

Being a cystic fibrosis carrier:



What does it mean
for you and your
family?

WE HAVE SOME GOOD NEWS FOR YOU!

Your baby does not have cystic fibrosis. Your baby will never develop cystic fibrosis.

Your baby's newborn screening test showed that he/she carries one altered copy of a CF gene tested for by the blood test. Your baby then had a negative sweat test. This means that your baby is *only* a carrier of an altered CF gene, and does not have the disease.

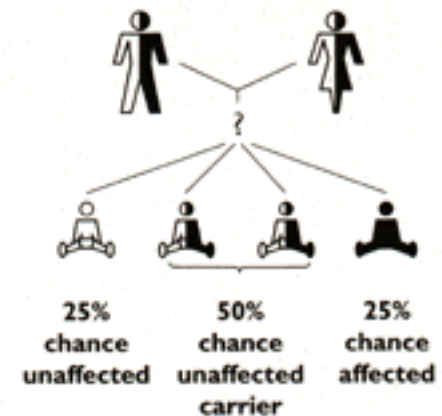
A CARRIER MEANS YOUR BABY WON'T BE SICK FROM CYSTIC FIBROSIS

We all have thousands of pairs of genes in our bodies. Each pair of genes "tells" our bodies how to look and act, how tall we will be, what color our eyes will be, and so on. Everybody has two CF genes. However, to have cystic fibrosis, a person has to have two altered copies of the CF gene. A person having only one altered copy of the CF gene is called a CF carrier. A *carrier does not have, and will never develop cystic fibrosis.*

CF IS INHERITED FROM YOUR PARENTS

Approximately 1 out of every 30 white Americans, and 1 out of every 65 African Americans are carriers of an altered CF gene. If both parents are carriers, then three possibilities can occur when they have children: 1) they can have a child with cystic fibrosis, 2) they can have a child who is a CF carrier, or 3) they can have a child who does not carry the altered CF gene. See Figure 1.

Figure 1

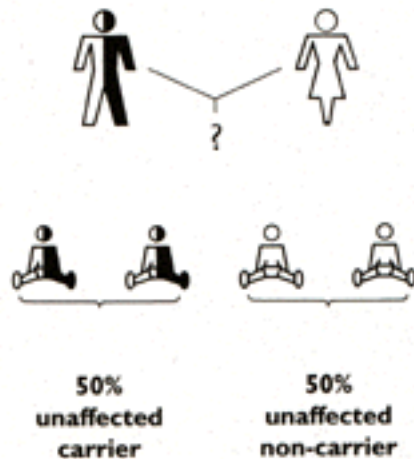


When both parents are CF carriers, each of their children has:

- a 1 in 4 (25%) chance of having CF;
- a 1 in 2 (50%) chance to be a CF carrier; and
- a 1 in 4 (25%) chance of not carrying the altered gene.

If one parent is a CF carrier, and the other parent is not a carrier, then there are two possibilities that can occur when they have children. See Figure 2.

Figure 2



If one parent is a CF carrier, and the other parent is not a carrier, then each of their children has:

- a 2 in 4 (50%) chance of being a CF carrier; and
- a 2 in 4 (50%) chance of not carrying the altered CF gene.

Any baby born to this couple would not have cystic fibrosis but could be a carrier.

KNOWING YOU ARE A CF CARRIER IS IMPORTANT TO YOU AND YOUR FAMILY

Your child will have no health problems related to being a CF carrier. Tell your child that (s)he is a CF carrier. Help your child understand that this is inherited and that it can be passed on to his/her children. Your child should talk with a doctor or genetic counselor about this before deciding to become a parent. This information may also be helpful to you, as parents, if you are planning to have more children. Some parents may want to be tested to find out whether or not they are both carriers.

QUESTIONS? WE ARE HERE TO HELP YOU...

We understand that this can be a very confusing and frightening time for you and your family. We encourage you to make an appointment with a genetic counselor who can sit down with you and answer all of your questions about being a carrier for the CF gene. Research is continually finding new information about cystic fibrosis, and so our knowledge is always expanding.

To schedule an appointment with a genetic counselor, you can call:

The Waisman Center
UW Madison
(608) 262-2507

Children's Hospital of Wisconsin
Milwaukee
(414) 266-3345

St. Vincent Hospital
Green Bay
(920) 433-8634

Marshfield Medical Center
(715) 387-5089

LaCrosse Regional
Genetics Services
(608) 791-6681

Department of Health and Family Services
Division of Health
Bureau of Public Health

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