



Fontan Outcomes Network (FON)

About Us: FON was conceptualized in 2016, began design in August 2017 (in alignment with an astrologically auspicious solar eclipse!) and launched with 12 pilot centers in 2021. There are currently 36 participating centers. FON has over 300 participants, including physicians/researchers, team members (e.g., nursing, administrative and research), and parent/patients. FON has utilized co-design and co-production to develop this lifespan learning health network which has prioritized the optimization of three key drivers: physical health and functioning, neurodevelopment, and emotional health. Four workgroups support learning and infrastructure: community building and engagement; quality improvement; data and analytics; and research. FON's registry went live in late 2022 and has enrolled over 230 patients at 9 centers through early May. For more information:

www.fontanoutcomesnetwork.org

Our Vision: To improve outcomes and quality of life for all individuals affected by single ventricle heart disease and Fontan circulation.

Our Goals:

- Enroll 1 000 patients by June 2024.
- Gather initial data to use for improvement and research.
- Grow the single ventricle community, including patients, clinicians, families, and researchers.
- Collect data to identify and address disparities.

Exciting Work:

- 1) **Physical Activity and Exercise Project:** Care Centers will begin the network's initial quality improvement effort by testing tools from the recently developed Toolkit for Active Living with Fontan Circulation: Pre-K/Grade School Edition.
- 2) **Liver Health Project:** the project team has written a charter and is beginning design for an improvement project to ensure reliable assessment of Fontan-Associated Liver Disease. The associated data will provide rich learning for improvement and research.
- 3) **Case review conferences:** These conferences promote exchange and engagement among FON care centers through patient-based case presentations and discussion, to share knowledge, improve clinical care and promote thoughtful, evidence-based best practices.
- 4) **Single Ventricle Patient Day:** This opportunity was designed for patients by patients with the intent to connect and empower teens and adults with single ventricle circulation, so they feel supported and uplifted, while gaining tools to take greater control of their CHD care.
- 5) **Systems inventory:** A project team is developing a survey to understand variation among clinical processes and structure, to identify opportunities for learning and improvement.

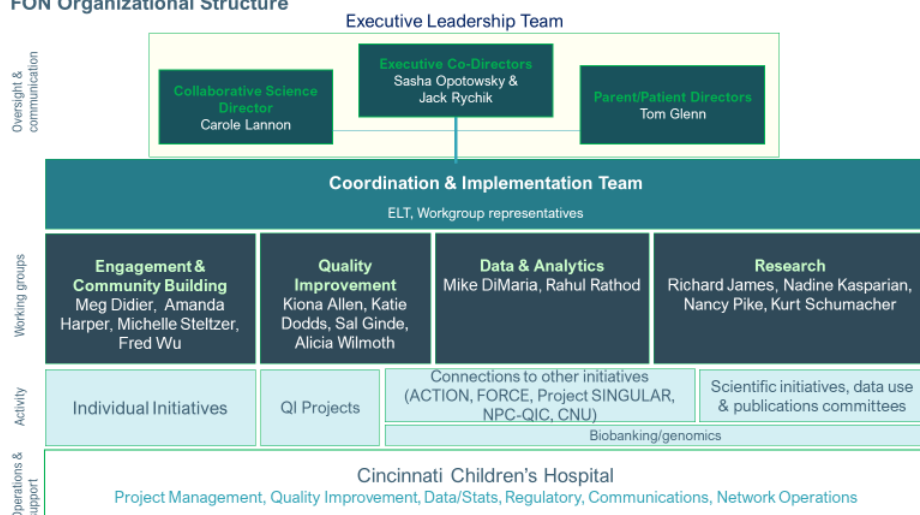
Summary of Core Strategic Priorities: FON is taking an ambitious approach to enroll [care centers](#) and [patients](#) in the registry with a goal of engaging 50 care centers and enrolling 10,000 patients in our first three years. We strive to enroll as many patients as soon as possible because we understand the need for high-quality data to be available as quickly as possible to researchers and care centers for improvement.

Leadership & Project Teams: [Our Team — Fontan Outcomes Network](#)

Org Chart

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FON Organizational Structure



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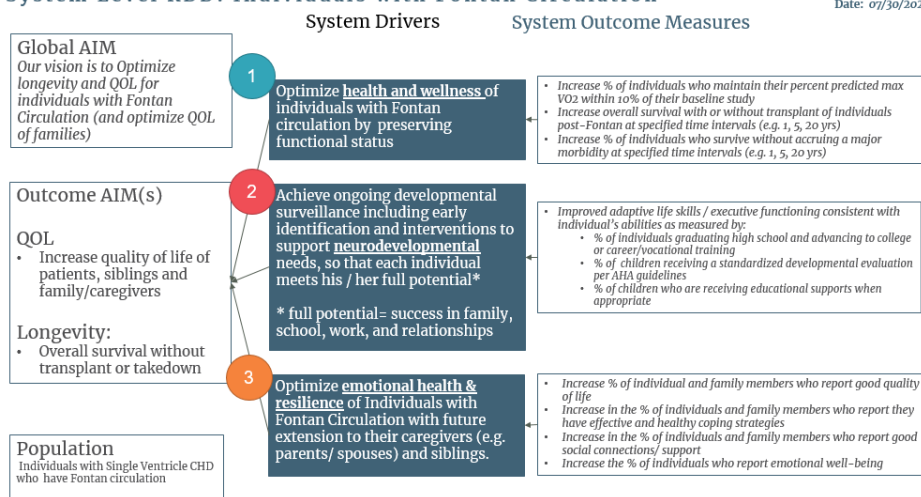
Site List/Geographic Spread: [Overview - Care Centers — Fontan Outcomes Network](#)

Network Toolkits & Change Packages: Physical Activity and Exercise grade school toolkit is currently being tested by centers in the network.

Measures:

System Level KDD: Individuals with Fontan Circulation

Revision
Date: 07/30/2021



Description of Data Repository (e.g., # patients, etc.):

- The FON registry, hosted on the CCHMC/CCTST REDCap instance, collects clinical data for learning and improvement, and to map the clinical trajectory of individuals with single ventricle heart disease.
- The types of data collected include demographics, medical and surgical history, emotional health and neurodevelopment evaluations, cardiac imaging reports, and labs. The types of data to be collected will expand to meet the needs of QI and research.
- The FON registry launched approximately 9 months ago, and there are currently **334 patients who have been added to the registry, from 10 participating care centers.**

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Funding Sources: FON is funded by the Congenital Heart Alliance of Cincinnati (CHAOC), care center participation fees, and individual donations.

Publications: [Research Publications — Fontan Outcomes Network](#)

Additional resources you identify:

