

# Launching the Multidisciplinary Fontan Management Program to Advance Care and Value for Single Ventricle Patients



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## Background

In the United States, more than 900 Fontan operations are performed each year with 97% early survival. By age 20 years, only one-third of patients are in optimal condition defined as good cardiac function with no clinically apparent end-organ disease. Many more harbor clinically silent liver, kidney, and pulmonary disease as well as systemic inflammation. This multi-organ disease state is progressive, shortens life expectancy, and is associated with poor quality of life.

Access to integrated and coordinated care is suboptimal as the population navigates a complex care pathway with multiple obstacles. Care is delivered by disparate, frequently siloed services (inpatient, outpatient, ICU, OR, division-based versus interdisciplinary care). Healthcare costs are a critical component of the value equation for the Fontan population and are present and different for each phase of care. The perspectives of the path navigated, and challenges faced, by the patient and family as they navigate their care are likely not recognized by providers. Rather than continuing to address complex care issues on a patient by patient basis, we seek to apply an innovative care approach derived from a better understanding of the needs of, and path navigated by, the Fontan population.

Few if any centers in the nation or the world have the expertise and infrastructure to adequately care for the Fontan population, decrease the barriers to collaboration, and implement effective multidisciplinary care. CCHMC, however, has significant expertise in adult congenital heart disease, heart failure, imaging of chronic liver disease and liver tumors, hepatology, and system approach and improvement. The bariatric, pancreas, and liver tumor programs at CCHMC serve as examples of the capacity of CCHMC to take on such a challenge. Currently, there are other clinics that care for the Fontan patient population, but none have a specific heart-liver focus. As such, there is an opportunity for CCHMC to establish itself as a leader in the care of this patient population, particularly in the area of heart-liver disease.

Working across disciplines under the umbrella of the Heart Institute, we proposed to nucleate a team with diverse expertise to design and launch an integrated and highly specialized interdisciplinary program focused on the comprehensive care of adolescents and young adults with a Fontan circulation; the result of which is coordination and execution of an evidence-based, patient-centric plan.

## Approach and Methods

A qualitative study of operational efficiencies in the care for Fontan patients at CCHMC was completed to standardize key processes, decrease barriers, improve communication and coordination and reduce costs incurred by patients. The Heart Institute (HI) at CCHMC used coordination of care strategies to nucleate an interdisciplinary team of clinical, research, improvement and administrative experts. Human-centered design methodologies were leveraged to provide meaningful and actionable insight and understanding.

Key goals and objectives of the Program include:

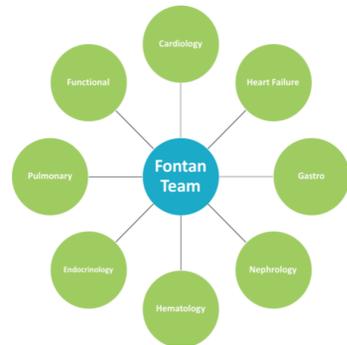
- The Steering Committee has been tasked with standardizing key processes (improving efficiency and decreasing waste), focusing on processes that are reliable and reproducible, including steps from intake scheduling, standard care protocols, and billing,
- The Clinical Operations team aims to decrease the barriers and support complex-decision making. This team will establish an organizational structure and develop processes that promote coordination of care across existing boundaries that is customized to the needs of patients and based on a broader, growing evidence base.



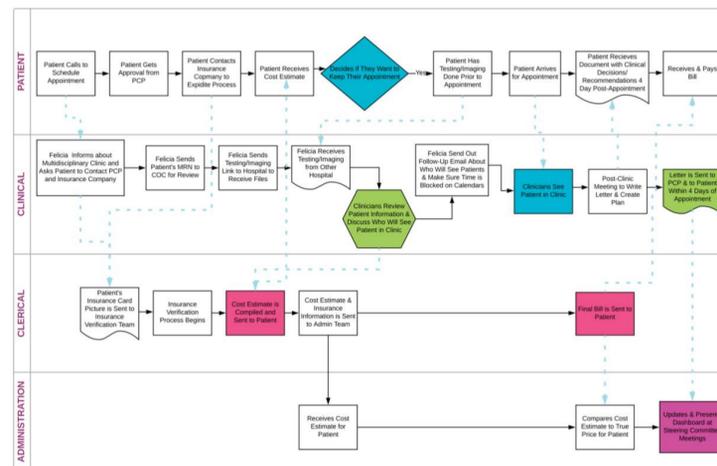
Currently, there are other clinics that care for the Fontan patient population, but none have a specific heart-liver focus. Therefore, CCHMC has the opportunity to be the leader in the care of adolescents and young adults with a Fontan circulation, particularly in the area of heart-liver disease. The need for an adult combined heart-liver transplant program has become apparent. The programmatic framework and processes are under development in collaboration with the University of Cincinnati Medical Center and the comprehensive program is estimated to go live in 2019.

## Clinical Framework

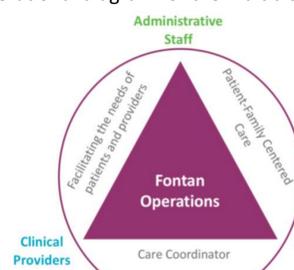
Long-term survivors of the Fontan operation must coordinate much of their care across a complex health care system. We seek to change this paradigm by formalization of an integrated Fontan Management Program that includes each of the subspecialties critical to the care of this complex population (Cardiology, Radiology, Hepatology, and Nephrology) and interfaces with other subspecialty teams (e.g. Hematology, Endocrinology, Cardiovascular, and Pediatric Surgery). This team will seek to optimize, facilitate, and advance care for the Fontan population. Moreover, we will link cost, charge, and revenue data to process of care through creation of a clinical data registry to uncover drivers of cost, unnecessary variation, and waste. If successful and effective, we forecast better value through more effective decision-making and execution at the patient and program level.



