



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

[http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453401/k.8D6A/Spina\\_Bifida.htm](http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453401/k.8D6A/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 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](mailto: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](http://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](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.

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

**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](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.

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

**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.

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

**Spina Bifida Resource Network (SBRN)**

84 Park Avenue, Suite G-106  
Flemington, NJ 08822

Phone: 908-782-7475

Email: [info@thesbrn.org](mailto: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**

- **Answering Your Questions About Spina Bifida.** Washington, DC: Children's National Medical Center, 1995.
- Appelmann, Larry E. **Living With Spina Bifida.** Victoria, BC, Canada: Trafford, 2002.

An autobiography.

- Charles, Beverly and Brooke Klemme. **Brooke's Journey of Heart: A Mother & Daughter Story of Spina Bifida, Home and Family.** Bloomington, Ind.: AuthorHouse, 2012.  
Biography
- Cornell, Marly. **The Able Life of Cody Jane: Still Celebrating.** Minneapolis, MN: Lightlight, 2011.  
Biography of Cornell's daughter.
- Davison, Al. **The Spiral Cage.** Los Angeles: 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.
- **The Future is Now: First World Congress on Spina Bifida Research and Care March 15-18, 2009.** Washington, DC: U.S. Department of Health and Human Services, 2009.
- Gaul, Gilbert M. **Giant Steps: The Story of One Boy's Struggle to Walk.** New York: St. Martin's Press, 1993.  
A father's story of life with his son.
- **Guidelines for Spina Bifida Health Care Services Throughout the Lifespan.** Mark J. Merkens, editor. Washington, DC: Spina Bifida Association, June 2006. Professional Advisory Council.
- 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, NC: 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 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.
- 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](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)
- **Shakisha and Friends**. University of Maryland Video Press, 2008. DVD (28 minutes) [www.videopress.umaryland.edu](http://www.videopress.umaryland.edu)
- **The Spiral Cage**. New York: Filmmakers Library, 1991. (25 minutes)  
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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This project was supported, in part by grant number 90PR3002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorships are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.