
Genetics and Spina Bifida

August 2025

What Is Spina Bifida?

Spina Bifida happens when a baby's spine doesn't close all the way during early pregnancy. About eight babies are born each day in the U.S. with Spina Bifida or a similar problem with the brain or spine. This happens in the first month of pregnancy, often before a woman knows she is pregnant.

What Causes Spina Bifida?

Doctors aren't exactly sure what causes Spina Bifida. They believe it may be caused by a mix of things, like:

- A person's genes (family history)
- The environment
- Nutrition

Some people may be born with genes that make them more likely to have a baby with Spina Bifida.

Can Spina Bifida Be Prevented?

There's no way to fully prevent birth defects, but the **risk** of Spina Bifida can be lowered. Studies show that taking **folic acid** before and during early pregnancy can lower the risk by up to 70%.

All women who could become pregnant should take **400 micrograms (mcg)** of folic acid every day. This is especially important starting **at least one month before pregnancy** and during the first three months.

Women who have had a pregnancy with Spina Bifida should take more—**4,000 mcg (4.0 mg)** a day. This higher dose must be prescribed by a doctor. Do not take extra multivitamins to get more folic acid, because too much of other vitamins can be harmful.

Folic acid doesn't prevent all cases of Spina Bifida, but it can help lower the risk.

Who Can Have a Baby with Spina Bifida?

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

Most people with Spina Bifida do **not** have a family history of it. In fact, 95 out of 100 babies with Spina Bifida are born to families with no history of the condition.

But some people have a **higher risk**, including:

- Someone who already had a baby with Spina Bifida (4% chance in next pregnancy)
- A mother who has Spina Bifida (4% chance)
- A mother who had **two** pregnancies with Spina Bifida (10% chance in the next one)
- Mothers with diabetes that requires insulin
- Mothers who take certain seizure medications (not all seizure meds cause this)
- Mothers who have medically diagnosed obesity
- Hispanic women have the highest number of babies born with Spina Bifida, followed by non-Hispanic white and Black women
- About 1 out of every 2,700 babies in the U.S. is born with Spina Bifida (about 1,500 each year)

Other things that may raise the chance (but are not fully proven) include:

- High fevers early in pregnancy (over 102°F)
- Long use of hot tubs or saunas in early pregnancy
- A parent's exposure to chemicals like Agent Orange

Can Research Help?

Yes. Scientists believe that genes play a role in Spina Bifida. They are working to find which genes are involved. In the future, this may help create better treatments—or even a cure. Research may also help doctors better predict who is at risk for having a baby with Spina Bifida.

If you want to learn more about your own chances, talk to a **genetic counselor**. They can:

- Suggest helpful tests
- Explain test results
- Talk about options
- Answer your questions

How Can I Find a Genetic Counselor?



SPINA BIFIDA
ASSOCIATION

National Resource Center
jpanlener@sbaa.org
1-800-621-3141 x800
Hablamos español

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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

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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.