Should I Have A Cystic Fibrosis Carrier Test?

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What is Cystic Fibrosis (CF)?
CF is a disease that causes breathing and digestion problems. Symptoms usually begin in the first year of life and get worse over time. Some children are very sick; others are not. Problems may include coughing, repeated pneumonia, lung damage, diarrhea and poor growth. People with CF are not mentally retarded. Their appearanceis not affected. Life is usually shortened, but most children with CF live 20 to 35 years. There is no cure. Treatment is usually medicine and physical therapy.

What causes CF?
CF is an inherited disorder. It is caused by having a pair of genes that are both changed (not working). A person with only one changed gene (also called a mutation) of the pair is called a "carrier." Carriers are not sick. Genes do not change during one's lifetime. Therefore a carrier will always be a carrier, but will never get sick with CF.

How could my child have CF?
First, both parents must be carriers. If you are both carriers there is a 1 in 4 chance (25%) that your baby will have CF. Even if you are both carriers, there is still a 3 out of 4 chance (75%) that your baby will not have CF.

What is the chance I am a carrier?
Your chance of being a carrier depends on whether someone in your family has CF and on your race (ethnic group). Your chance is highest if you have a close relative with CF. The exact chance depends on how you are related to the person with CF. If no one in your family has CF and you are white, the chance you are a carrier is about 1 in 30 (3%). This means there is 97% chance a white person is not a carrier. The chance to be a carrier is much smaller for nonwhites (Asians, Latin Americans, Native Americans and African Americans).

What is the chance my child will have CF?
If both you and your partner are white, your chance of having a child with CF is about 1/3500 (0.3%). If only one of you is white, it is smaller. If neither of you is white, your chance of having a child with CF is very small.

How can I find out if I am a carrier?
There is now a blood test that looks for the changed gene. If you want to have the blood test, a small sample of blood will be taken from your arm.

Why would I want to have this blood test?
To find out whether you are at high risk to have a baby with CF. If the carrier test shows you have an increased risk, more tests would be needed to find out whether the baby actually has CF. If this is important for you to know, have the test.

Why wouldn't I want to have this blood test?
If it is not important for you to find out whether or not your child might have CF, it might be better for you not to have the test. Having the blood test may lead to other tests that have a small risk of miscarriage. If the father of the baby cannot have his blood tested, you might decide not to have the test. If you are past 20 weeks of pregnancy, it may be too late to make any difference in this pregnancy. Talk to your health care provider to find out.

What does my health care provider recommend?
If either you or the father of the baby is white, your health care provider recommends you think about having the test. If neither of you

is white, the benefits of having the test are not as clear. However, you can have the test if you'd like to.

How accurate is the carrier test?
It depends on your race. It is most accurate for people who are white. It is least accurate for Hispanic Americans and Native Americans.

Can I have a baby with CF even if my test result is normal?
Yes. A normal result means a changed gene was not found in you. But, the test cannot find all changed genes. It does find most gene changes in people who are white. It finds fewer of the changed genes in non-whites.

What if both my partner and I are carriers?
There is a 1 in 4 (25%) chance in each pregnancy for the baby to have CF. A test can be done during pregnancy (amniocentesis) to take fluid from near the baby to see if the baby has CF. See the brochure "My Partner and I Are Both Carriers for CF" and talk to a genetic counselor.

What if my partner can't be tested?
We probably won't be able to tell you for certain if the baby has CF. See the "So I Have a CF Gene But We Can't Test My Partner" pamphlet, and/or talk to a genetic counselor.

What if I find out during pregnancy the baby has CF?
There is no cure for CF and there is no treatment before birth. You can continue the pregnancy or have an abortion. The decision is up to you. Treatment after birth often helps, but not always. No one can predict how sick the baby will be.

If I want to have the carrier test, when will it be done?
It is best to take the test before you are pregnant. If you are already pregnant, you should have the test right away.

How much does it cost? Will my medical coverage (insurance/coupons) pay?
The CF carrier test costs about $200 – $300 per person. You need to check with your own insurance company to see if they will pay.

How can I get more information?
Talk to your health care provider. You can also talk with a genetics specialist, a genetic counselor. A genetic counselor is specially trained to help you decide what is best for you. The Cystic Fibrosis Foundation web site is: http://www.cff.org.

This fact sheet was written by the PacNoRGG (Pacific Northwest Regional Genetics Group) Education and Prenatal Genetics committees and is consistent with the 2001 Clinical and Laboratory Guidelines, *Preconception and Prenatal Carrier Screening for Cystic Fibrosis,* published by the American College of Obstetricians and Gynecologists and the American College of Medical Genetics. More detailed patient brochures, *Cystic Fibrosis Carrier Testing: The Decision is Yours,* and *Cystic Fibrosis Testing: What Happens If Both My Partner and I Are Carriers?* can be purchased from ACOG, http://www.acog.org 202/863-2518.
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