

Pulmonary Fibrosis
FOUNDATION

support group
leader network

PFF Celebrates One Year on Inspire.com

The Pulmonary Fibrosis Foundation (PFF) launched the Inspire PFF online support communities on May 15, 2012. Since then our membership has grown to over 2,000 members on the patient and caregiver communities!

Our caregiver group has 820 members from 50 US States and 31 countries and our patient group has grown to 1400 members from all 50 US States and 46 countries. The pulmonary fibrosis (PF) community is sharing much needed information about PF on every single continent (except Antarctica)! The PFF is privileged to help facilitate an online community that encourages PF patients and caregivers to connect with those facing similar experiences and challenges.

Thank you for encouraging your local support group members to join and help in making these online communities successful.

What Inspire members are saying:

"Thank you so much. This site is providing support and education in learning more about IPF. Thank you for making this site possible."

"Thank you...my father has pulmonary fibrosis and it helps just knowing there are people out there who care."

The PFF and RareConnect are supporting IPF patients globally!



The Pulmonary Fibrosis Foundation has partnered with the European Organization for Rare Diseases (EURODIS) and the National Organization for Rare Disorders (NORD) to connect patients with rare diseases globally. Join the new online community for patients with IPF at [RareConnect](#) and connect with others that suffer from idiopathic pulmonary fibrosis and other rare lung diseases. This new online community provides members the ability to easily communicate with others globally; members may post in English, German, Spanish, French, or Italian. To translate a post that is not in your native language, simply select "request to translate."

The Pulmonary Fibrosis Foundation has partnered with the European Organization for Rare Diseases (EURODIS) and

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Leanne Storch Support Group Fund 2013 Cycle Opens

Named for the Foundation's former Executive Director, who was diagnosed with the pulmonary fibrosis in 2003, the Leanne Storch Support Group Fund honors Leanne's continued passion for supporting those affected by pulmonary fibrosis.

Support groups may apply for awards of up to \$500 per award year. Funds may be utilized for speaker honorariums or travel expenses, meeting space rental, audio-visual equipment, and the printing of educational materials. **There are eight \$500 awards available in 2013.**

Applications will be reviewed and graded by at least 2 members of the PFF senior management team. Funding decisions will be made on quality of the meeting plan, expertise of faculty within the topics of the agenda, and cost effectiveness of the proposed budget.

Scoring Criteria

1. Do the topics within the agenda meet the needs of the PF community?
2. Does the proposal have a well-formed meeting plan?
3. Are the experts within the field and topic in which they are presenting?
4. Is the budget reasonable for programming provided and cost effective?

Each of the criteria will be scored on a scale of 0 - 5:

- 0 - 1 points = below minimum requirements
- 2 - 3 points = meets minimum requirements
- 4 - 5 points = exceeds minimum requirements

Total possible points = 20

Those groups that meet or exceed the minimum requirements are eligible to receive funding.

Below minimum requirements: 0 - 9

Meets minimum requirements: 10 - 15

Exceeds minimum requirements: 16 - 20

Apply for your 2013 Leanne Storch Support Group Award by September 1, 2013

Support Group Leader Resources

The Pulmonary Fibrosis Foundation (PFF) is dedicated to assisting the pulmonary fibrosis (PF) support group community as well as aiding in the establishment of new PF local and online support

groups globally. We understand that many times invested individuals lack the necessary resources to develop new groups, support established groups, or hold meaningful educational events for support group members and their families. The materials listed below are available to all Support Group Leaders and we encourage you to utilize the resources best suited to your support group's needs. We have recently added all the PFF Support Group Leader Network information to our website so you will have access to the slides from our quarterly conference calls, as well as the e-newsletters that are full of tips and best practices for your support group.

Support Group Leader Network eNewsletters

October 2012
April 2013

Slides from Quarterly Conference Calls

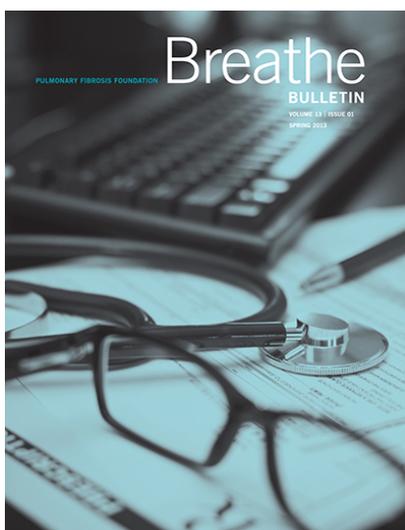
August 2012
December 2012

April 2013

2013 Meeting Schedule

- Monday, July 29, 2013, at 2:00 p.m. CDT
- Either Monday, September 23rd or Monday, October 7th at 2:00 p.m. CDT
- Support Group Leader Workshop meeting at the *PFF Summit 2013*, Friday, December 6th at 4:00 p.m.

