WORKING TOGETHER TO IMPROVE PATIENT OUTCOMES

PFF CARE CENTER NETWORK

Pulmonary Fibrosis FOUNDATION
PFF CARE CENTER NETWORK

The PFF Care Center Network (CCN) is a group of medical centers dedicated to improving the lives of those living with pulmonary fibrosis (PF). Care Centers have expertise in treating adult patients with fibrotic lung diseases and utilize a multidisciplinary approach to deliver comprehensive patient care, engage in patient-oriented PF research, and work with the PFF to provide educational materials and engage the local community through PFF programs.

MAJOR CRITERIA TO BE USED TO SELECT PFF CARE CENTERS

1. Personnel
   a. Care Center Director (see criteria below)
   b. Nurse (or equivalent clinical staff) who has effort dedicated toward working with patients to aid in obtaining medications, durable medical equipment (including oxygen), prior authorizations, etc. to improve patient care
   c. Radiologist with expertise in thoracic imaging
   d. Pathologist with expertise in pulmonary pathology

2. Easy, fast appointment
   a. Wait time for new appointment: “usual” waiting time 4 weeks or less; urgent consults within 2 weeks
   b. Phone number available to patients to reach the ILD program directly

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

4. Availability of a local support group

5. Willingness to provide and modify the HRCT acquisition and reconstruction protocol used at their center

6. Access to clinical research, with an emphasis on clinical trials, for patients
ADDITIONAL CRITERIA

Additional Personnel

1. Associate Director (may be waived in some circumstances)
2. Other pulmonologists, nurses and allied health professionals (involved in the care of ILD)
3. Research Coordinator
4. Cardiologist
5. Pulmonary hypertension specialist
6. Rheumatologist
7. Gastroenterologist
8. Geneticist/Genetic Counselor
9. Infectious Disease Specialist

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

Facilities

ACCESS TO OUTPATIENT AND INPATIENT FACILITIES AND SERVICES AS DESCRIBED BELOW:

a) Intensive Care Unit
b) Respiratory Care
c) Social Work
d) Outpatient Clinic
e) Clinical Research Program
f) Lung Transplant Program
g) Accreditation by an entity that is approved by CMS
h) Laboratories
   I. Pulmonary function
   II. Sleep study lab
i) Multi-specialty team approach to diagnosis
j) Pulmonary Rehabilitation Program

Process/Other

1. Referral plan for procedures or services not found at the CCN site.
2. Mechanism to deliver outpatient clinic reports and discharge summaries to referring physicians.
3. Minimum of equivalent of ½ day clinic every week dedicated to ILD patient care
**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 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 Volunteer Meeting* and *PFF Summit*.

*Associate Center Director (ACD) Qualifications & Responsibilities*

The ACD should have the same or comparable training and certification as the Center Director to serve as interim director. 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.
PFF CARE CENTER ACTIVITIES

CCN sites will work with the PFF to promote its mission to mobilize people and resources to provide access to high quality care and leads research for a cure so people with pulmonary fibrosis will live longer, healthier lives. CCN sites will use their local expertise and selected PFF programs to engage the local PF community to further clinical care, research and provide education.

The core team of each center will participate in a PFF-facilitated information session on the programs and materials available to Care Centers.

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

- Provide support and information through the PFF Support Group Leader Network.
- Distribute PFF educational materials during to patients.
- Assign a Center staff member associated with the PF support group to participate in quarterly PFF Support Group Leader Network teleconferences.
- Provide PFF patient education materials, logos and templates.
- Have access to an available existing support group or, if an existing support group does not exist, develop a support group within 6 months of Care Center designation.
- Promote the Center support group through calendar listings on the PFF website, social media.