

# **2016 IPF Workshop hosted by the EU-IPFF**

**18-19 November 2016**

# Agenda

Day 2		
Time		Agenda item
9:00	10:45	<b><i>Session 4 - Working together – making the most of resources and tools</i></b>
<b>10:45</b>	<b>11:15</b>	<b><i>Coffee break</i></b>
11:30	12:30	<b><i>Session 5 - Working together – collaboration beyond EU-IPFF</i></b>
12.30	13.00	Concluding remarks (10') + questionnaire ( <i>interpreters/B-M help needed</i> )
<b>13:00</b>	<b>14:00</b>	<b><i>Lunch and goodbyes</i></b>

## *Working together – making the most of resources and tools*

# Setting the scene



# Setting the scene

**Can the EU-IPFF and other organisations work together to become greater than the sum of their parts?**



**Do tools, resources, projects and know-how exist amongst patients' organisations that others could benefit from?**

**Many challenges are common, and many tools are applicable from country to country**

**Is there anything to lose by pooling some resources?**

# Setting the scene

Each organisation has its own national challenges, but many similarities are found

Is it possible to develop or procure tools, resources or projects together?

Is it possible to directly translate tools, resources or projects produced in one country and use them in another?



# Setting the scene

Annual IPF workshop allows everyone to come together and take part in discussion

- Since November 2015, how many of you have spoken to each other?

Is cooperation across borders and across languages feasible?



# *Setting the scene*



**UK-Ireland-US-Canada?**

**France-Belgium?**

**Germany-Austria?**

**Spain-Latin America?**

# Setting the scene

What tools, resources, projects and know-how are available to organisations here today which they believe could be used by other organisations?



*Guest speaker*



***Patti Tuomey, PFF (US)***

# Pulmonary Fibrosis

## FOUNDATION

Patti Tuomey, EdD  
President and Chief Executive Officer

# Who We Are



## Our Mission

The Pulmonary Fibrosis Foundation mobilizes people and resources to provide access to high quality care and leads research for a cure so people with pulmonary fibrosis will live longer, healthier lives.

