
Materials for pediatricians and family physicians who treat children

Connect Children with Heart Defects to the Care They Need

Children with heart defects need to see a pediatric cardiologist regularly to make sure they stay healthy as they grow. But did you know that many children with congenital heart defects aren't getting cardiac care at all?

As a primary care physician, **you play an important role in connecting children with heart defects to the care they need.**

Take these steps to connect children with heart defects to congenital cardiac care:

- Ask parents and caregivers if children are seeing a pediatric cardiologist — a specialist who treats children who were born with heart defects. If a child isn't, explain why lifelong congenital cardiac care is so important.
- Refer children who aren't getting care to a pediatric cardiologist.

It's also important to help teens with heart defects transition to adult congenital cardiac care. That's because many people never make the transition from a pediatric congenital cardiologist to a cardiologist who sees adults.

Take these steps to connect teens with heart defects to congenital cardiologists who treat adults:

- Tell teens they'll need lifelong congenital cardiac care to make sure they stay healthy as they get older. Explain that many pediatric cardiologists can only see them until they reach a certain age.
- Refer older teens and young adults to a congenital cardiologist who sees adults. If you need help finding congenital cardiologists for adults in your area, check out the [ACHD Clinic Directory](#).

To learn more, check out:

- [The AAP congenital heart defects toolkit](#)
- [Congenital heart defects resources from CDC](#)
- [The Congenital Heart Public Health Consortium](#)

With your help, we can make sure children with congenital heart defects get the care they need to lead long, healthy lives!

How to Talk to Parents About Congenital Cardiac Care for Children with Heart Defects

Children with heart defects need to see a pediatric cardiologist regularly. As a primary care physician, you can help make sure they do.

Specifically, it's important to tell parents and caregivers why children with heart defects need to see a pediatric cardiologist — and to refer children who aren't seeing one. When you do, you'll help children with heart defects stay healthy and safe.

Use these talking points to help start the conversation.

1. Explain why children with heart defects need to see a pediatric cardiologist

“Heart defects last for a lifetime, even after heart surgery. Heart defects can also get worse over time — but they may not cause symptoms right away. That’s why children with heart defects need to see a pediatric cardiologist regularly.”

If a heart defect isn't causing any symptoms, parents and caregivers may not realize the child needs to see a pediatric cardiologist. Explain that symptoms can develop over time and that pediatric cardiologists can catch problems early to help make sure children *stay* healthy.

2. Describe what a pediatric cardiologist does

“A pediatric cardiologist is a doctor who’s trained to treat heart problems in children. They know how to tell if a heart problem is getting worse and how to help children with heart defects stay healthy.”

Some parents and caregivers may not understand why children with heart defects need to see another physician, so it's important to explain what a pediatric cardiologist does. Emphasize that pediatric cardiologists know more about heart defects in children than anyone else — including which medicines or procedures children may need. Pediatric cardiologists can also help parents and caregivers understand things like which sports are safe for children and how to choose healthy foods.

3. Tell parents and caregivers you can make a referral

“I can refer your child to a pediatric cardiologist to make sure they’re getting the care they need.”

Navigating the health care system can be overwhelming and stressful for patients and their families — so reassure parents and caregivers that they're not alone. Tell them you can help them find a pediatric cardiologist.

Talk to teens about transitioning to adult care!

People with heart defects need lifelong congenital cardiac care, but many people never transition from a pediatric cardiologist to an adult congenital cardiologist. That's why it's especially important to talk with teens about transitioning to adult congenital cardiac care — and to make referrals for older teens and young adults who need them. You could say:

“Your pediatric cardiologist can only see you up to a certain age. When you’re old enough, it’s important to start seeing an adult congenital cardiologist. They can help make sure you stay healthy as you get older.”

To learn more, check out:

- aap.org/CHDcare
- cdc.gov/heartdefects
- chphc.org

Social Media Graphic 1

Graphic Text

Many children with congenital heart defects aren't getting the cardiac care they need. Connect them to a pediatric cardiologist to help them stay healthy as they grow up!

