PCD on the Move 2025 - Preliminary Agenda

Wednesday, August 20th, 12:00 pm - 4:30 pm
Registration Opens at 10:00am

PCD Nuts & Bolts		
Session Chair: Thomas Ferkol, MD		
12:00 - 12:05	Welcome and Introduction	Michele Manion, PCD Foundation
12:05 - 12:10	Chair Welcome	Thomas Ferkol, MD
12:10 - 12:35	Evolving Understanding of PCD—A Historical Perspective	Thomas Ferkol, MD
12:35 - 1:00	Screening and Diagnostic Guidelines	Amjad Horani, MD
1:00 - 1:25	PCD Genetics	Alexander Ing, CGC
1:25 - 1:50	Treatment & Management	Adam Shapiro, MD
1:50 - 2:15	Building a PCD Center	Anne Griffiths, MD
BREAK 2:15 – 2:30		
Living With PCD **Session Chairs: Billy Anton, PCD Foundation and Michele Manion, PCD Foundation**		
2:30 - 3:15	**Living With PCD** • Chair Welcome & Patient Experience Video • Daily management and challenges • Planning for the future in the face of uncertainty • Participating in clinical trials --an urgent call to action	Patient Panel
Hands On Experience: 3:20 – 4:20		

PCD Nuts & Bolts: Hands On Experiences
   • Measuring NNO (30 min) – TJ Baker
   • Genetics - Bring Your Challenging Cases (1 hour) – Alex Ing CGC; Maimoona Zariwala CGC
   • Airway Clearance Modalities (30 min) - Katie Johnson RT; Andrena Moser RT
   • Ask an ENT (30 min) - Alex Coyne, PA		

PCDF – CRCN Directors Meeting 3:20 – 4:20		

5:00 to 6:00 pm
Join us for a Welcome Reception

PCD on the Move 2025

Thursday, August 21st, 8:00am - 4:45pm

Breakfast 7:00 – 7:45AM

Session I: PCD and Motile Cilia Basics

Session Chair: Anne Griffiths, MD

7:50 - 8:00	Opening Remarks - Welcome and Introduction	Michele Manion, PCD Foundation
8:00 - 8:05	Chair Welcome	Anne Griffiths, MD
8:05 - 8:15	Patient/Parent Speaker	Patient Family
8:15 - 8:40	Defining the pathogenesis of motile cilia disorders	Steven Brody, MD
8:40 - 9:05	Lower Airway Disease in PCD	BreAnna Kinghorn, MD
9:05 - 9:30	Laterality defects and other congenital anomalies	Adam Shapiro, MD
9:30 - 9:55	ENT Issues in PCD	Adam Kimple, MD, PhD

BREAK 9:55– 10:10 AM

Session II: Molecular Derangements in PCD
Session Chair: Amjad Horani, MD

10:10 - 10:15	Chair Welcome	Amjad Horani, MD
10:15 - 11:00	**KEYNOTE**: Why you should understand cilia assembly: The case of the CCDC39 and CCDC40 variants	Susan Dutcher, PhD
11:00 - 11:25	Non-ciliary effects of variants in DNAH5 and the role of cilia protective mechanisms	Amjad Horani, MD
11:25 - 11:50	Exploring cilia diversity – patient-driven gene discovery leads the way	Pleasantine Mill, PhD

Concurrent Session: Nurses & Social Workers Meeting

LUNCH 12:00 - 1:00 pm

Concurrent Session III A - Pediatric Focus
Treatment Approaches in Pediatric PCD
Session Chair: Wilfredo De Jésus Rojas, MD

- 1:00 - 1:05: Chair Welcome
- 1:05 - 1:15: Patient Speaker
- 1:15 - 1:40: Approach to Hearing Loss in Children with PCD (Asitha Jayawardena, MD)
- 1:40 - 2:05: Neonatal PCD: Timing of Treatment Initiation (Sharon Dell, MD)
- 2:05 - 2:30: Heterotaxy and Congenital Heart Disease: Palliative Care and Transplantation (Thomas Saba, MD)
- 2:30 – 2:55: The Role of Chronic Inflammation in PCD: Recent Advances (Ricardo Mosquera, MD)

