



**PFF Care Center Network**<sup>™</sup>  
Care. Education. Innovation.

**CARE CENTER NETWORK CRITERIA 2024**  
**CARE CENTERS**  
**CLINICAL ASSOCIATES**





## PFF CARE CENTER NETWORK

First established in 2013, and thanks to ongoing efforts and collaboration of the PFF and the PF healthcare community, the PFF Care Center Network (CCN) has 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. Through the CCN, Care Centers and Clinical Associates collaborate to promote and provide quality care to those living with PF. The diagram below illustrates the focus of the patient within the relationships between the PFF, CCN and community.



- 1** Pulmonary Fibrosis Foundation
- 2** Pulmonary Fibrosis Community
- 3** Care Center Network
  - Care Centers
  - Clinical Associate Sites



**PFF Care Center Network™**

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The Care Center Network utilizes a multidisciplinary approach to deliver comprehensive patient care, participates in patient-oriented PF research, provides interested patients with information on relevant clinical trials, and works with the PFF to provide educational materials and engage the local community through PFF programs and advocacy.

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.

For centers interested in joining the CCN, more information is available in the eligibility criteria chart in the following pages to help determine which CCN membership category might be the best fit.



## MAJOR CRITERIA FOR PFF CARE CENTERS AND CARE CENTER CLINICAL ASSOCIATES<sup>1</sup>

	Care Center	Clinical Associate
<b>Center Director</b>	This role is required	This role is required
	Is Board certified in Pulmonary Medicine	Is Board certified in Pulmonary Medicine
	Has at least <b>three (3) years</b> post-pulmonary fellowship clinical experience in the care of patients living with PF	<i>Preferred but not required:</i> Has at least <b>two (2) years</b> post-pulmonary fellowship clinical experience in the care of patients living with PF
	Is responsible for providing the operational oversight of the Center including all patient programs	Is responsible for providing the operational oversight of Clinical Associate
	Coordinates the PF efforts of the institution and core care team to provide care, teaching, and research at the Center	
	Coordinates the provision of education to the institution and/or affiliated schools regarding recent advances in PF research and clinical care	
	Coordinates the research responsibilities of the Center. This should include establishing ongoing	

<sup>1</sup> Approved by CCN Steering Committee in March 2023



	Care Center	Clinical Associate
	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	
<b>Center Associate Director</b>	This role is required	<i>This role is preferred but not required.</i> However, if this role does not exist at the Center, then there must be at least one additional physician to support the PFF efforts
	Is Board certified in Pulmonary Medicine	Is Board certified in Pulmonary Medicine
	Has at least <b>three (3) years'</b> post-pulmonary fellowship clinical experience in the care of patients living with PF	Has at least <b>one (1) year</b> post-pulmonary fellowship clinical experience in the care of patients living with PF
	Provides the operational oversight of the Center including all patient and affiliate programs in collaboration with Center Director	Provides the operational oversight in-collaboration with the Director
	Coordinates the provision of education to the institution and/or affiliated schools regarding recent advances in PF research and clinical care	



	Care Center	Clinical Associate
	Coordinates the research responsibilities of the Center. This should 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	
<b>Center Lead Site Coordinator</b>	Is a Nurse or Allied Health Professional with ILD experience in the outpatient and inpatient delivery of care or research with patients living with ILD	Is a Nurse or Allied Health Professional with ILD experience in the outpatient and inpatient delivery of care or research with patients living with ILD
	Serves as a representative to the Nursing and Allied Health Network	Serves as a representative to the Nursing and Allied Health Network
<b>Personnel<sup>2</sup></b>	Pulmonary hypertension specialist †	Has the ability to refer to a <b>Pulmonary hypertension specialist</b> and can identify upon request the individual or site typically used

<sup>2</sup> † 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.

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



	Care Center	Clinical Associate
	Lung transplant specialist (Center must have capacity to coordinate pre-transplant care) †	Has the ability to refer to a <b>Lung transplant specialist</b> and can identify upon request the individual or site typically used
	Rheumatologist †	Has the ability to refer to a <b>Rheumatologist</b> and can identify upon request the individual or site typically used
	Thoracic surgeon / pulmonary interventionalist ◇	Has the ability to refer to a <b>Thoracic surgeon / pulmonary interventionalist</b> and can identify upon request the individual or site typically used
	Other pulmonologists, nurses and allied health professionals (involved in the care of ILD) ◇	
	Cardiologist ◇	
	Gastroenterologist ◇	
	Geneticist/Genetic Counselor ◇	



	Care Center	Clinical Associate
	Infectious Disease Specialist ◇	
	Social worker ◇	
<b>Facility</b>	Referral plan for procedures or services not found at the CCN site	Referral plan for procedures or services not found at the Clinical Associate
	Accreditation by an entity that is approved by CMS	Accreditation by an entity that is approved by CMS
	Access to Intensive Care Unit	Access to Intensive Care Unit (even if not onsite, able to identify which ICU is used)
	Access to Outpatient Clinic	Access to Outpatient Clinic
	Access to Pulmonary function	Access to Pulmonary function
	Access to Respiratory Care	<i>Preferred but not required:</i> Access to Respiratory Care
	Access to Clinical Research Program	<i>Preferred but not required:</i> Access to Clinical Research Program





