



## FACT SHEET

### SPINA BIFIDA

### Pennsylvania Chapter

#### ***What is Spina bifida?***

Spina bifida or myelomeningocele is the second most common birth defect (after Trisomy 21 or Down Syndrome). The baby is born with an opening in the back, through which the spinal cord protrudes. Surgery is usually done to close the opening shortly after birth, but this doesn't cure the nervous system problems.

#### ***What special care is needed for children who have myelomeningocele?***

The problems an individual child may have depends on the level of the myelomeningocele. In general, children with higher openings on the back have more difficulties.

#### ***Hydrocephalus:***

Children with myelomeningocele may have blockage of the normal routes of drainage of the cerebrospinal fluid (the fluid that surrounds the brain and spinal cord). About  $\frac{3}{4}$  of children with myelomeningocele need a special tube (shunt) placed between the brain and some other part of the body to help drain off the fluid. These shunts may become blocked or infected. If the child has a fever, or begins to vomit, act very sleepy or irritable, notify the parents immediately.

#### ***Orthopedic (Bone) Problems:***

Children with spina bifida may have problems with their feet which require casts. Many children with spina bifida cannot move muscles in their legs. Some children with spina bifida can walk with the use of special equipment. If they injure their legs, they might not be able to feel it. Special care must be given to the skin when an injury or skin breakdown occurs.

#### ***Urinary Problems:***

A child with spina bifida may have a flaccid (loose, floppy) bladder or a spastic (poorly coordinated) bladder. Many children with spina bifida need their bladders emptied with a catheter. The use of a catheter helps the child empty his/her bladder, which prevents bladder infection and prevents the kidneys from being damaged. If the child's urine looks cloudy or smells bad, it may be a sign of infection and the parent should be notified.

#### ***Bowel Problems:***

Some children with spina bifida cannot be toilet trained because they cannot control the muscles to the rectum. Most can learn control. Preventing constipation and a diet high in fiber can help. Check with the family or the child's doctor for individual recommendations.

#### ***Intelligence:***

About  $\frac{2}{3}$  of children with spina bifida have normal intelligence. About  $\frac{3}{4}$  of children with spina bifida attend regular school. Attending a regular school is important to help these children develop socially and emotionally. Each child with spina bifida is different. The parent can help by describing his/her individual needs. All these children should be encouraged to do as much as they can by themselves, as they can lead very productive lives.

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