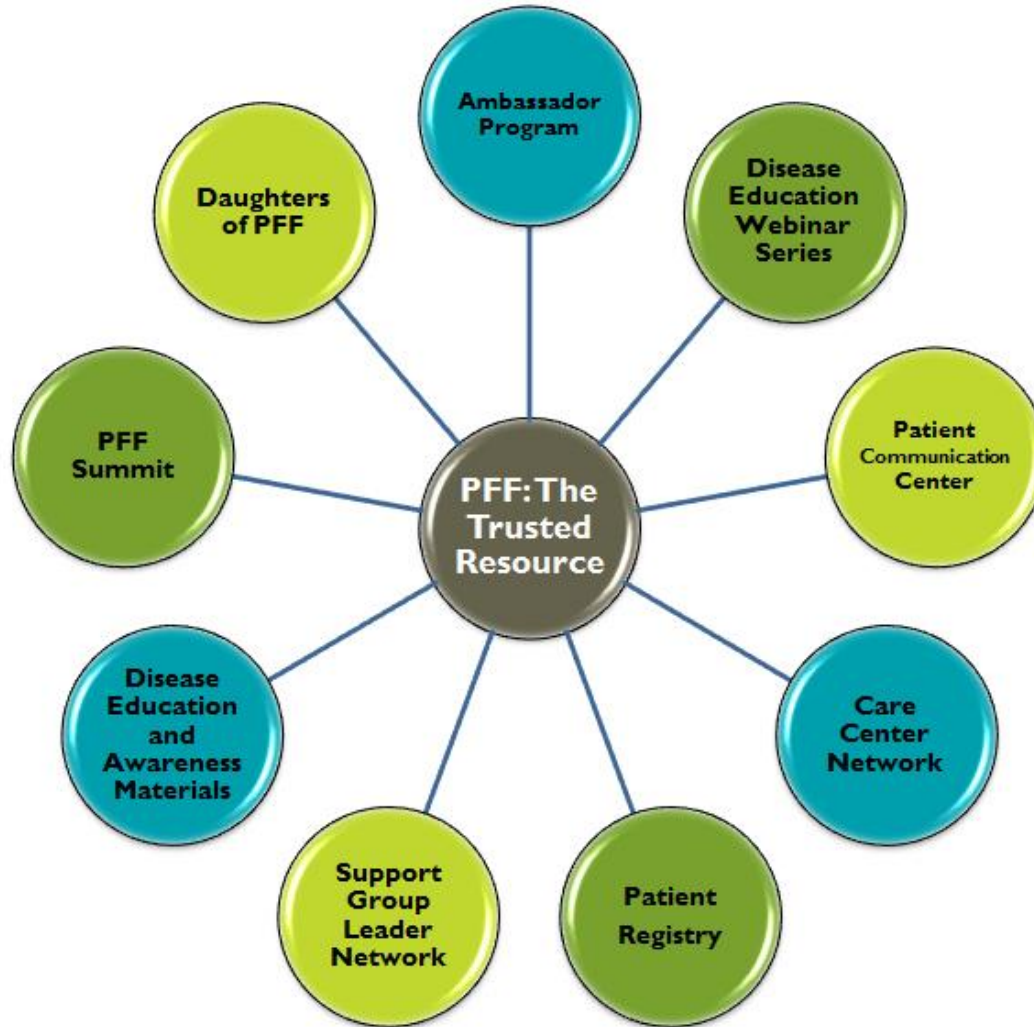
# Our Programs and Resources



The Pulmonary Fibrosis Foundation (PFF) engages with the pulmonary fibrosis community, like-minded organizations, donors and sponsors to both develop programs and provide resources for those affected by pulmonary fibrosis. These programs and resources aim to increase awareness of the disease, help those affected by the disease, and work toward finding a cure, and include:

- The PFF Care Center Network
- The PFF Patient Registry
- The Patient Communication Center
- Education Materials
- Webinars
- A Support Group Network
- Team PFF

# What Makes the PFF



# Care Center Network Sites

**EU-IPFF**  
EUROPEAN IDIOPATHIC PULMONARY FIBROSIS  
& RELATED DISORDERS FEDERATION



**78% of patients in MSAs are within 2 hours of a current site**

Note: 2 hour driving distance defined as 120 miles; analysis only includes population living within MSAs (86% of total US population), metropolitan statistical areas (MSAs) defined by the OMB include population centers with over 50K residents and their adjacent communities

Source: PFF, US Census Bureau

# Care Center Network



The PFF Care Center Network (CCN) is a growing group of medical centers that have experience and expertise in treating patients with fibrotic lung disease and are dedicated to improving the lives of those living with PF.

CCN sites provide necessary resources for patients to obtain medical expertise and specialized staff to fully manage their disease.

Experts, including those in pulmonary medicine, rheumatology, radiology and pathology, all specializing in interstitial lung disease, comprise the care team at each CCN site.

There are currently 40 CCN sites throughout the United States, with a CCN site no further than a 2-hour drive, which covers approximately 78% of the United States.

# *PFF Patient Registry*



The PFF Patient Registry was launched in March 2016 and is a collaborative effort to bring together multiple stakeholders including patients, health care providers, and researchers.

The PFF Patient Registry will help PFF Care Center Network sites develop effective treatment protocol and best practices for the management of pulmonary fibrosis. The Registry collects information on approximately 2000 patients suffering from IPF and PF who are seen at any of our participating Care Center Network sites across the United States.

