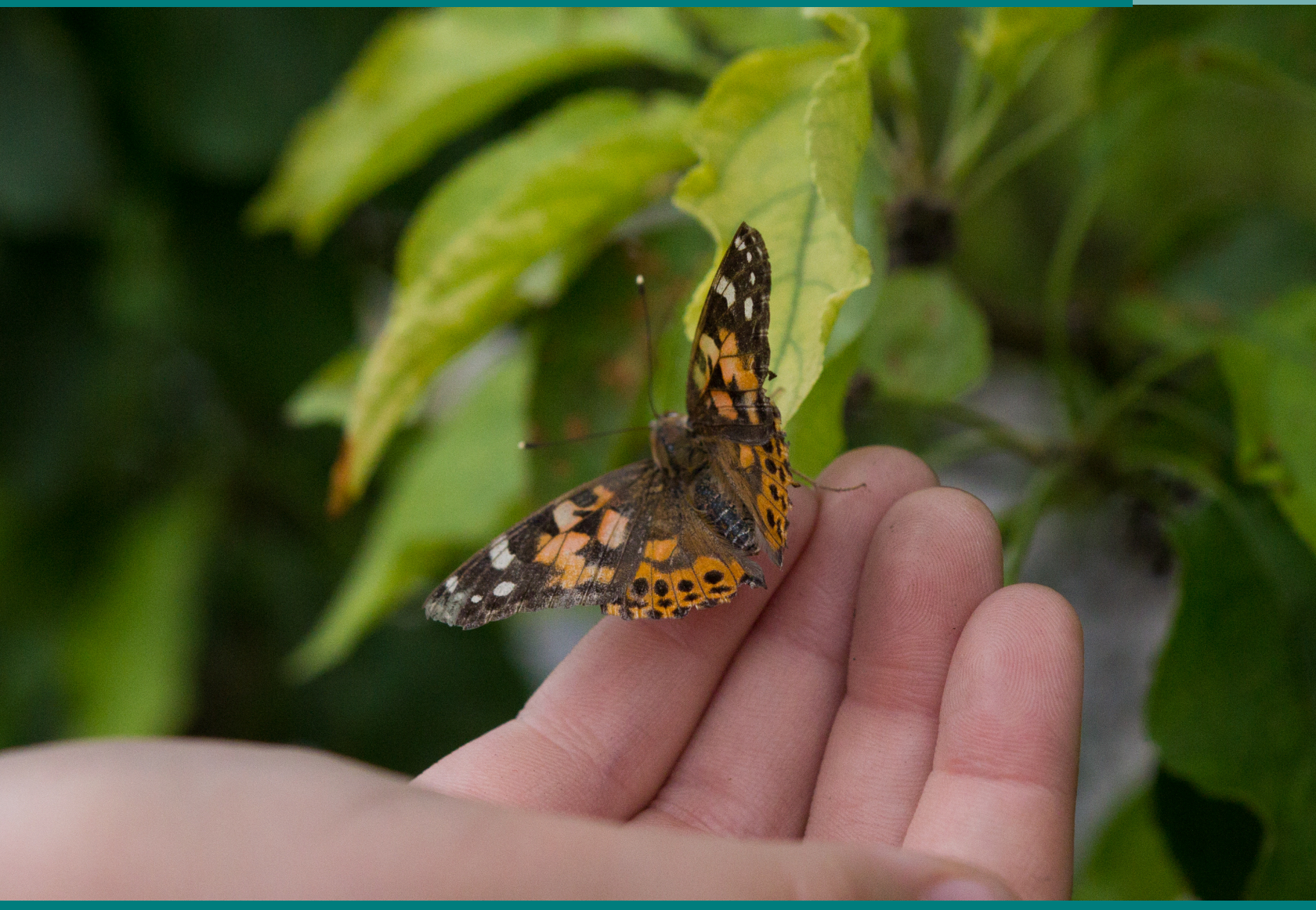
FACING HETEROTAXY TOGETHER

October
9-12, 2025
Boston, MA

2025

A Scientific and Family Conference



HETEROTAXY™ CONNECTION

HRC3 HETEROTAXY Research & Clinical Care Collaborative

Boston Children's Hospital | Benderson Family Heart Center

Not all heroes wear capes!

Will you be a part of our success story?

Scan here
to learn more about
Together We Thrive Monthly

Since its inception...

- Heterotaxy Connection maintains a global support system
- Offers educational resources
- Hosts awareness campaigns
- Honors Heterotaxy Warriors that have passed on
- Collaborates with experts and helped form HRC3
- Published a consensus paper
- Hosted multiple conferences, bringing in medical experts to collaborate with families
- Hosted the first ever Scientific conference dedicated to Heterotaxy in 2024, with over 200 registrants

HETEROTAXY™ CONNECTION

Heterotaxy Connection was formed in 2014 by 2 moms who wanted to make the Heterotaxy journey easier than what they had experienced. They banded together to create a safe place for families to gain knowledge and support.

Originally there were under 100 families, but over time, Heterotaxy Connection has grown to over 2,000 families that represent over 25 countries. We work with dozens of doctors to advance knowledge and education in the medical field.

