

FOR IMMEDIATE RELEASE

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Heterotaxy Connection Announces Heterotaxy Awareness Day 2022

DRAPER, UT – Heterotaxy Connection, a nonprofit organization dedicated to supporting, educating, and empowering families affected by heterotaxy syndrome, is pleased to announce this year's Heterotaxy Awareness Day will be celebrated on May 4, 2022. This annual event honors Heterotaxy Heroes, both those fighting heterotaxy and the angels that have been laid to rest.

"We are excited to announce the 9th annual Heterotaxy Awareness Day," said Necia Sabin, President and Co-Founder of Heterotaxy Connection. This year's awareness day theme is 'Navigating Uncharted Waters.' The theme will address topics of 'the unknown,' 'ups and downs,' and 'toward the light.' "We feel that this theme embodies the ever-changing experience of our heterotaxy families. From diagnosis day, to the unknown that follows, the dramatic highs and lows, and inevitable transformation, walking the road of heterotaxy is unpredictable," said Alison Chandra, Vice President of Heterotaxy Connection.

The goal of Heterotaxy Awareness Day is to raise awareness and inform the public about this rare medical condition. It is a day for heterotaxy families to rally together and tell their stories.

Founded in 2014, Heterotaxy Connection is committed to providing families with the support they need while walking the hard road of heterotaxy. A major goal of the organization in 2022 is to continue fostering relationships with medical experts working to improve heterotaxy-related medical care. These experts are conducting valuable research that will provide needed guidance to the broader medical community.

"One of the major problems faced within our community is that medical professionals are often uninformed about heterotaxy and best practices for treatment and management of the condition. This year, we are committed to continue working toward educating medical professionals. We will let the stories of our heterotaxy angels guide the way to a brighter future for those currently living with the condition," said Sabin.

About Heterotaxy Connection: Heterotaxy Connection is a registered 501(c)3 non-profit dedicated to supporting, educating, and empowering families affected by heterotaxy syndrome. We connect families with resources and with each other. Heterotaxy syndrome is a congenital condition that results in internal organs being misplaced, malformed, multiplied, or missing. The causes of heterotaxy syndrome are not fully understood. Individuals with heterotaxy syndrome require lifelong multidisciplinary care and medical monitoring. Visit <https://www.heterotaxyconnection.org/> to learn more.



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