



Spina Bifida

Spina bifida is a type of neural tube defect (NTD). The term means cleft spine, or incomplete closure in the spinal column. The most serious form of spina bifida may include muscle weakness or paralysis below the cleft area, loss of sensation below the cleft, and loss of bowel and bladder control.

In general, there are three types of spina bifida (from mild to severe):

1. Spina bifida occulta: an opening in one or more of the vertebrae (bones) of the spinal column without apparent damage to the spinal cord.
2. Meningocele: The meninges, or the protective covering around the spinal cord, pushes out through the opening in the vertebrae in a sac called the meningocele. The spinal cord remains intact; this can be repaired with little or no damage to the nerve pathways.
3. Myelomeningocele: This is the most severe form of spina bifida, in which a portion of the spinal cord itself protrudes through the back. In some cases, sacs are covered with skin; in others, tissue and nerves are exposed.

Approximately 40 percent of all Americans may have spina bifida occulta, but because they experience little or no symptoms, very few of them ever know that they have it.

The other two types of spina bifida, meningocele and myelomeningocele, are known collectively as spina bifida manifesta, and occur in approximately one out of every thousand births.

A common effect of myelomeningocele is an accumulation of fluid in the brain (a condition known as hydrocephalus). A large percentage of children born with myelomeningocele have hydrocephalus, which is controlled by a surgical procedure called shunting. This relieves the fluid buildup in the brain and reduces the risk of brain damage, seizures or blindness. Hydrocephalus may occur without spina bifida, but the two conditions often occur together.

Examples of secondary conditions associated with spina bifida are latex allergy, tendinitis, obesity, skin breakdown, gastrointestinal disorders, learning disabilities, attaining and retaining mobility, depression, and social and sexual issues.

In some cases, children with spina bifida who also have a history of hydrocephalus experience learning problems. They may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school.

Although spina bifida is relatively common, until recently most children born with a myelomeningocele died shortly after birth. Now that surgery to drain spinal fluid and protect children against hydrocephalus can be performed in the first 48 hours of life, children with myelomeningocele are much more likely to live. Quite often, however, they must have a series of operations throughout their childhood.

Spina bifida usually is an isolated birth defect. Although scientists believe that genetic and environmental factors may act together to cause this and other neural tube defects, 95 percent of babies with spina bifida are born to parents with no family history of the disorder. While spina bifida appears to run in certain families, it does not follow any particular pattern of inheritance.

Women with certain chronic health problems, including diabetes and seizure disorders (treated with certain anticonvulsant medications), have an increased risk (approximately 1/100) of having a baby with spina bifida.

Birth defects can happen in any family. Many things can affect a pregnancy, including family genes and things women may come in contact with during pregnancy. Recent studies have shown that folic acid is one factor that may reduce the risk of having an NTD baby. Taking folic acid before and during early pregnancy reduces the risk of spina bifida and other neural tube defects.

Sources: Spina Bifida Association of America, National Institute of Neurological Disorders and Stroke, March of Dimes Birth Defects Foundation

The above excerpt is from the Christopher & Dana Reeve Foundation Paralysis Resource Center website. <https://www.christopherreeve.org/living-with-paralysis/health/causes-of-paralysis/spina-bifida>

Web Sites

Spina Bifida Association (SBA)

<http://spinabifidaassociation.org/>

200 Duke St., Suite 300

Alexandria, VA 22314

Phone: 800-621-3141

E-mail: sbaa@sbaa.org

SBA serves adults and children who live with the challenges of Spina Bifida. The organization has a national resource center with many publications, a network of chapters and support groups throughout the U.S., and a toll-free information and referral service.

Center for Disease Control & Prevention: National Spina Bifida Program

www.cdc.gov/ncbddd/spinabifida

The CDC works on various projects related to spina bifida.

Center for Disease Control & Prevention: Living with Spina Bifida

https://www.cdc.gov/spina-bifida/living-with/?CDC_AAref_Val=https://www.cdc.gov/ncbddd/spinabifida/living.html

Columbia Presbyterian Department of Neurological Surgery

<http://www.columbianeurosurgery.org/conditions/spina-bifida/>

This page discusses spina bifida and provides links to the pediatric neurosurgery team.

March of Dimes

<http://www.marchofdimes.com/>

National Office

1550 Crystal Dr., Suite 1300

Arlington VA 22202

Phone: 888-663-4637

The March of Dimes works to help mothers have full-term pregnancies and to research problems that threaten babies' health. The site offers a lot of information on birth defects, including spina bifida. The organization has local chapters in all 50 states and Puerto Rico that offer a variety of resources.

Medline Plus: Spina Bifida

<http://www.nlm.nih.gov/medlineplus/spinabifida.html>

This page has information on spina bifida, including links for and about children and teenagers with the condition.

National Institute of Neurological Disorders and Stroke (NINDS): Spina Bifida Info Page

<https://www.ninds.nih.gov/Disorders/All-disorders/Spina-Bifida-Information-Page>

This page has information on spina bifida, including treatment, prognosis and current research.

National Institute of Neurological Disorders and Stroke (NINDS): Spina Bifida booklet

<https://www.ninds.nih.gov/sites/default/files/2025-05/spina-bifida.pdf>

Patsy Reeve Foundation

<https://camppatrick.com/>

Phoenix, AZ 85021

Phone: 602-614-2572

Email: katie@camppatrick.com

This foundation offers an overnight camp for children aged 6-18 years with Spina Bifida. The camp has many accessible activities including horseback riding, archery, arts and crafts, sports, fishing, movie night, and more.

Shine (formerly the Association for Spina Bifida and Hydroencephalus)

<http://www.shinecharity.org.uk/>

Shine, Unit 4 - The Forum
Minerva Business Park
Peterborough, PE2 6FT
UK

Phone: 01733 555988

Shine is a community of 75,000 individuals, families, friends, and professionals, sharing achievements, challenges and information on living with hydrocephalus, or spina bifida, and related issues.

Spina Bifida Resource Network (SBRN)

<http://www.thesbrn.org/>

84 Park Avenue, Suite G-106
Flemington, NJ 08822
Phone: 908-782-7475

Email: info@thesbrn.org

SBRN is a source of support and information for people living with spina bifida. The network conducts direct family support service programs and advocacy.

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