PFF Care Center Network™

Care. Education. Innovation.

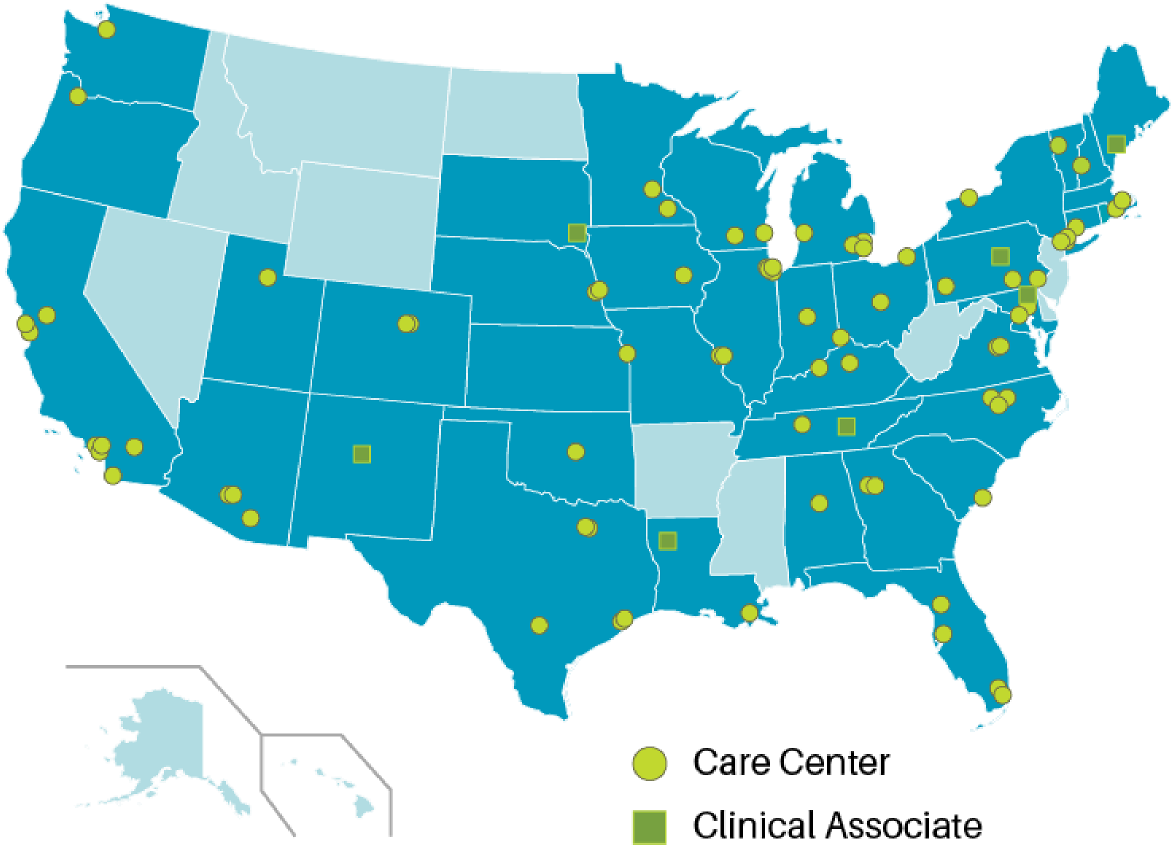
PFF CCN Committees and Working Groups Annual Report

January 2025 - December 2025

The Pulmonary Fibrosis Foundation (PFF) is dedicated to promoting earlier recognition and diagnosis of pulmonary fibrosis and ensuring that patients receive the highest quality healthcare. As part of that commitment, the Foundation worked with the PF medical community to establish the PFF Care Center Network in 2013, where people with PF can find experienced medical professionals who understand their disease and support services to improve the quality of their lives.

Thanks to ongoing efforts and collaboration of the PFF and the PF healthcare community, the PFF Care Center Network (CCN) has since grown to include both Care Centers and Clinical Associates. All members of the CCN have expertise in treating adult patients with fibrotic lung diseases. Patients living with PF can find experienced medical professionals who understand their disease and support services to improve the quality of their lives. Clinical Associate members are community-based institutions that partner with Care Centers to share resources they may not otherwise have access to. Clinical Associates join the CCN with the goal of growing into a Care Center member or to remain a Clinical Associate indefinitely. Through the CCN, Care Centers and Clinical Associates collaborate to promote and provide quality care to those living with PF.

