



Consent for Cystic Fibrosis Carrier Testing

What is Cystic Fibrosis?

Cystic Fibrosis (CF) is a genetic condition affecting the ability to secrete mucous fluids normally. Individuals with CF commonly have problems with the lungs, digestive, and reproductive systems. They often suffer from pulmonary infections and organ damage due to difficulty in clearing secretions. The severity of CF varies from person to person. The condition does not affect intelligence, appearance, or development. There is no cure for CF currently. The average life expectancy is 30 years, but children born today with CF may live longer as treatments improve. Currently, CF is diagnosed by blood testing when a pediatrician suspects the condition during childhood.

How Common is CF?

African-American	Ashkenazi Jewish	Asian	European Caucasian	Hispanic
1/15,300	1/3,300	1/32,000	1/3,000	1/8,500

Could I have a child with CF? How do I know if I carry the gene?

CF is a recessive condition, therefore IF BOTH PARENTS ARE CARRIERS; there would be a 25% chance of the child having the disease. Carrier frequency varies by ethnic background:

African-American	Ashkenazi Jewish	Asian	European Caucasian	Hispanic
1/62	1/29	1/90	1/25	1/46

A blood test can be performed to detect if you are a carrier, but accuracy also varies by ethnic background. The test will detect the following percentage of carriers:

African-American	Ashkenazi Jewish	Asian	European Caucasian	Hispanic
69%	97%	30%	80%	57%

How much does the testing cost?

As of January 2002, ACOG recommends discussing CF testing with all couples. However, this recommendation does not imply that insurance will necessarily cover the cost of the screening. Coverage varies, and patients need to contact their insurer directly.

What if my spouse and I are carriers? Can the baby be tested?

Fetal testing can be done via amniocentesis. Results may take several weeks to complete.

- Yes, I wish to have my blood drawn for cystic fibrosis carrier testing. It's my responsibility to check with my insurance regarding coverage.
- No, I do not want to have my blood drawn for cystic fibrosis testing.

Signature: _____ Date of Birth: _____ Date: _____

ACOG Recommendations: (January 2002)

CF carrier testing is offered to all European/Caucasian couples, those with a family history of CF, or partners of individuals with CF. Written informed consent is required for these groups. Individuals of other ethnic backgrounds should be provided with written material about testing, but written consent is not mandatory.

Lone Star OB/GYN Associates Policy

Given the multi-ethnic background of many of our patients, consent information is to be given to all couples by nurse at first prenatal visit. They should be informed that screening is optional, but if elected, best performed early in the pregnancy. They should return their signed consent to testing/refusal of testing at the first or second prenatal visit