

Spina Bifida

Version: April 2009

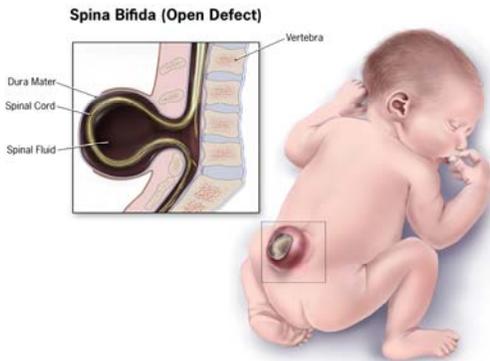


Image credit: Centers for Disease Control and Prevention (CDC)

Condition & Description

Spina bifida 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 neural tube does not close properly, leaving an opening in the spinal cord and backbone. In California, spina bifida is found in about 1 in 2,860 pregnancies. There are three main types of spina bifida. The most serious form is called myelomeningocele, in which there is exposed tissue and nerves around the spinal cord. Meningocele occurs when the nerves and tissue form a cyst through the opening along the spine. The mildest form, called occulta, results from a small gap in one or more of the bones of the spine⁸.

Associated Conditions

Children and young adults with spina bifida may have medical and developmental problems. Symptoms vary depending on the location of the defect. In severe forms of spina bifida hydrocephalus may also occur. Hydrocephalus is a condition in which there is extra fluid in the brain⁶. Oftentimes, the inability to empty the bladder can lead to urinary tract disorders⁸.

Causes & Risk Factors

Mothers with the following characteristics have been found to be at higher risk for having a baby with spina bifida:

- Maternal lack of folic acid and vitamins³
- Previous baby & family history of spina bifida⁷
- Maternal obesity⁴
- Diabetes during pregnancy⁴
- Maternal stress⁵
- Woman who has epileptic seizures⁸
- Maternal fever in the first trimester²
- Hispanic background⁵

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 micrograms of folic acid per day through dietary supplements or foods that are fortified with folate³. It has been shown that the recommended dose reduces risk of spina bifida by 70%⁴. Screening tests such as an ultrasound examination, a blood test called the maternal serum alpha-fetoprotein (MSAFP) or amniocentesis help identify fetuses at increased risk of an NTD¹. 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.

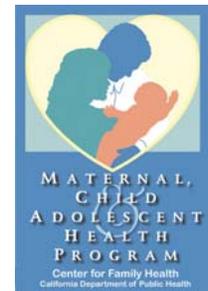
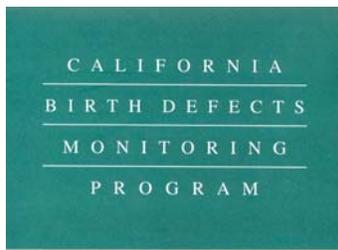
Medical Care

There is no cure for spina bifida. However, surgery that occurs within the first days of life can assist and help improve the quality of life of these children. Generally, children with the mild form need no treatment. The key priority for treating spina bifida is to prevent infection (including meningitis) from developing through the exposed nerves and tissues⁸. Thus, the fetus should be delivered at a facility that has personnel capable of handling all aspects of neonatal care¹.

Complications of spina bifida range from minor physical problems to severe physical and mental disabilities. Other problems include paralysis or muscle weakness of the lower limbs, gastrointestinal disorders, and skin breakdown¹.

Long Term Outcomes

With surgical procedures, about 90% of babies born with spina bifida live to be adults and lead full lives¹. Life-long coordinated interdisciplinary care from a team of medical specialists is necessary to provide optimum care³.



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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: 1-888-422-2437 www.marchofdimes.com
- National Center for Birth Defects and Developmental Disabilities: 1-770-488-7160 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>
- California Prenatal Screening Program: <http://www.cdph.ca.gov/programs/pns/Pages/default.aspx>

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6. National Institute of Neurological Disorders and Stroke. (2007). Spina Bifida Fact sheet. Retrieved on April 8, 2009 from www.ninds.nih.gov/disorders/spina_bifida.
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