Encephalocele

What is it?

An encephalocele (pronounced en-sef-a-lo-seal) is a rare birth defect affecting the brain. It is one type of neural tube defect. The **neural tube** is a channel that usually folds and closes during the first few weeks of pregnancy. Normally, it forms the brain and spinal cord. Neural tube defects occur when the neural tube does not close as a baby grows in the womb. Neural tube defects can range in size and occur anywhere along the neck or spine. An **encephalocele** is a sac-like projection of brain tissue and membranes outside the skull. Encephaloceles can be on any part of the head but often occur on the back of the skull, as pictured below.



Image courtesy of the Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities

Children with an encephalocele may have additional birth defects, such as hydrocephalus, microcephaly, seizures, developmental delay, intellectual disability, and problems with coordination or movement.

Hydrocephalus is extra fluid around the brain and is also called "water on the brain." Microcephaly is a small head size.

How common is it?

About 375 babies in the United States are born with an encephalocele each year. That's about 1 in every 10,000 babies.

What causes it?

The cause of encephaloceles is unknown in most babies. There may be many factors that cause it. Taking folic acid can decrease the chance of having a baby with neural tube defects. Women who want to become pregnant or are pregnant should take folic acid every day. Having one child with a neural tube defect increases the risk of having a second child with one.

How is it diagnosed?

An encephalocele can be seen during pregnancy. Screening tests are done to check for birth defects, and a special test called an **ultrasound** may be performed to determine the severity of the defect. After birth, an encephalocele is usually seen right away. Sometimes small encephaloceles in the nose and forehead may not be noticed at first.

How is it treated?

Surgery can be done to place the brain tissue and membranes back in the skull and correct any skull or facial defects. Multiple surgeries may be necessary depending on the type of encephalocele. Other treatments depend on the condition of your child. Your child's doctor will discuss treatment options with you.



For more information:

Centers for Disease Control and Prevention
https://www.cdc.gov/ncbddd/birthdefects/encephalocele.html

National Institute of Neurological Disorders and Stroke https://www.ninds.nih.gov/Disorders/All-Disorders/Encephaloceles-Information-Page