HC
HETEROTAXY™
CONNECTION

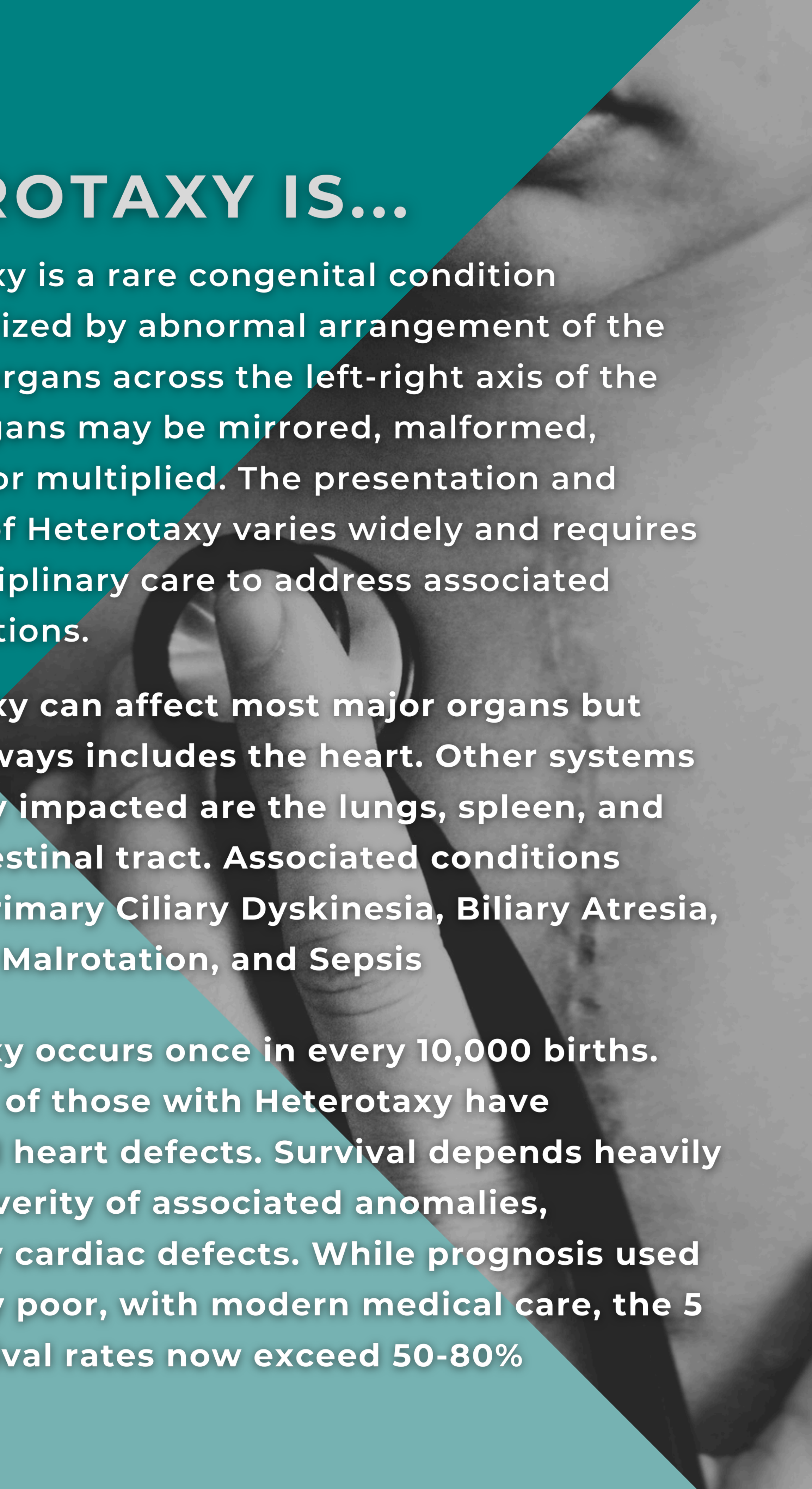
FACING HETEROTAXY TOGETHER 2025

SPONSORSHIP
GUIDE

In collaboration with

HRC3 | HETEROTAXY Research & Clinical Care Collaborative

Boston Children's Hospital | Benderson Family Heart Center



HETEROTAXY IS...

- Heterotaxy is a rare congenital condition characterized by abnormal arrangement of the internal organs across the left-right axis of the body. Organs may be mirrored, malformed, missing, or multiplied. The presentation and severity of Heterotaxy varies widely and requires multidisciplinary care to address associated complications.

