

Living with
PRIMARY CILIARY DYSKINESIA

German Support Group for patients and their families

PCD often affects:



EARS



SINUSIS



HEART



LUNGS

WHAT IS PCD?

- + PCD is a **rare genetic disorder** associated with chronic infections of **lungs and sinuses**
- + Due to **restricted mobility of cilia**, mucus and bacteria remain in the airways, leaving them susceptible to inflammations
- + **50%** of those affected, show a **situs inversus** [displaced arrangement of internal organs] This associated occurrence is called **Kartagener syndrome**
- + PCD affects approximately **1:15,000**



SYMPTOMS

- + **Strained breathing**
- + Neonatal respiratory distress syndrome
- + Nose blocked with secretion
- + **Persistent cough**, parts of the lung collapse
- + Inflammation of sinuses and nasal polyps
- + Chronic bronchitis and **pneumonia**
- + **Ear infections**, decreased hearing ability
- + Respiratory insufficiency
- + Reduced fertility
- + **Bronchiectasis**



DIAGNOSIS

PCD is an **incurable** disease. **Early diagnosis** helps to prevent severe lung damage and is essential for therapy. Finding and detecting **genetic defects** is being researched.

- + Measurement of nasal NO concentration
- + Immunofluorescence Microscopy [IF]
- + Genetic analysis
- + High frequency video microscopy analysis [HVMA]
- + Transmission electron microscopy [TEM]



THERAPY

Regular monitoring (e.g. lung function test and sputum examination) and **therapy treatment** coordinated by an experienced doctor.

- + Chest **physiotherapy** and **inhalation therapy** for mobilization of mucus in the lungs
- + **Nasal irrigation** and inhalation for clearing the upper airways
- + Targetted **antibiotic therapy**
- + Pneumococcal and annual flu **vaccination**



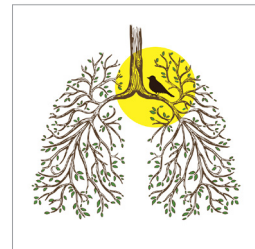
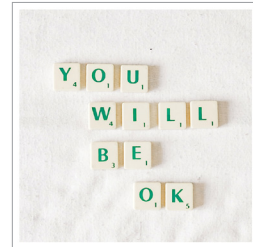
GERMAN PCD SUPPORT GROUP

Our goals are:

- + Early diagnosis, raise awareness for PCD
- + Improvement of **medical care** for patients
- + Supporting scientific **research**

Our ways to achieve them:

- + **Exchange** of information between medical specialties and affected patients
- + **Seminars** and patient education
- + Supporting research by awarding the **Manes Kartagener Prize**
- + Public relations work



read
online
now

ZILIENFOCUS

- + Our magazine **Zilienfocus** [focus on cilia] informs about PCD
- + Available for members and the public
- + Have a look and spread the word
- + Donations always welcome



more

ON OUR
WEBSITE



CHRISTINE BRAUNE

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- + Christine.Braune@pcd-ks.info
- + Soon to come: our new website
www.pcd-ks.info



more

ON OUR
WEBSITE