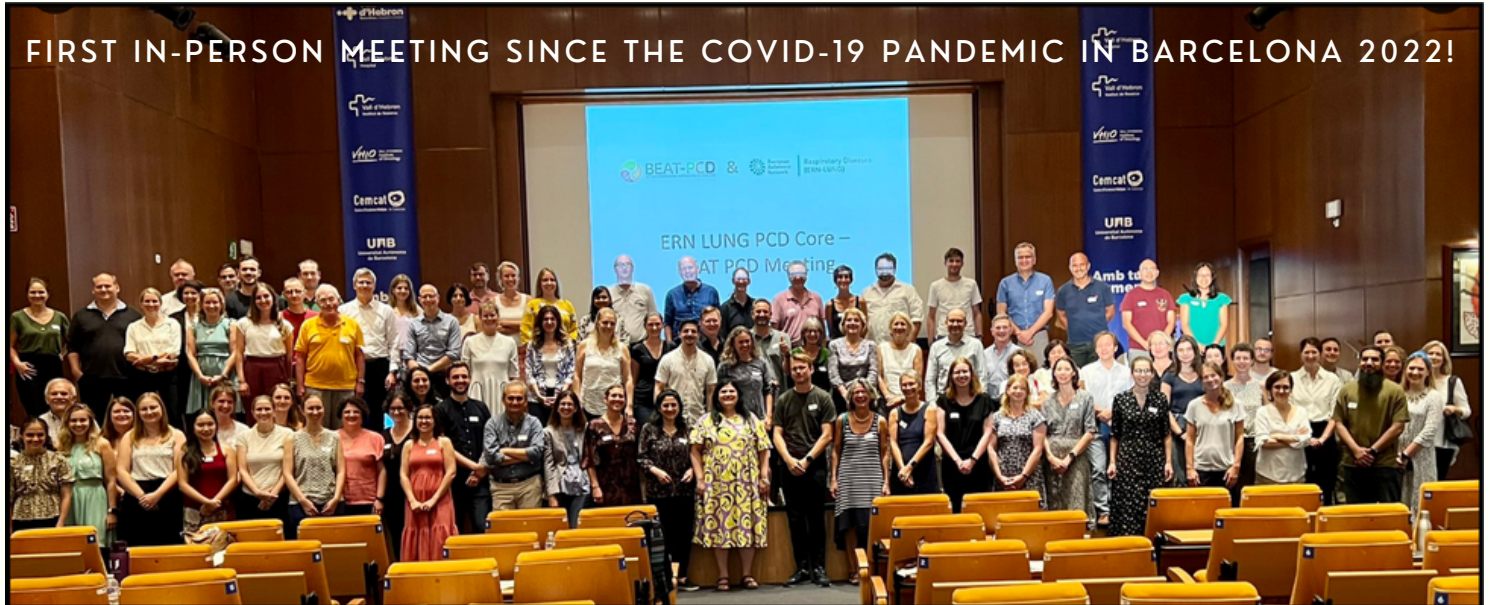


# Newsletter



## Retrospect: A look back at some of the BEAT-PCD ERS CRC achievements from 2020 to 2023

### Impactful patient engagement activities

The patients and family members of those affected by PCD are at the heart of our activities. Over the previous three years, there have been regular meetings with support group representatives and patient volunteers. The '[COVID-PCD](#)' study is an excellent example of patient involvement in research, leading to several publications including the study overview and vaccines, facemasks, and COVID-19 infections in PCD.



The first international PCD Patient Conference 2022, organised jointly by BEAT-PCD and patient representatives worldwide, was a roaring success, with 330 registered participants. Feedback included:

**"Friendly and encouraging atmosphere"**

**"I loved the patient videos... really brought some of the issues to life"**

Recordings can be accessed [here](#)

## Improvement of PCD diagnosis



Several steps have been taken towards strengthening PCD diagnostics with support being offered to new diagnostic centres, frequent difficult diagnostic case meetings, a [comparison of diagnostic algorithms in clinical practice](#), and the development and use of artificial intelligence '[PCD-AID](#)'.

Working with our colleagues in North America, we applied for a joint ERS/ATS guideline for the diagnosis of PCD - this has been approved.

Most recently, the nNO ERS Taskforce published a [technical standard for the measurement of nasal nitric oxide in children](#).

## Development of PCD research databases and collaborations

Also aiming to improve PCD diagnosis, the CiliaVar database now includes more than 2000 gene variants which, when published as an online open access database, will increase access to PCD variant information. We established in collaboration with ClinGen a work group to define the motile ciliopathy causing genes and variants to aid interpretation of PCD genetic reports ([motile ciliopathy expert panel](#)).

