

Birth Defect Fact Sheet

Birth Defect Research for Children

Spina Bifida

What is Spina Bifida?

Spina bifida is one of a number of defects called neural tube defects. The neural tube is the group of cells that form during fetal development and will eventually form the brain and spinal cord of the embryo. The term spina bifida means cleft (or split) spine and is characterized by incomplete formation of the bones in the spine (vertebrae) that fail to completely cover the baby's spinal cord.



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There are several types of spina bifida:

Occulta: This is the most common type and mildest form of spina bifida. It is a malformation of the spine that results in a small gap in one or more of the vertebrae. The nerves within the spinal column are generally unaffected meaning this type often has no serious symptoms and generally requires no treatment. The term “occulta” refers to the hidden nature of the condition and the fact the condition often goes undiagnosed. External signs could be an unusual tuft of hair, a collection of fat or a dimple on the spine. An X-Ray can be used to confirm the spina bifida occulta.

Meningocele: In this type, part of the spinal cord’s protective sheath (meninges) protrudes through the cleft, often filled with spinal fluid. Depending on severity, individuals with meningocele can have anything from no symptoms to symptoms as severe as complete paralysis with bladder and bowel dysfunction.

Myelomeningocele: This is most severe form of spina bifida. The spinal cord containing the deeper nerves of the spinal column protrudes from the open spine without a protective covering of the skin. Spinal fluid may leak out and infection can be a serious problem. This defect usually occurs at the lower end of the spine resulting in paralysis of the baby’s legs along with poor bladder and bowel control. Between 70% and 90% of these children also have fluid on the brain because the spinal fluid cannot drain properly. A shunt is needed to relieve the pressure on the brain.

How Many Children Are Born With Spina Bifida?

According to the National Institute of Neurological Disorders and Stroke (NINDS), 1500-2000 children are born with the more serious types of spina bifida (meningocele and myelomeningocele) out of 4 million births annually. That equates to between 1 in 2000-2700 births. Spina bifida occulta is much more common, occurring in between 10% and 20% of the population. Because of the “hidden” nature of spina bifida occulta, it is hard to get an accurate estimate since many cases go undiagnosed.

What Causes Spina Bifida

Neural defects (including spina bifida) are in a category of birth defects called polygenic or multifactorial. This means that NTDs are caused by one or more genes interacting with an environmental factor. Environmental triggers for NTDs that are being studied include viruses, vitamin and mineral deficiencies, chemicals, drugs, and maternal illness like diabetes.

How Can You Help A Child With A Spina Bifida?

Prenatal testing: Early intervention is important. If you know ahead of time that your baby may be born with spina bifida, you can arrange for prompt and expert medical treatment. A blood test has been developed which can help determine whether and unborn baby has a serious NTD. The AFP screening test measures the amount of a substance called alpha-fetoprotein in the mother’s blood.

Spina Bifida



The most severe neural tube defects will often leak AFP resulting in an increase in AFP levels in the mother's bloodstream. The AFP test should be performed between 16 and 18 weeks of pregnancy. The serum AFP screening test may detect 64-80% of babies with spina bifida. Combining AFP screening with ultrasound and amniocentesis (a test of the fluid surrounding the baby) increases the reliability of the test.

Medical treatment: When a baby is born with one of the more severe forms of spina bifida, surgery is usually performed within 24 to 48 hours of birth. Doctors try to remove the cyst protruding from the spine and cover the wound with muscle and skin. Even this, however, may not prevent paralysis of the legs and lack of feeling. Fluid must be drained from the brains of babies who have problems draining spinal fluid. A special tube called a shunt is inserted to help this excess fluid pass out of the body.

Prenatal surgery is also an option. It takes place before the 26th week of pregnancy and surgeons repair the baby's spinal cord after entering the mother's uterus surgically. Some think the baby is less likely to suffer nerve damage if the surgery is done before birth. This surgery is still considered experimental and is only offered at selected medical centers.

Twenty to 50 percent of children with myelomeningocele will develop progressive tethering, otherwise known as tethered cord. This condition can cause loss of muscle function to the legs as well as changes to bowel and bladder function. Surgical options can ease the effects of tethered cord.

Physical therapy: It is extremely important for children with spina bifida to begin physical therapy. The therapist teaches parents how to exercise their baby's feet and legs to prepare for walking with leg braces and crutches.

Some children will need instruction to use wheelchairs. The physical therapist can also help parents teach children bladder and bowel control.

Support groups: National organizations provide the latest information on spina bifida and other NTDs through newsletters, brochures, and conferences as well as training in rehabilitation. By joining local support groups, parents of children with NTDs can share experiences and helpful strategies on coping with the challenges of raising their children.

Education: It is important for your child to be placed in the least restrictive school setting as early as possible. Children with spina bifida may require special building modifications to attend school in wheelchairs or wearing braces. Federal funds have been provided throughout the nation to help renovate school buildings with ramps and elevators and other structural changes that make it easier for handicapped children to attend regular classes.

Can Spina Bifida Be Prevented?

New research has suggested that taking vitamins with folic acid prior to and during early months of pregnancy may significantly reduce the occurrence of neural tube defects. As a result of these studies, some experts are now advising women who are

Spina Bifida



trying to become pregnant to take multi-vitamins under their doctor's supervision. No woman should self-administer large doses of vitamins during pregnancy, however, because megadoses of some vitamins can increase the risk of other birth defects.

Fact Sheet by:

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for Children, Inc.
www.birthdefects.org**