

CONGENITAL HEART DEFECT

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Welcoming your new baby into your family.

Your baby was born with a special condition. This condition is known as congenital heart defect, which is a birth defect of the heart. We know this is not easy for you and you may not know how to feel. That's okay. Parents of children with congenital heart defects feel shock, denial, grief, and even anger. It is all right to feel like this and no one will blame you. It will get better. You are not alone. Soon you will find lots of people and programs to help you. Get to know your baby. Enjoy your baby.

What is a congenital heart defect?

- A congenital (say: kon-je-ni-tl) heart defect is a problem in the development of the heart that is present when a baby is born. It happens while a baby is forming in the mother's womb.
- There are many kinds of congenital heart defects, some minor and others very severe.
- Heart defects may affect any part of the heart and may also affect how it works.

How many babies are born with a congenital heart defect?

- Heart defects affect one in every 100 babies. This means that congenital heart defects are very common.
- Any baby can be born with a congenital heart defect.

Why are babies born with a congenital heart defect?

- Most of the time we do not know.
- Sometimes they may be caused by illness (diabetes, lupus, German measles and other infections) in the mother during pregnancy. Other times they may be caused by medicines or other things the mother took during pregnancy. Drinking alcohol during pregnancy can also cause heart defects.
- Some heart defects are more common in some families.

How will this affect my baby?

- Some babies with heart defects don't have any signs or symptoms.
- Other babies have problems breathing and/or feeding.
- Some babies have cyanosis (say: sy-ah-noe-sis). This means the skin and lips are blue. The baby is called a "blue baby".
- Other babies' hearts may beat very fast or very slowly.
- Some children may get tired very easily, mostly when they exercise.
- Your baby's doctor will talk to you about any problems your baby may have.

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How are heart defects treated?

- The care (treatment) for heart defects depends on the kind of defect your baby has.
- Some children need medicine to help them live a healthy life. Other children may need surgery to help fix their heart.
- Some children with heart defects need special medicine (antibiotics) when they go to the dentist or before they have surgery.
- Your baby's doctor will refer him or her to a pediatric cardiologist (say: kar-dee-ah-luh-jist)--a doctor who knows about heart problems in children. He or she will talk to you about the right care for your baby.

If we have more children will they have a heart defect?

Once you have one baby with a heart defect your chances of having a baby with a heart problem may be increased. If you plan to have another baby, it would be important to talk to your doctor before you become pregnant. He can refer you to see a geneticist (a person who knows about diseases that run in families).



What's in store for my baby's future?

- Some parents worry that their child might die all of a sudden. This is not common for children.
- Most children with heart problems live an active and healthy life.
- Your child's doctor can tell you what your child can or cannot do.

Where can I go for help?

- American Heart Association: 1-800-242-8721 or www.americanheart.org
- Children's Medical Services (CMS): call your local county health department for a CMS clinic in your area or visit: www.cms-kids.com
- For information, resources, and support contact:
Congenital Heart Information Network: www.tchin.org or 215-493-3068
- For support, resources, networking contact:
Little Hearts, Inc.: www.littlehearts.org or (toll free) 1-866-435-HOPE
- March of Dimes: visit marchofdimes.com

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