

# Facing Heterotaxy Together

*A Virtual, Multidisciplinary Conference Presented by the  
Heterotaxy Research and Clinical Care Collaborative and  
Heterotaxy Connection*

## Day 1 Agenda

**September 11, 2024 - 10 AM to 2 PM Eastern Time**

<i>Welcome and Introduction</i> Thomas Saba, MD (Session Chair) and Necia Sabin	10:00 AM - 10:10 AM
<i>Defining Laterality</i> Stephanie Ware, MD, PhD	10:10 AM - 10:20 AM
<i>At the Heart of Heterotaxy</i> Emily Bucholz MD, PhD, MPH and Stephen Spurgin, MD	10:20 AM - 10:40 AM
<i>Planning Surgery of Complex Congenital Heart Disease in Heterotaxy</i> David Hoganson, MD	10:40 AM - 11:00 AM
<i>Respiratory Disease and Ciliary Dysfunction in Heterotaxy</i> Andrea Garrod, MD	11:05 AM - 11:25 AM
<i>Gastroenterology Considerations in Heterotaxy</i> Michaela Tracy, MD	11:25 AM - 11:45 AM
<i>Immunologic Management in Heterotaxy and Asplenia/Polysplenia Syndrome</i> Douglas McDonald, MD, PhD	11:45 AM - 12:05 PM
<i>Keynote Address: Perspectives in Heterotaxy Care</i> Gerald Marx, MD	12:05 PM - 12:25 PM
<i>Family and Parent Perspectives</i> Jessica Dalton and Rachel Mattingly	12:25 PM - 12:45 PM
<i>Question &amp; Answer Session</i> Thomas Saba, MD; David Schidlow, MD, MMus; and Stephanie Ware, MD, PhD (Moderators)	12:45 PM - 1:00 PM
<i>Ask the Experts</i> Thomas Saba, MD; David Schidlow, MD, MMus; and Stephanie Ware, MD, PhD (Moderators)	

## Day 2 Agenda

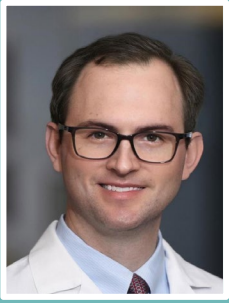
### September 12, 2024 - 10 AM to 1 PM Eastern Time

<i>Welcome and Introduction</i> David Schidlow, MD, MMus (Session Chair)	10:00AM –10:05 AM
<i>Navigating Heterotaxy: Advances, Challenges, and Future Horizons in Research</i> Emily M. Bucholz, MD, PhD, MPH	10:05AM –10:25 AM
<i>Practical Considerations of Genetic Assessment for Patients with Heterotaxy</i> Gabrielle C. Geddes, MD	10:25 AM –10:45 AM
<i>Cilia and Respiratory Dysfunction in CHD with Heterotaxy: Is It Undiagnosed PCD?</i> Cecilia W.Lo, PhD	10:45AM –11:05 AM
<i>Caring for the Adult with Heterotaxy</i> Christopher Broda, MD	11:05AM –11:25 AM
<i>Building a Heterotaxy Program: From Idea to Implementation</i> David Schidlow, MD, MMus; Caitlin O’Connell, NP; and Stephen Spurgin, MD	11:25AM –11:45 AM
<i>Case Presentations</i> Kathryn Chatfield, MD; Kenan Haver, MD; and Adam Shapiro, MD (Moderators)	11:50AM –12:30 PM
• <i>Case One: Complex Congenital Heart Disease, Lung Disease, and Biliary Atresia</i> Prasanna Ramachandran, MD, PhD; Ye Sun, MD, MPH; and Benjamin Zielonka, MD (Fellow Presenters)	
• <i>Case Two: Primary Ciliary Dyskinesia and Asplenia</i> Vincent Lavoie, MD and Sundus NoorSaeed, MBBS (Fellow Presenters)	
• <i>Case Three: Single Ventricle Palliation and Primary Ciliary Dyskinesia</i> Khalifah Aldawsari MD	
<i>Question &amp; Answer Session</i> Thomas Saba, MD; David Schidlow, MD, MMus; and Stephanie Ware, MD, PhD (Moderators)	12:30 PM - 1:00 PM

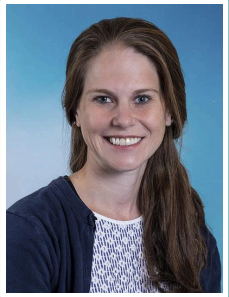
Free Conference Registration:

