

Adult Congenital Heart Disease Program



With the success of congenital heart surgeries in infancy and childhood, patients with congenital heart disease (CHD) are living longer into adulthood. However, as patients age, they can become vulnerable to various health issues.

The Heart Institute at Cincinnati Children's Hospital Medical Center offers a robust program including evidence-based approaches for adolescents and adults with congenital heart disease (ACHD). Our team specializes in caring for patients with uncommon and complex conditions, providing the clinical care needed to help them enjoy the best health possible for the rest of their lives.

CONTACT US

For patient referrals and non-urgent consultation during business hours:

Phone: **513-803-2243**

Email: ACHD@cchmc.org

For urgent issues, or to speak with the specialist on call 24/7:

Physician Priority Link: **1-888-987-7997**

For international inquiries:

Phone: **+1-513-636-3100**

Email: international@cchmc.org

www.cincinnatichildrens.org/achd



The Heart Institute at Cincinnati Children's is part of the Joint Heart Program.

A collaboration between Cincinnati Children's and Kentucky Children's Hospital, the Joint Heart Program is ranked nationally by *U.S. News and World Report*.

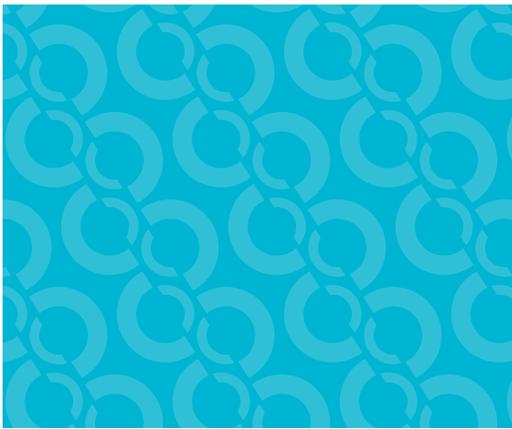


HOW WE'RE DIFFERENT

Patients who were treated for CHD as children need to remain under the expert care of congenital heart specialists to ensure their complex needs are met and problems are addressed proactively. Adults newly diagnosed with CHD also benefit from the expertise of physicians with formal training and experience with these less common adult diagnoses.

- Our ACHD program includes a team of internationally renowned faculty with more than 100 years combined experience caring for adults with CHD.
- **The Adult Congenital Heart Disease (ACHD) Program at Cincinnati Children's is an ACHD Accredited Comprehensive Care Center.** We were one of the first centers in the nation to earn this distinction, which is the highest level of ACHD care recognized by the Adult Congenital Heart Association. The ACHA Accreditation Program is a critical landmark, as it now provides adult congenital heart patients with a means to find high-quality ACHD programs throughout the U.S.
- Cincinnati Children's pediatric and adult congenital heart specialists work with our teenage patients to ensure a smooth transition to our ACHD Program.
- We partner closely with referring providers, operating with a shared care model that facilitates communication between us, our patients and their other care providers.
- Our program helps connect adults with congenital heart defects who are not currently accessing care with our specialists to ensure ongoing surveillance and treatment.
- Cincinnati Children's offers a Heart Transplant Program along with a joint Heart-Liver Transplant Program that combines the expertise of our Fontan Management Clinic with UC Health's outstanding adult transplant team.
- Our program has grown more than two-fold over the last five years. We now see patients at more than 14 locations throughout southwest Ohio, eastern Indiana, and Kentucky. In addition, we have expanded access to telemedicine for our patients.
- Our one-year survival rate for adult congenital heart surgery is 98%*.

*Society for Thoracic Surgeons, all index primary procedures from 7/1/2018–6/30/2021.



GLOBAL ACCESS

Several times every month our team meets with colleagues throughout the world using robust telemedicine links. Our Center for Telehealth allows us to share our expertise with other providers, no matter where a patient lives. We offer the latest equipment for connecting our specialists with providers and colleagues around the globe.

SECOND OPINIONS

We regularly provide second opinions to reassure patients they are receiving the best possible care elsewhere, and when appropriate, will offer insights about other treatment options.

TREATMENT APPROACH

Our ACHD Program provides a comprehensive range of tests, therapies and resources to care for each patient based on his or her individual needs. Our program includes:

- Lifelong surveillance designed to prevent complications such as arrhythmia, heart failure, heart valve issues, stroke and premature death.
- Education services tailored to each patient's needs. Our areas of expertise include managing the full spectrum of congenital heart disease, especially in patients of moderate or greater complexity, the Fontan circulation, pregnancy care, cardiovascular genetics and counseling, exercise physiology, pulmonary hypertension and much more.
- A transition education program for patients 12 to 18 years old to help them take ownership and manage their health. The program includes engagement by pediatric cardiologists, pediatricians and primary care physicians.
- Cardiac catheterization-based interventions and cardiac surgical procedures and medical care after these procedures for adult patients whose congenital heart conditions require intervention.