# Patient Communication Center



The PFF Patient Communication Center (PCC) is the central information resource for patients, families, caregivers, and health providers. The PCC staff answers questions via phone and email, providing personalized information for each individual. Available services and resources include:

- Accurate, up-to-date information about pulmonary fibrosis
- Help finding PFF Care Center Network sites and other medical centers that treat interstitial lung disease, access in-person and online support groups, and obtain available treatment options
- Information on disease management, supplemental oxygen, and pulmonary rehabilitation
- Information on lung transplantation
- Help locating clinical trials and PFF Patient Registry sites
- More information on the PCC can be found in the quarterly Breathe Bulletin

The PFF utilizes several publications to keep our community aware and informed.

- **The Breathe Bulletin** is our biannual magazine containing all the latest information on living with PF, including research and clinical trials. Readers also learn how the Foundation is raising awareness, and providing disease education and funding for the PF community.
- **The Pulmonary Fibrosis Information Guide** gives patients, caregivers, and medical professionals comprehensive information about pulmonary fibrosis, treatment options, tips for monitoring your health, and ways to maintain your care. This guide is ideal for those who are newly diagnosed or wish to learn more about this disease.
- **The Physician Notepad** facilitates conversation between a physician and a patient.

# Webinar Series



**The PFF Disease Education Webinar Series**, a sponsored collaboration, engages the pulmonary fibrosis community in an online webinar discussion, where they learn from, connect with, and pose questions to leading pulmonary fibrosis specialists each month.

- Webinars are a great tool for support groups to utilize at meeting or other events
- An archive of past webinars can be found in the Educational Resources section of our website

With more and more organizations and individuals across the world participating in Global Pulmonary Fibrosis Awareness Month, the PFF provided real-time translations of the PFF Disease Education Webinar into several languages.

# Support Group Network



The PFF Support Group Leader Network provides a forum for support group leaders to connect, exchange ideas, and share best practices.

- Now offering a new toolkit that makes it even easier to start or revitalize a support group.

The Leanne Storch Support Group Fund further enhances the support group experience and assists the needs of the Network by funding educational events, helping establish new groups, and supporting related activities.

The PFF currently has approximately 100 support groups throughout the world.

# Opportunities to Get Involved



There are many opportunities for individuals and organizations to get involved with the PFF and the pulmonary fibrosis community at large:

- Attend the Summit 2017 in Nashville, TN, November 9-11, 2017
- Participate in educational programs such as our webinars and contact our Patient Communication Center at (+1 844 825 5733)
- Collaborate around educational materials
- Partner with the PFF during Global Pulmonary Fibrosis Awareness Month in September 2017
- For additional information, visit us on the web at [www.pulmonaryfibrosis.org](http://www.pulmonaryfibrosis.org)

# *PFF Through the Years*



The PFF has undergone substantial changes in the past few years.

