Inaugural Conference
COST Action 1407: BEAT-PCD
7th - 9th December 2015 Venue: Chilworth Manor, Southampton, UK
Registration and posters abstracts: Lynn Reeves: L.E.Reeves@soton.ac.uk

Goal: Meeting of PCD experts and people in training from a broad range of disciplines, aiming to:
- Identify the urgent research and clinical needs in basic science, epidemiology, clinical care and outcome measures
- Identify which questions we can answer with existing data, and which need prospective data collection through new studies.
- Develop detailed plans for future studies and projects in small groups, including concrete ideas for study design, potential collaborators, funding.
- Identify potential host centres and study subjects for Short Term Scientific Meetings.
- Present recent work in poster format (posters previously presented at conferences are welcome).

Outputs:
- A road map from each work group of how they will achieve their goals for this grant period, with vision for future grant periods.
  o Research needs
  o Concise project plans with timelines
  o List of host centres for short term scientific visits
  o Opportunities for funding
- Published conference proceedings: Research needs in PCD

Format:
Invited lectures: 30-45 minute lectures. Experts are not exclusively engaged in PCD research enabling us to learn from academics working in different areas relevant to our aims.
Bite size talks: 15min (10min talk plus 5 min discussion) highlighting what is known, and the gaps are in knowledge. The aim of these talks is to stimulate discussion in the breakout sessions (BS).
Breakout sessions (BS): opportunities for small groups (specialty groups, WGs, sub-groups, etc) to debate and discuss the issues relating to PCD research and clinical care (see strategic questions). Discussions can be stimulated by bite sized lectures but should not be restricted or constrained. Groups are likely to change throughout the meeting.
Plenary discussions: opportunities to feed back ideas from the breakout sessions and ask the wider group for guidance. An opportunity to summarise findings and set the ground work for the next BS.
Posters: An opportunity to share research relevant to PCD with a multidisciplinary audience. Posters from previous meetings are welcome. Please send abstracts to Lynn Reeves by 14th November 12:00hrs.

Overarching strategic questions
SCOPE: what are the key areas of research and clinical developments to be coordinated by BEAT-PCD?
ORGANIZE: How will we structure and organize ourselves to deliver our objectives? How do we start the collaborations needed to answer the questions? What expertise is missing? Where will we find that expertise?
EVOLVE: How will we collaborate to achieve funding for research? How do we plan to build the capacity of PCD research through education, training and mentoring of all participants engaged in BEAT-PCD?
Monday 7th December

**Morning: Arrivals and Registration.** Informal discussions and networking for those who arrive early. Conference facilities will be available from 09.30, coffee from 11am. Please contact Lynn Reeves if you require a small meeting room.

13.00 Buffet Lunch

14.00 Welcome and overview of BEAT-PCD (Jane Lucas)

14.30 Overview of Inaugural conference format (Claudia Kuehni)

14.45 Bite-size talks; What are the major questions, gaps and controversies in PCD?:
- Basic Science (Dominic Norris)
- Epidemiology (Claudia Kuehni)
- Clinical care (Kim Nielsen)
- Clinical outcomes (Phillip Latzin)

16.00 Coffee and Cake

16.30-18.00 Break out sessions

19.00 Pre-dinner drinks & poster session

20.00 Dinner

Tuesday 8th December

7.30 Management Committee meeting (MC members only)

**Chair:** Claudia Kuehni

8.30 Plenary Session: feedback from breakout sessions

**Chairs:** Cordula Koerner-Rettberg, Guillaume Thouvenin

9.00 Lectures:
- Pulmonary morbidity in congenital heart disease and the shared genetic etiology of PCD and heterotaxy. Cecilia Lo, University of Pittsburgh
- Methodological approaches to overcome the difficulties of conducting research in rare diseases. Egbert Biesheuvel (FP7 ASTERIX)

11.00 Tea, coffee and Danish pastries

**Chairs:** Estelle Escoudier, Nisreen Rumann

11.30 Training School and Short Term Scientific Meetings (Claire Hogg)
11.45  Bite-size talks,
  • iPCD cohort and other current and future data (Myrona Goutaki)
  • Microbiome- pointers from CF (Mary Carroll)
  • In vivo models of PCD (Susana Lopes)
  • Patients’ perspectives (Fiona Copeland)
  • Genetics, how to take things forward (Hannah Mitchison)

13.00 Buffet Lunch

14.00 Break out sessions

16.00 Coffee, tea and cakes

**Chairs: Claudia Kuehni and Jane Lucas**

**16.30- 18.00 Plenary Session: to discuss outcomes from breakout sessions**

20.00 Conference Dinner

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**Wednesday 9th December**

**Chairs: Mauro Pistello and Woolf Walker**

08.30 Bite-size talks,
  • Computational methods to analyse ciliary beat (Chakra Chennubhotla)
  • Health related quality of life measures for PCD (Laura Behan)
  • Pseudomonas infection – a growing problem in PCD (Kim Nielsen)
  • Multiple-Breath Washout – (Philipp Latzin)

09.30  Break out sessions (WGs and sub groups- to finalize WG road maps, identify projects and collaborations etc)

10.45  Tea Break

11.15 Break out sessions continue

12.15 Lecture TBC

13.00 Finger Buffet Lunch

**Chairs: Claire Hogg and Jane Lucas**

14.00 Poster Bazaar (details during the conference)

15.00 Plenary session- overview of road map for this year and projects for next year from each of the WG leaders

16.00 Coffee and close