Spring 2013 Breathe Bulletin Now Available



The Spring 2013 issue includes articles on the importance of a PFF Pulmonary Fibrosis Registry and Care Center Network, as well as information about the upcoming *PFF Summit: From Bench to Bedside*.

Read **online** or email Courtney Firak, Support Services Coordinator, at cfirak@pulmonaryfibrosis.org to request hard copies for your support group.

PFF Summit 2013 - Register Today!



register now

HYATT REGENCY LA JOLLA AT AVENTINE
LA JOLLA, CALIFORNIA
DECEMBER 5-7, 2013

visit
www.pffsummit.org

PFF
SUMMIT
FROM BENCH TO BEDSIDE 2013

PRESENTED BY Pulmonary Fibrosis
FOUNDATION

CERTIFIED BY National Jewish
Health*

Thank you to our Everest Sponsors:



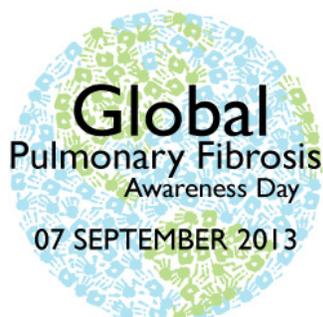
For more information and to register:

www.pffsummit.org

or call 888.733.6741 or +1 312.587.9272.

Early bird registration ends on June 30, 2013.

Global Pulmonary Fibrosis Awareness Day



The PFF is encouraging our Support Group Leader Network to participate in **Global Pulmonary Fibrosis Awareness Day** on Saturday, September 7, 2013. Here are several ways for your support group to get involved on this important day:

- Show the webinars from Global Pulmonary Fibrosis Awareness Day 2012, available **online** or contact Courtney

Firak at cfirak@pulmonaryfibrosis.org for a DVD.

- If there is another support group near you, you can combine the groups and plan a full day of educational and social activities for your members. The work for planning the day could be split between the support group leaders.
- Ask your support group members to invite a guest or two to learn about pulmonary fibrosis.
- Plan a social event for your group where you will venture out into your community to spread awareness.

However you decide to celebrate the day with your support group members, please be sure to take a lot of pictures and share them with the PFF.

Recruiting Support Group Members

Promoting your support group can be a challenge whether you are just starting out or looking to grow your membership. There are a variety of ways that you can promote your group to make sure recently diagnosed patients and their families are aware of the opportunity to interact with other PF patients and caregivers:

- **Utilize local hospitals, pulmonary rehab centers, and physicians' offices to promote your group; provide them with a flyer and/or brochures with details about your meeting**
 - Marcy from the Piedmont Hospital group in Atlanta used the respiratory therapy department to promote her group and found that aligning with a medical institution really helped drive her membership
 - Even if your group is not located at, or affiliated with, a medical institution, you can still utilize your local pulmonary departments to advertise your group
- **Many support group leaders of established groups have found word of mouth to be a great promoter**
 - Anne from the Hershey, PA, IPF support group has found success through physician recommendations, as well as word of mouth at pulmonary rehab programs
- **Utilize Facebook and other social media to promote your group**
 - Laura from the newly established Boise, ID support group has been actively promoting her group on the PFF's Facebook page, as well as creating her own

Facebook page for her group

- The groups in Minnesota and San Antonio also have their own pages for their support groups
- **Contact your local newspaper to be included in their health calendar**
 - Jane from the Falls Church, VA, IPF support group has promoted her group using her local newspaper's health calendar. These listings are usually free and they can post the information a week before the event.
 - In addition to newspaper's health calendars, contact the local chambers of commerce and senior centers in your city to post your group's information
- **Finally, remember to communicate with the PFF's Patient Services team so we can post the information on our website and utilize our online support communities to help you promote your group.**

Courtney's Corner

Medicare's Competitive Billing Program

July 1, 2013, marks the expansion of Medicare's Competitive Bidding Program (CBP) from nine service areas to 100 service areas. This expansion may affect users of supplemental oxygen in a variety of ways and you may get questions from your support group members. Below is some background on the program, as well as the potential effects to individuals who utilize supplemental oxygen.

Medicare established the Competitive Bidding Program (CBP) in 2011 in nine metropolitan areas as a way to limit the amount of contract suppliers that can supply durable medical equipment, prosthetics, orthotics, and supplies (DMEPOS). This was done in an effort to set appropriate reimbursement amounts for these items, as well as limit the out-of-pocket expenses for Medicare beneficiaries.

The CBP is now expanding to 91 new service areas beginning on July 1, 2013. Suppliers in these 91 areas were able to submit a bid to be a CBP supplier, or to "grandfather" their current users into the program, until their contracts expire; this is only for supplemental oxygen users because the equipment is actually rented from the supplier. The contract suppliers were notified about whether their bids were approved earlier this year. To find a CBP contract supplier in your area, please visit the [directory](#).