Several outputs have been published from collaborative datasets focusing on '[lung function](#)', '[characteristics and outcomes of adults with PCD](#)', '[otologic](#)' and '[sinonasal](#)' disease in the [EPIC-PCD study](#).



## Development of clinical trials

Consensus statements have been developed to define a core set of outcome measures for pulmonary disease interventions in PCD research. Scoping reviews on 'lower airway' and 'ear and upper airway' clinical outcome measures in PCD have been conducted. Multidisciplinary international experts reached a consensus statement on ENT exacerbations definitions in PCD research.

## Towards improvement of clinical patient care

FOLLOW-PCD patient questionnaire (symptoms & lifestyle) is translated and available in 10 languages. The questionnaire has been piloted in several studies. Efforts have been made to improve transition to adult care with the development of forms.

## Development of strong and active early career researchers' network

Originally kicked-off to maintain networking during the COVID-19 lockdown, the online expert talk series has continued for over 2 years, providing regular educational '[webinars](#)'.

The BEAT-PCD network expanded with even more people from more countries and disciplines.



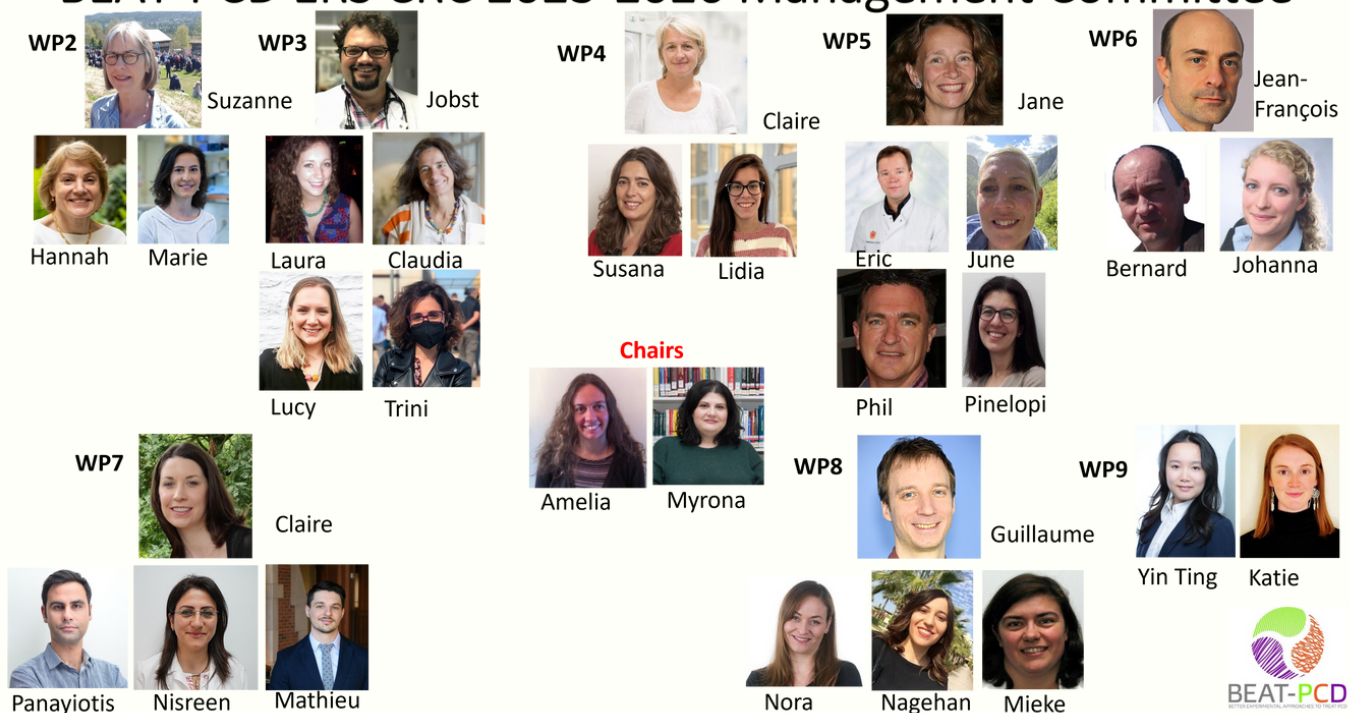
**Thank you** to everyone who has contributed to the success of the previous BEAT-PCD ERS CRC!

We are very much looking forward to the ERS Congress 2023, where we have submitted 23 PCD abstracts!

## Prospect: The ERS has renewed the support towards BEAT-PCD for a new 3-year period!

We will continue our work from before and have added some new exciting work packages. More information will be given at our meeting in Milan on 8th September and via our [website](#).

### BEAT-PCD ERS CRC 2023-2026 Management Committee



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