

Encephalocele

What is encephalocele?

Encephalocele (en-SEF-ah-lo-SEEL) is one of a group of birth defects known as neural tube defects (NTDs). Encephalocele occurs when the neural tube does not close properly, allowing brain tissue to protrude from the skull into a sac. This tube normally closes around the third or fourth week of pregnancy, before most women even know they are pregnant.

What types of problems occur with encephalocele?

The brains of babies with encephalocele do not form normally, which may result in developmental delays, learning problems, mental retardation, or blindness. It is estimated that only 20% of infants with encephalocele are born alive and, of those, about 50% survive.

How common is encephalocele?

One out of every 5,000 babies born in the United States has encephalocele. In Kentucky, only three babies out of every 100,000 will be born with encephalocele. Of babies with encephalocele in the back of the skull, 70% are female. Encephalocele that occurs in the front of the brain typically affects males.

Some families have more than one person with encephalocele. Encephalocele does not occur in a set pattern in these families. Parents of a child with encephalocele have a higher chance of having another child with encephalocele (about 1 in 25). A genetic counselor or geneticist can help you to determine the risks for your family and situation.

What causes encephalocele?

It is believed that most encephalocele 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 encephalocele.

How is encephalocele treated?

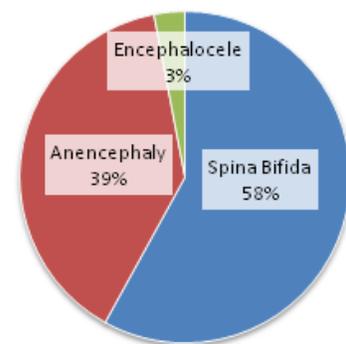
Treatment for encephalocele usually includes surgery within the first few months of life. Children with encephalocele will require life-long care from neurologists, psychiatrists, urologists, and orthopedists. Mobility is often the highest priority for the child to promote independence.

What can I do to prevent encephalocele?

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. Therefore, the U.S. Public Health Service recommends that all women of childbearing age consume 400 mcg of folic acid daily. This regimen will help ensure enough folic acid in a woman's system should she become pregnant. Studies have shown that up to 70% of encephalocele cases could be prevented if women of childbearing age had enough folic acid in their bodies.



Types of Neural Tube Defects
in Kentucky



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. However, to make sure that you're getting enough folic acid, a supplement or multivitamin that contains 400 micrograms of folic acid is recommended along with eating the fortified foods.

It is absolutely vital that women who have already had a child with encephalocele 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 milligrams) 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?

This is a very stressful 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 go for more information about encephalocele?

Kentucky Resources

www.firstcandle.org First Candle – Your Gateway to Information and Support
<http://chfs.ky.gov/ccshcn/> KY Commission for Children with Special Health Care Needs
http://mhmr.ky.gov/mhsas/ofl_supportgroups.asp Kentucky Parent Support Groups
<http://chfs.ky.gov/dph/firststeps> KY First Steps Program (Early Intervention System)

National Resources

March of Dimes 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

Sources of Folic Acid Vitamin B9

