

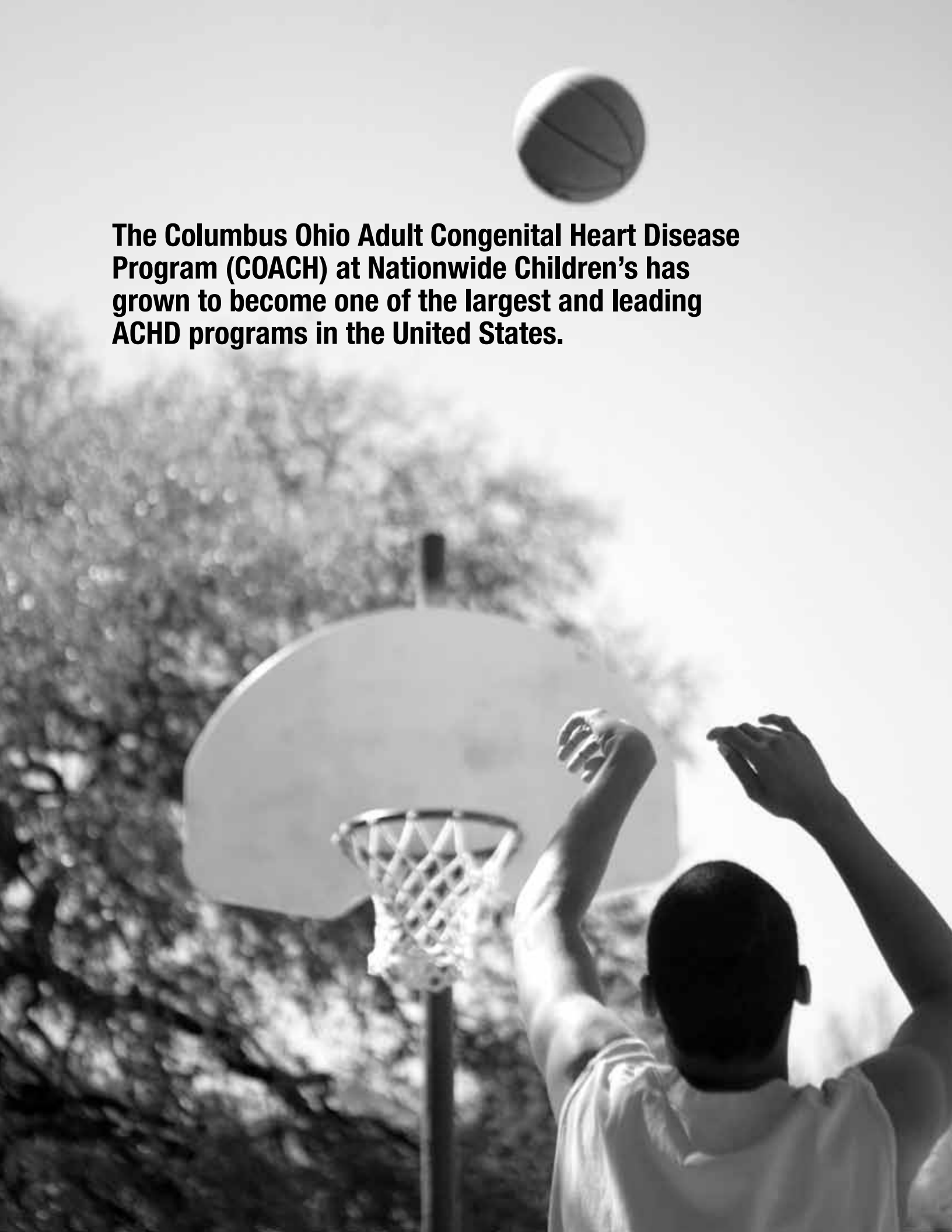


The Heart Center
700 Children's Drive
Columbus, OH 43205-2696
(614) 722-6200
NationwideChildrens.org/ACHD



**We're taking extraordinary
measures to treat
adult congenital heart disease.**





The Columbus Ohio Adult Congenital Heart Disease Program (COACH) at Nationwide Children’s has grown to become one of the largest and leading ACHD programs in the United States.

Table of Contents

Overview2

Fellowship Training4

Cardiac Catheterization and Interventional Procedures6

Comprehensive Cardiothoracic Surgical Repair8

Cardiopulmonary Failure and Transplant Program.....10

Extended Services.....11

Outpatient Services14

Research.....16

Outcomes at a Glance17

Referral Information.....19



Ranked Top 5 in the country as one of the America’s best for cardiology and heart surgery by *U.S.News & World Report*.



