

Fact Sheet

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Spina Bifida

What is spina bifida?

Spina bifida is one of a group of birth defects known as neural tube defects (NTD). The neural tube is the structure in a growing baby that closes to form the spinal cord and brain. This tube normally closes around day 28 of growth. Spina bifida occurs when the neural tube does not close properly.

Is there more than one type of spina bifida?

There are three main types of spina bifida.

- **Myelomeningocele**: The most serious form of spina bifida is called myelomeningocele. A myelomeningocele occurs when the tissues around the spinal cord, the nerves of the spinal cord, and sometimes the spinal cord itself come out through an opening along the spine. A cyst may enclose these items, or an area of the spinal cord and nerves may be exposed. Surgery is needed to close the opening.
- **Meningocele**: The second form of spina bifida is called meningocele. A meningocele occurs when the tissues around the spinal cord push through the opening along the spine forming a cyst or “meningocele.” Often, the cyst can be surgically removed with limited or no long-term problems.
- **Occulta**: The mildest form of spina bifida is called occulta. Spina bifida occulta results from a small gap in one or more of the bones of the spine. The spinal cord and nerves are normally without damage. Spina bifida occulta usually does not result in symptoms. People with spina bifida occulta normally do not experience problems.

What types of problems occur with spina bifida?

The location and size of the opening in the neural tube can affect how serious the problems are for the child. Medical problems due to spina bifida are most common for those children with a myelomeningocele, the most serious form of spina bifida. Common problems, despite surgery, include some degree of paralysis or muscle weakness below the area of the opening, and bladder and bowel control issues. Hydrocephalus (buildup of extra spinal fluid around the brain) also commonly occurs in up to 90 percent of individuals with myelomeningocele. This extra fluid can be removed through a process called shunting. Without shunting, brain damage may occur.

How common is spina bifida?

Spina bifida is one of the most common birth defects and occurs in about 2,000 children in the United States each year. In Virginia, approximately 40 children are born yearly with spina bifida.

What causes spina bifida?

Approximately 95 percent of children with spina bifida are born into families with no family history of spina bifida or a neural tube defect. It is believed that most spina bifida occurs due to a combination of environmental and genetic factors. Women with certain health problems such as diabetes and seizure conditions can also be at higher risk of having a child with spina bifida.

In some families, more than one person may have spina bifida. However, spina bifida does not occur in a

specific pattern in these families. Parents of a child with spina bifida have a higher chance of having another child with spina bifida. This chance is estimated to be about 1 in 40. For families with two children with spina bifida, the chance of having another child with spina bifida may be about 1 in 20.

Usually, spina bifida does not occur with other birth defects. (It is an isolated finding.) Sometimes, however, spina bifida does occur with other birth defects as part of a syndrome or collection of findings. The way in which a syndrome is passed through the family is specific to the given syndrome. A genetic counselor or geneticist can help you to determine the risks for your family and situation.

How is spina bifida treated?

Surgery is normally needed for both the myelomeningocele and meningocele forms of spina bifida. During surgery, the nerves and spinal cord are put back inside the body and covered with muscle and skin. Surgery is normally done the first 24 to 48 hours after birth to stop added nerve damage. Spina bifida occulta usually needs no treatment.

In addition to surgery, children often have physical therapy to help with symptoms of paralysis and prepare for the use of walkers or a wheelchair. Training to control the bladder and bowel may also be needed. In some cases, a child needs to have a tube (catheter) inserted to help in urination.

What can I do to prevent spina bifida?

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 (also known as folate) 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 cereals, or in supplements such as multivitamins.

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.

Women who have already had a child with spina bifida or another neural tube defect need a higher daily dose of folic acid. Women should begin taking this higher dose at least one month before becoming pregnant. This higher dose (4 milligrams) must be prescribed by a doctor.

Where can I go for more information about spina bifida?

Spina Bifida Association of America
www.sbaa.org 1-800-621-3141

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

Easter Seals – National Office
www.easter-seals.org 1-800-221-6827

Infant and Toddler Connection of Virginia (Early Intervention Services)
www.infantva.org 1-800-234-1448

** This publication was supported by grant number U50/CCU321127-02 from the Centers for Disease Control (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.*