

## Anencephaly

### What is anencephaly?

Anencephaly (AN-en-SEF-ah-lee) is one of a group of birth defects known as neural tube defects (NTDs). 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 occur). This tube normally closes around the third or fourth week of pregnancy.



### 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. The baby will be blind, deaf, unconscious, and unable to feel pain. The baby may also have a cleft palate (roof of the mouth), congenital heart defects, and malformations of the ears.

### How common is anencephaly?

Between 1,000 – 2,000 babies with anencephaly are born in the United States each year. In Kentucky, 1 of every 10,000 babies are born with anencephaly. Anencephaly is more common among girls, but it can occur in both boys and girls.

Around 95% of babies born with anencephaly are born into families with no family history of anencephaly or a neural tube defect. Some couples may have more than one baby with anencephaly, but anencephaly doesn't occur in a set pattern in these families. Parents of a child with anencephaly have a higher chance (about 1 in 25) of having another child with anencephaly. For families with two children with anencephaly, the chance may be 1 in 10. A genetic counselor or geneticist can help you determine the risks for your family and situation.

### What causes anencephaly?

It is believed that most anencephaly occurs due to a combination of environmental (like not having enough folic acid or vitamins in the diet or being exposed to environmental toxins like pesticides) and genetic factors. Women with certain health problems like diabetes or seizure conditions can also be at a higher risk of having a child with anencephaly.

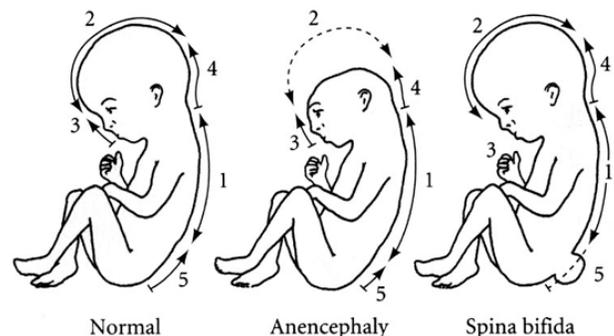
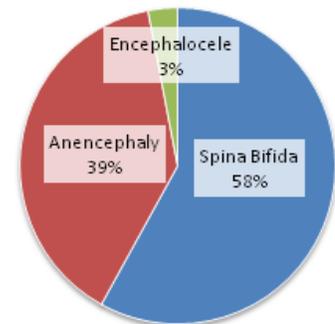
### How is anencephaly treated?

Unfortunately, there is no treatment for children with anencephaly. Most affected babies will die within a few hours or days after birth.

### What can I do to prevent anencephaly?

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 when this problem occurs.

Types of Neural Tube Defects  
in Kentucky



Source: Neurosurg Focus (c) 2004 American Association of Neurological Surgeons

Therefore, the U.S. Public Health Service recommends that all women of childbearing age consume 400 mcg of folic acid daily. This amount will help ensure enough folic acid in a woman's system should she become pregnant. 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 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 cereal. However, to make sure that you're getting enough folic acid, a supplement or multivitamin that contains 400 mcg of folic acid is recommended along with eating fortified foods.

It is absolutely essential that women who have already had a child with anencephaly or another neural tube defect take a higher daily dose of folic acid since future pregnancies have a higher than normal risk of having another child with this disorder. A higher dose of folic acid should begin at least one month prior to any pregnancy. This higher dose (4 m) must be prescribed by a doctor. In addition to taking folic acid, women can take steps before and during pregnancy to be healthy, including not smoking, taking illegal drugs, or drinking alcohol during pregnancy.

### **Where do I go from here?**

We are very sad to hear that your baby has anencephaly and we know that this isn't an easy time for you. You may not know how to feel. Most parents feel denial, grief, and even anger. It's okay to feel that way and no one will blame you. You haven't done anything wrong, and you're not alone. Soon you will find other people and programs to help you through this. You may want to join a support group. Most importantly, take care of yourself. Be patient with yourself while you're grieving, and remind yourself that things will get better. We've provided some information below to help you.

### **Where can I get more resources about anencephaly?**

#### **Kentucky Resources**

[www.firstcandle.org](http://www.firstcandle.org) First Candle – Your Gateway to Information and Support

<http://tcfbluegrass.org/kychapters.html> The Compassionate Friends network

[http://mhmr.ky.gov/mhsas/ofl\\_supportgroups.asp](http://mhmr.ky.gov/mhsas/ofl_supportgroups.asp) Kentucky Parent Support Groups

#### **National Resources**

March of Dimes Foundation [www.modimes.org](http://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](http://www.cdc.gov/ncbddd)  
1-770-488-7160

## **Sources of Folic Acid Vitamin B9**