Our mission

The mission and goals of the COACH Program at Nationwide Children’s Hospital and The Ohio State University Wexner Medical Center is to provide comprehensive care for the adolescent and adult with congenital heart disease, regardless of age or severity of illness.



As the number of adult congenital heart disease patients grows, so do our capabilities.

The Heart Center at Nationwide Children's Hospital is a leader in pediatric cardiac care, and recently ranked in the top 5 of America's best for Heart and Heart Surgery by *U.S. News & World Report*. From the world's first Hybrid Cardiac Catheterization Suites to the nation's first Hybrid Congenital Cardiac Operating Room, our world-class team of cardiologists, surgeons, intensivists, nurses and technicians has comprehensive services and resources readily available for you and your patients.

Congenital heart disease (CHD) is the most common birth defect in this country, affecting one out of every 120 babies. Currently, there are estimated to be more than one million adults with CHD in the United States and this number increases approximately five percent each year.

Due to major advances in medical and surgical care over the past 40-plus years, more than 90 percent of children with CHD are living into adulthood. As a result of this trend, there has been a large increase in the adult congenital heart disease (ACHD) population. As patients with CHD become adults, they may develop heart failure and arrhythmia problems. For these reasons, ACHD patients should continue to be followed by an expert CHD specialist, trained in the field of ACHD care, to keep their heart healthy.

We're one of the largest programs in the country. Established in 2000, the COACH Program at Nationwide Children's is now one of the largest and leading ACHD programs in the U.S., with an average annual patient growth of 30 percent. We are currently caring for more than 2,500 patients

at both Nationwide Children's and The Ohio State University Wexner Medical Center. This allows patient care to be individualized, utilizing the most appropriate resources from each institution.

The COACH Program is involved in designing the future of ACHD care by participating in and leading national strategic initiatives through the Adult Congenital Heart Association, the American College of Cardiology and the International Society for Adult Congenital Heart Disease. Our priority is to provide quality care and outcomes through a multi-specialty approach of expert clinical evaluation and treatment, research and education for every patient every day.

Our team's expertise is unrivaled.

Our expert team consists of three highly specialized attending cardiologists who are board certified in both pediatric cardiology and internal medicine, with expertise in evaluating and treating complex CHD. Each of the program's nurse practitioners has received additional training and education in CHD. To complete the staff, there are three nurses and four ACHD fellows-in-training.

Our expertise includes:

- Adults with CHD
- Transcatheter valve therapy
- Stent therapy for COA, PA stenosis
- ASD, PFO closure
- Heart failure, heart and heart-lung transplants
- Complex arrhythmia management
- Advanced pulmonary hypertension therapy
- Cardiovascular connective tissue disorders
- Pregnancy and heart disease
- Transition of adolescents with CHD into ACHD care
- Training of future ACHD providers

Stephen R. Crumb, DNP, COACH Program (right), with a patient



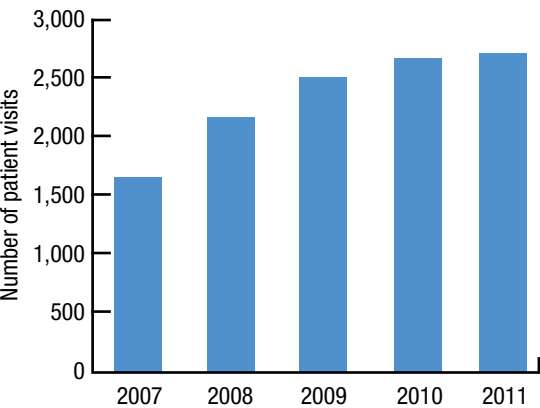
Our training program isn't just outstanding, it's one of a kind.

The Schooler Family Foundation Adult Congenital Heart Disease Fellowship Program at Nationwide Children's and The Ohio State University is a fully funded, 24-month ACHD training program for those interested in a cardiovascular career specializing in the care of adults with CHD. Cardiovascular fellows completing either internal medicine or pediatric cardiology are eligible to apply. The training program is specifically designed to follow and meet proposed guidelines for subspecialty ACHD training. The Schooler fellow will train within The Heart Center at Nationwide Children's and The Ohio State University as part of the Columbus Ohio Adult Congenital Heart Disease (COACH) Program.

