

Pulmonary Fibrosis
FOUNDATION

support group
leader network

Dear Support Group Leaders,

Please accept my heartfelt thanks for your continued efforts in supporting the PF community, the Pulmonary Fibrosis Foundation (PFF) and our initiatives. It is through continued collaborative efforts that we will enhance and grow the resources available to the PF community.

This newsletter will summarize information shared during our first face-to-face support group leader meeting in La Jolla, California, as well as provide additional information on resources that we hope to benefit you and your support group members.

We were so very pleased that many of you were able to attend the *PFF Summit 2013* and want to thank you for your participation. Your feedback is important to improving our programming; please feel free to contact us with suggestions and comments.

Earlier this month we announced two key additions to the PFF staff. Gregory P. Cosgrove, MD, has been named Chief Medical Officer and Kevin R. Flaherty, MD, MS, has been named Chairman of the Steering Committee of the PFF Care Center Network and PFF Patient Registry. We are pleased to expand our team with these recognized leaders in the pulmonary fibrosis community.

The Patient Services team looks forward to continuing to work with you to strengthen and grow the PFF Support Group Network in 2014.

Sincerely,

Dolly Kervitsky, RCP, CCRC
Vice President, Patient Relations and Medical Affairs

BREAKING NEWS!

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Latest News

2/25 InterMune Reports Phase 3 ASCEND Trial Results of Pirfenidone in Idiopathic Pulmonary Fibrosis (IPF) >

2/10 Burn Pits and Post-Iraq Lung Disease - PFF Comment >

2/4 Pulmonary Fibrosis Foundation Expands with Two New Leadership Positions >

[MORE NEWS >](#)

"Data presented today from the InterMune-sponsored ASCEND trial demonstrates efficacy and safety of pirfenidone in the treatment of patients with idiopathic pulmonary fibrosis. The identification of a treatment for patients with IPF is of paramount importance to all those affected

by this devastating disease. We believe it is a major step forward

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toward identifying a cure for pulmonary fibrosis and enhancing the lives of those in the pulmonary fibrosis community."-- **Gregory P. Cosgrove, MD, PFF Chief Medical Officer**



InterMune Reports Phase 3 ASCEND Trial Results of Pirfenidone in Idiopathic Pulmonary Fibrosis (IPF)

Since 2001, over 2 million United States military men and women have deployed as part of Operation Iraqi Freedom and Operation Enduring Freedom. In the past few years, evidence has emerged that U.S. military personnel who have deployed to Iraq and Afghanistan may be at increased risk for developing lung symptoms and, in some cases, disabling chronic lung diseases including asthma, constrictive bronchiolitis and based on information presented at the American Thoracic Society in 2012 a fibrotic lung disease similar to idiopathic pulmonary fibrosis (IPF).

Vet's post-Iraq lung disease fuels burn pit discussion: Operation Iraqi Freedom veteran Will Thompson came back with severe lung complications

PFF SUMMIT 2013: A RECAP

An Environment to Improve Education, Facilitate Research, and Increase Disease Awareness

The *PFF Summit* brought together 520 medical professionals, patients, and caregivers from 16 countries to collaborate, educate, and inspire one another. Scientific sessions for professionals, included presentations on lung injury and repair, genetics and biomarkers, and drug development. Topics discussed during the clinical sessions included: difficulties in making a confident diagnosis, available treatment options, how to treat co-morbidities, and effectively communicating with patients and caregivers. The program for patients, family members, and caregivers addressed their educational needs as well a discussion on how to live better with pulmonary fibrosis.

All recorded sessions are available on the [PFF Summit website](#).

[View the Professional Sessions](#)
[View the Patient & Caregiver Sessions](#)

We look forward to seeing you all at *PFF Summit 2015*, November 12-14, 2015, location to be announced later this year!

ANNOUNCING THE PFF CARE CENTER NETWORK & PFF PATIENT REGISTRY

At the *PFF Summit 2013* the Foundation announced its plans to establish the PFF Care Center Network (CCN) and the PFF Patient Registry. These initiatives will improve the health and quality of life

of patients suffering from pulmonary fibrosis and provide the medical research community with critical insights to assist in developing effective therapies.



[Learn More About the PFF Care Center Network](#)

[Learn More About the PFF Patient Registry](#)

[Read Full Press Release](#)

APPLICATION TO BECOME A PFF CARE CENTER NETWORK SITE

The PFF will begin accepting applications to join the PFF Care Center Network on May 15, 2014. To learn more about the application process, please contact Lisa Barker at CCN@pulmonaryfibrosis.org.

PFF PATIENT AMBASSADOR PROGRAM

The Patient Services team is currently creating a PFF Ambassador Program with the generous support of InterMune. PFF Ambassadors will be trained to share their story (patients and caregivers) or medical information (professionals) at events, educational meetings, support group meetings, video productions, and documentaries. Ambassadors may also form teams where Patient and Professional Ambassadors will share their experience and expertise collaboratively. [SNOW Companies](#), an industry leader in creating disease related patient ambassador programs, will conduct ambassador training in April 2014.

