

# PFFSUMMIT2017

NASHVILLE, TN  
NOVEMBER 9-11, 2017

PRESENTED BY

Pulmonary Fibrosis  
FOUNDATION

## agenda all attendees

The PFF Summit 2017 program includes breakout sessions that were designed to suit the needs of different categories of attendees. However, you may attend any session that interests you.

**A sessions** are designed for health care professionals. CME/CE is provided for A sessions unless noted otherwise. (\*)

**B sessions** are designed for recently diagnosed patients and their caregivers.

**C sessions** are designed for those who have been living with PF for a while.

**D sessions** are designed for individuals who are not currently living with PF, such as transplant recipients and individuals who have lost a loved one.

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### THURSDAY, NOVEMBER 9

#### REGISTRATION

7:30 A.M. - 8:00 P.M.

#### COMMUNITY PULMONOLOGISTS AND ILD FELLOWS (CME)

10:00 A.M. - 4:00 P.M.

How to assess for autoimmune disease in your ILD patient

Aryeh Fisher, MD

Evaluating an occupational exposure history

Mridu Gulati, MD

MDD and an accurate diagnosis in ILD

David Lederer, MD

How to effectively read an HRCT and utilize its clues for differential diagnosis in ILD

Mary Salvatore, MD

Approach to pathological analysis of ILDs

Joyce Johnson, MD

#### Lunch provided

Utility and options for lung biopsy: Emerging utility of bronchoscopic cryobiopsy

Fabien Maldonado, MD

Approved therapies for IPF: A review of the data

Sonye Danoff, MD

Safety and management of side effects of pirfenidone and nintedanib

Wendi Mason, MSN

# agenda

THURSDAY, NOVEMBER 9



Stem-cell and cell-based therapies in lung disease (paucity of data in just IPF)  
Non-pharmacological management of IPF/ILD  
Palliative care and hospice  
Evaluation for lung transplant

Marilyn Glassberg, MD  
Amy Olson, MD  
Kathy Lindell, PhD, RN  
Tim Whelan, MD

## **PATIENTS AND CAREGIVERS: INTRO TO THE PFF, YOUR CALL TO ACTION, AND UNDERSTANDING THE BASICS OF RESEARCH**

1:00 P.M. – 4:00 P.M.

Introduction of the PFF and the Care Center Network

Kevin Flaherty, MD, MS

Research 101: Understanding the process, terminology, and definitions and how a drug is brought to market

Hal Collard, MD.,  
PFF Ambassador, and  
David McNinch

Q&A

All

Break (15 minute)

All

Need Meets Action Part I: Overview of volunteering at the PFF

PFF Development Team  
and Panel Volunteers

Need Meets Action Part II: Overview of effective fundraising

PFF Development Team  
and Panel Volunteers

Q&A

All

### **Breakouts and Rotating Roundtable Discussions**

- » For patients: Roundtable networking by diagnosis and/or topic
- » For Caregivers: Roundtable discussions by topic

All

## **FOCUS GROUPS**

1:00 P.M. - 5:00 P.M.

Focus Group 1 (1:00 P.M. - 2:00 P.M.)

Focus Group 2 (2:00 P.M. - 3:00 P.M.)

Focus Group 3 (3:00 P.M. - 5:00 P.M.)

# agenda

FRIDAY, NOVEMBER 10



FRIDAY, NOVEMBER 10

## REGISTRATION AND CONTINENTAL BREAKFAST

7:00 A.M. - 8:00 P.M.

## PLENARY SESSION I: PROMISE OF GENETICS AND PERSONALIZED MEDICINE IN PF (CME)

8:00 A.M. – 10:00 A.M.

National Heart, Lung and Blood Institute (NHLBI) support for personalized therapy in lung disease	Jim Kiley, PhD
Genetic and environmental influences in ILD	Jeff Trent, PhD
Current status of clinical genetic testing in ILD	Jim Loyd, MD
A genetic counselor's perspective: Impact of genetic information for patients and families	Janet Talbert, MS, CGC
Panel discussion	Jim Kiley, Jeff Trent, Jim Loyd, Janet Talbert, Carolyn Adams-Duda, Heather Kagel
30 minute break and networking	All

## SESSION 1A: GENETICS OF ILD (CME)

10:30 A.M. - 12:15 P.M.

Poster winner: Abstract talk I	TBA
Spectrum of telomere-related ILD	Mary Armanios, MD
Progression and outcome of telomere-related ILD	Christine Garcia, MD
New genes associated with familial ILD	Jon Kropski, MD
Results of whole genome sequencing in sporadic IPF	Brian Yaspan, PhD*

## SESSION 1B, C, D: KIDBILLY MUSIC - PRESENTED BY GENENTECH

10:30 A.M. – 12:15 P.M.

