

ERN-LUNG PCD Meeting Cyprus, 10-12 April 2024

Day 1

Wednesday, April 10th, 18:00 – 20:00 - Welcome Session

Venue: “Bank of Cyprus Cultural Foundation”, Nicosia Old City

Registration starts 17:00

18:00 – 18:30 **Welcome notes**

Opening Remarks

Panayiotis Yiallourous – Local Host

Tasos Christofides – UCY Rector

18:30 – 19:00 **History & Culture**

Medieval Nicosia (*Anna Marangou – Archeologist*)

19:00 – 19.30 **Plenary Lecture**

The role of nodal cilia to break left-right asymmetry (*Hiroshi Hamada*)

19.30 – 20:00 Welcome drinks

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Day 2

Thursday, April 11th, 09:00 – 17:00 – Scientific Programme – Diagnostics

Venue: *Shakolas Educational Center of Clinical Medicine*

08:00 – 09:00 Registration – Arrival – Welcome coffee

09:00 – 09:20 Opening Remarks

Heymut Omran – ERN LUNG-PCD core Coordinator

Panayiotis Yiallourous – Local Host & Georgios Hadjigeorgiou – Medical School Dean

Iliana Georgiou - Cyprus Patient Representative (10 min)

09:20 – 09:40 PCD Diagnostics – Current differences of diagnostic guidelines in Europe and the USA

Eric Haarman (15 min + 5 min discussion)

09:40 – 11:00 Pro & Con debate on use of current PCD diagnostic tools and critical assessment of evidence chair: *Nicola Ullmann, Heymut Omran*

HVMA & *in vitro* ciliogenesis advantages *Mieke Bohn*; limitations *Loretta Müller* (15 min + 5 min discussion)

nNO advantages *June K Marthin*, limitations *Magee Leigh* (15 min + 5 min discussion)

TEM & IF advantages *NN*; limitations *Niki Tomas Loges* (15 min + 5 min discussion)

Genetic approaches advantages *Amjad Horani*; limitations *Heymut Omran* (15 min + 5 min discussion)

11:00-11:30 Coffee Break

11:30 – 12:15 Complex PCD phenotypes chair: *Eitan Kerem*

Non-ciliary phenotypes in PCD *Susan Dutcher* (10 min + 5 min discussion)

Jeune Syndrome *Panayiotis Yiallourous* (10 min + 5 min discussion)

Oral-facial digital syndrome & mental retardation & RPGR *Zuzanna Bukowy-Bieryłło* (10 min + 5 min discussion)

12:15 – 13:15 IF consensus *Niki Tomas Loges* (15 min + 5 min discussion)

Oral presentations selected from abstracts chair: *Francesca Santamaria*

Abstract 1 (to be selected) (7 min + 3min discussion)

Abstract 2 (to be selected) (7 min + 3min discussion)

Abstract 3 (to be selected) (7 min + 3min discussion)

Abstract 4 (to be selected) (7 min + 3min discussion)

13:15 – 15:00

Lunch – Finger Food including Poster Session (Organization, Evaluation Committee)

After Lunch

15:00 – 15:20

Updates ERN-LUNG PCD Core *Petra Pennekamp and Heymut Omran* (15 min + 5 min discussion)
ERN-LUNG (evaluation, new funding period/general projects within ERN-LUNG (PROs, Quality Indicators for Care, ERN-LUNG goes east etc; funding opportunities))

15:20 – 17:00

ERN LUNG PCD Core Studies chair: *Marcus Mall*

15:20-15:40

Are official ERN-LUNG PCD Key Performance Indicators for PCD still valid or do the need an update ? *Heymut Omran* (10 min + 10 min discussion)

15:40-16:05

Lung Function, Nasal NO production rates, Microbiology [Pseudomonas etc] study *Johanna Raidt* (15 min + 10 min discussion)

16:05-16:30

PICADAR/Clinical Index (CI)/NA-CDCF as screening tool, SNOT-22, QoL, PROssen in distinct genotypes *Heymut Omran* (10 min + 5 min discussion)

16:30-16:45

Siblings' Phenotypic Concordance Study *Panayiotis Kouis* (10 min + 5 min discussion)