If you have a patient and or caregiver in your group that would like to become a PFF Patient or Caregiver Ambassador please have them contact SNOW Companies by phone at 1.855.292.1531 or via email at IPFAmbassadors@snow-companies.com.

SAVE THE DATE!

Global Pulmonary Fibrosis Awareness Month

September 2014

The PFF will celebrate Global Pulmonary Fibrosis Awareness for the entire month of September in



2014. Mark your calendars! More information will be coming about how you and your support group members can get involved and *let the world know about PF.*

EXPANDED LEANNE STORCH SUPPORT GROUP FUND PROGRAM

2014 Cycle Opens April 1, 2014

The PFF is pleased to announce the opening of the 2014 grant cycle where we will be offering eighteen (18) \$500 grant awards. These grant funds may be utilized by the awardee to establish a new pulmonary fibrosis support group, host an educational event, or defray the expenses of running a monthly or quarterly support group, including printing costs for educational materials, refreshments, location requirements, and/or speaker fees. The PFF will accept applications for the Leanne Storch Support Group Fund Grants between April 1 and August 1, 2014. The selected awardees will be announced during Global Pulmonary Fibrosis Awareness Month in September 2014.

SUPPORT GROUP LEADER NETWORK ANNOUNCEMENTS



As a thank you to the members of the PFF Support Group Leader Network, we are offering a 25% discount on all items in Shop PFF. You can stock up on Breathe Bracelets for your support group or pick up a PFF t-shirt, iPhone 4

case, or awareness car magnet for yourself. Check [Shop PFF](#) and use the promo code: **LEADER2014** at checkout.

Additionally, please check your support group listing on the PFF [website](#) and let the patient services team know if any changes are needed. Call 888.733.6741 or email Courtney Firak at cfirak@pulmonaryfibrosis.org with any changes.

COURTNEY'S CORNER:

Dr. Molly Bourne's talk at the PFF Summit

Many of you have remarked on how difficult it is to discuss palliative care and hospice topics during your meetings. In response to your concerns, we invited Dr. Molly Bourne from Hospice by the Bay to present on these important issues during the *PFF Summit* on December 5, 2013. Dr. Bourne provided excellent suggestions on

how to discuss these topics with your groups. Below are some highlights of her presentation, also, be sure to check out the [webinar](#) of her talk during the patient and caregiver session, "The Final Stages of Pulmonary Disease."

General Information

- Patients with advanced lung disease live on average 9 months longer when utilizing hospice services.
- People's fears about death are not usually well articulated, so it is important to utilize every opportunity to discuss the topic.
- 5 main fears about death & dying
 - Am I going to miss out on important events? What do I really want to do before I die?
 - Am I going to die alone?
 - Am I going to be in pain?
 - Will I be lucid? I don't want to die confused.
 - Will I feel like I'm suffocating or drowning?
- You can use these fears to help people figure out what they can control and what is possible to accomplish before they die.
 - For example, consider the question "Am I going to miss out on important events?" It may be impossible for the person to see their grandchild graduate from high school but they can write them a letter to be given to them on graduation day.

How to work with HIPAA

- HIPAA laws **do** survive the patient, however his/her durable Power of Attorney (POA) can give permission to tell the group members of the loved one's death.
- You can invite the spouse and/or other family members to the support group.
- You can ask the POA to write a statement to read to the support group.

What you can do in your support group

- Incorporate an annual ritual to honor or remember those that have passed and invite family members to the group to share their memories.
 - This ritual will send a message to other members of the group that they will remain important and thought of even after they pass away. They will be remembered.
- At each meeting you could incorporate a ritual to honor or recognize those that have passed by reading a poem, having a moment of silence, or incorporating something meaningful to your group.
- Several of you remarked that when hospice or end of life care is the topic, the attendance is much lower than normal. However, after the session people are always glad to have heard the information. Some solutions to this are:
 - To utilize one of your members to raise the topic and gauge the interest of the group.

- Do not use "end of life" or "hospice" in the topic, substitute other language to make the topic more appealing.
- Utilize an event, like National Healthcare Decisions Day on April 16th to lead the discussion. To learn more about this program, please visit their [website](#).

Overall, it is important to remember that you are not expected to be an expert on the topic of end of life care, so invite speakers to cover what you may not know. It is an important topic to cover with your support group. One of the support group leader attendees compared presenting hospice information to the presentation of oxygen therapy information and remarked, "Not discussing oxygen with your group would be considered negligent."

MARK YOUR CALENDARS

2014 Support Group Leader Teleconference Schedule

Monday, March 24, 2014

Monday, July 21, 2014

Monday, October 20, 2014

Monday, December 15, 2014

All calls are from 2:00 p.m. to 3:00 p.m. CST.

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. *PFF Summit 2015: From Bench to Beside*, the PFF's third biennial international scientific conference, will be held November 12-14, 2015. For more information visit www.pulmonaryfibrosis.org or call 888.733.6741 or +1 312.587.9272 from outside of the US.

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