HRC3 | HETEROTAXY Research & Clinical Care Collaborative

The Heterotaxy Research & Clinical Care Collaborative (HRC3) is an initiative focused on fostering collaboration among families, medical professionals, and researchers to advance understanding, care, and outcomes for individuals with Heterotaxy. The platform serves as a hub for clinicians and researchers, driving progress through education, research, and advocacy.

Boston Children's Hospital | Benderson Family Heart Center

The Boston Children's Benderson Family Heart Center is dedicated to achieving the best possible outcome for every patient, while providing long-term support for every family. Their team treats the full spectrum of heart conditions, including the rarest and most complex congenital heart defects.

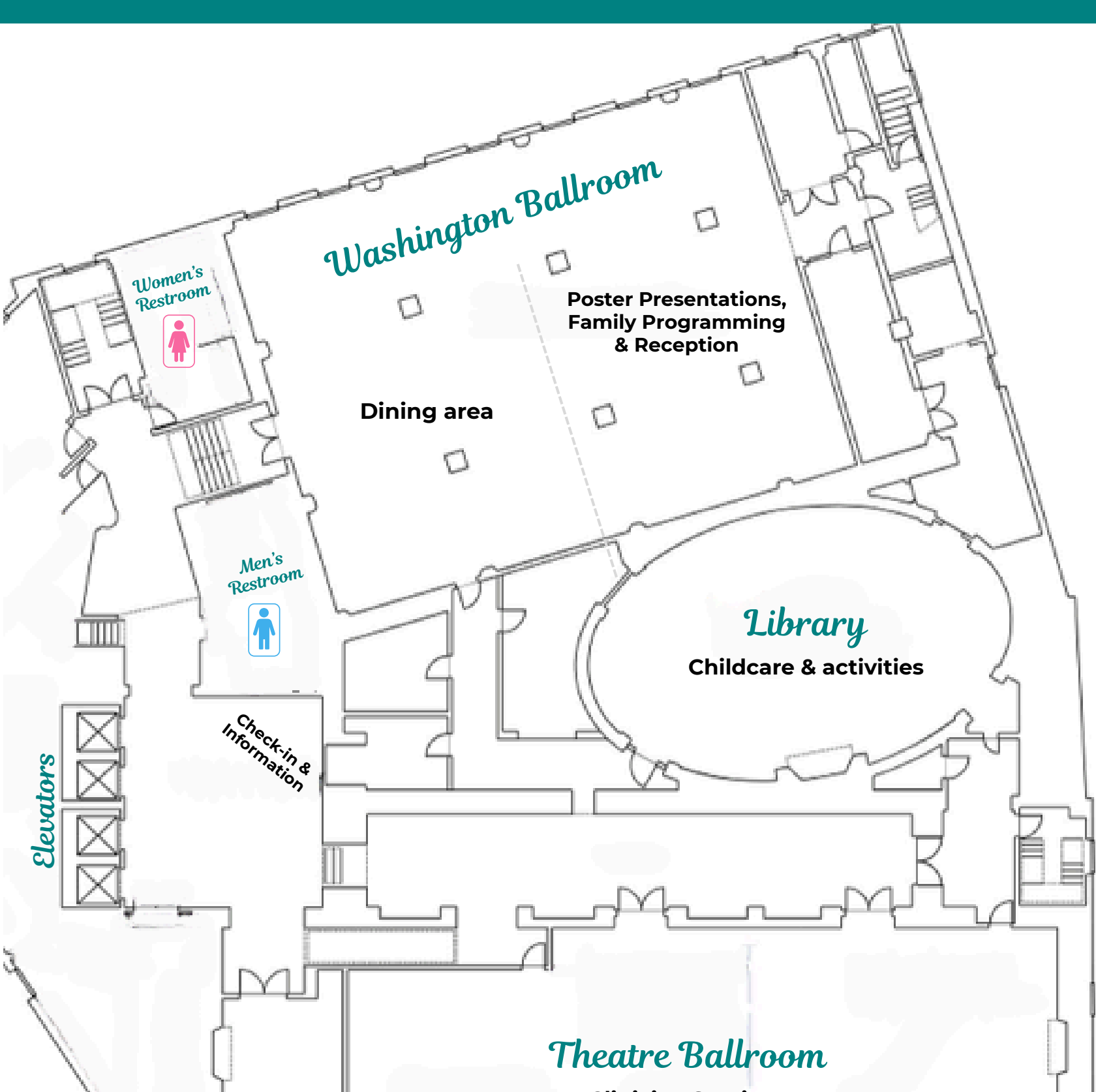
Heterotaxy Program

The Heterotaxy Program at Boston Children's Hospital provides comprehensive care to infants and children with heterotaxy syndrome. Their team of expert clinicians from across disciplines provides a full range of lifetime care for patients, from diagnosis and treatment to follow-up examinations and consultations.

Each child with heterotaxy has a unique set of health challenges. Clinicians across relevant specialities will examine your child and work together to create a personalized treatment plan to best fit their care needs.

