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The Participation Program for Pulmonary Fibrosis

July 2014 ISSUE

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Introduction to the P_3F

Mission

Our mission is to promote understanding of what it's like to live with pulmonary fibrosis (PF), to find ways to make life better for patients who suffer from this disease and ultimately, to help discover its cure.

Who We Are

The Participation Program for Pulmonary Fibrosis (P_3F) is an innovative new program whose overarching purpose is to identify and motivate patients to participate in the process of advancing knowledge of PF.

The Director of the P_3F is Dr. Jeff Swigris from National Jewish Health in Denver, Colorado. Other P_3F team members include patients with PF, nurses with expertise in caring for patients with PF, patient advocacy group representatives and PF support group leaders. The P_3F was borne out of a desire to unite people who share the goals of expanding PF research opportunities to patients across the U.S. – not just those who live near subspecialty clinics – and to improve the lives of patients with this terrible disease. The P_3F creates a transparent, trustworthy environment in which members can share ideas, keep up with the progress and results of P_3F-related research, play a role in disseminating new information about PF and get answers from people with expertise in PF.

The P_3F recognizes the importance of including "the patient's perspective" in our programs and research. "The patient's perspective" means finding out from patients exactly which research questions to ask and drawing on patient input to design the studies that will yield the answers. You, the patient (and caregiver), are the experts here: you know better than anyone else what it's like to live with pulmonary fibrosis.

CONTACT US

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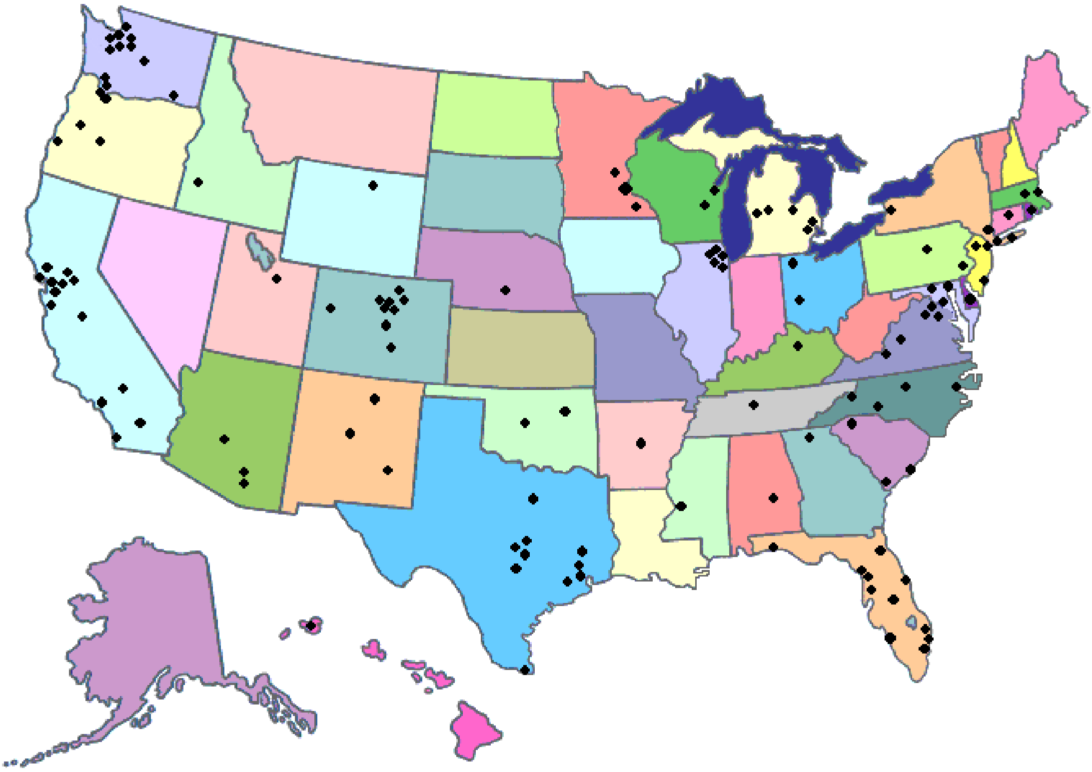
Contact Registry

What Is It?

The P_3F Registry is a confidential database of individuals diagnosed with PF (and/or their primary supporters/caregivers) who wish to be contacted about participating in research projects as they become available. To be eligible to enroll in the Registry, you must be over the age of 18 and either a patient with PF, or a primary supporter/caregiver of someone with PF. Enrollment in the Registry allows the P_3F to house your information in a confidential and secure database. You are likely receiving this newsletter because you enrolled in the P_3F Contact Registry.

Current Enrollment Updates

As of June 24, 2014 the P_3F Contact Registry had enrolled 154 participants. Participants represent 36 states and 5 countries, including the United States, Canada, England, India, and New Zealand. Of those 154 participants, 92 are male, and the average age is 64.7 years. Patient participants have various types of PF, with idiopathic being the most commonly reported cause, followed by connective tissue disease and hypersensitivity pneumonitis. Ten of the participants report themselves as being a caregiver of somebody with PF.