Perspectives from All: Songwriting for team-building, networking, and emotional healing	Kidbilly Music
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\* CME credit not provided

# agenda

FRIDAY, NOVEMBER 10



## SESSION 2A: ENVIRONMENTAL INFLUENCES (CME)

1:15 P.M. - 2:50 P.M.

Poster winner: Abstract talk II	TBA
The microbiome in IPF	Phil Molyneaux, PhD
Gastroesophageal Reflux Disease (GERD) in ILD	Ganesh Raghu, MD
Sleep apnea in ILD	Lisa Lancaster, MD
Autoimmune mechanisms of pulmonary fibrosis: CTD-ILD	Aryeh Fischer, MD

## SESSION 2B: UNDERSTANDING ILD AND IPF

1:15 P.M. - 2:55 P.M.

Part I: Overview of ILD, IPF, and connective tissue disease	Kristin Highland, MD
Part II: Understanding your test results: HRCT, 6MWT, PFTs, and oximetry	Mary Beth Scholand, MD
Q&A	All

## SESSION 2C: QUALITY OF LIFE: NEXT STEPS

1:15 P.M. - 2:55 P.M.

Part I: Evaluation for lung transplantation	Josh Mooney, MD, MS
Part II: Using mindfulness for stress management in chronic disease	Linda Manning, MD
Part III: TBA	TBA
Q&A	All

## SESSION 2D: CALL TO ACTION, PART I

1:15 P.M. - 2:50 P.M.

Part I: Transitioning after the loss of a loved one, after a transplant (two roundtables)	Kathy Lindell, PhD, RN and John Mulder
Part II: How to participate in legislative advocacy	Kate Gates
Group Activity	All
30 minute break and networking	All

## SESSION 3A: DISEASE MECHANISMS I (CME)

3:15 P.M. - 4:50 P.M.

Poster winner: Abstract talk III	TBA
Pre-clinical modeling of telomerase deficiency	Paul Wolters, MD
Lessons from other rare genetic diseases, such as Hermansky-Pudlak Syndrome	Victor Thannickal, MD
Epithelium as the guardian of the lungs: Response to injury	Tushar Desai, MD, MPH
Mechanism of alveolar epithelial cell renewal: Impact on ILD	Paul Noble, MD

## SESSION 3B: OXYGEN THERAPY, PULMONARY REHABILITATION, AND SYMPTOM MANAGEMENT

3:15 P.M. – 4:55 P.M.

Part I: Living with oxygen therapy and PF	
» Overview of various types of POCs, compressed gas units, trans-fill systems, and backpacks	Susan Jacobs, RN, MS
» How can I be active and travel with O2 (MedJet and other emergency travel services)?	
Part II: Pulmonary rehab: What is it and how can it help me?	Trina Limberg, BS, RRT
Part III: Symptom management: Cough, dyspnea and fatigue	Mary Strek, MD
Q&A	All

## SESSION 3C: WHAT'S IN THE PIPELINE? CURRENT CLINICAL TRIALS, POTENTIAL THERAPIES, AND HOW THE PROCESS WORKS

3:15 P.M. - 4:55 P.M.

Part I: Understanding how clinical trials work and the therapeutic process to bring a drug to market	Bill Bradford, MD, PhD
Part II: Current clinical drug trials in the pipeline for IPF and PF, and an overview of potential therapies moving forward	Gregory Cosgrove, MD
Q&A	All

# agenda

FRIDAY, NOVEMBER 10



## SESSION 3D: CALL TO ACTION PART III: USING YOUR PASSION TO UNDERSTAND SOCIAL MEDIA AND ADVOCACY

3:15 P.M. - 4:50 P.M.

Part I: How to use social media effectively for awareness and advocacy

TBA

Part II: Transitioning after the loss of a loved one / after a transplant

Kathy Lindell, PhD, RN

Q&A

Victor Thannickal, MD

## NETWORKING COCKTAIL HOUR

5:30 P.M. - 6:30 P.M.

## NETWORKING DINNER WITH ENTERTAINMENT BY KIDBILLY MUSIC AND THE PFF COMMUNITY, PRESENTED BY GENENTECH

6:30 P.M. - 9:00 P.M.

## SATURDAY, NOVEMBER 11

### CONTINENTAL BREAKFAST

7:00 A.M. - 8:00 A.M.

### PLENARY SESSION II: MAXIMIZING THE IMPACT OF AVAILABLE THERAPIES IN IPF (CME)

8:00 A.M. – 10:00 A.M.

