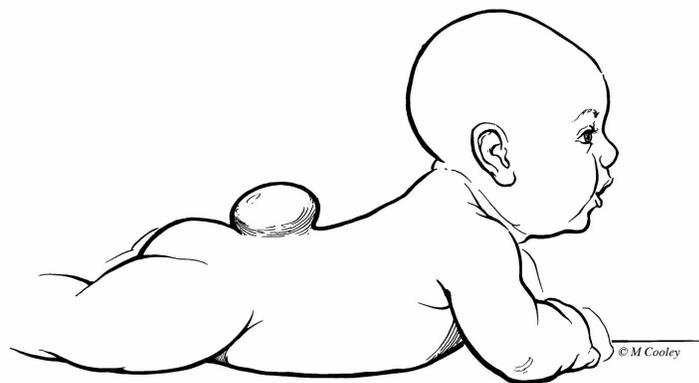


# SPINA BIFIDA

## OVERVIEW

Spina bifida is a *congenital* (happening before birth) condition where a part of the baby's spinal cord develops outside, instead of inside, the bones of the spine. The condition can be found during *pregnancy*, but some cases may not be discovered until after the baby is born.

There are *different* types of spina bifida, and treatment will depend on how much of the spinal cord is exposed or has been affected. In some cases, no treatment is required, but some babies will require surgery and lifelong medical care.



Spina bifida is one of the most common birth defects in the world. While no one knows what causes spina bifida, there is proof that women who eat a lot of foods containing folic acid (Vitamin B9) during pregnancy are less likely to deliver a baby with spina bifida.

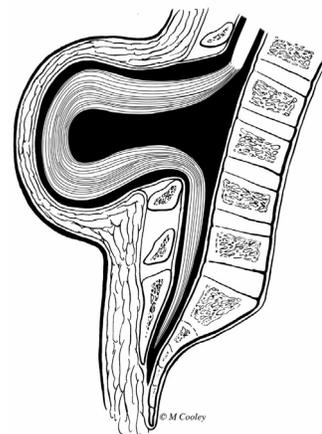
## HOW SPINA BIFIDA IS FOUND

During pregnancy, there are several tests (called *prenatal* tests) that can help tell if your baby has spina bifida:

- **Blood test.** This test looks for **alpha-fetoprotein (AFP)** in the mother's blood. AFP passes from the baby to the mother. A high level of AFP might mean the baby has spina bifida.
- **Ultrasound.** An ultrasound can sometimes detect differences in a baby's developing spine, or note club feet, which can be associated with spina bifida
- **Amniocentesis.** A small sample of the amniotic fluid surrounding the baby in the womb is taken and tested for AFP.
- **MRI:** if your obstetrician (OB) has concerns based on ultrasound findings or a blood test, you may be referred for a fetal MRI (magnetic resonance imaging). This type of image gives more detailed pictures of the fetus's brain and spine

## Types of Spina Bifida

**Myelomeningocele.** This is a serious condition, and the most common type of spina bifida. The spinal cord and nerves develop outside of the body in a sac of fluid that comes through an opening in the baby's back. Sometimes, the sac breaks, leaving the spinal cord and nerves exposed. *Surgery* is needed within 24-72 hours after birth to close the opening. Surgery cannot fix the damage that has already occurred to the nerves, but can help prevent further damage and reduce the chance for infection.



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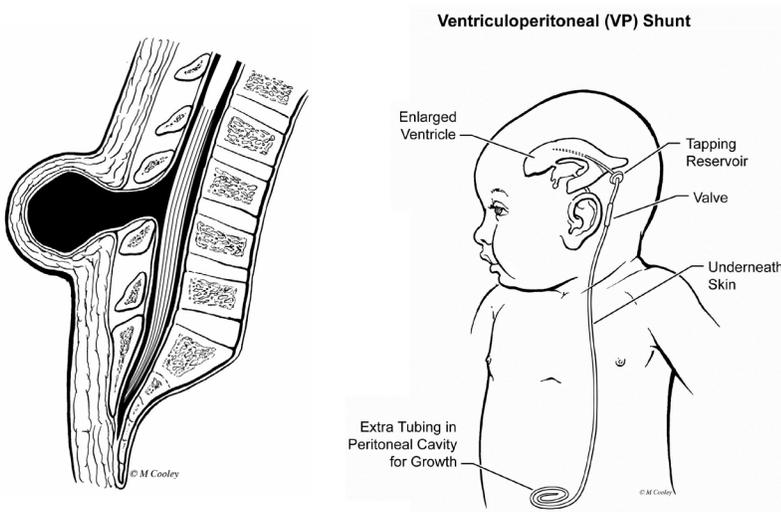