TREATMENT TEAM

ACHD Specialists

Sasha Opotowsky, MD, MMSc,
Director
Craig Alexander, MD
Nicole Brown, MD
Felicia Eichelbrenner, MSN, RN
Bradley Keller, MD
Adam Lubert, MD
Nicollette Millard, BSN, RN
Andrew Redington, MD
Amy Rich, MSN, APRN, CNP

Cardiothoracic Surgeons

Carl Backer, MD
David Lehenbauer, MD
David Morales, MD
David Winlaw, MD

Integrated Specialists

Meredith Jenkins, PharmD, BCPPS
Stacey Morrison, MA, PsyD
Linda Smets-Ullrich, LISW-S

Program Management Coordinator

Mark Fogel

In addition, we collaborate formally with more than 35 specialists from many disciplines, including:

- Behavioral medicine and psychology
- Cardiac imaging
- Cardiac rehabilitation
- Cardiovascular genetics
- Electrophysiology
- Heart failure management
- Interventional catheterization
- Nursing
- Pulmonary hypertension
- Social work



FACTS ABOUT ACHD

- Data show that adults with congenital heart disease who need surgery are best treated by a congenital heart surgeon in a pediatric hospital. Mortality rates are nearly tripled when surgery is performed by an adult surgeon not specialized in CHD; and mortality rates are more than doubled when performed at a general adult hospital versus a children's specialty hospital.
- Following CHD patients throughout adulthood is critical even when a patient is asymptomatic. As a repaired heart from early childhood grows and adapts through life, negative changes can take place, such as heart rhythm disturbances, leaky valves, strokes, obstruction, or heart failure.
- If deterioration in heart function is caught early, several therapies can prevent severe side effects from happening.

CONDITIONS TREATED

Our dedicated ACHD specialists have extensive experience treating adolescents and adults with all forms of CHD, and those with problems related to prior surgery for CHD. Some of these conditions include:

- Aortic and mitral valve atresia
- * Atrial and atrioventricular septal defects
- Bicuspid aortic valve
- Coarctation of the aorta
- Congenital valve defects, including aortic, mitral, pulmonary and tricuspid valve defects
- Cyanotic defects
- Double outlet ventricles
- Ebstein anomaly
- Eisenmenger syndrome
- Fontan circulation
- Pulmonary arterial hypertension
- Pulmonary atresia
- Tetralogy of Fallot
- Total and partial anomalous pulmonary venous connection
- Transposition of the great arteries
- Tricuspid atresia
- Truncus arteriosus
- Ventricular septal defects

We also care for ACHD patients who are pregnant or thinking of becoming pregnant.

SHARED CARE

Our goal is to work with the healthcare providers our patients already see. We partner with other doctors—from adult cardiologists to primary care physicians to OB/GYNs—and make decisions together with the patient. This approach means our patients benefit from the care of a doctor who knows them well, and specialists who know CHD well.

- We work under a co-management model to provide the specialized congenital heart disease care, while our patients' other medical issues continue to be followed by the referring physician or primary care provider.
- Our team keeps in close communication with referring physicians and primary care providers to ensure the best possible care.
- After an ACHD intervention, patients will return to our center for follow-up care, and we will continue to partner with their primary care providers.

JOINT HEART PROGRAM

Our collaboration with Kentucky Children's Hospital also increases access to advanced pediatric and adult congenital heart disease care for Kentucky patients. Our goal is to provide uncompromising care close to home. For more information, visit www.cincinnatichildrens.org/service/j/joint-heart-program.

ACHD CLINIC LOCATIONS:

Ohio Locations

- Cincinnati Children's Main Campus
- Liberty Township
- Green Township
- Hillsboro
- Dayton
- TriHealth's Center for Maternal Care
- UC Health's Maternal Fetal Medicine Program

Kentucky Locations

- Louisville
- Elizabethtown
- Bardstown
- Danville
- La Grange
- Owensboro
- Shelbyville
- Ashland

Indiana Locations

- Madison

Specialty Clinics

Fontan Management Clinic

The Fontan Management Clinic at Cincinnati Children's is an integrated and highly specialized interdisciplinary program focused on adolescents and young adults with Fontan circulation. Our Fontan experts look beyond the heart, applying a comprehensive approach to care, with particular expertise in liver and blood clotting abnormalities.

Cincinnati Children's is a pioneer and leader in Fontan care, playing a major role in spearheading the Fontan Outcomes Network, a nationwide learning network focused on improving outcomes for individuals with a Fontan circulation.

TREATMENT APPROACH

Prevention of complications as well as early detection and treatment when issues arise, are the mainstays of the Fontan Management Clinic. Our team brings together experts from multiple specialties to provide the best care possible. We collaborate closely on each individual patient plan, so patients receive coordinated and convenient care at each visit.

Our team offers an integrated and coordinated approach to address patients' complex needs, including:

- An active surveillance program to improve quality and length of life
- Palliative and quality-of-life therapies when symptoms return, including diagnostic and invasive cardiac catheterization
- Highly specialized interventions, such as left ventricular assist devices, total artificial hearts and both heart and heart-liver transplantation
- Thoughtful approaches to health concerns that stem from the Fontan circulation such as liver disease and sleep problems
- Extensive education and training in coping strategies for patients and their families

Maternal Cardiac Care

Our ACHD physicians perform a comprehensive assessment of possible cardiac risks during pregnancy and ways to lessen those risks. We work in close coordination with maternal-fetal medicine physicians and others—such as fetal cardiologists and genetic counselors—to optimize the outcome for mothers and their babies.

TREATMENT APPROACH

An initial assessment is conducted by our ACHD physicians and high-risk maternal-fetal medicine physicians. This includes a thorough evaluation of the maternal and fetal risks of pregnancy, along with recommendations to mitigate those risks.

The patient and physician then discuss diagnostic findings, possible risks associated with pregnancy, and genetic factors that could influence the child's health. This conversation can include pre-conception counseling and advice on contraception, when appropriate.



PREGNANCY CARE

When adults with congenital heart disease become pregnant, our team collaborates closely with our patients' obstetricians and maternal-fetal medicine (MFM) specialists, including those at TriHealth and UC Health, to provide optimal care for mother and baby. Our specialists draw on the extensive resources available through the Cincinnati Children's Fetal Care Center.