



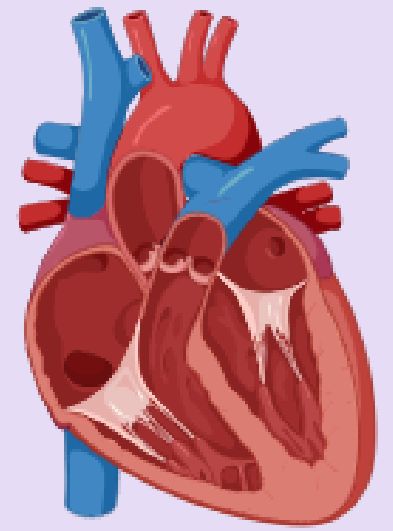
EMPOWER
MY CONGENITAL HEART

A Guide to Choosing Your Care Team for Congenital Heart Health



What is a Congenital Heart Defect?

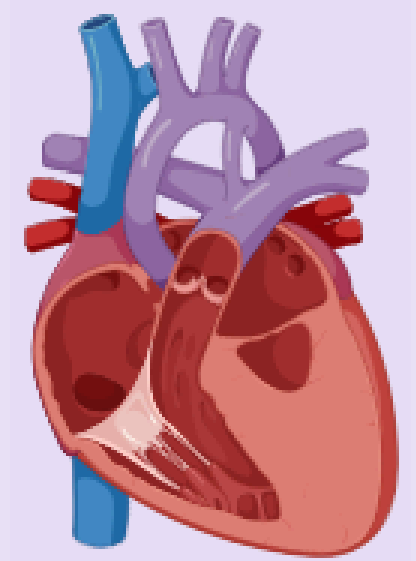
A **healthy heart** is like a strong pump with chambers that keeps oxygenated and deoxygenated blood separate and allows blood to flow in the correct direction.



Normal Heart Structure

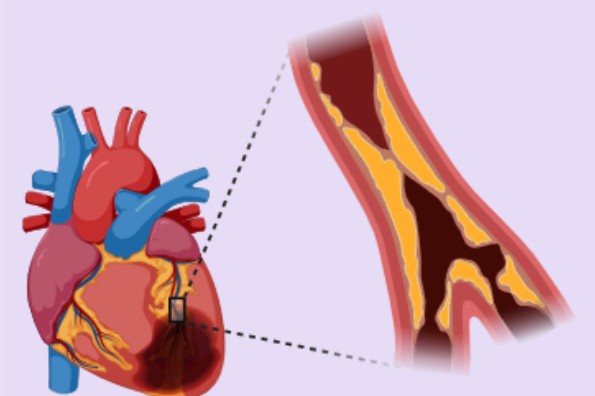
A **congenital heart defect (CHD)** is a structural issue with the heart, valves, or blood vessels that someone is born with.

Doctors can discover it at any age, and people with CHD often need **lifelong care from specialized heart doctors** who may perform procedures or surgeries.



Single Pumping Chamber

CHD is quite different from **acquired heart disease** (e.g. heart attack), a condition that usually develops later in someone's lifetime, often from lifestyle choices. Most heart doctors often manage acquired heart disease.



Clogged Heart Artery

Defect vs Disease

Congenital heart defects and congenital heart disease are closely related, but they aren't exactly the same.

Congenital Heart Defect

A congenital heart defect refers to the **structural problems** in the heart that are present from birth. These defects can often be **repaired** to **improve** heart function.

Congenital Heart Disease

Congenital heart disease refers to the **long-term effects** that these heart defects have on your heart health. Even after repairs, your heart will need ongoing **specialized care** and monitoring **throughout your life**.

Who Should I See for My Heart?



An **Adult Congenital Heart Disease (ACHD) Team!**

An ACHD Team could include the following:

ACHD Cardiologist:

Are heart doctors with additional years of training specifically in caring for adult CHD patients.

ACHD Surgeons/ Interventionalists:

Surgeons and cardiologists with special training and experience in CHD-specific procedures.

Often these doctors work with a team of:

- ACHD Nurse Practitioners (NPs)
- Nurses
- Social Workers
- Patient Care Coordinators/ Navigators
- Psychologists, and others

EMPOWERMENT: Often, over time you build strong relationships with the **nurses, social workers, and care coordinators** in the team who can help with insurance approvals, disability forms, etc.

