

APPLICATION FOR PCD FOUNDATION CLINICAL CENTER STATUS

Thank you very much for your interest in applying to become a PCD Foundation-approved Clinical Center. Centers that meet criteria for this designation will have demonstrated their commitment to continuous improvement in PCD diagnosis and care.

The first step in the process to achieve PCD Foundation Clinical Center status is completion of this application. A copy of the current guidelines for PCD Clinical Centers is attached to the back of this application. Center status is associated with the following benefits:

1. Listing of your center as PCD Clinical Center on the PCD Foundation website
2. Referral of patients by the PCD Foundation to your center.
3. Inclusion of your medical director (and other faculty as appropriate) in relevant communications from the PCD Foundation.
4. Inclusion of your center in the planning process, as appropriate, for various PCD programs such as:
 - North American PCD Registry (NAPCDR)
 - PCD Clinical Trials
 - PCD Advocacy
 - PCD Education

Application Instructions

1. The application pages for PCD specialists (adult pulmonologist, pediatric pulmonologist and otolaryngologist) should be completed by these persons directly and signed (these are the core or mandatory faculty). One of these specialists should be designated as PCD Clinical Center Director.
2. If there will be co-directors, have both persons fill out a separate PCD specialists page.
3. Please include the following with your application:
 - Curriculum vitae for PCD specialists (if desired, forward by email).
4. Send the completed application and all related documentation to the PCD Foundation:
 - Email: info@pcdfoundation.org
 - Fax: +1 866.371.7575
 - Mail: PCD Foundation, Attention: PCDF Clinical Center Committee, 10137 Portland Avenue, South Minneapolis, Minnesota 55420 USA
5. **Please direct questions to the PCD Foundation at +1 952.303.3155.**

Application Process

1. Review PCD Clinical Centers Guidelines (attached to the back of this application).
2. Complete and return this application to the PCD Foundation.
3. Applications will be reviewed for completeness and forwarded to the PCDF Center Committee for further review.
4. Prospective centers that meet center guidelines will be offered a site visit by members of the PCDF Center Committee.
5. Following the site visit, the PCD Center Committee will discuss the prospective center, vote on center status, and forward their recommendations to the PCD Foundation board of directors (additional materials may be requested from the prospective center during this process).
6. The PCD Foundation board of directors will make a final determination about PCD Clinical Center status.

Additional Site Considerations

By completing and submitting this application, you are committing to collaborative efforts to:

1. Enhance diagnostic accuracy in PCD, including:
 - Provide diagnostic data
 - Participate in TEM review exercises
 - Work with the PCD Clinical Center Network to develop and implement standard operating procedures (SOPs) for nasal nitric oxide (nNO) collection and analysis and securing the necessary IRB approval and informed consents for using nNO at your site.
2. Develop standards of care for diagnosis and treatment of PCD

Facility Information

Main Clinical Facility: The clinical facility where most PCD-related visits and tests will occur

Name:
Address:
Main Phone:
Facility Type: Academic Private

Affiliated Hospitals and Facilities*

Code	Name	Distance
B		
C		
D		
E		
F		

*Code = arbitrary facility code that will be used in the next section and the last section (the main hospital is code A); Distance = the distance from the main facility in tenths of miles.

Service Availability*

Service	Available	Facility Code	Comments
PCD Clinic—Main			
ENT Clinic			
Genetics Clinic/Genetic Counseling			
Ciliary Biopsy—EM Analysis			
Nasal Nitric Oxide			
Sputum Cultures			
Pulmonary Function Tests			
Chest CT Imaging for Bronchiectasis			
Sinus CT Imaging for Sinusitis			

*Indicate the availability of each service by placing a Yes or No in column 2. Indicate the physical location(s) of each service by listing the facility code(s) (A-F) in column 3.

PCD Specialist

Please Indicate Specialty: Adult Pulmonologist Pediatric Pulmonologist Otolaryngologist

Will this Person be the Designated Center Director? Yes No

General Information

Name:	
Office Address:	
Email:	Office Tel:
Cell:	Fax:
Title:	Degrees:
Specialty and Subspecialty:	
Academic Affiliation:	
Which PCD Clinical Center have you visited? When?	
Will there be a co-director at your Center? Yes No	
If yes, co-director Name:	

Post-College Training

(Graduate/Medical School, Residency, Fellowship, etc.)

Program (i.e. Medical School)	Institution Name	State (if in US)	Dates (Years)

PCD Experience

How many PCD or suspected PCD patients has your center identified in the past 3 years?
Have you had the opportunity to attend a PCD-related conference or lecture at a national meeting? If so, which ones?

Signature

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PCD Specialist

Please Indicate Specialty: Adult Pulmonologist Pediatric Pulmonologist Otolaryngologist

Will this Person be the Designated Center Director? Yes No

General Information

Name:	
Office Address:	
Email:	Office Tel:
Cell:	Fax:
Title:	Degrees:
Specialty and Subspecialty:	
Academic Affiliation:	
Which PCD Clinical Center have you visited? When?	
Will there be a co-director at your Center? Yes No If yes, co-director Name:	

Post-College Training

(Graduate/Medical School, Residency, Fellowship, etc.)

Program (i.e. Medical School)	Institution Name	State (if in US)	Dates (Years)

PCD Experience

How many PCD or suspected PCD patients has your center identified in the past 3 years?
Have you attended a PCD-related conference or lecture at a national meeting? If so, which ones?

