

CARE CENTER NETWORK GUIDELINES

The PFF Care Center Network (CCN) is a growing group of medical centers with expertise in treating patients with fibrotic lung disease and is dedicated to improving the lives of those living with pulmonary fibrosis (PF). CCN sites utilize a multidisciplinary approach to deliver comprehensive patient care. Members of the CCN work with the PFF to actively engage their local PF community by offering patients and caregivers up-to-date educational materials and access to PFF Signature Programs. For further information, please see the PFF CCN Fact Sheet at www.pulmonaryfibrosis.org/our-role/news-media/media-resources.

Below you will find a description of the components utilized to evaluate and select CCN sites.

Core Components of PFF CCN Site

Care & Infrastructure

CCN sites are required to maintain the following infrastructure:

Core Care Team

1. Director (physician as described in this document)
2. Associate Director (physician as described in this document)
3. Clinic Coordinator (team member other than physician)
4. Social Worker
5. Nurse Specialist and/or Respiratory Therapist
6. Research Coordinator

Team members must regularly attend outpatient clinics and team conferences and be available for inpatient consultation or coordinator of care with inpatient staff.

Facilities

1. Outpatient and inpatient facility or affiliation with an inpatient facility for inpatient care and services as described below:
 - a) Intensive Care Unit
 - b) Respiratory Care Department
 - c) Social Work Department
 - d) Identifiable Outpatient Clinic area
 - e) Clinical Research Program
 - f) Lung Transplant Program
 - g) Accreditation by an entity that is approved by CMS
2. Laboratories
 - a) Pulmonary function
 - b) Sleep study lab
3. Multi-specialty team approach to diagnosis
4. Access to a Pulmonary Rehabilitation Program
5. Consultative Personnel (may be included on Core Care Team)

CARE CENTER NETWORK GUIDELINES

- a. Pulmonologist
- b. Cardiologist
- c. Gastroenterologist
- d. Geneticist/Genetic Counselor
- e. Infectious Disease Specialist
- f. Psychiatrist and/or Psychologist
- g. Pathologist-Pulmonary
- h. Sleep Medicine Specialist
- i. Radiologist-Thoracic
- j. Surgeon-General & Thoracic

Other

1. Referral plan for procedures or services not found at the CCN site.
2. Mechanism to deliver outpatient clinic reports and discharge summaries sent to referring physician.
3. Minimum of equivalent of 1/2 day clinic every week.

Staffing

CCN Center Director (CD) Qualifications & Responsibilities

Qualifications:

The Center Director must be board certified in Pulmonary Medicine and have at least three (3) years post-fellowship clinical experience in the care of PF patients. The PFF may allow other subspecialties to serve as CD if their clinical training included extensive contact with PF patients.

The Center Director 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 Center Director 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. The Center Director should attend the biennial PFF Summit.

CARE CENTER NETWORK GUIDELINES

Associate Center Director (ACD) Qualifications & Responsibilities

The ACD should have the same or comparable training and certification as the Center Director so that he/she is fully capable of assuming directorship in the Center Director's absence. The ACD must be involved on a day-to-day basis 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.

Responsibilities & Activities of PFF Care Center Network Sites

PFF CCN sites will work the Pulmonary Fibrosis Foundation to actively engage their local PF community, further clinical care, instructional and research objectives through participation in selected PFF Signature Programs. CCN sites will work with the PFF to promote the Mission of the PFF.

Community Engagement Activities

Each Center will participate in the following engagement activities:

1. PFF & Center Engagement Training
 - a. Members of the Core Care Team will participate in a PFF facilitated informational session to discuss the programs and materials available to the site.
 - i. The Center Director and Clinical Coordinator are required for this training and other members of the Core Care Team are invited to attend.
 - b. Members of the Core Care Team are strongly encouraged to attend a biennial CCN & Registry meeting to be held in conjunction with the PFF Summit. Those who cannot attend in person can attend via teleconference.
2. Host an annual Patient & Caregiver and/or Healthcare Professional Educational Event.
3. PFF Support Group Leader Network
 - a. Each Center will help run a PF support group that meets at least quarterly.
4. PFF Ambassador Program
 - a. The Center is encouraged to utilize the PFF Ambassador Program during their quarterly or monthly support group meetings as well as their educational event.
5. PFF Disease Education Webinar Series
 - a. The Center will support this program by facilitating knowledge of the series to their patients and helping with the development and presentation of content as applicable.
6. PFF Patient Communication Center (PCC)
 - a. The Center will have information about the PCC available in their clinics as part of the educational materials and collateral distribution.