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Cystic Fibrosis

Cystic fibrosis (CF) is a disease affecting primarily the lungs and the digestive system. Affected individuals have difficulty fighting lung infections and problems digesting food appropriately resulting in life long care. CF is a genetic disease where affected persons inherit a mutated gene from both parents. Individuals with only one gene mutation are called carriers. These individuals are not affected with CF but have a 50% chance of passing the gene to their children. If two carriers produce a pregnancy together, there is a 25% chance with each pregnancy that the child will be affected by CF and a 75% chance that the child will be normal (2/3 will be carriers). An individual's risk of being a carrier varies by ethnicity and ancestral origins.

American College of Obstetricians and Gynecologists (ACOG) Guidelines

In October 2001, ACOG released new guidelines for screening for cystic fibrosis. Currently, ACOG recommends that **screening be offered** to the following groups:

- Individuals at high risk for being a carrier for CF (a family history of CF; reproductive partners of individuals who have CF; couples in whom 1 or both partners are Caucasians of European or Ashkenazi Jewish descent)
- Low-risk couples of other racial or ethnic groups in prenatal care

Informed Consent/Decline

You should be certain you understand the six items listed below. If you are not certain about any of them, please ask your health care provider to explain them further before signing this form accepting or declining CF carrier testing.

1. I understand that the decision to be tested for CF carrier status is completely mine.
2. I understand that the test detects most but not all CF carriers.
3. I understand that if I am a carrier, testing the baby's father will help me learn more about the chance that my baby could have CF.
4. I understand that if one parent is a carrier and the other is not, it is still possible that the baby will have CF, but that the chance of this is very rare.
5. I understand that if both parents are carriers, additional testing may be done in order to know whether or not the baby will have CF.

I have read and understand this information and:

_____ I do not want CF carrier testing

_____ I want CF carrier testing

_____ I have already been tested for CF, and my lab results are located at _____

Signed: _____ Date: _____