CONFERENCE MAP

5TH FLOOR



AGENDA
CLINICIAN TRACK

10/10/2025 FRIDAY

THEATRE BALLROOM

BREAKFAST	**6:30 AM**
WELCOME AND INTRODUCTIONS	**8:00 AM**

SECTION 1: CLASSIFICATION, DEVELOPMENT, AND PRENATAL DIAGNOSIS

DEFINING HETEROTAXY *Tal Geva*	**8:10 AM**
EXPLORING THE MAJOR UNANSWERED QUESTIONS IN HETEROTAXY (PANEL) *TBD*	**8:30 AM**
THE FETUS AND HETEROTAXY: PRENATAL DIAGNOSIS AND COUNSELING *Sarah Morton*	**8:50 AM**
HETEROTAXY AND DEVELOPMENT: HOW SIDEDNESS HAPPENS *Elle Geddes*	**9:10 AM**
LIVING WITH HETEROTAXY: FAMILY EXPERIENCES *Alison Chandra*	**9:30 AM**
QUESTIONS - *Tom Saba*	**9:50 AM**
BREAK	**10:10 AM**

SECTION 2: PULMONARY DISEASE AND CILIOPATHIES

CILIARY PATHOPHYSIOLOGY *Cecelia Lo*	**10:20 AM**
PRIMARY CILIARY DYSKINESIA & HETEROTAXY-RELATED RESPIRATORY CILIARY DYSFUNCTION (HR-RCD) *Yadira Rivera-Sanchez*	**10:40 AM**
TESTING FOR PULMONARY AND CILIARY FUNCTION IN HETEROTAXY *Adam Shapiro*	**11:00 AM**
USING STRUCTURAL BIOLOGY TO UNCOVER THE COMPOSITION & MOLECULAR ORGANIZATION OF CILIA *Alan Brown*	**11:20 AM**
QUESTIONS- *Ken Haver*	**11:40 AM**
LUNCH	**12:00 PM**

SECTION 3: CARDIAC

GENETICS, *CILIA & THE LINK TO CONGENITAL HEART DISEASE* *Martina Brueckner*	**1:00 PM**
COMPUTATIONAL FLOW MODELING & ADVANCES IN SINGLE VENTRICLE PALLIATATION *David Hoganson*	**1:20 PM**
SURGERY *& PRE-OPERATIVE PLANNING FOR COMPLEX BIVENTRICULAR CIRCULATIONS* *David Hoganson*	**1:40 PM**
ELECTROPHYSIOLOGY *& INTRAOPERATIVE ELECTROPHYSIOLOGY MAPPING IN HETEROTAXY* *Elizabeth DeWitt*	**2:00 PM**
HEART TRANSPLANT OUTCOMES IN HETEROTAXY - *Ryan Butts*	**2:20 PM**
QUESTIONS - *David Schidlow*	**2:40 PM**
BREAK	**3:00 PM**

SECTION 4: GI, IMMUNOLOGY, INFECTIOUS DISEASE

DIAGNOSIS & MANAGEMENT OF BILIARY ATRESIA IN POLYSPLENIA/LEFT ATRIAL ISOMERISM *Natasha Corbitt*	**3:20 PM**
ABDOMINAL SURGICAL CONSIDERATIONS IN HETEROTAXY: MALROTATION & MORE *Benjamen Zendejas-Mummert*	**3:40 PM**
GLOBAL ASSESSMENT OF IMMUNE FUNCTION AND HYPOSPLENISM *Douglas McDonald*	**4:00 PM**
MITIGATING INFECTIOUS RISK IN HETEROTAXY: VACCINATION & PROPHYLAXIS *Jo Wilson*	**4:20 PM**
QUESTIONS	**4:40 PM**
POSTER PRESENTATIONS AND NETWORKING WITH RECEPTION	**5:00 PM**

AGENDA
CLINICIAN TRACK

10/11/2025 SATURDAY

THEATRE BALLROOM

BREAKFAST **6:30 AM**

INTRODUCTIONS **8:10 AM**

SECTION 5: FRONTIERS IN HETEROTAXY RESEARCH AND CLINICAL CARE

KEYNOTE **8:15 AM**

HUMANITY IN HEALTHCARE: A FATHER'S PERSPECTIVE
James Robinson

CURRENT LANDSCAPE OF RESEARCH IN HETEROTAXY **9:00 AM**
Steve Spurgin

LEVERAGING EXISTING REGISTRIES FOR HETEROTAXY RESEARCH **9:15 AM**
Emily Bucholz

BUILDING A SUCCESSFUL HETEROTAXY CLINICAL PROGRAM: LESSONS LEARNED **9:30 AM**
Caitlin O'Connell, David Schidlow, Steve Spurgin

HETEROTAXY CENTERS OF EXCELLENCE & PROGRAM BUILDING TOOLKIT **9:50 AM**
Yadira Rivera-Sanchez, Chris Mathis

HETEROTAXY CONNECTION AND HETEROTAXY RESEARCH & CLINICAL CARE COLLABORATIVE **10:10 AM**
Necia Sabin, Tom Saba, David Schidlow

