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The future is now for transforming outcomes nationally: the Fontan Outcomes Network

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ABSTRACT

The Fontan Outcomes Network aims to dramatically improve longevity and quality of life for people living with Fontan circulation. This mission will be achieved by improving physical health, resilience and emotional health, and neurodevelopment for these individuals and their families. Co-produced by patients, parents, clinicians, and researchers, this national initiative has been strategically designed and built on a scalable learning health network platform to address key gaps in the field, support discovery, and accelerate improvements in outcomes.

1. Introduction

1.1. Vision 2020: paradigm shift

Advances in the management of single ventricle congenital heart disease have transformed lives over the past 40 years. Our prior aspirational dreams that these children would live into adulthood have come to fruition. Most individuals with Fontan circulation now survive into adulthood, and of the current worldwide population living with Fontan circulation, nearly half are adults [1–8]. In 2000, when a child with Fontan physiology survived, even if malnourished, blue, and frail, it was considered an acceptable outcome. By 2010, these children's elementary and middle school joys were celebrated by the field. Now, individuals with Fontan circulation are young adults contributing to their families and communities, as illustrated in Fig. 1 and by the accompanying article in this special edition by clinician-patient authors Houlihan and Wilmoth.

While many successes have been realized, new challenges have emerged. Teens and young adults often progressively accrue morbidity- such as anxiety, issues with executive function, diastolic ventricular dysfunction, arrhythmias, rising pulmonary vascular resistance, liver fibrosis, or lymphatic failure. Neurodevelopmental issues, challenges of managing a chronic condition, and fear of shortened life expectancy significantly impact quality of life for both patients and their families. Currently, the absence of identified best care practices and effective treatments to maintain circulatory performance and optimize overall patient outcomes presents significant challenges for patients, clinicians, and health care systems [1,7–9].

In 2020, it is time to expand our vision and set new goals and intentions. How will we transform the decades ahead for people with Fontan circulation and their families?

To optimize wellness and overcome complications, scientists, bioengineers, patients, families, and clinicians must work synergistically in novel ways to better understand mechanistic origins of single ventricle congenital heart disease, to map the trajectory of organ-specific health, and predict the course of each patient over time, and to prevent and treat complications and co-morbidities. Other chronic conditions in which outcomes have been transformed in the last two decades- such as cystic fibrosis, childhood leukemia, or human immunodeficiency virus-model paths forward.

In 2020, it is time for a paradigm shift in single ventricle lifelong care. The new vision focuses on optimizing functional outcomes at both the population and precision health level and calls for multicenter, collaborative research, quality improvement, and advocacy. This paper

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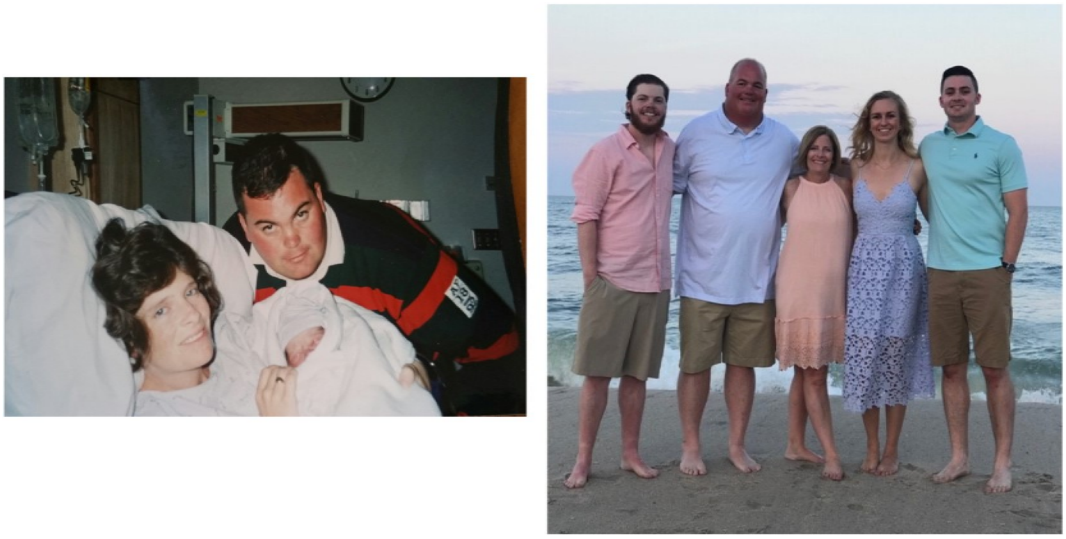