The National Institutes of Health, National Heart, Lung and Blood Institute awarded researchers at Nationwide Children's and Ohio State's Wexner Medical Center a five-year, \$1.4 million grant to provide in-depth training to clinicians and basic scientists in congenital and acquired heart disease. This training program is the first in the

country that focuses on cardiovascular disease as a continuum from fetal life to senescence, allowing Nationwide Children's and The Ohio State University to be well-positioned to have a measurable impact on cardiovascular disease, and to foster new collaborative opportunities between two nationally ranked hospitals and programs.

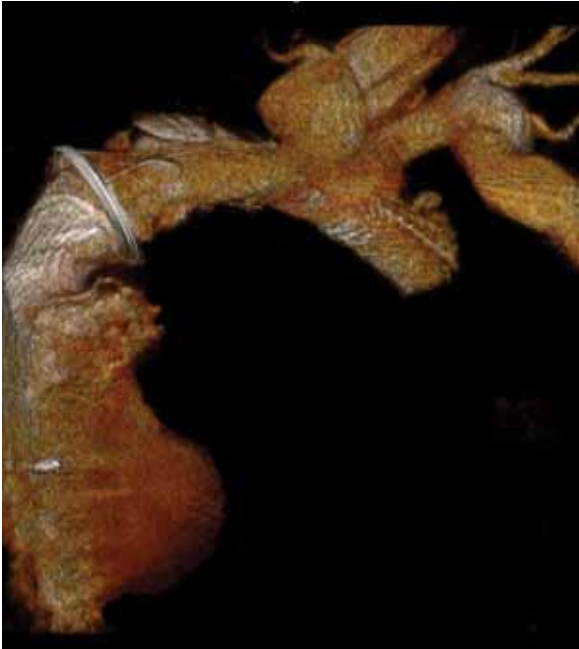
Columbus Ohio Adult Congenital Heart Disease Program



“My training in ACHD will provide the foundation for my career as an ACHD cardiologist. The clinical experience and the research opportunities have been outstanding and diverse. The entire COACH team makes quality of care the top priority and I hope to continue this tradition of excellence into my own career.” – Marc Cribbs, MD, Schooler ACHD fellow

*Curt J. Daniels, MD, Director, COACH Program (left)
and Marc Cribbs, MD, Schooler ACHD fellow (right)*

Failed Hancock pulmonary valve, pre-Melody



Post-Melody pulmonary valve replacement



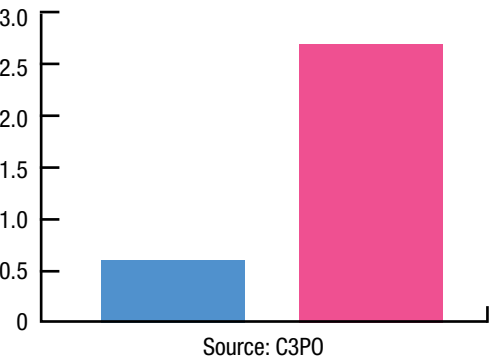
The latest equipment allows for the most advanced care.

Interventional cardiology provides a full spectrum of diagnostic and interventional cardiac catheterization procedures for ACHD patients.

Two custom-built Hybrid Cardiac Catheterization laboratories are equipped with state-of-the-art technology to provide interventional treatment for patients with congenital and acquired heart disease at all ages, from a 700g premature infant to an 80-year-old adult.

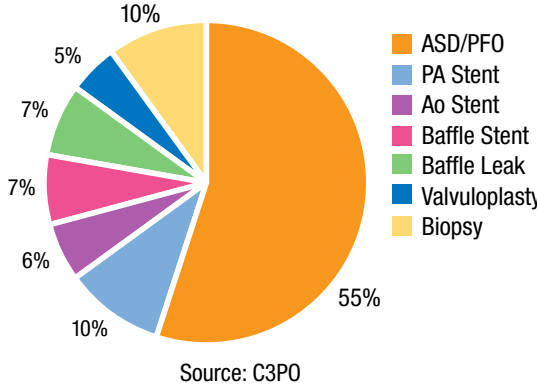
- Balloon valvuloplasty and angioplasty: all cardiac valves, arteries and veins, including d-transposition of the great vessels
- Transcatheter closure of intra- and extracardiac shunts: atrial septal defects, patent foramen ovale, ventricular septal defects, patent ductus arteriosus
- Stent therapy for vascular obstructions associated with congenital heart disease: pulmonary artery stenosis, coarctation of the aorta, venous obstruction
- Unique availability of new medical devices restricted to FDA-sponsored clinical trials
- Transcatheter pulmonary valve replacement

