

FACING HETEROTAXY TOGETHER



October
9-12, 2025
Boston, MA

A Scientific and Family Conference



HETEROTAXY
Research & Clinical
Care Collaborative



OCTOBER 9, 2025
THURSDAY

9:00 AM - 5:00 PM

INTRODUCTIONS

Welcome commentary

8:30 AM

HETEROTAXY AS A WHOLE

Supporting the perspective of Heterotaxy seen as a whole-body condition, and building a care team with this perspective in mind.

8:40 AM

PALLIATIVE CARE

What is palliative care and how is it different from other care programs? Who qualifies to receive care and how can we access palliative care for our warriors?

9:10 AM

SECOND OPINIONS

Every person with Heterotaxy has unique care needs. Second opinions can change the course of treatment and help find answers. This session will provide insight on how to obtain and cover the costs of opinions from other hospitals.

9:40 AM

BREAK

10:10 AM

NEURODEVELOPMENT

Understanding the implications of complex medical conditions like Heterotaxy on neurodevelopment.

10:30 AM

PANEL DISCUSSIONS

Rare But Mighty: Building Community in Isolation

11:00 AM

IEP AND 504 PLANS FOR SCHOOL

Supporting your medically complex child in the school setting.

11:30 AM

LUNCH

12:00 PM

1:00PM

TRANSITIONING TO ADULT CARE

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.

1:30 PM

AIRWAY CLEARANCE WORKSHOP

Learn about various methods and tools to assist with airway clearance for those with and without Primary Ciliary Dyskenesia.

BREAK

2:00 PM

2:20 PM

FEVER PROTOCOLS, IMMUNIZATIONS, AND ANTIBIOTIC PROPHYLAXIS

Understanding the most up-to-date recommendations for immunizations and emergency treatment protocols. This includes what, when and why antibiotic prophylaxis is used, and considerations when deciding to continue or discontinue treatment.

3:20PM

NUTRITION AND TUBE FEEDING

Addressing unique challenges with nutrition and feeding in Heterotaxy.

4:00 PM

AFTERNOON TEA TIME - RESOURCE SHOWCASE

An informal opportunity to mingle, collaborate, and share ideas. Partnerships and resources will be showcased.

AGENDA FAMILY TRACK

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Benderson Family
Heart Center

OCTOBER 10, 2025
FRIDAY

8:00 AM - 5:00 PM

8:00 AM - 5:00 PM

CLINICIAN PRESENTATIONS

Family members are invited to attend any and all presentations in the clinician track today.



CHILD/FAMILY GATHERING ROOM ACTIVITIES

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. Activity details TBD once attendance details are more solidified.

6:30 PM

FAMILY ENGAGEMENT ACTIVITY (TBD)

All families are invited to gather to relax, connect, and build connections.

AGENDA FAMILY TRACK

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OCTOBER 11, 2025
SATURDAY
8:15 AM - 4:00 PM

KEYNOTE - JAMES ROBINSON: HUMANITY IN HEALTHCARE - A FATHER'S PERSPECTIVE

8:15 AM

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.

REMEMBRANCE CEREMONY

12:00 PM

All attendees are invited to honor and remember our Heterotaxy Angels.



NAVIGATING HEALTH INSURANCE

2:00 PM

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.

NATURAL HISTORY REGISTRY CITIZEN HEALTH

2:30 PM

Learn about how you can contribute to a powerful registry that brings all of your medical history into one searchable database. Patients will be empowered with access to critical information when they need it most, as well as an opportunity to share the information with researchers.

HOW TO IDENTIFY AND COMBAT MEDICAL GASLIGHTING

3:00 PM

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

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.

AGENDA FAMILY TRACK

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Benderson Family
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OCTOBER 12, 2025
SUNDAY

8:15 AM - 4:00 PM

AGENDA

FAMILY TRACK

INTRODUCTION

9:00 AM

TEACHING YOUR CHILD TO SELF-ADVOCATE

9:10 AM

Children with Heterotaxy are incredible warriors who often face stressful medical situations. Helping them to understand that they have choices during their time in the hospital can minimize their anxiety and fears. Learning to self-advocate early on will pay off immensely throughout their lives.

THE SIBLING EXPERIENCE

9:40 AM

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.

EMOTIONAL RESILIENCE

11:00 AM

Angel Swinton is a parent to a Heterotaxy Warrior, as well as a marriage and family therapist in training. She will discuss implications and strategies for emotional resilience in the wake of medical trauma and unpredictability.

FAMILY PANEL: BUILDING RESILIENCE

11:30 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.

