

# Let's Talk About...

## Spina bifida

This handout will give you basic information about babies born with open spine (spina bifida). Spina bifida (SPY-nuh BIH-fih-duh) affects each child differently. You will receive more detailed information later.

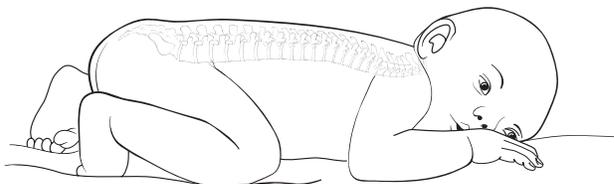
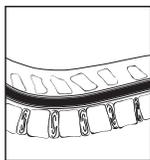
### How common is spina bifida and what causes it?

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 it is more common in families who already had a baby with spina bifida. Importantly, we know that taking folic acid before pregnancy and during early pregnancy can reduce the risk of spina bifida.

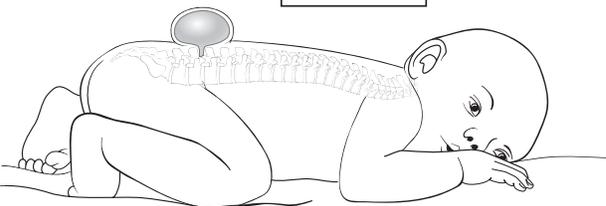
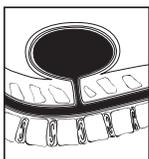
### How does spina bifida happen?

Spina bifida happens when a baby's developing spine does not close. During the first month of pregnancy, a hollow tube of cells develops into the brain and spinal cord. The cells start out flat and then fold in to form the tube. The 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. Normally, the spinal cord sends nerves to the legs, bladder, and anus. Unfortunately, in spina bifida, some of these nerves may not connect to the legs, bladder and anus.

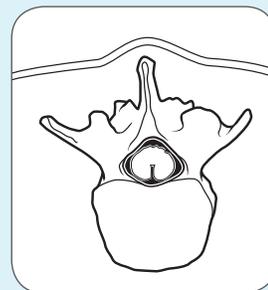
Baby with normal spine



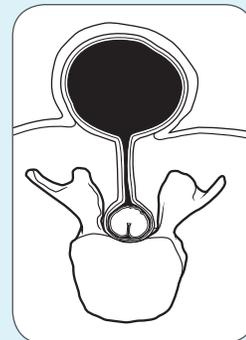
Baby with spina bifida



Cross-section of completely formed spine



Cross-section of incompletely formed spine



There are several words used to describe spina bifida.

The most common ones are:

- Spina bifida
- Open spine
- Myelomeningocele (My-el-oh-meh-NINN-joe-seal)
- Myelodysplasia (my-el-oh-diss-PLAY-shia)

The sac can be at different places along the back. It may be larger in some babies than in others. For these reasons, babies have different physical problems.

Some common problems include the following:

- **Hydrocephalus** (high-drow-SEFF-ah-luss). Hydrocephalus means water of the brain. It happens when too much fluid collects in the cavities (ventricles) of the brain. Most babies with spina bifida develop hydrocephalus.
- **The bladder and bowel do not work normally.** Almost all infants with spina bifida do not have nerves to the bladder and bowel. This means that your baby may not be able to empty their bowel or bladder completely.
- **Paralyzed legs.** With spina bifida, there are fewer nerves to the legs and feet. Because of this, 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 their legs and feet because they have fewer nerves. However, above the sac, they should have near-normal strength and feeling.

## What kind of treatment will my baby receive at first?

- Your baby will be admitted to the hospital. The neurosurgeon will discuss with you the treatment they plan for your baby.
- Your baby will have surgery. This is when the neurosurgeon closes your baby's sac.
- After surgery, the surgeon and nurses will watch for signs of increased pressure in the brain due to hydrocephalus.
- If your baby develops hydrocephalus, the neurosurgeon will talk with you about treatment options. Before the surgery, your baby will have an

MRI brain scan and the neurosurgeon will look at it. This is to see which surgery would be right for your baby. The options may include the following:

- **Shunt placement:** The neurosurgeon puts a shunt (tube) in the ventricles of the brain to remove the excess fluid.
- **Third ventriculostomy\Choroid plexus coagulation:** This is a surgery where the surgeon makes a small opening in the bottom of the third ventricle of the brain. This lets cerebrospinal fluid exit the ventricles and at the same time decreases the amount of spinal fluid produced. This is a way to treat hydrocephalus without a shunt.
- Many babies go home from the hospital before having either of the above procedures. Your baby will need follow-up appointments with the neurosurgeon, Spina bifida clinic, and pediatrician.

## Urinary catheter and urinary care:

- Your baby will have a urinary catheter. This is a small tube put in the bladder to drain urine out of the body. This is to make sure your baby's bladder empties during surgery. The tube will stay in the bladder for several days after surgery.
- Your baby will have an ultrasound to see if their bladder empties.
- Your baby will be placed on a three-day catheterization regimen to assure that their bladder empties completely. Before being discharged to go home, the hospital staff will teach you how to catheterize your baby. This is to familiarize you with the procedure. At some point in your baby's life, you will probably need to perform this procedure at home.
- Several specialists from the Spina bifida clinic will examine your baby. These specialists include a urologist, orthopedic surgeon, and a physical therapist. The nurse practitioner from the Spina bifida clinic will review their recommendations with you.

## What kind of follow-up care will my baby receive after they go home?

Before your baby leaves the hospital, they will be fitted with a car bed seat. The car bed seat is on loan from the hospital and will be used for two weeks to assure that there is no pressure on your baby's back during the ride home from the hospital and for other necessary transport. The car bed seat is usually returned to the hospital at the first clinic visit, at which time your baby will begin to use their own car seat.

Once your baby leaves the hospital, you will need to schedule periodic checkups and continued care with the Spina bifida clinic. The people who will give you this care are the same doctors and professionals you will meet in the hospital.

You will also need to make an appointment with your baby's pediatrician for well-child care including immunizations.

Babies with spina bifida should be involved in an early intervention program. These programs are supported through your local school district. The program provides therapies in your home such as physical therapy and occupational therapy. The hospital will make the referral and the program will contact you when your baby is at home.

## Who can I call if I have questions?

Much of the initial treatment for your baby will start while you are in the hospital or while you are making arrangements to travel to Primary Children's Hospital. This can be a very stressful time for 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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