FIND YOUR CONNECTION!

Here at Heterotaxy Connection, we foster a supportive online community for parents, caregivers, and adults with heterotaxy. Collective wisdom and shared burdens mean that no one has to walk this road alone.

MAIN SUPPORT GROUP

Our main support group is open to individuals with heterotaxy, their primary caregivers, and extended family with approval from the primary caregivers or the individual with heterotaxy.

ADULTS WITH HETEROTAXY

This is a group for those members of our community, aged 18 and over, to connect with one another and share the challenges and triumphs that come with living with this rare disease.

BEREAVEMENT SUPPORT

This online support group was formed to provide a source of inspiration, hope, love, friendship, and healing for anyone who has lost someone to heterotaxy. Please know that you are never alone in this journey; we walk this road of grief right alongside you.

www.heterotaxyconnection.org

Unexpected paths, unwavering support.

Journey with us.

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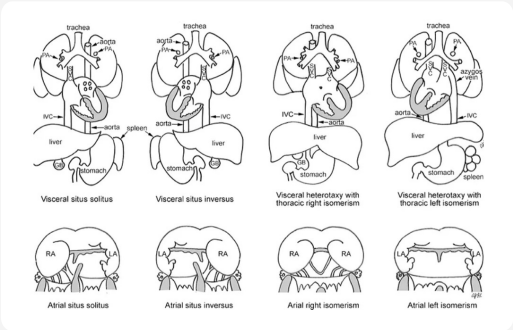
HETEROTAXY CONNECTION

SUPPORT – EDUCATE – EMPOWER

ABOUT HETEROTAXY

Heterotaxy is a congenital condition that disrupts the normal left-right asymmetry of the body. This can result in any of the internal organs being **misplaced**, **malformed**, **multiplied**, or **missing** entirely. This disruption in asymmetry ensures that no two cases of heterotaxy are exactly alike.



Heterotaxy most often occurs **spontaneously**, but it can also be linked to a number of different **gene changes**, so genetic testing is recommended to determine which is the case.

Heterotaxy can also show up along with other syndromes, so thorough evaluation is important to guide and inform care.

DID YOU KNOW?

The chance of being born with heterotaxy is close to 1:10,000. You have the same odds of finding a four leaf clover!

This list is just a starting point! Because everyone with heterotaxy has their own unique anatomy, you'll need to talk to your team to make sure all the necessary diagnostic testing and ongoing monitoring takes place.

ALL SYSTEMS GO

- **CARDIAC** - Over 80% of people with heterotaxy will have one or more heart defects. Many, but not all, require surgery.
- **IMMUNE** - In around 90% of cases, heterotaxy is associated with either polysplenia or asplenia, both of which typically result in impaired splenic function.
- **GASTROINTESTINAL** - Intestinal malrotation is present in 50-70% of heterotaxy cases. Routine prophylactic surgery is not recommended, but may become necessary.
- **LIVER** - Biliary atresia is found in around 6% and will always require surgery.
- **LUNGS** - Heterotaxy is associated with an increased risk for ciliary dysfunction and PCD.

ABOUT US

Heterotaxy Connection is a registered 501(c)3 nonprofit dedicated to supporting, educating, and empowering families affected by heterotaxy through comprehensive medical collaboration, education, and support to ensure accurate diagnosis, effective treatment, and ongoing research, ultimately fostering a world where heterotaxy is understood, managed, and treated.

With online support groups, in-person family conferences, gifts for new families and those facing hospitalization and loss, we are always looking for ways to support our community.