MCG
Reproductive Medicine & Infertility Associates

CYSTIC FIBROSIS CARRIER TESTING
The Choice is Yours

What is Cystic Fibrosis?

Cystic Fibrosis is a genetic disease that causes problems with breathing and digesting food. Children with cystic Fibrosis need breathing therapy every day, and may need to take medicine to help them digest food. Children with Cystic Fibrosis often get sick enough to be in the hospital. People with Cystic Fibrosis die very young, usually by age 30.

What causes Cystic Fibrosis?

Everyone has two copies of the gene for Cystic Fibrosis. One copy comes from the mother and the other from the father. Cystic Fibrosis is caused by a change in the gene. If you have one copy of the gene with a change you are a carrier. If you have a change in both copies of the gene you will have Cystic Fibrosis.

Why is it important to know if I am a carrier of Cystic Fibrosis?

People who are carriers of Cystic Fibrosis do not have health problems themselves, but can have children with Cystic Fibrosis. If both the mother and father are carriers there is a ¼ (or 25%) chance that each of their babies could have Cystic Fibrosis.

What is the chance I am a carrier of Cystic Fibrosis?

The chance of being a carrier of Cystic Fibrosis depends on your family history and ethnic/racial background. If someone in your family has Cystic Fibrosis or is a carrier, you will have an increased risk of being a carrier.

If you are European, Caucasian, or Ashkenazi Jewish your risk is	1/29
If you are Hispanic your risk is	1/46
If you are African American your risk is	1/65
If you are Asian your risk is	1/90

How do I get carrier testing?

The test is a special blood test that can be done at your doctor's office. The results are usually available in a week to ten days.

Can the test be wrong?

There are many different possible changes in the gene for Cystic Fibrosis. We cannot test for all of them. A negative test lowers your risk to be a carrier but cannot make it zero. A positive test means you are a carrier.

Should the father of my baby be tested?

For a baby to have Cystic Fibrosis both the mother and the father have to give the baby a changed gene. We need to know about both the mother's and the father's genes for us to give you the most accurate information about your baby's chance to have Cystic Fibrosis.

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CYSTIC FIBROSIS SCREENING

I have received the information sheet on Cystic Fibrosis Screening.

I understand that my risk for being a carrier of Cystic Fibrosis depends on my ethniclracial background.

_ I am European Caucasian or Ashkenazi Jewish, my risk to be a carrier is 1/29.
_ I am Hispanic, my risk to be a carrier is 1/46.
_ I am African American, my risk to be a carrier is 1/65.
_ I am Asian, my risk to be a carrier is· 1/90.

I understand the risk that my baby will have Cystic Fibrosis depends on both the mother's and the father's ethnic/racial background. I have been told what the risk is for this baby to have Cystic Fibrosis based on our carrier risk.

_ We are both European Caucasian and Ashkenazi Jewish, our risk for a child with Cystic Fibrosis is 113364.
_ We are both Hispanic, our risk for a child with Cystic Fibrosis is 1/8464.
_ We are both Asian our risk to have a child with Cystic Fibrosis is 1/32400.
_ I am _____, the baby's father is _____ , our risk to have a child with Cystic Fibrosis is _____.

Based on this information I would like to:
_ Talk to the Genetic Counselor about my risk.
_ Have Cystic Fibrosis carrier testing.
_ Do not want Cystic Fibrosis carrier testing.

_____ _____
Patient Signature Date

CYSTIC FIBROSIS RISK CALCULATIONS

Caucasian/Jewish and Hispanic 1/29 X 1/46 X 1/4 = 1/5336

Caucasian/Jewish and African American 1/29 X 1/65 X l/4 = 1/7540

Caucasian/Jewish and Asian 1/29 X 1190 X 1/4= 1110440

Hispanic and African American 1/46 X 1/65 X 114 = 1111960

Hispanic and Asian 1/46 X 1/90 X 114 = 1116560

African American and Asian 1/65 X 1/90 X 114 = 1/23400