

# Pulmonary Fibrosis

## FOUNDATION

## Support Group Leader Network Newsletter

### Dear Support Group Leader,

I would like to express my gratitude for your efforts in making the PFF Support Group Community stronger. Your dedication and participation in the PF Support Community is instrumental in making support groups an invaluable resource for patients and family members. Working together I know we can greatly enhance our member's quality of life through the development and implementation of a robust and coordinated support group program. The PFF Support Group Leader Network has been developed with this goal in mind, and we hope that you find the network to be a source of support, sharing tips and best practices through our PFF-facilitated quarterly conference calls and e-newsletters. Participation in our first teleconference held on August 27, 2012 was terrific, with many of you sharing your experiences and ideas for meetings and support for patients and families. This first e-newsletter will summarize information shared during this meeting, as well as provide additional information on resources that we hope to be a benefit to you and your support group members.

Thank you again for your participation, it is our hope that these meetings will assist you in making your groups more successful.

Looking forward to working with you to strengthen the PFF Support Group Leader Network.

Sincerely,

Dolly Kervitsky, RCP,CCRC  
Vice President, Patient Relations

## ABOUT THE PFF SUPPORT GROUP LEADER NETWORK

### *Local Support Groups*

Local or "in-person" support group information is listed by state and country on the PFF website at [www.pulmonaryfibrosis.org/supportgroups/local](http://www.pulmonaryfibrosis.org/supportgroups/local).

If you would like to update your listing, please contact Courtney Firak, Support Services Coordinator, at 312.854.1940 or [cfirak@pulmonaryfibrosis.org](mailto:cfirak@pulmonaryfibrosis.org).

### *Online Support Community on Inspire.com*

Everyday more patients and caregivers sign up to be a part of the [Pulmonary Fibrosis Foundation's online support community](#). While the "patient" group is primarily intended for pulmonary fibrosis patients, you are not prohibited from joining and as discussed, being informed about what topics are being discussed in this forum may give support group leaders an opportunity to learn about issues important to support group members. There is also a support group for caregivers that we invite you to join.

To Join the PFF Online Caregiver or Patient Community  
<http://www.pulmonaryfibrosis.org/supportgroups/online>

### *PFF Remote Support Group Network*

The PFF believes access to support groups should be available to everyone, regardless of location or technological know-how, and we are pleased to offer the *PFF Remote Support Group Network*. This network will allow patients and family members the opportunity to participate in a professionally led support group virtually, by phone, or computer connection. Many support group leaders have expressed an interest in learning more about how to facilitate remote meetings, we will update the network as our test group in Denver, Colorado discovers the best practices for this process.

### ***Leanne Storch Support Group Fund Awards***

Named for the Foundation's former Executive Director, Leanne Storch, diagnosed with the disease in 2003, the *Leanne Storch Support Group Fund* honors Leanne's continued passion for supporting those affected by pulmonary fibrosis. Groups may apply for awards of up to \$500 per award year, and funds may be used towards meeting educational programming, educational materials, or location requirements.

The 2012-2013 Awardees were formally announced at the Pulmonary Fibrosis Foundation's *Breathe Benefit 2012: Community Inspiring a Cure* on October 13, 2012 in Chicago, IL at The Drake Hotel.

Congratulations to our winners!

University of Pittsburgh Dorothy P. & Richard P. Simmons Center for Interstitial Lung Disease at UPMC Support Group  
"Stem Cell Research & IPF" meeting on November 5, 2012  
Awarded to Support Group Leader: Dr. Kathleen Lindell

Eastern Idaho Pulmonary Fibrosis Support Group  
Eastern Idaho Regional Medical Center  
2012 and 2013 Support Group Meetings & Newsletters  
Awarded to Support Group Leader: Myrna Taylor

Minnesota Pulmonary Fibrosis Support Group in conjunction with The University of Minnesota Pulmonary Fibrosis Patient Education Day October 6, 2012  
Awarded to: Dr. Hyan Kim and Mel Bors, RN, BSN, MA Care Coordinator ILD, submitted by Paul Fogelberg

IPF Support Group of Montgomery  
Baptist Medical Center South  
"Acute Respiratory Failure, Mechanical Ventilation, and ICU Admission: The Implications"  
March 2013 meeting  
Awarded to Support Group Leader: Dr. Maryluz Fuentes

Edwards Hospital Pulmonary Fibrosis Support Group  
Edwards Hospital, Naperville, IL  
"Massage Therapy and Nutrition for Pulmonary Fibrosis Patients" meeting  
Awarded to Support Group Leader: Donna Serlin, RRT

Pulmonary Fibrosis Support Group in San Antonio  
Church Triumphant Church Hall, San Antonio, TX  
2012 and 2013 Support Group Meetings  
Awarded to: Dr. Anoop Nambiar

*Applications for the 2013 funding cycle will start being accepted by the PFF on May 1, 2013.*

