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CYSTIC FIBROSIS SCREENING

Definition

1. Cystic fibrosis (CF) is a genetic disorder that causes problems with breathing and digestion. It is caused by an abnormal *gene* that is passed from parent to child. There is no cure for cystic fibrosis, but it can be treated. Testing can be done to see if a person carries the gene and if there is a risk of passing it on to a child.
2. Cystic fibrosis is a lifelong illness that can affect all of the organs of the body.
3. Cystic fibrosis poses a serious risk to a person's health and shortens life span.
4. It does not affect a person's looks or mental ability.

Both parents must carry a copy of the abnormal gene for the problem to occur in their child. A person who has one copy of an abnormal gene for a recessive disorder is a *carrier* for that disorder, even though he or she may show no signs of the disorder. If both parents are carriers, each of their children has a 25% chance of having the disorder. The risk of being a CF carrier is higher in certain races and ethnic groups. It occurs more often in white people than in other racial groups. The risk also is increased in families with a history of cystic fibrosis.

How do you test for CF?

Carrier testing can be done to find out if a person has a copy of the CF gene. The test is done on a blood sample. Carrier testing can be done for couples planning a pregnancy to assess their risk. Carrier testing also is available to all pregnant women. If testing shows that a couple is at high risk, more testing can be done during pregnancy to see whether their baby will have CF.

Test Results

One parent normal: If your test results are normal, the chance that you are a CF carrier is small.

One parent a carrier: If the test shows that one partner is a carrier, the next step is to test the other partner. Both parents must be CF carriers for the baby to have CF. If one parent has a normal test result, the chance that the baby will have CF is small. Because the risk is small, if one partner is a carrier but the other has a normal result, no further testing is recommended.

Testing of the baby can be done by amniocentesis.

Follow-up Tests

If both partners are CF carriers, further prenatal testing can be done to see if the baby has CF. This testing is not recommended when only one partner is a carrier. Parents may want to know if the baby will have CF



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so that they can prepare for the care of a child with special health care needs, or they may choose to end the pregnancy.

I have read the above and desire CYSTIC FIBROSIS testing:

Signature _____ Date _____

I have read the above and DO NOT desire CYSTIC FIBROSIS testing:

Signature Date _____ Witness _____ Date _____

