



The Leeds
Teaching Hospitals
NHS Trust



The North of England Primary Ciliary Dyskinesia Service

Information
for healthcare
professionals

Welcome to the adult Primary Ciliary Dyskinesia (PCD) service for the North of England. We have been commissioned by NHS England to provide a management service for the region and this leaflet aims to explain what we do and how we can support you as a clinician.

Who are we?

Our multidisciplinary team consists of;

-  Professor Daniel Peckham - Consultant
-  Dr Giulia Spoletini - Consultant
-  Dr Ian Clifton - Consultant
-  Nicola Burke - Lead Nurse
-  Connie Webster - Highly Specialised Physiotherapist
-  Emma Farrell - PCD Highly Specialised Dietician
-  Ann Jones and Sharon Mobbs - Administrators

We have access to ENT, fertility, psychology and audiology as required. Additionally we also provide a diagnostics service and accept referrals from across the North of England.

What do we do?

The European Respiratory Society (ERS) and NHS England recommend highly specialised management is needed for patients with a suspected, or known, diagnosis of PCD. Early diagnosis and appropriate treatment can reduce morbidity, mortality and disease progression.

Currently, there is little research into treatment for PCD and practice varies from hospital to hospital.

Our aim is to collaborate together and support the development of a fantastic, inclusive and friendly adult Northern network with close links to paediatrics.

- **We want to develop a network and national guidelines** to standardise care for patients with PCD. Collaborating with the people who know your patients best- you!
- **Ensure that patients have access to optimal care, wherever they live.** Linking in with teams across Northern England, paediatrics and other regional centres.
- **We want to increase awareness and education about PCD** thus leading to new diagnoses, and improved care. This includes both healthcare professionals and patients. Think PCD!
- **We aim to support and plan with yourselves what is best for your patients and your teams.** This would usually involve joint clinics annually at your usual workplace, although this may not suit all teams and other arrangements can be made.
- **We want to contribute to a PCD registry database,** helping to inform future research and guide health improvements. Annual assessments allow us to collect the majority of data required for the registry.
- **Our team are happy to meet to discuss further and answer any questions or concerns. We are looking forward to working together.**

What is Primary Ciliary Dyskinesia?

PCD is a rare, inherited disease resulting in abnormal ciliary motility. Cilia can be dyskinetic, immotile or even absent completely. This prevents effective mucociliary clearance from the lungs, paranasal sinuses and ears and can result in repeated infections.

Some signs and symptoms of PCD may include;

- Productive, wet cough (even when well)
- Breathlessness / wheeze
- Sinusitis
- Rhinitis



- Hearing problem / recurrent ear infections
- Fertility problems
- 50% of individuals with PCD have organ laterality defects including *Situs Inversus* or *dextrocardia*

Repeated respiratory infections can lead to chronic airways infection and progressive lung disease and *bronchiectasis*.

Useful contacts

Our outpatient clinics are held at Seacroft Hospital main outpatients.

Seacroft Hospital
York Road
Leeds
LS14 6UH

0113 206 6816

Clinical Nurse Specialists are available weekdays 8am-4pm for clinical issues/questions.

Or please contact Lead Nurse

Niccola Burke via email:

niccola.burke@nhs.net

Referrals can be made via

Ann Jones

ann.jones27@nhs.net

or **Sharon Mobbs**

Sharon.Mobbs@nhs.net