QUESTIONS **10:20 AM**
Emily Bucholz

BREAK **10:40 AM**

SECTION 6: CASE AND POSTER PODIUM PRESENTATIONS

CASE REPORT POSTER PRESENTATIONS **11:00 AM-11:55 AM**

REMEMBRANCE CEREMONY **12:00 PM**

LUNCH **12:30 PM**

SECTION 7: SMALL GROUP INNOVATIONS

SUBSPECIALTY MEETINGS TARGETING UNIQUE CHALLENGES IN HETEROTAXY **1:30 PM**

LARGE GROUP REPORTING ON BREAKOUT SESSIONS AND WRAPUP **2:00 PM**

HRC3 COMMITTEE MEETINGS **2:30 PM**

AGENDA
FAMILY TRACK

OCTOBER 9, 2025
THURSDAY

WASHINGTON BALLROOM
Childcare is located in the Library

BREAKFAST — **7:00 AM**

INTRODUCTIONS — **8:30 AM**

HETEROTAXY AS A WHOLE & PALLIATIVE CARE — **8:40 AM**
Dr. Shih-Ning Liaw, Chelsea Heneghan, MSN, CNP
Heterotaxy affects the whole body and the whole family, and requires a care team that takes this big picture perspective into account. In this session, the palliative care team will explore how palliative care fits into this holistic approach. We'll discuss what palliative care is, how it differs from and complements other types of medical care, who is eligible to receive it, and how families can access these services for their heterotaxy warriors.

SECOND OPINIONS — **9:40 AM**
René Harrell
Second opinions can change the course of treatment and help find answers. This session will provide insight on how to obtain opinions from other hospitals.

BREAK — **10:10 AM**

NEURODEVELOPMENT — **10:30 AM**
TBD
Understanding the implications of complex medical conditions like Heterotaxy on neurodevelopment.

PANEL DISCUSSIONS — **11:00 AM**
Rare But Mighty: Building Community in Isolation

IEP AND 504 PLANS FOR SCHOOL — **11:30 AM**
TBD
Supporting your medically complex child in the school setting.

LUNCH — **12:00 PM**

NATURAL HISTORY REGISTRY CITIZEN HEALTH — **1:00PM**
Necia Sabin
A powerful registry that brings all of your medical history into one searchable database. Become empowered with access to critical information when you need it most.

AIRWAY CLEARANCE WORKSHOP — **1:30 PM**
Sarah Mozzochi, PT, DPT
Learn about various methods and tools to assist with airway clearance for those with and without Primary Ciliary Dyskenesia.

BREAK — **2:00 PM**

FEVER PROTOCOLS, IMMUNIZATIONS, AND ANTIBIOTIC PROPHYLAXIS — **2:20 PM**
Dr. Douglas McDonald
Understanding up-to-date recommendations for immunizations and treatment protocols. This includes what, when, and why antibiotic prophylaxis is used, and considerations when deciding to continue or discontinue treatment.

NUTRITION AND TUBE FEEDING — **3:20PM**
Beth Gore - Oley Foundation
Addressing unique challenges with nutrition and feeding with Heterotaxy.

AFTERNOON TEA TIME - RESOURCE SHOWCASE — **4:00 PM**
An informal opportunity to mingle, collaborate, and share ideas. Partnerships and resources will showcased.

AGENDA
FAMILY TRACK

OCTOBER 10, 2025
FRIDAY

BREAKFAST **6:30 AM**

8:00 AM - 5:00 PM

CLINICIAN PRESENTATIONS

Family members are invited to attend any and all clinician presentations in the Theatre Ballroom.

CHILDCARE AND ACTIVITIES LOCATED IN THE LIBRARY

Available 10/9-10/12 during session hours.

Screened volunteers will monitor children in the family room throughout each day to allow adults to attend presentations. A variety of scheduled and free choice activities will be available.

AGENDA
FAMILY TRACK

OCTOBER 11, 2025
SATURDAY

WASHINGTON BALLROOM
Childcare is located in the Library

BREAKFAST — **6:30 AM**

KEYNOTE - JAMES ROBINSON: HUMANITY IN HEALTHCARE - A FATHER'S PERSPECTIVE — 8:15 AM
LOCATED IN THE THEATRE BALLROOM

Author of *More Than We Expected*, a memoir. In it, he details his five years parenting a child born with Heterotaxy, a globe-spanning medical odyssey that revealed unexpected truths about what it means to live, grow and heal.

FRONTIERS IN HETEROTAXY RESEARCH & CLINICAL CARE *(SEE CLINICIAN AGENDA)* — 9:00 AM
LOCATED IN THE THEATRE BALLROOM

REMEMBRANCE CEREMONY — 12:00 PM
All attendees are invited to honor and remember our Heterotaxy Angels.

LOCATED IN THE THEATRE BALLROOM

LUNCH — **12:30 PM**

NAVIGATING HEALTH INSURANCE — 2:00 PM
Alison Chandra

The realm of health insurance is ever-changing. This session can help demystify your options to access coverage for the unique and ongoing needs that Heterotaxy brings.

TEACHING YOUR CHILD TO SELF-ADVOCATE — 2:30 PM
Monica Bloom

Children with Heterotaxy are incredible warriors who often face stressful medical situations. Learning to self-advocate early on will pay off immensely throughout their lives.

IDENTIFY AND COMBAT MEDICAL GASLIGHTING — 3:00 PM
Alison Chandra

Receiving appropriate care for a rare disease can be a daunting task. Patients need a medical team that is able to think outside of the box. This session can help you identify medical gaslighting and ensure you and your care team are communicating effectively.

