



Just decades ago, children born with Single Ventricle Congenital Heart Disease (SVCHD) weren't expected to live past childhood. But today, due to major advancements in medical and surgical care, that is all changed. A strategy of treatment leading to the Fontan operation has created a pathway for survival and helped parents see their children live into adulthood, something unimaginable just a few years ago.

Now, with more than 70,000 people worldwide living with Fontan circulation, we're at a crossroads. While incredible strides have been made in the care for babies born with SVCHD, we've seen a lower quality of life from a host of unique complications and more premature death than the general population. Fontan patients are surviving at greatly increased numbers, but we haven't yet found a way to ensure normal quality and duration of life. We know we can do better and ensure these patients don't just survive but also thrive.

The Fontan Outcomes Network (FON) was created to align research and care, develop better clinical practices and share knowled-

ge among those dedicated to caring for people with SVCHD.

Our vision is to improve outcomes and quality of life for all individuals with Fontan circulation. We're bringing together patients, families, clinicians and researchers across the country to create a community that will transform the way people with Fontan circulation are treated.



*Landon Jones, an individual with single ventricle physiology, was born in 2014 with Shone Complex and hypoplastic left heart syndrome (HLHS).*

## Long Term Impact

By following a large cross-section of patients at every point along their life, collecting their medical data in one central location and making this vital longitudinal data widely available to experts for research and quality improvement science—we're driving improvement and sparking innovation that otherwise would not be possible. A better understanding of the life cycle and trajectory of people with Fontan circulation will help us improve physical health, neurodevelopment, and emotional health and resilience of those born with SVCHD.



## The Importance of Connection

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FON was designed by a collaborative team of pediatric and adult congenital heart disease cardiologists, surgeons, patients, families, neurodevelopmental and mental health providers, and quality improvement experts among 12 leading children's hospitals. Our goal is to create a network and enroll at least 50 partner centers and 10,000 patients within our first three years, with comprehensive data collection to build a lifespan registry of patients and their health trajectories.

We're using the successful model that has supported other learning networks to significantly improve health outcomes. This network framework has been shown to increase the average life span and quality of life for those living with other challenging, complex medical conditions. Using this proven approach, we know the impact we can make is limitless.

Once our registry is populated with data from all partner sites, we can leverage this information to begin discovery, quality improvement and research. These efforts will revolutionize care at all points of development for patients with Fontan circulation. With every patient enrolled, our picture of better health comes into sharper focus and our potential for improvement, research discoveries and clinical care improvements expands.

## It Takes Everyone's Help

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FON has received generous philanthropic support to launch, but funding is needed to grow and sustain the network. To achieve our transformational goals, we need to go beyond our data and medical partners. Individuals, families, businesses and philanthropic foundations can help accelerate research discovery and improve care for all our patients.

Donations are needed to support many key areas of effort, including the following.

### Scientific Research and Discovery

Funding is needed for the FON infrastructure to support high quality research discovery. While participating care centers contribute the data to populate FON, this data will be made available to researchers both within and outside of FON for research aimed at improving outcomes. This requires processes to ensure accurate data, create customized data reports, and provide technical assistance to researchers.

### Connections for Patients

While we know synergy among care providers is important, we also know patients benefit from a large network of others who face similar health challenges. Each fall, FON hosts a Patient Day that is designed by patients for patients. This event provides educational opportunities while connecting and empowering teens and adults living with single ventricle heart disease.

### Quality Improvement

FON will use registry data and employ improvement science methods to identify variation, support standardizing care processes, and optimize health outcomes. Our aim is to drive improvements across all participating care centers. These improvement strategies include using performance feedback, identifying successful examples and then coaching and supporting center teams in testing changes, and developing a collaborative "all teach, all learn" community with monthly webinars and semi-annual Learning Sessions.

### Network-Wide Education

As FON builds the longitudinal data registry, it is committed to providing education to participating care centers as well as the broader community of single ventricle patients, families, and clinicians. This will include educational materials, webinars, case review conferences, and learning sessions.

To learn more about FON and make a donation, visit [fontanoutcomesnetwork.org](https://fontanoutcomesnetwork.org) or contact Lauren Bosse at (513) 803-0639 or [lauren.bosse@cchmc.org](mailto:lauren.bosse@cchmc.org)

*All donations to FON will be processed through Cincinnati Children's, its fiduciary agent, and go directly to FON.*