

INVESTMENT IN RESEARCH SAVES LIVES AND MONEY

Spina Bifida

Spina bifida is a type of neural tube defect (NTD), usually apparent at birth, which can happen anywhere along the spine if the neural tube does not close all the way. When the neural tube doesn't close all the way, the backbone does not completely protect the developing nerves in the spinal cord.^{1,2} Spina bifida is the most common permanently disabling birth defect in the U.S.³ There are three common types of spina bifida: occulta, meningocele, and myelomeningocele. Spina bifida occulta is the mildest form with a small gap in the spine, which does not usually cause any disabilities. With spina bifida meningocele, a visible sac of fluid forms through the opening in the spine, usually with little to no nerve damage. Spina bifida myelomeningocele is the most serious type of spina bifida in which a sac of fluid forms through the opening in the back, and part of the spinal cord and nerves are in the sac. This type of spina bifida causes moderate to severe disabilities.¹ There is no cure for spina bifida.³

TODAY

1,500 to 2,000 babies are born with some form of spina bifida each year in the U.S.³

About **166,000** people in the U.S. are living with spina bifida.³

15% of Americans are living with spina bifida occulta and do not know it.⁴

COST⁵

\$791,900:

Estimated lifetime cost of care for a person with spina bifida in the U.S.

\$1.6 Billion:

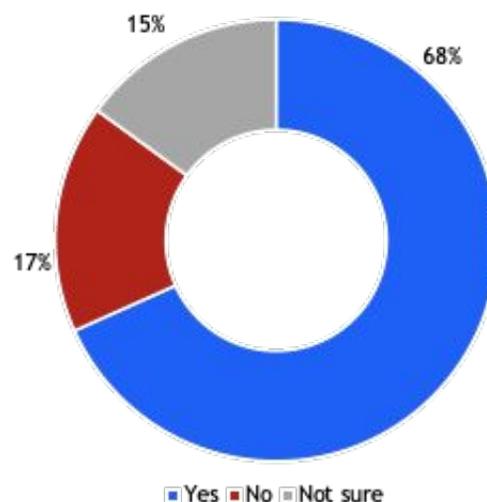
Annual cost of hospitalizations related to birth defects of the brain and spine, including spina bifida

Would you be willing to pay \$1 per week more in taxes if you were certain that all of the money would be spent on additional medical research?

Research Delivers Solutions

In a 2015 study, researchers looked to see how increased consumption of **folic acid** by pregnant women might reduce the risk of NTDs including spina bifida. The study used data from 19 states to estimate the change in NTDs after the U.S. began a public health intervention that required manufacturers to fortify cereal grain products with folic acid.^{6,7} They saw a 28% reduction in the number of spina bifida cases, as well as a larger reduction in cases where birth defect programs actively searched for NTDs compared to programs that did not actively look for NTDs. This study gives insight into the positive effects of folic acid fortification and may lead to improved forms of prenatal supplements.⁷

Another study examined folic acid in conjunction with a nutrient called **inositol**. Inositol can help prevent spinal and cranial NTDs like spina bifida. The study examined pregnant women who had previously had pregnancies complicated by NTDs. All of the 14 pregnancies in the folic acid + inositol group produced unaffected babies while the folic acid + placebo group produced 18 unaffected babies out of 19 pregnancies. While this study may show improvement for patients taking folic acid and inositol, more research is needed to elucidate the potential benefit that inositol may offer in preventing NTDs.⁸



Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2020

Spina Bifida

Then. Now. Imagine.

THEN

Before the 1960s, the survival rate for children with all forms of spina bifida was 10% to 12%.⁹

NOW

In 2003, the Management of Myelomeningocele Study (MOMS) Trial started, and found that prenatal surgery greatly improved outcomes for babies with spina bifida.¹⁰

