

Fact Sheet

Division of Child and Adolescent Health
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Anencephaly

What is anencephaly?

Anencephaly is one of a group of birth defects known as the neural tube defects (NTD). The neural tube is the structure in a growing baby that closes to form the spinal cord and brain. This tube normally closes around day 28 of growth. Anencephaly occurs when the neural tube does not close properly and the baby's brain and skull fail to form completely. The baby is born without the forebrain (front of the brain) and the cerebrum (area of the brain where thinking and coordination occurs).

What types of problems occur with anencephaly?

The brain of a baby with anencephaly has failed to form completely. Without a complete brain a baby's body cannot grow and function. Sadly, most babies with anencephaly die within a few days of birth.

How common is anencephaly?

Anencephaly occurs in about 450 births in the United States each year. In Virginia, approximately 10 children are born yearly with anencephaly.

Anencephaly occurs more often in girls but can occur in both girls and boys.

What causes anencephaly?

Approximately 95 percent of children born with anencephaly are born into families with no family history of anencephaly or a neural tube defect. It is believed that most anencephaly occurs due to a combination of environmental and genetic factors. Women with certain health problems such as diabetes and seizure conditions can also be at higher risk of having a child with anencephaly.

Some families have more than one person with anencephaly. Anencephaly does not occur in a set pattern in these families. Parents of a child with anencephaly have a higher chance of having another child with anencephaly. This chance is estimated to be about 1 in 25. For families with two children with anencephaly, the chance may be 1 in 10.

Usually, anencephaly is the only birth defect a child has (an isolated finding), but anencephaly can also occur with other birth defects as part of a syndrome (a collection of findings). The way in which a syndrome is passed through the family is specific to the given syndrome. A genetic counselor or geneticist can help you to determine the risks for your family and situation.

How is anencephaly treated?

Sadly, there is no treatment for children with anencephaly.

What can I do to prevent anencephaly?

Studies have shown that up to 70 percent of anencephaly cases could be prevented if women of childbearing age had enough folic acid in their bodies. Folic acid (also known as folate) is a B vitamin that occurs naturally in foods such as leafy green vegetables (for example, romaine lettuce, broccoli, spinach, and asparagus). It can also be found in enriched and fortified foods, such as enriched grain products and fortified breakfast cereals or in supplements, such as multivitamins.

Folic acid plays an important role during periods of rapid cell growth such as pregnancy. The most important time for women to have folic acid in their system is prior to pregnancy and during the first few weeks of pregnancy when the neural tube is forming. Most women do not even realize they are pregnant at this critical time. Therefore, the U.S. Public Health Service recommends that all women of childbearing age consume 400 micrograms of folic acid daily. This regimen will help ensure enough folic acid in a woman's system should she become pregnant.

Women who have already had a child with anencephaly or another neural tube defect need a higher daily dose of folic acid. This higher dose should begin at least one month prior to pregnancy. This higher dose (4 milligrams) must be prescribed by a doctor.

Where can I go for more information about anencephaly?

March of Dimes Birth Defects Foundation
www.modimes.org
1-888-MODIMES (1-888-663-4637)

National Center for Birth Defects and Developmental Disabilities
Centers for Disease Control
www.cdc.gov/ncbddd
1-770-488-7160

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