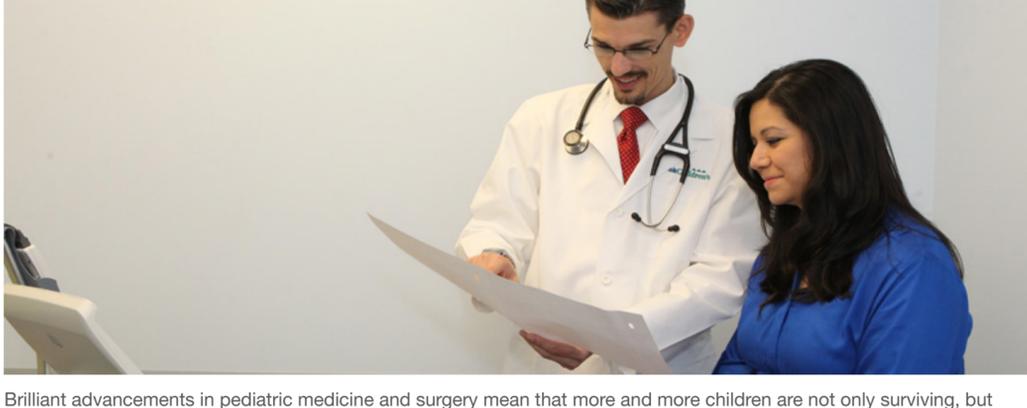


Advance Cardiology Programs

Adult Congenital Heart Disease (ACHD)



Brilliant advancements in pediatric medicine and surgery mean that more and more children are not only surviving, but growing up to become adults who are leading full lives. That also means that the need for ongoing care for adults with congenital heart defects is growing as well.

Here at Cook Children's, we care for the needs of patients with congenital heart disease from the moment they're born, and we stay with them all the way into adulthood. Our Adult Congenital Heart Disease (ACHD) is one of only a few formal programs nationwide to offer inpatient and outpatient care for teen and adult patients with congenital heart disease, because adulthood, like childhood, should be as simple as possible.

What is adult congenital heart disease?

The term congenital means to be born with. Congenital heart disease (CHD) is the most common birth defect, affecting nearly 1% of all newborns. The types of defects can range in severity from very simple congenital heart defects (holes between chambers and mild valve obstruction) to complex cases (missing valves or chambers). CHD used to be thought of as a pediatric, or childhood, condition. This was also due to the fact that many people born with serious congenital heart conditions didn't survive to adulthood.

Today that has changed, thanks to advances in medical and surgical care over the last several decades. Now, patients born with congenital heart defects are surviving and thriving well into adulthood. However, few types of congenital heart defects are considered "cured," and most require lifelong follow-up. This has created a growing population of adolescent and adult cardiac patients that continue to require specialized, life-long care. Conservative estimates predict that there are more than 1 million adults in the United States with congenital heart disease. This means there are currently more adults than children with congenital heart disease in the United States.

The health issues faced by this unique population are numerous and require specialists with a working knowledge of their congenital heart defect and how it might interact with adult onset disease processes. Joint guidelines published in 2008 by the American Heart Association and American College of Cardiology recommend that all adults with congenital heart disease be evaluated at least once in a formal program. The type and frequency of follow-up within the program is determined by the nature and complexity of the underlying heart defect. Unfortunately, less than 10 percent of adults with CHD receive this care currently. Cook Children's is helping to change those statistics.

What we do

Our expert team of cardiologists, cardiac surgeons, diagnosticians, technicians and health care professionals provide advanced, ongoing, care for adults with congenital heart disease, including:

- Initial diagnostic visits
- Congenital cardiothoracic heart surgery
- Transthoracic and transesophageal echocardiography
- Advanced imaging with cardiac magnetic resonance imaging (cMRI) and high resolution CT
- Diagnostic and interventional cardiac catheterization
- Invasive and non-invasive electrophysiology
- High risk fetal echocardiography
- Pulmonary arterial hypertension
- Routine care outpatient clinics
- Clinical social support

Our pioneering ACHD program coordinates with the following specialties to provide first-class comprehensive care of adults with congenital heart disease:

- Cardiothoracic surgery
- Pediatric surgery
- Fetal echocardiography
- Radiology
- Anesthesia
- Pulmonary medicine
- Genetics/genetic counseling
- Rehabilitation services
- Social workers

Who we treat

Childhood should be simple, and we believe that easing into adulthood should be simpler too. Our adolescent and adult care program is designed to meet the unique needs of teens and adults, transitioning them from pediatric care to the complex care necessary to ensure optimal outcomes throughout their lives.

