

The following information is about a blood test that can be done to determine if you and/or your partner carry the gene for cystic fibrosis.

CYSTIC FIBROSIS CARRIER TESTING

WHAT IS CYSTIC FIBROSIS?

- Cystic fibrosis (CF) is an inherited disease that affects more than 25,000 American children and young adults.
- Symptoms of CF vary but include lung congestion, pneumonia, diarrhea and poor growth. Most people with CF have severe medical problems and some die at a young age. Others have so few symptoms they are unaware they have CF.
- CF does not affect intelligence.
- Although there is no cure for CF at this time, scientists are making progress in improving treatment and in searching for a cure. In the past many people with CF died at a very young age. Today, many are living into their 20's and 30's.

IS THERE A CHANCE MY BABY COULD HAVE CYSTIC FIBROSIS?

- You can have a child with CF even if there is no history in your family (see chart below)

Approximate risk that a couple with *no family history* of CF will have a child with CF

Ethnic Background	Risk
Caucasian couple	1 in 2,500
Hispanic couple	1 in 8,000
African American couple	1 in 15,000
Asian American couple	1 in 32,000

- CF testing can help determine if you are a carrier and at risk to have a child with CF.
- If both parents are carriers, there is a 1 in 4 (25%) chance, with each pregnancy, that they will have a child with CF.
- Carriers have one normal CF gene and one altered CF gene.
- People with CF have two altered CF genes.
- Most people have two normal copies of the CF gene.

WHAT TESTING IS AVAILABLE?

- There is a blood test that can be done to find out if you or your partner is a carrier.
- It is important to understand that CF carrier testing does not detect all CF carriers.
- If the test shows that you are both CF carriers, your unborn baby can be tested to find out if the baby has CF.

HOW MUCH DOES IT COST TO HAVE CYSTIC FIBROSIS CARRIER TESTING?

- Cost and insurance coverage for CF carrier testing vary depending upon the laboratory used and your insurance policy.
- The average cost for CF carrier testing is \$463 per person.

Your genetic counselor can provide you with more information about cystic fibrosis carrier testing.

- I am interested in discussing carrier testing with a genetic counselor
- I am not interested in CF carrier testing or in receiving more information about CF carrier testing

Patient signature _____

Date _____