ACHD Cardiac Cath Major Adverse Events 2007–2011



Source: C3PO
■ NCH
■ Reported 2.7 Bergersen L. et al. (2008). *Congenital Heart Disease*, 3:90

ACHD Cardiac Cath Interventions



“The first percutaneous valve to be implanted in a human took place on September 12, 2000, in Paris, France by Professor Philipp Bonhoeffer. This was performed on a 12-year-old boy and no surgery was required. Nationwide Children’s was chosen as one of five sites in the United States to participate in a FDA trial evaluating the safety and probable benefit of this valve, the Medtronic Melody Transcatheter Pulmonary Valve (TPV). The valve was approved in January 2010 and there have been approximately 100 patients at Nationwide Children’s, both children and adults, who have had excellent results without the use of open heart surgery.” – John P. Cheatham, MD, FAAP, FACC, FSCAI



Mark Galantowicz, MD, Chief, Cardiothoracic Surgery, Nationwide Children's Hospital (right)



We're at the center of success.

According to the Society of Thoracic Surgery (STS) database, the outcomes of The Heart Center at Nationwide Children's rank among the best high-volume centers for both children and adults undergoing congenital heart surgery. The Heart Center's 2011 mortality rate for children was 1.9% and for adults 0%, while the four-year (2008-2011) average for children was 0.5% and adults 0.8%.

We provide a lifetime of care.

The Cardiothoracic Surgical Program is dedicated to the treatment of all patients, regardless of age, who are suffering from congenital disorders of the thorax, including heart, lung, mediastinum and chest wall.

Our program's key to success is the development of a nationally ranked, multidisciplinary team that tailors care to the individual patient.

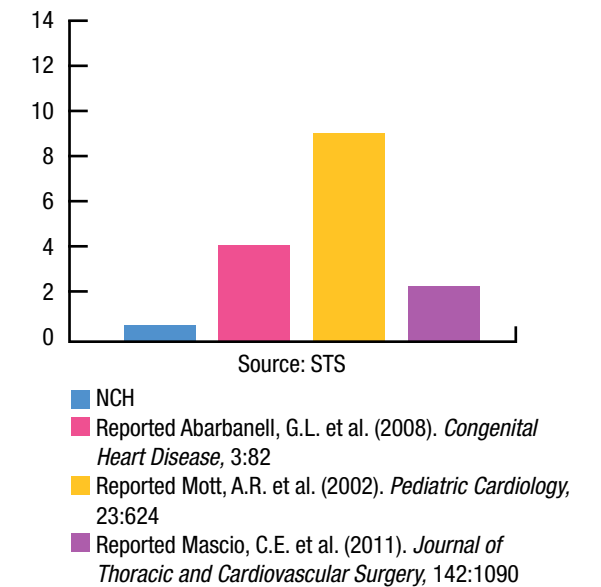
Pioneers in the development of novel treatment strategies, including the development of hybrid procedures, we are one of the only pediatric hospitals to use 3-D video-assisted thorascopy, allowing us to expand the use of minimally invasive techniques. Our goal is to improve the long-term quality of life for patients through the development of minimally invasive surgical approaches with shorter recovery time.

Procedures include:

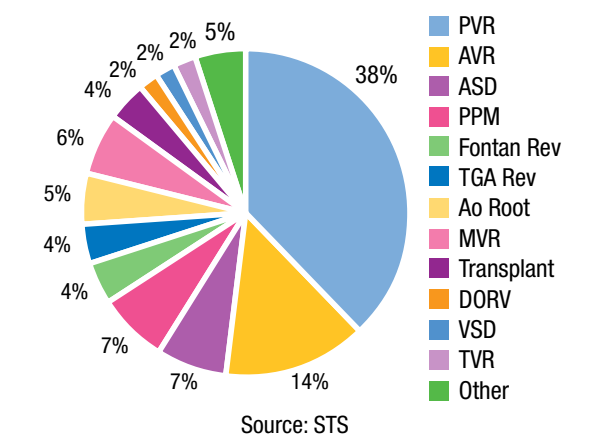
- Valve repair/replacement
- Fontan revision
- Valve-sparing aortic root replacement (Marfan syndrome)
- Surgical therapies for arrhythmias
- Hybrid surgical procedures

If a surgical evaluation is required, the cardiothoracic surgeons at Nationwide Children's and Ohio State's Medical Center have years of experience and training in CHD and connective tissue disorders, and in the care of adults with heart disease.

