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## We want to hear from you

We value the opinion of our readers and we are looking forward to receive your feedback about this newsletter.

Please send us a personal email with your suggestions or comments to the following address:

[BEATPCD@ersnet.org](mailto:BEATPCD@ersnet.org)



The BEAT-PCD Clinical Research Collaboration (CRC) is funded by the European Respiratory Society.

ISSUE 5 | AUGUST 2022

# BEAT-PCD NEWSLETTER



## ANNUAL EVENTS - September 3rd 2022

Separate registration for each event

### Training school 2022

*September 3rd 2022*

*09:00 - 12:00 CEST*

### Annual meeting 2022

*September 3rd 2022*

*13:00 - 19:00 CEST*



*Registrations for both events, agendas and further information are available on our website:*

<http://beat-pcd.squarespace.com/>

The annual PCD events take place before the ERS international congress. Additional info for the ERS hybrid event is provided [here](#).





## Message from the BEAT PCD chairs

*Welcome to the 5th edition of the BEAT-PCD newsletter.*

*This edition focuses on the upcoming BEAT-PCD in-person events that will take place on September 3rd, before the ERS international congress. Both the Training School and the meeting in collaboration with ERN-LUNG will take place at the Vall d'Hebron Hospital Universitari in Barcelona.*

*In this edition, you will find detailed agendas for both events along with the relevant registration links. In addition, this edition also features our BEAT-PCD guide with an overview of all talks and poster presentations that are relevant to PCD and cilia research and will take place at the ERS hybrid international congress between 4th and 6th of September. Lastly, we are proud to announce the BEAT-PCD patient conference 2022 that will take place in December 2nd-3rd. Early details and the registration link are provided.*

*We hope that you will enjoy reading this edition.*

*Amelia & Myrona*

[www.beat-pcd.squarespace.com](http://www.beat-pcd.squarespace.com)

## Training School 2022 - Agenda

### In-person event\*

Vall d'Hebron Institut de Recerca (VHIR), Vall d'Hebron Hospital Universitari, Vall d'Hebron Barcelona Hospital Campus  
Barcelona, Spain

**Saturday September 3rd 2022**

**09:00 - 12:00 CEST**

\*The Training School primarily targets Early Career Researchers but anyone is welcome to attend.

### TRAINING SCHOOL AGENDA

**09:00 - 09:10 - Welcome to Training School**

#### 1st session: PCD diagnostic testing

**09:10 - 09:30 - Immunofluorescence for PCD testing**

Noelia Baz Redon & Heymut Omran

**09:30 - 09:50 - Genetic testing for PCD training**

Nuria Camats & Hannah Mitchison

**09:50 - 10:10 - Submitted difficult IF & genetic cases**

**10:10 - 10:30 - Coffee break**

#### 2nd session: PCD management

**10:30 - 10:50 - Bronchiectasis management in adults with PCD**

Eva Polverino

**10:50 - 11:10 - LCI in PCD training**

Jobst Rohmel

**11:10 - 11:30 - Submitted difficult management cases**

#### 3rd session: Research update

**11:30 - 12:00 - What is new in PCD?**

Claire Hogg

**Register here:** [BEAT-PCD annual Training School](https://www.beat-pcd.squarespace.com)

**CALL for CASES:** Contact us (@[BEATPCD@ersnet.org](mailto:BEATPCD@ersnet.org)) to express interest to present a difficult case for discussion

# Annual meeting 2022

## In-person event

Vall d'Hebron Institut de Recerca (VHIR), Vall d'Hebron Hospital Universitari, Vall d'Hebron Barcelona Hospital Campus  
Barcelona, Spain

