Cystic Fibrosis Carrier Fact Sheet

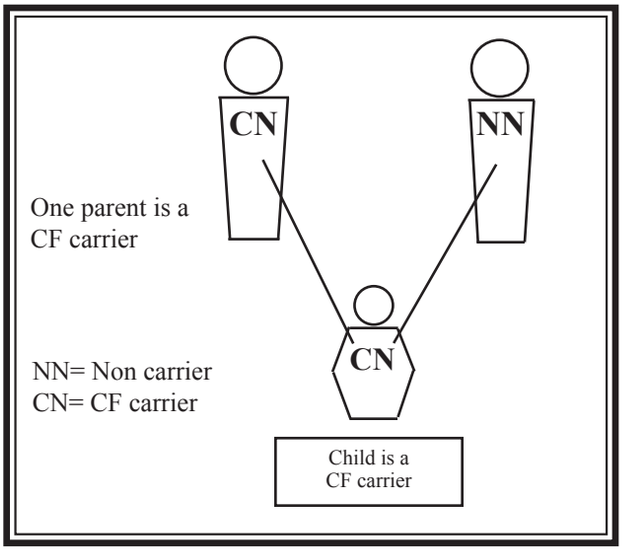
Your baby does not have cystic fibrosis.

What Is A Cystic Fibrosis Carrier?

Your baby's newborn screening test showed that he/she has, or *carries*, one mutation of a cystic fibrosis (CF) gene. Your baby then had a sweat test with normal results. This means that your baby is a *carrier* of a changed CF gene. *A carrier does not have the disease cystic fibrosis*. *A carrier will not develop signs or symptoms of cystic fibrosis*. However, as a parent of a cystic fibrosis carrier, you may still be at risk to have a child who has cystic fibrosis in a future pregnancy.

Why Is My Baby A CF Carrier?

Cystic fibrosis is inherited. This means it is passed down from parent to child through the genes. Your baby inherited a normal CF gene (N) from one parent, and a mutation of a CF gene (C) from the other parent. This means at least one parent (mother or father) is also a CF carrier. If one parent is a CF carrier, and the other parent is not a carrier, then for each pregnancy, there is a 50% chance of having a child that is a carrier for CF and a 50% chance of having a child that is not a carrier for CF.



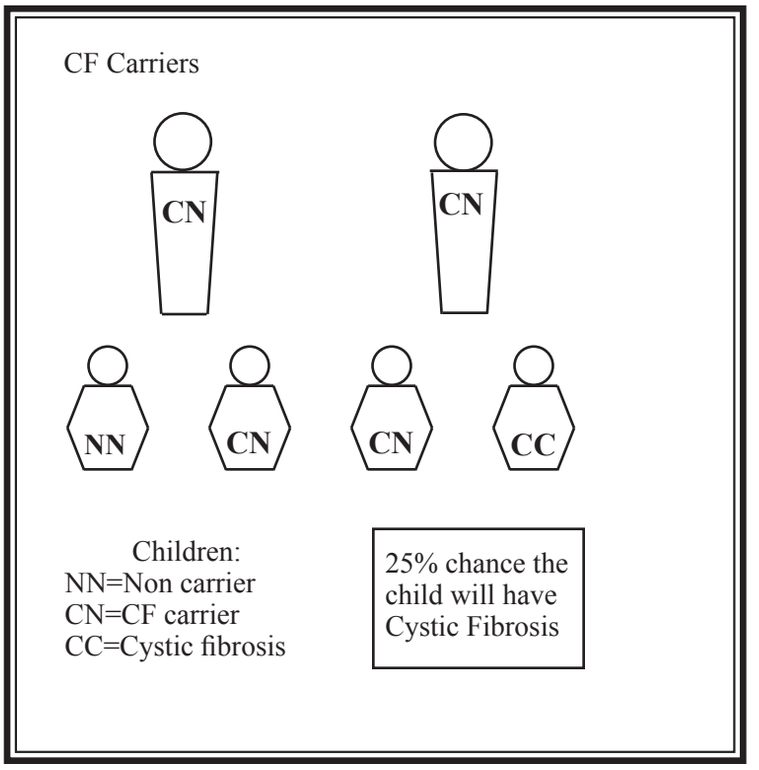
What Are Genes?

Genes are the instructions for making all of our body parts and features. They are the blueprints for making a human. Genes come in pairs. One copy of each gene comes from our mother through the egg and one copy comes from our father through the sperm. As a CF carrier, your child has one normally working gene (N) and one mutation of a CF gene (C).

(More on other side)

Why Would A Parent Want To Be Tested To Find Out If They Are A CF Carrier?

Most people who are carriers don't know it because it does not make them sick. About 1 out of every 30 Caucasians, and 1 out of every 65 African Americans are carriers of a CF mutation. If both parents, are carriers for CF, a future child could get two mutations, (C) one from each parent and therefore have cystic fibrosis. When **both** parents are carriers (CN), every baby has 25% chance of having **cystic fibrosis**. If testing shows one parent is a carrier and the other parent is likely not a carrier, the chance of having a child with cystic fibrosis is significantly reduced.



It is important to know if both parents are carriers for CF because a child who has cystic fibrosis can have significant medical problems. Children with CF have thick, sticky mucus making them more prone to respiratory infections and pneumonia. Problems in the digestive system may make it hard to digest food; this can cause diarrhea and poor growth.

How Do I Find Out If I Am A CF Carrier?

A special test can be done to find out if each parent is a CF carrier. This blood test is called a DNA test and is the only way to determine if a person is a CF carrier. You will not know about your own carrier status unless you ask to have this test. You may want to speak with a genetic counselor or your health care provider about your test results or the risks to your children. Tests done during a pregnancy can help you find out if the baby has CF. Genetic counselors can also tell you about these tests.

What Does My Child Need To Know About Being A CF Carrier?

As your child grows older, you should be certain that your child knows that he/she is a CF carrier. A genetic counselor or health care provider can help your child understand what is means to be a CF carrier and answer questions about risks to future pregnancies.

The content of this fact sheet has been reviewed by the NBS Advisory Subcommittee.

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