

ENT Prospective International Cohort of Primary Ciliary Dyskinesia patients (EPIC-PCD)

EPIC-PCD is the first multinational prospective study which aims to characterise upper respiratory disease in PCD patients and its association with lower respiratory disease, and to identify determinants of its prognosis. Specifically, the study aims to:

- a) Assess the prevalence and severity of sinonasal and otologic symptoms and the frequency and range of signs and physiological findings assessed during standardised ENT physical examination, and describe differences by age;
- b) Study the association of sinonasal and otologic disease with lower respiratory disease in PCD patients;
- c) Identify determinants of disease course and prognosis of sinonasal and otologic disease in PCD patients.

The study is embedded into routine patient care of participating reference centres for PCD and patients will be managed according to local procedures and guidelines.

FOLLOW-PCD, including the FOLLOW-PCD patient questionnaire is used for standardised data collection for the cohort.

All patients with PCD who are evaluated at minimum once a year by an ENT specialist are eligible. Recruitment has started in the first participating centres but more centres can join as the cohort progresses.

EPIC-PCD is hosted at the University of Bern in Switzerland (PI: Myrofora Goutaki).

Contact person: Yin Ting Lam (yin.lam@ispm.unibe.ch)