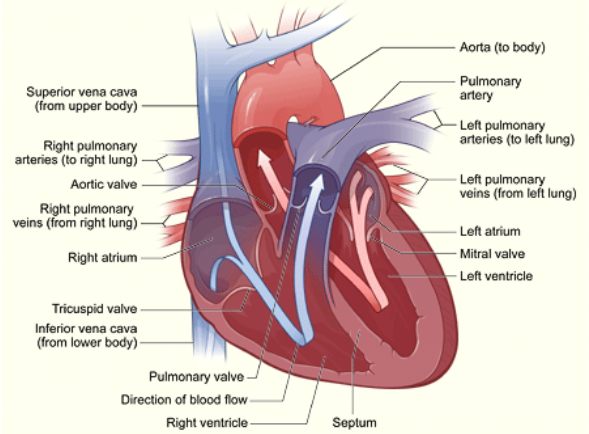
Heart Defects

Version: April 2009

Example of a Normal Heart



Condition & Description

As a whole, heart defects are the most common type of birth defect. There are several types of heart defects, many of which require complex treatment and often require surgery. Defects range from holes between chambers of the heart to very severe malformations, such as complete absence of one or more chambers or valves[1]. Nationally, heart defects occur in eight out of 1000 births. Approximately 35,000 babies are born with a heart defect each year[1]. Heart defects are the leading cause of birth defect-related deaths in this country[2].

Associated Conditions

Sometimes heart defects can be associated with other birth defects, such as abdominal wall malformations, inherited disorders or chromosomal abnormalities. For example, at least 30 percent of Down syndrome babies also have structural heart defects[3].

Causes & Risk Factors

For the most part, scientists do not know what makes a baby's heart develop abnormally. It appears that genetic and environmental factors come into play. Since the 1990s, scientists have identified about 10 gene mutations (changes) that can cause isolated heart defects[4].

Prevention

Most congenital heart defects cannot be prevented. There are a number of steps a woman can take to reduce her risk of having a baby with a birth defect. Please see CBDMP's fact sheet on *Reducing the Risk of Birth Defects*.

Preconception & Prenatal Care

Women who take multivitamins containing folic acid near the time of conception have a 43% less chance of having babies with conotruncal (outflow tract) defects[5].

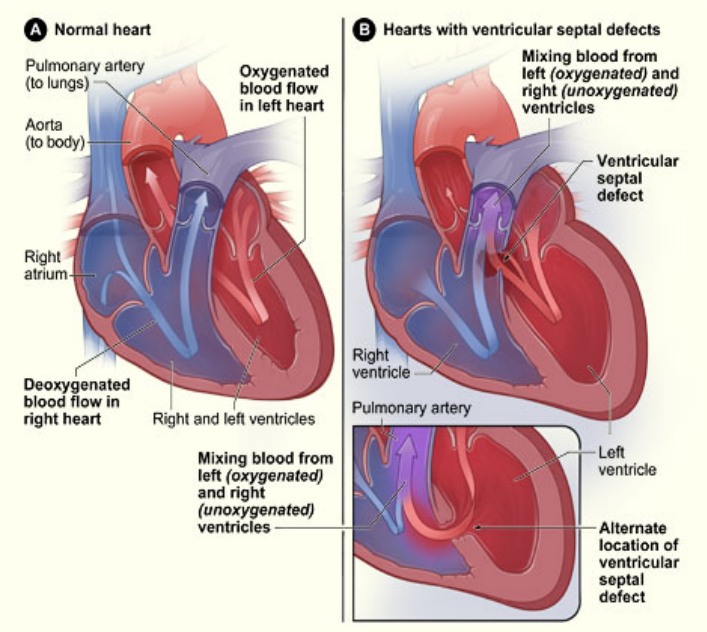
Long Term Outcomes

The most common course of action for most babies who have one or multiple heart defects is surgery. Early corrective surgery often prevents development of more complications.

For some defects, limitations include decreased exercise capabilities. Some children with heart defects remain at increased risk of infection. For example, there may be a need to take antibiotics before dentist visits.

