The Adolescent & Adult Congenital Heart Disease Transition Education Program

Transitioning Adolescents and Young Adults to Adult Congenital Heart Disease Care
The Heart Center at Nationwide Children's Hospital

The Heart Center at Nationwide Children’s Hospital has earned an international reputation for innovation and forward-thinking. From the creation of the world’s first Hybrid Cardiac Catheterization Suites and the first Hybrid Operating room in the nation, to the development of a comprehensive adolescent and adult congenital program, The Heart Center team is constantly looking to improve care options. Recently ranked in the top ten by U.S. News and World Report for Heart and Heart Surgery, you can be assured that you have access to the expertise and resources that can handle any level of care necessary.

The Adolescent & Adult Congenital Heart Disease program encompasses a heightened level of expertise, innovation, and advancements allowing us to provide our patients with life-long cardiac care within a caring, family-centered environment.

To learn more about The Heart Center at Nationwide Children’s Hospital, please visit us at www.NationwideChildrens.org/HeartCenter
Transition from Pediatric to Adult Cardiology Care

Congenital heart disease (CHD) (being born with a heart defect) is the most common birth defect in this country, affecting one out of every 120 babies. Due to major advances in medical and surgical care over the past 40+ years, more than 90% of these patients are living into adulthood. In 2005, it was estimated that for the first time in history, there are more adults living with CHD than children. Currently, there are estimated to be over 1 million adults with congenital heart disease in the United States and this number continues to grow about 5% each year.

Adolescents and adults with congenital heart disease have different things to think about compared to children. Because of these factors, special centers have been developed across the country to care for adolescents and adults, such as yourself, because most adult cardiologists are not trained in congenital heart disease. Nationwide Children’s Hospital is fortunate to have one such specialized program, allowing adolescents and adults to continue their cardiac care with us. This shift for adolescents from child-centered to adult-centered care is a gradual process that The Heart Center at Nationwide Children’s Hospital calls the “Transition Program”.

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The goals of transitioning from child to adult heart care are to emphasize the importance of:

:: Learning about your heart defect and the need for ongoing specialized heart care throughout adulthood
:: Assuming responsibility of health-care
:: Talking about concerns, symptoms, etc. to your cardiologist
:: Taking medicine as directed (including antibiotics for dental procedures, tattoos, and piercings as needed for your heart defect)
:: General information about birth control, pregnancy, and childbearing
:: Lifestyle choices and exercise
:: Insurance issues (medical and life insurance)
:: Societal support and benefits
:: Medication coverage
:: Career or job counseling
:: Advance Directive information
:: Local and national patient support groups
:: Psychosocial issues (depression, anxiety, etc.)
:: Other adult health problems
The Importance of Life-long Cardiac Care

Over the past 20 years, more children with congenital heart disease are living to adulthood. The result of this is a large rise in the adult congenital heart disease (ACHD) population. Pediatric cardiologists are trained in congenital heart disease, therefore understand the anatomy and special needs of children born with heart defects. Adult cardiologists receive little or no training in congenital heart disease, therefore often do not understand the anatomy and concerns of adults born with heart defects. As patients with congenital heart disease become adults, they may develop new problems and should continue to be followed by a congenital heart specialist to keep their heart healthy. Across the United States, less than 10% of ACHD patients are receiving the recommended cardiac care. There are many reasons for this, including:

- In some hospitals, pediatric cardiologists are not allowed to care for patients over the age of 18
- Patients do not continue with follow-up care
- Lack of education about their heart defect
- Belief they are “fixed” or “cured”
- No longer “want to deal with heart disease”
- A perceived lack of cardiac symptoms
- Transportation issues
- Insurance barriers
- Financial issues
- Relocation
- Unsure how to find a new congenital heart specialist

Adult Congenital Heart Disease Resources:

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<th>Resource</th>
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Taking the science of cardiac care to the next level

- Nation’s first Hybrid Congenital Cardiac Operating Suite
- World’s first Hybrid Cardiac Catheterization Suites dedicated to congenital heart disease
- Comprehensive Cardiothoracic Surgical and Interventional Catheterization teams
- Electrophysiology, Pacemaker and Ablation for Complex Arrhythmias
- Heart Transplantation and Heart Failure programs
- Dedicated Cardiac Intensive Care Unit
- Host of the International Symposium on the Hybrid Approach to Congenital Heart Disease (ISHAC)
- The Adolescent & Adult Congenital Heart Disease (ACHD) program
- Outpatient services including 11 regional outreach offices
- Center for Cardiovascular & Pulmonary Research

ICAEL Accredited Echocardiography Laboratory
OptumHealth Center of Excellence for Congenital Heart Disease (CHD), one of 14 centers in the U.S.
A U.S. News ranked top ten pediatric hospital in Heart and Heart Surgery