Today, though, Gibson says, doctors typically believe the number of people who will benefit from steroids is something like 15 of every 100 people who take them. Gibson, also the associate director of the Simmons center, is part of a team conducting a Phase III trial of interferon gamma, a drug originally developed to treat cancer that might show some promise in thwarting IPF.

The center makes great effort to let patients know what doctors do know. It is establishing a comprehensive website (http://www.ipf.upmc.com) and a patient support group. The group meets bimonthly, bringing patients together with doctors and other health care professionals for a few hours in a comfortable atmosphere to discuss the disease.

“You can see other people with the disease,” says one support group member in his 40s. The meetings give the man, diagnosed with IPF two years ago and now on oxygen full-time, a chance to measure himself on the scale of IPF’s severity. And he can talk to doctors. “You can see the very bare honesty, that they don’t know—and that’s a hard pill to swallow—but you can talk one on one with them. You’re more than just an appointment.”

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