

Cystic Fibrosis

What is Cystic Fibrosis?

Cystic Fibrosis (CF) is the most common genetic disorder in Caucasians of European descent. It can cause serious respiratory and digestion problems, as well as poor growth and infertility. One in 3,300 people in the United States is born with CF. The average lifespan of an individual with CF is 35 years. Cystic Fibrosis does not affect intelligence or appearance.

How is Cystic Fibrosis inherited?

The only way to get CF is by inheriting two CF genes – one from each parent who “carries” a CF gene. This is called recessive inheritance. Carriers have one CF gene and one normal gene and that allows them to remain healthy. When two carriers have a child, there is a 25 percent chance that the child will have CF. This chance is the same for each pregnancy, no matter how many children the couple has.

What is Cystic Fibrosis carrier screening?

If you are Caucasian of European descent and do not have any family history of CF, then your risk of being a carrier is between one in 25 and one in 29. CF carrier testing, which is 85 percent accurate, requires a small sample of blood or a cheek brush sample. If your result does not show a CF gene mutation, the chance that you are a carrier is less than one percent. The results are usually available in two weeks. Most insurance companies cover the screening. Please check with your insurance company to be certain if they cover screening. Costs for CF testing range from \$300-\$500.

What if your test result shows you are a CF carrier?

If you are found to be a CF carrier, it is recommended that your partner be tested. Prenatal testing for CF is also available. Remember, unless both parents are carriers, a child will not be affected. To discuss the implication of being a CF carrier in more detail, you will be referred to a genetic counselor.

To screen or not to screen...

Carrier testing is voluntary, and the decision is a personal choice. Once you have decided whether screening is appropriate for you, please let your doctor know. Your doctor can help answer other questions you may have.

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**Questionnaire on back
Please fill out**

Associates in Women's Care Genetics Questionnaire

Name: _____ Spouse's Name: _____

Please answer "yes" or "no", as appropriate, and bring this sheet with you to your next appointment.

YES NO

1. Will you be thirty-five or older at your due date?
2. Have you had an amniocentesis/CVS before?
3. Has anyone in your family been referred for a genetic evaluation?
4. Do you or your partner have any health problem?
5. Are you or your partner of:
 - Jewish background?
 - Black or African background?
 - Asian background?
 - French - Canadian background?
6. Have you taken any medications (prescription or over the counter) during this pregnancy?
7. Have you used any street drugs during this pregnancy?
8. During this pregnancy, have you taken Accutane, epilepsy medication, blood thinners, or lithium?
9. Have you had radiation therapy, x-rays or chemotherapy since your last period?
10. Have you or your partner been exposed to any hazardous chemicals or environmental toxins?
11. Are you or your partner related in any other way other than be marriage (such as cousins, etc)?
12. Have you, your partner or anyone in either family ever had:
 - A child with Down syndrome or other chromosome problems?
 - A child with mental retardation?
 - Open spine (spina bifida), skull defect or anencephaly?
 - Heart defect?
 - Muscle or neuromuscular disease (muscular dystrophy)?
 - Three or more miscarriages?
 - A still born baby?
 - A baby that died shortly after birth or in the first year?
 - Cystic fibrosis? - See reverse side-
 - Hemophilia sickle cell, thalassemia or other blood disorder?
 - Any birth defects or genetic disease not listed above?

COMMENTS: _____
