Let's Talk About...

# Spina bifida

This handout will give you basic information about babies born with open spine (spina bifida). Since spina bifida (SPY-nuh BI-fi-duh) affects each child differently, you will be given more information later.

## How common is Spina Bifida?

Every year, one out of every 1,000 babies born has spina bifida. We do not know the cause of spina bifida. However, we know that there is an increased risk in families who have had a baby with spina bifida. Importantly, we know that using folic acid before pregnancy and during early pregnancy can reduce the risk of spina bifida.

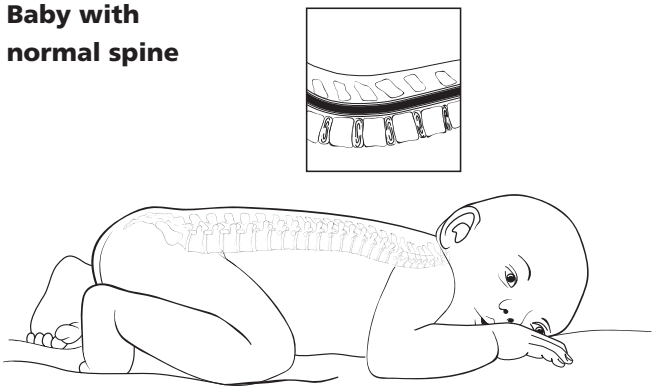
## What is Spina Bifida?

Spina bifida happens when a baby's developing spine does not close. During the first month of regnancy, the brain and spinal cord form from a hollow tube of cells. This tube closes between day 18 and day 28 of the pregnancy. If the tube does not close, a sac forms on the baby's back. This sac is soft and usually covered with very thin skin. The sac contains spinal fluid and the malformed spinal cord, which normally sends out nerves to the legs, bladder, and anus. Unfortunately, some of these nerves may not connect to the legs, bladder and anus.

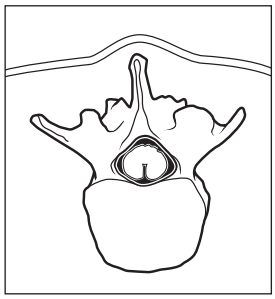
There are several words used to describe spina bifida. The most common ones include:

- Spina bifida
- Open spine

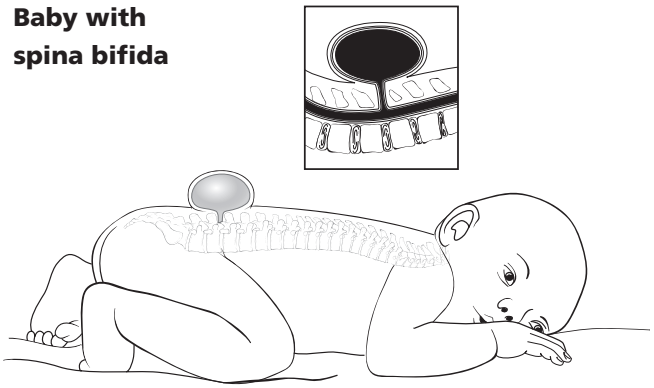
**Baby with normal spine**



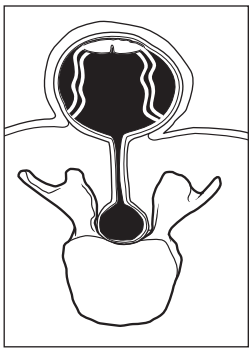
**Cross-section of completely formed spine**



**Baby with spina bifida**



**Cross-section of incompletely formed spine**



- Myelomeningocele
- Myelodysplasia

The sac can occur at different places along the back. It may be larger in some babies than in others. For these reasons, babies have different physical problems. Depending on the part of the spinal cord that has been damaged, some common problems include the following:

- **Hydrocephalus.** Hydrocephalus literally means water (hydro) of the brain (cephalic). It occurs when too much fluid collects in the cavities or ventricles of the brain. Hydrocephalus develops in most babies with spina bifida.
- **Impaired function of the bladder and bowel.** Almost all infants with spina bifida lack nerves to the bladder and bowel. This means that your baby may not be able to empty her bowel or bladder completely.
- **Paralysis of the legs.** There are fewer nerves to the legs and feet. Consequently, some or all of your baby's leg muscles may be paralyzed or not function as well as they should.
- **Lack of skin sensation.** Your baby may not feel pressure, pain, friction, heat, or cold in her legs and feet because of fewer nerves. However, above the sac, she should have near-normal strength and feeling.

## What is the initial treatment?

1. Your baby will be admitted to the medical infant unit or the newborn intensive care unit at Primary Children's Medical Center. The neurosurgeon will discuss with you the treatment for your baby. The neurosurgeon then will close the back with surgery and watch for signs of increased pressure due to hydrocephalus. If hydrocephalus develops, the neurosurgeon will talk with you about placing a shunt in the ventricles of the brain to remove the excessive fluid (see ***Let's Talk About… Hydrocephalus and Shunts***).
2. To ensure that your baby's bladder empties during surgery and after a catheter (drainage tube) will be placed in the bladder. Several days after surgery the catheter will be removed. A renal ultrasound will be completed and your baby will be monitored carefully to assure that the bladder empties.
3. Several specialists from the Spina Bifida Clinic will examine your baby. These specialists include a urologist, orthopedic surgeon and a physical therapist. Recommendations made by the specialists will be reviewed with you by the nurse practitioner from the spina bifida clinic.
4. Once your baby leaves the hospital, you will need to schedule periodic checkups and continued care with the Spina Bifida Clinic. The same physicians and professionals you meet while your baby is in the hospital will provide this care.

Much of the initial treatment for your baby will begin while you are in the hospital or while you are making arrangements to travel to Primary Children's Medical Center. This can be a very stressful time for both parents. To help you feel involved in the care of your baby, the nurse practitioner from the Spina Bifida Clinic is available to help you and to answer your questions.

For more information about spina bifida and the spina bifida program, please contact the office coordinator at 801.662.1675, or the nurse practitioner at 801.662.1678.

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