Signature

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PCD Specialist

Please Indicate Specialty: Adult Pulmonologist Pediatric Pulmonologist Otolaryngologist

Will this Person be the Designated Center Director? Yes No

General Information

Name:	
Office Address:	
Email:	Office Tel:
Cell:	Fax:
Title:	Degrees:
Specialty and Subspecialty:	
Academic Affiliation:	
Which PCD Clinical Center have you visited? When?	
Will there be a co-director at your Center? Yes No	
If yes, co-director Name:	

Post-College Training

(Graduate/Medical School, Residency, Fellowship, etc.)

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PCD Experience

How many PCD or suspected PCD patients has your center identified in the past 3 years?
Have you attended a PCD-related conference or lecture at a national meeting? If so, which ones?

Signature

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Adjunct Faculty*

Faculty	Name	Phone	Facility Code
Cardiologist			
Fertility/Reproductive Specialist			
Gastroenterologist			
Geneticist			
Infectious Disease Specialist			
Neonatologist			

Recommended Ancillary Faculty*

Faculty	Name	Phone	Facility Code
Nephrologist			
Neurologist			
Radiologist/Imaging Specialist			

*Please fill in the name for all faculty that have been identified as part of your prospective Center; if a specific individual has not been identified at this time, write in "None." Indicate the office location of each faculty by listing the appropriate facility code (A-F) from page 2.

Clinic Support Staff

Do You Have:

Respiratory/Physical Therapy Support for Patient Education on Airway Clearance Modalities and Inhaled Medication Delivery: Yes No

Nurse Coordinator: Yes No

Administrative Support: Yes No

Critical Path Items - What items does this site absolutely need to be operational for which there is no current or planned funding?

Line Item	Cost	Detail
a.	\$	
b.	\$	
c.	\$	
d.	\$	

GUIDELINES FOR PCD CLINICAL CENTERS

Definition

A primary ciliary dyskinesia (PCD) Clinical Center is defined as a medical team that has been recognized by the PCD Foundation as possessing the personnel and resources necessary to provide comprehensive evaluation, treatment, and education to persons with known or suspected PCD and to their health care providers. The necessary personnel and resources are outlined below.

PCD Clinical Centers are encouraged to engage in clinical and basic science research in PCD, to participate in clinical diagnostic and treatment trials, the North American PCD Registry when available and in PCD Foundation activities. PCD Clinical Centers will serve as primary access points for patient recruitment into clinical trials. The local institutional human assurance committee must approve any research protocols undertaken in PCD centers.

Evolving Standard of Care

PCD Clinical Care Centers will take the lead in educating healthcare professionals about PCD and will participate in developing standards of care for the diagnosis and treatment of PCD.

Personnel

Centers must have sufficient personnel with knowledge about PCD to be able to respond in a coordinated multidisciplinary way to patient inquiries, and coordinate evaluation, treatment and education of patients and their families in a timely manner. The recommended time commitments for selected staff are a minimum estimate and will likely increase with expansion of PCD Clinical Centers.

Core Staff, Capacities, and Facilities

The following personnel and facilities must be available at all centers:

1. **Center Director** Pediatric or adult pulmonologist or otolaryngologist (see below) with specialized knowledge of the manifestations of PCD and the ability to coordinate the multidisciplinary diagnosis and treatment of patients referred to the Center is critical. The center director spends part of his/her time devoted to: seeing patients in clinic, screening for progression/manifestations, following patients on other services while they are receiving care at the PCD center, and dealing with complex issues leading to referral. At most centers, he or she will eventually need at least a 5%-15% time commitment to PCD.
2. **Otolaryngologist** with experience and expertise in the treatment of PCD patients. This physician should be identified early in the formation of the center and may serve as center director.
3. **Administrative staff** with sufficient knowledge to respond to patient inquiries and coordinate patient care in a timely fashion. The administrative staff should have adequate financial support to allow at least a 5-15% time commitment to PCD.
4. **Respiratory and/or Physical Therapist** with experience and expertise in administering airway clearance and inhaled therapies and with patient and caregiver education for PCD.
5. **Provide nasal nitric oxide (NO) measurement** as a screening tool to identify possible undiagnosed cases of PCD.
6. **Support** patient data entry into the **North American PCD Registry (NAPCDR)** on an annual basis once the NAPCDR has been established.

Additional Faculty

In addition to the core staff above, a PCD Clinical Center should ideally have on site, or have ready access to the following personnel:

Adjunct Faculty:

1. Neonatologist to facilitate early identification of potential PCD patients presenting with unexplained neonatal respiratory distress
2. Cardiologist/pediatric cardiologist with knowledge of PCD/heterotaxy/CHD association
3. Genetic counselor or geneticist
4. Fertility specialist
5. Infectious disease specialist
6. Gastroenterologist

Recommended Ancillary Faculty (if needed to manage less common complications of PCD):

1. Nephrologist
2. Neurologist
3. Radiologist/imaging specialist

Facilities

To be listed on the PCD Foundation website, a PCD Clinical Center should have the core faculty (see above) on site to perform all of the procedures necessary to evaluate and treat PCD.

Center Certification

The above criteria are guidelines which enable a center to be listed on the PCD Foundation website as a certified PCD Clinical Center.

- Prior to being certified as a PCD Clinical Center, a site visit may be required.
- New facilities that are interested in seeking center status must complete the application for center status through the PCD Foundation.
- All centers will provide an annual written report and will undergo evaluation by site visit at least every 5 years to assure that they continue to meet center criteria.
- Centers that no longer meet center criteria will be granted a grace period of 1 year to re-establish center criteria. Center status will be rescinded after one year if criteria are not fulfilled in a satisfactory manner.