ACHD vs. Other Cardiologists

Pediatric Cardiologist

Training: in pediatric heart conditions, including CHD.

Focus: on infants, children, and adolescents.

Limitations: typically not trained to manage adult congenital heart disease.

Adult Cardiologist

Training: in heart conditions mostly in adults such as coronary artery disease, heart failure, and arrhythmias.

Focus: on adults.

Limitations: typically not trained in managing congenital heart disease.

Adult Congenital Heart Disease (ACHD) Cardiologist

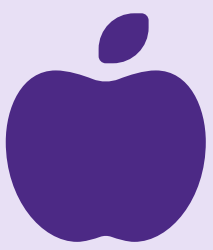
Training: beyond adult or pediatric cardiology, focusing specifically on CHD management in adults.

Focus: on adults with CHD.

Expertise: combines knowledge of both congenital heart issues and adult heart conditions to provide comprehensive care for CHD patients as they age.

Why Should I See an ACHD Cardiologist?

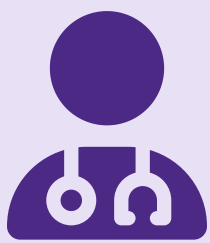
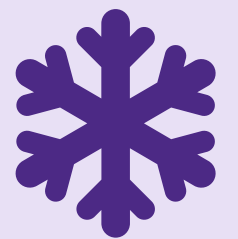
A unique heart has unique needs!



We cannot compare apples to oranges: *Patients with congenital heart conditions* require a different treatment approach from patients with *acquired heart conditions*.

No two snowflakes are the same:

Even individuals with the same congenital heart defect often have different needs!



Specialized ACHD centers and teams ensure you receive the **personalized care** you need.

Research shows that by regularly seeing an ACHD cardiologist, you are more likely to:

- ✓ **Live Longer!**
- ✓ **Live Healthier!**
- ✓ **Avoid Complications!**

When Should I Start Seeing an ACHD Cardiologist?

At **12-14 years of age**, start preparing to transition.

Consider transferring to an ACHD cardiologist around*:

18 🎂

However, it's **never too late!**



Don't wait until you are sick to see one!

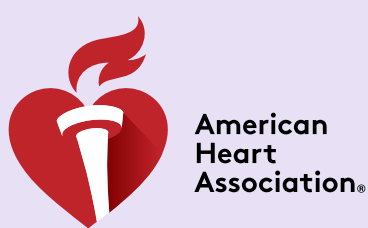


ACHD cardiologists can help **prevent symptoms and irreversible problems!**

**The exact timing might vary based on your individual situation. Please check with your pediatric cardiologist if you are seeing one.*

Did You Know?

- ◆ Only about **10% of adults with CHD receive care at specialized ACHD centers.**
- ◆ **Over half stop seeing a cardiologist after turning 18.**



If you have ever been told that you have CHD, it's recommended that you seek care from an ACHD cardiologist, even if you think you are 'fixed.'



Your primary care doctor or current cardiologist can provide a referral if you are not already seeing an ACHD cardiologist.

In some cases, such as when an ACHD center is far from your home, your local cardiologist and an ACHD cardiologist can work together to provide the care you need!



How Do I Find an ACHD Team?

- ◆ Often, your pediatric cardiologist refers you to an ACHD cardiologist after you turn 18.
- ◆ You might need to ask your primary care physician or an adult cardiologist to provide a referral.
- ◆ You can also check out this clinic directory by the **Adult Congenital Heart Association** to **find an ACHD doctor**:



www.AchaHeart.org/Directory



EMPOWERMENT: It is important to find a **provider who is a good fit for you**. If you don't feel a good connection with your ACHD cardiologist, it's okay to find another one.

If finding a new cardiologist is difficult:

1. Be open and clear about your needs with your current doctor and/or
2. Work with a local cardiologist for regular care, but visit a specialized ACHD center every one to two years.

Peer Voices

PEER-EMPOWERMENT

Aleah Sparks - Pulmonary Stenosis Patient

Personal Story.