# Family Relationships

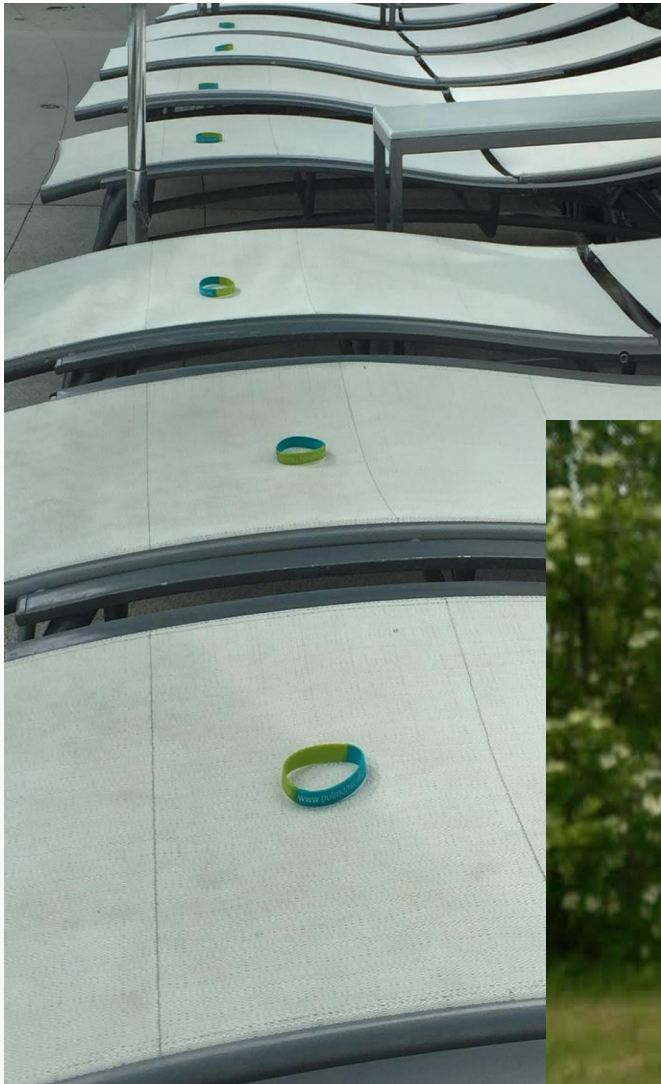


# *When the Going Gets Tough...*



# Social Media Doesn't Have to Cost a Lot





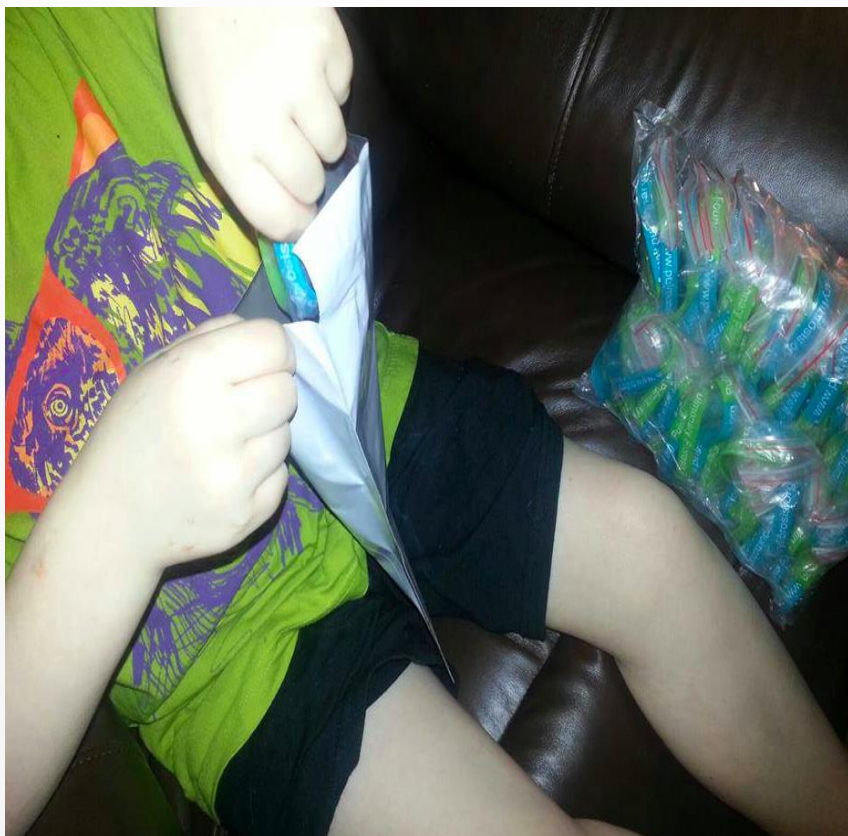
# We Have Fun



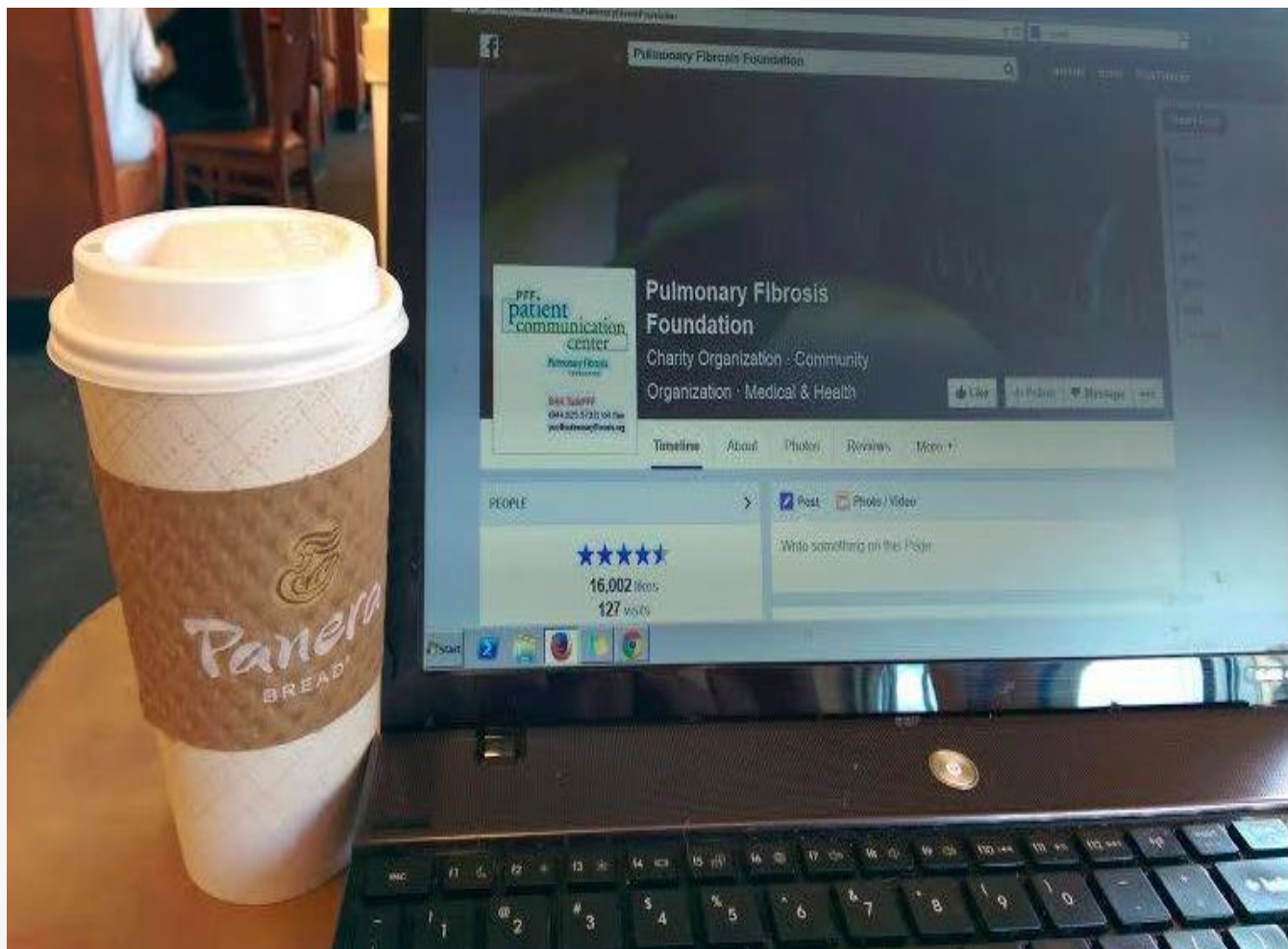
# We Take Advantage of What's Going On



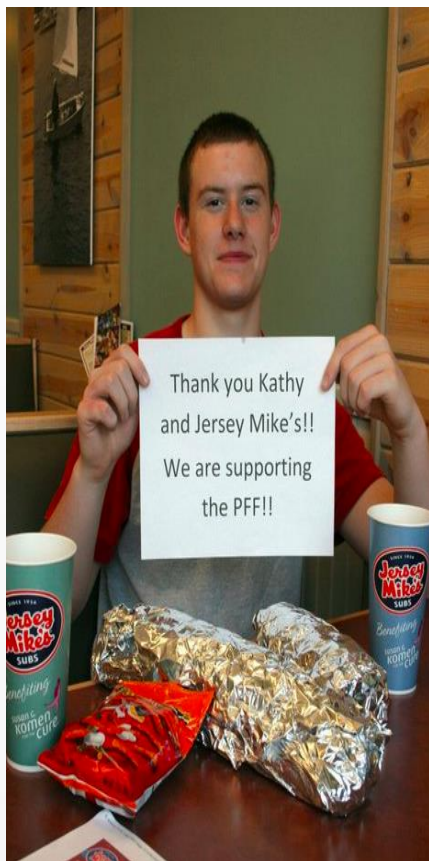
# Our Volunteers in the Early Days



# No Power? No Problem.



# Partnering with our Connections



# We Love Meeting our Social Media #PFWarriors



# We Love Meeting our Team PFF Event Leaders



# *We Participate in Challenges*



Help Us Win  
