

# PCD On the Move 2019!

## Draft Agenda v.3

Wednesday, August 21: Morning Session

PCD Nuts & Bolts Session (Optional)--Great Lakes Ballroom 7th Floor		
<b>Adam Shapiro, MD</b>		
9:00 – 9:05	Welcome and Introduction from the PCD Foundation	Michele Manion, Executive Director PCDF
9:05 - 9:25 Presentation 9:25 - 9:30 Discussion	PCD Clinical Phenotype	Margaret Rosenfeld, MD, MPH; University of Washington, Seattle
9:30 – 9:50 Presentation 9:50 – 9:55 Discussion	PCD Genetics: Understanding VUSs	Amjad Horani, MD Washington University, St. Louis (Invited)
9:55 – 10:15 Presentation 10:15 - 10:20 Discussion	ATS PCDF Diagnostic Guidelines	Thomas Saba, MD, University of Michigan
Hands-On Sessions		
10:20 – 11:00	Airway Clearance Modalities for PCD (lecture & hands-on)	Lisa Monchil, RRT-NPS, AE-C, CCM, CCRC, NYMC
11:00 – 11:40	Measuring Nasal Nitric Oxide (lecture & hands-on)	Michael O'Connor, MD Vanderbilt University
11:40 – 12:00	Pick up Box Lunches and Proceed to Afternoon Session	

Wednesday, August 21: Main Sessions Begin

12:00 – 12:05	Welcome and Introduction from the PCD Foundation	Amy Kovler, Chair, PCD Foundation
PCD Basic & Translational Science Session--Great Lakes Ballroom 7th Floor		
<b>Session Chairs: Larry Ostrowski, PhD/Steve Brody, MD</b>		
12:05 – 12:10	Introduction	Session Chairs
12:10 – 12: 45 Presentation 12:45 --12: 55 Discussion	KEYNOTE ADDRESS: Gene Editing	Pleasantine Mill, PhD, University of Edinburgh (Invited)
12:55 - 1:15 Presentation 1:15– 1:20 Discussion	RNA Transfer Therapy	TBD
1:20– 1:40 Presentation 1:40 – 1:45 Discussion	ATS PCDF Partner Grant Updates	Larry Ostrowski, PhD, University of North Carolina, Chapel Hill
1:45 – 2:05 Presentation 2:05 – 2:10 Discussion	Motile Ciliopathies: Beyond PCD	Steve Brody, MD, Washington University, St. Louis (Invited)
2:10 -- 2:30	Break	

Wednesday, August 21: Fellows Case Reports

<b>Fellows Case Reports</b>		
<b>Session Chairs: Thomas Saba, MD/ BreAnna Kinghorn, MD</b>		
2:30 – 2:35	Introduction by chairs	
2:35 – 2:45 Presentation 2:45 – 2:50 Discussion	CASE REPORT TO BE SELECTED	
2:50 – 3:00 Presentation 3:00 – 3:05 Discussion	CASE REPORT TO BE SELECTED	
3:05 – 3:15 Presentation 3:15 – 3:20 Discussion	CASE REPORT TO BE SELECTED	
3:20 – 3:30 Presentation 3:30 – 3:35 Discussion	CASE REPORT TO BE SELECTED	

3:35 to 6:00 pm Join us for a welcome reception!

Thursday, August 22: Morning Sessions

7:30 - 8:30 Buffet Breakfast 7 <sup>th</sup> Floor Foyer--Pick up Breakfast & Join Session		
PCD Diagnosis --Great Lakes Ballroom 7th Floor		
Session Chairs: Thomas Saba, MD		
8:00-8:05	Welcome and Introduction	Session Chairs
8:05 - 8:20 Presentation 8:20 - 8:25 Discussion	Nasal NO Levels in Infants with PCD	Margaret Leigh, MD, University of North Carolina, Chapel Hill
8:25 - 8:40 Presentation 8:40 - 8:45 Discussion	PCD vs. Primary Immunodeficiencies	Michael Knowles, MD, University of North Carolina, Chapel Hill
8:45 - 9:00 Presentation 9:00 - 9:05 Discussion	Bronchiectasis in Adults with PCD	Pamela McShane, MD, University of Chicago
9:05 - 9:20 Presentation 9:20 - 9:25 Discussion	Novel Diagnostic Techniques for Challenging Cases of PCD	Sharon Dell, MD, University of Toronto
9:25: - 9:40	Molecular Dx of PCD: Experience from a Clinical Laboratory	Keith Nykamp, PhD, Invitae, San Francisco, CA
9:45 - 10:00	Break	