Led by Scott Pilgrim, M.D., Medical Director, Adult Congenital Heart Disease Program, our team meets the very unique needs these patients, providing:

- Inpatient and outpatient consultation
- Echocardiography and advanced cardiac imaging
- Cardiopulmonary exercise stress testing
- Diagnostic and interventional cardiac catheterization
- Diagnostic and interventional electrophysiology
- Congenital cardiothoracic surgery

Any teenager or adult patient with a previously confirmed or newly suspected diagnosis of congenital heart disease should be referred to an ACHD program for a formal evaluation. Surveillance, diagnostic and interventional procedures are scheduled according to published guidelines.

Additionally, the ACHD program provides women of child-bearing potential with important education regarding birth control options, pre-pregnancy counselling and risk assessment. Women who are already pregnant are followed in conjunction with the obstetrician, maternal fetal medicine, fetal cardiology and anesthesia teams with a coordinated delivery plan.

The role of this program will vary based on the patient's needs and is not meant to replace the current care the patient is receiving. All ACHD patients should have a primary care physician and can continue with their local cardiologist, in addition to the ACHD specialist.

Conditions we treat

There are many different types of congenital heart defects ranging from very simple to extraordinarily complex lesions. Our nationally recognized cardiology team treats a wide range of adult congenital diseases, which include but are not limited to:

- Anomalous Pulmonary Venous Return (Partial and Total)
- Aortic Stenosis
- Aortopulmonary (AP) Window
- Arrhythmia
- Atrial Septal Defects
- Atrioventricular Canal Defect
- Bacterial Endocarditis
- Bicuspid Aortic Valve
- Coarctation of the Aorta
- Double Outlet Right Ventricle
- Ebstein's Anomaly
- Hypoplastic Left Heart Syndrome
- Patent Ductus Arteriosus
- Pulmonary Arterial Hypertension
- Pulmonary Stenosis
- Truncus Arteriosus
- Vascular Ring
- Ventricular Septal Defect

Cook Children's Adult Congenital Heart Disease team



Scott Pilgrim, MD
Medical Director, Adult Congenital Heart Disease

Education: St. George's University School of Medicine, Grenada, West Indies
Residency: Maimonides Medical Center, Brooklyn, NY
Fellowship: Pediatric Cardiology Schneider Children's Hospital, North Shore-Long Island Jewish Health System

Board Certification: American Board of Pediatrics; American Board of Internal Medicine; American Board of Pediatrics, Sub Board, Pediatric Cardiology

Languages: English



Deborah A. Schutte, MD
Medical Director, Cardiology

Education: University of Nebraska Medical Center, Omaha, NE
Residency: University of Virginia Health Sciences Center, Charlottesville, VA
Fellowship: The Ohio State College of Medicine, Children's Hospital, Columbus, OH; Interventional Fellowship at Texas Children's

Board Certification: Pediatrics & Pediatric Cardiology

Languages: English



Matthew Dzurik, MD
Medical Director, Cardiac Catheterization Laboratory

Education: Louisiana State University
Residency: Louisiana State University
Fellowship: Vanderbilt University Medical Center (Pediatric Cardiology & Pediatrics Electrophysiology)

Board Certification: IBHRE certified in Pediatric Electrophysiology

Languages: English



James Kuo, MD
Cardiology

Education: Medical College of Georgia
Residency: Carolinas Medical Center
Fellowship: Emory University School of Medicine
Board Certification: Pediatrics, Pediatric Cardiology

Languages: English



Steve Muyskens, MD
Medical Director, Cardiac MRI, 3-D aPROaCH Lab

Education: University of Iowa Carver College of Medicine
Residency: Saint Louis Children's Hospital, Washington University School of Medicine
Fellowship: Saint Louis Children's Hospital, Washington University School of Medicine
Board Certification: Pediatrics, Pediatric Cardiology

Languages: English



Vincent K.H. Tam, MD
Medical Director, Cardiothoracic Surgery

Education: University of Massachusetts Medical School, Worcester, MA
Residency: Johns Hopkins Hospital, Baltimore, MD
Fellowship: Johns Hopkins University, School of Medicine - Cardiac Surgery

Board Certification: Surgery, Surgical Critical Care and Thoracic Surgery

Languages: English

Lifelong adult congenital heart disease support

Lifelong adult congenital heart disease specialty services include:

- Non-invasive imaging, including cardiac MRI
- Digital echocardiography with 3-D imaging capabilities
- Electrophysiology services with 3-D mapping capabilities
- Cardiac catheterization and intervention, including rotational angiography and 3-D
- Cardiothoracic surgery

Through our Social Services program, we also work with teens and young adults to help them overcome unique obstacles such as:

- Managing their health and medications
- Balancing school, work, recreation and finances with their specific health needs
- Risk prevention, new treatments, managing other medical and physical conditions that can affect their heart condition and offering emotional support.

At Cook Children's Heart Center, many of our patients grow up with us. We want to be here to provide continual care for infants through adulthood, because when it comes to our patients, we're here for life.

Need help referring a patient?

Please call the International Patient Services department at +1-682-885-4685, send faxes to +1-682-885-2557, or email international@cookchildrens.org