	Care Center	Clinical Associate
	Access to Diagnostic Services	<i>Preferred but not required: Access to Diagnostic Services</i>
	Access to Sleep study lab	<i>Preferred but not required: Access to Sleep study lab</i>
	Access to Pulmonary Rehabilitation Program	<i>Preferred but not required: Access to Pulmonary Rehabilitation Program</i>
	Access to Palliative Care Program	<i>Preferred but not required: Access to Palliative Care Program</i>
	Access to Specialty Pharmacy	<i>Preferred but not required: Access to Specialty Pharmacy</i>
	Minimum cohort of <b>150 unique ILD patients</b> followed annually	Minimum cohort of <b>50 unique ILD patients</b> followed annually
	Multidisciplinary diagnosis meetings must be held at least monthly regardless of patient volume	<i>Preferred but not required: Multidisciplinary diagnosis meetings must be held at least monthly regardless of patient volume. If the MDD is not available at the CC Clinical Associate, then they must collaborate with a Care Center to facilitate accurate diagnosis</i>



	Care Center	Clinical Associate
	As feasible, incorporates use of the published PFF High-Resolution Computerized Tomography (HRCT) protocol	As feasible, incorporates use of the published PFF High-Resolution Computerized Tomography (HRCT) protocol
	Availability of a local support group that meets at least quarterly	Availability of a local support group or referral to PFF Support Group.
	Mechanism to deliver outpatient clinic reports and discharge summaries to referring physicians	
	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	
<b>Research</b>	Participates in clinical research, with an emphasis on clinical trials	<i>Preferred but not required:</i> Participates in clinical research, with an emphasis on clinical trials
	<i>Accelerate Research:</i> Participate in at least one of the following: <ul style="list-style-type: none"> <li>• Direct patients to the PFF Clinical Trial Finder tool and Clinical Trials Newsletter</li> <li>• Support the PFF Registry recruitment into the</li> </ul>	<i>Accelerate Research:</i> Participate in at least one of the following: <ul style="list-style-type: none"> <li>• Direct patients to the PFF Clinical Trial Finder tool and Clinical Trials Newsletter</li> <li>• Support the PFF Registry recruitment into the</li> </ul>



	Care Center	Clinical Associate
	Care Center Registry <ul style="list-style-type: none"> <li>• Submit ancillary studies to utilizing the PFF Registry</li> <li>• Submit local studies for inclusion in the collaborator dashboard</li> </ul>	Care Center Registry
<b>Engagement with the PFF</b>	Attend the biennial PFF Summit (Director <b>and</b> Site Coord representatives)	Attend the biennial PFF Summit (Director <b>or</b> representative)
	Make appropriate referrals to the PFF Help Center	Make appropriate referrals to the PFF Help Center
	<i>Improve the Diagnostic Process:</i> Distribute PFF educational materials to patients	<i>Improve the Diagnostic Process:</i> Distribute PFF educational materials to patients
	<i>Enhance the Quality of Care:</i> Participate in at least one of the following: <ul style="list-style-type: none"> <li>• Increase trainee participation at PFF summit</li> <li>• Promote existing PFF educational events during the year to support growth and outreach from established events</li> </ul>	<i>Enhance the Quality of Care:</i> Promote existing PFF educational events during the year to support growth and outreach from established events
	<i>Effectively Advocate for Needs of the PF Community:</i> Participate in at least one of the following: <ul style="list-style-type: none"> <li>• Distribute PFF educational materials to</li> </ul>	<i>Effectively Advocate for Needs of the PF Community:</i> Participate in at least one of the following: <ul style="list-style-type: none"> <li>• Distribute PFF educational materials to</li> </ul>



	Care Center	Clinical Associate
	<p>patients</p> <ul style="list-style-type: none"> <li>Participate in PFF Hill Day, advocacy surveys and projects</li> </ul>	<p>patients</p> <ul style="list-style-type: none"> <li>Participate in PFF Hill Day, advocacy surveys and projects</li> </ul>
<b>Engagement with the CCN</b>	Care Centers are not required to partner with a Clinical Associate, but if the Care Center is in good standing and wishes to pair with a Clinical Associate, the Care Center may discuss with the PFF CCN team about how to do so	Every Clinical Associate will be paired with a current Care Center in good standing. The Clinical Associate will be responsible for identifying their primary Care Center with which they partner
	<i>Enhance the Quality of Care:</i> Participate on CCN and NAHN Committees (at least one representative on a Committee or Working Group)	<i>Preferred but not required: Enhance the Quality of Care:</i> One representative on a CCN or NAHN Committee or Working Group
	Attend Network sponsored activities such as journal club, and meetings (Center has representatives at least 50% of meetings)	Attend Network sponsored activities such as journal club, webinars, and meetings
	Submit annual CCN Report	Submit annual Clinical Associate Report
	Participate in site visits with PFF CCN team upon request	Participate in site visits with PFF CCN team upon request
	Participate in CCN Annual Meeting	Participate in CCN Annual Meeting



	Care Center	Clinical Associate
	Volunteer to lead discussion at a support group	
<b>Engagement with the community</b>	<i>Improve the Diagnostic Process:</i> Collaborate with <b>community physicians and care providers</b> in the accurate diagnosis of ILDs	<i>Improve the Diagnostic Process:</i> Collaborate with <b>Care Center Network sites</b> in the accurate diagnosis of ILDs
	<i>Accelerate Research:</i> Support the PFF Registry recruitment into the Community Registry and submit ancillary studies to utilizing the PFF Registry	<i>Accelerate Research:</i> Support recruitment into the PFF Community Registry



## PFF CARE CENTER NETWORK ACTIVITIES

The CCN 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 and Clinical Associates 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 part of the CCN 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 and Clinical Associate 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 Care Center and Clinical Associate will assist with a PF patient/caregiver support group that meets at least quarterly.

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

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

## How the CCN 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

**CCN:** 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

**CCN:** 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

**CCN:** 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

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