FUTURE PROGRAMS OVERVIEW — 3:30 PM
René Harrell

The Heterotaxy Connection community is growing rapidly. This session provides insight to future programming and resources, as well as information about how you can get involved.

FAMILY ENGAGEMENT PARTY — 6:30 PM
Join us for an evening of connection and fun. We'll have games, goodies, photo opportunities, and more!

AGENDA
FAMILY TRACK

OCTOBER 12, 2025
SUNDAY

WASHINGTON BALLROOM
Childcare is located in the Library

BREAKFAST **7:00 AM**

INTRODUCTION **8:20 AM**

TRANSITIONING TO ADULT CARE **8:30 AM**

Alicia Lynch

Learn about the process of transitioning from pediatric to adult care, and how to shift aspects of decision-making from the caregiver to the patient.

THE SIBLING EXPERIENCE **9:00 AM**

Chrissy Salley, PhD

Caring for a child with a complex condition takes its toll on the entire family. In this session we will discuss the impact this may have on siblings living in the same home, and coping strategies to help them along the way.

BREAK **9:40 AM**

EMOTIONAL RESILIENCE **10:00 AM**

Aimee Lybbert

In this session, we'll challenge the "superhero parent" myth and explore how authentic connection, relational remedies, and community support can help families of medically complex children move beyond isolation toward healing and growth.

FAMILY PANEL: BUILDING RESILIENCE **11:00 AM**

Heterotaxy warriors and caregivers share and reflect on their lived experiences of trial and error while building resilience in our unpredictable world with heterotaxy.

CLINICIAN TRACK

PRESENTERS

Dr. Alan Brown

Alan Brown is an Associate Professor of Biological Chemistry and Molecular Pharmacology at Harvard Medical School. He obtained his PhD in 2010 from the University of Cambridge and was named a Pew Scholar in 2019. His laboratory uses structural and cell biological techniques to study cilia and flagella, with a particular emphasis on elucidating the mechanisms of ciliary motility, intraflagellar transport, and the regulation of the ciliary proteome.

Dr. Martina Brueckner

Martina Brueckner received her undergraduate and medical degrees from the University of Virginia, then trained in Pediatrics at the University of Pittsburgh and completed her Pediatric Cardiology fellowship at Yale. She has been on the faculty at Yale since 1991, where she is currently Professor of Pediatrics and Genetics. She provides clinical pediatric cardiology care and founded the Yale Pediatric Cardiac Genetics clinic. Her laboratory studies the mechanism by which cilia establish organismal LR asymmetry, identified cilia genes that are central to mouse left-right development and demonstrated that cilia are required to generate and sense flow at the left-right organizer. As part of the Pediatric Cardiac Genomics Consortium, the lab investigates the molecular and genetic causes of human congenital heart disease, with a special focus on the role of cilia in human heart development and disease.

Dr. Ryan Butts

Currently Professor of Pediatrics at University of Texas Southwestern, where I serve as the medical director of the Pediatric Heart Transplant program. I did undergraduate, medical school and Pediatric Cardiology training in Charleston, SC. In 2016, I joined the heart transplant program in Dallas and moved into the medical directorship in 2019. Over the past 6 years our program has had growth, performing 25-30 transplants per year, with about 80% of recipients with congenital heart disease, many with heterotaxy syndrome.

Dr. Emily Bucholz

Emily Bucholz is an Assistant Professor of Pediatrics at the University of Colorado School of Medicine and a pediatric cardiologist at Children's Hospital Colorado specializing in cardiac imaging and fetal cardiology. She is one of the founding leaders of the Boston Children's Hospital Heterotaxy Registry, where she helped develop one of the largest longitudinal cohorts of patients with heterotaxy syndrome. She also leads the research committee for the HRC3. Dr. Bucholz's research more broadly focuses on sociodemographic disparities in pediatric heart disease, quality measurement, and risk stratification in congenital heart disease.

Dr. Natasha Corbitt

Dr. Corbitt is a pediatric surgeon-scientist investigating genetic drivers of congenital hepatobiliary disorders. She earned her medical degree and a doctorate in cellular and molecular pathology at the University of Pittsburgh. She completed surgical residency at Vanderbilt University Medical Center and received advanced training in pediatric surgery at the University of Michigan.

Dr. Elizabeth DeWitt

Dr. Elizabeth DeWitt is an electrophysiologist at Boston Children's Hospital and an assistant professor of pediatrics at Harvard Medical School. She graduated from Middlebury College where she majored in physics and went on to Albert Einstein College of Medicine for Medical school. She came to Boston Children's Hospital for pediatrics residency and stayed on for fellowship in pediatric cardiology, where she served as Chief Fellow. She then completed a 4th year in electrophysiology prior to coming on faculty. She is the medical director of the Surgical Electrophysiology service and an associate program director of the cardiology fellowship. Her research interests include intraoperative identification of the conduction system in patients with complex congenital heart disease and heterotaxy to avoid inadvertent injury at the time of cardiac repair as well as inherited arrhythmias and arrhythmogenic cardiomyopathy.

