Allina Health

Cystic Fibrosis Carrier Testing

Cystic Fibrosis

Cystic fibrosis (CF) is a lifelong disease that causes breathing and digestion problems due to dry secretions. It does not affect intelligence or functions such as thinking, reasoning or remembering.

CF is normally diagnosed within the first few years of life, often by 7 or 8 months of age. According to the National Institutes of Health, more than 25,000 Americans have CF. About 850 new cases are diagnosed each year.

Cystic fibrosis is a genetic disease. This means a baby inherits it from the parents through their genes. Genes are blueprints for growth and development. Cystic fibrosis is passed on from a gene that has undergone changes (mutation).

People who have the CF gene are called carriers. Both parents must be carriers for a baby to be at risk. There does not have to be a family history of CF for a baby to be affected. Being a carrier does not put your own health at risk.

The signs and symptoms of CF — and how serious they are — vary from person to person. Medicine can help treat digestive problems and lung infections. Respiratory therapy can help clear mucus from the lungs.

Currently there is no cure for CF and it cannot be treated before birth.

Those More at Risk for CF

Cystic fibrosis can affect any ethnic group, but it affects Caucasians more than any other genetic condition. Hispanics and some Native American populations are also at higher risk. The disease is less common in blacks and Asian Americans.

For Caucasian couples who both have the CF gene, the chance of having an affected baby is 25 percent. The chance of not having an affected baby is 75 percent. If only one parent is a carrier, there is a 1 in 1,000 chance the baby will be affected.

CF Carrier Testing

Cystic fibrosis carrier testing may help tell if either parent carries the CF gene, and what the risks are for having children with CF. The blood test can find most (but not all) carriers. Even if the test is negative, there is still a slight risk of being a carrier.

If both parents are identified as carriers of a known mutation, an amniocentesis or a chorionic villus sampling test can determine if the baby has CF. The risk of miscarriage is 1 in 200 for amniocentesis and 1 in 100 for chorionic villus sampling.

Should you have a CF carrier test? The decision is yours. The goal of CF carrier testing is to provide people with information that will help them make informed decisions. Here is some information that may help you decide for or against the test.

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Reasons you **may want to have** CF carrier testing:

- You have a family history of CF or your partner has CF.
- You are pregnant, or thinking about becoming pregnant, especially if you, the baby's father, or both are in a high-risk group for CF.
- The information could help you decide whether or not to continue the pregnancy if your unborn child has CF.
- The information could help you prepare for the possible birth and care of a child with CF.

Reasons you **may not want to have** CF carrier testing:

- Your risk of being a carrier seems to be low.
- You would choose to continue a pregnancy regardless of the results of the test.
- The test is not 100 percent conclusive. It cannot identify all CF carriers.
- You prefer not to know whether or not you are a carrier.

Whom To Ask With Questions

If you have questions about CF carrier testing, talk with your health care provider or a genetic counselor.

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