Heart Defects, Structural

What are structural heart defects?

- Cyanotic congenital heart defects are a type of structural heart defects.
  - Cyanotic heart defects are serious and cause the baby to have very low oxygen levels shortly after birth.
  - Examples of cyanotic heart defects are transposition of the great vessels, tetralogy of Fallot, truncus arteriosus, tricuspid atresia, total anomalous venous return, and hypoplastic left heart syndrome.
  - These babies usually require heart surgery early in life and often undergo heart surgery multiple times to correct the defects.
- There are other types of congenital heart defects. Some make the heart work too hard because it has to pump blood against a blockage, and some increase the amount of blood that the heart has to pump.
- Congenital heart defects occur with a wide range of severity. Some congenital heart defects require surgery or other procedures, some require medications, and some require no special treatment. The timing of procedures also varies.
- Some babies with congenital heart defects might need surgery but may be able to wait awhile, to grow first. Examples of these defects are ventricular septal defects, atrial septal defects, and patent ductus arteriosus. Some valve problems such as pulmonary stenosis and aortic stenosis can also fall into this category.
- Most babies are now screened in the newborn period for critical congenital heart defects.

How common are they?

Thirty-five thousand babies are born every year in the United States with these problems, according to the American Heart Association.

What are some common characteristics of children who have heart defects or of heart defects as children present with them?

If the heart defect is minor or was repaired, the baby or child may appear normal except for a surgical scar on his or her chest. If the defect was not fully repaired, the baby or child may have

- Cyanosis, which is a blue color most easily seen around the mouth and lips.

IÑARRITU–CASTRO JM (UNBOUNDED MEDICINE)

A, Cyanosis. **B,** Clubbing in a child with tetralogy of Fallot.

- Feeding difficulties, or the baby or child may tire more easily with feedings or exercise. Some babies have difficulty gaining weight.
- Arrhythmias or irregular heartbeat. (See Heart Conditions, Nonstructural, Quick Reference Sheet [page 139] for more information.)

Who might be on the treatment team?

- Primary care provider in the medical home.
- Pediatric cardiac surgery is often performed in special centers that are equipped to handle babies and young children.
- Pediatric cardiologists are involved in the care along with the primary care provider in the medical home.
- Children who had cardiac surgery may need developmental therapy.
- Speech-language therapists and nutritionists may help with feeding issues.

Heart Defects, Structural (*continued*)

What adaptations may be needed?

The child should have a Care Plan that outlines what the individual needs are.

Medications

- Many children will not require medication. Those that do will usually have oral medications. These medications might be given at home.
- All staff who will be administering medication should have medication administration training (see Chapter 6).
- Digoxin (eg, Lanoxin) can be given to strengthen the heart. It must be given very carefully because it can cause irregular heartbeats if not dosed correctly.
- A diuretic such as furosemide (Lasix) may be given to reduce the fluid in the body. This diuretic will also likely be given at home. Diuretics can alter the body's balance of salts, so their use must be monitored closely. Some children may need extra potassium.
- No over-the-counter medications should be given unless approved by the child's doctor.

Dietary Considerations

- Some babies with heart defects may need extra calories to help them to grow.
- They may need small, frequent feedings if they tire easily, and they may feed more slowly than other babies or children in the group.

Physical Environment and Other Considerations

- Usually, few medical restrictions are placed on physical activity, but the child may tire more easily and should be allowed to rest.
- Influenza vaccine. All children and staff should get the influenza vaccine, but it is especially important for children with heart disease.

What should be considered an emergency?

- Heart defects can vary dramatically, and the Care Plan should outline the particular symptoms to watch for in that child and how to respond.
- Call emergency medical services (EMS) (911) immediately if the child is having serious symptoms.
- The Care Plan should outline when to call EMS (911) and when calling only the parents/guardians is sufficient.
- Symptoms such as paleness, sweating, dizziness, fainting, chest pain, and shortness of breath may be serious.
- Cyanosis, especially a blue color around the mouth, can be serious.
- A very rapid pulse or a very slow pulse may indicate an emergency. Learn to monitor a pulse.

What types of training or policies are advised?

- Training on how to check a pulse should be conducted.
- Pediatric first-aid training that includes CPR (management of a blocked airway and rescue breathing) with instructional demonstration and return demonstration by participants on a mannequin. *Pediatric First Aid for Caregivers and Teachers* is a course designed to teach these skills (www.pedfactsonline.com/about.aspx).
- It is important if you have a child with a serious arrhythmia to have a responsible caregiver who knows pediatric CPR, including cardiac resuscitation, on-site at all times.
- If the baby needs a special formula or is a slow feeder, training on feeding techniques by a nutritionist or a feeding therapist may be helpful.
- A CPR-trained person should be available during transport to and from the program if applicable.
- An AED (automated external defibrillator) should be available. Training on using an AED should be provided.

What are some related Quick Reference Sheets?

- Heart Conditions: An Overview (page 137)
- Heart Conditions, Nonstructural (page 139)

What are some resources?

Congenital Heart Information Network: http://tchin.org

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

The American Academy of Pediatrics is an organization of 67,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults.

American Academy of Pediatrics
Web site — www.aap.org