

# PCD on the Move 2019!

Wednesday, August 21: Morning Session: Great Lakes Ballroom, 7<sup>th</sup> Floor

<b>8:30 – 9:00 Pick up Breakfast Sandwiches and Fruit--7<sup>th</sup> Floor Foyer</b>		
<b>PCD Nuts &amp; Bolts (attendance optional)</b>		
<b>Session Chair: Adam Shapiro, MD; Michael O'Connor, MD</b>		
<b>9:00-9:05</b>	Welcome and Introduction from the PCD Foundation	Amy Kovler, PCDF Board Chair
<b>9:05-9:30</b>	PCD Clinical Phenotype	BreAnna Kinghorn, MD, MS; University of Washington, Seattle
<b>9:30-9:55</b>	PCD Genetics: Understanding VUSs	Amjad Horani, MD, Washington University, St. Louis
<b>9:55-10:20</b>	ATS PCDF Diagnostic Guidelines	Thomas Saba, MD, University of Michigan
<b>Hands-On Sessions</b>		
<b>10:20-11:05</b>	Airway Clearance Modalities for PCD (lecture & demo)	Lisa Monchil, RRT-NPS, AE-C, CCM, CCRC, NYMC
<b>11:05-11:50</b>	Measuring Nasal Nitric Oxide	Michael O'Connor, MD, Vanderbilt University
<b>Pick Up Box Lunches</b>		

Wednesday, August 21: Main Sessions Begin: Great Lakes Ballroom, 7<sup>th</sup> Floor

<b>12:30</b>	<b>PCDF Welcome to 2019 'OTM'</b>	<b>Michele Manion, PCDF; Margaret Rosenfeld, MD</b>
--------------	-----------------------------------	---

<b>PCD Basic &amp; Translational Science Session</b>		
<b>Session Chairs: Lawrence Ostrowski, PhD; Steven Brody, MD</b>		
<b>12:40-12:45</b>	Introduction	Session Chairs
<b>12:45-1:05</b>	Progress in Motile Cilia Assembly	Steven Brody, MD, Washington University
<b>1:05-1:25</b>	Ciliary Structure	Susan Dutcher, PhD, Washington University
<b>1:25-1:45</b>	Ciliary Genotype/Phenotype	Lawrence Ostrowski, PhD, UNC, Chapel Hill
<b>Break</b>		
<b>1:55-2:20</b>	Ciliated iPS Cells	Shimpei Gotoh, MD, PhD, Kyoto University
<b>2:20-2:45</b>	RNA Therapy for Ciliary Disorders	Brandon Wustman, PhD, TranscripTx
<b>2:45-3:10</b>	KEYNOTE ADDRESS: Gene Editing Ciliary Disorders	Pleasantine Mill, PhD, University of Edinburgh
<b>Break</b>		

<b>NIH Funding Opportunities</b>		
<b>3:20-3:45</b>	PCD Research and NHLBI Funding Opportunities	Marrah E. Lachowicz-Scroggins, PhD, Program Director, NHLBI.

<b>Fellows Case Reports</b>		
<b>Session Chairs: Thomas Saba, MD; BreAnna Kinghorn, MD</b>		
<b>3:45-3:50</b>	Introduction	Session Chairs
<b>3:50-4:05</b>	Low NNO and Clinical Features of PCD in a Child with Bardet-Biedl Syndrome	Alexander Ing, MS, CGC, Ann & Robert H. Lurie Children's Hospital, Chicago, IL
<b>4:05-4:20</b>	Infection with <i>Burkholderia Cepacia</i> Complex in PCD	K Kaspary, MD, CM, Montreal Children's Hospital, Montreal, Quebec, Canada.
<b>4:20-4:35</b>	Splenic infarct in a pediatric Primary Ciliary Dyskinesia patient	W.B. Wee, MD, Hospital for Sick Children, Toronto, Ontario, Canada
<b>4:35-4:50</b>	Ancestral Haplotypes Analysis of the RSPH4A founder mutation in Puerto Rico	Dalilah Reyes De Jesús, BS, San Juan Bautista School of Medicine, Caguas, PR

**5:00 to 7:00 pm**  
**Join us on the Skygarden (8<sup>th</sup> Floor) for a Welcome Reception Hosted By**  
**Theravance Biopharma**

# PCD on the Move 2019!

Thursday, August 22: Morning Sessions: Great Lakes Ballroom, 7<sup>th</sup> Floor

