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# Genetics and Spina Bifida

June 2022

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## What is Spina Bifida?

Spina Bifida happens when the spine of a baby does not close all of the way during pregnancy. 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 going to have a baby.

## What causes Spina Bifida?

No one knows for sure but experts think that genetics (one or more genes), the environment and nutrition all may influence whether a baby will have SB. 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.

## 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 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 at least one month before and through the first three months of pregnancy.

Women who have 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, folic acid 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 are approximately 65 million women of childbearing age in the United States, and any woman who is capable of becoming pregnant can have a baby with Spina Bifida. However, some studies show that a person with Spina Bifida or a mother who has had a pregnancy affected by Spina Bifida has about a 4 percent chance of having another pregnancy with Spina Bifida. Ninety-five percent of people with Spina Bifida have no family history (American College of Obstetricians and Gynecologists (ACOG), July 2003; reaffirmed 2008; ACOG practice bulletin. [Neural tube defects. Number 44, July 2003, Nancy Cheschier](#)).

Things we know can increase the risk of having a pregnancy impacted by Spina Bifida include:

- Spina bifida is present in about 1 in 2,700 births or 1500 births each year in the US
- Prior pregnancy with Spina Bifida (your risk will be 4%)
- Mother has a history of Spina Bifida (your risk is 4%)



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- Two previous pregnancies with Spina Bifida increases your risk to 10%
- Having insulin-dependent diabetes increases your risk
- Certain anti-seizure drugs (not all of them) increases your risk
- Mother with medically diagnosed obesity have an increased risk
- Pregnancies affected by Spina Bifida are highest in women who are Hispanic, followed by non-Hispanic whites and non-Hispanic African Americans.

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, (temperatures over 102 F or 38.9 C) might influence development of the baby.
- Extended hot tub or sauna use (water temperature of 101 F).
- Parental exposure to Agent Orange.

## 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 that new treatments or even a cure can be developed. This research may also lead to new tests that help people 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.

## How can I find a Genetic Counselor?

To find a genetic counselor, contact the [National Society of Genetic Counselors](https://www.nsgc.org/)  
330 North Wabash Avenue, Suite 2000, Chicago, IL 60611  
Phone: 312-321-6834  
<https://www.nsgc.org/>  
E-mail: [nsgc@nsgc.org](mailto:nsgc@nsgc.org)

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*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.*