**Saturday September 3rd 2022**

**12:00 - 19:00 CEST**



## ANNUAL MEETING AGENDA

**12:00 -13:00 Lunch**

**13:00 -13:30 - Welcome to the annual meeting and Patient Perspectives**

*Amelia Shoemark, co-chair, BEAT-PCD*

*Myrona Goutaki, co-chair, BEAT-PCD*

*Heymut Omran, coordinator, ERN-LUNG PCD CORE*

*Trini Lopez Fernandez, chair, PCD Spain*

*Lucy Dixon, chair, PCD Support UK*

**13:30 - 14:00 - Plenary Lecture: Milestones of the PCD research community**

*Eric Haarman, Vrije Universiteit Amsterdam, Netherlands*

**14:00 - 15:00 - ERN-LUNG PCD Registry Updates - General overview**

**14:10 - 14:20** - nNO study (TBD)

**14:20 - 14:30** - Genotype/Phenotype study (J Raidt)

**14:30 - 14:40** - PCD siblings study (P Kouis)

**14:40 - 14:50** - Exacerbation Study (P Anagnostopoulou)

**14:50 - 15:00** - Future studies (H Omran)

**15:00 -15:30 - Coffee break**

**15:30 - 15:40 - Clinical Trial Network (CTN) updates (ongoing & planned clinical trials)**

*Kim Nielsen, Copenhagen University Hospital, Denmark*

**15:40 - 15:50 - SOPs for outcomes of interest in RCTs**

*June K Marthin, Copenhagen University Hospital, Denmark*

**15:50 - 16:50 - BEAT-PCD led project updates**

**15:50 - 16:00** - CiliaVar database (S Crowley & H Mitchison)

**16:00 - 16:10** - Upper airways disease in PCD, EPIC-PCD study (YT Lam)

**16:10 - 16:20** - COVID-PCD study (L Schreck)

**16:20 - 16:30** - Core Outcome measures Set (COS) consensus (E Haarman)

**16:50 - 17:00 - Closing remarks**

**17:00 - 19:00 - Wine Reception**

Register here: [BEAT-PCD annual meeting](https://www.beat-pcd.squarespace.com)

# Detailed PCD and cilia programme at the International ERS 2022 congress

All times refer to local (Barcelona) time (CEST)

\*All e-posters are available at the ERS conference platform after August 22nd

**Sunday 04/09/2022**

## **08:30 – 09:30 Thematic poster sessions**

### **TP-15 Paediatric sleep disorders and management in various diseases**

Sleep disturbances in children with cystic fibrosis and primary ciliary dyskinesia at the beginning and in the first year of COVID-19 pandemic

*T. Şişmanlar Eyuboglu (Ankara, Turkey)*

### **TP-16 Cystic fibrosis in children and adolescents**

Ciliary dyskinesia might be secondary to chronic inflammation in cystic fibrosis

*R. Bonhiver (Liege, Belgium)*

Diagnostic testing in people with primary ciliary dyskinesia around the world: where do we stand?

*L. Schreck (Bern, Switzerland)*

### **TP-20 Bronchiectasis: 1**

Clinical characteristics and imaging of adult PCD patients: a single-center experience.

*C. Kosti (Gerakas, Greece)*

Primary ciliary dyskinesia in Volendam: diagnostic and phenotypic features in patients with a CCDC114 mutation.

*R. Kos (Soest, Netherlands)*

## **13:00 – 14:00 Thematic poster sessions**

### **TP-7 Contribution of host-microbe interactions to respiratory disease**

Method development for flow-cytometric analysis of primary human airway epithelia infected with non-typeable *Haemophilus influenzae*.

