

Disability Awareness Begins With You



Spina Bifida

What is Spina Bifida?

Spina bifida is the most frequently occurring permanently disabling birth defect. It affects approximately one out of every 1,000 newborns in the United States.

Spina bifida, the most common NTD (Neural tube defects), is one of the most devastating of all birth defects. It results from the failure of the spine to close properly during the first month of pregnancy. In severe cases, the spinal cord protrudes through the back and may be covered by skin or a thin membrane. Surgery to close a newborn's back is generally performed within 24 hours after birth to minimize the risk of infection and to preserve existing function in the spinal cord.

Because of the paralysis resulting from the damage to the spinal cord, people born with spina bifida may need surgeries and other extensive medical care. The condition can also cause bowel and bladder complications. A large percentage of children born with spina bifida also have hydrocephalus, the accumulation of fluid in the brain. Hydrocephalus is controlled by a surgical procedure called "shunting" which relieves the fluid build up in the brain by redirecting it into the abdominal area. Most children born with spina bifida live well into adulthood as a result of today's sophisticated medical techniques.

I've heard that children with spina bifida have learning problems. Is this true?

Some children with spina bifida do experience learning problems. They may have difficulty with paying attention, expressing or understanding language, organizing, sequencing and grasping reading and math.

How can we help those with learning

Early intervention can help considerably to prepare these children for school. Students should be in the least restrictive environment and their day to day activities should be as "normal" as possible. It often helps to have a psychological evaluation, which tests the child's intelligence, academic levels (reading, spelling, math etc.), and basic learning abilities (visual perception, receptive and expressive language skills).

What about the physical limitations?

Children with spina bifida need to learn mobility skills, and often with the use of crutches, braces, or wheelchairs can achieve more independence. Also, with new techniques children can become independent in managing their

bowel and bladder problems. Physical disabilities like spina bifida can have profound effects on the child's emotional and social development. It is important that health care professionals, teachers, and parents understand the child's physical capabilities and limitations. To promote personal growth, they should encourage children (within the limits of safety and health) to be independent, to participate in activities with their non-disabled peers and to assume responsibility for their own care.

What are secondary conditions associated with spina bifida?

Special attention is needed to identify and treat secondary disabilities. Due to the wide range of neurological damage and mobility impairment it can be difficult to identify some secondary disabilities. Attention should be focused on the psychological and social development of children and young adults with spina bifida. Many recent studies, including the SBAA's Adult Network Survey, clearly indicate the presence of emotional problems that result from factors such as low self-esteem and lack of social skills training.

Examples of secondary conditions associated with spina bifida are latex allergy, tendinitis, obesity, skin breakdown, gastrointestinal disorders, learning disabilities, attaining and retaining mobility, depression, and social and sexual issues.

What is latex allergy?

Allergic responses to latex (rubber) products. Typical symptoms include watery eyes, wheezing, hives, rash, swelling, and in severe cases, anaphylaxis (a life threatening reaction). These responses can occur when items containing latex touch the skin, the mucous membranes (like the mouth, genitals, bladder or rectum), open areas or bloodstream (especially during surgery).

Some cases of severe reaction following injection of medication through latex stoppers, IV ports or syringes have been reported. In addition, the powder from balloons or gloves can absorb particles and become airborne causing reactions when breathed by a latex sensitive person. Food that has been handled by latex gloves may also cause a reaction. And people who have allergic reactions may also be allergic to some foods, including bananas, chestnuts, avocados

and kiwi fruit.

Who is allergic to latex?

While it is not known exactly how this allergy develops, anybody can develop a latex allergy. However, certain groups of individuals have been identified as having a greater risk of becoming latex allergic. Those at higher risk include people who are frequently exposed to latex, such as children and adults with spina bifida and health professionals. Research has shown that spina bifida patients have the potential to become allergic (to some degree) to latex. Anyone with a latex allergy should avoid exposure to all products that contain latex.

What are some common products that contain latex?

Catheters, elastic bandages, baby bottle nipples, pacifiers and balloons are just a few common products that contain latex. For a more extensive list of items containing latex often found at home, in your community, and in hospitals, contact the SBAA. If you are in doubt about a specific product, check with its distributor or manufacturer.

Can anything be done to prevent spina bifida?

Yes. Recent studies have shown that one factor that increases the risk of having an NTD baby is low folic acid status before conception and during the first few weeks of pregnancy. If all women of childbearing age were to consume 0.4 mg of folic acid prior to becoming pregnant and during the first trimester of pregnancy, the incidence of folic acid preventable spina bifida and anencephaly could be reduced by up to 75%!!

What is Folic Acid?

Folic acid, a common water-soluble B vitamin, is essential for the functioning of the human body. During periods of rapid growth, such as pregnancy and fetal development, the body's requirement for this vitamin increases. Folic acid can be found in multivitamins, fortified breakfast cereals, dark green leafy vegetables such as broccoli and spinach, egg yolks, and some fruits and fruit juices. However, the average American diet does not supply the recommended level of folic acid.

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