Social Media Posts

Twitter

- Congenital heart defects last for a lifetime — so when you see children with heart defects, talk to their parents or caregivers about the importance of lifelong care. Learn more about heart defects: chphc.org [@AmerAcadPeds](https://twitter.com/AmerAcadPeds) #CHD #CHDCare4Life
- Some children with a congenital heart defect aren't seeing a pediatric cardiologist. It's up to you to refer them! [@AmerAcadPeds](https://twitter.com/AmerAcadPeds) has tips for starting the conversation: <https://bit.ly/3b3LZQa> #CHD #CHDCare4Life

Facebook

- Children with congenital heart defects need to see a pediatric cardiologist even when they're feeling healthy — but parents and caregivers may not know this. [@American Academy of Pediatrics](https://www.facebook.com/AmericanAcademyofPediatrics) is asking you to talk with them about the importance of congenital cardiac care. Learn more about heart defects: chphc.org #CHD #CHDCare4Life
- Do you have pediatric patients with congenital heart defects? Are they seeing a pediatric cardiologist? If you're not sure, ask! This conversation starter from [@American Academy of Pediatrics](https://www.facebook.com/AmericanAcademyofPediatrics) can help: <https://bit.ly/3b3LZQa> #CHD #CHDCare4Life

LinkedIn

- Congenital heart defects are the most common type of birth defect, and they last for a lifetime. When you see children with heart defects, talk to their parents or caregivers about the importance of lifelong care. Learn more about heart defects from [@American Academy of Pediatrics](https://www.linkedin.com/company/AmericanAcademyofPediatrics): chphc.org #CHD #CHDCare4Life
- Some parents and caregivers of children with heart defects don't realize their children need congenital cardiac care even when they're feeling healthy. It's up to you to tell families why it's so important for children with heart defects to see a pediatric cardiologist. [@American Academy of Pediatrics](https://www.linkedin.com/company/AmericanAcademyofPediatrics) has tips for starting the conversation: <https://bit.ly/3b3LZQa> #CHD #CHDCare4Life

Social Media Graphic 2

Graphic Text

Children born with heart defects need congenital cardiac care for life. As a primary care physician, you can help.

Social Media Posts

Twitter

- Children with heart defects need congenital cardiac care now and as they grow up. Make sure you talk to parents and caregivers about the importance of lifelong care. Learn more about heart defects from [@AmerAcadPeds](https://twitter.com/AmerAcadPeds): chphc.org #CHD #CHDCare4Life
- #DYK? Many children with heart defects aren't seeing a pediatric cardiologist. Talk to them — and their parents and caregivers — about congenital cardiac care. [@AmerAcadPeds](https://twitter.com/AmerAcadPeds) has tips on starting the conversation: <https://bit.ly/3b3LZQa> #CHD #CHDCare4Life

Facebook

- Calling pediatricians and family physicians! [@American Academy of Pediatrics](https://www.aap.org/) is asking you to talk with parents and caregivers about the importance of congenital cardiac care for children with heart defects. Learn more about heart defects: chphc.org #CHD #CHDCare4Life
- Did you know that many children with congenital heart defects aren't seeing a pediatric cardiologist? Talk to pediatric patients with heart defects and their families about the importance of congenital cardiac care! [@American Academy of Pediatrics](https://www.aap.org/) has tips on starting the conversation: <https://bit.ly/3b3LZQa> #CHD #CHDCare4Life

LinkedIn

- Help make sure children with congenital heart defects stay healthy as they grow up! Ask if they're seeing a pediatric cardiologist — and stress the importance of getting regular congenital cardiac care. Learn more about heart defects in children from [@American Academy of Pediatrics](https://www.aap.org/): chphc.org #CHD #CHDCare4Life
- As a primary care physician, it's up to you to explain why congenital cardiac care is so important for children with heart defects. Talk to pediatric patients with heart defects and their families about seeing a pediatric cardiologist. [@American Academy of Pediatrics](https://www.aap.org/) has tips to help you start the conversation: <https://bit.ly/3b3LZQa> #CHD #CHDCare4Life

Congenital Heart Defects: Make Sure Children Get the Care They Need

Did you know?

- About **40,000 babies** are born with a heart defect every year in the United States.¹ Heart defects are the most common type of birth defect.
- Researchers estimate that about **1 million children** in the United States are living with a heart defect.²
- Children with heart defects need to **see a pediatric cardiologist regularly** — even when they're feeling fine. But many of them aren't getting cardiac care at all.

3 Steps to Connect Children with Heart Defects to Cardiac Care

As a primary care physician, you have an important role to play in connecting children with heart defects to congenital cardiac care. Take these steps to help children with heart defects get the care they need:

1. Ask parents and caregivers if their child is seeing a pediatric cardiologist — and emphasize how important lifelong congenital cardiac care is.
2. Refer children who aren't getting the care they need to a pediatric cardiologist.
3. At every touchpoint with children who have heart defects, continue to stress the importance of seeing a pediatric cardiologist.

To learn more, check out aap.org/CHDcare, cdc.gov/heartdefects, or chphc.org.

¹ sciencedirect.com/science/article/pii/S0735109701012724?via%3Dihub

² ahajournals.org/doi/full/10.1161/CIRCULATIONAHA.115.019307