Facts about Anencephaly

Anencephaly (pronounced an-en-sef-uh-lee) is a serious birth defect in which a baby is born without parts of the brain and skull.

What is anencephaly?

Anencephaly is a serious birth defect in which a baby is born without parts of the brain and skull. It is a type of neural tube defect (NTD). As the neural tube forms and closes, it helps form the baby's brain and skull (upper part of the neural tube), spinal cord, and back bones (lower part of the neural tube).

Anencephaly happens if the upper part of the neural tube does not close all the way. This often results in a baby being born without the front part of the brain (forebrain) and the thinking and coordinating part of the brain (cerebrum). The remaining parts of the brain are often not covered by bone or skin.

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How Many Babies are Born with Anencephaly?

Researchers estimate that about 1 in every 4,600 babies is born with anencephaly in the United States.[1]

Causes and Prevention

The causes of anencephaly among most infants are unknown. Some babies have anencephaly because of a change in their genes or chromosomes. Anencephaly might also be caused by a combination of genes and other factors, such as the things the mother comes in contact with in the environment or what the mother eats or drinks, or certain medicines she uses during pregnancy.

Getting enough folic acid before and during early pregnancy can help prevent neural tube defects, such as anencephaly. If you are pregnant or could get pregnant, take 400 micrograms (mcg) of folic acid every day. If you have already had a pregnancy affected by an NTD, you can speak with your doctor about taking a higher dose of folic acid before pregnancy and during early pregnancy.

- Since the United States began fortifying grains with folic acid, there has been a 28% decline in pregnancies affected by neural tube defects (spina bifida and anencephaly).[1]
- In order to get the recommended 400 micrograms of folic acid every day, a woman of reproductive age can take a supplement containing folic acid or to eat foods fortified with folic acid, or both, depending on her dietary habits.

CDC is dedicated to better understanding the causes of birth defects. Understanding the factors that are more common among babies with a birth defect will help us learn more about the causes. CDC funds the Centers for Birth Defects Research and Prevention, which collaborate on large studies such as the National Birth Defects Prevention Study (NBDPS; births 1997-2011), to understand the causes of and risks for birth defects, including anencephaly.

If you are pregnant or thinking about becoming pregnant, talk with your doctor about ways to increase your chances of having a healthy baby.

Diagnosis

Anencephaly can be diagnosed during pregnancy or after the baby is born.

During Pregnancy

During pregnancy, there are screening tests (prenatal tests) to check for birth defects and other conditions. Anencephaly would result in an abnormal result on a blood or serum screening test or it might be seen during an ultrasound (which creates pictures of the body). For more information about screening and confirmatory tests during pregnancy, visit CDC's birth defects diagnosis web page.

After the Baby is Born

In some cases, anencephaly might not be diagnosed until after the baby is born. Anencephaly is immediately seen at birth.

Treatments

There is no known cure or standard treatment for anencephaly. Almost all babies born with anencephaly will die shortly after birth.

References

1. Mai CT, Isenburg JL, Canfield MA, Meyer RE, Correa A, Alverson CJ, Lupo PJ, Riehle-Colarusso T, Cho SJ, Aggarwal D, Kirby RS. National population-based estimates for major birth defects, 2010–2014. *Birth Defects Research.* 2019; 111(18): 1420-1435.

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