

Spina Bifida

Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities



CDC estimates that each year in the US, about 1,500 babies - 1 in every 2,500 - are born with spina bifida*. Spina bifida is a neural tube defect (NTD) and happens if the portion of the neural tube that forms the spinal cord does not close completely during the first month of pregnancy. Currently, there is no known way to prevent spina bifida, although steps can be taken to lower the risk. Studies have shown that the addition of the B vitamin folic acid to the diet of women who might become pregnant can greatly reduce the number of babies born with neural tube defects. Most children born with spina bifida live full lives, though they often have lifelong disabilities and need many operations.

Through the National Center on Birth Defects and Developmental Disabilities (NCBDDD), CDC works to:

- Learn more about the risk factors for spina bifida
- Help people with spina bifida live to the fullest
- Promote folic acid to help prevent spina bifida

Learning More about the Risk Factors for Spina Bifida

National Birth Defects Prevention Study

The National Birth Defects Prevention Study is the largest U.S. study looking at potential risk factors and causes of birth defects. Spina bifida research includes activities that will help us learn:

- How a woman's micronutrient intake, and the way her body uses folic acid may affect the risk for birth defects, including spina bifida and other NTDs, as well as heart defects.
- Why Hispanics are at higher risk for NTDs, and why folic acid is not as effective at preventing NTDs among Hispanics as it is among other groups.
- How folic acid education programs impact the use of folic acid and prevalence of NTDs.

U.S.-China Collaborative Project

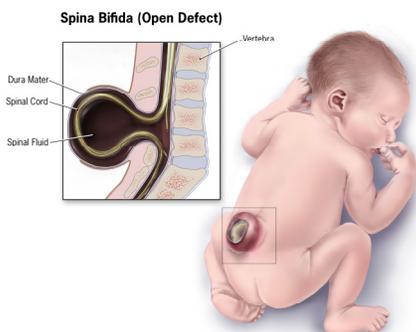
For more than 20 years CDC and the Peking University Health Science Center (PUHSC) have collaborated on birth defects research. In the mid 1990s, CDC and PUHSC evaluated a large-scale folic acid community intervention program in two regions of China. One region had NTD rates similar to those in the US, and the other had some of the highest reported rates in the world.

Researchers studied whether giving women 400 micrograms of folic acid before and during early pregnancy prevented NTDs. Among the babies of women who took the daily recommended amount of folic acid before and during early pregnancy, the risk of having an NTD dropped 85% in the high-prevalence area and 41% in the lower prevalence area. Research from this community intervention program also showed that using folic acid before and during early pregnancy did not increase the risk for miscarriage or multiple births.

CDC has used the China collaboration to study the prevalence of congenital heart defects; to learn whether folic acid use during pregnancy affects infant death rates, as well as growth, development and cognitive behavior in children; how different doses of folic acid affect blood folate levels; and to conduct long-term follow-up of women and children from the original community intervention program.

Multistate Collaborative Project on Spina Bifida Survival and Prevalence

Since the introduction of prenatal diagnosis and folic acid fortification in the 1990s, population-based birth defects surveillance programs have been able to document a decline in the birth prevalence of spina bifida in the United States. In addition, with advances in medical treatment, the survival experience of infants with spina bifida has been improving in recent years. However, information on the population-based prevalence of children and adolescents with spina bifida has been more limited. Over the past few years, CDC, in collaboration with state birth defects surveillance programs, has been conducting an evaluation of the survival and prevalence of children and adolescents with spina bifida in ten regions of the United States. This project will provide information that may be useful in deliberations on the public health impact of spina bifida beyond infancy.



Promoting the health of babies, children and adults,
and enhancing the potential for full, productive living.

www.cdc.gov/ncbddd

* Canfield MA, Honein MA, Yuskiv N, Xing J, Mai CT, Collins JS, et al. National estimates and race/ethnic-specific variation of selected birth defects in the United States, 1999-2001. Birth Defects Res Part A Clin Mol Teratol. 2006;76(11):747-56.

Helping People with Spina Bifida Live to the Fullest

Created in 2003, the National Spina Bifida Program has developed an array of programs, initiatives, and resources to support and empower patients, families, and health care providers with the information they need to prevent secondary effects and complications of spina bifida, and improve quality of life for individuals and families impacted by this birth defect. The National Spina Bifida Program works closely with the Spina Bifida Association on the following endeavors:



- Initiating a National Spina Bifida Patient Registry to collect and analyze data to help inform and improve the provision of care to individuals with spina bifida
- Creating and maintaining the National Spina Bifida Clearinghouse and Resource Center to provide information to expectant families, affected individuals and family members, and health professionals
- Collecting data to assess and evaluate the role of care coordination in improving access and care within the Spina Bifida Clinic System
- Developing an approach, with age appropriate interventions, for the successful transition of people with spina bifida from pediatric to adult health care and related services, social and vocational participation, and independent living
- Utilization of the Veterans Administration's Spina Bifida Database of 1,000 beneficiaries of the Agent Orange Program to study patterns of medical conditions, treatment, and costs across the life-span
- Developing a pilot program to increase knowledge of the natural history of spina bifida by prospectively studying children who are affected in the areas of medical, nutrition and physical growth; general health; development and learning; mobility and function; and family demographics and functioning
- Increasing knowledge of factors that improve urinary and bowel continence, while maintaining healthy kidneys
- Developing a national infrastructure for clinical research, and a systematic approach to improve the quality of spina bifida clinical care
- Increasing knowledge about health care utilization and expenditures for persons affected by spina bifida

Promoting Folic Acid to Help Prevent Spina Bifida

In 1992 the U. S. Public Health Service (USPHS) published the recommendation that all women of childbearing age consume 0.4 mg (400 micrograms) of folic acid daily to help prevent spina bifida and anencephaly. CDC estimates that 50-70% of these birth defects could be prevented if this recommendation were followed before and during early pregnancy. To promote folic acid among women of childbearing age, CDC engages in the following activities:



- Developing CDC websites that deliver current and accurate information for consumers and providers
- Creating and disseminating user-friendly and effective educational materials for use by health care providers and low literacy audiences alike
- Leading the development and dissemination of Spanish-language folic acid educational materials and messages and leading formative research efforts to identify materials and messages unique to Spanish-speakers that would be most effective in raising awareness and changing behavior
- Developing a continuing education tool for health care providers about vitamin B12 deficiency and folic acid fortification
- Effectively awarding funds and providing related oversight for 9 formative research projects to explore knowledge, attitudes, beliefs among women, couples and health care providers regarding barriers to and facilitators of reproductive health
- Effectively awarding funds and providing related oversight for increased research on folic acid awareness, knowledge, and consumption among Spanish-speaking Latinas of childbearing age through the leveraging of partnerships, and the implementation of Spanish-language radio media placements and community outreach efforts