**KEYNOTE:** Evaluation of the effectiveness of therapies in the real world

TBA

PFF Care Center Network and PFF Patient Registry

Kevin Flaherty, MD, MS

Improving care for PF patients and adherence to treatment plans: A physician family member's perspective

Jason Martin, MD

Flaherty, Martin,

**PANEL DISCUSSION:** Opportunities and obstacles to provide optimal care for PF in 2017

Cosgrove, Maryluz

Fuentes, MD, Jane

Nelson

30 minute break and networking

All

# agenda

**SATURDAY, NOVEMBER 11**



## **SESSION 4A: DIAGNOSIS OF IPF (CME)**

10:30 A.M. - 12:15 P.M.

Poster winner: Abstract talk IV	TBA
Advances in HRCT imaging, quantitative HRCT imaging in IPF trials and clinical care	Jonathan Goldin, MD, PhD
New approaches to diagnosis: Potential role for cryobiopsy	Fabien Maldonado, MD
Pre-clinical ILD	Gary M. Hunninghake, MD
Lessons from at-risk cohorts	Tim Blackwell, MD

## **SESSION 4B, C, D: BASICS OF GENETICS AND WHAT WE KNOW ABOUT STEM CELL THERAPY**

10:30 A.M. - 12:15 P.M.

Part I: Genetics 101 in IPF	Jim Loyd, MD
Part II: Stem cell therapies and biotourism	Sonye Danoff, MD
» What is stem cell therapy and what is it approved for?	
» Stem cell centers in the community	
Part III: Clinical trials with stem cells for ILD	Marilyn Glassberg, MD
Q&A	All

## **LUNCH AND NETWORKING**

12:15 P.M. - 1:15 P.M.

- Lunch with people who live in your region
- Off-site lunch for those who have lost a loved one and transplant recipients

## **SESSION 5A: THERAPEUTICS (CME)**

1:15 P.M. - 2:50 P.M.

Poster winner: Abstract talk V	TBA
Drug development in IPF: What is on the horizon	Andy Limper, MD
Stem cell therapies: Real possibility or not?	Ramona Doyle, MD*
Personalized medicine in IPF, integrating genetics in clinical trials	Imre Noth, MD
Role of biomarkers in diagnosis and treatment	Naftali Kaminski, MD

\* CME credit not provided

# agenda

SATURDAY, NOVEMBER 11



## SESSION 5B, C: APPROVED THERAPIES FOR IPF AND DIAGNOSIS AND TREATMENT OF COMORBIDITIES IN ILD

1:15 P.M. - 2:50 P.M.

Part I: Overview of pirfenidone and nintedanib

Joyce Lee, MD

Part II: Adherence to treatment plans: Safety and management of side effects with pirfenidone and nintedanib

Wendi Mason, MSN

Part III: How to qualify for reduced payment plans

Anne Turner, RN, BSN

### Breakout Discussions: Diagnosis and Treatment of Comorbidities

Obstructive sleep apnea (OSA)

Lisa Lancaster, MD

Gastroesophageal Reflux Disease (GERD)

Wendi Mason, MSN

Scleroderma

Kristin Highland, MD

Sarcoidosis

Bob Baughman, MD

## SESSION 5D: CALL TO ACTION PART III: PUTTING WHAT YOU'VE LEARNED INTO ACTION! (OFF-SITE ACTIVITY)

1:15 P.M. - 2:50 P.M.

## BREAK AND NETWORKING

2:50 P.M. - 3:15 P.M.

## SESSION 6A: DISEASE MECHANISMS II (CME)

3:15 P.M. - 4:50 P.M.

Lessons from other rare genetic diseases - Hermansky-Pudlak Syndrome

Lisa Young

Mechanoregulation of matrix deposition and fibrosis progression

Dan Tschumperlin, PhD

Epithelial-fibroblast interactions in lung fibrosis

Kevin Kim, MD

Immune/inflammatory cells in IPF

Erica Herzog, MD, PhD



# agenda

SATURDAY, NOVEMBER 11



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## SESSION 6B, C: ROUNDTABLE DISCUSSIONS

3:15 P.M. - 4:35 P.M.

Caregiver burnout

John Mulder

How to prepare for an effective clinical visit with your doctor

Dr. David Lederer, PFF  
Medical Team member  
and Michele Peters

Depression and anxiety in chronic disease

Jim Jackson, PhD

Palliative and hospice care

Kathy Lindell, PhD, RN

How to participate in legislative advocacy

PFF Development and  
Programs teams

## FOCUS GROUP 3

4:45 P.M. - 5:45 P.M.