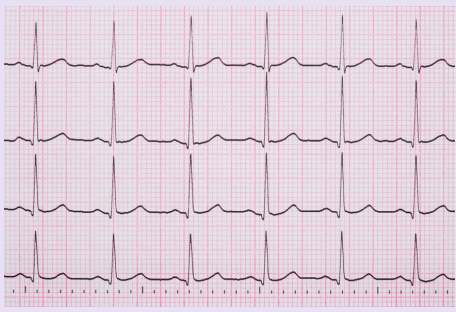
“ At 28 years old, I sat on the small exam table in the "under the sea" themed room, excitedly announcing, "I'm pregnant!" My long-time pediatric cardiologist, whom I loved and trusted and who had always provided me with excellent care, gently referred me to an adult congenital cardiologist. During my first appointment, I realized that **transitioning to ACHD care earlier**—at least a few years before—**would have been beneficial**. An ACHD provider could have more effectively managed the significant life changes I experienced between my late-teen years and pregnancy. Beyond that, it would have **given me time to build a strong, trusting relationship** with the specialist who would help me navigate one of the most important moments of my life—the birth of my first child.”

How Often Should I See My ACHD Cardiologist?

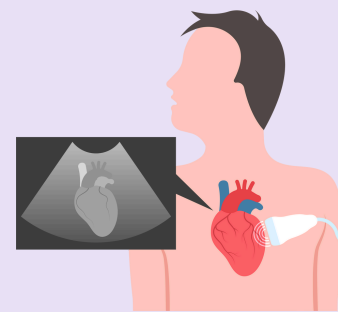
Routine visits are recommended **every 1-3 years**, depending on the heart condition*.

**Check with your ACHD doctor on your individual needs. You may need to be seen more or less frequently.*

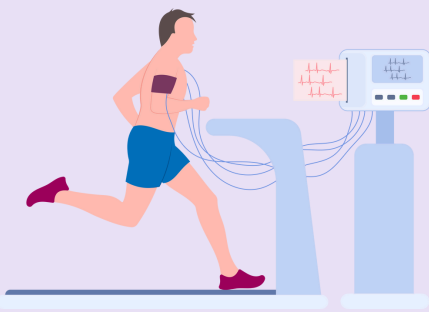
How often should I get testing?**



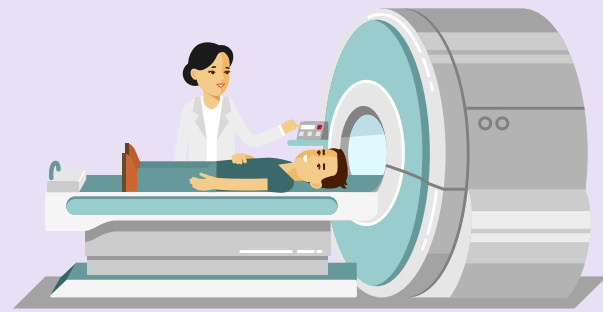
Electrocardiogram (EKG)
Every year



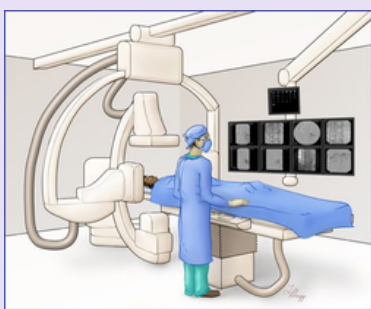
Echocardiogram
Every year



Exercise testing
Every 3-5 years



MRI or CT scan
Every 3-5 years



Heart Catheterization
As needed



Heart monitor
As needed

****Your individual needs might differ depending on your specific heart condition or it's severity.**

How Can I Learn More About My Heart Defect?



Download this
free Mobile app

- ◆ Available on **iPhone, iPad** and **Android**
- ◆ Developed by Cincinnati Children's Hospital Medical Center
- ◆ Offers interactive, **3D images** of a normal heart and the following congenital heart defects and their repairs.
- ◆ Provides **descriptions** of these defects and common surgeries to repair them.

Tetralogy of Fallot
Coarctation of the Aorta
Hypoplastic Left Heart Syndrome
Transposition of the Great Arteries
Ventricular Septal Defect
Patent Ductus Arteriosus
Atrioventricular Septal Defect
Interrupted Aortic Arch
Total Anomalous Venus Return
Truncus Arteriosus
Atrial Septal Defect
Ebstein's Anomaly

More information:

www.CincinnatiChildrens.org/Patients/Child/Encyclopedia/Heartpedia