- Heterotaxy can affect most major organs but almost always includes the heart. Other systems commonly impacted are the lungs, spleen, and gastrointestinal tract. Associated conditions include Primary Ciliary Dyskinesia, Biliary Atresia, Intestinal Malrotation, and Sepsis

- Heterotaxy occurs once in every 10,000 births. Over 90% of those with Heterotaxy have structural heart defects. Survival depends heavily on the severity of associated anomalies, especially cardiac defects. While prognosis used to be very poor, with modern medical care, the 5 year survival rates now exceed 50-80%

Heterotaxy Connection 501(c)3

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.

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 3 family conferences, bringing in medical experts to educate families
- Hosted the first ever Scientific conference dedicated to Heterotaxy in 2024, with over 200 registrants

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.

Growing interest with each conference

Each conference has grown and built more interest. After our second family conference, Necia Sabin, our Executive Director worked with a group of doctors to publish a consensus paper that outlines best practices for newly diagnosed Heterotaxy patients. During the third family conference, participating doctors were pulled together and HRC3 was formed. This led to our first scientific conference, presented virtually. The interest was great enough to justify our next in-person conference being a combined scientific and family conference.

Planned outcomes of future conferences

- Launch points for improving and creating research projects and beneficial programming
- Collaboration for a patient registry and diagnosis codes
- Shared resources and connections between medical entities and families for research and improved care outcomes

FACING HETEROTAXY TOGETHER 2025

Scientific and Family Conference
Boston, Massachusetts

Why Boston? Boston is a hub for world–class clinicians, researchers and leaders in the medical field, ensuring strong local participation and collaboration. It is also home to the first Heterotaxy Clinic, which we want to replicate in other institutions. Having the conference here gives our families the opportunity to be seen at the Heterotaxy Clinic if desired. It is an easy city in which to fly in and out, and the compact infrastructure makes it easy for attendees to navigate.

Conference Goals:

- ***Advance Research and Medical Knowledge***
  - Facilitate Collaboration
  - Promote Research Priorities
  - Introduce New Advances
- ***Improve Clinical Care and Outcomes***
  - Develop Best Practices
  - Educate Medical Professionals
  - Enhance Multidisciplinary Care
- ***Empower Families and Caregivers***
  - Provide Educations
  - Build Connections
  - Advocate for Patients
  - Foster Collaboration Between Families and Professionals
- ***Bridge the Gap***
  - Incorporate Patient Voices
  - Build Trust
- ***Raise Awareness and Drive Advocacy***
  - Highlight Challenges
  - Promote Rare Disease Awareness
  - Engage Policymakers

Sponsorship funding for the Heterotaxy Scientific and Family Conference will be strategically allocated to ensure the event's success, maximize its impact, and provide lasting benefits for the heterotaxy community. Here's a breakdown of how the funding will be used:

- Venue costs
- Event technology
- Event staffing
- Speaker support
- Resource Materials
- Media Campaigns
- Childcare Services
- Registration Fee Subsidies
- Travel and Accommodation Grants for families

SPONSORSHIP OPPORTUNITES

Empowerment Level

$50,000+

Helps to provide the most conducive environment for presentations, collaboration, and learning.

- Keynote presentation opportunity
- Complimentary booth space in event lobby
- Logo and recognition on all printed marketing materials, conference guides and signage.
- Verbal recognition during opening comments each day of conference
- Logo and sponsor recognition on website

Educational Level

$25,000+

Helps to bring in top level clinicians, researchers, and advocates to facilitate innovation

- Break out session presentation opportunity
- Complimentary booth space in event lobby
- Logo and recognition on all printed marketing materials, conference guides and signage.
- Logo and sponsor recognition on website

Support Level

$10,000+

Helps to support families to attend, participate, and find access to resources.

- Complimentary booth space in event lobby
- Logo and recognition on all printed marketing materials, conference guides and signage.
- Logo and sponsor recognition on website

To provide individual travel and accommodation scholarships, or in-kind donations, please email Necia Sabin at necia@heterotaxy.org

HC HETEROTAXY™ CONNECTION

Necia Sabin

Executive Director

✉ necia@heterotaxy.org
☎ (801) 899-5153

HRC3 HETEROTAXY Research & Clinical Care Collaborative

✉ hrc3@heterotaxy.org
🌐 https://www.hrc3.org

Boston Children's Hospital | Benderson Family Heart Center

HETEROTAXY™
CONNECTION

HRC3 HETEROTAXY Research & Clinical Care Collaborative

Boston Children's Hospital | Benderson Family Heart Center