16:45-17:00

Prospective PCD Exacerbations Study *Pinelopi Anagnostopoulou* (10 min + 5 min discussion)

17:00-17:15

Study 'Natural History of PCD' *Jobst Röhmel* (10 min + 5 min discussion)

17:15 – 17:45

ERN-LUNG PCD Core statement based on discussions *Heymut Omran*

17:45 - 18:00

Poster Prizes

20:00 – 23:00

Social Dinner , Venue: Central Nicosia TBD

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Day 3

Friday, April 12th, 08:30 – 14:00 – Scientific Programme - Clinical studies

Venue: *Shiakolas Educational Center of Clinical Medicine*

- 08:30 – 08:45** **ERN-LUNG PCD-CTN Welcome and Update** *Kim G Nielsen*
- 08:45-9:30** **Non-interventional studies** chair: *NN*
Observational studies for distinct PCD genotypes *Mathias Geldermann Holgersen* (10 min + 5 min discussion)
Radioaerosol Studies, novel clinical outcome parameter *June K Marthin* (10 min + 5 min discussion)
Clinical Biochemistry testing in PCD care *Sarah Altaraihi* (10 min + 5 min discussion)
- 9:30-10:30** **mRNA based therapies** chair: *Lorretta Müller*
9:30-10:00 Preclinical data *Heymut, Omran* (10 min + 5 min discussion)
Future clinical trial *Thomas Langenickel [Ethris]* (10 min + 5 min discussion)
10:00-10:30 Prelinical data *Jessica Couch [ReCode]* (10 min + 5 min discussion)
Future clinical trial *John Matthews [ReCode]* (10 min + 5 min discussion)
- 10:30-11:00** **Coffee Break**
- 11:00-11:30** **ENAC inhibition based therapies** chair: *Kim G Nielsen*
Safety and efficacy of the epithelial sodium channel blocker idrevloride in people with primary ciliary dyskinesia (CLEAN-PCD): a multinational, phase 2, randomised, double-blind, placebo-controlled crossover trial *NN* (15 min + 5 min discussion)
Future trials *Karl Donn [Parion]* (15 min + 5 min discussion)
- 11:30-12:00** **Conventional trials for PCD** chair: *Kim Nielsen*
Pari inhalation with hypertonic saline: ongoing, planned *Jobst Röhmel*, 10 min + 5 min discussion
Azithromycin trial in Australia *Phil Robinson* (10 min + 5 min discussion)
- 12:00-12:45** **Non-CF bronchiectasis trials with participation of PCD centers** chair: *NN*
ASPEN and coming studies – Insmed (*Carlos Fernandez/TBD*) (10 min + 5 min discussion)
AIRLEAF and coming studies – BI (*TBD*) (10 min + 5 min discussion)
Ongoing Studies – doctor’s experience *Tavs Qvist* (10 min + 5 min discussion)
- 12:45** **Closing remarks** *Panayiotis/Patient Representative*
- 12:45 – 13:45** **Lunch – Finger Food**

Afternoon Workshops Day 3

WORKSHOPS

- 14:00 - 16:00** **Workshop 1 - PCD diagnostic techniques for early career Clinician Scientists on nNO, HVMA, TEM, IF, genetics**
Panayiotis Kouis, Loretta Müller, Niki Tomas Loges, June K Marthin
- 14:00 - 16:00** **Workshop 2 - LCI training for clinical trials (training certificates)**
Jobst Röhmel, Pinelopi Anagnostopoulou, Rikke M Sandvik
Theoretical background and demonstration
Hands-on practice for participants
- 14:00 - 16:00** **Workshop 3 - Patient-oriented Research (SPOR)**
Petra Pennekamp, Pippa Powell/NN, Petra Tempels (ERN-LUNG), Benedikt König/Kartagener Syndrom und Primäre Ciliäre Dyskinesie e.V.)
Engage patients as partners (rather than patients as study subjects)
Focus on patient-identified priorities
Act as multidisciplinary teams in partnership with stakeholders
Apply the knowledge generated to improve health care systems and practices