

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

**Anencephaly Fact Sheet**

**What Is Anencephaly?**

- It is a condition that results in the absence of the skull ,scalp and most of the brain
- It occurs when the “neural tube” of the developing fetus does not close at the head during development.
- 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

- Family Village  
[www.familyvillage.wisc.edu/lib](http://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](http://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](http://www.ppm.org)  
410- 768-9100
- CDC National Center for Birth Defects and Developmental Disabilities  
<http://www.cdc.gov/ncbddd/birthdefects/index.html>
- National Organization of Rare Disorders (NORD)  
<http://www.rarediseases.org/>
- NIH Health information:  
<http://health.nih.gov/topic/BirthDefects>
- Birth Defects Research for Children, Inc  
<http://www.birthdefects.org/>