

## CYSTIC FIBROSIS

### What is Cystic Fibrosis?

CF is an inherited disease affecting about 1 in 3300 people in the United States. It is most common in Caucasians, but can occur in other ethnic backgrounds. CF causes parts of the body to produce thick mucus leading to pneumonia, diarrhea, poor growth and infertility. Intelligence is normal. Severely affected individuals die in childhood, but some people are only mildly affected. The average life span is around thirty years; this may improve as scientists search for better treatments.

### Why are some babies born with CF?

If both parents are carriers of a CF gene, each of their children has a 25% chance of having the disease and a 75% chance of not having it. These chances are the same for each pregnancy no matter how many children the couple has had, and are the same for boys and girls. Carriers are not themselves affected by the disease.

### Who are carriers and how can they find out?

If there is no one in your family with CF, your risk for being a CF carrier is shown below along with detection rates of the CF carrier test. If someone in your family has CF, then no matter what your ethnic background, your chance of being a carrier is increased. The chance is greater if the person with CF is a close relative.

<b>If you are:</b>	<b>Your chance of being a CF carrier is:</b>	<b>The carrier test detection rate is:</b>
Northern European	1/25 – 1/29	90%
Southern European	1/25 – 1/29	70%
Ashkenazi Jewish	1/26 – 1/29	97%
Hispanic	1/46	57%
African American	1/60 – 1/65	72%
Asian American	1/90	30%

### What if your test results show you are a CF carrier?

If your test shows you have one CF gene, then you are a CF carrier. This result does not affect your own health. If one member of the couple is a CF carrier and the other is not, then the risk is less than 1 in 1000 (0.1%) that any child of theirs would have CF. If both parents are CF carriers, each pregnancy has a risk of 1 in 4 (25%) that the child will be affected. If only one member of the couple has been tested and is found to be a carrier, the partner should be tested as soon as possible. The information from the carrier test may benefit you in your family planning. The information may also have implications for family members; if you are a CF carrier your relatives may also carry the gene and should be offered testing.

### What if your test results do not show a CF gene?

If your test results do not show a CF gene, the chance that you are a CF carrier is low but not zero. The test takes into account your ethnic background and any family history of CF. Because the test cannot find all CF carriers, the chance of being a carrier is never zero.

**I Want To Be Tested**

**I Decline Testing**

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date