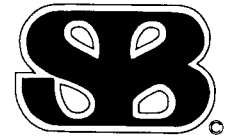




## Spina Bifida Association of America

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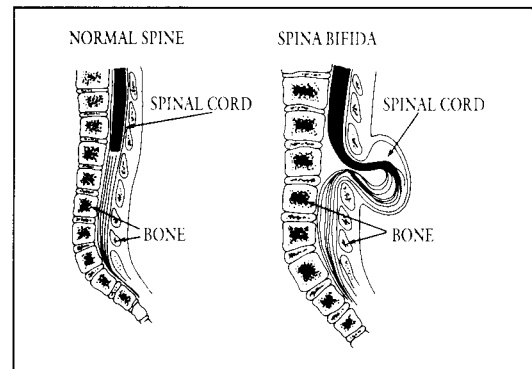
## What are neural tube defects?

Neural tube defects (NTDs) are serious birth defects that involve incomplete development of the brain, spinal cord and/or protective coverings for these organs. There are 3 types of NTDs: anencephaly, encephalocele, and spina bifida.

Babies born with anencephaly have underdeveloped brains and incomplete skulls. Most infants born with anencephaly do not survive more than a few hours after birth. Encephalocele results in a hole in the skull through which brain tissue protrudes. Although most babies with encephalocele do not live or are severely retarded, early surgery has been able to save a few children.

## 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. More children have spina bifida than have muscular dystrophy, multiple sclerosis, and cystic fibrosis combined.



Spina bifida, the most common NTD, 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, and sequencing and grasping reading and math.

## How can we help those with learning problems?

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?

Persons 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 conditions. Due to the wide range of neurological damage and mobility impairment it can be difficult to identify some secondary conditions. 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, 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).

### **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%!!

In September 1992, based on randomized control trials and observational studies, the U.S. Public Health Service published a recommendation, stating that "all women of childbearing age in the United States should consume 0.4 mg of folic acid daily to reduce the risk of having a pregnancy affected by a neural tube defect."

### **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. There are three ways for women to receive sufficient amounts of folic acid in their diet. Folic acid can be found in multivitamins, fortified breakfast cereals, and foods rich in folic acid (folate) such as broccoli, spinach, egg yolks, some fruit and fruit juices. However, the average American diet does not supply the recommended level of folic acid.

**Enclosed is my tax deductible donation/gift for:**

\$ \_\_\_\_\_ Donation/Gift

\$ \_\_\_\_\_ Research Gift

**Membership**

\$ \_\_\_\_\_ \$20.00 students, \$25.00 parents, individuals with spina bifida,  
\$40.00 professionals, \$50.00 International membership

**Method of payment**

\$ \_\_\_\_\_ Check (checks should be made payable to SBAA)

\$ \_\_\_\_\_ MasterCard

\$ \_\_\_\_\_ Visa

Account Number \_\_\_\_\_

Expiration Date \_\_\_\_\_

Signature (as shown on credit card) \_\_\_\_\_

Full Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_

Zip Code \_\_\_\_\_

Telephone \_\_\_\_\_

For additional information, contact the Information and Referral Department at the SBAA on Tel: 202-944-3285, Fax: 202-944-3295, e-mail spinabifda@aol.com, or write to the address below.

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**What is SBAA?**

SBAA was founded in 1973 to address the specific needs of the spina bifida community and serves as the national representative of over 70 chapters nationwide. SBAA is comprised of individuals with spina bifida, family members, parents, professionals, adults with spina bifida and interested members of the general public.

The mission of the Spina Bifida Association of America is to promote the prevention of spina bifida and to enhance the lives of all affected. The Spina Bifida Association of America is a 501(c)(3) non-profit organization. SBAA's efforts benefit thousands of infants, children, adults, parents and professionals each year.

**What does SBAA do?**

SBAA provides services such as:

- Toll Free 800 Information and Referral Service
- Bi-monthly Newsletter, *Insights*
- Publications
- Professional Advisory Council
- Nursing Council
- Annual National Conference
- Adult Network
- Scholarship Fund
- Public Awareness Campaigns
- Chapter and Member Services
- Individual and Systems Advocacy
- Research

**Tomorrow**

SBAA is moving in many different directions. The years ahead promise to be exciting ones as we work to prevent spina bifida and to enhance the lives of all affected. Help us to realize our goal by making a tax deductible donation and/or joining the SBAA today.