Concurrent Session III B - Adult Focus
Unique Challenges for Managing PCD in Adult Populations
Session Chair: Hili Metjian, MD

- 1:00 - 1:05 Chair Welcome
- 1:05 - 1:15: Patient Speaker
- 1:15 - 1:40: PCD in the ICU / adult lung transplantation (Raymond Coakley, MD)
- 1:40 - 2:05: Teasing out PCD in the idiopathic bronchiectasis clinic (Steven Lommatzsch, MD)
- 2:05 - 2:30: Managing DX reluctance in adult patient (Leigh Anne Daniels, MD)
- 2:30 - 2:55 TBD

BREAK 2:55 – 3:15

Fellows Abstracts & Case Reports

Session Chair: Pleasantine Mill, PhD

3 :20 - 3 :25	**Introduction**	Pleasantine Mill, PhD
3:25 - 3:37	Case Report/Abstract 1	TBD
3:37 - 3:49	Case Report/Abstract 2	TBD
3:49 - 4:01	Case Report/Abstract 3	TBD
4:01 - 4:13	Case Report/Abstract 4	TBD
4:13 - 4:25	Case Report/Abstract 5	TBD

4:25 - 4:45 PCD Awards

Poster Session
5:00 pm to 7:00 pm
Join us for Wine & Snacks

PCD on the Move 2025

Friday, August 22nd, 8:00am - 4:00pm

Breakfast Discussion Opportunity 7:00 – 8:00AM Expanding Phenotype / Genotype - CRCN Interest Group	

Session IV: Power of Registries and Population-Based Studies

Session Chair: Evans Machogu, MD

8:00 - 8:05	Chair Welcome	Evans Machogu, MD
8:05 - 8:30	CF Registry Experience	Margaret Rosenfeld, MD
8:30 - 8:55	Updates on the North American PCDF Registry	Michael O'Connor, MD
8:55 - 9:20	BRR Registry	Timothy Aksamit, MD

Concurrent Session: RT Meeting – Katie Johnson

BREAK 9:20 – 9:35AM

Session V: Model Organisms as Tools to Study PCD

Session Chair: Susan Dutcher, PhD

9:35 – 9:40	Chair Welcome	Susan Dutcher, PhD
9:40 - 10:05	Chlamydomonas	Susan Dutcher, PhD
10:05 - 10:30	A Porcine Model of PCD	Mahmoud Abou Alaiwa, MD
10:30 - 10:55	Mouse Model of PCD	Lance Lee, PhD
10:55 - 11:20	Tetrahymena	Chad Pearson, PhD

Transition to Lunch 11:20 – 11:30PM

LUNCH LECTURE 11:30 – 12:30pm

Inaugural Michael R Knowles Lecture – PCD Past, Present & Future
Urgent need for Clinical trials/Challenge of Limited Evidence to Direct Treatment in PCD/Current Studies Overview
Stephanie Davis, MD

BREAK 12:30 – 12:45PM

Session VI: Novel Approaches to Therapy

Session Chair: Kenneth Olivier, MD

12:45 - 12:50	Chair Welcome	Kenneth Olivier, MD
12:50 - 1:00	Patient Speaker	Patient Speaker
1:00-1:25	Anti-inflammatory therapy for PCD bronchiectasis, results of the WILLOW Study	Mark Metersky, MD
1:25 - 2:10	**KEYNOTE**: Identification of Treatable Traits for PCD Lung Disease	Richard Boucher, MD
2:10 - 2:35	Challenges in Airway Cell Delivery	Finn Hawkins, MD

Session VII – New Diagnostic Approaches

Session Chair: Amelia Shoemark, PhD

2:35 - 2:40	Chair Welcome	Amelia Shoemark, PhD
2:40 - 3:05	Long read sequencing for identifying variants in PCD	Alex Ing, CGC
3:05 – 3:30	Agnostic tools for defining motile cilia function defects	Amelia Shoemark, PhD
3:30 - 3:55	IF as a viable tool for the diagnosis of PCD	Robert Reklow, PhD

Closing: Michele Manion

OTM 2024 Meeting Adjourns