Determining the effects of supplemental oxygen on outcomes meaningful to patients with pulmonary fibrosis

What Is It?

The P_3F is conducting a real-world study of the effects of supplemental oxygen on outcomes meaningful to patients with pulmonary fibrosis. As it stands, the medical field knows very little about whether and how supplemental oxygen affects patients with PF and their loved ones. The main objective of this study is to find out whether supplemental oxygen makes people with PF feel and function better. Although we have finished enrolling PF patients currently **we are still looking to enroll PF patients not yet using supplemental oxygen during the day, caregivers of patients who are using supplemental oxygen, and prescribers of supplemental oxygen.** Contact the P_3F to find out if you qualify, or please visit our website www.PFresearch.org to learn more.

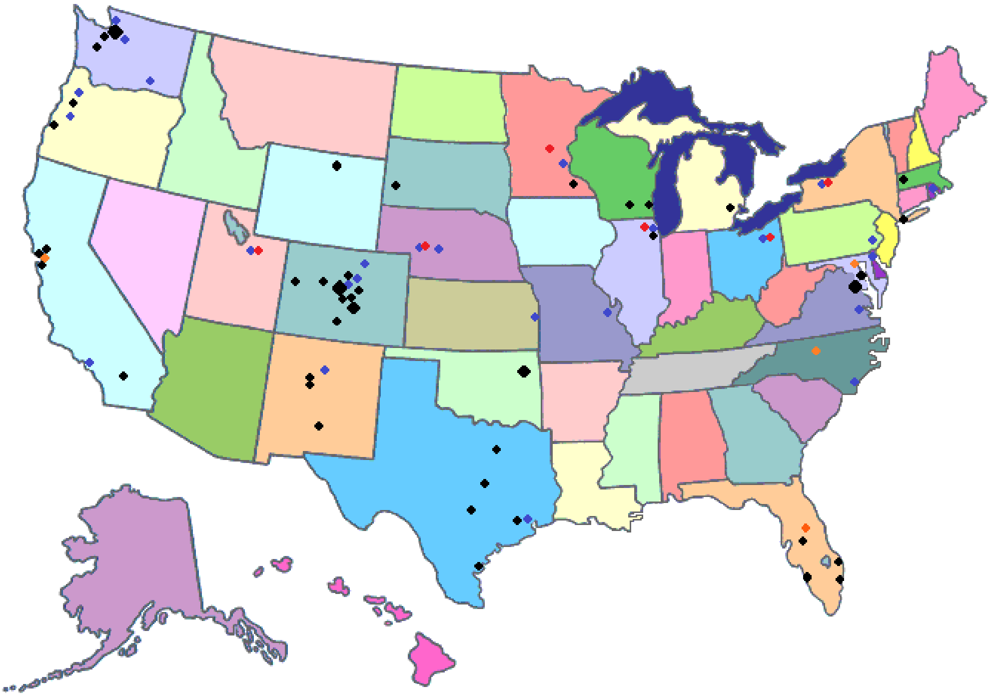
Current Enrollment Updates

As of June 24, 2014, enrollment for our supplemental oxygen study includes the following:

1) Persons with PF:
    Oxygen Users (blue): 27
    Non-oxygen Users (black): 49

2) Caregivers (red): 6

3) Prescribers (orange): 4



We need your help to reach our goal of enrolling 300 PF patients who are not yet using oxygen. If you believe you qualify or know someone who might, or you go to a support group or see a pulmonologist, please contact the P_3F and invite others to become involved in this exciting research opportunity.

Updates on Drug Trials

N-acetyl cysteine

The primary endpoint was change in FVC over time, and the trial did not meet its primary endpoint. The only real kicker—one that I believe is likely due to chance alone—is that among subjects enrolled before the Pred/Azathioprine/NAC (PAN) arm was halted, most of the outcomes (including FVC) trended toward favoring NAC over placebo (i.e., suggesting that NAC was beneficial). Things completely flipped among subjects enrolled after the PAN arm was halted. When you combine the “befores” and “afters”—as should be done—you get no effect. The upshot is that the preponderance of the data suggests NAC is not beneficial for halting disease progression among patients with IPF.

Nintedanib

The primary endpoint was change in FVC over 52 weeks: subjects in the placebo arms lost significantly more lung function (over 200ml) than subjects in the nintedanib arms (around 115 ml). Word is nintedanib will be presented to the FDA in pretty short order.

Pirfenidone

Analyses showed that, over 52 weeks, taking pirfenidone is associated with a 120 ml decline in FVC, but taking nothing (placebo) is associated with a 260 ml decline in FVC…for a difference of 140 ml. Pirfenidone will be presented to the FDA in short order as well.

There are many more interesting results, and you can read about them all in Dr. Swig’s blog post here: www.pulmonaryfibrosisresearch.org/ats-2014-debrief-explanation-of-results-from-four-ipf-drug-trials.

Website Update

Remember to visit our website to read our blog, hear about updates, or learn more about who we are. Our website will be undergoing changes in the next few weeks, so don’t be surprised if one day it looks a little different. We are working to move it onto the National Jewish Health web platform, so the layout of the website will be changing, but all the same information will be on there.