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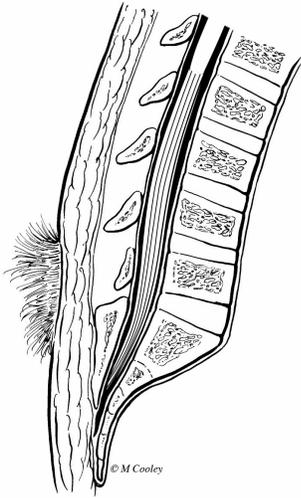
Some of the associated conditions seen in patients with myelomeningocele include:

- *Hydrocephalus* is a condition where the fluid inside and around the brain builds up, causing pressure on the brain or spinal cord. *Surgery* may be needed to relieve the pressure
- *Chiari II malformation* is associated with myelomeningocele. In Chiari II part of the cerebellum (the back part of the brain that controls coordination and balance) and brainstem (the part of the brain that controls basic functions such as breathing, heart rate and swallowing) is pulled down through the base of the skull. This can cause hydrocephalus, as well as other conditions. Surgery may be needed to relieve the pressure on the brain.
- *Neurogenic bladder* – The nerves in the spinal cord that control the bladder do not form properly. This means that the bladder will have trouble storing urine in the bladder, emptying the bladder, or both. Early catheterization of the child's lower urinary tract is recommended as a preventive treatment to preserve both kidney and bladder function in an attempt to maximize the child's long-term urologic functioning and overall health.
- *Neurogenic bowel* - The nerves that regulate the bowel often do not form properly and the bowel will have trouble storing stool in the rectum, emptying the rectum, or both. This typically does not become an issue until your child begins solid foods.
- *Leg weakness* and numbness, including paralysis (not being able to move). Some children may not be able to move parts of their body and will need a wheelchair as they get older. Others may be limited in the way they can move but will be able to walk with braces, crutches or walkers.
- *Clubfoot* is a condition where the bones of the foot and lower leg do not develop normally. The foot turns inward and downward and remains tight in this position. This can be associated with more severe leg weakness/paralysis in myelomeningocele.
- *Learning Problems* – Including executive function skill disorder, trouble paying attention, and problems with language, reading and math.

The full impact of all of these types of spina bifida is usually not known right after birth, but may be seen as the child grows and develops.



***Meningocele.*** This is a moderate form of spina bifida. A sac of fluid comes through the baby's back and can be seen outside as a lump or bulge along the spine. The spinal cord and nerves are not in the sac. This type of spina bifida can cause some problems. Timing of the surgery to close the meningocele is determined by neurosurgery.



***Spina bifida occulta.*** This is the mildest form of spina bifida. The spinal cord and nerves are inside the body, but the bones in the lower back do not develop normally, leaving a small gap in the spine. There is no opening you can see or sac on the baby's back. The baby may have a hairy patch, dimple, or birthmark over this opening. There may be a tethered spinal cord, a condition where the nerves at the end of the spinal cord have limited movement and may not work as they should. This type of spina bifida is not generally found prenatally.

