

# Should I have a Cystic Fibrosis Carrier Test?



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## What is Cystic Fibrosis (CF)?

CF is a disease some babies are born with that causes problems with breathing and digesting food. Symptoms usually begin during the first year of a baby's life, and get worse as the child grows up. Some children are very sick, and others are not. Problems may be coughing, lung infections that keep coming back, lung damage, diarrhea (many loose stools), and poor growth. People with CF are not mentally retarded. The disease does not change the way they look. Most people with CF live 20 to 35 years. There is no cure. Treatment is usually medicine and physical therapy.

## What causes CF?

CF is an inherited disease (can run in families), caused by genes that are not working. People who have CF have 2 genes that are not working - 1 from each parent. Carriers are people who only have 1 gene that is not working. Carriers are not sick with CF. Genes do not change during a person's lifetime. So a carrier will always be a carrier, but will never get sick with CF. There is now a blood test that looks for the gene that is not working. If you want to have the blood test, a small sample of blood will be taken from your arm.

## Why would I want to have this blood test?

The reason you may want to have this blood test is to find out whether or not you are at high risk to have a baby with CF. If this is important for you to know, then you should have the test.

### If the test shows that you are a carrier:

- You will meet with a genetic counselor.
- Your partner may be tested.
- More tests can be done to find out whether your baby does have CF.

## Why would I not want to have this blood test?

If it is not important for you to find out whether or not your baby might have CF, you may not want to have this test.

- Having the blood test may lead to other tests that have a small risk of miscarriage.
- If the father of the baby cannot have his blood tested, you might choose not to have the test.
- If you are more than 20 weeks pregnant, it is too late to have the test.
- If you have ever had this test before and it showed that you are not a carrier, there is no reason for you to have it again. The results will not change.

## How can I get more information?

- See Page 2 of this handout for more information.
- Call Parkland Hospital's Genetics Department at (214) 590-8704 if you have questions or if you would like to have the test. You can also ask your health care provider to have the test done today, if you want.
- The Cystic Fibrosis Foundation web site is: <http://www.cff.org>.

## **More information about Cystic Fibrosis (CF)**

### **What is the chance that I am a carrier?**

Your chance of being a carrier depends on your race (ethnic group). It also depends on whether someone in your family has CF. Your chance is highest if you have a close relative with CF.

The exact chance depends on how you are related to the person with CF.

- If you are Caucasian (white) and no one in your family has CF the chance you are a carrier is about 1 in 30 (3%). This means there is a 97% chance that you are not a carrier.
- If you are Hispanic and no one in your family has CF, the chance that you are a carrier is 1 in 46 (2%). This means there is a 98% chance that you are not a carrier.
- If you are Asian, Native American or African American, the chance of you being a carrier is even less than for Caucasian or Hispanic people.

### **Is the carrier test result always right?**

It depends on your race. Most of the time it is right for people who are Caucasian. It is less often right for people who are not Caucasian.

### **What is the chance my baby will have CF?**

- If both you and your partner are Caucasian, your chance of having a baby with CF is about 1 in 3500 (0.03%).
- If neither one of you is Caucasian, your chance of having a baby with CF is very small. For example, if you and your partner are both Hispanic, the chance for you to have a baby with CF is 1 in 8,500 (0.01%).

### **Can I have a baby with CF even if my test result is normal?**

Yes, because the test only picks up some (not all) of the changes in the genes that are not working.

### **What if I find out during my pregnancy that the baby has CF?**

There is no cure for CF, and there is no treatment before birth. Treatment after birth often helps, but not always. No one can say how sick the baby will be. If your baby has CF, a counselor will talk with you about your choices.

### **If I want to have the carrier test, when will it be done?**

It is best to take the test before you are pregnant. If you are already pregnant, you should have the test before you are 20 weeks pregnant.