## **Discussion Topics**

### ***Physician Supported Groups***

There are many groups that have a physician or health care professional associated with their

group but there remain groups that are without professional support. The importance of having a medical professional available to answer questions or to serve as a resource for accurate and up-to-date medical information is important to a successful group. For those groups without professional support the discussion included suggestions for locating a medical professional to associate with their group. It was suggested that allied health professionals and respiratory therapists associated with medical and pulmonary rehabilitation centers may be available and willing to act either as a group facilitator, or assist patient or family member co-lead groups. These professionals can assist in providing meeting space, providing accurate up-to-date medical information, making presentations to the group, and assist in arranging professional speakers. Contact the patient services team at the PFF for assistance in connecting your group to a medical institution, physician, nurse, or other health care professional.

### ***Clinical Trials and Research***

Clinical trials and research was an important topic of discussion, and while the discussion covered different facets of this topic, getting the most accurate and up-to-date information to support group members was considered most important to everyone. How to discuss the benefits of participation in clinical trials was also discussed. The following were points that many support group members and leaders felt to be important benefits of participating in a clinical trial:

- Assisting the medical community in finding a treatment
- Frequent follow up and better overall attention from an expert in PF
- Playing an active role in their own healthcare
- Gaining access to experimental therapy

Utilizing clinical research coordinators to present information to SG members can be helpful in providing a more complete perspective of clinical trials. Navigating members through the clinical trials website ([www.clinicaltrials.gov](http://www.clinicaltrials.gov)) to find trials in the local area that are recruiting participants, and explain how to sign up is also helpful to SG members.

### ***Publications***

Discussing published research journal articles with SG members was considered important to SG leaders and members. Many pulmonary fibrosis patients and their families are interested in current research and clinical trials being performed and their results.

### ***Research Trials and Stem Cell Therapy***

There is a lack of general knowledge about stem cells and if stem cell therapies that are advertised are FDA approved. It was noted that there seems to be very few, if any open trials for investigating stem cell therapy in the USA. Many questioned why there is a disparity between the USA and other countries in the area of stem cell research.

To meet the needs of Support Group Leaders and patients, the PFF plans to organize an educational webinar to answer many of the basic questions about stem cells and the potential for the development of therapies to treat PF. More information will be provided as it becomes available.

The University of Pittsburgh Dorothy P. & Richard P. Simmons Center for Interstitial Lung Disease at UPMC Support Group will cover the topic of stem cells during their November 2012 meeting.

#### ***PFF Comment on the use of Stem Cells for treating PF, Dolly Kervitsky***

The use of stem cells for treating lung diseases has great appeal. As we learn more about the therapeutic potential of stem cells and other cell therapies in clinical trials of non-lung diseases, we hope to move towards further consideration of these approaches in lung diseases such as PF.

There is very little known about the short and long-term effects of administering any type of stem cell therapy to patients with lung diseases in general. Until research provides the medical community with additional information, we must be concerned that the treatment could cause adverse effects and could worsen the patient's condition rather than improve it.

At present, there have only a small number of approved clinical trials in the United States, Europe, Australia, and Canada investigating cell therapy approaches for lung diseases. These can be found on the website of the National Institutes of Health at [www.clinicaltrials.gov](http://www.clinicaltrials.gov). We are hopeful that there will be more in the future.

You may come across information on the internet or other sources about stem cells being administered to patients with lung diseases, such as emphysema, pulmonary hypertension, and pulmonary fibrosis. These trials may be listed as occurring either in the US or in other countries. We **strongly** caution all patients that the claims of benefit being made by many of these programs have not been substantiated, nor have they been reviewed by experts in the field or any regulatory agency. Because of the potential for harm, the lack of any proven benefit, and the high fees that many of these programs charge, we strongly caution you not to participate in these or any other comparable unauthorized or unapproved stem cell administrations, unless independent, credible, reliable, and objective sources of information are available to substantiate the information and claims being made.

One such reliable source of information and scrutiny, endorsed by the American Thoracic Society, is the International Society for Stem Cell Research (ISSCR), which has developed an excellent web-based resource that includes the [ISSCR Patient Handbook](#). We recommend reading this website, which also provides mechanisms for monitoring or substantiating the claims being made by various organizations that claim to offer 'stem cell therapies'.

Please visit The International Society for Stem Cell Research [website](#) to learn more about stem cell research.

### ***Hospice & Palliative Care***

While hospice and palliative care can be a sensitive topic of discussion, understanding the benefits of hospice and palliative care is extremely valuable for patients and family members. Some support group leaders mentioned that they have received quite a bit of pushback from members when they mention covering this topic in a group setting. It was suggested that by identifying patients and family members who have had a positive experience with these services to speak to the group about their experience would make the topic better received. It was also recommended that including this topic within a meeting about lung transplantation may make the topic easier to introduce. Another suggestion was to title the topic as "Dispelling the Myths of Hospice and Palliative Care," so SG members can articulate what they may have heard, and then have a presentation with accurate facts.

