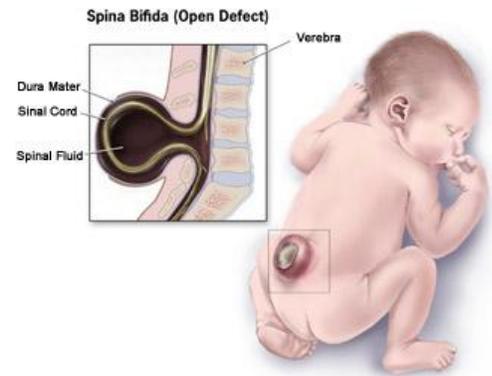


Spina Bifida

What is spina bifida?

Spina bifida (SPI-nuh BIF-id-uh) is one of a group of birth defects known as neural tube defects (NTDs). Spina bifida occurs when the neural tube does not close properly and the spinal column does not form around the spinal cord completely. This tube normally closes around the third or fourth week of pregnancy, before most women even realize they are pregnant.



What types of problems occur with spina bifida?

There are three forms of spina bifida, with complications ranging from very minor to severe. One type is called spina bifida occulta (SPI-nuh BIF-id-uh oh-KULT-uh). This is very common and usually causes no problems. About 20-30% of North Americans have undetected spina bifida occulta because the gap in the vertebrae is very small and the spinal cord is normal. The second type of spina bifida is called meningocele (meh-NIN-go-SEEL). This type is rare, accounting for about 4% of all NTDs. The defect in the spine is very small and fluid-filled tissues protrude through the opening in the bone. The spinal cord and nerves are intact. The third type is called myelomeningocele (my-uh-lo-meh-NIN-go-seel). This is the most common type of spina bifida and is typically the most severe. Some of the spinal cord tissue is visible through an opening in the baby's back.



Spina bifida occulta Meningocele Myelomeningocele

Image from Problems During Pregnancy.com

Complication of spina bifida can include partial or full paralysis of the legs, inability to control bowel or bladder function, obesity, skin breakdown, seizures, eye disorders, and learning disabilities. However, 90% of babies with spina bifida live well into adulthood and attend school with children their own age. Eighty percent of babies born with spina bifida are of normal intelligence and 75% take part in sports or recreational activities.

How common is spina bifida?

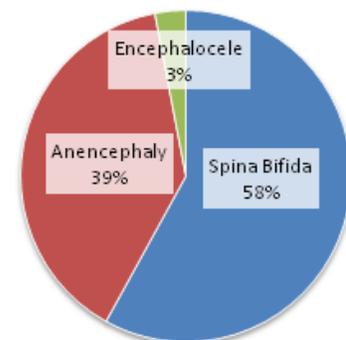
One out of every 1,300 babies born in the United States each year have spina bifida. In Kentucky, more than two out of every 1,300 babies are born with spina bifida. Hispanic and European babies are at an increased risk for spina bifida.

Some families have more than one person with spina bifida. Spina bifida does not occur in a set pattern in these families. Parents of a child with spina bifida have a higher chance of having another child with spina bifida (about 1 in 400). For families with two children with spina bifida, the chance may be 1 in 100. A genetic counselor or geneticist can help you to determine the risks for your family and situation.

What causes spina bifida?

About 95% of children born with spina bifida are born into families with no family history of spina bifida or neural tube defect. It is believed that most spina bifida occurs due to a combination of environmental (like not

Types of Neural Tube Defects in Kentucky



having enough folic acid or vitamins in the diet or being exposed to environmental toxins like pesticides) and genetic factors. Women with certain health problems like diabetes or seizure conditions can also be at a higher risk of having a child with spina bifida.

How is spina bifida treated?

Children with spina bifida will require life-long care from different types of medical specialists, including neurologists, urologists, and orthopedists. Mobility is often the highest priority for the child to promote independence.

What can I do to prevent spina bifida?

Folic acid plays an important role during periods of rapid cell growth such as pregnancy. The most important time for women to have folic acid in their system is prior to pregnancy and during the first few weeks of pregnancy when the neural tube is forming. Most women do not even realize they are pregnant at this critical time. Therefore, the U.S. Public Health Service recommends that all women of childbearing age consume 400 micrograms of folic acid daily. This regimen will help ensure enough folic acid in a woman's system should she become pregnant. Studies have shown that up to 70 percent of spina bifida cases could be prevented if women of childbearing age had enough folic acid in their bodies.

Folic acid is a B vitamin that occurs naturally in foods such as leafy green vegetables (for example, romaine lettuce, broccoli, spinach, and asparagus). It can also be found in enriched and fortified foods, such as enriched grain products and fortified breakfast. However, to make sure that you're getting enough folic acid, a supplement or multivitamin that contains 400 micrograms of folic acid is recommended along with eating the fortified foods.



It is absolutely vital that women who have already had a child with spina bifida or another neural tube defect take a higher daily dose of folic acid since future pregnancies have a higher than normal risk of having another child with this disorder. A higher dose of folic acid should begin at least one month prior to any pregnancy. This higher dose (4 milligrams) must be prescribed by a doctor. In addition to taking folic acid, women can take steps before and during pregnancy to be healthy, including not smoking, taking illegal drugs, or drinking alcohol during pregnancy.

Where do I go from here?

This is a very stressful time for you. You may not know how to feel. Most parents feel denial, grief, and even anger. It's okay to feel that way and no one will blame you. You haven't done anything wrong, and you're not alone. Soon you will find other people and programs to help you through this. You may want to join a support group. Most importantly, take care of yourself. Be patient with yourself while you're grieving, and remind yourself that things will get better. We've provided some information below to help you.

Where can I go for more information about spina bifida?

Kentucky Resources

<http://www.sbak.org/> Spina Bifida Association of Kentucky

<http://chfs.ky.gov/ccshcn/> KY Commission for Children with Special Health Care Needs

http://mhmr.ky.gov/mhsas/ofl_supportgroups.asp Kentucky Parent Support Groups

<http://chfs.ky.gov/dph/firststeps> KY First Steps Program (Early Intervention System)

National Resources

March of Dimes Foundation www.modimes.org 1-888-MODIMES (1-888-663-4637)

National Center for Birth Defects and Developmental Disabilities Centers for Disease Control

www.cdc.gov/ncbddd 1-770-488-7160