CYSTIC FIBROSIS SCREENING

CYSTIC FIBROSIS – The Disease

Cystic fibrosis (CF) is an inherited disease that affects the mucous producing organs in the body like the lungs, nose, and intestines. It is a lifelong illness that requires lifetime treatment. It may be mild or severe and currently there is no cure. CF does not affect intelligence.

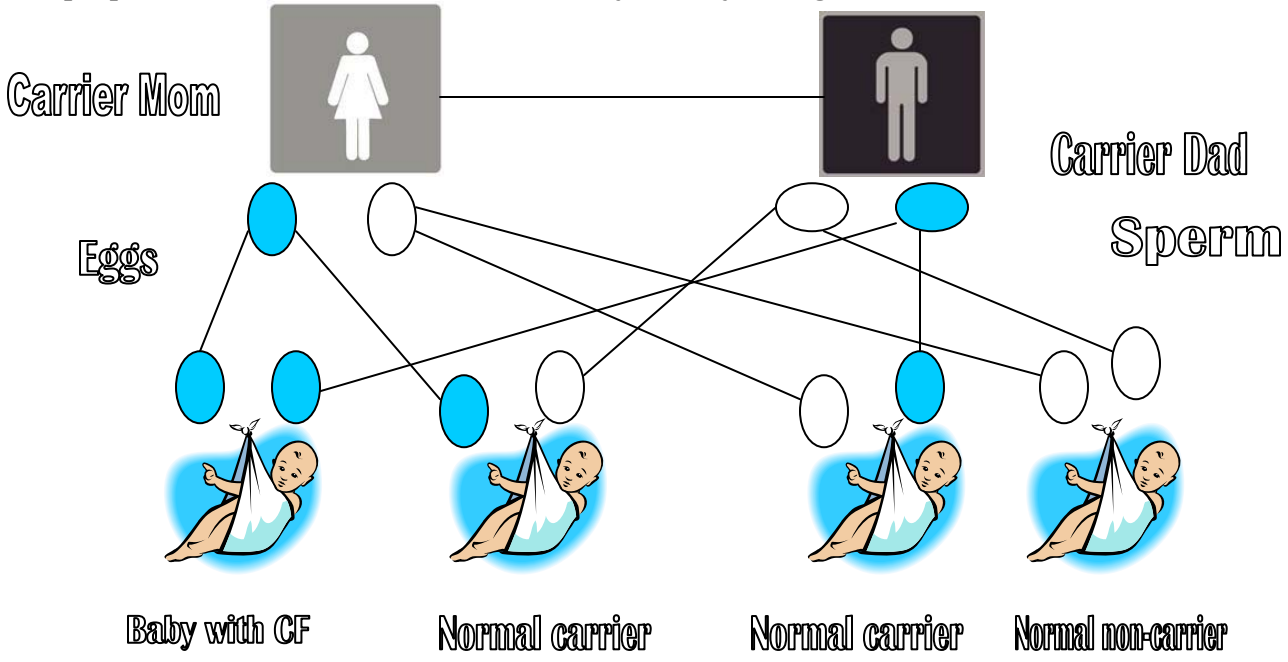
A thick mucous clogs the lungs which may cause difficulty breathing and makes individuals with CF more prone to infections. These infections may become more and more difficult to treat over time requiring intensive treatment at home or in the hospital. Mucous can also block the pancreas which affects the ability of the digestive enzymes to break down food and prevent important nutrients from being absorbed. This may affect the child's growth, especially if the disease is undetected. Sinus blockage and infection can also occur as a result of the thick mucous production. Men with CF may be infertile.

CF Treatment

Respiratory breathing treatments and antibiotics can be used to help the lungs and medications are available to aid in digestion. Usually medications are needed daily along with close follow-up with a physician. Despite treatment, liefe-span in patients with CF is usually shorter, with only half living beyond the age of 31 according to the National Patient Registry.

CF Carrier Testing

You are being offered carrier testing to determine if you are at increased risk to deliver a baby with CF. Each person has two genes for every characteristic they have. Each parent gives one of each of these genes to their child. Cystic fibrosis is an autosomal recessive gene which means that in order to have cystic fibrosis, it is necessary to have two genes that code for cystic fibrosis (one from each parent). For that reason, you and the father of the baby may each have one gene for CF and now know it since you do not have the disease. If one one of you gave your child the gene for CF, then your child will not have cystic fibrosis nor be a carrier. So even if you have children now that do not have CF, it is still possible to have a child that does, if both you and the father of your baby have or "carry" the gene. If you both carry the gene, prenatal diagnosis will be offered. Prenatal diagnosis will be offered. Prenatal diagnosis cannot tell you how severe the disease will be in your child, but can identify an affected child.
The purpose of carrier screening is to find out if you carry a CF gene.



Carrier Frequency

The gene is more common in people of European descent, one in 29 Caucasians carry the gene. 1 in 46 Hispanics, 1 in 65 African-Americans and 1 in 90 Asians carry the gene. If the test finds that you carry the gene for CF, you will be referred for genetic counseling.

CF Detection

Not all carriers can be detected. The likelihood that testing can detect a mutation depends on the ethnic group. 80% of European Caucasians, 97% of Ashkenazi Jewish, 69% of African Americans, and 57% of Hispanic Americans carriers can be detected by this test. It is unknown what the ability to detect a carrier is for the Asian American population. If there is a family history of CF you will be offered genetic counseling and at that time your child's risk can be determined and prenatal diagnosis may be offered.

Benefit of Prenatal Diagnosis for CF

The family can prepare for the birth of a baby with special needs.
Baby will benefit from early treatment from birth to improve health.
Some couples may choose not to continue a pregnancy if they now their baby is affected with CF.

Informed Consent

I UNDERSTAND THAT THE DECISION TO HAVE MY BLOOD CHECKED FOR THE CF CARRIER STATUS IS MINE.

I UNDERSTAND THAT THE TEST DOES NOT DETECT ALL CF CARRIERS.

IN UNDERSTAND THAT IF I AM A CARRIER FOR CF THAT TESTING THE FATHER WILL HELP DETERMINE THE ODDS THAT MY BAY COLD HAVE CF.

I UNDERSTAND THAT IF ONE PARENT IS A CARRIER AND THE OTHER IS NOT, THAT THERE IS STILL A VERY SMALL CHANCE THAT THE BABY WILL HAVE CF.

I UNDERSTAND THAT IF BOTH PARENTS ARE CARRIERS THAT ADDITIONAL TESTING CAN BE DONE IN ORDER TO DETERMINE WHETHER THE BABY WILL HAVE CF.

I UNDERSTAND THAT IF THERE IS A FAMILY HISTORY OF CF OR IF I AM FOUND TO BE A CARRIER THAT I WILL BE REFERRED FOR GENETIC COUNSELING.

I UNDERSTAND THAT NOT ALL CASES OF CF WILL BE DISCOVERED EVEN AFTER PRENATAL DIAGNOSIS.

I have read and discussed with my provider the above information concerning CF screening, and as a result:

__ I do not want CF carrier testing.

__ I do want CF carrier testing.

Signature:_____

Date: _____

PRINT RESET FORM