Spina Bifida is a birth defect that happens when a baby's spine (backbone) doesn't form the right way. Spina bifida is part of a group of birth defects known as neural tube defects or birth defects that affect the spine of a baby.

There are two types of spina bifida—closed spina bifida (spina bifida occulta) and open spina bifida (meningomyelocele).

Closed Spina Bifida
Closed spina bifida happens when the baby's bones of the spine (backbone) form differently or may be absent. It is called a closed spina bifida because the baby's skin covers the bones that have formed differently or are absent.

Open Spina Bifida
Open spina bifida happens when the baby's bones of the spine (backbone) form differently or may be absent. It is called an open spina bifida because there is an opening in the baby's skin. This opening is usually on the middle or lower part of the back. This opening in the skin allows the baby's spinal cord (tube of nerves running down the middle of the back) to stick or bulge out of the opening.

What Causes Spina Bifida
No one is certain what causes spina bifida, but we do know that women who do not have enough folic acid in their diet have a higher chance of having a baby with spina bifida. Folic acid is a vitamin the mother's body needs to help form the baby's spine and other parts of the body.

How Spina Bifida is Found
Before the baby is born most cases of open spina bifida are found on an ultrasound. If spina bifida is suspected, the doctor may suggest an amniocentesis test to confirm if the baby has spina bifida.

Some mothers choose to have a Maternal Serum Alpha Fetoprotein (AFP) test at around 15 to 21 weeks in their pregnancy. This test looks at the level of AFP in the mother's blood. If it is very high, she will see a Maternal Fetal Medicine doctor (specialist for high risk pregnancies) who will do an ultrasound to look for spina bifida.

After Diagnosing Spina Bifida
When spina bifida is found, the pregnant mother should be seen by a Maternal Fetal Medicine specialist who has experience treating women with complicated pregnancies. The mother will have regular ultrasounds to make sure the baby is growing normally and does not have any other birth defects.

Because spina bifida is a complicated condition that requires special treatment, the mother and her support people will meet with a team of experts that will be taking care of her and her baby both before and after the baby is born. Some of these team members include the following:

• Maternal Fetal Medicine Specialist
• Neonatologist (a doctor taking care of newborns who need special care)
• Pediatric surgeon (a doctor that performs surgery on babies)
• Pediatric neurologist (a doctor that treats babies and children with brain, nerve, and spine problems)
• Social worker (a person also helps to coordinate transportation, financial support, insurance coverage, parenting help, supplies for the baby, etc.)

Together these people and many more make up a team that will work together to give you, your family, and your baby the most rewarding outcome possible.

Spina bifida is a complicated diagnosis. Some women's lives are such that they cannot support a child with potential special needs, and they may choose not to continue the pregnancy. Our maternal fetal medicine specialists will discuss all options with the mother, to ensure she is comfortable and making the right decision for her and her baby.
A Baby with Spina Bifida

Babies with spina bifida can be affected in different ways depending on:

• How far along the pregnancy is when the baby delivers
• Whether the baby has any other birth defects or problems
• Where on the spine or backbone the spina bifida is
• Whether there is hydrocephaly (too much fluid on the brain)

Often, babies with spina bifida have some or all of these symptoms:

• Problems with legs – weakness or being unable to move the legs
• Being unable to feel some or all of the lower part of the body
• Learning disabilities, attention problems, communication problems
• Problems controlling bowel movements or urination

It is impossible to know before a baby is born how they will be affected by spina bifida. After a baby is born, there are many ways to care for the baby.

• The baby will need surgery after birth to close the open area of the back or spine.
• The baby will need ultrasounds and special tests to decide if the baby has hydrocephaly.
  ‣ If hydrocephaly is present, the baby will need a shunt (a tube that goes into the fluid part of the brain to lower the amount of swelling in the baby's head).
• As the baby grows, develops, and gets older, they will need lifelong treatments such as:
  ‣ Wheelchairs
  ‣ Leg braces
  ‣ Catheter (tube to drain the bladder)
  ‣ More surgeries to fix problems in the spine or legs
  ‣ Testing to check for learning problems

What do I need to know for future pregnancies?

A woman who has had a child with spina bifida will need to take 4 milligrams of folic acid for at least 1 month before trying to become pregnant. Folic acid helps the spine and other body parts of a baby form. Having enough folic acid may help to lower the chance that you will have a baby with a spine problem.

It is important that you tell your doctor or nurse midwife if you have had a past pregnancy with spina bifida because you will need a detailed ultrasound, and may want to have an alpha fetoprotein test (AFP) during the pregnancy to look for spina bifida.