ACHD Surgical Mortality (%) 2007-2011



ACHD Operations





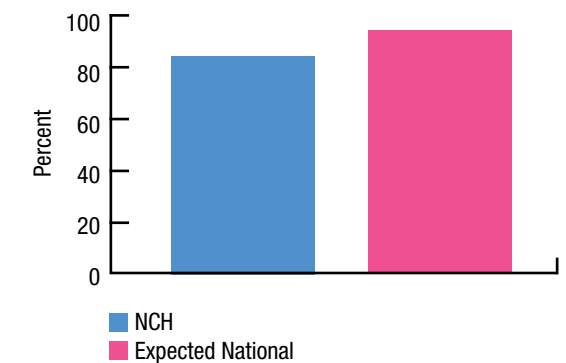
It's the very best expert care – start to finish.

The Heart Failure and Heart Transplant Program provides comprehensive services, including care before and after heart transplantation. Heart failure is the leading cause of death for ACHD patients, therefore it is very important to be able to provide comprehensive care to this population.

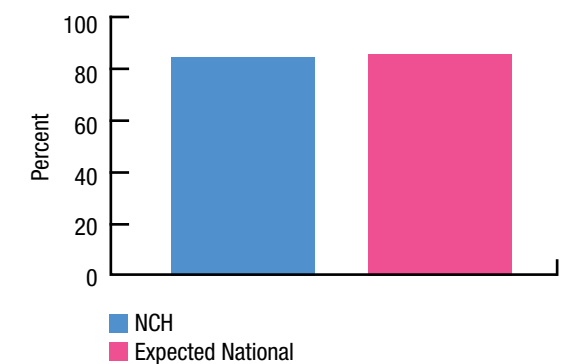
With expertise in outpatient and inpatient care, noninvasive imaging, including the latest in MRI techniques, catheterization, electrophysiology and device therapy for both adult congenital and acquired heart disease, the program has received international recognition and has garnered Center of Excellence recognition through OptumHealth, Aetna and Cigna Lifesource for high-quality care.

Always looking for ways to improve patient care, our program participates in several ongoing trials and registries, most notably, the Pediatric Heart Transplant Study Group, the NIH/Pediatric Heart Network Perioperative Working Group and the Congenital Cardiac Catheterization Outcomes Project.

Heart Transplant 30-Day Survival Outcomes



Heart Transplant 1-Year Survival Outcomes



The Heart Center at Nationwide Children's is one of only a few centers in the country to offer heart and heart-lung transplants for ACHD patients.

Curt J. Daniels, MD, Director, COACH Program

We offer everything an ACHD patient needs.

Imaging

Our Noninvasive Cardiac Imaging Program is one of the few able to provide high-level, vastly skilled diagnostic imaging techniques. Patients are able to receive complex imaging services all in one facility, including:

- Cardiac MRI
- Cardiac CT
- Live 3-D transthoracic and transesophageal echocardiography

Pulmonary Hypertension Services

We are the leading and largest PH program in the Midwest offering:

- Intravenous and subcutaneous prostacyclin therapy
- Oral endothelin blockers
- Clinical trials for new medical therapies

Electrophysiology Services

We offer comprehensive electrophysiology care including:

- Diagnostic EP
- SVT/VT ablation (removal of tissue)
- Atrial fibrillation/flutter ablation associated with congenital heart disease
- Pacer/ICD implantation
- Noninvasive and invasive arrhythmia management

Patient Education

We believe in empowering our patients through education. Our team enhances patient learning by utilizing diagrams, diagnostic imaging, and models to depict each patient’s unique cardiac anatomy and physiology.

We have also developed a library of educational handouts that detail congenital heart defects, outline testing, explain surgical and interventional procedures, and discuss potential long-term complications associated with each defect. The handouts address other considerations, such as the need for lifelong care, health insurance, antibiotics, and leading a healthy lifestyle.

Throughout the year, we offer our patients the opportunity to gather with other patients, nurses and physicians to discuss a variety of topics related to ACHD provided by leading experts.

Cardiopulmonary Exercise Testing

Our Exercise Physiology Lab and Cardiac Rehabilitation Program assesses the ability of patients to perform physical activities. The exercise lab is equipped and staffed to perform clinical exercise testing, rehabilitative exercise and clinical research. Additional services include stress echocardiography and exercise prescription.