The PFF Care Center Network (CCN) currently includes 86 individual centers across the country, 80 Care Centers and six Clinical Associates, as shown in the below map. The Network provides an opportunity for these expert care teams to work together to improve the quality of care for patients, collaborate in research projects to expedite and broaden scientific discoveries, and work with the PF community to increase the awareness and understanding of the disease.



Care Center Network Committees and Working Groups

The Care Center Network is actively involved in the implementation of the PFF CCN strategic goals: Improve Diagnosis Process | Enhance Quality of Care | Accelerate Research | Effectively advocate for the PF Community. *The vision of the CCN is that every patient receives a prompt, accurate diagnosis and receives the highest quality, patient-centered care.*

Membership of CCN Working Groups and Committees is composed of PFF staff and leadership, healthcare providers from the Network, and community stakeholders. Individuals whose primary employment is with pharmaceutical companies are typically excluded.

Below is a list of accomplishments for the PFF 2025 year for current CCN committees and working groups.

Best Practices Committee

The Best Practices Committee is engaged in a multi-center, mixed method research study in identifying best practices across the network. Site visits were ongoing throughout 2025. This project is projected to have preliminary results in 2026. Joyce Lee, MD and Jessica Shore, PhD, RN are leading this project.

Rural Health Outreach Committee

The Rural Health Outreach Committee is led by co-chairs Ryan Boente, MD (Indiana University) and Hyun Kim, MD (University of Minnesota). This committee's goal is to increase and improve access to pulmonary care for patients living in rural areas and to develop tools that are specific for rural areas for providers caring for patients living with PF. Accomplishments over the 2025 year include:

- Creation of a virtual multidisciplinary discussion conference template with a focus on accurate, timely diagnosis using consistent, evidence-based MDD
- Design of a Rural Health Community Registry Survey to ascertain rural community perspectives on clinical trials
- Progress on strategic plan to reduce barriers to, and increase recruitment in, clinical trials in rural communities
- Publication: Caring for Rural Patients With Interstitial Lung Disease DeDent, Alison M. et al. CHEST Pulmonary, Volume 3, Issue 3, 100136.

ILD Fellows Curriculum Working Group

The ILD Fellows Curriculum Working Group is led by co-chairs Tristan Huie, MD (National Jewish Health) and Maryl Kreider, MD, MSCE (Penn Medicine). This committee's goal is to develop a curriculum for ILD Fellow subspecialty training. This committee made progress toward the following projects:

- Educational resources needs survey
- Currently available resources collection
- Reading list to be published on PFF website
- Publication: Defining Interstitial Lung Disease Education in Pulmonary Fellowship: A Mixed Methods Study King, Samantha Irene, et al., CHEST Volume 168, Issue 4, October 2025, Pages 967-979

Nurse and Allied Health Network (NAHN)

The Nurse and Allied Health Network is led by co-chairs Janell Reichuber, MSN, RN (The University of Kansas Health System) and Lori Flint, RN (Michigan Medicine)[1]. The goal of NAHN is to encourage collaboration and professional development among the allied healthcare teams who manage patients diagnosed with PF to confidently deliver exemplary healthcare and improve patient outcomes. Accomplishments over the 2025 year include:

- Formalized chair succession plan and welcomed new chair

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[1] In June 2025, Ms. Lori Flint replaced previous co-chair Jamie Lederer, MSN, CRNP (University of Pennsylvania Health System), who served in this role January 2025 to March 2025.

- Held 3 meetings with attendance from nearly 30% of Care Center Network sites represented, with increasing attendance throughout the year
- Added nearly 100 new members
- Organized and executed the 2025 NAHN Summit Session for the PFF Summit with 125 members registering for the session
- Established the Mentorship working group (see below for working group updates)

NAHN Mentorship Working Group

- Established two subgroups: onboarding and one to one mentorship
- Developed onboarding email series: A series of three emails sent to new members that provide introduction to the PFF, NAHN, an overview of resources available, and connections with other NAHN members
- Launched one to one mentorship pilot program: 3 mentorship pairs were matched and began a 6-month pilot program in the Fall of 2025 with plans to survey participants at 3- and 6-month mark to refine mentorship program and launch broader program mid 2026