### ***Support Group Mailing Lists***

Joining other support group mailing lists provides an opportunity to see how other groups communicate with their members, receiving emails and newsletters that each group provides to their membership. If you would like to add support group leaders to your mailing lists, please contact Courtney Firak at [cfirak@pulmonaryfibrosis.org](mailto:cfirak@pulmonaryfibrosis.org).

### ***Support Group Member Requests***

Listening to what SG members want to learn is incredibly important when planning meetings. Some SG members have expressed they would like to have more discussions and fewer formal presentations; allowing time to talk about the issues they face living day-to-day with pulmonary fibrosis. Also many SG Leaders noted professional speakers who can articulate their presenting information to members at a level where everyone can understand the topic is very important. Groups can be diverse and communication at a level of understanding for a broad patient audience is key to members getting the full benefit of the presentation.

Providing a survey for member feedback is a great way to figure out what topics are important to SG members and can provide assistance in planning future meetings. It was suggested that by making the survey anonymous, SG members may not be embarrassed to ask about something they may think they should already know. This is especially important when newly diagnosed patients come into the group, as it is always difficult to learn the abbreviations and medical terms used. Most everyone agreed that members are open to hearing some topics repeated

more frequently. [Click here for a sample survey that you can use.](#)

Social events are also important for SG members. A summer picnic or a holiday party at the end of the year is a terrific way to get support group members out of their normal routine and focus on something besides their PF.

## **"Courtney's Corner" Patient Support Resources**

### ***National Institutes of Health "Clinical Research and You" website***

[www.nih.gov/health/clinicaltrials/index.htm](http://www.nih.gov/health/clinicaltrials/index.htm)

This website has the most comprehensive information on clinical trials that I have come across. There is a question and answer section which covers basic questions about clinical trials like "What is clinical research" and "What do I need to know if I am thinking about participating?" The answers are explained in such a way that if you did not have previous knowledge of clinical research, you could easily grasp the information. It also includes personal stories and patient testimonies, a glossary of common terms, and educational resources. You can click on "[Finding a clinical trial](#)" for a few different websites to search clinical trials recruiting in your area.

### ***Local Area Agencies on Aging***

This is a wonderful resource I find myself utilizing over and over when I receive questions about local services for patients and their families, and I may take for granted people know about these programs. Here's a little history:

Back in 1965, the Older Americans Act (OAA) was established by President Johnson because of a lack of community based social services for older adults. This act established the Administration on Aging (AoA) whose mission is "to develop a comprehensive coordinated and cost-effective system of home and community based services that helps elderly individuals maintain their health and independence in their homes and communities." Each state has a unit of the AoA which oversees the Area Agencies on Aging, as well as their Local Service Providers which are generally divided up by county, zip code, or parish.

The program was expanded in 2006 to include elder justice, elder abuse services, mental health, benefits counseling, healthy lifestyle programs, the National Family Caregiver Support Program, and expanded services for older adults with limited English proficiency. Each Local Service Provider has programs which could include case management, homemaker services, home delivered meals, adult day services, insurance counseling, caregiver support, health screenings, etc. While each local service provider receives federal funding through the OAA, many of them are charitable non-profit organizations so their range of services relies heavily on individual funding sources.

To find your local Area Agency on Aging, Google "Area Agency Aging" and your state. This will generally take you to your state's Department of Aging website and you can look up the local offices by county.

For example: Googling "Area Agency on Aging" and "Utah", led me to this website: [www.hsdaas.utah.gov](http://www.hsdaas.utah.gov), which then has a listing of all Local Service Providers in the state: [www.hsdaas.utah.gov/pdf/utah\\_area\\_agencies\\_on\\_aging.pdf](http://www.hsdaas.utah.gov/pdf/utah_area_agencies_on_aging.pdf).

I clicked on the first entry for the *Bear River Area Agency on Aging* ([www.brag.utah.gov/](http://www.brag.utah.gov/)) and can look on their website for contact information and what services they provide.

These agencies are also a great place to advertise your support group as many of them provides a community calendar of events which are of interest to the older adult population.

### ***Support Group Highlight***

For the upcoming e-newsletters, we would like to feature a support group and interview the

support group leader. If you are interested in having your support group featured, please email Courtney Firak at [cfirak@pulmonaryfibrosis.org](mailto:cfirak@pulmonaryfibrosis.org) for more details.

## Support Group Leader Network Teleconference Slides

Here are the slides from our first Support Group Leader Network Teleconference:

**[Slides from August 2012 Teleconference](#)**

## Save the Date

The next Support Group Leader Network Teleconference will be held on Monday December 3rd from 2pm to 3pm CST. More details to follow.

**[Forward this email](#)**



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