

Genetics and Spina Bifida

Many factors may cause 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 (SB) 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 pregnant.

What causes Spina Bifida?

No one knows for sure. Experts think that both genetics (one or more genes) and the woman'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.

Can Spina Bifida be prevented?

There is no way to prevent 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 at least one month before and through the first three months of pregnancy. (See the SBA's info sheet on folic acid.)

Women who have no personal or family history of SB and have not had a pregnancy affected by SB should take 400 mcg of folic acid every day. Women who have had a pregnancy with Spina Bifida should take 4000 mcg (4.0 mg) every day but require a prescription to get that dose the proper way. 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 prevent 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?

Any woman who is capable of becoming pregnant can have a baby with Spina Bifida, and there are approximately 65 million women of childbearing age in the United States. Although people with a first-degree relative (parent, sibling) with Spina Bifida are 5 to 10 times more likely to have Spina Bifida than the greater population, there is no way to tell which women will have babies with Spina Bifida. Ninety-five percent of people with SB have no family history. Many things affect pregnancy, including genes, environment and certain illnesses or drugs. These include:

- Prior pregnancy with Spina Bifida (the chance of the next pregnancy being affected is 20-50 times greater)
- Family history of SB
- Mother with insulin-dependent diabetes
- Mother with medically diagnosed obesity





Can research help?

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

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.

- Race and ethnicity. (SB is more common in Caucasians than African-Americans and more common in Hispanics than non-Hispanics.)
- Mother's use of some prescription drugs, which may include anti-seizure medications and fertility drugs, among others. This information should be discussed with the prescribing physician and the obstetrician before becoming pregnant.

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
- Extended hot tub or sauna use
- Parental exposure to Agent Orange.

How can I find a Genetic Counselor?

To find a genetic counselor, contact:

National Society of Genetic Counselors

401 N. Michigan Avenue

Chicago, IL 60611

Phone: 312-321-6834

Fax: 312-673-6972

E-mail: nsgc@nsgc.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.