



PFF Care Center NetworkTM
Care. Education. Innovation.

CARE CENTER NETWORK
FULL MEMBERSHIP CRITERIA 2022





PFF CARE CENTER NETWORK

Since 2013, the PFF has worked with the PF healthcare community to establish and expand the PFF Care Center Network (CCN) to 68 Care Centers. Care Centers 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.

Care Centers utilize a multidisciplinary approach to deliver comprehensive patient care, participate in patient-oriented PF research with a focus on clinical trials, and work with the PFF to provide educational materials and engage the local community through PFF programs and advocacy.

Care Centers are 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.

MAJOR CRITERIA TO BE USED TO SELECT PFF CARE CENTERS

Core Personnel

- *Care Center Director (CCD)*
 - The CD must be board certified in Pulmonary Medicine and have at least three (3) years' post-pulmonary fellowship clinical experience in the care of patients living with PF.
 - The CD is responsible for providing the operational oversight of the Center including all patient and affiliate programs. The administrative role of the CD is to coordinate the efforts of the institution and core care team to provide the care, teaching and research at the Center. The CD will coordinate the provision of education to the institution and/or affiliated schools regarding recent advances in PF research and clinical care. The CD will also coordinate the research responsibilities of the Center which include establishing ongoing collaborations with other investigators within the institution, seeking out local and/or national funding for research by the core center staff, and providing access for research fellows, residents, medical students, and allied health professionals to become involved in PF-related research areas.
 - The CD will act as the main contact person between the Center and the PFF and is responsible for the CCN Annual Report and Annual Center Visit. The CD or designee will attend the biennial PFF Volunteer Meeting and PFF Summit. The CD will ensure the Center provides a representative on a CCN or NAHN Committee or Working Group.



- *Associate Director*: The ACD should have the same or comparable training and certification as the CD in order to serve as interim director if necessary. The ACD must be involved with inpatient and/or outpatient care and be knowledgeable about the administrative aspects of the Center program. The ACD is also strongly encouraged to attend the biennial PFF Summit.
 - *Nurse or allied health professional (or equivalent clinical staff)* who has effort dedicated to working with patients to aid in obtaining medications, durable medical equipment (DME) (including oxygen), prior authorizations, etc., to improve patient care*
 - *Lead Site Coordinator**: Nurse or Allied Health Professional with ILD experience in the outpatient and inpatient delivery of care or research with patients living with ILD. The Lead Site Coordinator will serve as a representative to the Nursing and Allied Health Network.
 - Research Coordinator*
 - Radiologist with expertise in thoracic imaging
 - Pathologist with expertise in pulmonary pathology
- *A staff member may serve in multiple roles

Easy, fast appointment

- Wait time for new appointment: “usual” waiting time 4 weeks or less; urgent consults within 2 weeks
- Phone number or electronic option available to patients to reach the ILD program directly

Multidisciplinary diagnosis meetings must be held at least monthly regardless of patient volume

Availability of a local support group

As feasible, incorporate use of the published [PFF High-Resolution Computerized Tomography \(HRCT\) protocol](#)

Participation in clinical research, with an emphasis on clinical trials

ADDITIONAL CRITERIA

Please note that a team member may serve multiple roles.

Required Additional Core Personnel: For these roles, the Center must either have these personnel on site or be able to refer patients through an established connection and referral process, demonstrating that a network of care is available. These team members must regularly attend outpatient clinics and/or team conferences which can take place outside of home institution.

- Pulmonary hypertension specialist
- Lung transplant specialist (Center must have capacity to coordinate pre-transplant care)
- Rheumatologist

Additional Personnel: These team members must be available for consultation/
coordination of care.

- Other pulmonologists, nurses and allied health professionals (involved in the care of ILD)



- Cardiologist
- Gastroenterologist
- Geneticist/Genetic Counselor
- Infectious Disease Specialist
- Social worker
- Thoracic surgeon

Facilities

Facilities should have accreditation by an entity that is approved by CMS as well as access to outpatient and inpatient facilities and services as described below:

- Intensive Care Unit
- Respiratory Care
- Outpatient Clinic
- Clinical Research Program
- Diagnostic Services
 - Pulmonary function
 - Sleep study lab
- Pulmonary Rehabilitation Program
- Palliative Care Program
- Access to Specialty Pharmacy

Process/ Other

- Referral plan for procedures or services not found at the CCN site.
- Mechanism to deliver outpatient clinic reports and discharge summaries to referring physicians.
- Minimum cohort of 150-200 ILD unique patients followed annually

PFF CARE CENTER ACTIVITIES

CCN sites will work with the PFF to promote its mission: To accelerate 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 PFF expects Care Centers to take part in activities and opportunities to the fullest extent possible and to document participation through the PFF CCN reporting process. While the PFF recognizes that consistent participation may not always be possible, continuation as a CCN site is dependent upon active engagement with the Network. Engagement opportunities include:

- Joining a CCN or NAHN Committee



- Attending Network sponsored activities such as journal club, webinars, and meetings
- Volunteering to lead discussion at a support group
- Attending Quarterly CCN and NAHN meetings

The core team of each Care Center will connect patients to the resources available through the Pulmonary Fibrosis Foundation by:

- Providing PFF educational [materials](#) (in English and Spanish), such as the [Pulmonary Fibrosis Information Guide](#), [Oxygen Basics Booklet](#), informational [videos](#), and the [Pulmonary Rehabilitation Toolkit](#)
- Making appropriate referrals to the [PFF Help Center](#)
- Making available PFF [programs](#) and [webinars](#)

Each Center will assist with a PF patient/caregiver support group that meets at least quarterly.

Each Center will attend annual CCN meetings, participate in CCN committees and/or projects and attend the Annual PFF Conference.

Each Center will be routinely reviewed (every 3-5 years) to ensure compliance with criteria.

Sites which do not qualify for CCN designation may also apply for individual provider or center clinical associate status. For individual providers, programs, or sites outside of the CCN designation interested in affiliating with the PFF, please contact ccn@pulmonaryfibrosis.org to learn about opportunities to participate.

How Care Centers can participate in patient-centered activities in coordination with the PFF

Improve the Diagnostic Process

PFF: Evaluate the diagnostic process and time to diagnosis, share recommendations and identified barriers to shorten the time to diagnosis

Care Center: Distribute PFF educational materials to patients
• Collaborate with community physicians and care providers in the accurate diagnosis of ILDs

Enhance the Quality of Care

PFF: Establish best practices across the CCN to identify PF standards of care • Promote the Care Center support group through calendar listings on the PFF website, social media

Care Center: Increase trainee participation at PFF summit • Promote existing educational event during the year to support growth and outreach from established events • Participate on CCN and NAHN Committees



PATIENTS

Accelerate Research

PFF: Facilitate greater research collaboration among the CCN centers

Care Center: Direct patients to the PFF Clinical Trial Finder tool and Clinical Trials Newsletter • Support the PFF Registry recruitment into the Community and Care Center Registries and submit ancillary studies to utilizing the PFF Registry • Submit local studies for inclusion in the collaborator dashboard

Effectively Advocate for Needs of the PF Community

PFF: Provide support and information through the PFF Support Group Leader Network • Provide PFF patient education materials, logos and templates

Care Center: Distribute PFF educational materials to patients
• Participate in PFF Hill Day, advocacy surveys and projects