<https://www.heterotaxyconnection.org/scientific-conference-2024>

# FACULTY



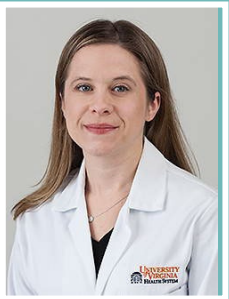
**Christopher R. Broda, MD**  
Adult Congenital Heart disease  
Baylor College of Medicine  
Texas Children's Hospital



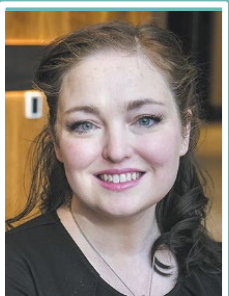
**Emily Bucholz, MD, PhD, MPH**  
Cardiology  
University of Colorado Denver, Anschutz Medical Campus  
Children's Hospital Colorado



**Kathryn Chatfield, MD, PhD**  
Cardiology, Clinical Genetics and Genomics  
University of Colorado Denver, Anschutz Medical Campus  
Children's Hospital Colorado



**Andrea Garrod, MD**  
Pulmonology  
Director, Primary Ciliary Dyskinesia Center  
University of Virginia



**Gabrielle C. Geddes MD**  
Medical Director, Cardiovascular Genetics  
Indiana University School of Medicine  
Riley Hospital for Children



**Kenan Haver, MD**  
Pulmonology  
Boston Children's Hospital  
Harvard Medical School

# FACULTY



**David Hoganson, MD**  
Cardiothoracic Surgery  
Co-Director, Heterotaxy Program  
Harvard Medical School  
Boston Children's Hospital



**Gerald Marx, MD**  
Senior Associate, Cardiology  
Harvard Medical School  
Boston Children's Hospital



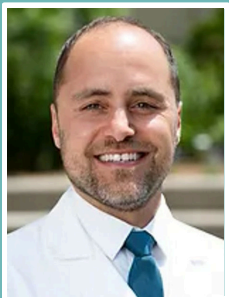
**Douglas R McDonald, MD, PhD**  
Allergy/Immunology  
Harvard Medical School  
Boston Children's Hospital



**Caitlin O'Connell, DNP, RN, CPNP-PC/AC**  
Nurse Practitioner, Heterotaxy Program  
Boston Children's Hospital



**Cecilia W. Lo, PhD**  
Chair, Department of Developmental Biology  
University of Pittsburgh



**Thomas G. Saba, MD**  
Pulmonology  
Director, Primary Ciliary Dyskinesia Center  
University of Michigan  
C.S. Mott Children's Hospital

# FACULTY



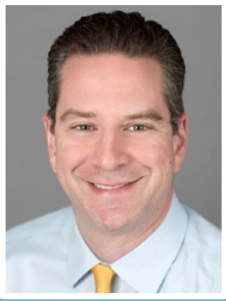
**Adam Shapiro, MD**

Pulmonology

Montreal Children's Hospital

McGill University Health Centre

Director -PCD Foundation Clinical and Research Center Network



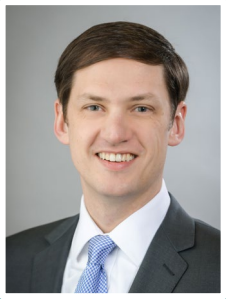
**David Schidlow, MD, MMus**

Cardiology

Director, Heterotaxy Program

Harvard Medical School

Boston Children's Hospital



**Stephen Spurgin, MD**

Cardiology

Children's Health

University of Texas Southwestern Medical Center



**Michaela Tracy, MD, MPH**

Gastroenterology

Harvard Medical School

Boston Children's Hospital



**Stephanie Ware MD, PhD**

Chair, Department of Medical and Molecular Genetics

Indiana University School of Medicine

# FELLOW CASE PRESENTERS



**Khalifah Aldawsari, MD**  
Cardiology  
Children's Hospital Colorado



**Prasanna Ramachandran, MD, PhD**  
Gastroenterology  
Boston Children's Hospital



**Vincent Lavoie, MD**  
Pulmonology  
Montreal Children's Hospital



**Ye Sun, MD, MPH**  
Pulmonology  
Boston Children's Hospital



**Sundus NoorSaeed, MBBS**  
Allergy and Immunology  
Montreal Children's Hospital



**Benjamin Zielonka, MD**  
Cardiology  
Boston Children's Hospital

# PARENT/FAMILY PRESENTERS



**Jessica Dalton**  
Parent



**Necia Sabin**  
Executive Director,  
Heterotaxy Connection



**Rachel Mattingly**  
(and Owen)  
Parent