Clinical Features and Manifestations of PCD--Great Lakes Ballroom 7th Floor		
Session Chair: Margaret Rosenfeld, MD		
10:15 - 10:20	Welcome and Introduction	Chair
10:20 – 10:50 Presentation 10:50 – 10:55 Discussion	PCD Microbiology	Kenneth Olivier, MD, NHLBI
10:55 – 11:15 Presentation 11:15 - 11:20 Discussion	PCD/Cystic Fibrosis Comparison	BreAnna Kinghom MD, University of Washington
11:20 – 11:40 Presentation 11:40 – 11:45 Discussion	ENT Features of PCD	Adam Kimple, MD, University of NC, Chapel Hill
11:45 - 1:00 Box Lunch in the Foyer--7th Floor		
PCD Clinical Caregivers Roundtable (Nurses, RTs, SWs, Research Coordinators)--St. Croix Room		Chairs: Jane Quante, RN & Virginia Gonzalez, RN
CRNC Directors Meeting – Room TBD		Chairs: Adam Shapiro, MD & Michele Manion

Thursday, August 22: Afternoon Breakout Sessions

1:00-- 1:45 Breakout Session I		
If you have an 'A' on your badge	Hands on Nasal NO Training--CALHOUN Room	TBD
If you have a 'B' on your badge	Psychosocial Aspects of PCD--GREAT LAKES Ballroom	Tamara Vance, LICSW; Minneapolis Children's Hospital
1:45 - 3:30 Breakout Session II		
If you have an 'A' on your badge	Psychosocial Aspects of PCD--GREAT LAKES Ballroom	Tamara Vance, LICSW; Minneapolis Children's Hospital
If you have a 'B' on your badge	Hands on Nasal NO Training--CALHOUN Room	TBD
1:30 – 3:30 Breakout Session III—Invitation Only		
	REGISTRY Training	REGISTRY PILOT SITES ONLY

**3:30 - 5:30 Poster Session Reception and PCD Foundation Awards**

Friday, August 23: Morning Sessions

**8:00 - 9:00 Buffet Breakfast 7<sup>th</sup> Floor Foyer**

**PCD Genetics**

**Session Chair: Heymut Omran, MD (Invited)**

8:00 - 8:05	Introduction	
8:05 - 8:45 Presentation 8:45 - 8:50 Discussion	Keynote: Positioning of PCD genetics in the PCD diagnostic pathway	Marie LeGendre, Sorbonne Université, Paris, France (Invited)
8:50 - 9:10 Presentation 9:10 - 9:05 Discussion	PCD VUSs: Systemic Approach to Validation	Alexander Ing, MS CGC, Lurie Children's Hospital (Invited)
9:05 - 9:25 Presentation 9:25 - 9:30 Discussion	GDMCC Update on PCD Genetics	Maimoona Zariwala, PhD, University of North Carolina (Invited)
9:30 - 9:50 Presentation 9:50 - 9:55 Discussion	Creating an International PCD Genetics Working Group	Heymut Omran, University of Muester, Germany

**Research Update and Future Directions**

**Session Chair: Michele Manion**

9:55- 10:00	Introduction	
10:00 - 10:20 Presentation 10:20 - 10:25 Discussion	Creating a PCD Data Collection EcoSystem	Michael O'Connor/Carey Kauffman
10:25 - 10:45 Presentation 10:45 -10:50 Discussion	A Clinical Trial for Primary Ciliary Dyskinesia: Update	Thomas Ferkol, MD; Washington University, St. Louis
10:50 - 11:10 Presentation 11:10 -11:15 Discussion	Azithromycin in PCD: Results of the BestCilia Azithromycin Trial	Kim Nielsen, MD, University of Copenhagen (Invited)
11:15 - 11:35 Presentation 11:35 - 11:40 Discussion	International Collaboration to Accelerate PCD Research	Heymut Omran, MD, University of Muenster
11:40 - 12:00 Presentation 12:00 - 12:05 Discussion	PCD Research: Next Steps & New Directions	Michael Knowles, MD; UNC, Chapel Hill
12:10	Closing Remarks	