

Empower

Understand

Thrive



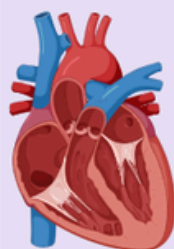
EMPOWER
MY CONGENITAL HEART

**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 keep oxygenated and deoxygenated blood separate and allow blood to flow in the correct direction.



Normal Heart Structure

A **congenital heart defect (CHD)**

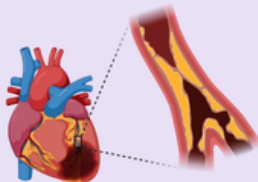
is a structural issue with the heart, valves, or blood vessels that someone is born with.

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 are not the same.



Congenital Heart Defect

A congenital heart defect is a **structural problem** in the heart that is 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:

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.

These doctors may work with a team of:

- ◆ ACHD Nurse Practitioners (NPs)
- ◆ Nurses
- ◆ Social Workers
- ◆ Patient Care Coordinators/Navigators
- ◆ Psychologists
- ◆ And more



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Over time, you often build strong relationships with the **nurses, social workers, and care coordinators** on the team who can help with insurance approvals, disability forms, etc.

ACHD vs. Other Cardiologists



Pediatric Cardiologist

Training: pediatric heart conditions, including CHD.

Focus: infants, children, and adolescents.

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



Adult Cardiologist

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

Focus: 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: adults with CHD.

Expertise: combines knowledge of both congenital heart issues and adult heart conditions to provide comprehensive care for patients with CHD 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?

Around **12 - 14 years old**, start preparing to transition to adult care.

Consider transferring to an ACHD cardiologist around*:

18 

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



Don't wait until you are sick to see an ACHD cardiologist!



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".



American
Heart
Association.



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



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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:

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



Peer Voices



PEER EMPOWERMENT

Aleah Sparks, Patient with Pulmonary Stenosis

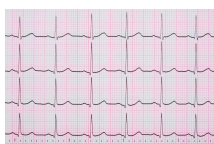
“ At 28 years old, I sat on the small exam table in the "under the sea" themed room, excitedly announcing, "I'm pregnant!" My long-time pediatric cardiologist, whom I loved and trusted and who had always provided me with excellent care, gently referred me to an adult congenital cardiologist. During my 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. ”

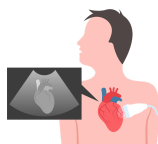
How Often Should I See My ACHD Cardiologist?

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

How often should I do testing?*



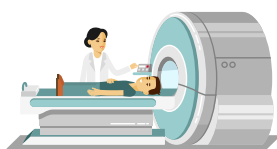
Electrocardiogram (EKG/ECG)
Every year



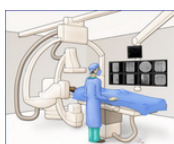
Echocardiogram
Every year



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 its severity. Check with your ACHD doctor to confirm how often you need to be seen.*

How Can I Learn More About My Heart Defect?



Download the
Heartpedia app

- ◆ Available for free 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, along with their repairs.
- ◆ Provides **descriptions** of several defects and common surgeries to repair them, including:



For More Information:

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