Cystic Fibrosis Carrier Screening Information

What is Cystic Fibrosis?

Cystic fibrosis (CF) is a common genetic disease that affects up to 1 of every 3000 babies born. Boys and girls have an equal chance to have CF. It is not contagious or caused by an infection, and nothing the parents do during the pregnancy causes the baby to have CF. CF is a chronic disease that usually grows progressively more severe throughout a person's life. The life expectancy for a person with CF, on average, is shortened compared to people without CF. However since the severity of symptoms can be very different in different people, some people with CF may die younger, and some may live a normal life span. The first symptoms of classic CF usually occur in childhood and affect the lungs and digestion. In the lungs, abnormally thick mucus causes frequent lung infections, which may lead to permanent lung damage. In the digestive system, people with CF often have difficulty digesting their food, causing problems with gaining weight and growing. CF does not affect intelligence.

How is CF treated?

There is currently no cure for CF, but recent research has resulted in much better treatments. Most people with CF need lung treatments including antibiotics to reduce problems. Some people with CF need to be hospitalized periodically. Many people with CF also must take medications to help them digest their food. Continuing treatment advances will allow children born today with CF to live longer, healthier lives than those born in the past.

How does a person get CF?

For a person to have CF, the person has to get the abnormal gene from both parents. The parents of a child with CF each carry one abnormal CF gene and one normal CF gene. Carrier parents do not have CF and are perfectly healthy. Each time two carriers have a baby there is a 1 in 4 (25%) chance that the baby will have CF.

Could I be a CF carrier?

About 1 in every 29 white Americans is a carrier for CF. It is less common in Hispanics (1 in every 46), African Americans (1 in every 62) and Asian Americans (1 in every 90). Most people who are CF carriers do not have a relative with CF and do not know they are carriers. If you do have a relative with CF, then your chance to be a CF carrier is greater than those chances listed above, and you should discuss this with your doctor.

How can I find out if I am a CF carrier?

A DNA test is available to all women to tell them if they are carriers for CF. It is a regular blood test and can be ordered by your doctor. If it says that you are a CF carrier, you definitely are. However if it does not detect that you are a CF carrier, there is still a small chance that you could be—the test identifies most, but not all CF carriers. Once you have had the CF carrier test, you will not need to have it again in future pregnancies or as you get older since the result will not change.

What if I am found to be a CF carrier?

If a woman is found to carry the CF gene, she will be referred to have her partner tested. Remember, it takes both parents being carriers for a baby to be at risk for CF. If a woman's partner is not found to be a carrier, the couple could still have a baby with CF, but the chance with that partner is very small. If the woman and her partner are both CF carriers, they have a 1 in 4 chance with each pregnancy to have a child with CF. They could choose to test the fetus for CF during the pregnancy or notify the pediatrician soon after delivery so that the baby can be tested and treated if found to have CF.

Will CF Carrier Screening be covered by my insurance?

Most of the major insurance companies in United States have agreed to cover this testing. It is recommended by The American College of Obstetrics and Gynecology. However since insurance coverage may vary, you should call your insurance company directly to inquire about your coverage.