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

Web Sites

http://www.sbaa.org
Spina Bifida Association (SBA)
1600 Wilson Blvd. Suite 800
Arlington, VA 22209
Phone: 202-944-3285
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.

<www.cdc.gov/ncbddd/spinabifida>
Center for Disease Control & Prevention: National Spina Bifida Program
The CDC works on various projects related to spina bifida.

<http://www.waisman.wisc.edu/~rowley/sb-kids/index.html>
Children and Adults with Spina Bifida and Hydrocephalus
This site is associated with SB-List, the first Internet discussion list for parents of children with spina bifida. In particular, the focus of this site and SB-List is myelomeningocele, the most severe form of spina bifida. The site has information on many topics including assistive technology, durable medical equipment, and educational issues, as well as links to other resources.

<http://www.columbianeurosurgery.org/conditions/spina-bifida/>
Columbia Presbyterian Department of Neurological Surgery
This page discusses spina bifida and provides links to the pediatric neurosurgery team.

<http://kidshealth.org/kid/health_problems/bone/spina_bifida.html>
KidsHealth: Spina Bifida
This page has information on spina bifida written for children.

<http://www.marchofdimes.com/>
March of Dimes
National Office
1275 Mamaroneck Avenue
White Plains, NY 10605
Phone: 914-997-4488
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
This page has information on spina bifida, including links for and about children and teenagers with the condition.

<http://www.ninds.nih.gov/disorders/spina_bifida/spina_bifida.htm>
National Institute of Neurological Disorders & Stroke: Spina Bifida
This page has information on spina bifida, including treatment, prognosis and current research.
Shine (formerly the Association for Spina Bifida and Hydroencephalus)
42 Park Road
Peterborough
PE1 2UQ
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)
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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The following books and videos are available for free loan from the PRC library. For more information, please visit the online catalog at:
http://www1.youseemore.com/ReevePRC/default.asp

Books for Adults


An autobiography.

  Biography

  Biography of Cornell’s daughter.

  Autobiography in comic book format.


  Teenage fiction. Maya wants a job and boyfriend for the summer.


  A father’s story of life with his son.

  Professional Advisory Council.

  Tanni Grey is the two-time winner of the London Wheelchair Marathon and holder of 4 gold medals from the 1992 Paralympic Games. She was born in Wales and has been unable to walk since the age of eight.

• Kalloo, Naida. **Disability or Equalizer: It Really Depends on Attitude.** Baltimore: PublishAmerica, 2002. Fiction. Main character has spina bifida.


• McLone, David G. and Joy Ito. **An Introduction to Spina Bifida.** Chicago, IL: Children’s Memorial Spina Bifida Team, 1998.


**Books for Children**


• Herrera, Juan Felipe. **Featherless/Desplumado.** San Francisco, CA: Children’s Book Press/Editorial Libros para Niños, 2004. Tomasito is a wheelchair user who plays soccer. His father gives him a bird who is a little different. Tomasito has spina bifida. The book is in English and Spanish.

• Hull, Katie. **Katie Can Do…And You Can Too!** North Charleston, SC: CreateSpace, 2013. This book educates the reader about spina bifida while sharing Katie’s inspiring triumphs in racing, pageants, and more.


Fiction


  A little boy with spina bifida makes friends with a lizard who has a disabled limb.


Videos

- **The Challenge.** Spina Bifida Association of America, 1992. (15 minutes)

- **Going for the Gold: A Tale of Three Kids.** Triple Knot Productions, 2006. DVD. (23 minutes) [www.tripleknotproductions.org](http://www.tripleknotproductions.org)  
  The story is about disabled athletes, one of whom is a girl with Spina Bifida, one of the other kids has an undiagnosed disability which is similar to Spina Bifida.

- **I’ll Find a Way.** Solano Beach, CA: National Film Board of Canada, 1977. (26 minutes)

- **In the Middle.** Boston, MA: Fanlight Productions, 1987. (26 minutes)

- **Mister Rogers’ Neighborhood. Disabilities Episode #1389 A Visitor Who Uses Leg Braces.** The Fred Rogers Company 2010.  
  Originally aired in 1975. DVD Mister Rogers has a discussion with Chrissie Thompson, a young girl with spina bifida.

- **Protecting Against Latex Allergy.** Spina Bifida Association of America. (7.5 minutes)

- **Shakissha and Friends.** University of Maryland Video Press, 2008. DVD (28 minutes) [www.videopress.umaryland.edu](http://www.videopress.umaryland.edu)

  Documentary of Al Davis.

- **Teens on the Move: An Exercise Video for Teens with Spina Bifida.** NCPAD, DVD and VHS. (76 minutes)

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