

# PCD on the Move 2025 Agenda

**Wednesday, August 20, 12:00 - 4:30PM**

**Registration Opens at 10:00AM; Mezzanine Foyer**

## PCD Nuts & Bolts

**Session Chair: Thomas Ferkol, MD**

**Lecture 12:00 – 3:15PM, Marquette IV, V, VI, VII**

<b>12:00 - 12:05</b>	Welcome and Introduction	Michele Manion, PCD Foundation
<b>12:05 - 12:10</b>	Chair Welcome	Thomas Ferkol, MD
<b>12:10 - 12:35</b>	Evolving Understanding of PCD—A Historical Perspective	Thomas Ferkol, MD
<b>12:35 - 1:00</b>	Screening and Diagnostic Guidelines	Amjad Horani, MD
<b>1:00 - 1:25</b>	PCD Genetics	Alexander Ing, CGC
<b>1:25 - 1:50</b>	Treatment & Management	Adam Shapiro, MD
<b>1:50 - 2:15</b>	Building a PCD Center	Anne Griffiths, MD

**BREAK 2:15 – 2:30PM**

## Living With PCD

**Session Chairs: Billy Anton, PCD Foundation and Michele Manion, PCD Foundation**

<b>2:30 - 3:15</b>	Living With PCD	Patient Panel
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## Hands On: 3:20 – 4:20PM

3:20 – 3:50; 3:50 – 4:20	Measuring NNO	TJ Baker; Andrena Moser, RT	Orchestra AB
3:20 – 4:20	Genetics	Alexander Ing, CGC; Maimoona Zariwala, PhD, MSc, FACMG	Marquette IV, V, VI, VII
3:20 – 3:50; 3:50 – 4:20	Airway Clearance Modalities	Katie Johnson, RT; Melissa Damas, RRT-NPS, AE-C	Orchestra C
3:20 – 3:50; 3:50 – 4:20	Ask an ENT	Alex Coyne, PA	Orchestra D

**PCDF – CRCN Directors Meeting 3:20 – 4:20PM, Marquette I, II**

## Welcome Reception

**5:00 to 6:00 PM**

**Target Atrium, Orchestra Hall - Minnesota Orchestra  
1111 Nicollet Mall, Minneapolis, MN**

# PCD on the Move 2025

Thursday, August 21, 8:00AM - 4:45PM

Breakfast 7:00 – 7:45AM: Orchestra Ballroom AB

## Session I: PCD and Motile Cilia Basics; Marquette IV, V, VI, VII

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 Family Speaker	Patient Speaker
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– 10:10AM; Orchestra Foyer**

## Session II: Molecular Derangements in PCD; Marquette IV, V, VI, VII

Session Chair: Amjad Horani, MD

10:10 - 10:15	Chair Welcome	Amjad Horani, MD
10:15 - 11:00	<b>KEYNOTE:</b> 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; Marquette I, II

**LUNCH 12:00 - 1:00PM; Orchestra AB**

## Concurrent Session III A - Pediatric Focus; Marquette IV, V, VI, VII

### Treatment Approaches in Pediatric PCD

Session Chair: Wilfredo De Jesús 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; Orchestra AB

### 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: When to Consider Sinus Surgery for PCD (Erin O'Brien, MD)

**BREAK 2:55 – 3:15PM; Orchestra Foyer**

## Fellows Abstracts & Case Reports; Marquette IV, V, VI, VII

Session Chair: Pleasantine Mill, PhD

3:20 - 3:25	<b>Introduction</b>	Pleasantine Mill, PhD
3:25 - 3:37	Primary Ciliary Dyskinesia Associated with Compound Heterozygous CEP135 Variants	Abigail Bergman-Sieger, MD
3:37 - 3:49	The Mirror Doesn't Lie: Situs Inversus Unveils PCD and the Need for Expanded Reproductive Genetic Screening	Federica Chironi, MD
3:49 - 4:01	Variants in a primary cilia gene, RPGRIP1L, causing disrupted planar polarization of motile cilia and Primary Ciliary Dyskinesia phenotype	Akansha Jain, MD, PhD

## PCD on the Move 2025

**Thursday, August 21, 8:00AM - 4:45PM**

### **Fellows Abstracts & Case Reports Continued; Marquette IV, V, VI, VII**

<b>4:01 - 4:13</b>	What Are We Missing? A Case Series of Divergent Outcomes in Siblings with PCD Sharing the Same Mutation and Environmental Exposure	Ivan Magana Ceballos, MD
<b>4:13 - 4:25</b>	Genetic Diagnosis of Primary Ciliary Dyskinesia in Childhood in Kenya: A Prospective Pilot Study	Elizabeth Mwailongo, MD

### **Concurrent Session: ENT Meeting; Orchestra AB**

**4:25 - 4:45: Abstract Flash Talks; Marquette IV, V, VI, VII**

### **Poster Session**

**5:00 to 7:00 PM**

*Posters: Orchestra CD*

*Wine & Snacks: Orchestra Foyer*

# PCD on the Move 2025

Friday, August 22, 8:00AM - 4:00PM

Breakfast Discussion Opportunity 7:00 – 8:00AM; Orchestra AB  
The Role of Phenotype / Genotype in PCD Disease Expression

**Session IV: Power of Registries and Population-Based Studies; Marquette IV, V, VI, VII**

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 – Marquette I, II

BREAK 9:20 – 9:35AM; Orchestra Foyer

**Session V: Model Organisms as Tools to Study PCD; Marquette IV, V, VI, VII**

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; Box Lunch Available in Orchestra Foyer

LUNCH LECTURE 11:30 – 12:30 PM; Orchestra AB

*Inaugural Michael R Knowles Lectureship – PCD Past, Present & Future*  
Stephanie Davis, MD

BREAK 12:30 – 12:45PM; Orchestra Foyer

**Session VI: Novel Approaches to Therapy; Marquette IV, V, VI, VII**

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 Bronchiectasis: Translatable to PCD?	Pamela J. McShane, MD
1:25 - 2:10	<b>KEYNOTE:</b> 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; Marquette IV, V, VI, VII**

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	Alexander 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; Marquette IV, V, VI, VII

OTM 2024 Meeting Adjourns