

Let's Talk About...

Prenatal Counseling: Spina bifida

What is spina bifida?

Spina bifida [SPY-nuh BIF-ih-duh] occurs when a developing baby's spine does not close within the first month of pregnancy. The spinal cord and fluid then fill a soft sac covered with thin skin on the baby's back.

One out of every 1,000 babies is born with spina bifida. Myelomeningocele [My-el-oh-meh-NINN-joe-seal] is the most severe form and can cause severe nerve damage and other problems.

The **Utah Fetal Center team** will help you make the best possible decisions about your baby's diagnosis. The team includes maternal-fetal medicine specialists for the pregnant mother, neonatologists who are specially trained to care for newborns, and pediatric specialists to help with your baby's needs before and after delivery.

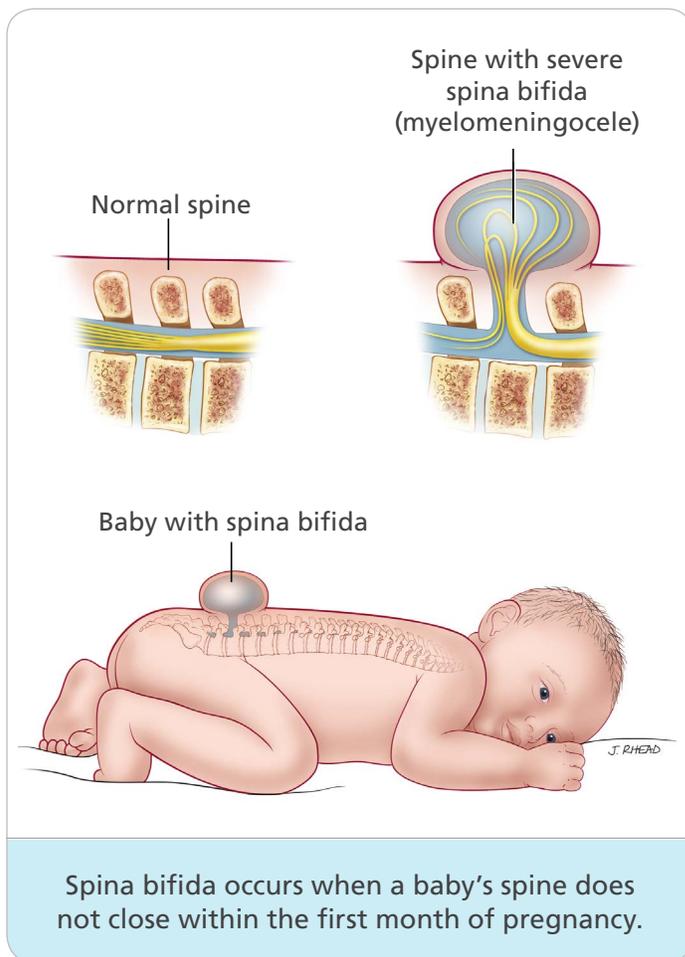
What causes spina bifida?

Some babies get spina bifida because of a family history of the disease, but most of the time doctors don't know what caused it. However, taking folic acid before pregnancy and during early pregnancy can reduce the risk of spina bifida.

How is spina bifida diagnosed?

Spina bifida is often diagnosed after the **alpha-fetoprotein (AFP)** test, around 15 weeks of pregnancy. After the AFP test shows a problem, the doctor may do an ultrasound to look for spina bifida.

The fetal center then recommends ultrasounds and a fetal MRI, another imaging test. These tests can tell providers more about how spina bifida may affect your baby.



Spina bifida occurs when a baby's spine does not close within the first month of pregnancy.

How does spina bifida affect my baby?

Normally, the lower spinal cord sends nerves to the legs, bladder, and anus. A baby who has spina bifida may not have some of these connecting nerves, causing:

- **Bladder and bowel problems.** Many babies have problems with urination (peeing) and constipation (being unable to poop).
- **Leg weakness.** Some or all of your baby's leg muscles may not work as well as they should.

When the sac is higher on your baby's back, your baby may also have:

- **Lack of feeling in the skin.** Your baby may not feel pressure, pain, heat, or cold in their legs and feet.
- **Hydrocephalus** [high-dro-SEFF-ah-luss]. Fluid collects in the open spaces (ventricles) in the center of the brain, putting pressure on the surrounding brain tissue. Most babies develop hydrocephalus.

How is spina bifida managed during pregnancy?

In some cases, a surgeon can close your baby's spine while they are still developing in the uterus (called fetal surgery). Fetal surgery can decrease the risk of some spina bifida-related problems, such as hydrocephalus and leg weakness.

Your baby must have fetal surgery between 19 to 26 weeks into the pregnancy. The fetal center team will discuss the risks and benefits with you and your family. If this surgery is an option for your baby, the fetal center will help arrange this treatment.

For additional information

Utah Fetal Center

intermountainhealthcare.org/locations/primary-childrens-hospital/medical-services/utah-fetal-center

Centers for Disease Control and Prevention (CDC)

cdc.gov/ncbddd/birthdefects/gastroschisis.html

American Association of Neurological Surgeons

aans.org/en/Patients/Neurosurgical-Conditions-and-Treatments/Spina-Bifida

March of Dimes

marchofdimes.org/complications/spina-bifida.aspx

Intermountain Spina Bifida Support Group

Utahspinabifida.org

Where should I deliver my baby?

You should deliver your baby at the University of Utah Hospital. Your baby will then receive care at Primary Children's Hospital.

How is spina bifida managed after delivery?

After your baby is born, a **pediatric neurosurgeon** [NUR-oh-SUR-jun], or brain surgeon, will examine them and discuss the treatment plan with you. They will usually close your baby's sac and watch for signs of hydrocephalus after surgery.

If your baby develops hydrocephalus, treatment options may include:

- **A ventriculoperitoneal** [ven-TRICK-you-low-per-ih-toh-NEE-ul], or **VP, shunt**. The surgeon will insert a shunt (tube) with one end in the ventricle and the other end in the abdomen. This creates a new path for the fluid to drain so the brain is no longer under pressure.
- **Third ventriculostomy** [ven-TRICK-you-LOST-uh-me]. The surgeon makes a small opening in a specific area of the brain to create a new way for fluid to drain. Before the surgery, your baby will have a brain scan to see if the surgery is right for them.

When can my baby go home?

Many babies with spina bifida go home before needing a shunt or ventriculostomy. However, they will need to follow up with their pediatrician and the spina bifida team. This includes a neurologist [new-RAHL-oh-jist] (brain doctor), a neurosurgeon, and multiple other pediatric specialists.

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

Your baby should participate in an early intervention program through your local school district. Early intervention programs provide therapy in your home, such as physical therapy and occupational therapy. The hospital will refer you to your local early intervention program, and a program coordinator will contact you when your baby is home.

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