The Congenital Heart Collaborative

University Hospitals Rainbow Babies & Children's Nationwide Children's Hospital









The Congenital Heart Collaborative

University Hospitals Rainbow Babies & Children's Hospital and Nationwide Children's Hospital have formed an innovative affiliation for the care of patients with congenital heart disease from fetal life to adulthood. The innovative collaboration provides families with access to one of the most extensive and experienced heart teams – highly skilled in the delivery of quality clinical services, novel therapies and a seamless continuum of care.

Fetal Heart Program

The Fetal Heart Program is designed to provide compassionate, state-of-the-art care to the expectant family and fetus with heart disease. Utilizing a multidisciplinary approach, our highly coordinated team of experts provides a comprehensive, knowledge-based learning experience for the expectant family carrying a fetus with heart disease. In addition, our physician-scientists are dedicated to advancing our understanding and knowledge in the field of fetal heart science.

Congenital heart defects (CHDs) are structural defects within the heart that occur during gestation. Some defects can affect the way the heart functions as well as how blood is delivered to the rest of the body. CHDs are the most common type of birth defect, affecting approximately one in 100 children. CHDs can vary from mild (requiring no intervention) to severe (requiring multiple surgeries and interventions).

In many cases, CHDs can be diagnosed prenatally during an echocardiogram. Prenatal diagnosis and management of CHDs can improve outcomes by monitoring the progression of the defect and coordinating treatment plans for delivery and after birth, as well as continued family education and support throughout the pregnancy.

Comprehensive Team:

- Three physicians dedicated to fetal scanning five days a week at multiple locations
- Families provided with detailed orientation and anticipatory guidance to prepare them as much as possible for the care their child will receive after delivery
- Integrated perinatal team that includes neonatologists, geneticists, genetic counselors, multiple pediatric subspecialists, maternal-fetal medicine specialists and high-risk obstetricians
- Strong relationships with community maternal-fetal specialists with dedicated fetal outreach clinics
- Strong relationship with University Hospitals MacDonald Women's Hospital, connected to UH Rainbow Babies & Children's Hospital via bridge access that allows for moderateand high-risk patients to deliver under one roof and also provides inpatient service for prenatal patients in need of fetal arrhythmia management
- Dedicated cardiothoracic ICU and pediatric cardiac step-down units that house all patients born with critical heart disease
- Family-centered care in which parents can room with their child during the entire stay
- Dedicated fetal echo sonographers
- Dedicated nurse practitioner who coordinates the fetal heart program

Timing of Fetal Echocardiogram

The timing in gestation in which a fetal echocardiogram is performed is dependent on a variety of factors. Most frequently it is obtained between 18 and 22 weeks gestation.

Indications for Fetal Echocardiography

Genetic	Fetal	Maternal
 First-degree relative with CHD Mendelian syndromes that include CHD Noonan syndrome Tuberous sclerosis DiGeorge syndrome Chromosomal syndromes associated with CHD including but not limited to trisomy 21, 13 and 18 and Turner syndrome 	 Abnormal ultrasound or cardiac screening Increased NT measurement Abnormal heart rate or rhythm Abnormal heart views Fetal chromosomal abnormality Hydrops fetalis TRAP sequence Monochorionic twins Extracardiac anomalies Congenital pulmonary airway malformation – CPAM Congenital diaphragmatic hernia – CDH Omphalocele Duodenal atresia Spina bifida Vertebral anomalies Limb abnormalities Abnormality of umbilical cord/placenta 	 CHD Teratogen exposure Lithium Antiseizure medications Cocaine Retinoids Metabolic disorder Diabetes Phenylketonuria Autoimmune antibodies Systemic lupus erythematosus (SLE) +Anti-Ro (SSA)/Anti-La (SSB) Sjögren's In vitro fertilization Infections CMV Toxoplasmosis Lyme disease Etc. BMI > 40 Age > 40

Early Fetal Echocardiogram

An advanced early fetal echocardiogram can be conducted by the specially trained Congenital Heart Collaborative cardiologists at 14 – 16 weeks gestation utilizing the latest equipment for some patients who present with the following indications:

- First-degree relative with CHD
- Abnormal finding on an ultrasound
- Abnormal genetic screening

Indications for an early fetal echocardiogram are:

- Abnormal nuchal translucency (greater than or equal to 3 mm, or greater than or equal to 99th percentile)
- Abnormal ductus venosus flow
- Presence of tricuspid regurgitation
- Abnormal cardiac axis (normal 40 60 degrees)
- Presence of pericardial/pleural effusion
- Maternal/paternal CHD or previous child with heart defect (especially when associated with high prevalence of gene disorders)
- Abnormal screens

