

International ERN LUNG – PCD Meeting

10TH – 12TH April 2024

NICOSIA, CYPRUS

Day 1: Wednesday, April 10th, 18:00 – 20:00 - Welcome Session

Venue: Bank of Cyprus Cultural Foundation, Nicosia Old City

Registration starts at 17:00

18:00 – 18:30 **Welcome – Opening Remarks**

Panayiotis Yiallourous – Local Host

Tasos Christophides – 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**



Day 2: Thursday, April 11th, 09:00 – 18:00 – Scientific Programme – Diagnostics

Venue: *Shiakolas 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

Georgios Hadjigeorgiou – Medical School Dean

Christos Christou - CEO OKYPY - Local Health Care Provider

Iliana Georgiou - Cyprus Patient Representative

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

Eric Haarman (15 min + 5 min discussion)

09:40 – 11:00 Advantage & limitation debate on use of current PCD diagnostic tools and critical assessment of evidence - Chairs: *Nicola Ullmann, Heymut Omran*

HVMA & *in vitro* ciliogenesis

Advantages *Mieke Boon*; limitations *Loretta Müller* (15m + 5m discussion)

Nasal Nitric Oxide

Advantages: *June K Marthin*; limitations *Magee Leigh* (15m + 5m discussion)

TEM & IF

Advantages: *Zuzanna Bukowy-Bierytło*; limitations *Niki Tomas Loges* (15m + 5m)

Genetic approaches

Advantages: *Amjad Horani*; limitations *Heymut Omran* (15 m + 5 m 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)

Phenotypes of IFT74 variants

Panayiotis Yiallourous/Heymut Omran (10 min + 5 min discussion)

Oral-facial digital syndrome & mental retardation & RPGR

Zuzanna Bukowy-Bierytło (10 min + 5 min discussion)

12:15 – 12:35 IF Consensus

Niki Tomas Loges (15 min + 5 min discussion)

12:35 – 13:30 Oral presentations selected from abstracts – Chairs: *Francesca Santamaria, Marco Zampoli*

Enhancing PCD Care in Latin America: A Multifaceted Approach to Overcome Diagnostic and Management Challenges

Wilfredo De Jesús Rojas (7 min + 3 min discussion)

Lung transplantation for primary ciliary dyskinesia - a single center review

Moshe Heching (7 min + 3 min discussion)

JNK as a novel ciliogenesis regulator controlling actin driven processes

Maria Chatzifrangkeskou (7 min + 3 min discussion)

The site of airway remodeling is different in end-stage PCD compared to CF

Astrid Vermaut (7 min + 3 min discussion)

A randomized cross-over analysis of the mutual influence of Multiple Breath Washout and Spirometry in children with Cystic Fibrosis and PCD

Anne Schlegtendal (7 min + 3 min discussion)

13:30 – 15:00 Lunch – Finger Food & Poster Session

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 they need an update?

Heymut Omran (10 min + 10 min discussion)

15:40 – 16:05 Lung Function, Nasal NO production rates, Microbiology study

Johanna Raidt (15 min + 10 min discussion)

16:05 – 16:30 PICADAR/Clinical Index (CI)/NA-CDCF as screening tool, SNOT-22, QoL, PROs and other stuff in distinct genotypes

Heymut Omran (10 min + 5 min discussion)

16:30 – 16:45 Familial 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 (10 min + 20 discussion)

17:45 – 18:00 Poster Prizes

20:00 – 23:00 Social Dinner, Venue: Macedonia Hall, Cleopatra Hotel, Nicosia

Day 3: Friday, April 12th, 08:30 – 14:00 – Scientific Programme - Clinical studies

Venue: Shiakolas Educational Center of Clinical Medicine

08:00 – 08:30 Arrival – Welcome coffee

08:30 – 08:45 ERN-LUNG PCD-CTN Welcome and Update

Kim G Nielsen (15 min)

08:45 – 09:30 Non-interventional studies – Chair *Panayiotis Yiallourou*

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)

09:30 – 10:30 mRNA-based therapies - Chair: *Lorretta Müller*

09:30 – 10:00 Preclinical data

Heymut Omran (10 min + 5 min discussion)

Future clinical trial

Thomas Langenickel [Ethis] (10 min + 5 min discussion)

10:00 – 10:30 Preclinical data

Kai Wohlgemuth (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: *Tavs Qvist & 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 and future trials

Kim G Nielsen (30 min + 5 min discussion)

11:30 – 12:00 Conventional trials for PCD – Chair: *Tavs Qvist & Kim G Nielsen*

Creating evidence on the use of hypertonic saline in PCD (HELP-PCD)

Jobst Röhmel (10 min + 5 min discussion)

Azithromycin trial in Australia

Phil Robinson (10 min + 5 min discussion)

12:00 – 12:50 Non-CF bronchiectasis trials with participation of PCD centers – Chair: *Tavs Qvist & Kim G Nielsen*

Bronchiectasis - basics and new developments

Marcus Mall (20 min)

AIRLEAF and coming studies

Manuela Timmermans [Boehringer Ingelheim] (10 min + 5 min discussion)

Ongoing Studies – doctor's experience

Tavs Qvist (10 min + 5 min discussion)

12:50 – Closing remarks – *Panayiotis Yiallourous / Patient Representative*

13:00 – 14:00 Lunch – Finger Food

14:00 – 16:00 Parallel workshops – *Details available in next page*

WORKSHOPS

14:00 – 16:00 Workshop 1 - PCD diagnostic techniques for early career Clinician Scientists on nNO, HVMA, TEM, IF, genetics

Panayiotis Kouis, Louiza Potamiti, Loretta Müller, Niki T Loges, June K Marthin

Practical information and demonstration

14:00 – 16:00 Workshop 2 - MBW training for clinical trials (organized by the PCD-CTN training committee)

Jobst Röhmel, Pinelopi Anagnostopoulou

Theoretical background and demonstration & Hands-on practice for participants

14:00 – 16:00 Workshop 3 - Patient-oriented Research (POR)

Petra Pennekamp, Gergely Meszaros, Dimitrios Kontopidis, 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.