*K. Horton (Southampton, United Kingdom)*

Single cell mRNA sequencing of nasal swabs indicate an impaired ciliated cell function in COVID-19 convalescents with persisting dyspnea

*S. Trump (Berlin, Germany)*

### **TP-18 Updates on physical activity, exercise and nonconventional therapies**

Musculoskeletal (MSK) assessment in children and young people (CYP) with Primary Ciliary Dyskinesia (PCD)

*J. Simpson (Birmingham, United Kingdom)*

### **TP-20 Pleural and other respiratory infections**

Pleuropneumonia caused by *Nocardia cyriacigeorgica* in a 14-year-old girl with PCD

*R. Urbantat (Berlin, Germany)*

## **14:15 - 15:30 Oral presentations**

### **8M Chronic airway diseases: from phenotypes to severity**

**14:35** - A primary ciliary dysfunction might be present in severe asthma

*C. Kempeneers (Liège, Belgium)*

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## Monday 05/09/2022

### 08:30 – 09:30 Thematic poster sessions

#### **TP-3 Management of respiratory chronic conditions in primary care**

Relation of health-related quality of life and caregiver anxiety and depression in primary ciliary dyskinesia.

*M. Hizal (Ankara, Turkey)*

#### **TP-5 Advanced models for drug discovery and functional changes in lung disease**

Autosomal recessive mutations in TP73 cause a mucociliary clearance disorder and lissencephaly.

*H. Omran (Münster, Germany)*

High through-put computerised image analysis for PCD diagnostics.

*C. Jackson (Southampton (Hampshire), United Kingdom)*

Relating ciliary dysfunction to clinical phenotypes in COPD.

*J. Tonkin (London, United Kingdom)*

#### **TP-10 Comorbidities in chronic airway diseases**

Longitudinal variation of nasal nitric oxide in patients with Primary Ciliary Dyskinesia and healthy controls.

*C. Pioch (Berlin, Germany)*

#### **TP-15 Lung infections in children: from COVID-19 to postinfectious bronchiolitis obliterans**

Efficacy of antibiotic eradication therapy of early *Pseudomonas aeruginosa* infection in children with primary ciliary dyskinesia.

*D. Gatt (Beer Sheva, Israel)*

The airway microbiota in siblings with primary ciliary dyskinesia: related factors and correlation with clinical characteristics.

*D. Ademhan Tural (Ankara, Turkey)*

#### **TP-18 Basic science of respiratory infection**

IL-4 levels in sputum correlate with increased mucus production and ciliary dysfunction

*E. Cant (Dundee, United Kingdom)*

The influence of the storage medium on respiratory ciliary beating.

*N. Bricmont (Liège, Belgium)*

### 09:45 - 11:00 Oral presentations

#### **8N Chronic and acute lung infections in children**

**09:45:** Reticular basement membrane thickness for prediction of subsequent lung function in children with primary ciliary dyskinesia: follow up study.

*V. Koucký (Tanvald, Czech Republic)*

**09:50:** Distinct inflammatory responses & effect of Azithromycin on respiratory cells in PCD.

*Ž. Varényiová (Prague, Czech Republic)*

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## Monday 05/09/2022

### 12:45 – 14:00 Oral presentations

#### **8N Latest news from paediatric population-based and clinical cohort studies**

**13:20:** Otologic features in patients with Primary Ciliary Dyskinesia- an EPIC-PCD study.  
*M. Goutaki (Bern, Switzerland)*

**13:25:** Comparison of longitudinal outcomes in children with primary ciliary dyskinesia and cystic fibrosis.  
*M. Rosenfeld (Seattle, United States)*

### 13:00 - 14:00 Thematic poster sessions

#### **TP-7 Novel discoveries in immune (dys)function in lung disease**

The role of airway neutrophils in primary ciliary dyskinesia  
*M. Blanter (Leuven, Belgium)*

#### **TP-8 Identifying therapeutic targets and novel drug strategies in pulmonary diseases**

CFAP74-mutations as cause of Primary Ciliary Dyskinesia (PCD): Clinical presentation and diagnostic challenges.  
*L. Biebach (Münster, Germany)*

#### **TP-16 Hot topics in paediatric bronchology**

Do lower airway infections occur concomitant or subsequent to upper airway infections in children with primary ciliary dyskinesia (PCD)?  
*J. Dhanik (Leicester, United Kingdom)*

Association between airway pathogens and lung function in children with Primary Ciliary Dyskinesia (PCD) - a longitudinal study  
*M. Nazari (Leicester, United Kingdom)*