Fig. 1. In 2020, many individuals with Fontan circulation are young adults contributing to their families and communities.
In the left panel: Diane and Bill Pickles welcome their newborn son, Jake, who has Hypoplastic Left Heart Syndrome, on September 2, 1994.
In the right panel: The Pickles family today. Jake is the smiling 25 year old man with a beard, standing to the right of his father.

introduces the Fontan Outcomes Network (FON), which aims to dramatically improve longevity and quality of life for all individuals with Fontan circulation. Co-produced by patients, parents, clinicians, and researchers, this national initiative has been strategically designed and built on a scalable learning health network platform to address key gaps in the field, support discovery, and accelerate improvements in outcomes in three key areas- physical health, resilience and emotional health, and neurodevelopment.

1.2. Journey to FON: context of multicenter momentum

The creation of the Fontan Outcomes Network occurred in the context of increased energy and momentum in multi-institutional collaboration around Fontan care. Fig. 2 summarizes these efforts, which represent the work of many in the field over the last decade. The National Pediatric Cardiology Quality Improvement Collaborative (NPCQIC), the first cardiology learning health network, started as a 6 center pilot in 2006 with the aim of reducing Norwood interstage mortality [10]. In 2008, NPCQIC launched with 30 US centers. Internationally that same year, the Australia New Zealand Fontan Registry (ANZFR) launched [11]. Concurrently, the Pediatric Heart Network (PHN) published the "Fontan 1" cohort study, and the American Heart Association (AHA) established the Fontan Associated Liver Disease workgroup- both of which continued for multiple years [12–16]. In 2011, Sisters By Heart- the parent advocacy group for Hypoplastic Left Heart Syndrome families- partnered with NPCQIC. 2016 marked the formation of the International Fontan Interest Group (IFIG) [17]. That year, a Fontan practice variability study was started which led to the formation of an informal working group of cardiologists focused on Fontan care from 11 US centers who were later instrumental in FON design [18]. Meanwhile, the AHA convened a formal workgroup to write a Scientific Statement on Fontan care, and parents, patients, and clinicians involved in NPCQIC's infant single ventricle work began discussing potential expansions of the collaborative into Fontan care

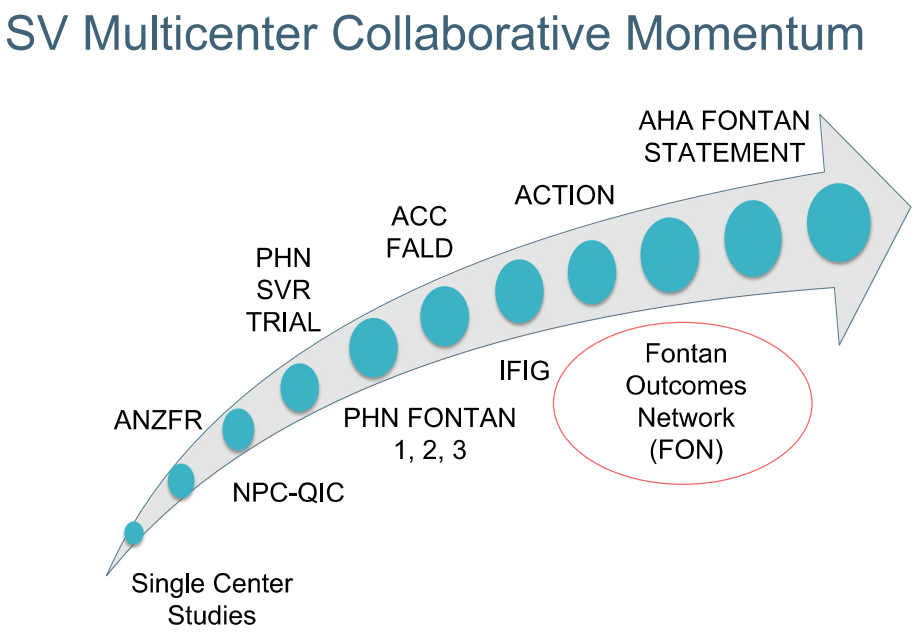

Fig. 2. Single ventricle multicenter collaborative momentum.
SV = Single ventricle, ANZFR = Australia New Zealand Fontan Registry, NPCQIC = National Pediatric Cardiology Quality Improvement Collaborative, PHN = Pediatric Heart Network, SVR = Single Ventricle Reconstruction, ACC = American College of Cardiology, FALD = Fontan Associated Liver Disease, IFIG = International Fontan Interest Group, ACTION = Advanced Cardiac Therapies Improving Outcomes Network, FON = Fontan Outcomes Network, AHA = American Heart Association.

