

## DAVID W.

### TAKES ONE STEP AT A TIME

He has been preparing to fight IPF from the beginning



My symptoms began in April of 2004 with a very irritating, shallow cough that was most disruptive when I talked at

length, as I often have to do as an attorney. I live in an area with huge pine trees, so I thought it was just allergies.

Then I noticed that I was out of breath when I walked up steps, which was unusual because I was in pretty good health. My doctor referred me to an ear, nose, and throat doctor. Several months later, I went to see a pulmonary specialist. Once my biopsy results came back confirming my idiopathic pulmonary fibrosis (IPF) diagnosis, I took three immediate steps that helped me to move forward:

#### STEP ONE:

**I made sure that my family would be taken care of.** I have a wife and two daughters in their 20s and it was hard for them to hear the diagnosis. I reviewed all my insurance policies and financials to make sure they were in good order. Another part of taking care of my family was giving them confidence by taking every step possible to fight IPF.

#### STEP TWO:

**I tried to learn as much as I could about this disease and its potential treatments.**

As the patient, I'm my own best advocate. The more I know about what the doctors are doing, the more I can be part of the process. I take every opportunity to learn, but I try not to waste too much time searching for something that's not there.

I did a lot of research to find a medical team with proven experience and a good reputation. I think it helps that I have confidence in my medical team and listen to them; they've helped me get where I need to go. I also wanted to see if I was an eligible candidate for an investigational clinical trial, and my team helped me. It's been a really positive experience. The doctors and nurses running the study have been incredibly helpful and straightforward.

#### STEP THREE:

**I decided to deal with today and look forward as best I can.** I resolved not to waste time wondering why. I don't have any control over that. A lot of things that I had planned for retirement moved up in the calendar. I also started to prioritize my family and my friends before work, which has always been difficult as a lawyer. But I'm really enjoying it.

**I told my doctor that I was prepared to be the first person healed of this illness. I think we're a long way from that, but you never know. Somebody's got to be first.**

# ONE BREATH AT A TIME

## Tips from a dietician regarding loss of appetite

Chris Bannister, RD, CNSD, is the Assistant Clinical Nutrition Manager at the Medical University of Southern Carolina (MUSC) Hospital. She works with several IPF patients a month to individualize their diets based on their specific situations and needs.



Depending on the stage of disease, some people with IPF may experience weight loss or difficulty eating. Here are a few simple tips from Chris that may help:

- Eat more frequent, smaller meals; schedule mealtimes if necessary
- Walk before meals to increase appetite
- Don't drink a lot of fluids with meals; drink between meals instead
- Add one to two tablespoons of olive oil to increase calories in your meal
- Keep nutritious, high-calorie snacks on hand, such as nuts, trail mix, dried fruit, and cheese
- Eat with someone else; studies show that people eat more with others versus eating alone
- Keep a meal journal and discuss it with your doctor
- Try Meals on Wheels to help you with meal preparation; many churches offer similar services
- Try making double portions and freezing extra servings for some easier nutritious meals

To find a local dietician or to get more information on healthy eating, go to the American Dietetic Association Web site at [www.eatright.org](http://www.eatright.org), as well as the [www.coalitionforipf.org](http://www.coalitionforipf.org) and [www.nutrition.musc.edu](http://www.nutrition.musc.edu) sites. Also, watch for the upcoming article about managing weight gain.

## IPF Diagnosis and Tracking

**Pulmonary function tests (PFTs)** are used to measure the capacity of your lungs. The most basic PFT is spirometry, in which you take a full breath and exhale into a tube attached to a device that takes measurements.

- **Forced expiratory volume (FEV)** is the amount of air you can exhale, measured in seconds (FEV<sub>1</sub> is the amount exhaled in the first second, and FEV<sub>6</sub> is the amount in the sixth second)
- **Forced vital capacity (FVC)** is the total amount of air you can force from your lungs

*Checking these results over time is one of the ways your doctor can test your lungs and adjust treatments as needed.*

To access previous newsletters and additional resources for people with IPF and their caregivers

VISIT [WWW.FIGHTIPF.COM](http://WWW.FIGHTIPF.COM)

## NETWORK EXCHANGE

### Reading room for caregivers

#### **Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill**, Second Edition

Cappy Capossela  
and Sheila Warnock

*Share the Care offers a unique group approach that can turn a circle of ordinary people into a powerful caregiving team.*

#### **A Caregiver's Survival Guide: How to Stay Healthy When Your Loved One Is Sick**

Kay Marshall Strom

*After caring for her spouse, who for ten years suffered from a rare, debilitating disease, Kay Marshall Strom is able to bring a voice of experience and compassion to this important topic.*

#### **Chicken Soup for the Caregiver's Soul: Stories to Inspire Caregivers in the Home, the Community and the World**

Jack Canfield,  
Mark Victor Hansen,  
LeAnn Thieman

*These stories soothe and nourish family members and professionals devoting themselves to the care of those who are ill or disabled.*