Veterans Working Group

The Veterans Working Group is led by co-chairs Bhavika Kaul, MD MAS (UCSF), Jessica Shore, PhD, RN (PFF), and Jennifer H. Wescoe, M.Ed., NCC (The Wescoe Foundation). The goal of the Veterans Working Group is to focus on care, education and research for veterans and families. Accomplishments over the 2025 year include establishing the three pillars of this Working Group and related goals, as follows:

- Clinical Care: The short-term goal is to define criteria to designate VAs as Centers of Excellence. The medium-to-long term goal is to identify the VAs that meet these criteria, invite them to apply, then publish this network on the PFF website
- Patient Education/Support: Determine list of resources to prioritize and distribute in the short-, medium-, and long-term, including increased access to clinical trials, input on exposures, and clinician engagement; participation in Veteran specific session at the PFF Summit
- Research: Determine research priorities to consider in the short-, medium-, and long-term, including VA biorepositories, industry support, recommendations on data collection and presentation, and the process of imaging sent to specialists

Familial PF Working Group

The Familial PF (FPF) Working Group, established in 2025, is led by co-chairs Joyce Lee, MD, MS (University of Colorado School of Medicine; PFF) and Chad Newton, MD (UT Southwestern). The goal of the FPF Working Group is to focus on the emerging, complex care of families and to identify gaps in care, research, and education. Accomplishments over the 2025 year include establishing the four FPF subgroups, as follows:

- Clinical Evaluation: Co-chairs Brad Bemiss, MD (Northwestern) and Mary Beth Scholand, MD (University of Utah) - Seven members held four meetings in 2025
- Definition & Epidemiology: Chair Bess Flashner, MD (Beth Israel Deaconess) - Seven members held four meetings in 2025
- Genetic Testing: Janet Talbert, MS, CGC, LGC (Vanderbilt) and Jennie Vagher, CGC (University of Utah) - Eight members held nine meetings in 2025
- Treatment/Management: David Zhang, MD (Columbia) and Krishna Thavarajah, MD, MS (Henry Ford Health) - Six members held two meetings in 2025

During the 2025 year, these subgroups started the process to create an outline, conduct literature reviews, and draft content to contribute to the PFF Familial PF position statements for healthcare providers and patients/families, to be finalized and shared in the 2026 year.

CCN Journal Club

At least six months a year, CCN hosts a virtual event where a guest speaker discusses a published article of interest to ILD healthcare professionals. Events are recorded and made available to the Network as a resource. During the 2025 year, the CCN held 6 Journal Clubs, with the highest attendance at 52 attendees. CCN journal club remains unique in that most journal club presenters are authors of the article being discussed.

- January 15, 2025: Aubree Carlson, PhD, RN: “Pulmonary Rehabilitation in Idiopathic Pulmonary Fibrosis”
- March 14, 2025: Dr. Kevin Flaherty: “Meaningful Endpoints for IPF Clinical Trials: Emphasis on Feels, Functions, Survives”
- April 17, 2025: Dr. Margaret Salisbury: “Progressive Early Interstitial Lung Abnormalities in Persons at Risk for Familial Pulmonary Fibrosis”
- June 6, 2025: Dr. Angela Suen: “Differences in Health Care and Palliative Care Use at the End of Life: A Comparison Study Among Lung Cancer, COPD, and IPF” and Kathryn Fenwick, DNP, CRNP: “The Development and Clinical Impact of an Innovative Palliative Care Lever Tool for Individuals With IPF: A Quality Improvement Project”
- August 15, 2025: Dr. Daniel Dilling and Dr. Rachana Krishna: “Fibroneer Phase III Trial Findings”
- December 8, 2025: Dr. Behram Khan: “Management of ILD in the ICU”

PFF Strategic Plan

Representatives from across the CCN contributed their time and expertise to the development of **The PFF is ME**, the Pulmonary Fibrosis Foundation’s Strategic Plan for 2025-2030, through six different working groups: Advocacy, Corporate Partnerships, Fundraising, Patient Education & Support, Quality of Care, and Science & Research.

For more information, visit the PFF CCN page here. Email questions and comments to ccn@pulmonaryfibrosis.org