**\$250,000** for  
RESEARCH  
AWAWARENESS  
ADVOCACY  
SUPPORT

Pulmonary Fibrosis  
FOUNDATION



CHASE  
COMMUNITY GIVING  
you make a difference

Vote September 6–19 at <http://bit.ly/votePFF>

# We Celebrate Our Milestones!



**Jennifer Bulandr** shared Pulmonary Fibrosis Foundation's photo.

November 9, 2013 at 1:29pm · 🌐 ▼

As you may know pulmonary fibrosis is a large part of my life. We are trying to spread awareness of this little know disease that has no FDA approved treatment and no cure. Please consider giving the Pulmonary Fibrosis Foundation facebook page a "LIKE" and learning more about what we are doing at the PFF.



**Pulmonary Fibrosis Foundation**

November 7, 2013 at 4:30pm · 🌐

We'd love to get 13,000 LIKES on our facebook page by the end of the 2013! Please help us by inviting your family/friends to join. This is a great and easy way to spread awareness of pulmonary fibrosis.



**Jennifer Bulandr**

November 9, 2014 at 5:08pm · 🌐 ▼

The PFF FB page has 19,999 followers!!  
Who is going to be number TWENTY THOUSAND??  
Invite a friend to join the page and there may be a PFF Fun Pack involved!!

