

**Office for Genetics
and
Children with Special Health Care Needs**

Anencephaly Fact Sheet

What Is Anencephaly?

- It is a neural tube defect that occurs when the “cephalic” or head end of the neural tube does not close during development.
- This results in the absence of the skull ,scalp and most of the brain
- An infant born with anencephaly is usually blind, deaf , unconscious and unable to feel pain

Signs and Symptoms

- Blindness
- Deafness
- Inability to feel pain
- Stillbirth
- Absence of large portions of the brain
- Malformation of Brainstem

What is the cause?

- The cause of anencephaly is unknown
- Recent research has shown that child bearing women who get 0.4mg of folic acid per day before they are pregnant and through early pregnancy may reduce the risk of having an infant born with anencephaly
- There may be genetic and environmental factors involved

Is there any treatment?

- Currently, there is no treatment for infants born with anencephaly

Support Groups/Resources

- Anencephaly/Family Village
www.familyvillage.wisc.edu/lib
1-888-206-7526
- Kennedy Krieger Institute
<http://www.kennedykrieger.org>
443-923-9200
- March of Dimes
www.marchofdimes.com
1-410-546-2241
- Office for Genetics and Children with Special Health Care Needs
<http://fha.maryland.gov/genetics/bdris.cfm>
1-800-638-8864
- The Parents' Place Of Maryland
www.ppm.org
410- 768-9100