

Anencephaly

Version: April 2009



Image credit: Centers for Disease Control and Prevention (CDC)

Condition & Description

Anencephaly is one of a group of birth defects known as neural tube defects (NTD). It occurs in the first month of fetal life when the brain and skull do not form completely. Without a brain, a baby's body cannot grow and function⁵. All babies with anencephaly will be stillborn (die before birth), miscarried, or die within a few days of birth. In California, anencephaly is found in about 1 in 3,380 births. Females are affected five times more frequently than males¹.

Associated Conditions

Usually, anencephaly is the only birth defect the child has, but anencephaly can occur with other birth defects as part of a syndrome (a collection of findings)⁵. Polyhydramnios (excess of amniotic fluid in the sac) is a common condition among babies diagnosed prenatally with anencephaly¹.

Causes & Risk Factors

The causes for anencephaly are unknown. However, it has been shown that genetic and environmental risk factors play an important role. Mothers with the following characteristics have been found to be at higher risk for having a baby with anencephaly:

- Maternal lack of folic acid and vitamins⁴
- Previous NTD-affected pregnancy (1 in 25)⁵
- Family history of anencephaly⁵
- Maternal obesity³
- Diabetes during pregnancy⁵
- Maternal stress⁶
- Woman with history of epileptic seizures⁵
- Hispanic background⁴

Prevention

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

Folic acid is a B vitamin that plays an important role in the development of the fetal brain and spinal cord during very early pregnancy, often before many women know they are pregnant. For this reason and because many pregnancies are unplanned, it is recommended that all women of childbearing age take 400 (0.4mg) micrograms of folic acid per day through dietary supplements of foods that are fortified with folate². It has been shown that the recommended dose reduces the risk of anencephaly by 70%⁵. Screening tests such as an ultrasound examination, a blood test called the maternal serum alphafetoprotein (MSAFP) or amniocentesis helps identify fetuses at increased risk of NTDs¹. The prenatal detection of anencephaly helps a family consider options for their unborn child. Women who think that they may be in a high risk category should have genetic counseling. For more information, please visit the [California Prenatal Screening Program](#) website.

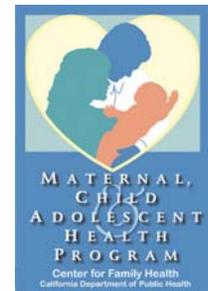
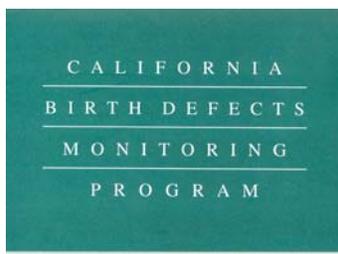
Medical Care

There is no cure or treatment for children with anencephaly. Sadly the condition is not correctable or reversible. Parts of the brain that are absent control all the higher functions that we need to live. These include sight, hearing, and intellect. Overall treatment is aimed at comfort for the baby during its short life and support for the family.

Long Term Outcomes

Anencephaly represents the most severe form of NTD, and is uniformly fatal in the neonatal period. Approximately 25 percent of babies may be born alive but will survive only hours to days and rarely weeks¹.

It is important to understand that whenever an anencephalic baby is born, the outlook is the same; he or she will not survive.



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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

- Regional Centers in California: nonprofit private corporations that contract with the Department of Developmental Services to coordinate services and provide support for individuals with developmental disabilities. www.dds.ca.gov/RC/Home.cfm
- March of Dimes Birth Defects Foundation: 1-888-422-2437. www.marchofdimes.com
- National Center for Birth Defects and Developmental Disabilities: 1-770-488-7160 www.cdc.gov/ncbddd
- Anencephaly Global Network: <http://www.anencephalie-info.org/index.php>
- NINDS Anencephaly Information Page: <http://www.ninds.nih.gov/disorders/anencephaly/anencephaly.htm>
- California Prenatal Screening Program: <http://www.cdph.ca.gov/programs/pns/Pages/default.aspx>

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5. Deak, KL et al. (2008). Further evidence for a maternal genetic effect and a sex-influenced effect contributing to risk for human neural tube defects. *Birth Defects Research Part A: Clinical and Molecular Teratology*, 82(10): 662-669.
6. Jaquier, M., Klein, A. & Boltshauser, E. (2006). Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly, *BJOG* 2006, 113: 951-953.