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National Center on Birth Defects and Developmental Disabilities Division of Birth Defects and Developmental Disabilities

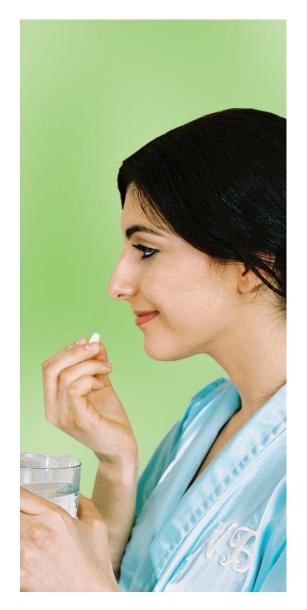


Countries and Organizations United for Neural Tube Defects Prevention

At-A-Glance



and brain.



Spina Bifida (Open Defect)



## What Are Neural Tube Defects?

Neural tube defects are serious birth defects that occur along the neural tube and are a significant cause of death and lifelong disability worldwide. The two most common neural tube defects are spina bifida and anencephaly<sup>(1)</sup>.

Spina bifida happens when the backbone that protects the spinal cord does not form and close as it should. It can happen anywhere along the spine if the neural tube does not close all the way. Spina bifida causes a range of lifelong disabilities <sup>(1, 2)</sup>.

An encephaly is a fatal birth defect that occurs when the upper part of the neural tube does not close all the way. Infants with an encephaly are often born without part of the skull and brain and die shortly after birth <sup>(1)</sup>.

#### Why Are Neural Tube Defects A Public Health Concern?

#### Neural tube defects are prevalent, severe, and costly.

- Prevalent. Globally, there are more than 300,000 babies born with neural tube defects each year<sup>(3)</sup>. They occur widely and among diverse populations, varying levels of economic development, and in different geographic areas<sup>(4)</sup>.
- Severe. Infants born with an encephaly do not survive, and those born with spina bifida have varying degrees of lifelong disabilities<sup>(2)</sup>.
- Costly. The lifetime direct cost of care for one child born with spina bifida in the United States is estimated to be \$706,000<sup>(5)</sup>. There also are great social and emotional costs for children with spina bifida and their families.

#### What Can Be Done To Address Neural Tube Defects?

Women can consume folic acid through diet, supplements, and fortified foods. In 1992, the U.S. Public Health Service recommended that all women of childbearing age capable of becoming pregnant consume 400 micrograms (mcg) of folic acid daily to prevent neural tube defects. In 1998, fortification of cereal grain products labeled as enriched was mandated by the U.S. Food and Drug Administration. In the United States, fortification led to a 36% decrease in rates of neural tube defects <sup>(4, 6, 7)</sup>. Fortifying foods with folic acid is an effective way to increase a woman's intake of folic acid without changing her dietary habits.

Worldwide, most neural tube defects are not being prevented<sup>(8)</sup>. Expanding the reach of global folic acid fortification in low-and middle-resource countries can lead to the prevention of 150,000–210,000 neural tube defects each year<sup>(4)</sup>. Countries such as Chile, South Africa, Canada and Costa Rica have seen a decrease in neural tube defects as a result of fortification. These successes can serve as examples for other countries considering fortification with folic acid.

#### The Centers for Disease Control and Prevention's Response

The Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities developed Birth Defects COUNT, a global initiative to significantly reduce death and lifelong disability resulting from neural tube defects. Through this initiative, CDC provides scientific and programmatic expertise to help expand neural tube defects prevention and strengthen birth defects surveillance worldwide.

Birth Defects COUNT relies on three pillars to advance and support effective neural tube defects prevention efforts: science, partnerships, and public health policy.

# Science (Surveillance, Epidemiology, and Laboratory Capacity)

Public health surveillance and epidemiology provide the data and information necessary to make informed decisions related to birth defects efforts and to assess whether these efforts are meeting their intended goals.

Many countries do not have surveillance systems that capture neural tube defects and other visible birth defects. Further, laboratory capacity to analyze blood folate concentrations is not available in most countries. Currently, CDC is collaborating with the World Health Organization (WHO) and the International Clearinghouse for Birth Defects Surveillance and Research to provide countries with guidance on how to develop and strengthen birth defects surveillance, epidemiology, and laboratory capacity for birth defects prevention.

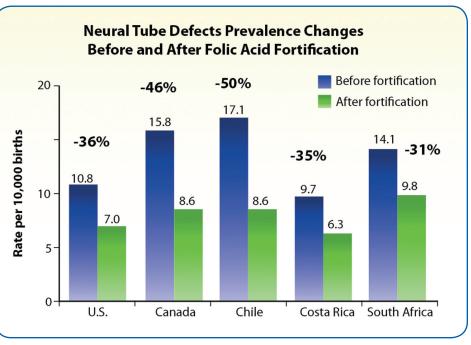
# **Partnerships**

Establishing a global network of partners with expertise in conducting folic acid interventions and neural tube defects surveillance is a key piece of the initiative. CDC recognizes the vital role partners play in advancing birth defects prevention globally. Currently, CDC is engaging partners in South-East Asia, East and Central Africa, and Latin America to strengthen and support birth defects prevention efforts through fortification and supplementation.

## **Public Health Policy**

Building on the success of folic acid fortification in the United States and other countries, CDC is partnering with WHO, the Flour Fortification Initiative, and others by supporting the development of global guidelines, working to increase the number of countries with fortification policies that include folic acid, and determining a global optimal blood folate concentration for neural tube defects prevention.

# **Before and After Folic Acid Fortification**



NOTE: Graph references are indicated with an asterisk on the last page.