[1]. Within the adult congenital domain, the Alliance for Adult Research in Congenital Cardiology (AARCC) promoted and supported multicenter Fontan research [19].

Overall, in order to drive discovery that was impossible through single center research, collaboration among congenital heart centers had been enhanced, with an emphasis on co-production with patients and families, quality improvement (QI), and research [20,21]. All of this activity converged to create the landscape for the development of the Fontan Outcomes Network and led up to an initial design meeting in August 2017, marked emphatically by nature with a total solar eclipse.

At the time of the initial design meeting, there were multiple key structural gaps in the field identified. No platform for broader collaboration and collection of longitudinal lifespan data existed for this population. Overall, there was a need for scalable infrastructure with broad scope to 1) foster ongoing collaboration and communication for all stakeholders, 2) facilitate collection and sharing of data and biospecimens, and 3) accelerate discovery through multicenter research and quality improvement science. An important gap was a robust information technology platform that allows data integration across clinical, administrative, and biologic data sources and accelerates the spread of information.

Subsequently, the volume and impact of publications from the ANZFR have demonstrated the power of a multicenter, longitudinal clinical registry, which until now has not existed in the US. Cardiac Networks United (CNU), a consortium of pediatric and congenital cardiology networks, was formed to better integrate efforts across cardiology to accelerate learning and discovery through collaborative sharing of data [22]. Most recently, the AHA Scientific Statement on Fontan evaluation and management has provided a comprehensive review of the current state and future areas of research and put forth the concept of a surveillance matrix by age with a detailed proposal for two-tiered cardiac and end-organ surveillance [1]. Existing in synergy with FON, this document will serve as a foundational support for many of the action items to come from the FON.

2. Fontan Outcomes Network design

2.1. Initial design: intention setting

In August 2017, a systematic design process was initiated by key stakeholders from across the nation- patients, parents, clinicians, and researchers- with design and project management support from the National Pediatric Cardiology Quality Improvement Collaborative. The initial design meetings focused on intention setting. The mission, vision, and global aims of FON were defined. The FON *vision* is to dramatically improve the outcomes of individuals with Fontan physiology. The FON *mission* is to optimize the longevity and quality of life for individuals with Fontan physiology and their families by improving their physical health and functioning, neurodevelopment, and resilience and emotional health.

Expanded early on to include wider representation, the design team engaged adult patients, parents, cardiologists (both pediatric and adult congenital), cardiology nurse practitioners, AHA writing group members, cardiac surgeons, psychologists, social workers, QI science experts, and PHN researchers. All of these committed, passionate teammates are acknowledged at the end of the manuscript.

2.2. Structural framework: the Learning Health Network model

The next step was to choose the best structure to achieve the mission. The optimal structure needed to be sustainable, scalable, and modifiable to amplify the impact and serve important functions for decades to come. A Learning Health Network (LHN) provides both a registry with integrated data and analytics and a dynamic platform for community learning that accelerates improvement and discovery (Fig. 3) [23]. The LHN aligns with the National Academy of Medicine framework of a Learning Healthcare System that is “designed to generate and apply the best evidence for the collaborative choices of each patient and provider; to drive the process of discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in health care” [24]. This robust platform of multi-institutional collaboration for QI and research facilitates identification of best clinical practices, rapid sharing of data to improve outcomes, performance of clinical trials, generation of new knowledge, and translation of research into practice [25–28]. It also fosters and supports community engagement and communication, with real-time sharing of tools and resources, and can link to industry and government.