Longer term problems may include:

- Learning problems, including trouble paying attention and problems with language, reading, and math.
- Bowel and bladder control
- Risk for bladder infections

## **CAUSE OF SPINA BIFIDA**

Spina bifida occurs in the first few weeks of pregnancy when the brain and neurological system are just starting to grow. While no one knows what causes spina bifida, there are factors that may impact its development:

### **1) Nutrition and health before pregnancy and very early in pregnancy**

- Obesity
- Diabetes in the mother
- Seizures and some seizure medicine
- Lack of proper vitamins and nutrients
- Certain prescription drugs
- Chronic or "binge" alcohol use
- Fever early in pregnancy

### **2) Genetics and heredity**

- Genes inherited from both parents

### **3) Environmental factors**

- Being exposed to unsafe chemicals, such as pesticides

Spina bifida is also seen more often in young mothers, those with a history of miscarriage, and those with a poor diet.

## **The role of folic acid**

Research also shows that women who have had a baby with spina bifida can reduce their chances of having a second baby with the condition by taking more folic acid. Folic acid is found in leafy green vegetables, nuts, beans, citrus fruits, and fortified breakfast cereals. It is also found in prenatal vitamins.

## CARE DURING YOUR PREGNANCY

If a test finds you are carrying a baby with spinal bifida, you will continue to receive care from your doctor. You may also be referred to the Ohio Fetal Medicine Collaborative (OFMC).

Through the OFMC, you will see a doctor who takes care of high-risk patients. You may also meet with a multidisciplinary team including neonatologists (a doctor who specializes in newborn care), neurosurgeons (brain surgeon) and nurses from the Myelomeningocele Program at Nationwide Children's Hospital to learn more about your baby's care after birth. Nationwide Children's has a special Myelomeningocele Clinic to care for children with Myelomeningocele. Nurse coordinators will help answer your questions and concerns, guide you through your pregnancy, and prepare you for what to expect.

Your doctor will watch your pregnancy closely, and will deliver your baby at a hospital that is prepared to care for high-risk babies. Contact your doctor if you ever have any concerns.

## CARE AFTER YOUR BABY IS BORN

At the delivery hospital, a **neonatologist** will manage the care of your baby. Babies born with more severe forms of spina bifida (*meningocele* or a *myelomeningocele*) require care in the Neonatal Intensive Care Unit (NICU) and will need surgery shortly after birth.

Right after delivery:

- An **intravenous** line (IV) will be started in your baby's arm, hand, foot, or head. The IV provides fluids, medicines, nutrients, and antibiotics to prevent dehydration and infection.
- Your baby will be transferred to the NICU at the main campus of Nationwide Children's Hospital for further care.

Your baby may not be able to breastfeed or bottle feed right away. We encourage you to pump and store breast milk for your baby until he or she is ready to start feeding.

### Treatment of spina bifida

The most important goals of treatment are:

- To prevent infection
- To preserve the spinal cord.
- Maximize function and prevent additional problems

### Surgical repair for babies with spina bifida after birth:

- Neurosurgery leads the team that will close and repair the opening in the back.
- Hydrocephalus can be treated by surgery with a hollow tube (called a shunt) that drains the extra fluid. This may be done with the first surgery to close the opening, or at a later date, depending on your baby's symptoms and overall condition

### Care after surgery

After surgery, your baby will continue to receive care in the NICU. Your baby may need to be on a ventilator (breathing machine) until fully recovered from surgery. The total length of time your baby will stay in the hospital will vary, depending on whether he or she is born with other health issues.

Besides surgery, postnatal (right after birth) care of babies with spina bifida involves many different teams of doctors, support and therapy services. Additional tests and imaging studies and procedures will be needed as well. Some of these may include:

