FACT SHEET

Spina Bifida

What is Spina Bifida?

The human nervous system develops from a small, specialized plate of cells along the back of an embryo. Early in development, the edges of this plate begin to curl up toward each other, creating the neural tube—a narrow sheath that closes to form the brain and spinal cord of the embryo. As development progresses, the top of the tube becomes the brain and the remainder becomes the spinal cord. This process is usually complete by the 28th day of pregnancy. But if problems occur during this process, the result can be brain disorders called neural tube defects, including spina bifida.

Spina bifida, which literally means "cleft spine," is characterized by the incomplete development of the brain, spinal cord, and/or meninges (the protective covering around the brain and spinal cord).

How is it manifested?

There are four types of spina bifida: **occulta, closed neural tube defects, meningocele**, and **myelomeningocele**.

Occulta is the mildest and most common form in which one or more vertebrae are malformed. The name "occulta," which means "hidden," indicates that the malformation, or opening in the spine, is covered by a layer of skin. This form of spina bifida rarely causes disability or symptoms.

Closed neural tube defects make up the second type of spina bifida. This form consists of a diverse group of spinal defects in which the spinal cord is marked by a malformation of fat, bone, or membranes. In some patients there are few or no symptoms; in others the malformation causes incomplete paralysis with urinary and bowel dysfunction.

In the third type, **meningocele**, the meninges protrude from the spinal opening, and the malformation may or may not be covered by a layer of skin. Some patients with meningocele may have few or no symptoms while others may experience symptoms similar to closed neural tube defects.

Myelomeningocele, the fourth form, is the most severe and occurs when the spinal cord is exposed through the opening in the spine, resulting in partial or complete paralysis of the parts of the body below the spinal opening. The paralysis may be so severe that the affected individual is unable to walk and may have urinary and bowel dysfunction

The symptoms of spina bifida vary from person to person, depending on the type. Often, individuals with occulta have no outward signs of the disorder. Closed neural tube defects are often recognized early in life due to an abnormal tuft or clump of hair or a small dimple or birthmark on the skin at the site of the spinal malformation.

Who is affected?

It is estimated that 1 in every 1,000 children born in North America are diagnosed with spina bifida.

How is it diagnosed or detected?

In most cases, spina bifida is diagnosed prenatally, or before birth. However, some mild cases may go unnoticed until after birth, or postnatally. Very mild cases, in which there are no symptoms, may never be detected. Tests and procedures that may be used to diagnose spina bifida include:

- Blood tests
- Evaluation of the fluid that surrounds the brain and spinal cord
- Ultrasound

The content contained in this document is for general information purposes. It is not the intention to diagnose or treat a child.

- Urinary tract evaluation, including a urinalysis
- X-rays of the spine, skull, hips and legs if they are badly formed

Additional Resources:

THE SPINA BIFIDA AND HYDROCEPHALUS ASSOCIATION OF ONTARIO

www.sbhao.onc.a

416-214-1056
Toll Free: 1-800-387-1575
The SB& H Association of Ontario is an organization that has been committed for over 30 years to making a positive difference in the lives of people with SB&H, an association of volunteers providing a comprehensive range of help to parents, families, youth and adults with SB&H.

NATIONAL INFORMATION CENTRE FOR CHILDREN AND YOUTH WITH DISABILITIES

www.nichcy.org

This national information and referral centre provides information on disabilities, and disability related issues for families, educators, and other professionals. Its special focus is children and youth (0-22 years).

Books and Literature:

PARENTBOOKS

www.parentbooks.ca

Parentbooks offers one the most comprehensive selection of resources available anywhere from planning a family, to everyday parenting issues, to special needs of all kinds. It also has a selection of resources for caregivers, counsellors, therapists, educators, and clinicians.

CHILDREN WITH SPINA BIFIDA: A PARENT'S GUIDE

By: Marlene Lutkenhof

The chapters deal with issues parents will face, from prenatal diagnosis to adulthood -legal issues, education, health concerns, treatments, therapies, and causes.

SPINABILITIES

By: Marlene Lutkenhof

A guide to coping with the medical, self-care, and emotional issues of spina bifida, with an emphasis on becoming as independent as possible.

LIVING WITH SPINA BIFIDA: A GUIDE FOR FAMILIES AND PROFESSIONALS

By: Adrian Sandler

Dr. Sandler offers useful information on the medical, developmental, and psychological aspects of this condition. Accurate, accessible, and up-to-date, "Living with Spina Bifida" is written especially for families and professionals who care for children, adolescents, and adults with spina bifida.

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