

# **ANENCEPHALY**

Also called: Aprosencephaly with open cranium

Anencephaly is one of the most severe forms of a neural tube defect (NTD) and is typically not compatible with life. The neural tube is the developing structure that becomes the brain, skull, and spine. Anencephaly occurs when the "cephalic" or head end of the neural tube fails to close, resulting in the absence of a major portion of the brain, skull, and scalp. Infants with this disorder are born without a forebrain (the front part of the brain) and a cerebrum (the thinking and coordinating part of the brain). The remaining brain tissue is often exposed--not covered by bone or skin. NTDs in general are one of the most common birth defects, occurring in approximately 1 in 1,000 to 2,500 births.

A baby born with anencephaly usually has minimal development of the brain and is usually blind, deaf, unconscious, and unable to feel pain. Although some babies with anencephaly may be born with a rudimentary brain stem, the lack of a functioning cerebrum permanently rules out the possibility of ever gaining consciousness. Reflex actions such as breathing and responses to sound or touch may occur.

There is no cure or standard treatment for anencephaly. Treatment is supportive because the prognosis for babies born with anencephaly is extremely poor.

NOTE: This Web page was compiled from a variety of sources including the online resources of Medline Plus, the National Institute of Neurological Disorders and Stroke, the U.S. National Library of Medicine, Duke Center for Human Genetics and other resources listed below, but is not intended to substitute or replace the professional medical advice you receive from your physician. The content provided here is for informational purposes only, and was not designed to diagnose or treat a health problem or disease. Please consult your health care provider with any questions or concerns you may have regarding this specific condition.

## **RESOURCES**

NOTE: This page contains links to other World Wide Web sites with information about this disorder. The Department of Health and Senior Services (DHSS) hopes you find these sites helpful. Please remember the DHSS does not control nor does it necessarily endorse the information presented on these Web sites.

For a complete list of resources related to birth defects, including state programs and resources, support groups and not-for-profit organizations click on the following link. <https://health.mo.gov/living/families/genetics/birthdefects/resources.php>

**Fetal Health Foundation**

<https://www.fetalhealthfoundation.org/fetal-syndromes/anencephaly/>

**Genetic Alliance**

<http://www.geneticalliance.org>

**MedLinePlus**

<http://www.medlineplus.gov>

**National Institutes of Health**

<http://www.nih.gov/>

**GENETIC TERTIARY CENTERS****How to Obtain Genetic Services**

Your family physician can usually provide information regarding genetic services in your area. Genetic clinics are periodically held in a location near you. For information please contact one of the centers listed below.

**Genetic Tertiary Centers****[Cardinal Glennon Children's Hospital](#)**

St. Louis, Missouri

314-577-5639

**[Children's Mercy Hospital](#)**

Kansas City, Missouri

816-234-3290

**[St. Louis Children's Hospital](#)**

St. Louis, Missouri

314-454-6093