



# 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

FON has a range of events open to different community members. Learn more on the back.

### 2. Talk to Your Care Center About Joining FON

FON 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 or to learn how your center can join our network.

### 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

Engage with us on Facebook, Twitter, and Instagram to stay up to date on all things FON.

### 6. Share a Single Ventricle Story

Nominate someone for our Heart Hero Spotlight or complete a Social Media Takeover.

For more information regarding FON, please email [info@fontanoutcomesnetwork.org](mailto:info@fontanoutcomesnetwork.org)

## Our Network

FON is a network of 31 of the most advanced pediatric and adult hospitals from across the U.S. and Canada

In 2022, we will launch enrollment of our longitudinal network data registry

Our data registry will facilitate impactful novel research and quality improvement work across the lifespan for individuals with single ventricle physiology



## Learn or Connect with Community Members at a FON Event

### Educational Webinar

These bimonthly virtual events are open to the entire Single Ventricle community, and aim to educate individuals with single ventricle, parents/caregivers, families, and clinicians on a range of topics related to Fontan care.

### Single Ventricle Connection Chat

These bimonthly events are dedicated to bringing individuals with single ventricle and parents/caregivers together to share experiences, build friendships, and learn more about the FON and available resources.

### Case Review Conference

Participating Care Center team members engage with one another and exchange learnings through these highly clinical patient-based case presentations and discussions. The purpose of these events is to share knowledge, improve clinical care and promote thoughtful, evidence-based best practices.

### Single Ventricle Patient Day

This annual event was designed for patients by patients with the intent to connect and empower teens and adults with single ventricle circulation ages 14-plus so they feel supported and uplifted, while gaining tools to take control of their care.

### Learning Sessions

This semi-annual event serves as an important opportunity for Care Center teams to gather to build community, learn about the network's latest work, share learnings, discuss important topics, and outline key actions to take through the next six months called the Action Period.

Scan the QR code to explore upcoming FON events on our website!



## Thank You To Our Financial Sponsors

**ADDITIONAL**  
VENTURES

