

## International ERN LUNG – PCD Meeting

10<sup>TH</sup> – 12<sup>TH</sup> April 2024

NICOSIA, CYPRUS

### Day 1: Wednesday, April 10<sup>th</sup>, 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 Yiallouros* – 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 – 17:00 – 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

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

*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 Pros & Cons 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 *Margaret Leigh* (15m + 5m discussion)

**TEM & IF**

Advantages: *Zuzanna Bukowy-Bieryłło*; 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* (10 min + 5 min discussion)

**Oral-facial digital syndrome & mental retardation & RPGR**

*Zuzanna Bukowy-Bieryłło* (10 min + 5 min discussion)

**12:15 – 12:35 IF Consensus**

*Niki Tomas Loges* (15 min + 5 min discussion)

**12:35 – 13:15 Oral presentations selected from abstracts – Chair: Francesca Santamaria**

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

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

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

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

**13:15 – 15:00 Lunch – Finger Food****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 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: Central Nicosia TBD**

### 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 TBD**

##### **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**

*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**

*TBD* (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: TBD****ASPEN and coming studies***Insmed (Carlos Fernandez/TBD) (10 min + 5 min discussion)***AIRLEAF and coming studies***Boehringer Ingelheim (TBD)***Ongoing Studies – doctor's experience***Tavs Qvist (10 min + 5 min discussion)***12:45 – Closing remarks – Panayiotis Yiallourous / Patient Representative****12:45 – 13:45 Lunch – Finger Food****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 &amp; Hands-on practice for participants

**14:00 – 16:00 Workshop 3 - Patient-oriented Research (SPOR)***Petra Pennekamp, 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