

The facts about **SPINA BIFIDA**

What is spina bifida?

Spina bifida is the most common neural tube defect. Near the end of the first month of pregnancy the two sides of an embryo's spine usually close together. Spina bifida occurs when the spine does not completely close. The words spina bifida literally translate as "split spine."

As with many birth defects, the exact cause of spina bifida is still unknown. Scientists believe that a combination of genetic, dietary and environmental factors may combine to cause the disruption in spinal closure during gestation. Studies indicate that consumption of folic acid, a common B vitamin, before and during early pregnancy can decrease the chance of spina bifida and other neural tube defects.⁽¹⁾

Three distinct types of spina bifida can occur:

- Occulta – This mild form of spina bifida often does no damage to the spinal cord. The malformation is covered by a layer of skin. Occulta spina bifida rarely causes symptoms or disability. A birthmark, dimple, or small patch of hair may be present on the lower spine.
- Meningocele – In meningocele, the membranes covering the spinal cord (meninges) protrude through an opening in the spine. This opening may or may not be covered by a layer of skin. This condition is rare, and may result in minor damage.
- Myelomeningocele (sometimes called meningocele) – In this most common type, the spinal cord is exposed through the opening in the spine resulting in partial or complete paralysis and bladder and bowel dysfunction.

Symptoms

Symptoms can be non-existent or can include physical and cognitive issues such as paralysis and in rare cases, learning disabilities. As a child matures, other symptoms such as allergy to latex, bladder and bowel dysfunctions, and gastrointestinal problems can occur. Children with spina bifida are more prone to bone fractures than typical children. In addition, the range of motion in major joints may be limited due to an imbalance of the underlying muscles and tendons in the joint.

In severe cases of spina bifida, a common complication is Chiari II. This condition can cause an abnormal build up of cerebrospinal fluid in the brain, resulting in hydrocephalus. A shunt, a thin tube, can be implanted to drain the fluid and relieve pressure inside the skull.

Treatment Options

Many treatments are available to manage spina bifida and reduce neurological damage. These can include surgery, medications, and different types of therapy services, depending on the type and severity of the case. Adaptive equipment can help children improve mobility and performance of daily tasks. To provide the most effective treatment

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for a child with spina bifida, family members and professionals must work together in understanding the child's strengths and weaknesses and determining the best interventions.

Limitations in motor skills can lead to frustration and contribute to behavior issues in young children with physical disabilities. Behavior management strategies and visual support tools can be used to promote communication and self control. As children get older, their dependence on parents and the potential difficulty in cultivating relationships among peers can contribute to their attitudes and conduct. Many resources are available to give parents a better understanding of the challenges their children face and provide strategies that will help their children handle feelings of frustration or disappointment.

Parents should feel comfortable taking an active role in their child's treatment programs. This involves not only disclosing important medical information to professionals, but also understanding treatment goals and strategies. With this knowledge, parents can learn how to integrate therapy into everyday life and support the child's progress between formal therapy sessions. Parents can share these ideas with child care providers, educators, and others who can also contribute to the child's success by incorporating activities that promote development.

Next Steps

Learning that a child has spina bifida is an emotional adjustment. Parents may need time to work through feelings of grief, disappointment or anxiety. The effect the diagnosis has on a family will depend on the type and severity of spina bifida identified in the diagnosis. Connecting with other families of children with spina bifida may help both parents and children with the process of understanding the disorder and adjusting to the effect it will have on the family as a whole.

Quality educational programs, good health care, and positive support from family, friends and the community enable people with spina bifida to develop to their full potential. According to IDEA, children with a disability that adversely affects their educational experiences are eligible to receive special education services and related services. To determine if your child is eligible to receive services, contact your community's local educational agency for children. For a child birth through two years of age, the child's state early intervention agency can be contacted to acquire more information on eligibility and services. For children three years and older, the child's local educational system should be contacted.

Looking to the Future

Siskin Children's Institute is here to serve as a resource to families as they learn about and adapt to their child's diagnosis. We have resources, educational opportunities, and family events that will help you support your child's needs. Please contact our Outreach and Resource Center to learn more about spina bifida and take advantage of the opportunities available to your family.

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Lending Library Resources on Spina Bifida

Parent Resources

- Children with Spina Bifida: A Parent's Guide
- Kids with Differences (DVD)
- Living with Spina Bifida: A Guide for Families and Professionals (Sandler)

Children's Books

- All Kinds of Friends, Even Green (Senisi)
- SPINAilities: A Young Person's Guide to Spina Bifida

Helpful Websites

- Kids Health (www.kidshealth.org)
- March of Dimes Birth Defects Foundation (www.marchofdimes.com)
- National Dissemination Center for Children with Disabilities (www.nichcy.org)
- National Institute of Neurological Disorders and Stroke (www.ninds.nih.gov)
- Spina Bifida Association (www.spinabifidaassociation.org)

This website offers several fact sheets on various aspects of living with spina bifida.

1. Katherine Daniel, Joseph Mulinare (1999)
2. Alysoun Reichard (1999)