

# **A Patient Perspective**

My UIP/IPF Journey  
Participating in Clinical  
Trial



# The Journey Begins

- My Symptoms
- Primary Care orders X-rays
- Pulmonary Doctor Visit
- HRCT & PFT
- Second Opinion

# The Journey Continues

- Surgical Biopsy (VATS)
- Pirfenidone Clinical Trial (CAPACITY)
- Pirfenidone Open Label (RECAP)
- Discovering I was in placebo group

# Pirfenidone Clinical Trial experience

- The Legal Agreement
- Randomization for Capacity
- Keep track of drugs taken and doses missed
- Record any and all symptoms of relevance
- Visits vary (ECG, Blood draw, PFT, 6MWT, Exam, Health Questionnaires)
- Turn in pills & diary and get new ones

# Disease Progression

- Supplemental Oxygen
- Using the Pulse Oximeter to measure Saturation
- PFT
- 6MWT

# Lack of Treatment Options

- Prednisone dreaded miracle drug
- Pulmonary Rehab
- Natural Supplements (NAC 600)
- Imuran
- Clinical Trials
- Transplant

# Related Diagnosis

- GERD
- RA
- Other Auto-Immune System disorders

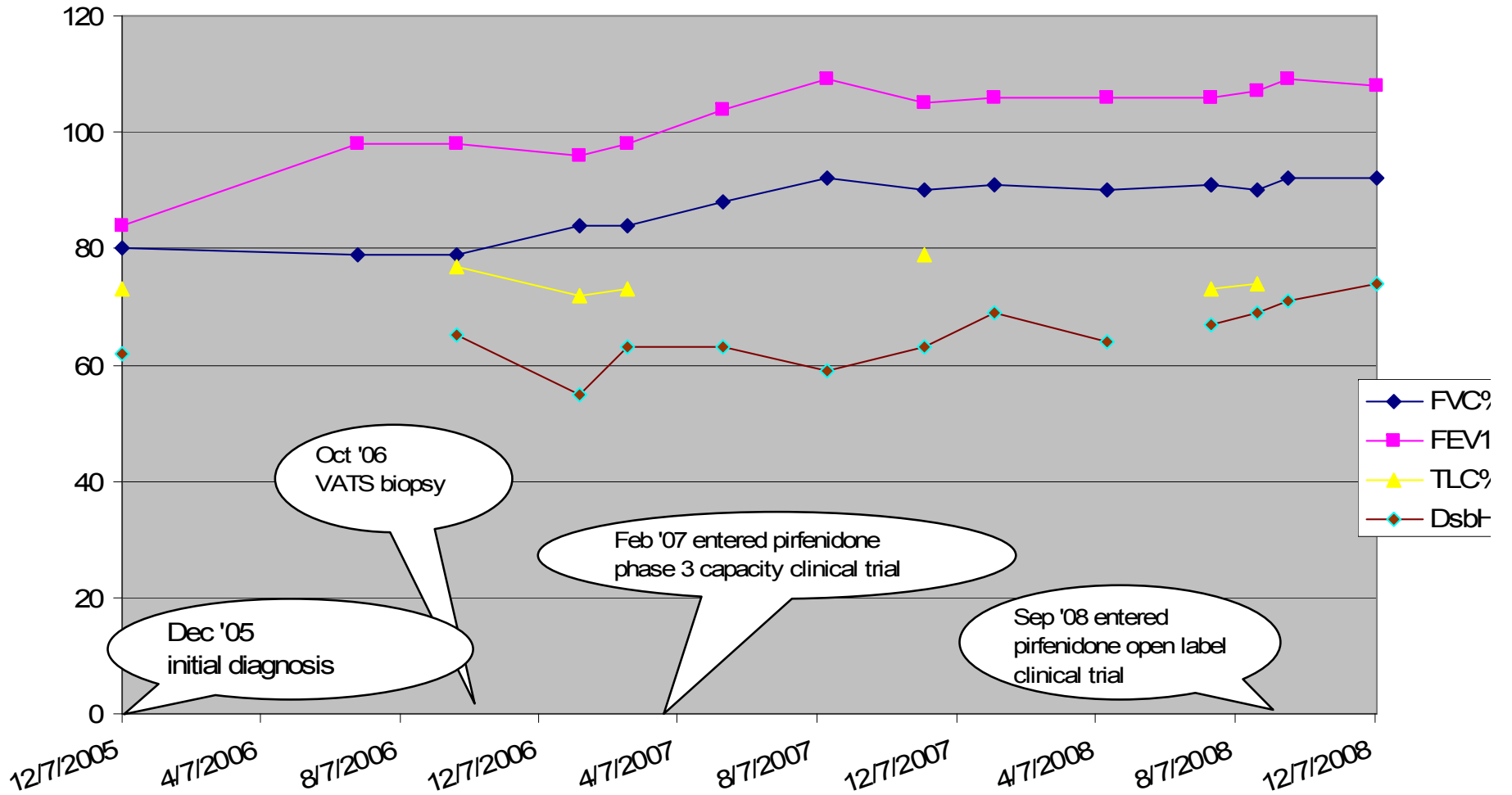
# Personal recommendations

- Don't agree to things you aren't comfortable with
- Keep your own records of test results
- Track your progress
- Exercise (Use it or Lose it)
- Pulmonary Specialist you trust
- Teaching Hospital or Research Center
- 22 centers of excellence (IPFNet)

# Practical Solutions

- Conserve your energy
- Stairs (exhale on up steps)
- Showers (Use Oxygen and shower seat)
- Naps (Don't be intimidated)
- 15 minute rule (work in short increments and rest in between)
- Work sitting down (bending over makes it hard to breathe)

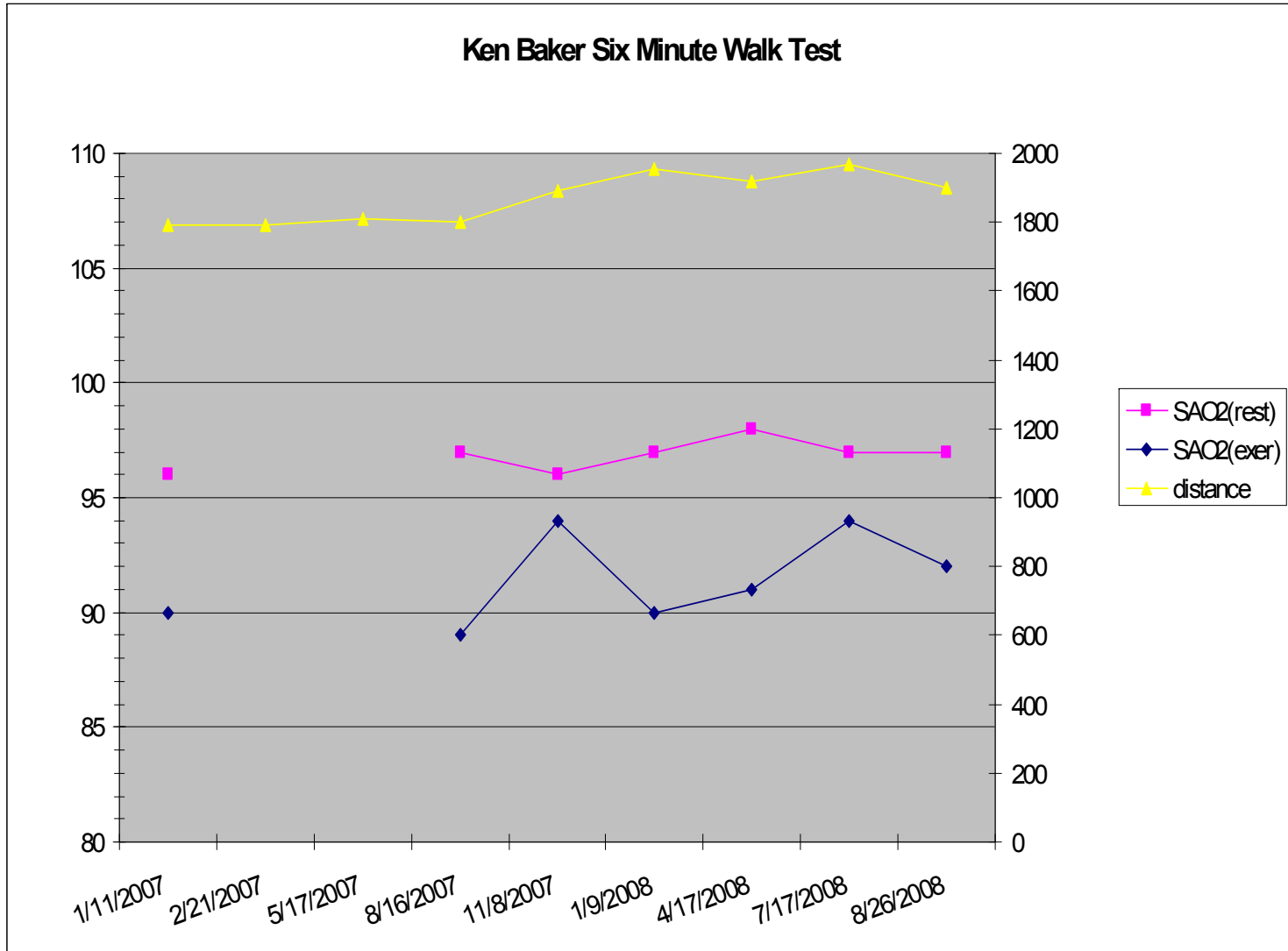
# Ken Baker PFT Results Percent of Predicted