Is genotype a guide for phenotype in primary ciliary dyskinesia?  
*P. Asfuroglu (Ankara, Turkey)*

Primary ciliary dyskinesia: genotype characterization and lung function in a group of Italian patients  
*L. Petrarca (Roma (RM), Italy)*



# Detailed PCD and cilia programme at the International ERS 2022 congress

All times refer to local (Barcelona) time (CEST)

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## Tuesday 06/09/2022

### 08:30 – 09:30 Thematic Poster sessions

#### **TP-7 Emerging therapeutic targets, biomarkers and mechanisms of chronic lung disease**

No effect of lidocaine on ciliary beating frequency and pattern of human nasal epithelial cells in vitro

*S. Savas (Giessen, Germany)*

Basal airway epithelial cells from PCD have distinct proliferative and inflammatory responses

*Ž. Varényiová (Prague, Czech Republic)*

#### **TP-18 Novelties in respiratory muscle testing, training and airway clearance**

Personalising airway clearance in PCD, exploring expert physiotherapist decision making.

*L. Schofield (Leeds, United Kingdom)*

#### **TP-21 Bronchiectasis: 2**

Do adults with Primary Ciliary Dyskinesia (PCD) have a positive experience of home spirometry?

*S. Peake (London, United Kingdom)*

Optimizing the diagnostic approach for Primary Ciliary Dyskinesia with normal ultrastructure

*J. Raidt (Münster, Germany)*

#### **TP-26 Multimodality respiratory imaging research: what is novel in 2022**

PET/MR to study lung morphology and inflammation in children and adolescents with Primary Ciliary Dyskinesia.

*V. Ferraro (Rosa' (VI), Italy)*

Feasibility of Hyperpolarized <sup>129</sup>Xe MRI in Primary Ciliary Dyskinesia.

*W. Wee (Toronto (ON), Canada)*

### 11:15 - 12:30 Oral presentations

#### **8L Bronchiectasis**

**11:20** The role of the NLRP3 inflammasome in mucociliary clearance in bronchiectasis: The EMBARC-BRIDGE study

*L. Perea Soriano (Barcelona, Spain)*

**11:35** Genome sequencing reveals underdiagnosis of primary ciliary dyskinesia in bronchiectasis

*A. Shoemark (Dundee (Angus), United Kingdom)*

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All times refer to local (Barcelona) time (CEST)

\*All e-posters are available at the ERS conference platform after August 22nd

## Tuesday 06/09/2022

### 13:00 – 14:00 Thematic Poster sessions

#### **TP-16 Viral respiratory infections and primary ciliary dyskinesia**

Low incidence and severity of SARS-CoV-2 infections in people with PCD.  
*E. Pedersen (Bern, Switzerland)*

Research priorities for Primary Ciliary Dyskinesia- experts' perspective.  
*M. Goutaki (Bern, Switzerland)*

Research priorities in Primary Ciliary Dyskinesia - patients' perspective.  
*Y. Lam (Bern, Switzerland)*

Sinonasal features in patients with Primary Ciliary Dyskinesia - an EPIC-PCD study.  
*Y. Lam (Bern, Switzerland)*

Evaluating transmission electron microscopy as the sole laboratory test for clinically-suspected PCD cases in a South African public hospital.  
*M. Birkhead (Johannesburg, South Africa)*

Body composition in Primary Ciliary Dyskinesia, does it matter?  
*R. Gaupmann (Wien, Austria)*

PICADAR - is there a need for a separate paediatric score?  
*K. Wallace (West Calder, United Kingdom)*

Anxiety and depression in children with primary ciliary dyskinesia – Experience from a tertiary respiratory centre in the northwest United Kingdom.  
*D. Wood (Chapel Hill, United States)*

