



PFF Care Center Network™
Care. Education. Innovation.



Care Center Network Working Groups Report 2024

The [Care Center Network](#) (CCN) works with the Pulmonary Fibrosis Foundation (PFF) to promote its mission of accelerating the development of new treatments and ultimately a cure for pulmonary fibrosis. Until this goal is achieved, the PFF is committed to advancing improved care of patients with PF and providing unequalled support and education resources for patients, caregivers, family members, and health care providers.

The CCN 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 completed projects, current initiatives, and goals as of December 2024 as reported at the CCN Annual Meeting, for current CCN and NAHN Committees and Working Groups.

Network-directed projects

CCN Research Collaboration Dashboard: CCN sites collaborate by sharing their ILD registry data

CCN Clinical Trial Interest Dashboard: CCN sites indicate which clinical trials they are already enrolling as well as their ability to take on new trials, and in which phase

Position statements: As the field of pulmonary fibrosis continues to grow, sometimes issues arise where clinicians desire additional perspectives based on the currently available evidence, or in some cases, lack of published research on a particular subject. In a desire to meet these needs, working groups have been developed to provide views on these topics.

Rural Health Outreach Committee

Chairs: Ryan Boente, MD (Indiana University) and Hyun Kim, MD (University of Minnesota)

Committee Goal: 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

Completed projects:

- Position Statement on Rural Health for [healthcare providers](#) and for [ILD Patients](#)

- PFF CCN Rural Health Survey and manuscript
- Access to care and outcomes for rural ILD patients project and manuscript

Current initiatives:

- Clinical Trials with a focus on outreach to rural communities for inclusion in clinical trials
- Virtual Multidisciplinary Discussion conference with a focus on accurate, timely diagnosis using consistent, evidence-based MDD
- Improving rural provider representation on the Rural Health Outreach Committee and the working groups

Next steps/goals:

- Recommendations for inclusion of rural communities in clinical trials
- Leverage the Clinical Associate program to gain more perspective on rural community needs
- Rural Health Community Registry Survey- What are rural communities' perspectives on clinical trials

ILD Fellows Curriculum Working Group

Chairs: Tristan Huie, MD (National Jewish Health) and Maryl Kreider, MD, MSCE (Penn Medicine)

Working Group Goal: Develop a curriculum for ILD Fellow subspecialty training

Completed projects:

- Surveyed program directors and trainees on the current state of training. Jake Natalini, MD; University of Pennsylvania; *ATS Scholar 2020*. Variable trainee exposure to ILD across fellowships. Graduating fellows have less confidence in managing ILD compared to other conditions
- Define content outline for general pulmonary fellow. Mixed methods study with semi-structured interviews and modified Delphi process. Samantha King, MD; University of Colorado. 41 members of expert panel: geographically diverse group that included 24 with ILD expertise; 16 general pulmonary; 78% academic medical centers; 90% regularly teach fellows. Consensus content: initial evaluation, diagnostic procedures; diagnosis; and management of ILD patients. Manuscript drafted

Current initiatives:

- Catalog current online educational resources. Josephine Hwang, Tanzira Zaman; Cedars Sinai; Giuliana Cerro Chiang; Yale. Initial search strategy to identify and categorize free online resources. Manuscript under preparation
- Develop a Recommended Reading List to be hosted by PFF. Alaa Abu Sayf; Henry Ford; Diana Gomez Manjarres; University of Florida; Ali Rueschhoff; University of Kansas; Stacey-Ann Brown, Johns Hopkins. Annotated reading list categorized as Core; Landmark; or Advanced

Next steps/goals:

- Identify gaps and develop resources to support fellow education

- Top 3: Annotated reading list; online case review (Mock MDD); online didactics
- Collaboration with Nurse and Allied Health Network
- Define expertise vs competency
- Develop mentoring program

Nurse and Allied Health Network (NAHN)

Chairs: Jamie Lederer, MSN, CRNP (University of Pennsylvania Health System) and Janell Reichuber, MSN, RN (The University of Kansas Health System)

Committee Goal: To encourage collaboration and professional development among the allied healthcare teams who manage patients diagnosed with PF in order to confidently deliver exemplary healthcare and improve patient outcomes

Completed projects and current initiatives:

- Held virtual meetings to bring NAHN members together
- Nearly 250 members registered for the NAHN session at 2023 PFF Summit
- Active Journal Club
- NAHN representation on foundation wide working groups

Next steps/goals:

- Develop mentorship program Develop Advanced Practice Provider group
- Pulmonary Rehab position statement
- Develop NAHN session for 2025 PFF Summit

Veterans Working Group- New for 2025

Chairs: To be determined

Committee Goal: Focus on care, education and research for veterans and families

Upcoming priorities:

- PFF Summit 2025 Veterans' Session
- How to apply for VA care
- Access points for ILD care in the VA system
- Access points for Pulmonary Rehab, Palliative and Hospice Care
- Unmet needs in research

Familial PF Working Group- New for 2025

Chair: Joyce Lee, MD, MS (University of Colorado School of Medicine; PFF)

Committee Goal: To focus on care of families and identify gaps in care, research and education

Upcoming priorities:

- Will build upon the PFF genetic testing position statements for [healthcare providers](#) and

[patients/families](#)