Transition Program

The goal of this program is to provide these patients with the skills needed to assume responsibility for their health care. We help them understand the need for lifelong specialized cardiac care, provide counseling on adult issues, and offer resources to the adolescent patient with chronic heart disease. This counseling aids in successfully transitioning adolescents with congenital heart disease from their pediatric cardiologist to an adult congenital heart disease specialist. Every adolescent congenital heart patient, 15 years and older, and

their family meets with a nurse from our program several times during the adolescent years to address:

- The importance of lifelong care
- Assuming independent health care responsibility or, if appropriate, guardianship
- How to discuss concerns and symptoms with a cardiologist
- Lifestyle choices and exercise
- Insurance issues and medication coverage
- Career counseling
- Birth control and pregnancy
- Local and national support groups

Through this program, each patient participates in developing an individualized transition plan, which provides seamless transition from a pediatric to adult provider. The program helps patients remain in care and avoid a crisis situation.



Jill Swinning, MSN, ACNS-BC, COACH Program



Our goal is to successfully transition every child with CHD to an adult who understands the specialized care they need and takes responsibility for engaging the appropriate resources throughout their lives. To date, we have transitioned over 300 patients.



Convenient care increases patient compliance – and leads to positive outcomes.

Now that children and adolescents with heart disease are reaching adulthood, they require ongoing, specialized cardiovascular care.

For our patients' convenience, the cardiologists at Nationwide Children's have clinics at Nationwide Children's main campus, Nationwide Children's Mansfield and Ironton *Close To Home*SM Centers, Ohio State's Medical Center and Dayton Children's, housing full-service evaluation and testing by the ACHD team.

The COACH Program at Nationwide Children's and Ohio State's Medical Center is staffed by board-certified, adult and pediatric cardiologists, with specific interests and training in adult congenital heart disease, connective tissue disorders, pregnancy and cardiac disease, and premature coronary artery disease. The ACHD team utilizes subspecialists from both Nationwide Children's and The Ohio State University to provide comprehensive care to ACHD patients.

Consultations and cardiovascular care include:

- Medical and surgical evaluations of patients with congenital heart disease
- Pre-pregnancy cardiac examinations and continual medical care for patients with heart disease
- Care of patients with connective tissue disorders, such as Marfan syndrome

- Pulmonary hypertension
- Noninvasive imaging
- Heart failure/transplant evaluations
- Cardiac catheterization and interventional procedures
- Electrophysiologic procedures
- Comprehensive surgical repair

Pregnancy and Heart Disease

To appropriately manage women with cardiovascular disease, the COACH program incorporates a multidisciplinary team of highly specialized cardiologists trained in the field of ACHD, advanced practice nurses all of whom are adult-trained specializing in ACHD, dedicated maternal fetal medicine specialists, and obstetrical and cardiac anesthesiologists. This dedicated team meets on a regular basis to discuss each patient and develop an individualized plan for pregnancy, delivery and post-partum care. The plan is reviewed, revised as needed, and documented in the patient's medical record.

Over the past seven years, we have evaluated more than 400 pregnant patients with heart disease. Approximately 10 percent of these women had high-risk features: severe LV outflow tract obstruction, cardiomyopathy, valvular disease, pulmonary hypertension, cyanotic heart disease and complex CHD. Our outcomes have been better than predicted using existing risk-prediction models.

Sharon L. Roble, MD, COACH Program (left) with patient

We're leading the way.

Nationwide Children's is the only hospital in the country doing pediatric translational research on individual heart cells. Ultimately, this research will help us determine the effectiveness of therapeutic interventions, including medication and surgery.

Ninety percent of all infants born with CHD are expected to survive into adulthood, making adults with CHD one of the fastest-growing populations within cardiology. The COACH faculty has continuously advocated for quality cardiovascular care by promoting research in this growing population. Since the inception of our program, we have continually expanded our collaborative research efforts, working with the Divisions of Adult and Pediatric Electrophysiology, Interventional Cardiology, Cardiac Imaging and the Division of High Risk Obstetrics and Gynecology at The Ohio State University and Nationwide Children's.

The COACH faculty has also been part of the Alliance for Adult Research in Congenital Cardiology (AARCC) and the Adult Congenital Cardiac Care Associates Research Network (ACCCA) in promoting multi-center clinical research fostering collaborative relationships

between programs, physicians and nonphysician investigators, and furthering innovative investigations to improve outcomes in ACHD. Our team has also been actively involved with other leading ACHD centers collaborating on research funded by a National Institutes of Health (NIH) grant to facilitate ACHD research through automated electronic integration of data sources called REACH (Research Empowerment for Adult Congenital Hearts).

