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The Participation Program for Pulmonary Fibrosis

March 2015 Issue

In this issue….

- The P_3F at Chest 2014
- Our study on Symptoms and Activity in Pulmonary Fibrosis
- The P_3F Contact Registry
- Doc, which of the two new drugs for IPF should I take?
- Website Updates

Chest 2014

In October 2014 members of the P_3F team – including Dr. Jeffrey Swigris, Research Coordinator Kaitlin Fier, and two patient consultants – traveled down to Austin, Texas where the patients presented two posters on research papers written by the P_3F team. Mark McCormick presented a poster titled “A pulmonary fibrosis research contact registry” and Tom Vierzba presented a poster titled “Protocol for a mixed-methods study of supplemental oxygen in pulmonary fibrosis.” You can read more about our time at Chest on Dr. Swig’s blog post here.

Mission Statement:

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:

At the P_3F, our overarching purpose is to identify and motivate patients to participate in the process of advancing knowledge of PF.

Located in Denver at National Jewish Health, we accomplish this goal by including the “patient’s perspective” when developing our programs and research. Learn more about our program on our website: www.pfresearch.org.

CONTACT US

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A Study of Symptoms and Activity in Pulmonary Fibrosis

What Is It?

The P_3F is conducting a real-world study of how symptoms and activity levels change in patients with PF, from before to after daytime oxygen is initiated. As it stands, the medical field knows very little about how symptoms and activity levels change over time, or in response to supplemental oxygen use, in patients with PF. The main objective of this study is to find out whether supplemental oxygen makes people with PF feel and function better, and whether it alters their symptoms and activity levels. Although we have finished enrolling PF patients currently using daytime supplemental oxygen, **we are still looking to enroll PF patients not yet using supplemental oxygen during the day and also prescribers of supplemental oxygen.** Contact the P_3F to find out if you qualify, or please visit the current studies page of our website to learn more. A larger image of the map can also be found on our website here.

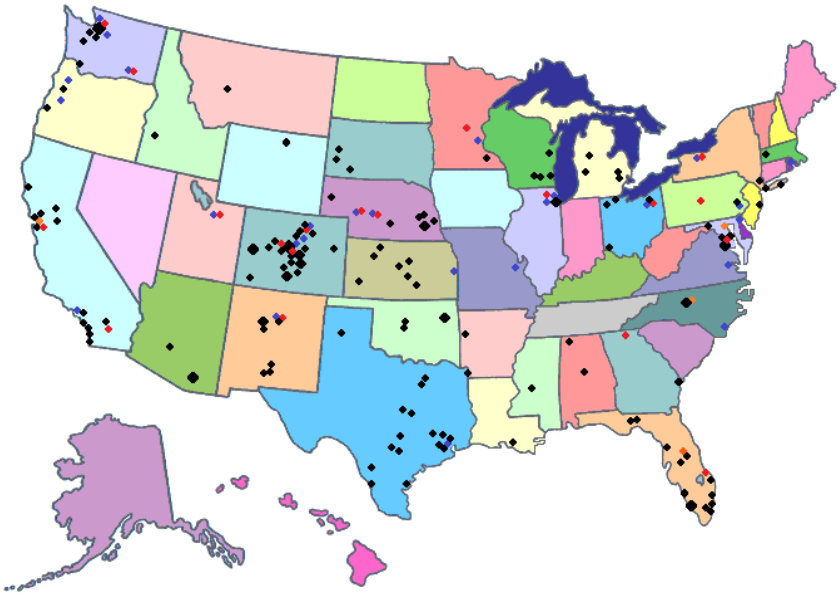
Current Enrollment Updates

As of March 12, 2015, enrollment for our supplemental oxygen study includes the following:

1) Persons with PF:
    Oxygen Users (blue): 28 – enrollment is complete
    Non-oxygen Users (black): 223

2) Caregivers (red): 21 – enrollment is complete

3) Prescribers (orange): 4



We Need Your Help

Although we are getting closer to reaching our enrollment goals, we need your help to reach our goal of enrolling 300 PF patients who are not yet using oxygen, and also our goal of enrolling 20 oxygen prescribers. **If you believe you qualify or know someone who might**, or you go to a support group, or believe your physician may be willing to participate, **please contact the P_3F and invite others to become involved in this exciting research opportunity.**

