

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			
Lecture 12:00pm – 3:15pm, Marquette IV, V, VI, VII			
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 <ul style="list-style-type: none">• 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: 3:20 – 4:20			
3:20 – 3:50; 3:50 – 4:20	Measuring NNO	TJ Baker	Orchestra AB, C, or D - TBD
3:20 – 4:20	Genetics	Alex Ing CGC; Maimoona Zariwala CGC	Marquette IV, V, VI, VII
3:20 – 3:50; 3:50 – 4:20	Airway Clearance Modalities	Katie Johnson RT; Andrena Moser RT	Orchestra AB, C, or D - TBD
3:20 – 3:50; 3:50 – 4:20	Ask an ENT	Alex Coyne PA	Orchestra AB, C, or D - TBD
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: 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/Parent 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– 10:10 AM; 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	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; Marquette I

LUNCH 12:00 - 1:00 pm; Orchestra AB

Concurrent Session III A - Pediatric Focus

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

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 *Talk Title TBD – Adult ENT* (Erin O'Brien, MD)

BREAK 2:55 – 3:15; Orchestra Foyer

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

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

Concurrent Session: ENT Meeting; Marquette I

4:25 - 4:45 PCD Awards; Marquette IV, V, VI, VII

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; Orchestra AB

The Role of Phenotype / Genotype in PCD Disease Expression- CRCN Interest Group

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 – Katie Johnson; Marquette I

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 – 12:30pm; Marquette IV, V, VI, VII

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; 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?	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; 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	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; Marquette IV, V, VI, VII

OTM 2024 Meeting Adjourns