In addition to the financial impact of a baby born with a heart defect, the emotional toll on families may be even greater. When a child survives serious heart complications, he/she may have considerable developmental delays or learning difficulties, and may need to rely on community and school-based resources.

Example of Ventricular Septal Defects



Heart Defects

Version: April 2009

Medical Care

Surgery is an integral part of the treatment plan for many babies born with a serious heart defect. Some of the specific heart defects and their recommended treatment is given below[6]:

- ***Coarctation of the aorta:*** The large artery that sends blood from the heart to the rest of the body may be too narrow for the blood to flow evenly. Surgery can remove the narrow part and sew the wider ends together. A blood vessel from another part of the body may be used to bridge the gap.

- ***Heart valve abnormalities:*** If heart valves do not open and close normally, surgery can repair or replace the valves. Balloons or catheters may fix faulty valves as well.

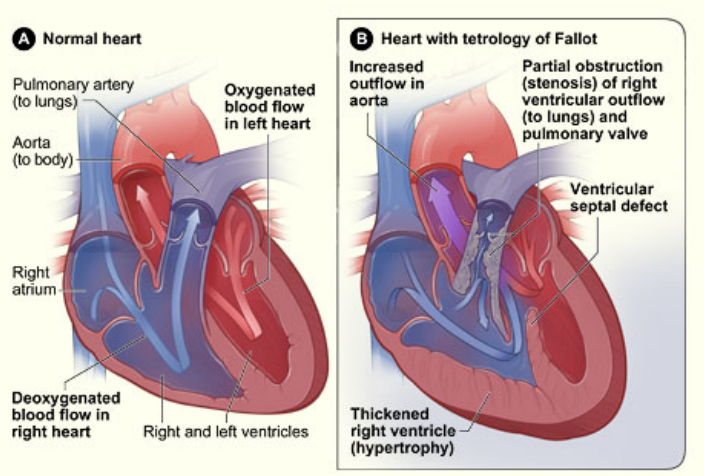
- ***Hypoplastic left heart syndrome:*** This occurs when the left ventricle (the heart's main pumping chamber) is too small to support life. This defect is often fatal in the first few weeks of life. Over the last 25 years, survival rates have improved with the development of new surgical procedures.

- ***Septal defect***: This is a hole in the wall that divides the right and left sides of the heart. Some atrial septal defects can be repaired by placing a thin, flexible tube (catheter) into the heart via an artery in the leg. A surgeon can close a septal defect by sewing or patching a hole.

- ***Tetralogy of Fallot:*** A combination of four heart defects which prohibits blood from traveling to the lungs. As a result, not enough oxygen is pumped to the body. This type of defect should be surgically repaired within the first few months of life.

- ***Transposition of the Great Arteries:*** This occurs when the two major arteries leaving the heart are physically reversed, pumping blood into the wrong chambers. Recent surgical advances (if performed during the newborn period) have proven successful in correcting this serious defect.

Example of Tetralogy of Fallot



More Images & Examples of Defects

The Mayo Clinic on-line has a slideshow of congenital heart defects with full-color illustrations as well as a section on congenital heart defects in children.
http://www.mayoclinic.com/health/congenital-heart-defects/CC00026 &
http://mayoclinic.com/health/congenital-heart-defects/DS01117

Images for this fact sheet came from the National Heart Lung and Blood Institute and can be viewed at: http://www.nhlbi.nih.gov/health/dci/Diseases/chd/chd_types.html