Fetal Cardiac Intervention

Fetal cardiac intervention is performed by team members from The Congenital Heart Collaborative from UH Rainbow Babies & Children's Hospital, Nationwide Children's Hospital and UH MacDonald Women's Hospital. We have a dedicated team of fetal cardiologists, maternal-fetal medicine specialists, interventional cardiologists and anesthesiologists who intervene on fetal hearts to alter the progression of the heart disease in utero. Our team can intervene on cardiac defects such as aortic stenosis (AS) with evolving hypoplastic left heart syndrome (HLHS), HLHS with intact or highly restrictive atrial septum, and pulmonary atresia with intact ventricular septum. If you identify a candidate for fetal cardiac intervention, call 1-866-929-2099 to connect with the fetal cardiac intervention team.

Fetal Arrhythmia Team

Fetal arrhythmias are fairly common in pregnancy, occurring in 1 – 3 percent of all pregnancies. Fetal tachycardia and bradycardia can lead to nonimmune hydrops fetalis. The Fetal Heart Program at UH Rainbow Babies & Children's Hospital provides a multidisciplinary team approach to diagnosing, treating and monitoring the fetus with an arrhythmia. The team consists of fetal pediatric cardiologists, pediatric electrophysiologists, maternal-fetal medicine specialists, adult electrophysiologists and a dedicated Fetal Heart Program nurse practitioner. Special care paths have been designed to safely administer anti-arrhythmic medications to the fetus and provide guidance for safety monitoring of the maternal-fetal pair.

Fetal Heart Program Team

The Fetal Heart Program includes a dedicated team of specially trained fetal cardiologists, fetal sonographers and nurse practitioners, all of whom are committed to providing the care, education and resources needed to facilitate the best outcome for babies with heart disease and their families. We also work closely with maternal-fetal medicine specialists, genetic counselors and social workers.

Fetal Cardiologists	Other Services Offered
James Strainic, MD	Cardiothoracic surgery
Director,	Cardiac catheterization
Fetal Heart Program	EP/Ablation
Sarah Plummer, MD, Pediatric Cardiologist	Cardio-genetics
Tiffanie McCourt, CPNP,	NICU/CTICU/Step-down unit
Fetal Heart Program	Nurse coordinators
Coordinator	Fetal care patient navigator
	Maternal fetal medicine
	Social services
	Nutritionalists
	HOME (high-risk outpatient monitoring & education) team

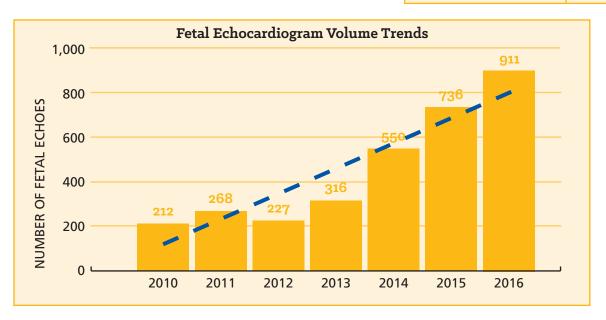


Table 1.
Fetal echocardiogram volume at UH Rainbow Babies & Children's Hospital over the past six years.

Locations

The Fetal Heart Program has four locations throughout Northeast Ohio. We have fetal echocardiogram availability Monday through Friday at the following locations.

UH RAINBOW BABIES & CHILDREN'S HOSPITAL (MONDAY – FRIDAY)

2101 Adelbert Road, 6th Floor Cleveland, Ohio 44106

UH LANDERBROOK HEALTH CENTER (THURSDAY)

5850 Landerbrook Drive, Suite 240 Mayfield Heights, Ohio 44124

UH MEDINA HEALTH CENTER (FRIDAY)

4001 Carrick Drive, Suite 220 Medina, Ohio 44256

UH WESTLAKE HEALTH CENTER (WEDNESDAY)

960 Clague Road, Suite 1600 Westlake, Ohio 44145

For appointments, call 216-844-3528

Reference:

Donofrio M., et al. Diagnosis and treatment of fetal cardiac disease: A scientific statement from the American Heart Association, Circulation, 2014:129: 2183 – 2242.





Fetal Heart Program (Scheduling a fetal echocardiogram and consultation)

266-844-1337

Fetal Cardiac Intervention (For fetal intervention candidates only)

1-866-929-2099

Physician-to-Physician Consultation Line

216-UH4-ADOC (216-844-2362)

Rainbow.org