In pediatric inflammatory bowel disease, the LHN has improved remission rates from 55% to 82% with enrollment of 30,000 patients across 4 continents [29–31]. For single ventricle infants, specifically those with Hypoplastic Left Heart Syndrome, NPCQIC has significantly reduced growth failure and improved interstage survival by 40% since 2009 using the LHN model [32,33]. The benefits of the LHN include a systematic approach to framing global improvement aims, a relentless focus on outcomes, community co-production between multidisciplinary clinicians/researchers and patients/parents to prioritize outcomes, and the opportunity to leverage the existing culture of collaboration across 68 cardiac centers. These demonstrated successes and benefits of the LHN led our FON design group to embrace this model to transform outcomes for the Fontan population.

Since 2017, NPCQIC has supported multiple design meetings held during Fontan-specific symposia, cardiology/cardiothoracic surgery national meetings, and the NPCQIC semi-annual learning sessions. Under the oversight of NPCQIC's Executive Leadership Team, a FON design leadership team was created which consists of cardiology content leads- two pediatric cardiologists (JR and GW) and the parent of a young adult living with Fontan circulation (DP)- collaborative science lead (CL), quality improvement specialist (SW), and a Project Management specialist (ME). The design process used previously described methods to successfully develop learning health networks [10,23,25,34]. There has been active bridging and intentional synergy with related single ventricle work through NPCQIC's infant work, adult Fontan efforts through AARCC, and heart failure initiatives through the Advanced Cardiac Therapies Improving Outcomes Network (ACTION).

2.3. Key drivers: aims, outcome and process measures, and registry data elements

Three areas of focus were identified at the initial design meeting: 1) physical health and functioning, 2) resilience and emotional health, and 3) neurodevelopment. Three workgroups were established to lead the design of FON components targeting each of these focus areas. Each workgroup was co-led by a clinician and patient or parent dyad and populated by approximately a dozen patients, parents, and multidisciplinary clinicians. The workgroups developed key driver diagrams, following the Model for Improvement determining the aims, measures, and strategies for improving outcomes in each domain (Fig. 4, System Level Key Driver Diagram). Next, necessary data elements were identified to assess longitudinal outcomes aligned with each team's aims [23]. Table 1 highlights the key drivers and objectives for each domain. The multidisciplinary workgroups met weekly or bi-weekly between April 2018 and October 2019. The NPCQIC Learning Network staff (Quality Improvement, Project Specialist, and Data Analyst) facilitated this systematic design process.

A longitudinal lifespan registry, enrolling as many individuals with Fontan circulation across the nation as possible, is foundational to accomplishing the network's global aims. Baseline data will be obtained at enrollment, which may occur at the time of the Fontan operation or any visit after the registry go-live date. Ongoing collection of longitudinal data will occur at follow-up clinic visits and with prompts for annual visit follow-up and specific assessments. Patient-reported outcomes about emotional health and neurodevelopment will be incorporated

