



**SPINA BIFIDA
ASSOCIATION**

GENETICS AND SPINA BIFIDA

What is Spina Bifida?

Spina Bifida happens when the spine of a baby in the womb does not close all of the way. Every day, about eight babies who are born in the U.S. have Spina Bifida or a similar birth defect of the brain and spine. It occurs within the first month of pregnancy — often before most women even know that they are going to have a baby.

What Causes Spina Bifida?

No one knows for sure. Experts think that both genetics (one or more genes) and the person's environment might interact to cause Spina Bifida. It is possible that a person inherits multiple genes that make them susceptible to having Spina Bifida, but something in the environment triggers the Spina Bifida to develop.

How Can Spina Bifida Be Prevented?

There is no way to stop a baby from having a birth defect. It is only possible to reduce the risk. Studies show that the risk is reduced up to 70 percent when women take folic acid before and through the first three months of pregnancy. That is why all women who could possibly become pregnant should take 400 mcg (0.4 mg) of folic acid each day. It is especially important for them to take it one month before and through the first three months of pregnancy.

Women who had a pregnancy with Spina Bifida should take even more folic acid. They should take 4000 mcg (4.0 mg) every day, but should only get this much folic acid through a prescription. Also, it should be taken under a doctor's supervision. Do not raise the dose by taking more of a multivitamin because the high levels of the other vitamins are harmful.

Folic acid does not stop all cases of Spina Bifida. There is still a chance that some babies will have it even when women take the right amount every day.

Who is at Risk for Having a Baby with Spina Bifida?

There is no way to tell which women will have babies with Spina Bifida. Ninety-five percent of people with it have no family history.

Any woman who is capable of becoming pregnant can have a baby with Spina Bifida. There are approximately 65 million women of childbearing age in the United States.

What Raises the Chance of a Pregnancy with Spina Bifida?

Many things affect pregnancy, including genes, environment and certain illnesses or drugs. These include:

- a prior pregnancy with Spina Bifida (the chance of the next pregnancy being affected is 20-50 times greater);
- a family history of Spina Bifida;
- a mother with insulin-dependent diabetes;
- the mother's use of certain anti-seizure drugs;
- a mother with medically diagnosed obesity; and
- race and ethnicity. (Spina Bifida is more common in Caucasians than African-Americans and more common in Hispanics than non-Hispanics.)

Other things may raise the chance of having a baby with Spina Bifida, but they are not as well understood. These things include:

- exposure to high temperatures in early pregnancy, such as prolonged high fevers and extended hot tub or sauna use; and
- a father's exposure to Agent Orange.

Can Research Help?

Experts know that genes play a role. Now, they are looking for the exact gene(s) that cause Spina Bifida. In time, this research should make clear how Spina Bifida develops so there can be new treatments or even a cure. This research may also lead to new tests that help people or couples find out their chance for having a baby with Spina Bifida.

Should I Speak with a Genetic Counselor?

To learn more about your chance for having a baby with Spina Bifida or other neural tube defects, speak with a genetic counselor. This person can suggest tests, explain test procedures and results, present options and answer questions.

How can I find a genetic counselor?

To find a genetic counselor, contact:

National Society of Genetics Counselors
 233 Canterbury Drive
 Wallingford, PA 19086-76708
 610-872-7608
 E-mail: nsgc@aol.com
 Web: www.nsgc.org

Fact Sheet Contributor:

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Questions?

Call 800-621-3141

Web: www.spinabifidaassociation.org

This information does not constitute medical advice for any individual. As specific cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.

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