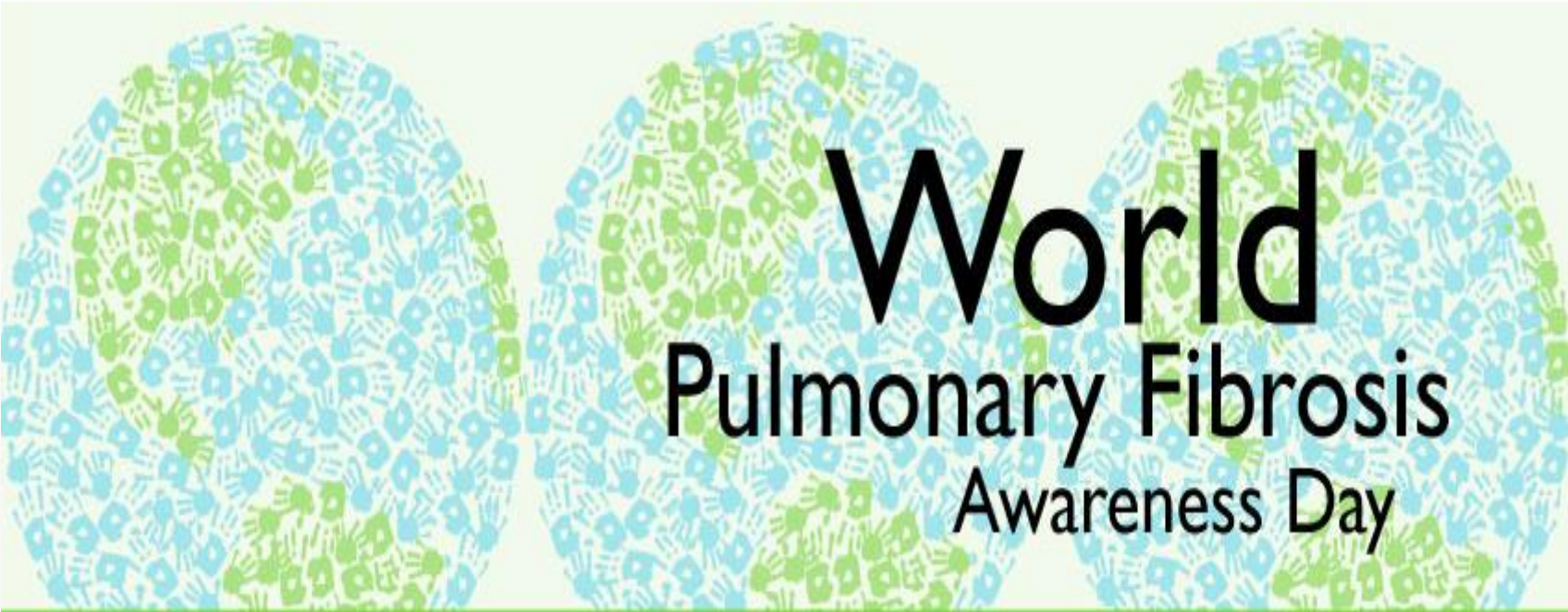
2011

**PFF**

**IPF AWARENESS WEEK**

**September 18 - 24**

2012



# World Pulmonary Fibrosis Awareness Day

22 SEPTEMBER 2012

2013

**JOIN US**  
07 September



PRESENTED BY **Pulmonary Fibrosis**  
FOUNDATION

global  
**PULMONARY FIBROSIS**  
AWARENESS DAY **2013**

visit  
[www.globalPFawareness.org](http://www.globalPFawareness.org)  
to learn more

2014

PRESENTED BY **Pulmonary Fibrosis**  
FOUNDATION



2015

SEPTEMBER 2015  
Let the world know.



