

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.

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.

THURSDAY, NOVEMBER 9

REGISTRATION

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

COMMUNITY PULMONOLOGISTS AND ILD FELLOWS

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

How to assess for autoimmune disease in your ILD patient	TBA
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



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
TBA

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: Overview about how to effectively fundraise, and how volunteering impacts research needs at the PFF

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.)

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

8:00 A.M. – 10:00 A.M.

Genetic and environmental influences in ILD	TBA
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	Gibbons, Loyd, Talbert, Carolyn Adams-Duda, Heather Kagel
30 minute break and networking	All

SESSION 1A: GENETICS OF ILD

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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SESSION 2A: ENVIRONMENTAL INFLUENCES

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	TBA
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	TBA
Acupuncture, nutrition, and alternative therapies	TBA
Q&A	All

SESSION 2D: CALL TO ACTION, PART I: UNDERSTANDING HOW TO FUNDRAISE AND VOLUNTEER

1:15 P.M. – 2:50 P.M.

Part I: How to host a fundraising event	PFF Development Team
Part II: How you can volunteer for the PFF: Panel discussion with volunteers	PFF Development and Programs Teams
Group Activity	All
30 minute break and networking	All

SESSION 3A: DISEASE MECHANISMS I

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
- » How can I be active and travel with O2 (MedJet and other emergency travel services)?

Susan Jacobs, RN, MS

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

SESSION 3D: CALL TO ACTION PART II: 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

Jennifer Bulandr

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

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

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

Flaherty, Martin,

Cosgrove, Maryluz

Fuentes, Jane Nelson

30 minute break and networking

All

SESSION 4A: DIAGNOSIS OF IPF

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

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

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

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

Role of aging and senescence in IPF

TBA

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

SESSION 6B, C: ROUNDTABLE DISCUSSIONS

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

Financial considerations (insurance, reduced payment plans for IPF drugs, Medicare/Medicaid, estate planning, etc.)

TBA

Caregiver burnout

TBA

How to prepare for an effective clinical visit with your doctor

PFF Medical Team members 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

Jennifer Bulandr, PFF Development and Programs teams

FOCUS GROUP 3

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