Dr. Tal Geva

Dr. Geva is Chairman of the Department of Cardiology at Boston Children's Hospital and the Alexander S. Nadas Professor of Pediatrics at Harvard Medical School. His major clinical and research interests are multimodality imaging of congenital heart disease. His research has focused on the use of echocardiography and cardiovascular magnetic resonance to define imaging biomarkers predictive of outcomes of pediatric and congenital heart disease. Together with collaborators from North America and Europe, he has established the INDICATOR cohort, a multicenter international registry of patients with repaired tetralogy of Fallot. Dr. Geva has been a member of ASE for more than 30 years, chaired the Pediatric/Congenital Council in 2006-2007, and was the recipient of the Council's Teaching Award in 2014 and the Founders' Award for Lifetime Achievement in Echocardiography for Pediatric and Congenital Heart Disease in 2024.

Dr. Elle Geddes

Dr. Elle Geddes is a cardiovascular geneticist at Riley hospital for children in Indianapolis with a special interest in the care for patients with heterotaxy.

Dr. Ken Haver

Director, Boston Children's Hospital
Primary Ciliary Dyskinesia Diagnostic and Treatment Center
Boston Children's Hospital Heterotaxy Program
Core Clinical Faculty – Pulmonary Division of Pulmonary Medicine, Boston Children's Hospital
Associate Professor of Medicine, Harvard Medical School

CLINICIAN TRACK

PRESENTERS

Dr. David Hoganson

Dr. Hoganson is an Assistant in Cardiac Surgery, Department of Cardiac Surgery at Boston Children's Hospital, and is an Assistant Professor of Surgery at Harvard Medical School. His clinical focus is on neonates and children with congenital heart disease. He has co-lead development of patient specific 3D modeling and computational flow modeling of complex cardiac disease for improved pre-operative planning and intraoperative guidance. His lab also focuses on development of medical devices to improve the safety and effectiveness of cardiac surgery. Dr. Hoganson has a background in engineering and industry experience developing cardiovascular medical devices prior to medical school. He graduated from the Temple University School of Medicine in 2004 and completed his general surgery residency and CT fellowship at the Washington University in St. Louis, and completed a congenital cardiac surgery fellowship at the Boston Children's Hospital in 2016.

Dr. Cecilia W. Lo

Cecilia W. Lo received her B.S. from the Massachusetts Institute of Technology and her PhD from Rockefeller University. After postdoctoral training at Harvard Medical School, she began her academic career as faculty in the Department of Biology at the University of Pennsylvania, rising through the ranks to full Professor. Subsequently, she relocated to NIH as the NHLBI Chief of the Laboratory of Developmental Biology and Director of the Genetics and Developmental Biology Center, later relocating to the University of Pittsburgh School of Medicine, where she currently holds the F Sargent Cheever Chair and is Professor in the Division of Genomics and Medical Genetics in the Department of Pediatrics. Her research focuses on the genetic, epigenetic and developmental etiology of congenital heart disease (CHD) using mouse models and with parallel clinical translational studies. Some of her research interests include hypoplastic left heart syndrome, and left-right patterning in the developmental etiology of complex congenital heart disease associated with heterotaxy

Dr. Chris Mathis

I am a pediatric cardiologist with advanced imaging training and a particular interest in improving care of patients with heterotaxy. I graduated medical school from the Saint Louis University School of Medicine in St. Louis, Missouri and completed residency in Pediatrics at the University of Michigan in Ann Arbor, Michigan. I completed my cardiology fellowship and additional advanced imaging training at Children's Mercy Kansas City where I am currently serving as faculty. I have developed a local protocol for standardized evaluation and management of heterotaxy and excited to be part of the HRC3 clinical care committee to further standardize heterotaxy care.

Dr. Douglas McDonald

Dr. Douglas McDonald is a senior associate physician in pediatrics at Boston Children's Hospital in the division of Allergy and Immunology. He graduated from Case Western Reserve Medical school with a PhD in Neurosciences and MD. His pediatric residency was completed at Cincinnati Children's hospital. Dr. McDonald completed fellowship training in Allergy and Immunology at Boston Children's hospital studying primary immune deficiencies involving defects in NFkB. He currently treats patients with a wide variety of allergic and immunologic disorders.

Dr. Sarah Morton

Sarah is a physician scientist at Boston Children's Hospital. She works in the neonatal intensive care unit and runs a research group focused on how genetic and other factors impact lifelong health for people with congenital heart diseases including heterotaxy.

Caitlin O'Connell, DNP, RN, CPNP-PC/AC

I have enjoyed working with pediatric cardiology patients for the entirety of my nursing career, including the last 16 years as a pediatric cardiology nurse practitioner. I became the nurse practitioner for the Heterotaxy Program at Boston Children's Hospital 3 years ago and continue to be incredibly proud of the tremendous growth of our program. Together, we have (1) offered comprehensive multidisciplinary evaluations to all children with heterotaxy, (2) implemented prenatal heterotaxy consultations for expectant families in whom a diagnosis of fetal heterotaxy is suspected, and (3) developed a standardized post-operative airway clearance regimen for all children with heterotaxy undergoing cardiac surgery in an effort to improve post-operative outcomes. I have met so many wonderful families through this work and remain devoted to helping them seek the best care for their child.