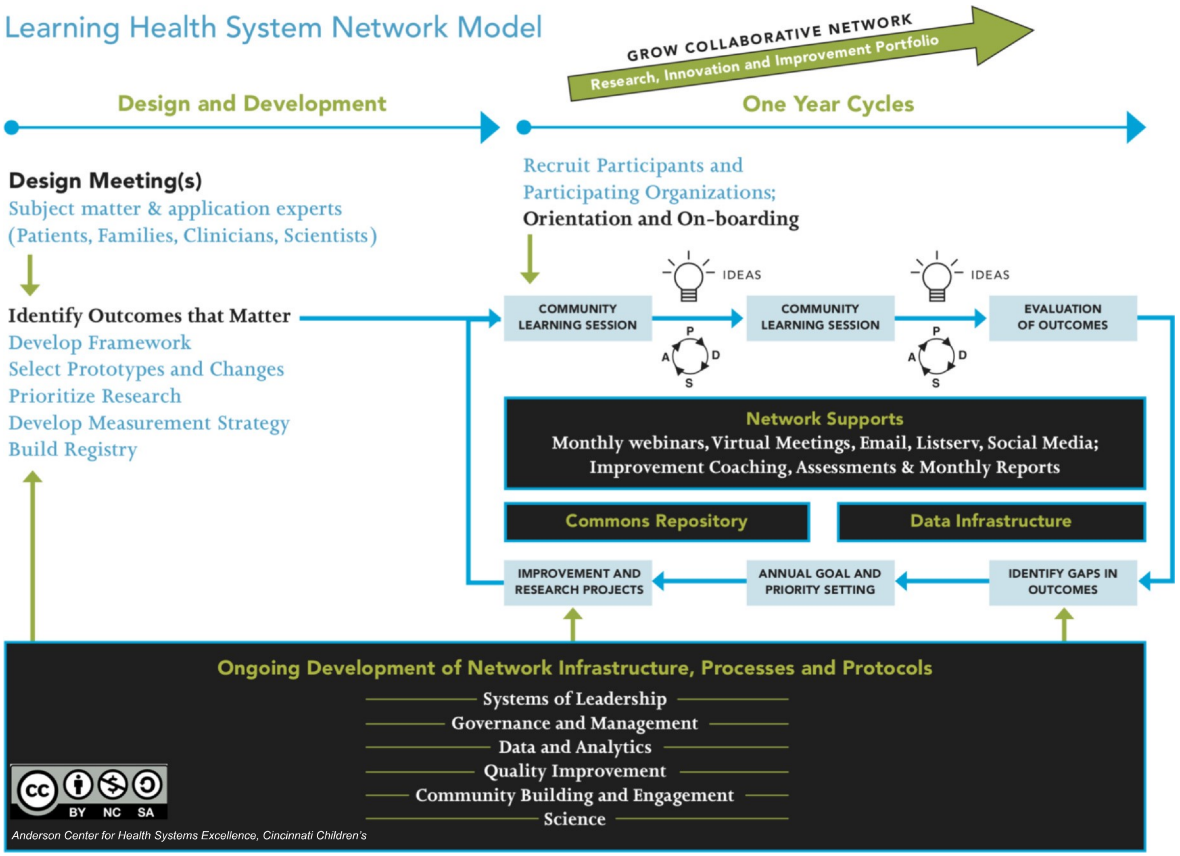

Fig. 3. Learning Health System Network model.
Anderson Center for Health Systems Excellence, Cincinnati Children's Hospital Medical Center.

initially, and others integrated later. Establishment of and linkage to a biorepository is a crucial element, which will be developed shortly after launch and will provide rich opportunities for research.

The registry will be launched with consensus driven, prioritized, core data. The development of the measures and data variables was iterative and based on published research on important outcomes in each FON domain and expert consensus. Co-production with all stakeholders, including patients and parents, guided prioritization. Once

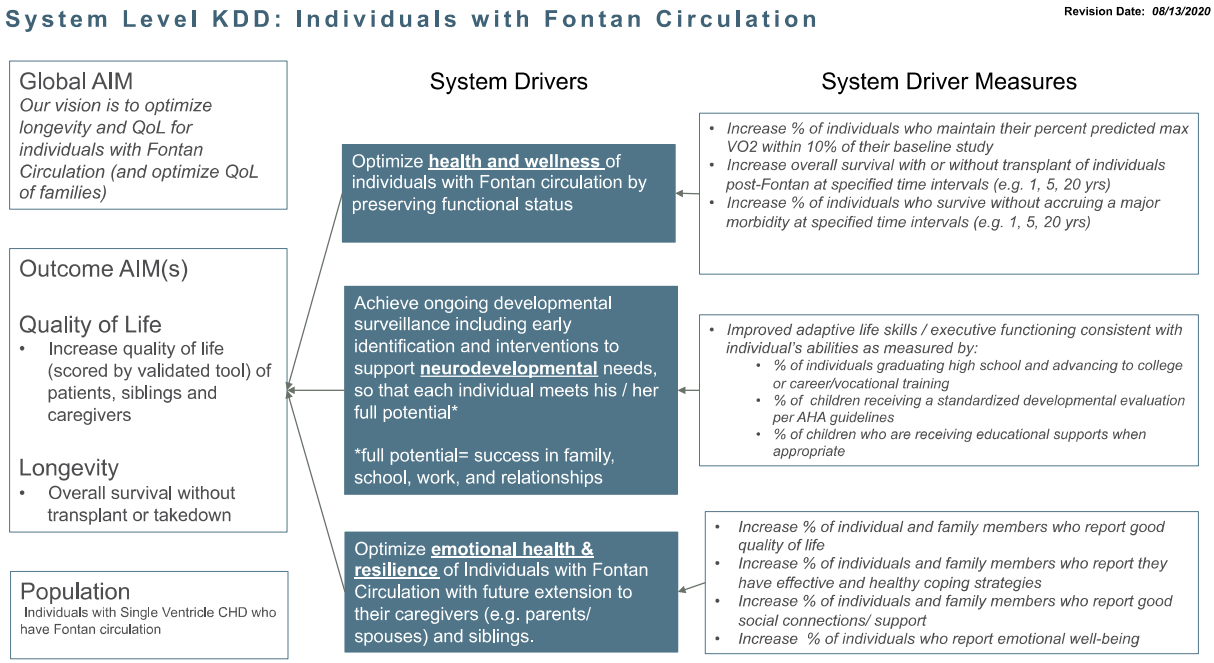

Fig. 4. Fontan outcomes network: system level key driver diagram.
KDD = Key Driver Diagram, QoL = Quality of Life, CHD = Congenital Heart Disease, max V02 = maximal oxygen uptake.