### 15:45 - 17:00 Oral presentations

#### **8F New insights into diagnostic and experimental paediatric pulmonology**

**15:55** Comparison of the lung clearance index in preschool children with primary ciliary dyskinesia and cystic fibrosis.  
*J. Röhmel (Berlin, Germany)*

**16:00** Low nitric oxide in Primary Ciliary Dyskinesia due to impaired NOS activity – data driven hypothesis.  
*A. Schlegtendal (Bochum, Germany)*

**16:10** The Relationship of Radiological Scoring with Clinical Findings and Pulmonary Function Decline in Primary Ciliary Dyskinesia.  
*N. Emiralioğlu (Ankara, Turkey)*



# PCD Patient Conference 2022

**ONLINE event**  
**FREE of charge**

The conference is organised by the **BEAT-PCD network and PCD support groups in Europe with the European Lung Foundation.**

**Friday December 2nd and 3rd 2022**



Please register at: [Primary ciliary dyskinesia patient conference 2022](https://beat-pcd.squarespace.com/events)

## **Main topics covered will be:**

- 1) introduction to PCD and its diagnosis,
- 2) living with PCD and managing the disease at all ages,
- 3) current standards of care and future treatments, and
- 4) bringing people with PCD together through support groups.

**The full agenda will be circulated closer to the conference.**

**Language:** The conference will include live presentations from experts and pre-recorded videos from patient volunteers. The talks will be held in English and the patient videos will be in each speaker's language, however we are organising translations of all the presentations and subtitles for the videos in other languages. We will also organise volunteers for the day who would help to translate questions and answers in several languages. If anyone would like to support this effort to make the conference accessible to more patients, please contact us!

**Primary Ciliary Dyskinesia (PCD) Patient Conference**

**Friday December 2nd and Saturday 3rd 2022**

**Topics:**

- PCD the basics
- Getting a diagnosis
- Living with PCD
- Current care and future treatments
- Bringing people with PCD together

**#PCD2022**

**FREE REGISTRATION:** <https://beat-pcd.squarespace.com/events>

# BEAT-PCD Website

The BEAT-PCD website is available in English language and is updated regularly. It provides an overview of the network and describes the the project's aims and objectives, introduces the seven Work Packages, provides resources for both health professionals and patients and is frequently updated with BEAT-PCD related research projects, training activities as well as networking and other events.



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## Projects

### BEAT-PCD supported research projects

For a rare disease such as PCD, international collaboration is essential to improve diagnosis and care. Therefore, BEAT-PCD supports international collaborative projects that aim to fill knowledge gaps and answer important questions for PCD research.

If you would like your project to be supported by BEAT-PCD please contact BEAT-PCD team.

For additional information for each project, check the list below:



Microbial diversity in Primary Ciliary Dyskinesia compared to idiopathic bronchiectasis. A BEAT-PCD and EMBARC biobank study.

Principal Investigator: Stefano Aliberti

Contact Person: Martina Orzano

### Quick links

- Resources
- Upcoming Events
- Twitter



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## Home

Primary ciliary dyskinesia (PCD) is a rare genetic disease

Cilia that line the mucosal surface are dysfunctional and cannot clear mucus leading to neonatal respiratory distress, persistent daily wet cough, recurrent upper and lower airway infections, bronchiectasis, hearing impairment and persistent rhinosinusitis.

Cilia are common structures throughout the body, so PCD may affect other organs, for example leading to situs inversus, congenital heart defects and infertility. Mutations in 50 different genes have been identified to date, accounting for approximately 70% of PCD.

### News and Quick links

- Short term scientific missions
- Upcoming events
- Working groups

Twitter

In addition, the BEAT-PCD website aims to showcase all PCD related research, published from members of the network. To acknowledge the participation to BEAT-PCD, authors are invited to include the following statement in the declarations section of their manuscript:

*"Study authors and data contributors participate in the BEAT-PCD clinical research collaboration, supported by the European Respiratory Society."*

## Find us online

### BEAT-PCD ON SOCIAL MEDIA