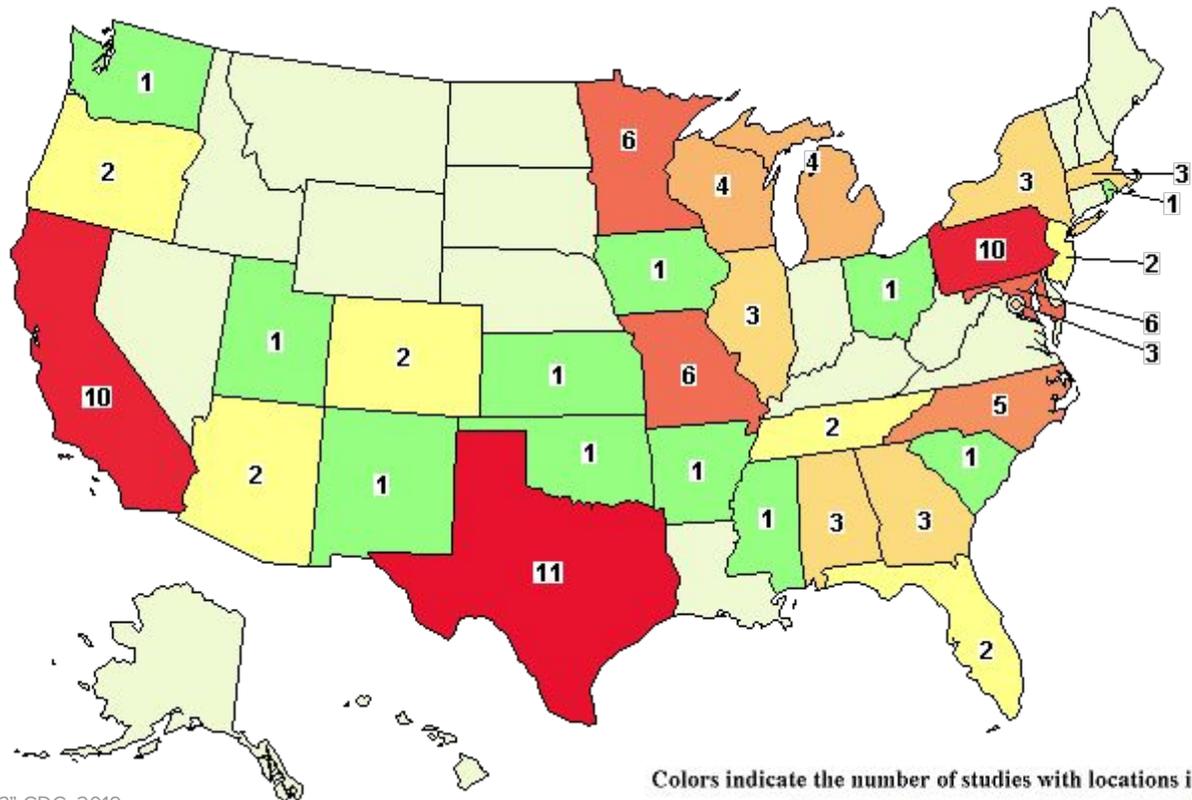
IMAGINE

Effective preventative treatment for spina bifida.

MOMS Study - Phase Two

In January 2020, results from phase two of the Management of Myelomeningocele (MOMS) study were released. The purpose of MOMS2 was to compare the long-term effects of prenatal surgery and postnatal surgery for myelomeningocele on the child's behavior, physical and cognitive function, health and wellbeing. The study found significant physical and emotional benefits in children who received prenatal surgery for myelomeningocele. The findings provide valuable insight into the outcomes of fetal surgery and provide more information to physicians and families to help them make better informed choices about the treatment options available.¹¹

Number of Clinical Trials for Spina Bifida by State



Colors indicate the number of studies with locations in that region.

Least Most
Labels give the exact number of studies.

SOURCE: "Spina Bifida" ClinicalTrials.gov N.d.

1. "What is Spina Bifida?" CDC. 2019.
2. "Spina Bifida." GHR. 2020.
3. "Spina Bifida Fact Sheet." NINDS. 2019.
4. "What is Spina Bifida?" Spina Bifida Association. N.d.
5. "Spina Bifida." CDC. 2019.
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7. Williams et al. "Updated estimates of neural tube defects prevented by mandatory folic acid fortification – United States, 1995-2011." CDC MMWR. 2015;64(01):1-5.
8. Greene et al. "Inositol, neural tube closure and the prevention of neural tube defects." Birth Defects Research. 2017;109(2):68-80.
9. Pruitt, L.J. "Living with spina bifida: A historical perspective." Pediatrics. 2012;130(2):181-183.
10. "SBA History." SBA. N.d.
11. "MOMS2: Follow up of the Management of Myelomeningocele Study." Children's Hospital of Philadelphia. N.d.

Research!America 241 18th St S, Arlington, VA 22202 | 703-739-2577
www.researchamerica.org | info@researchamerica.org

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