The Effect of CBP on Supplemental Oxygen Users

1. If you do *not* live in one of the CBP areas, there should be no changes with your oxygen supply company.

2. If you *do* live in one of the expanded CBP areas and your supply company was offered a CBP bid, your service should *not* be affected. It may be affected if you are utilizing liquid oxygen (see "The Effect on Liquid Oxygen Users" below).
3. If you *do* live in one of the expanded CBP areas and your oxygen supply company was *not* offered a CBP bid, but you are currently in the rental period for your oxygen equipment (the first 36 months), then it may be possible for you to continue with your current supplier if they elected to become a "grandfathered" supplier.
 - o This means the current supplier can continue to rent and service your existing equipment if you were renting from them before July 1, 2013.
 - o If you rent additional equipment, Medicare will not pay for this equipment.
 - o After your rental period has ended, you will need to find a new CBP approved supplier.
4. If your rental period has ended, you are a new oxygen user, or your supplier did not elect to become a grandfathered supplier, then you will have to choose a new CBP approved oxygen supplier.
 - o Your current supplier may have already informed you in writing of this change. Utilize the [directory](#) to search for a new approved supplier in your area.

The Effect on Liquid Oxygen Users

In addition to the 2% reduction to Medicare's fee-for-service claim payments that went into effect on April 1, 2013, as a result of the across the board sequestration cuts, the expansion of the CBP comes with a 45% cut in reimbursements. Additionally, only 799 DMEPOS providers will be contracted to supply all Medicare beneficiaries in the 91 new communities reducing the choices beneficiaries have for their needed medical equipment. Suppliers who previously offered liquid oxygen may no longer carry these products because the suppliers are losing a significant amount of revenue from their Medicare reimbursements. Liquid oxygen users require more frequent delivery and service calls than users of home concentrators and E-tanks cylinders.

What Can Support Group Members Do?

If you are a liquid oxygen user:

A supplier cannot refuse to provide you with liquid oxygen when the prescription from your physician specifically prescribes liquid oxygen, rather than just supplemental oxygen in general. They either

have to transfer your prescription to another provider, or supply the liquid oxygen themselves. However, this may cost you more out-of-pocket so be sure to discuss all your options with your current supplier.

If you are having any issues accessing your home medical equipment:

1. Call the Medicare Helpline at 1.800.Medicare. This is a 24/7 helpline with information available in English and Spanish. To speak to an agent immediately after calling, dial '0' or say "agent" and you will be connected to a person.
2. The COPD Foundation has created an Infoline to track any and all complaints about accessing your home oxygen and/or liquid oxygen through the new expanded Competitive Bidding Program. Call 1.866.316.2673 to report the complaint and they will direct you to the Centers for Medicare and Medicaid Services (CMS) to officially file a complaint. The COPD Foundation Infoline is collecting data from anyone who files an official complaint to the CMS in order to advocate for policy changes that will ensure continued access to quality home medical equipment. The COPD Foundation has extended this service to the PF community, even if you have not been diagnosed with COPD.
3. Speak to a staff member at your Congressional member's local field office. You can find the local contact information for your district's representatives at: [Senate](#) or [House of Representatives](#)

Sources

1. Centers for Medicare & Medicaid. "What You Should Know if You Need Medicare-covered Equipment or Supplies." Accessed May 20, 2013, [Available at website](#)
2. COPD Foundation. "Competitive Bidding Fact Sheet."
3. Michael Dorris, Congressional Outreach Liaison at National Government Services. Personal interview at Elmhurst support group. May 30, 2013
4. Alpha-1 Foundation, "Alpha-1, COPD patients fear losing liquid oxygen with Medicare competitive bidding." Accessed May 20, 2013, [Available at website](#)
5. Aimee Balthuis, Assistant Director of Public Policy and Advocacy at COPD Foundation. Personal phone call. May 29, 2013.

Mark Your Calendars

The next Support Group Leader Network Teleconference is scheduled for **Monday, July 29 at 2:00 p.m. CDT.**

Please email Courtney Firak, Support Services Coordinator, at cfirak@pulmonaryfibrosis.org with any feedback, questions, or discussion topic suggestions for future meetings.

About the Pulmonary Fibrosis Foundation

The mission of the Pulmonary Fibrosis Foundation (PFF) is to help find a cure for idiopathic pulmonary fibrosis (IPF), advocate for the pulmonary fibrosis community, promote disease awareness, and provide a compassionate environment for patients and their families. The PFF collaborates with physicians, organizations, patients, and caregivers worldwide. December 1-3, 2011, the PFF hosted its first biennial international scientific conference, *IPF Summit 2011: From Bench to Bedside*, in Chicago; *PFF Summit 2013* will be held December 5-7, 2013, in La Jolla, California. For more information visit www.pulmonaryfibrosis.org or call 888.733.6741.

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