For parents who have
Lost a pregnancy
Or had a child with
Spina bifida,
Anencephaly,
Or
Encephalocele

What You Should Know About Folic Acid

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When parents have had a child with a birth defect, some important questions they may ask are "What caused this to happen?" "Will it happen again?" and "Can we reduce the chances of it happening in a future pregnancy?" This pamphlet may help answer these questions for parents who have had a child with a neural tube defect.

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What are neural tube defects?

Neural tube defects are a group of birth defects involving the spine or brain.

Spina Bifida occurs when a baby's spine does not form properly. Part of the spinal cord may be outside the bones of the spine (vertebrae) and is often not properly formed. This can lead to varying degrees of muscle weakness, paralysis, loss of sensation in the legs, and/or poor bladder and bowel control. Some babies with spina bifida also develop fluid on the brain (hydrocephalus) which occasionally causes brain damage.

Anencephaly is a neural tube defect in which the top part of the skull and brain fail to form properly. Babies with anencephaly may be miscarried, stillborn, or die shortly after birth.

Encephalocele is another less common neural tube defect. This occurs when part of a baby's skull does not form properly, and part of the brain is outside of the skull. Babies with this type of neural tube defect usually die. Babies who survive may have physical and mental handicaps.

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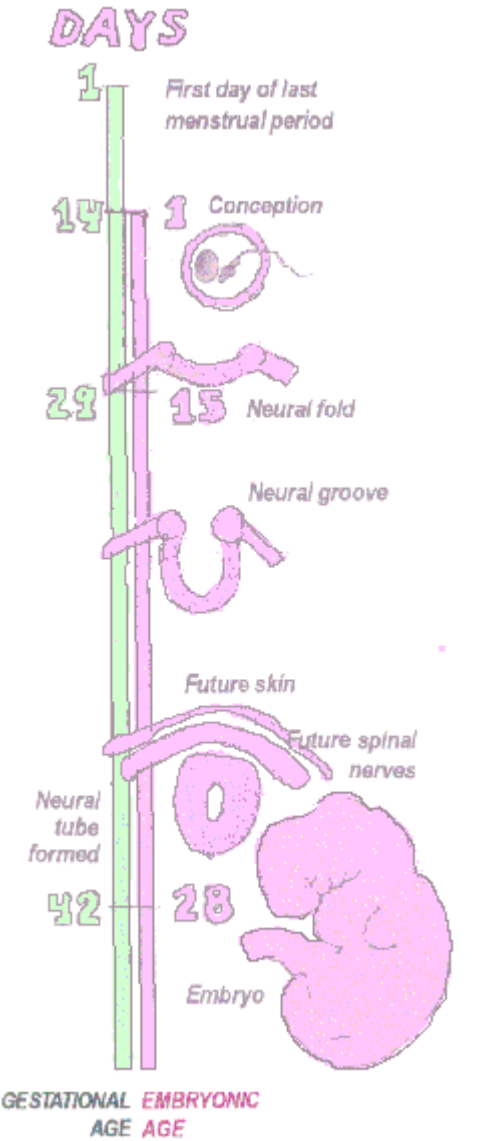
What are the chances of having a baby with a neural tube defect?

The chances of having a child with a neural tube defect for those without a family history are approximately 1/500- 1/1,000 (0.1-0.2%), although this can vary depending on the region where one lives or one's race. Once a couple has had a child with a specific neural tube defect, their chances of having a child with any of the three types of neural tube defects increase to approximately 1/30 or 3%. This means that there is about a 97% chance that a neural tube defect will **not** occur in a future pregnancy.

When do neural tube defects occur during pregnancy?

Neural tube defects occur in the first few weeks after the egg and the sperm come together to create a baby (conception). This is near the time a woman misses her period. Therefore, neural tube defects may occur in an unborn baby before a woman realizes she is pregnant.



Gestational age is measured from the first day of a woman's last menstrual period. This is how doctors date a pregnancy.

Embryonic age is measured from conception, which usually occurs fourteen days after the first day of a woman's last menstrual period.

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What causes neural tube defects?

It is likely there are multiple causes of neural tube defects. One of the causes is lack of a vitamin called folic acid (folate) when the neural tube is forming. There may be a lack of folic acid even if a woman eats well and does everything she can to have a healthy baby. Some women and babies may have a higher need for folic acid, and there is currently no way to tell who they are prior to pregnancy.

Other risk factors for having a child with a neural tube defect include insulin-dependent diabetes in the mother and certain medications which may be used to control maternal epilepsy. It has also been questioned whether elevations in a woman's body temperature when the neural tube is forming, either from a high fever or prolonged exposure to hot tubs or saunas, can cause neural tube defects. Finally, neural tube defects can be part of a genetic condition that has other features as well. If you have questions regarding your own situation, a genetic counselor may be able to help.

What about prevention of neural tube defects?

It is important for couples who have had a child with a neural tube defect to plan subsequent pregnancies since more than half (50%) of recurrences of neural tube defects can be prevented by taking folic acid prior to conception. It must be stressed that a woman must consume folic acid **before** she knows she is pregnant, because the brain and spinal cord may have already begun to form by this time.

The most effective way to prevent the recurrence of a neural tube defect is to consume **4.0 milligrams (mg)** of folic acid daily at least one month prior to conception and throughout the first three months of pregnancy. A woman should not do this by taking large doses of multiple vitamins, since too much of certain other vitamins can actually cause birth defects. A woman should consult with her health care provider to determine how to obtain the proper dosage. (This is often achieved with a multiple vitamin supplemented with extra folic acid.) It is also important to consult with a health care provider since taking extra amounts of folic acid may make it more difficult to detect a rare health condition called vitamin B12 deficiency, or pernicious anemia. In addition, women who have epilepsy need to consult with their physicians, because extra folic acid might affect how their medications control their seizures.

Since over half of all pregnancies are unplanned, even if a woman is **not planning** a pregnancy and is using an effective method of birth control, she should take a vitamin supplement containing 0.4 milligrams (mg), also written as 400 micrograms (mcg), of folic acid daily in case a pregnancy does occur. This is the amount recommended by the U. S. Public Health Service for all women capable of becoming pregnant, regardless of whether they are planning to do so, in hopes of preventing many first occurrences of neural tube defects. (Again, when **actively planning** a pregnancy, the recommended amount of folic acid for those who have had a child with a neural tube defect is ten times greater than that recommended for the general population.)

In addition to a vitamin supplement, women can also increase their folic acid intake by eating certain foods. Foods that are good sources of folic acid are green leafy vegetables (spinach, broccoli, turnip greens, asparagus); dried navy and other beans; lentils; split peas; liver; wheat bran; some fortified cereals; nuts; and orange juice.

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Where can I get more information about folic acid?

More information can be obtained from your physician, health care provider, or by calling a Genetic Center or Spina Bifida (Myelodysplasia) Clinic in your local area.

For copies of this booklet contact:

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