

**CAPITAL AREA OBSTETRICS AND GYNECOLOGY
CYSTIC FIBROSIS CARRIER TESTING**

WHAT IS CYSTIC FIBROSIS?

- Cystic fibrosis (CF) is an inherited lung and digestive disease. More than 25,000 American children and young adults have CF. About 850 cases of CF are diagnosed each year.
- Symptoms of CF vary but include lung congestion, pneumonia, diarrhea and poor growth. Many 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 a person's learning ability or what he/she looks like.
- Although there is no cure for CF at this time, scientists are making progress in improving treatment and in searching for a cure. The average person with CF lives to age 30. A baby born with CF today may live longer.

IS THERE A CHANCE MY BABY COULD HAVE CYSTIC FIBROSIS?

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

ETHNIC BACKGROUND	CHANCES YOU ARE A CARRIER	RISK OF A BABY WITH CF	DETECTION RATE
Caucasian couple	1 in 29	1 in 3,300	80%
Ashkenazi Jewish couple	1 in 29	1 in 3,300	97%
Hispanic couple	1 in 46	1 in 8,000	57%
African American couple	1 in 65	1 in 15,300	69%
Asian couple	1 in 90	1 in 32,100	

- Most people have two normal copies of the CF gene.
- If both parents are carriers (have 1 abnormal CF gene), there is a 1 in 4 (25%) chance, with each pregnancy, that they will have a child with CF.
- Carriers have one normal copy and one abnormal copy of the CF gene.
- People with CF have two abnormal (non-working 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 might carry a gene for CF (is a carrier). This is a voluntary blood test.
- It is important to understand that carrier testing does not detect all CF carriers (people with 1 CF gene).
- If the test shows that you both have a CF gene, your unborn baby can be tested to find out if the baby has CF. Testing of the pregnancy is voluntary.

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

- Cost and insurance coverage for CF carrier testing depends upon your insurance policy. Please ask to speak to a financial counselor if you would like information about this.

Your doctor or a genetic counselor can provide you with more information about this testing and answer any of your questions. They can also give you a detailed brochure about CF and your testing options.

No. I am not interested in CF carrier testing.

Yes. I would like to have CF carrier testing. Test ordered _____

Date

Patient Signature: _____ Date: _____

Reviewed by: _____ Date: _____