Saturday May 2, 2009

Ken Baker Diag UIP Dec '05

### Ken Baker Six Minute Walk Test



Saturday May 2, 2009

Ken Baker Diag UIP Dec '05



# Pedometer

## Monthly Steps Record

Record for 8/2009

Viewing Options

Daily

Weekly

Monthly

Yearly

Total

Previous

Next

Most Recent

### Changing Graph

Steps Graph

Aerobic Walking Time Graph

Calories Graph

Distance Graph

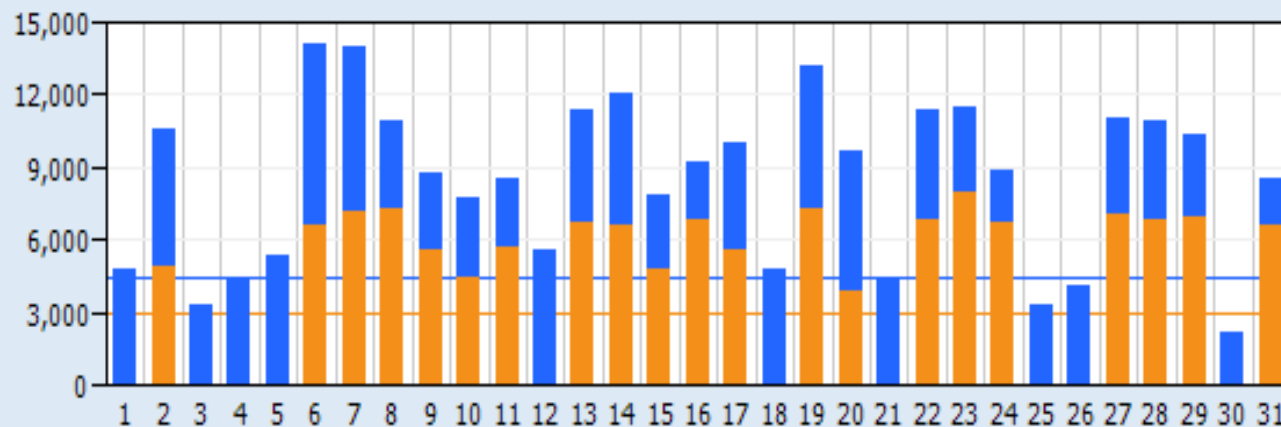
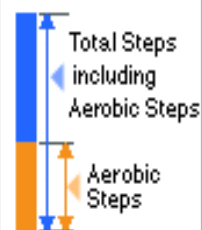
Fat Burned Graph

### Walking Report

	Monthly Total	Daily Average	Daily Goal	Achievement Level	
Steps	263,531	8,501	4,500	189%	😊
Aerobic Steps	133,003	4,290	3,000	143%	😊
Aerobic Walking Time (min.)	1,163	38	30	127%	😊
Calories (kcal)	10,546	340	200	170%	😊
Distance (mile)	114.51	3.69	1.85	199%	😊
Fat Burned (g)	673.4	21.7	21.0	103%	😊

### Steps

#### How to read graph



Date

# Websites

- <http://www.pulmonaryfibrosis.org/home.htm>
- <http://www.coalitionforpf.org/>
- <http://www.nlm.nih.gov/medlineplus/pulmonaryfibrosis.html>
- <http://www.lungusa.org/site/pp.asp?c=dvLUK9O0E&b=35436>
- [http://www.nhlbi.nih.gov/health/dci/Diseases/ipf/ipf\\_w\\_hatis.html](http://www.nhlbi.nih.gov/health/dci/Diseases/ipf/ipf_w_hatis.html)
- <http://www.caringbridge.org/>
- <http://www.ipfnet.org/>

# A Patient Perspective

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