

**MIDWEST REPRODUCTIVE CENTER, PA**

*~Carrier Testing For Cystic Fibrosis~*

In the Caucasian population, about 1 in 2500-3000 infants is born with cystic fibrosis, making it one of the most common genetic diseases. Cystic fibrosis does not affect intelligence, but does cause many health problems. Cystic fibrosis can affect several organs in the body, including the lungs, pancreas, intestines, liver and reproductive organs. Children with cystic fibrosis have a thick mucous in their lungs, which increases the risk of infections and causes damage to the lungs. Cystic fibrosis can cause problems with digestion, and children with cystic fibrosis are often small for their age. Currently, the average life expectancy of someone with cystic fibrosis is about 30 years. A child born with cystic fibrosis today may live longer as treatment improves.

In compliance with the National Institute of Health (NIH) recommendation, we are offering carrier testing for cystic fibrosis to all couples who are trying to conceive. Carrier testing is performed by blood sampling or a cheek swab. To be at risk to have a child with cystic fibrosis, both parents must be carriers. Approximately 1 in 25 Caucasians of Northern European descent are carriers of cystic fibrosis, and most carriers have no symptoms. Other ethnic groups are less likely to be cystic fibrosis carriers. A negative family history does not rule out the possibility of cystic fibrosis in your baby.

Direct testing of the cystic fibrosis gene can detect approximately 85-90% of those who carry this specific gene. Thus, while most carriers are identified, it is possible to have a negative test result and still be a carrier for cystic fibrosis. If both parents are carriers, prenatal testing for cystic fibrosis is available through amniocentesis or chorionic villus sampling. Cystic fibrosis carrier testing must be done as early as possible to allow potential prenatal testing during this pregnancy.

Carrier testing may not be covered by your insurance plan. The cost of testing is between \$200 -\$500.

\_\_\_\_\_ I have already tested for cystic fibrosis through my OB/GYN physician's office.

\_\_\_\_\_ Yes, I wish to pursue cystic fibrosis carrier testing. It is my responsibility to check with my insurance carrier to determine if cystic fibrosis carrier testing will be covered.

\_\_\_\_\_ No, I am not interested in cystic fibrosis carrier testing. If I change my mind, I will notify your office.

**Patient Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Print Name:** \_\_\_\_\_ **Date of Birth** \_\_\_\_\_