

PCD on the Move 2022!

Thursday, August 4 8:45 am – 1:40 PM (All times US Eastern Daylight Savings Time)

Welcome: Day 1

8:45-8:50	PCD Foundation	Michele Manion, Executive Director, PCD Foundation
8:50-9:00	Conference Chairs	Margaret Leigh, MD; Deepika Polineni, MD
Moving Towards PCD Therapies		
9:00-9:25	Clinical Studies & Clinical Trials Progress to Date	Stephanie Davis, MD, University of North Carolina
9:25-9:50	Clinical Studies & Clinical Trials Overview: Trials in the Pipeline Panel Discussion	Margaret Leigh, University of North Carolina
9:50-10:15	Developing a Clinical Trials Management Network	Kim Nielsen, MD, University of Copenhagen
10:15-10:30	Discussion	Group
Break		
10:45-11:30	Keynote: Phenotyping and Endotyping in non-CF Bronchiectasis	James Chalmers, MD, University of Dundee

PCD Scientific Reports

Session Chairs: Evans Machogu, MD; Amjad Horani, MD

11:30-11:35	Introduction	Session Chairs
11:35-11:50	Therapeutic Oligonucleotides to Correct Splicing Mutations Causing Primary Ciliary Dyskinesia	Silvia Kreda, PhD, University of North Carolina
11:50-12:05	Genotype to Phenotype: Measuring Mucociliary Clearance in Primary Ciliary Dyskinesia	Sara Abu-Nasser, DO, University of North Carolina
12:05-12:20	Genetics and Olfactory Dysfunction in Primary Ciliary Dyskinesia	Zainab Farzal, MD, University of North Carolina
12:20-12:35	Lung Function in Primary Ciliary Dyskinesia by Genotype: DNAH11 versus other outer dynein arm genes	Kunal Jakharia, MD, University of North Carolina
12:35-12:50	Heterotaxy Syndrome and Primary Ciliary Dyskinesia: Outcomes for Infants with Complex Congenital Heart Disease	Jonathan Marquez, MD, PhD, University of Washington
12:50-1:05	Microbiological Profiling and BAL Immunophenotype of PCD Patients with the Puerto Rican RSPH4A Founder Mutation	Andre Marra Nazario, BS, Ponce Health Sciences University
1:05-1:120	HYDIN in plain sight: A Seemingly Rare Primary Ciliary Dyskinesia Gene is Common in French-Canadians	Adam Shapiro, MD, McGill University
1:20-1:35	Intra-day reliability of multiple breath washout in pediatric primary ciliary dyskinesia	Wallace Wee, MD, University of Toronto

Closing Remarks: Michele Manion, Executive Director, PCDF

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Tuesday, August 09, 11:45AM –4:30 PM (All times US Eastern Daylight Savings Time)

Welcome: Day 2

11:45-11:50	PCD Foundation	Michele Manion, Executive Director, PCD Foundation
11:50-12:00	Conference Chairs	Margaret Leigh, MD; Deepika Polineni, MD
Moving towards Genetic Therapies		
12:00-12:25	Challenges of Genetic Diagnosis	Marie Legendre, PhD, PharmD, Sorbonne University
12:25-12:50	PCD Diagnosis: The Puerto Rican Experience	Wilfredo De Jesus Rojas, MD, FAAP, MSc Ponce Health Science University
12:50-1:15	Primary Ciliary Dyskinesia Among Children with Heterotaxy	Tom Saba, MD, Mott Children's Hospital
1:15-1:40	Strategies for Personalized Treatment of PCD	Larry Ostrowski, PhD, University of North Carolina
Break		
1:50-2:35	Keynote: Regenerative medicine approaches to model and treat PCD	Finn Hawkins, MBBch, Boston University School of Medicine
2:35-2:50	Trial Strategies for Small Populations: CF Modulator Experience	Deepika Polineni, MD, Washington University
Break		
3:00-3:25	PCDF Registry Updates	Michael O'Connor, MD, Vanderbilt University

CRCN and Extended Network Case Reports

Session Chairs: Hili Metjen, MD; Catherine Sanders, MD		
3:25-3:30	Introduction	Session Chairs
3:30-3:45	Twins with pathogenic variants in CCNO causing PCD: Interplay of Pulmonary and Gastrointestinal Manifestations	Alex Despostes, MD, University of North Carolina
3:45-4:00	Persistence pays off: expanding genetic analyses to identify disease-causing variants in previously discovered genes in primary ciliary dyskinesia (PCD).	R. Drew Gardner, MD, University of North Carolina
4:00-4:15	Solving the PCD Puzzle: Are ABC9A or FAM105A Genes New Missing Pieces?	Jesus Melendez-Montañez, BS, Ponce Health Sciences University
4:15-4:30	A deep intronic, pathogenic variant in DNAH11 causes Primary Ciliary Dyskinesia	Maimoona Zariwala, PhD, University of North Carolina

Closing Remarks: Michele Manion, Executive Director, PCDF