

What you should know about your child's **congenital heart disease**



Congenital heart disease (CHD) is a lifelong condition. Although heart defects can be managed and even repaired, most people with CHD will need to see a cardiologist for their whole lives. It is important to know about your child's CHD and what questions to ask your CHD team in order to best advocate for them and to teach them self-advocacy.

Here are the most important details you should be familiar with:

Know the name of their heart defect

Be able to name and describe their diagnosis so that they can get the right treatment

Know their medication(s)

Are they taking medications (heart medications and others)? What type, how much, and how often?

Know how to contact their CHD team

Carry their contact information with you



Know their CHD medical history

Know the name of their surgery or procedure(s), and carry a summary with you. Some examples: Fontan, heart catheterization, pacemaker or artificial valve.



Carry their medical information:

For yourself

On a card in your wallet or purse, or phone/device in an app or note. Give your child a copy to carry in their wallet or backpack as well

For others

Wear a medical ID or jewelry that identifies their health condition(s)



Your child's family doctor, walk-in clinic and other health care providers will need this information to support their cardiology team in keeping them healthy.

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