

Spina Bifida

What is Spina Bifida?

Spina Bifida is also called a neural tube defect. It occurs when the neural tube, which includes the brain and spine of the embryo, fails to close. This happens during the first month of pregnancy, often before the mother knows she is pregnant. There are many forms of neural tube defects.

1. Spina Bifida Occulta (oh-cull-tuh)

In this form, an opening exists in one or more of the bones (vertebrae) that make up the spine. Most of the time there are no symptoms. These openings can be seen by X-ray only. The spinal cord, nerves and skin covering are normal. In fact, up to 10% of all Americans may have this most mild form of the disease. Most of the time children with this form of neural tube defect do not experience problems.

2. Spina Bifida Aperta (ay-per-tuh)

In these forms, the neural tube fails to close, and parts of the vertebrae are missing. A cyst or lump pokes out from the opening in the spine. There are two types of spina bifida aperta:

A. **Meningocele** (muh-ninge-oh-seal)

The cyst is covered with skin and most of the time there is minimal, if any, paralysis. Most children with meningocele grow normally. Your child with meningocele should be checked for fluid on the brain (hydrocephalus) and bowel and bladder problems so they can be treated promptly.

B. **Meningomyelocele** (muh-ninge-oh-my-uh-low-seal)

This is the most severe form of neural tube defect. The open defect contains nerve roots of the spinal cord and the cord itself. There may or may not be a cyst that can be seen. Most often there is damage to the nerves, which cannot be reversed. Your child will most likely have some degree of limb paralysis, sensory, bladder and bowel problems. Prompt surgery helps prevent further nerve damage from infection or trauma. A child with meningocele also often has:

- Fluid on the brain (hydrocephalus). A child may need a tube (shunt) to help the flow of brain fluid back into the child's body. About 90% of children with meningocele have hydrocephalus.
- Some degree of leg paralysis. This varies by child and the level of their defect on the spinal cord.
- Bowel and bladder problems, which can be managed well.
- Compression of the brain at the base of the skull (this is called Chiari II (key-are-ee) Malformation).
- A malformed brain and learning disabilities. At least 70% of children with spina bifida have normal intelligence, although most children have learning problems. Some have mental retardation.

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Can neural tube defects be prevented?

Studies have found that the B-vitamin folic acid may help to prevent spina bifida in some cases. Women who have a family history of these defects and could become pregnant should take a vitamin with 4000 micrograms of folic acid daily. They should also eat foods rich in folic acid such as green vegetables and whole grains. The key is having enough folic acid in the system before and during the early weeks of pregnancy, before the neural structures close.

How is spina bifida detected?

Blood tests of the mother and an ultrasound of the baby in the uterus may find the defect. Most health care providers now offer pregnant women a blood test called the maternal serum alpha-fetoprotein (MSAFP) screening test. It is part of the “triple screen” test. When a neural tube defect is diagnosed before birth, health care providers can provide you with information and support. They can plan for the best method of delivery, often by cesarean section, to prevent infection and damage to the nerves in the sac.

Resources

- Evergreen Spina Bifida Association
(253) 589-3700
- Spina Bifida Association of America (SBAA), Washington, DC
(800) 621-3141
- Within Reach
(800) 322-2588

Web sites

- Evergreen Spina Bifida Association
www.evergreenspinabifida.org
- Management of Myelomenigocele Study
www.spinabifidamoms.com
- National Dissemination Center for Children with Disabilities (NICHY)
www.nichy.org
- National Center for Birth Defects and Developmental Disabilities – Center for Disease Control and Prevention (CDC)
www.cdc.gov/ncbddd
- Spina Bifida Association of American
www.sbaa.org
- University of Wisconsin Waisman Center Resources for Parents of Children with Spina Bifida.
www.waisman.wisc.edu/~rowley/sb-kids/

Information compiled from March of Dimes and the Division of Genetics and Developmental Medicine of Children’s Hospital and the University of Washington.

TO LEARN MORE

- **Neurodevelopmental / Birth Defects (206) 987-2184**
- **Your Child’s Health-Care Provider**

Children’s will make this information available in alternate formats upon request. Please call the Family Resource Center at (206) 987-2201.

This handout has been reviewed by clinical staff at Children’s Hospital. However, your child’s needs are unique. Before you act or rely upon this information, please talk with your child’s health-care provider.