# 2016



global  
**PULMONARY FIBROSIS**  
awareness month  
**SEPTEMBER**

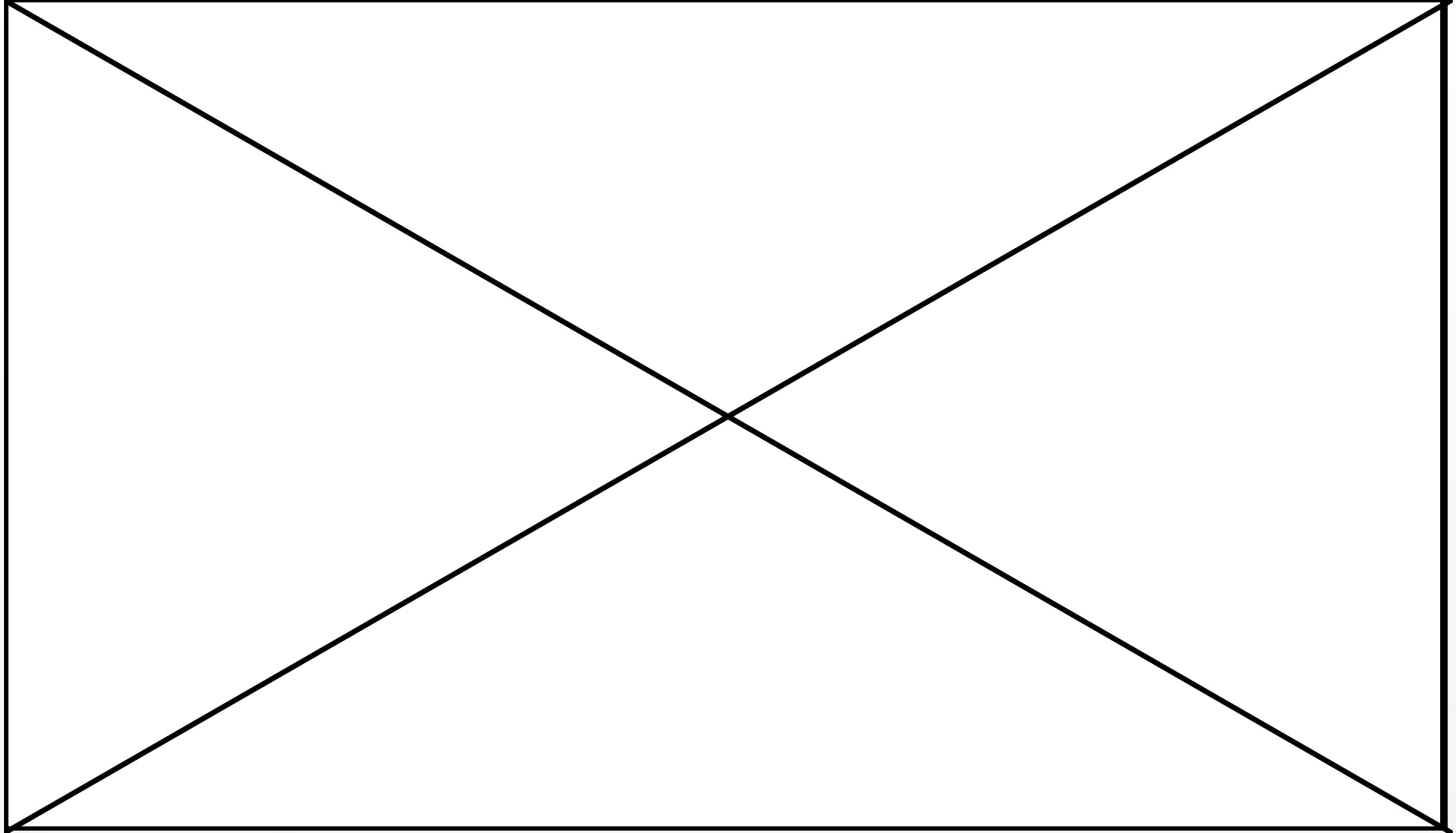
PRESENTED BY **Pulmonary Fibrosis**  
FOUNDATION

For more information, visit  
[pulmonaryfibrosis.org](http://pulmonaryfibrosis.org)

**#GPFAM**  
**#BLUEUP4PF**

# *Questions?*

*Thank you!*



# ***IPF GP toolkit***



- **Brochures to GPs**
- **Brochures to pharmacists**
- **Tools to illustrate symptoms to GPs**
- **Self-diagnosis tools**
- **Guide on how to speak to doctors**
- **Clinical guidelines**

# *Coffee break*

# Session 5

## *Working together – collaboration beyond EU-IPFF*

# How can the EU-IPFF collaborate with organisations globally ?

No EU-IPFF members in:

- Brazil
- Israel
- Argentina
- Canada
- US
- Australia
- But also some European organisations are not members



# Some key dates

## Rare Disease Day 2017

- 28 February 2017
- Theme: “Research brings hope to people living with a rare disease”



## Global Pulmonary Fibrosis

### Awareness Month

- 1 – 30 September 2017
- Worldwide



## IPF World Week 2017

- Date TBC – September 2017?
- Theme TBC



## PFF Summit 2017

- 9-11 November 2017
- Nashville, Tennessee (USA)



# *What key dates or initiatives exist for groups*

- Europe
- Us
- Brazil
- Canada



# Key initiatives?



- Europe – building on European Parliament Written Declaration
- ?
- ?

# *Discussion*

# *Conclusions*

# *Feedback*

# *Closing*