

SPINA BIFIDA

March of Dimes • University of South Florida • Florida Department of Health

Welcoming your new baby into your family.

Your baby has been identified as having a special condition. This condition is known as spina bifida. We know this is not easy for you and you may not know how to feel. That's okay. Parents of children with spina bifida feel shock, denial, grief, and even anger. It is all right to feel like this and no one will blame you. It will get better. You are not alone. Soon you will find lots of people and programs to help you. You may want to join a support group. Get to know your baby. Enjoy your baby.

What is spina bifida?

- Spina bifida is a birth defect of the spine (backbone).
- Inside your spine is the spinal cord; it is like a closed tube made up of nerves. Babies with spina bifida have an opening in the tube because it has not completely closed.
- It happens in the first month of pregnancy, before many women know they are pregnant.
- Myelomeningocele (say: my-uh-low-meh-**nin**-jo-seel) is a common type of spina bifida. The layers that cover the spinal cord (meninges) and nerves come out through an opening in the baby's back. There is nerve damage that can cause different types of problems. These include control of the bladder and intestine (not knowing when to go to the bathroom) and problems walking.



How many people have spina bifida?

Spina bifida affects 1 out of every 1,300 births.

Why do some babies have spina bifida?

- We know some babies are born with spina bifida because their mothers did not have enough folic acid (B vitamin) in their bodies early in the pregnancy. Many women do not know they are pregnant when this happens.
- Sometimes babies are born with spina bifida-even though the mother had enough folic acid in her body. Folic acid provides much protection from spina bifida, but this protection is not 100%.

How will this affect my baby?

Many babies with spina bifida have hydrocephalus (say: hi-dro **seh**-fuh-lus). Hydrocephalus means that a baby has fluid in the brain and needs surgery. The doctor puts a thin tube called "shunt" in the brain. The shunt helps drain the fluid.

- Other health problems that might happen with spina bifida are that your child:
- May not be able to move his or her legs (paralysis).
 - May not know when he or she needs to go to the bathroom.
 - May take longer to learn things.

Will my baby be able to walk?

- Some children will be able to walk by themselves.
- Other children will need crutches, leg braces, or walkers.
- Other children will need to use a wheelchair.
- The care your doctor gives your baby depends on the type of spina bifida he or she has.



What about my baby's future?

- Most babies will live a normal life.

Where can I go for help?

- Call the Early Steps Program in your county right away.
 - Early Steps services can help your child get a good start during his or her first three years.
 - They offer free services to help your child grow and learn. They help you care for your child.

Other Resources

- All Children's Hospital: 727-898-7451
- Children's Medical Services (CMS): call your local county health department for a CMS clinic in your area or visit: www.cms-kids.com
- Florida Directory of Early Childhood Services: 1-800-654-4440. They can refer you to the Early Steps Program in your area and to other programs.
- March of Dimes: visit marchofdimes.com
- National Dissemination Center for Children with Disabilities: 1-800-695-0285
- Shriner's Hospital for Children: 813- 972-2250
- Spina Bifida Association of Florida: 1 -800- 722-6355

Can it happen again?

- Now that you have had a baby with spina bifida, you are more at risk of having another baby with spina bifida.
- Folic acid can help prevent spina bifida before your baby is born. Folic acid is a B vitamin that helps you build healthy cells.
- Ask your doctor about the right amount of folic acid you will need before you become pregnant. He or she will give you a prescription for a high dose of folic acid that you will need.
- Take folic acid everyday. It is important to take it before and during pregnancy.
- Ask your doctor for a referral to see a genetic counselor (a person who knows about diseases that run in families).

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