



The following excerpt has been taken from the Christopher & Dana Reeve Foundation Paralysis Resource Center website.

http://www.paralysis.org/site/c.erJMJUOxFmH/b.1293657/k.8FB3/Spina_Bifida.htm

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 Associations of America, National Institute of Neurological Disorders and Stroke, March of Dimes Birth Defects Foundation

Web Sites

Spina Bifida Association of America

www.sbaa.org

Promotes the prevention of spina bifida and works to enhance the lives of all affected. Offers a toll-free information and referral service and numerous publications.

March of Dimes Birth Defects Foundation

www.modimes.org

Offers information about the four major problems that threaten the health of America's babies: birth defects, infant mortality, low birth weight, and lack of prenatal care. Good resources and information on SB.

The Spina Bifida Research Resource

www.sbr.info

Texas A&M University System
Health Science Center
Institute of Biosciences and Technology
2121 W. Holcombe Blvd.
Houston, TX 77030
1-866-521-SBTX

The SBRR is a project funded by the National Institutes of Health to study the causes of spina bifida and anencephaly.

Children and Adults with Spina Bifida and Hydrocephalus

<http://www.waisman.wisc.edu/~rowley/sb-kids/index.html>

This website 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.

If you are an adult with spina bifida, or the parent of a child with a different type of spinal dysraphism (spina bifida occulta, lipomyelomeningocele, tethered cord syndrome, etc) please see the Resources & Links page for discussion lists and information related to your issues

National Institute of Neurological Disorders & Stroke: Spina Bifida

www.ninds.nih.gov/health_and_medical/disorders/spina_bifida.htm?format=printable

Information on spina bifida, including treatment, prognosis and current research.

Family Village: Spina Bifida

http://www.familyvillage.wisc.edu/lib_spin.htm

Provides links to organizations to contact, lists of chat rooms, and related websites.

Columbia Presbyterian Department of Neurological Surgery

http://www.cumc.columbia.edu/dept/nsg/ct/spina_bifida.html

Discusses Spina Bifida and provides links to the pediatric neurosurgery team.

Association for Spina Bifida and Hydroencephalus

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

42 Park Road
Peterborough

PE1 2UQ

Tel: 0845 450 7755

Fax: (01733) 555985

Email : helpline@asbah.org

ASBAH is the leading UK registered charity providing information and advice about Spina Bifida and hydrocephalus to individuals, families and carers.

Medline Plus: Spina Bifida

www.nlm.nih.gov/medlineplus/spinabifida.html

Information on Spina Bifida, including links for and about children and teenagers who have spina bifida.

Kids Health: Spina Bifida

http://kidshealth.org/kid/health_problems/bone/spina_bifida.html

Information on Spina Bifida geared toward kids.

Spina Bifida Resource Network

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

The following books and videos are available for free loan from the PRC library. For more information, please see www.paralysis.org and click the Lending Library tab.

Books for Adults

- **Answering Your Questions About Spina Bifida.** Washington, DC: Children's National Medical Center, 1995.
- Appelmann, Larry E. **Living With Spina Bifida.** Victoria, Canada: Trafford, 2002.
An autobiography.
- Davison, Al. **The Spiral Cage.** Los Angeles, CA: Active Images, 2003.
Autobiography in comic book format.
- Davoli, Cecilia. **Medical Facts About Spina Bifida.** Baltimore, MD: Kennedy Krieger Institute, 1995
- Dicken, Janny J. **Cody's Story: Living One Day at a Time with Spina Bifida.** Baltimore, MD: Publish America, 2005.
- Ellis, Kathryn. **Maya (A DeGrassi Book).** Toronto: James Lorimer and Co., 1991.
Teenage fiction. Maya wants a job and boyfriend for the summer.

- Gaul, Gilbert M. **Giant Steps: The Story of One Boy's Struggle to Walk.** New York, NY: St. Martin's Press, 1993.
A father's story of life with his son.
- **Guidelines for Spina Bifida Health Care Services Throughout the Lifespan.** Washington, DC: Spina Bifida Association, June 2006. Professional Advisory Council. Mark J. Merkens, editor.
- Harrison, Ted. **Tanni: The Inspiring Story of a World-Class Athlete.** London: CollinsWillow, 1996.
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.
- **Health Guide for Parents of Children Living with Spina Bifida.** Washington, DC: Spina Bifida Association, 2006.
- Kalloo, Naida. **Disability or Equalizer: It Really Depends on Attitude.** Baltimore: PublishAmerica, 2002. Fiction. Main character has spina bifida.
- Lutkenhoff, Marlene. **Children With Spina Bifida: A Parent's Guide.** Bethesda, MD: Woodbine House, 1999.
- Lutkenhoff, Marlene and Sonya G. Oppenheimer. **SPINAbilities: A Young Person's Guide to Spina Bifida.** Bethesda, MD: Woodbine House, 1997.
For teens or young adults.
- McLone, David G. and Joy Ito. **An Introduction to Spina Bifida.** Chicago, IL: Children's Memorial Spina Bifida Team, 1998.
- Sandler, Adrian. **Living With Spina Bifida: A Guide for Families and Professionals.** Chapel Hill, CA: The University of North Carolina Press, 1997.
- Sloan, Stephen L. **Sexuality and the Person With Spina Bifida.** Washington, DC: Spina Bifida Association of America, 1993.
- Travis, Karen Snyder. **Christal: Coping with Spina Bifida.** Wellesley, MA: Branden Books, 2001.
A mother's story of her daughter.

Books for Children

- Bevins, Rose. **Friends, No Matter What.** Logan, IA: Perfection Learning Corporation, 2002. Fiction
- Herrera, Juan Felipe. **Featherless/Desplumado.** San Francisco, CA: Children's Book Press/Editorial Libros para Ninos, 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.
- Lutkenhoff, Marlene. **Detour Ahead.** Washington, DC: Spina Bifida Association of America, 2008.
- Panzarino, Connie. **Follow Your Dreams.** Bethesda, MD: National Spinal Cord Injury Association, 1995. Fiction
- Powell, Jillian. **Sam Uses a Wheelchair.** Philadelphia: Chelsea House Publishers, 2005. (Like Me Like You series).
- Senisi, Ellen. **All Kinds of Friends, Even Green!** Bethesda, MD: Woodbine House, 2002. A little boy with spina bifida makes friends with a lizard who has a disabled limb.
- Watson, Stephanie. **Spina Bifida.** New York: Rosen Publishing, 2009. Genetic and Developmental Diseases and Disorders series.

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 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. (25:47 Minutes).
- **In the Middle.** Boston, MA: Fanlight Productions, 1987. (26 minutes)
- **Protecting Against Latex Allergy.** Spina Bifida Association of America. (7.30 minutes)
- **Shakisha and Friends.** University of Maryland Video Press, 2008? DVD 28 minutes. www.videopress.umaryland.edu

- **The Spiral Cage.** New York, NY: Filmmakers Library, 1991. (25 minutes)
Documentary of Al Davis.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.