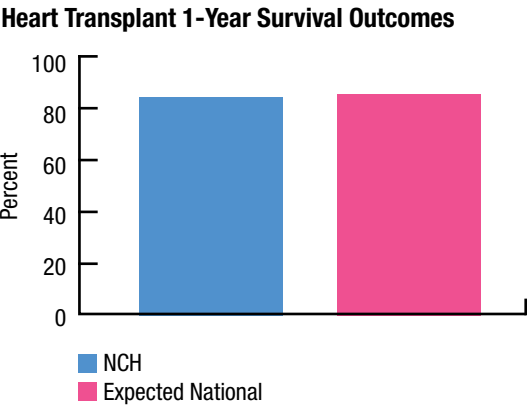
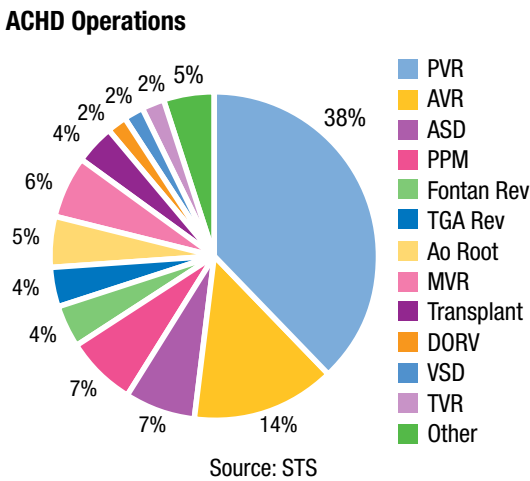
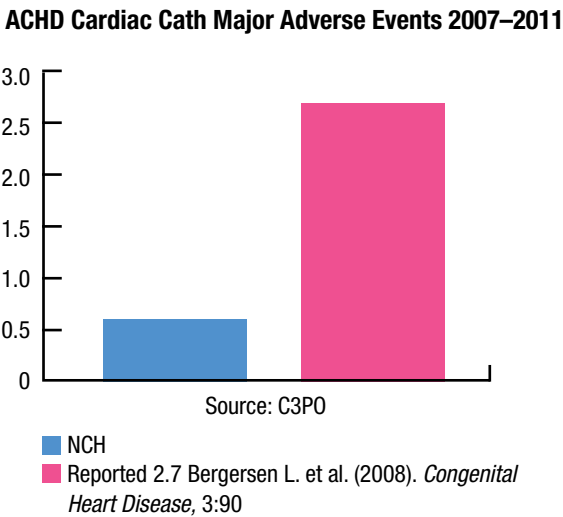
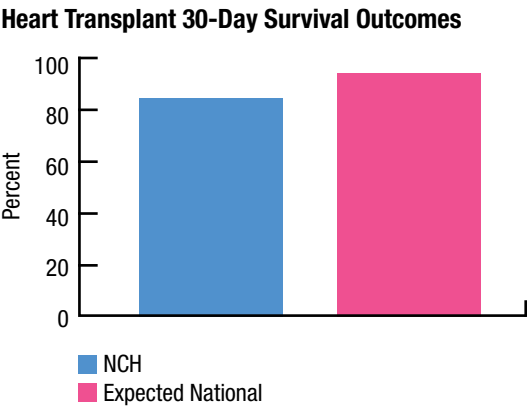
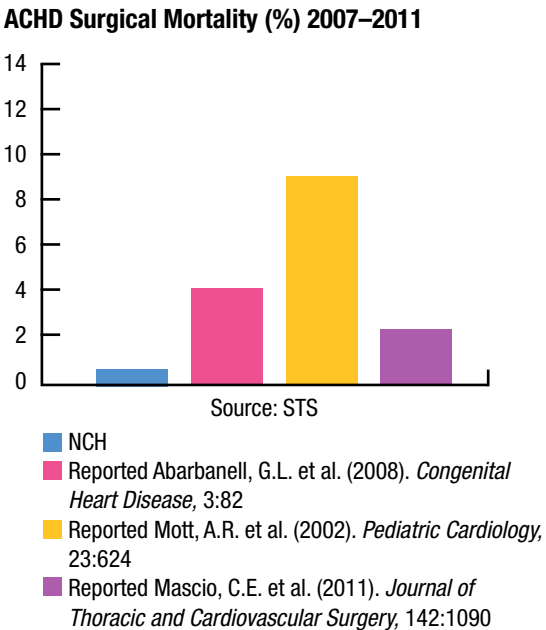
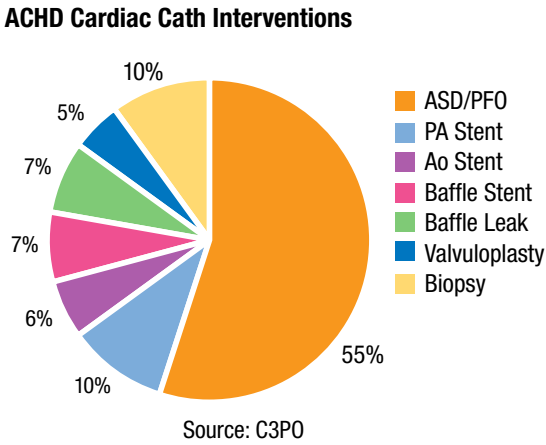
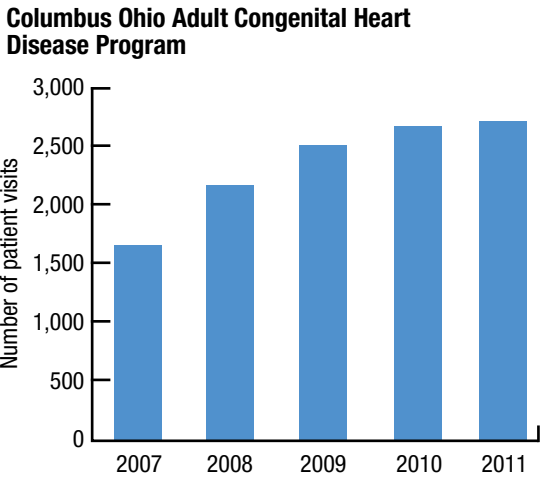
In addition to actively participating in local and national research, the NIH and the National Heart, Lung and Blood Institute (NHLBI) recently awarded researchers at Nationwide Children's and Ohio State's Medical Center a five-year, \$1.4 million grant to provide in-depth training to clinicians and basic scientists in congenital and acquired heart disease. This training program is the first in the country that focuses on cardiovascular disease as a continuum from fetal life to senescence, allowing Nationwide Children's and Ohio State to be well-positioned to have a measurable impact on cardiovascular disease, and to foster new collaborative opportunities between two nationally ranked hospitals and programs.