References

1. American Heart Association (2009). Congenital Heart Defects in Children Fact Sheet, Retrieved November 2008, from http://www.americanheart.org/print_presenter.jhtml?identifier=12012
2. Jenkins, K. A., Correa, A., Feinstein, J. A., Botto, L., Britt, A. E., Daniels, S. R. et al. (2007). Non-inherited Risk Factors and Congenital Cardiovascular Defects: Current Knowledge: A Scientific Statement from the American Heart Association Council on Cardiovascular Disease in the Young. *Circulation*, 115: 2995-3014.
3. American Academy of Pediatrics Committee on Genetics. (2001). Health Supervision for Children with Down syndrome. *Pediatrics*, 107(2): 442-449.
4. Pierpont, M.E., Basson, C. T., Benson Jr., D. W., Gelb, B. D. Gilgia, T. M., Goldmuntz, E. et al. (2007). Genetic Basis for Congenital Heart Defects: A Scientific Statement from the American Heart Association Congenital Cardiac Defects Committee, Council on Cardiovascular Disease in the Young. *Circulation*, 115, 3015-3038.
5. Botto, L. D., Khoury, M. J., Mulinare, J., & Erickson, J. D. (1996). Periconceptional Multivitamin Use and the Occurrence of Conotruncal Heart Defects: Results From a Population-based, Case-Control Study. *Pediatrics*, 98(5): 911-917.
6. March of Dimes. (2008). Congenital Heart Defects *Fact Sheet,* Retrieved on November *2008*, from http://www.marchofdimes.com/professionals/14332_1212.asp.

Heart Defects

Version: April 2009

Resources For Families

California Children's Services (CCS)

California Children's Services (CCS) is a state program for children with certain diseases or health problems. Through this program, children up to 21 years old can get the health care and services they need. CCS will connect you with doctors and trained health care people who know how to care for your child with special health care needs.
(Service eligibility is income-based, but you may be eligible for services if the health care costs exceed 20% of your income.)

Find your local CCS Office –

- In the phone book under *California Children's Services* or *County Health Department*
- Or online at: www.dhs.ca.gov/ccs

Family Resource Centers Networks of California

Their mission is to support families of children with disabilities, special healthcare needs, and those at risk by ensuring the continuance, expansion, promotion and quality of family-centered, parent-directed, family resource centers.

Find your local Family Resource Center –

- In the phone book business pages under *Social and Human Services for Families and Individuals* or *Family Resource Centers*
- Or online at: http://www.frcnca.org/

California Healthy Families Program

Healthy Families is low cost insurance for children and teens. It provides health, dental and vision coverage to children who do not have insurance and do not qualify for free Medi-Cal.

- Phone: 1-800-880-5305 if you do not already have a child enrolled in Healthy Families.
- E-mail: HealthyFamilies@MAXIMUS.com
  Be sure to include your name and phone number.
- In person: Many community organizations have people who are trained to help you apply. Call to find a *Certified Application Assistants, or CAAs* in your area: 1-888-747-1222. The call is free.
- Website: www.healthyfamilies.ca.gov

Birth Defects Research for Children, Inc.

Birth Defect Research for Children is a resource for free birth defect information, parent networking and birth defect research through the National Birth Defect Registry.

- Birth Defect Research for Children, Inc.
  800 Celebration Avenue, Suite 225
  Celebration, FL 34747
- Phone: 407-566-8304
- Fax: 407-566-8341
- Website: http://www.birthdefects.org/

Other Information & Support Groups

Congenital Heart Information Network
An International organization and resources to families of children with congenital heart defects and acquired heart diseases, and the professionals who work with them.
Address: 600 North 3rd Street - First Floor
Philadelphia, PA 19123-2902
Phone: 215-627-4034, Fax: 215-627-4036
www.tchin.org

California Heart Connection
An organization which provides a network of support, information and resources for children affected by congenital heart defects.
Address: P.O. Box 50063
Irvine, CA 92619
Phone: 949-653-6421
www.caheartconnection.org

Little Hearts, Inc.
A national non-profit, membership organization providing support, resources, networking and hope to families affected by congenital heart defects.
Address: P.O. Box 171
110 Court Street, Suite 3A
Cromwell, CT 06416
Toll Free Phone: 866-435-HOPE
www.littlehearts.org

Congenital Heart Defects
Provides information and resources for the Congenital Heart Defects community on-line.
Address: 3910 Sierra Blanca Blvd.
Temple, TX 76502
Toll Free Phone: 888-222-4649
www.congenitalheartdefects.com

California Parents Helping Parents
An organization which provides lifetime guidance, support and services to families of children with any special need and the professionals who serve them.
Address: 1400 Parkmoor Avenue, Suite 100
San Jose, CA 95126
Phone: 408-727-5775, Fax: 408-286-1116
www.php.com