

Your tests are performed by Legacy Laboratory Services, which uses state-of-the-art technology for prenatal screenings.

For more information about cystic fibrosis testing, please speak with your provider or request a referral to a genetic counselor.

To reach Legacy genetic assessment and counseling, please call 503-413-1122 or 360-487-2870.

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# Information on carrier testing for cystic fibrosis

Cystic Fibrosis Genetic Testing



## Legacy Laboratory Services



EMANUEL Medical Center	GOOD SAMARITAN Medical Center	MERIDIAN PARK Medical Center	
MOUNT HOOD Medical Center	SALMON CREEK Medical Center	THE CHILDREN'S HOSPITAL Legacy Emanuel	
LEGACY MEDICAL GROUP	LEGACY LABORATORY	LEGACY RESEARCH	LEGACY HOSPICE

# Cystic fibrosis carrier testing

**Cystic fibrosis** carrier testing is available to you on a voluntary basis. It can be right for some and not right for others, depending on your level of risk, your insurance coverage or religious beliefs. Legacy Laboratory Services and Legacy Medical Group–Maternal-Fetal Medicine provide the following information on cystic fibrosis and cystic fibrosis carrier testing for patients.

Carrier testing is a personal decision; the information in this brochure is provided to assist you and the baby's father in making an informed decision.

If you decide to have the test, once you have read this brochure or if you have further questions about cystic fibrosis, please speak with your health care provider, or contact the Legacy Medical Group–Maternal-Fetal Medicine at 503-413-1122 with your questions. You should also contact your insurance company to determine if the test is a covered service and what portion of the cost may be your responsibility.

## **What is cystic fibrosis (CF)?**

CF is a disease that causes breathing and digestion problems. Symptoms usually begin in the first year of life and get worse over time. Problems may include coughing, repeated pneumonia, lung damage, diarrhea and poor growth. People with CF are not at an increased risk of mental retardation. Their appearance is not affected. Current life expectancy for individuals with CF is approximately 30 years of age. This may increase further with improved treatments. However, at this time, there is no cure.

## **What causes CF?**

CF is an inherited disorder. It is caused when a person inherits two CF genes, one from their mother and one from their father. A person with only one changed gene (also called a mutation) of the pair is called a "carrier." Carriers are not sick. Genes do not change during one's lifetime. Therefore, a carrier will always be a carrier, but will never get sick with CF.

## **How could my child have CF?**

First, both parents must be carriers. If you are both carriers, there is a 1 in 4 chance (25 percent) that your baby will have CF. Even if you are both carriers, there is still a 3 out of 4 chance (75 percent) that your baby will not have CF.

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

Your chance of being a carrier depends on whether someone in your family has CF and on your race (ethnic group).

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 no one in your family has CF and you are Caucasian, the chance you are a carrier is about 1 in 30 (3 percent) in this example, this means there is a 97 percent chance a Caucasian person is not a carrier. The chance to be a carrier is much smaller for Asians, Latin Americans, Native Americans and African Americans.

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

If both you and your partner are Caucasian, your chance of having a child with CF is about 1 in 3,500 (0.03 percent). If only one of you is Caucasian, the chance is even smaller. If neither of you is Caucasian, your chance of having a child with CF is very small.

### **How can I find out if I am a carrier?**

A blood test looks for the most common forms of the changed gene. If you decide 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?**

Some people wish to know whether they are at high risk to have a baby with CF. If the test shows you are a carrier, your partner would be offered testing. If your partner is also a carrier, more tests would be needed to find out whether the baby actually has CF. If this is important for you to know, have the test.

### **Why wouldn't I want to have this blood test?**

If it is not important for you to find out whether or not your child might have CF, it might be better for you not to have the test. Talk to your health care provider to find out. Keep in mind that all babies born in Oregon and Washington are automatically screened for CF after birth through newborn screening.

### **What does my health care provider recommend?**

If either you or the father of the baby is Caucasian, the American College of Obstetrics/Gynecology (ACOG) recommends that your health care provider should tell you the test is available. However, the decision to be tested is up to you.

### **How accurate is the carrier test?**

The biggest factor is your race. The test is most accurate for people who are Caucasian. It is less accurate for Asians, Latin Americans, Native Americans and African Americans, but can still be performed.

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

Yes. A normal result means that the most common forms of the changed CF gene were not found in you. However, the test cannot find all changed genes. It does find most CF gene changes in people who are Caucasian. It finds fewer of the changed CF genes in non-Caucasians.

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

There is no cure for CF and there is no treatment before birth. Many people would want to know ahead of time if the baby has CF so they can learn as much as possible about it and be prepared. Some people would choose to end a pregnancy if the baby had CF. Treatment after birth often helps, but not always. No one can predict how sick or healthy the baby will be.

### **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 and decide to be tested, you should have the test as early in the pregnancy as possible.

## How can I get more information?

Talk to your health care provider. You can also talk with a genetic counselor who is specially trained to help you decide what is best for you. You can contact a Legacy genetic counselor at 503-413-1122 with your questions.

The Cystic Fibrosis Foundation website is: [www.cff.org](http://www.cff.org)

Portions of this brochure were adapted from the Pacific Northwest Regional Genetics Group PacNoRGG website: [http://www.westernstatesgenetics.org/pacnorgg\\_page.htm](http://www.westernstatesgenetics.org/pacnorgg_page.htm)

## Consent/Decline for Cystic Fibrosis (CF) Carrier Testing

You should be certain you understand the six items listed below. If you are not certain about any of them, please ask your health care provider to explain them further before signing this form accepting or declining CR carrier testing.

1. I understand that the decision to be tested for CF carrier status is completely mine.
2. I understand that the test does not detect all CF carriers.
3. I understand that if I am a carrier, testing the baby's father will help me learn more about the chance that my baby could have CF.
4. I understand that if one parent is a carrier and the other is not, it is still possible that the baby will have CF, but that the chance of this is very small.
5. I understand that if both parents are carriers, additional testing can be done in order to know whether or not the baby will have CF.
6. I understand that if the baby has inherited a changed CF gene from each parent, the baby will develop CF and there is not prenatal treatment available to prevent this from occurring.

## I have read and understand the information provided to me by

(Name) \_\_\_\_\_

I do not want CF carrier testing

I want CF Carrier testing

Signed: \_\_\_\_\_

Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

