



*Beth Mittelstadt*

PULMONARY FIBROSIS

*“As my disease progressed, requirements increased as did the complications.”*

I noticed that I had difficulty breathing after jogging or biking, but I assumed it was just because I was out of shape. When I was pregnant with my first daughter a few years later, I mentioned it to my obstetrician, who said it was exercised induced asthma. After my daughter was born, I saw an allergist who prescribed an inhaler to use when I exercised, but I didn't really see any difference.

Several years later, my husband and I attended a Christmas party in a restaurant where there were several smokers in a small space (this was 1997). I had difficulty breathing throughout the night, and I saw my allergist the next morning. He told me that my condition had progressed to full blown asthma.

We spent the next 12 months trying different medications and dosages to get the breathing under control but nothing worked. After some time, I visited a pulmonologist who listened to my chest and looked at x-rays and said I probably had interstitial lung disease. The pulmonary function tests were completed and showed an FVC of 70 percent, an FEV1 of 65 percent, and DLCO of 55 percent. I was pregnant with my second son, so the high resolution CT scan was postponed until the second trimester. Months later, I had an acute episode of shortness of breath and ended up in the ER. After this I had to use oxygen when active. A CT scan revealed mild interstitial lung disease.

I chose to go ahead with a video assisted thoroscopic lung biopsy at Porter Hospital in Denver. Reports showed usual interstitial pneumonia, and I took prednisone, Cytoxan, N-Acetyl Cysteine, and prophylactic antibiotics. The disease continued to progress, and I was listed for a transplant at the University of Colorado Hospital.

## PULMONARY FIBROSIS

- Pulmonary Fibrosis is a debilitating disease-marked by progressive scarring of the lungs that gradually interferes with a person's ability to breathe.
- Every day in the United States 128,000 people are suffering from pulmonary fibrosis.
- Every day in the United States 130 people will be diagnosed with pulmonary fibrosis.
- Every day in the United States 110 people will die from pulmonary fibrosis.

Source: Coalition for Pulmonary Fibrosis—  
[www.coalitionforpf.org](http://www.coalitionforpf.org)

I have a high level of PRA in my blood and all attempts to reduce it in order to facilitate transplant have failed, so I placed myself on inactive status with the transplant team. I haven't participated in any drug trials as I have lost too much lung function to take a chance. Cytoxan and prednisone put the disease in a holding pattern, and I can't ask for more than that.

Since March 2000 my disease has remained stable with normal variables for weather, season and overall sense of well-being. Temperatures above 90 or below 20 increase the difficulty breathing. High humidity makes breathing harder as does a drop in barometric pressure. Breathing is easier at sea level and requires more oxygen at this altitude.

When I first started using oxygen, it was only with activity and one liter per minute. As my disease progressed, requirements increased as did the complications. Using 6-10 liters per minute has a detrimental effect on the sinuses—increased infections, nose bleeds and hearing difficulty. I had trans tracheal oxygen placed in October 2003 and have never regretted it.

*Beth Mittelstadt was a patient speaker at the ATS 2011 International Conference in Denver, Colo.*