Table 1
FON key drivers and objectives by domain.

Global aims: improve longevity and quality of life		
Domains	Drivers	Specific objectives
Physical health and functioning	Optimize physical health & wellness by preserving functional status	• Overall survival and average lifespan • Survival without a major morbidity • Maintenance of percent predicted maximum oxygen uptake on exercise testing
Resilience and emotional health	Optimize resilience & emotional health	• Good perceived quality of life • Strong social connections • Emotional well-being
Neurodevelopment	Achieve surveillance to support neurodevelopmental needs	• Formal developmental evaluations • Appropriate educational supports • High school graduation

Fontan outcomes network: key drivers and objectives by domain - physical health and function, resilience and emotional health, and neurodevelopment.

teams agreed upon prioritized outcomes, detailed operational definitions of measures and key clinical terms were created to ensure all necessary data variables would be collected. Early on, the ANZFR collaboratively shared all of its data definitions, data dictionary, and forms, which accelerated initial FON data development. When possible, there was intentional alignment of FON data variables with those used in other registries to facilitate future data linkages. A data collection pilot study was performed and assessed the feasibility of the data collection forms as well as the availability of specific data elements across 10 participating pilot centers; data collection forms were refined further based on pilot feedback [35]. The registry build will have interoperability with Cardiac Networks United and other databases. Based on experience in other Learning Health Networks, some degree of automated data extraction from the electronic health record is anticipated. Monthly data reports on key metrics will be available to facilitate chronic disease management, identify improvement opportunities, and provide data to stimulate research questions.

3. Network launch

Guided by registry data, the network aims to describe the current status of the US Fontan population across the lifespan, depict the lifespan trajectory of individuals with Fontan circulation, accelerate learning about short- and long- term morbidities, identify measures related to long-term wellness, determine best surveillance practices, and promote multi-institutional, multidisciplinary research to develop new therapies.

Launch of the network will occur in 2021 with registry development and testing by pilot centers which have been involved in FON design and are already NPCQIC participating centers. There will be an inaugural FON Learning Session for the network community and a separate Single Ventricle Teen and Adult Patient Day. Thereafter, other cardiac centers will be encouraged to join, and participation by community cardiologists will also be supported.

Design and initiation of improvement work will be possible early on, even while accrual of data commences. For example, initial cardiac center activities may address standardizing care protocols to align with the AHA recommendations for neurodevelopmental assessment and other end organ surveillance. Other early tests of change may be exercise prescriptions for physical activity, tools for resiliency building, or use of existing bundles for adolescent care transitions.

4. Conclusion

The Fontan Outcomes Network has been strategically designed to transform outcomes for children and adults with Fontan circulation over the next decade. Built on a scalable learning network platform with a proven record of success, FON will accelerate dramatic improvements and drive discovery.

Envision the future. In two years, when data on over 1000 individuals with Fontan circulation will be available, it will be possible to track population outcomes locally and nationally as well as begin to understand an individual's trajectory. The foundation will be laid for the development of data-driven, health optimization strategies, clinical trials, and evidence-informed advocacy for mental health and education services. Within a few years, with linkage to a biorepository, deep phenotyping will generate knowledge of underlying etiologies and identify targets for the development of personalized therapies.

Guided by data and ignited by community engagement, the national Fontan Outcomes Network will soon propel the field far beyond what is imaginable with our vision in 2020.

Declaration of competing interest

No financial disclosures, except for Carole Lannon (who is one of several faculty) named as an inventor of technology to support Learning Health System Networks that has been licensed to Hive Networks by Cincinnati Children's Hospital Medical Center.

We confirm that there are no known conflicts of interest associated with this publication, and there has been no significant financial support for this work that could have influenced its outcome.

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