## 7:30 - 8:30 Buffet Breakfast 7<sup>th</sup> Floor Foyer--Pick up Breakfast & Join Session

### PCD Diagnosis

**Session Chair: Thomas Saba, MD**

8:30-8:35	Introduction	Thomas Saba, MD, C.S. Mott Children's Hospital
8:35-8:55	Nasal NO Levels in Infants with PCD	Margaret Leigh, MD, UNC, Chapel Hill
8:55-9:15	PCD vs. Primary Immunodeficiencies	Michael Knowles, MD, UNC, Chapel Hill
9:15-9:35	Bronchiectasis in Adults	Pamela McShane, MD, U of Chicago
9:35-9:55	Novel Diagnostic Techniques for Challenging Cases of PCD	Sharon Dell, MD, University of Toronto
9:55-10:15	Molecular Dx of PCD: Experience from a Clinical Laboratory	Keith Nykamp, PhD, Invitae, San Francisco, CA

Break

### Clinical Features and Manifestations of PCD

**Session Chair: Margaret Rosenfeld, MD**

10:30-10:35	Introduction	Margaret Rosenfeld, MD, U of Washington, Seattle
10:35-11:00	PCD Microbiology	Kenneth Olivier, MD, NHLBI
11:00-11:25	PCD/Cystic Fibrosis Comparison	BreAnna Kinghorn, MD, MS
11:25-11:50	ENT Features of PCD	Adam Kimple, MD, University of NC, Chapel Hill

Break for Lunch and Proceed to Roundtables

## Lunch Roundtables 12 – 1:15

**PCD Clinical Caregivers Roundtable (formerly 'Nurses Roundtable')** Chairs: Jane Quante, RN; Virginia Gonzales, RN  
Great Lakes Ballroom—7<sup>th</sup> Floor

**CRCN Director's Meeting (by invitation)** St. Croix Room Chairs: Adam Shapiro, MD; Michele Manion

Thursday, August 22: Afternoon Breakout Sessions

### Breakout Session I 1:15-2:00

'A' Badges	NIH Funding Opportunities Roundtable Calhoun Room	Marrah E. Lachowicz-Scroggins, PhD, Program Director, NHLBI
'B' Badges	Hands On Nasal NO Training—Lake Harriet Room	Milan Hazucha, PhD, UNC, Chapel Hill
'C' Badges	PCDF Registry Pilot Training (invite only—lasts both sessions) Great Lakes Ballroom	Carey Kauffman, PCDF

### Breakout Session II 2:00-2:45

'A' Badges	Hands on Nasal NO Training—Lake Harriet Room	Milan Hazucha, PhD, UNC, Chapel Hill
'B' Badges	NIH Funding Opportunities Roundtable—Calhoun Room	Marrah E. Lachowicz-Scroggins, PhD, Program Director, NHLBI

### PCD Awards—Congratulations Awardees! Great Lakes Ballroom Michele Manion

2:45	Comments	Michele Manion, PCD Foundation
2:50-3:00	PCD Director's Awardee: Thomas Ferkol, MD	Washington University, St. Louis
3:00-3:10	PCD Emeritus Awardee: Milan Hazucha, PhD	University of North Carolina, Chapel Hill
3:10-3:30	PCD Founder's Awardee: Surprise awardee!	

3:30 to 5:30 pm

Join us for a Wine & Snacks in the Fireside Room (7<sup>th</sup> Floor)

Poster Session

# PCD on the Move 2019!

Friday, August 23: Morning Session

7:30-8:30 Breakfast 7 <sup>th</sup> Floor Foyer		
PCD Genetics Session		
Session Chairs: Heymut Omran, MD; Maimoona Zariwala, PhD		
8:30-8:35	Introduction	Session Chairs
8:35-9:00	PCD VUSs: Systematic Approach to Validation	Alexander Ing, MS, CGC, Lurie Children's Hospital
9:00-9:25	Update on GDMCC Genetics	Maimoona Zariwala, PhD
9:25-9:50	Creating an International PCD Genetics Working Group	Heymut Omran, MD, University of Münster

9:50 – 10:00	Break
--------------	-------

Research Update and Future Directions		
10:00-10:05	Introduction	Michele Manion
10:05-10:30	Creating a PCD Data Collection EcoSystem	Carey Kauffman, PCDF Michael O'Connor, MD, Vanderbilt
10:30-10:55	The Genetic Disorders of Mucociliary Clearance Consortium: The Next Phase.	Thomas Ferkol, MD, Washington University
10:55-11:20	Azithromycin in PCD: Results of the BestCilia Azithromycin Trial	Kim Nielsen, MD, University of Copenhagen
11:20-11:45	International Collaboration to Accelerate PCD Research	Heymut Omran, MD, University of Münster
11:45-12:10	PCD: Next Steps and Future Directions	Michael Knowles, MD, UNC, Chapel Hill
12:10-12:15	Closing remarks and adjourn	