Dr. Yadira Rivera-Sánchez

Dr. Yadira Rivera-Sánchez is an Associate Professor of Pediatrics in the Division of Pulmonology and Sleep Medicine at the University of Texas Southwestern Medical Center. She earned her medical degree at Ponce Health Sciences University in Puerto Rico, followed by a pediatrics Residency at the University of Puerto Rico Medical Sciences Campus. She went on to complete her fellowship in pediatric pulmonary at Boston Children's Hospital, Harvard Medical School. At UT Southwestern and Children's Health Dallas, Dr. Rivera-Sánchez serves as Medical Director of the Primary Ciliary Dyskinesia Center and the pulmonary leader for the Heterotaxy Center. She also serves as the Medical Director for Culture and Opportunity for the Department of Pediatrics, where her work focuses on supporting junior faculty recruitment and retention. Nationally, she contributes to health equity initiatives as a member of the ATS. Health Equity and Diversity Committee. Her research interests center around PCD and advancing health equity in pediatric pulmonary care.

CLINICIAN TRACK

PRESENTERS

James G. Robinson, author, *More Than We Expected* (morethanamemoir.com)

James G. Robinson is the author of More Than We Expected (morethanamemoir.com), a memoir that Booklist calls "a giving, thought-provoking, and heart-tugging family saga." In it, he details his five years parenting a child born with a serious heart defect caused by heterotaxy, an experience that revealed unexpected truths about what it means to live, grow and heal. James has spent nearly two decades at The New York Times, where he helps the company use data to better understand its audience. His essay "Road to Recovery," published in the Times shortly after his son's death, was selected as a notable essay in The Best American Travel Writing 2018. A lifelong resident of Brooklyn, NY, he has taught expository writing at NYU and is currently an adjunct professor at Columbia Journalism School.

Dr. Thomas G. Saba

Thomas Saba is a Pediatric Pulmonologist at C.S. Mott Children's Hospital at the University of Michigan. He is the Director of the primary ciliary dyskinesia Clinical and Research Center and serves on the PCD Foundation Registry Data Growth and Development Committee and the PCD Foundation Infection Prevention and Control committee. Dr. Saba's main clinical and research interests focus on mucociliary clearance disorders among people with heterotaxy and infection epidemiology and laterality defects in PCD. He works in cardiology clinics focused on pulmonary hypertension and Single Ventricle physiology to better explore the role of cilia in complex cardiopulmonary disorders. Dr. Saba is a founding member and the Co-Director of the Heterotaxy Research and Clinical Care Collaborative.

Necia Sabin

Necia Sabin is a dedicated patient advocate and co-founder of Heterotaxy Connection (HC), where she works to educate families, build supportive communities, and advance resources for those affected by heterotaxy syndrome. She also serves in the executive leadership of HRC3 (Heterotaxy Research Collaborative Clinical Consortium), helping to unite clinicians, researchers, and families to accelerate progress in research and care. Necia's work bridges the lived patient experience with scientific collaboration, ensuring that the voices of families remain central in shaping best practices and future innovations.

Dr. David N. Schidlow

David N. Schidlow, MD, MMus is a pediatric cardiologist at Boston Children's Hospital specializing in complex congenital heart disease, with particular expertise in cardiac imaging and heterotaxy syndrome. He founded and co-directs the Boston Children's Hospital Heterotaxy Program and serves as co-executive director of the Heterotaxy Research and Clinical Care Collaborative (HRC3). His work integrates clinical care, quality improvement, and research, with a focus on improving outcomes through multidisciplinary collaboration. Dr. Schidlow is an Associate Professor of Pediatrics at Harvard Medical School and a dedicated educator, having trained many fellows and junior faculty. He holds degrees in both clarinet performance and music history and performs regularly in the Boston area.

Dr. Adam J. Shapiro

Associate Professor of Pediatric Respiratory Medicine at the McGill University Faculty of Medicine in Montreal, Quebec, Canada. Creator and director of the first and only clinic for Primary Ciliary Dyskinesia in Quebec. Medical Director of the North American Clinical and Research Center Network for the PCD Foundation. Ongoing research in heterotaxy and associated respiratory issues, non-CF bronchiectasis, and Primary Ciliary Dyskinesia through the Genetic Disorders of Mucociliary Clearance Consortium.

Dr. Stephen Spurgin

I am a physician scientist with training in developmental and vascular biology, currently working to understand how primary cilia coordinate cell-cell signaling in lung development, and how the pulmonary vasculature adapts to single ventricle palliation. My scientific efforts aim to complement my clinical work, as I strive to improve the clinical care of our heterotaxy patients through our multidisciplinary program. After my undergraduate at Stanford, I completed all of my medical and research training at UT Southwestern, where I am currently Assistant Professor of Pediatric Cardiology.

Jo L. Wilson, M.D.

Jo Wilson is an Assistant Professor in the Division of Pediatric Allergy, Immunology, and Rheumatology at the University of Wisconsin–Madison. She provides specialized care for children with primary immunodeficiencies, including those with heterotaxy syndrome, functional asplenia, and asplenia. Her clinical work focuses on infection risk assessment, immunization strategies, and long-term immune management in medically complex pediatric populations. Dr. Wilson's research centers on respiratory mucosal biology, with a particular focus on genetic risk factors for asthma development. She studies epithelial barrier dysfunction and repair using primary human nasal epithelial cells, aiming to understand how allergic inflammation and viral infections interact with genetic susceptibility. Dr. Wilson is committed to integrating clinical insight with translational research to improve outcomes for children.