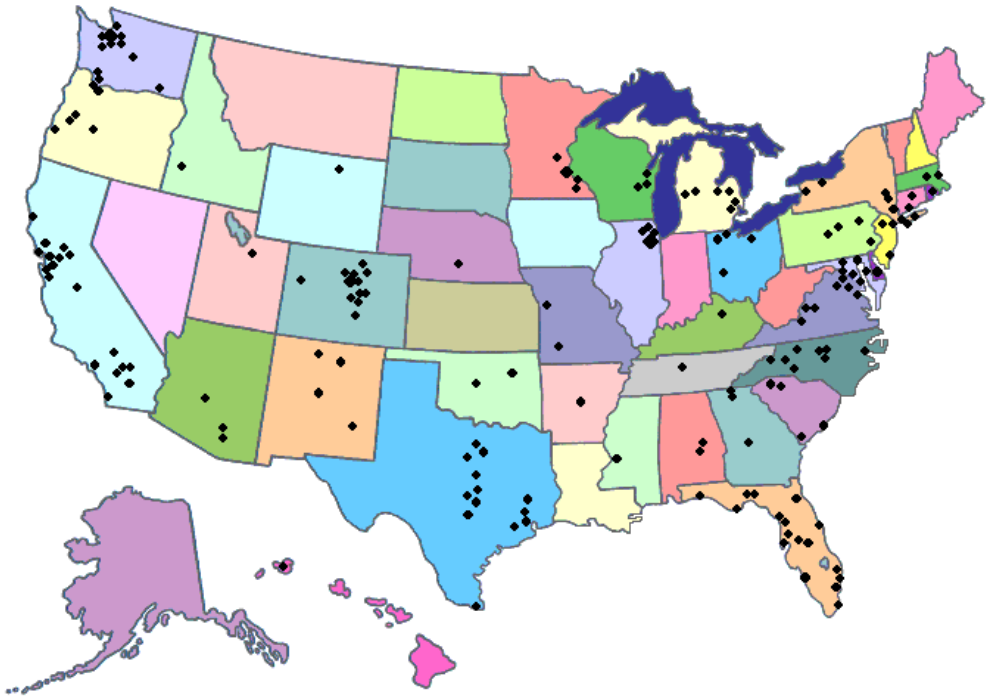
Contact Registry

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. You can learn more about the P_3F contact registry on the registry page of our website.

Current Enrollment Updates

As of March 12, 2015 the P_3F Contact Registry had enrolled 218 participants. Participants represent 37 states and 6 countries, including the United States, Canada, England, India, New Zealand, and Ireland. Of those 218 participants, 120 are male, and the average age is 64.2 years. Patient participants have various types of PF, with idiopathic being the most commonly reported cause, followed by connective tissue disease and hypersensitivity pneumonitis. Seventeen of the participants report themselves as being a caregiver of somebody with PF. Fifty-nine of the Registry participants have enrolled in the P_3F's current study on symptoms and activity in PF.



Dr. Swigris' Blog

Doc, which of the two new drugs for IPF should I take?

To those of you looking for a definitive answer, recipe, algorithm or roadmap, I apologize—this post will leave you disappointed. That's definitely not my intention; it's just that there is no "one right answer," and there certainly is no recipe. The good news is that for the first time EVER, there are options for treatment that have good data backing them.

Before I get into the nuts and bolts, let's make sure we're all on the same page: the two drugs nintedanib and pirfenidone (alphabetical order—don't infer anything) are FDA approved for the treatment of idiopathic pulmonary fibrosis (IPF). We've spent some page space on this blog talking about all the different forms of pulmonary fibrosis (PF) and how one arrives at a diagnosis of IPF. We've tried to convey the nuance involved in the diagnostic process and the fact that in the PF world, there is far more gray than black or white.

Many of my patients with non-IPF pulmonary fibrosis have shared with me their frustration around the fact that these drugs are not available to them. I've told them to hang in there; there are studies in the works to examine whether these drugs are effective for non-IPF pulmonary fibrosis.

The other thing to realize about nintedanib and pirfenidone is that they DO NOT CURE IPF. On average, they don't halt progression. I'm not trying to dash anyone's hope—David Lederer reminds us on his blog page that "no one is average"—but I do think it's important to know the data and be realistic about expectations if you start taking either drug.

One of the shortcomings of trials (many trials, not just the ones for nintedanib and pirfenidone) is that we often have no data on how patients were doing before they enrolled. We don't know if patients in either trial were declining (some likely were) or entirely stable (some likely were). I believe it's particularly challenging to discuss treatment options in patients who have been entirely stable for several months. Some docs might frame the discussion like this: I expect this disease to worsen at some point. I don't know when. I would "prefer" my patients take one of these drugs, because maybe it will "keep them stable longer." Other docs might lean away from therapy until there is evidence of progression by some clinical parameter (e.g., the patient says s/he's getting worse, declining FVC, declining DLCO, etc.).

In terms of efficacy, most people view the trial results as entirely overlapping: each drug slowed progression to a similar degree…

Please click here to read the full blog post written by Dr. Swigris.

Website Update

Thank you everyone for your support during the transition of our website from our old web platform onto the National Jewish Health server. We know there were a few kinks that needed to be worked out, but we believe everything is now running smoothly. Don't forget to check out both our blog and forum. **Also, if you have ideas or thoughts on subjects for blog posts, feel free to email the team at support@pfresearch.org to share your ideas!**