- *Brain imaging*: Doctors perform a head ultrasound or MRI to check out your baby for hydrocephalus and Chiari II malformation.
- *Urology consult*: Experts will examine your baby to check out how your baby's kidneys and bladder are working. Your baby will need to have frequent bladder catheterizations (a small tube inserted into the urethra, where urine comes out of the body) to ensure the bladder is emptying normally. If needed, parents can be taught to perform this procedure at home.
- *VCUG and Renal US*: imaging studies that can provide doctors with information about how the bladder and kidneys are working
- *Orthopedic surgery consult*: Orthopedic (bone) specialists will come to check out your baby for spine, hip, leg and clubfoot conditions.
- *Physical Medicine consult*: Physical Medicine is the specialty who diagnose and treat disorders related to the nerves, muscles, bones and brain that may produce temporary or permanent impairment
- *Genetics consult*: A geneticist will evaluate and discuss the risk of recurrence in a future pregnancy
- *Developmental Pediatrics and Myelo*
- *Myelo Nurse Coordinator*
- *Physical and occupation therapy evaluation*: Early intervention and therapy are needed to maximize function in babies with spina bifida. Therapists will provide:
  - Therapeutic exercises
  - Positioning aids (to help the child sit, lie, or stand)
  - Braces and splints (to help the shaping of limbs, for support, or for protection )

### **Preparing for Home:**

We will teach you to care for your baby at home. We will show you how to:

- Take care of your baby's skin to prevent skin breakdown and pressure sores
- Care for bowel and bladder
- Feed your baby
- Help your baby move
- Interact with your baby

### **LOOKING AHEAD**

Your baby will need regular follow-up appointments to measure growth, development, and nutrition. You will want to find a local doctor who cares for children to take care of the routine checkups, immunizations, and doctor's visits. The program coordinator can help if needed.

The Spina Bifida Clinic at Nationwide Children's will also provide follow-up care for your baby's specialized medical needs. It is a multidisciplinary clinic which meets once a week on Friday mornings from 8 am to noon. During this visit you will see providers from the following specialties: developmental pediatrics, genetics, neuropsychology, nursing, occupational therapy, orthopedics, physical medicine, physical therapy, social work and urology. Visits are scheduled every three months during the first year and every 6-12 months after 1 year of age, or more often, based on your child's individualized needs.

The *Spina Bifida Clinic* at Nationwide Children's will also provide follow-up care for your baby's medical and surgical needs. This is a multidisciplinary clinic which means you can see the multiple doctors and therapists involved with your baby's care in one visit.

- Some babies may need more surgery in the future to help correct bone problems, such as curving in the back or hip dislocations, or to help with bowel or bladder issues.

### **Lifelong Considerations**

Spina Bifida is a lifelong condition that is not curable. Care for children born with spina bifida focuses on preventing problems and maximizing your child's abilities. With help, children with Spina Bifida can lead full lives. Most do well in school, and many play in sports. Because of today's medicine, about 90 percent of babies born with Spina Bifida now live to be adults. As type and level of severity differ among people with Spina Bifida, each person with the condition faces different challenges and may require different treatments. The best way to manage Spina Bifida is with a team approach. Members of the team may include developmental pediatrics, neurosurgery, urology, orthopedics, physical medicine, advanced practice nurses, nurse, physical and occupational therapists, orthotists, neuropsychologists and medical social workers. Physical and occupational therapy, early intervention, and appropriate educational interventions through a multidisciplinary approach are important in helping your child. The full extent of Spina Bifida is usually not completely known or understood immediately after birth, but may be revealed as the child grows and develops.

### **Future Pregnancies**

Your doctor may recommend genetic counseling to discuss risks for a future pregnancy. Women who have a child with Spina Bifida should take 400 mcg (4 MG) of folic acid daily for one to 3 months before pregnancy and continue during the first 3 months of pregnancy. Taking folic acid before and during the first three months of pregnancy does not guarantee the baby will not have Spina Bifida, but it can significantly reduce the risk.

### **ADDITIONAL RESOURCES**

- **March of Dimes** — <http://www.marchofdimes.org/baby/spina-bifida.aspx>
- **Spina Bifida Association** — <http://www.spinabifidaassociation.org/site/c.evKRI7OXIoJ8H/b.8028963/k.BE67/Home.htm>
- **National Institute of Neurological Disorders and Stroke** — [http://www.ninds.nih.gov/disorders/spina\\_bifida/detail\\_spina\\_bifida.htm#261933258](http://www.ninds.nih.gov/disorders/spina_bifida/detail_spina_bifida.htm#261933258)
- **Center For Disease Control** — <http://www.cdc.gov/ncbddd/spinabifida/>

