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## 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?

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

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

European/Caucasian:	80%	African American:	69%
Ashkenazi Jewish:	97%	Asian:	30%
Hispanic:	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 screen. 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 is my responsibility to check with my insurance regarding coverage.  
 No, I do not want to have my blood drawn for cystic fibrosis carrier testing.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

To learn more about Cystic Fibrosis, contact

1. Cystic Fibrosis Foundation 1-800-FIGHT CF (1-800-344-4823) [www.cff.org](http://www.cff.org) E-mail: [info@cff.org](mailto:info@cff.org)
2. National Society of Genetic Counselors 1-610-872-7608 Press 7 [www.nsgc.org](http://www.nsgc.org) Click on Resource Link
3. Genetic Alliance 1-800-336-4363 [www.geneticalliance.org](http://www.geneticalliance.org) E-mail: [info@geneticalliance.org](mailto:info@geneticalliance.org)