



# Spina Bifida

## ◆ Definition ◆

Spina Bifida means cleft spine, which is an incomplete closure in the spinal column. In general, the three types of spina bifida (from mild to severe) are:

**Spina Bifida Occulta:** There is an opening in one or more of the vertebrae (bones) of the spinal column without apparent damage to the spinal cord.

**Meningocele:** The meninges, or protective covering around the spinal cord, has pushed out through the opening in the vertebrae in a sac called the “meningocele.” However, the spinal cord remains intact. This form can be repaired with little or no damage to the nerve pathways.

**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. Generally, people use the terms “spina bifida” and “myelomeningocele” interchangeably.

## ◆ Incidence ◆

Approximately 40% 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. Of these infants born with



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“spina bifida manifesta,” about 4% have the meningocele form, while about 96% have myelomeningocele form.

## ✧ Characteristics ✧



The effects of myelomeningocele, the most serious form of spina bifida, may include muscle weakness or paralysis below the area of the spine where the incomplete closure (or cleft) occurs, loss of sensation below the cleft, and loss of bowel and bladder control. In addition, fluid may build up and cause an accumulation of fluid in the brain (a condition known as hydrocephalus). A large percentage (70%-90%) of children born with myelomeningocele have hydrocephalus. Hydrocephalus is controlled by a surgical procedure called “shunting,” which relieves the fluid buildup in the brain. If a drain (shunt) is not implanted, the pressure buildup can cause brain damage, seizures, or blindness. Hydrocephalus may occur without spina bifida, but the two conditions often occur together.

## ✧ Educational Implications ✧

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. School programs should be flexible to accommodate these special needs.

Many children with myelomeningocele need training to learn to manage their bowel and bladder functions. Some require catheterization, or the insertion of a tube to permit passage of urine.



### Don't Be Shy!

All of our publications and resource lists are online—help yourself! Visit us at:

**[www.nichcy.org](http://www.nichcy.org)**

If you'd like personalized assistance, email or call us:

**[nichcy@aed.org](mailto:nichcy@aed.org)**

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The courts have held that clean, intermittent catheterization is necessary to help the child benefit from and have access to special education and related services. A successful bladder management program can be incorporated into the regular school day. Many children learn to catheterize themselves at a very early age.

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.

Successful integration of a child with spina bifida into school sometimes requires changes in school equipment or the curriculum. In adapting the school setting for the child with spina bifida, architectural factors should be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving federal funds make their facilities accessible. This can occur through structural changes (for example, adding elevators or ramps) or through schedule or location changes (for example, offering a course on the ground floor).

Children with myelomeningocele need to learn mobility skills, and often require the aid of crutches, braces, or wheelchairs. It is important that all members of the school team and the parents understand the child's physical capabilities and limitations. Physical disabilities like spina bifida can have profound effects on a child's emotional and social development. To promote personal growth, families and teachers should encourage children, within the limits of safety and health, to be independent and to participate in activities with their nondisabled classmates.

## Other Helpful Things to Know

These NICHCY publications talk about topics important to parents of a child with a disability.

*Parenting a Child with Special Needs*

*Your Child's Evaluation*

*Parent to Parent Support*

*Questions Often Asked by Parents About Special Education Services*

*Developing Your Child's IEP*

All are available in English and in Spanish—on our Web site or by contacting us.

*In some cases, children with spina bifida who also have a history of hydrocephalus, experience learning problems.*

## ✧ Resources ✧

Lutkenhoff, M. (Ed.). (1999). *Children with spina bifida: A parents' guide*. Bethesda, MD: Woodbine House. (Phone: 800.843.7323. Web: [www.woodbinehouse.com](http://www.woodbinehouse.com))

Lutkenhoff, M., & Oppenheimer, S. (1997). *SPINAbilities: A young person's guide to spina bifida*. Bethesda, MD: Woodbine House. (See contact information above.)

National Institute of Neurological Disorders and Stroke (NINDS). (2001). NINDS spina bifida information page. Available online at: [www.ninds.nih.gov/health\\_and\\_medical/disorders/spina\\_bifida.htm](http://www.ninds.nih.gov/health_and_medical/disorders/spina_bifida.htm)

Sandler, A. (1997). *Living with spina bifida: A guide for families and professionals*. Chapel Hill, NC: University of North Carolina Press. (Phone: 800.848.6224. Web: [uncpress.unc.edu/](http://uncpress.unc.edu/))

Spina Bifida Association of America. (n.d.). *Facts about spina bifida*. Washington, DC: Author. (See "Organizations." Available online at: [www.sbaa.org/html/sbaa\\_facts.html](http://www.sbaa.org/html/sbaa_facts.html))

## ✧ Organizations ✧

Spina Bifida Association of America  
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800.621.3141  
[sbaa@sbaa.org](mailto:sbaa@sbaa.org)  
[www.sbaa.org](http://www.sbaa.org)

March of Dimes Birth Defects Foundation  
1275 Mamaroneck Avenue  
White Plains, NY 10605  
914.428.7100  
888.663.4637  
[askus@marchofdimes.com](mailto:askus@marchofdimes.com)  
[www.marchofdimes.com](http://www.marchofdimes.com)

Easter Seals—National Office  
230 West Monroe Street, Suite 1800  
Chicago, IL 60606  
312.726.6200; 312.726.425 (TTY)  
800.221.6827  
[info@easter-seals.org](mailto:info@easter-seals.org)  
[www.easter-seals.org](http://www.easter-seals.org)

National Rehabilitation Information Center  
(NARIC)  
4200 Forbes Boulevard, Suite 202  
Lanham, MD 20706  
301.459.5900; 301.459.5984 (TTY)  
800.346.2742  
[naricinfo@heitechservices.com](mailto:naricinfo@heitechservices.com)  
[www.naric.com](http://www.naric.com)

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