



FONTAN

OUTCOMES NETWORK



The Fontan Outcomes Network (FON) is a lifespan learning health network created by and for a community of patients, families, clinicians, and researchers who together seek to transform outcomes for all people affected by single ventricle heart disease by leveraging data to facilitate research, drive improvement, and spark innovation.

Our Vision

FON's vision is to dramatically improve outcomes and quality of life for all individuals with Fontan physiology.

Our Mission

FON's mission is to optimize longevity and quality of life by improving physical health and functioning, neurodevelopment, and emotional health and resilience for individuals with Fontan circulation and their families.

Addressing a Growing Need

We are currently at a crossroads for the more than 70,000 individuals living with Fontan circulation worldwide. Incredible strides have been made in the care for babies born with single ventricle circulation. However, as these individuals age, a lack of research and aligned optimal care has led to premature mortality, morbidity, and lower quality of life.

How Does FON Work?

To achieve our mission and vision, FON will:

- Build a community of patients, families, clinicians, and scientists
- Develop and support a robust registry of clinical data for learning, improvement, and mapping the clinical trajectory of individuals with single ventricle heart disease across the lifespan
- Apply quality improvement science and a collaborative learning platform
- Conduct investigation, exploratory research, and clinical trials
- Partner with diverse stakeholders to augment the impact of the network

Ways to Engage

1. Participate in Our Events!

Biannual learning sessions allow the community to discuss learnings, share the latest research, and push our work forward, while annual Single Ventricle Patient Days provide opportunities for individuals with SV circulation to connect and gain resources for their CHD care.

2. Talk to Your Care Center About Joining FON

FON started in 2021 with 12 founding Care Centers, but hopes to engage 50 Care Centers and enroll 10,000 patients in our first three years.

3. Get Involved at Your Local Care Center

The best place to begin your involvement with FON is through your local Care Center. Contact FON to be connected with your Care Center champion.

4. Sign Up for the FON Monthly Newsletter

Stay updated on the work of the network, meet members of our FON community, hear about further engagement opportunities, and more!

5. Follow us on Social Media to Stay Engaged

For more information regarding FON, please email info@fontanoutcomesnetwork.org