The team consists of specialists from a number of departments. Each patient is also reviewed by a radiologist prior to their appointment.

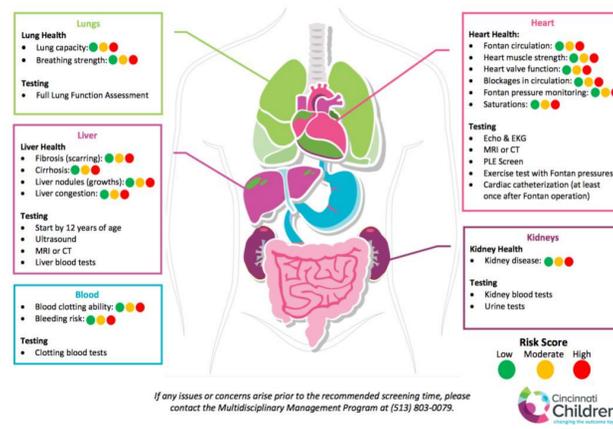


The current process flow is shown above for each stakeholder involved. The swimlane diagram shows how each individual interacts with one another. The figure below depicts the overall operational diagram for the multidisciplinary team.



Providing patients and families with materials upon leaving clinic is extremely important in the overall plan of care. Patients are now more aware of their current state, their plan of care, and testing/imaging to complete before their next visit.

## Multidisciplinary Fontan Management Program Individualized Screening and Treatment Plan



## Clinical Research and Data Registry

**Clinical Research:** Fontan-associated liver disease (FALD) occurs in a majority of patients palliated with the Fontan operation and is suspected to be driven by chronic passive liver congestion. However, the severity, specific phenotype of disease, and timing of onset is variable. Understanding these processes will be critical for advancing the care of the Fontan population but such understanding requires a systematic, multi-year effort which can be achieved in the context of this program. Details of pilot research projects, including rationale, are provided below:

- Research Project #1: *Can Ultrasound Liver Stiffness Pre-Fontan, Post-Fontan, or Change over time Predict Onset and Severity of Fontan-Associated Liver Disease*
- Research Project #2: *Development of Novel Imaging Methods for Detecting, Discriminating, and Measuring Liver Fibrosis and Congestion in Fontan Patients*

**Seminar Series:** We will engage local/national/international experts who can share their research and clinical advances and will engage trainees, including fellows, post-docs, and students who will work together to develop and advance clinical care and research efforts and present ongoing work on the proposed projects.

**Data Registry:** Detailed, population level, longitudinal data is lacking for patients who have undergone Fontan palliation of congenital heart disease. Such data is critical for understanding complications and outcomes of the procedure (many of which occur at a prolonged interval from the procedure, and some of which are uncommon) and for optimizing population and patient-level care (personalized medicine). Existing registries are largely voluntary and thus are limited by incomplete data and non-standard clinical care and testing.

## Results and Outcomes

### Results

Since the launch of the formalized multidisciplinary clinic in February 2018, 61 Fontan patients have been evaluated. The program generated 10 new clinic referrals, 6 transplant referrals that are currently under evaluation and one completed heart transplant. Both research projects are well underway and are on target to be completed in half the time that was initially set.

### Path of the Patient Work: Incorporating Parent, Patient, and Staff Feedback

- "Increase communication. There are so many opportunities for professionals and staff to be more clear and open with patients and families." – SV Parent
- "Some pathways are formal and some aren't, but cardiologists don't want to be robots, we went into cardiology because we like to think. Care is generally better when standardized and there's totally non-standardized care for long-term Fontan patients." – SV Staff
- "We've already started down the path of preparation, but it feels like departments are working in silos while they will need to work together in surgery. I'm probably going to have to be the one to orchestrate it all and urge everyone to get on the same page. It just seems like that should be done by the hospital." – SV Parent

### Patient Cost Savings

- Testing:** Collaborative pre-visit discussion and care planning eliminates duplicate testing and fosters more thoughtful decision-making for less costly test options. As a result, patients can save up to \$5,000 on testing annually.
- Clinic Visit:** When the patient sees several providers at a time, there is a reduction in hospital fees incurred by the patient. Depending on the number of providers involved, the patient saves between \$155 to \$465 in just one multidisciplinary clinic visit. Furthermore, patients who are seen on a quarterly basis can save up to \$1,860 annually.

Annual patient cost savings based on number of providers seeing the patient and the number of clinic visits (not including testing)

	1 Clinic Visit	2 Clinic Visits	3 Clinic Visits	4 Clinic Visits
2 Providers	\$155	\$310	\$465	\$620
3 Providers	\$310	\$620	\$930	\$1,240
4 Providers	\$465	\$930	\$1,395	\$1,860

## Conclusions and Next Steps

### Conclusion

The multidisciplinary approach to care for complex patients is extremely important and is currently underutilized. Multidisciplinary care is more convenient for patients, allows for better coordination of care, reduces the cost for patients and improves the quality of the care they receive. This clinic continues to expand in order to improve patient access and the number of specialties involved has increased to provide more personalized patient-centered care.

### Next Steps

- The data registry has just begun to take form. This is an essential part of the clinic and is a priority in the next phase of this work.
- Once the clinic is fully established, more specialties (primary care, infectious disease, gynecology, will be added depending on the needs of the patients.
- Developing a forum for clinicians to enhance their knowledge of the Fontan population in conjunction with the need for multidisciplinary care. This would be accomplished through multiple educational channels including: hospital-wide seminars, guest speakers, and grand rounds to expose to best practices and recently published Fontan-related research.