

Press Release: For release on October 2, 2024

## Heterotaxy Connection Awarded Rare As One Grant by Chan Zuckerberg Initiative

Heterotaxy Connection is thrilled to announce that it has been selected as a Cycle 3 grantee of the Chan Zuckerberg Initiative's prestigious *Rare As One* grant. This \$800,000 grant, distributed over five years, will enable Heterotaxy Connection to collaborate with the Chan Zuckerberg Initiative, patient-led organizations, clinicians, and scientists to advance research and improve diagnosis and treatment for those affected by heterotaxy.

Through this grant, Heterotaxy Connection will have the resources to:

- Establish a patient registry to accelerate research efforts and enhance clinical care.
- Foster scientific collaboration via the Heterotaxy Research and Clinical Care Collaborative.
- Advance family support by funding both scientific and family conferences, bringing together researchers, clinicians, and families to exchange knowledge and provide critical support.

Necia Sabin, Executive Director and Co-Founder of Heterotaxy Connection, reflected on the significance of this achievement:

"All of this was born out of a connection between just two moms on the internet, trying desperately to make sure their kids got the best care possible. And now we're going to make that hope a reality for heterotaxy families around the world."

This grant marks an incredible milestone for Heterotaxy Connection, furthering its mission to drive scientific discovery, improve clinical care, and support families affected by heterotaxy worldwide.

To learn more about the Chan Zuckerberg Initiative's Rare As One program and fellow grantees, visit https://chanzuckerberg.com/science/programs-resources/rare-as-one/.

## **About Heterotaxy Connection:**

Heterotaxy Connection is a nonprofit organization dedicated to supporting families affected by heterotaxy, a rare congenital condition that impacts the arrangement of organs in the body. Through advocacy, education, and research, Heterotaxy Connection strives to improve the quality of life for those living with heterotaxy.

## **Contact Information:**

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