

## Neural Tube Defects (NTD)

Version: April 2009



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

### Condition & Description

Neural tube defects (NTDs) are one of the most common birth defects, and occur within 30 days of conception. As the embryo forms, 2 tissues do not fuse together to form the neural tube (which is the beginning of the brain and spinal cord). In turn, the brain and spine do not develop properly. In California, NTDs are found in about 1 in 1,480 pregnancies. The most common types of NTDs are spina bifida, anencephaly and encephalocele.

### Associated Conditions

Each type of NTD is accompanied by various conditions, causing a range of disabilities. About 20% of infants with an NTD have other major birth defects as well<sup>1</sup>. See specific NTD factsheets for more information.

### 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 an NTD:

- Maternal lack of folic acid and vitamins<sup>3</sup>
- Previous baby with an NTD (1 in 20 chance)<sup>4</sup>
- Family history of NTDs<sup>4</sup>
- Maternal obesity<sup>5</sup>
- Maternal stress<sup>7</sup>
- Woman who has epileptic seizures<sup>2</sup>
- Maternal fever in the first trimester<sup>6</sup>
- Hispanic background<sup>7</sup>

### 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

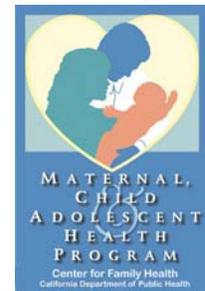
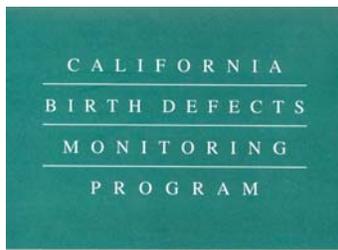
Folic acid is a B vitamin that plays an important role in the development of the fetal brain and spinal cord during very early pregnancy, often before many women know they are pregnant. For this reason and because many pregnancies are unplanned, it is recommended that all women of childbearing age take 400 (0.4mg) micrograms of folic acid per day through dietary supplements or foods that are fortified with folate<sup>3</sup>. It has been shown that consuming the recommended dose can reduce the risk of an NTD by 36% (low risk women) and 82% (high risk women)<sup>1</sup>. To help identify fetuses at increased risk of NTDs, screening tests such as an ultrasound examination, a blood test called the maternal serum alphafetoprotein (MSAFP) or amniocentesis have been established<sup>2</sup>. More than 90% of all children with NTDs are born to women with no family history of NTDs, therefore the MSAFP screening helps identify affected fetuses<sup>1</sup>. Women who think that they may be in a high risk category should have a referral from their family doctor for genetic counseling. For more information, please visit the [California Prenatal Screening Program](#) website.

### Medical Care

Treatments vary depending on the type of neural tube defect. Some mild versions of spina bifida need minimal treatment, but other forms of NTD require surgery to correct the problems. Even after certain procedures are performed, medical care for these babies remains complex and challenging<sup>2</sup>. The route of delivery (vaginal or cesarean) should be discussed and individualized for each patient based on the mother's and baby's condition. The fetus should be delivered at a facility that has personnel capable of handling all aspects of neonatal complications<sup>1</sup>.

### Long Term Outcomes

With surgical procedures, some NTDs can be treated. However, many infants born with an NTD do not survive beyond the first month<sup>1</sup>. Babies born with spina bifida who survive to adulthood may experience paralysis and bladder incontinence<sup>3</sup>.



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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](http://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](mailto: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](http://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](http://www.dds.ca.gov/RC/Home.cfm)
- March of Dimes: 1-888-422-2437. [www.marchofdimes.com](http://www.marchofdimes.com)
- National Center for Birth Defects and Developmental Disabilities: 1-770-488-7160 [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)
- Spina Bifida Association: <http://www.spinabifidaassociation.org>
- Association for Spina Bifida Hydrocephalus: <http://www.asbah.org>
- Children & Adults with Spina Bifida & Hydrocephalus: <http://www.waisman.wisc.edu/~rowley/sb-kids/index.html>
- Anencephaly Global Network: <http://www.anencephalie-info.org/index.php>
- NINDS Encephalocele Information Page: <http://www.ninds.nih.gov/disorders/encephaloceles/encephaloceles.htm>
- California Prenatal Screening Program: <http://www.cdph.ca.gov/programs/pns/Pages/default.aspx>

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