# 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 ♦

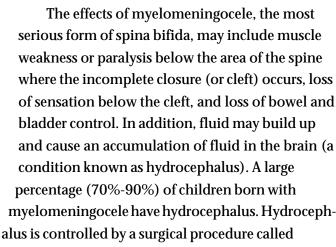
Approximately 40% of all
Americans may have spina bifida
occulta, but because they experience
little or no symptoms, very few of
them ever know that they have it. The
other two types of spina bifida,
meningocele and myelomeningocele,
are known collectively as "spina bifida
manifesta," and occur in approximately 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.





"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 myelomening ocele 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 myelomening ocele 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.



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

nichcy@aed.org 1.800.695.0285 (V/TTY) 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 myelomening ocele 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.

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#### ♦ Resources ♦

Lutkenhoff, M. (Ed.). (1999). *Children with spina bifida: A parents' guide*. Bethesda, MD: Woodbine House. (Phone: 800.843.7323. Web: 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

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/)

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)

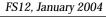
## ♦ Organizations ♦

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March of Dimes Birth Defects Foundation 1275 Mamaroneck Avenue White Plains, NY 10605 914.428.7100 888.663.4637 askus@marchofdimes.com 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 www.easter-seals.org

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