Dr. Benjamin Zendejas-Mummert

Benjamin Zendejas-Mummert, MD, MSc is an Associate Professor of Surgery at Harvard Medical School and pediatric surgeon at Boston Children's Hospital. He serves as Surgical Director of the Esophageal and Airway Treatment Center and Co-Surgical Director of the Vascular Ring Program. In addition to his expertise in complex esophageal and airway reconstruction, Dr. Zendejas is the general surgical representative on the Boston Children's Hospital Heterotaxy Group, where he helps develop guidelines for screening and management of intestinal malrotation and surgical treatment strategies.

FAMILY TRACK

PRESENTERS

Monica Bloom

Before becoming a caregiver, Monica Bloom was a music teacher, runner, and singer. When her daughter Lauren was diagnosed with Heterotaxy, she leaned on those skills—discipline, creativity, and perseverance—to advocate for her care while living far from home. Monica now channels that same energy into supporting the rare disease community, guiding both Lauren and other families to find their voices in the face of medical complexity.

Alison Chandra

Alison Chandra combines her background as a nurse and parent with a passion for advocacy, working to bridge the gap between clinicians and patients. She is dedicated to ensuring that every family impacted by Heterotaxy has access to the best possible care.

Beth Gore, PhD

Beth Gore, PhD is the Chief Executive Officer of the Oley Foundation, a national nonprofit dedicated to supporting people who rely on home parenteral and enteral nutrition. A longtime patient-safety advocate, author, and speaker, Dr. Gore brings deep expertise in vascular access and nutrition support to her leadership role. She champions the voice of the patient on national committees, boards, and task forces, striving to shape policy and practice to improve outcomes and quality of life. A mother to six adopted children with special needs—including a son who depends on a central line for lifelong nutrition support—Beth's advocacy is grounded in lived experience and unwavering commitment to her community.

René Harrell

Rene Harrell is the Director of Programming at Heterotaxy Connection, where she develops resources, peer mentorship programs, and educational initiatives. Inspired by her daughter Seraphina, Rene is committed to expanding support for families navigating the challenges of living with a heterotaxy diagnosis.

Aimee Lybbert

Aimee Lybbert is a heterotaxy parent and clinical social worker at a unique pediatric skilled nursing facility whose mission is to help children leave the hospital sooner, provide families opportunities to practice medical caregiving skills in real-life settings, and offer wraparound support as children transition home.

Alicia Lynch

Alicia Lynch is a Heterotaxy Warrior who was diagnosed at Boston Children's Hospital shortly after being transferred from Emerson Hospital. Her journey has included numerous procedures and interventions, including the Bi-directional Glenn, LADD procedure, multiple catheterizations, and a Fontan revision. Despite the challenges of heterotaxy, which has affected her cardiovascular, GI, lymphatic, and liver systems, Alicia embraces life with creativity and passion. She loves yoga, painting, drawing, and belly dancing, and finds strength in expressing herself through movement and art.

Chelsea Heneghan, MSN, CNP

Chelsea Heneghan, MSN, CNP, is a pediatric nurse practitioner at Boston Children's Hospital who transitioned into pediatric palliative care in 2018 after years in pediatric oncology. She specializes in supporting children with oncologic, pulmonary, and cardiac conditions, bringing compassionate, family-centered care to children with complex medical needs.

Sarah Mozzochi, PT, DPT

Sarah Mozzochi, PT, DPT earned both her undergraduate degree and Doctor of Physical Therapy from Boston University. She currently serves as Physical Therapist I in the Department of Physical Therapy at Boston Children's Hospital. Her practice focuses on pediatric rehabilitation in the context of complex congenital and multisystem conditions; she brings a research-informed, interdisciplinary lens to improving functional outcomes and quality of life for children and families.

Dr. Chrissy Salley

Dr. Chrissy Salley, PhD, is a pediatric psychologist specializing in children with medical and developmental challenges and the families who support them. With experience in pediatric hospitals, oncology, and rare disease settings, she now focuses her private practice on helping caregivers navigate complex child health and parenting issues. She also serves as Director of Clinician Engagement & Outreach for Courageous Parents Network, a national nonprofit supporting families of seriously ill children, and holds leadership roles in the Society of Pediatric Psychology. Dr. Salley earned her PhD at Ohio State University and completed training at Nemours/Alfred I. duPont Hospital for Children, NYU Langone's Hassenfeld Children's Center, and Memorial Sloan Kettering.

Dr. Shih-Ning Liaw

Dr. Shih-Ning "Suny" Liaw is an attending physician with the Pediatric Advanced Care Team (PACT) at Boston Children's Hospital and an Instructor of Pediatrics at Harvard Medical School. He is board certified in General Pediatrics and Hospice & Palliative Medicine, with a focus on caring for children with medical complexity and integrating palliative approaches into pediatric care. At Boston Children's, he also serves as the Pediatric Site Director for the Harvard Interprofessional Palliative Care Fellowship.

Notes

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