This T-32 grant has allowed the opportunity for a dedicated postdoctoral fellow to spend two years at our facility to study the psychological impact in ACHD. Our first postdoctoral fellow was enrolled in this program in the fall of 2011.

Ali N. Zaidi, MD, Director of Research, COACH Program (right), and Vidu Garg, MD, Director of Translational Research, The Heart Center and Center for Cardiovascular and Pulmonary Research (left).

For your convenience, here is the outcome-related data presented on the previous pages.





Web

NationwideChildrens.org/ACHD

Physicians

Physician Direct Connect Line (614) 355-0221 or (877) 355-0221

Education Series

For information on our Adult Congenital Patient Education Series at Nationwide Children’s, visit NationwideChildrens.org/ACHD or email ACHD@NationwideChildrens.org.

Clinics

Nationwide Children’s

700 Children’s Drive, Columbus, OH 43205

- Every Monday, Wednesday and Thursday of the month
- Nurse Practitioner Clinics every Friday

Mansfield *Close To Home*SM Center

680 Park Ave. W., Suite G05, Mansfield, OH 44906

- Third Wednesday of the month

Ironton *Close To Home*SM Center

2301 S. Seventh St., Ironton, OH 45638

- Second Thursday every other month

Ohio State’s Richard M. Ross Heart Hospital

452 W. 10th Ave., Columbus, OH 43210

- Every Tuesday, Wednesday and Thursday of the month
- Nurse Practitioner Clinics every Friday

The Children’s Medical Center of Dayton

1 Children’s Plaza, Dayton, OH 45404

- Every Monday, Wednesday and Thursday

For an appointment or questions regarding patient care, call (614) 722-5622.

How to Refer

To refer a patient to The Heart Center for ACHD care, please call (614) 722-6200, or fax referrals to (614) 722-4000. You can also refer a patient, or get more information, by visiting us online at NationwideChildrens.org.



This QR code can be scanned by a smartphone or tablet to open additional information. To load a free QR reader on your phone, go to: get.beetagg.com.

