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Youth and Spina Bifida

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What is Spina Bifida?

Spina bifida means literally “split spine.” It is a neural tube defect occurring during the first month of pregnancy in which the spinal column does not completely close. Damage to the spinal cord can occur because of this.

What Causes Spina Bifida?

The exact cause of spina bifida is unknown. However, low levels of folic acid intake before and during pregnancy are related to a higher incidence of spina bifida. Because of how early in the pregnancy this defect occurs, all women able to bear children should get at least 400 micrograms (mcg) of folic acid daily. For women who have already had a child with spina bifida, the recommendation for daily folic acid intake is increased tenfold. Other factors that may contribute to spina bifida are the environment and genetics.

What are the Types of Spina Bifida?

There are three types of spina bifida:

1. **Spina Bifida Occulta**—This is the hidden form. It usually causes no problems. It may appear as a dimple or small hair growth on the back.
2. **Spina Bifida Cystica, Menigocele**—Spinal column is not closed. The spinal cord is contained in a sac that contains tissues that protect it.
3. **Spina Bifida Cystica, Myelomenigocele**—The spinal column, which is not closed, is not in a protected sac and is damaged. This is the most serious and unfortunately the most common form of the defect.

What Are the Symptoms Caused by Spina Bifida?

- Hydrocephalus—fluid on the brain,
- Problems with bladder and bowel control,
- Learning disabilities,
- Possible paralysis,
- Latex allergy,
- Memory problems,
- Impulsivity,

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- Problems with organizing and reasoning,
- Average IQ but low math skills,
- Poor hand-eye coordination.

How is Spina Bifida Treated?

Initial treatment includes surgery shortly after birth to close the spinal column and insert a shunt to remove fluid from the brain. A latex allergy has developed in many individuals with spina bifida because of over exposure early in life to the substance. This latex allergy may be mild to severe with symptoms ranging from itchy eyes to life-threatening changes in blood pressure and circulation. Because of this, it is recommended that latex exposure be limited in and out of a hospital setting. Proper methods to work with a child's learning disabilities are also needed.

Important Issues for Extension Educators and 4-H Leaders to Consider:

1. Have contact information for parents or guardians and the member's doctor in accessible places. An example of this would be behind the child's nametag and in the medical forms box which should be in the main office at 4-H events. This form should include information such as what kinds of medication the child is taking, allergies, if any adaptive devices are used, and other health conditions.
2. Visit with the member and his or her parent about the member's spina bifida. Questions that can be asked include: "What symptoms of spina bifida do you have?" and "Do you have a latex allergy?"
3. If a leader is working with a member having a latex allergy, it is important to remember that latex is included in many items that are often overlooked. These include adhesive bandages and tape, elastic bandages, and medical gloves. Even food served with latex gloves can cause a reaction in some individuals. Use only non-latex products when working with a member having a latex allergy.
4. People with latex allergies are also often allergic to bananas, chestnuts, avocados, and kiwis. Even if an allergy to these is not specifically known, it would be best to avoid these foods when planning meals or snacks for activities involving a member with a latex allergy.
5. If a member has learning disabilities from his or her spina bifida, make sure to take this into account when planning activities, giving feedback, and judging record books and projects.

For More Information Contact:

Spina Bifida Association of America
4590 MacArthur Blvd, NW, Suite 250
Washington, DC 20007-4226
Phone: (800) 621-3141
Web site: www.sbaa.org
(Web site active as of May 6, 2005)

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