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CYSTIC FIBROSIS

Cystic Fibrosis is one of the most common genetic diseases; it results in life-long illness and a shortened life expectancy. The disorder, usually diagnosed within the first few years of life, causes problems with digestion and breathing. Cystic Fibrosis does not affect intelligence or appearance.

Cystic Fibrosis is a genetic disorder that results from mistakes/changes in a certain gene. All genes come in pairs, one from the mother and the other from the father. Cystic Fibrosis develops only when an individual inherits two changed (abnormal) genes, one from each parent. When an individual has one changed gene and one normal gene, the person is a carrier. No significant health problems are caused from being a carrier of Cystic Fibrosis (one copy of the abnormal gene). The change of an individual being a carrier for Cystic Fibrosis depends on the family history and ethnic back- ground. You can be a carrier for Cystic Fibrosis even if no one in your family has Cystic Fibrosis.
If no one in your family has Cystic Fibrosis, then your risk of being a carrier for Cystic Fibrosis is:

- One in 29 for non-Hispanic Caucasians.
- One in 46 for Hispanics
- One in 65 for African Americans
- One in 90 for Asians

If a relative has Cystic Fibrosis or is a carrier of Cystic Fibrosis, then your risk of being a carrier is much higher.

Both parents have to be carriers of Cystic Fibrosis to have a child with Cystic Fibrosis. The risk of having a child with Cys- tic Fibrosis is one in 4 (25%) if both parents are carriers.

A blood test is available that will identify most of the carriers of Cystic Fibrosis. When couples are found to be at high risk of having a pregnancy with Cystic Fibrosis , they may consider prenatal diagnosis (CVS, Amniocentesis). Cystic Fibrosis cannot be treated before birth. The purpose of the testing prior to birth is to allow couples to make decisions regarding the pregnancy and possibly prepare for the birth of a child with special healthcare needs. Prenatal diagnosis of Cystic Fibrosis may lead to earlier treatment and improved outcome in the child.

This test cannot identify all carriers of Cystic Fibrosis and therefore, cannot rule out all people at risk for having a child with Cystic Fibrosis. The chance a person is a carrier for Cystic Fibrosis after a negative carrier test is very small.

It is your decision whether or not to have Cystic Fibrosis testing.

Some of the reasons people have given FOR having Cystic Fibrosis carrier testing are:

- Risk of being a carrier seems high. This may be especially true in families with a history of Cystic Fibrosis.
- Cystic Fibrosis seems like a very serious disorder to you.
- If you would consider prenatal diagnosis (Amniocentesis, CVS) to help you make decisions regarding the pregnancy or help you prepare for the birth of a baby with Cystic Fibrosis. Prenatal diagnosis would only be indicated if both parents were found to be carriers.
- Test results are usually reassuring.
- The cost of testing is covered by your insurance company.

(over)

Some reasons people have given FOR NOT having Cystic Fibrosis carrier testing include:

- Risk of being a carrier does not seem very high. This may be especially true if you are Asian or African-Ameri- can.
- Cystic Fibrosis does not seem like a very serious disorder to you.
- You would not consider prenatal diagnosis (Amniocentesis, CVS) to help you make decisions regarding the pregnancy or help you prepare for the birth of a baby with Cystic Fibrosis, even if you were both carriers and at high risk of having a child with Cystic Fibrosis.
- The test is not perfect and will not identify all carriers.
- The cost of testing is not covered by your insurance company.

The cost of testing is approximately $600.00 and may not be covered by your insurance company. Please

review the information in this handout and discuss your questions and decisions
with your healthcare provider.

☐ I have reviewed the information in this handout.

Ô **PLEASE CHOOSE YOUR SELECTION BELOW:**

☐ I am interested in pursuing Cystic Fibrosis carrier testing.

☐ I am NOT interested in pursuing Cystic Fibrosis carrier testing.

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SUBSTANCE ABUSE SCREENING

Please initial next to each statement.

☐ I,______________________________________am aware that a drug screen will be run on me periodically throughout my pregnancy.

☐ I understand that if I test positive during my pregnancy, I will be required to actively participate in a drug rehabilitation program throughout my pregnancy.

☐ Dr.______________________________________and staff have my permission to re- lease my medical records to the appropriate rehabilitation center.

☐ I give my permission for the rehabilitation center to release information to Dr.______________________________________.

☐ I agree to give advance notice if my appointments cannot be kept and will at that time reschedule.

☐ I also understand and accept that if I miss two or more appointments without prior cancellation, or if I do not comply with the urine drug screens or rehabilitation guidelines, I will be discontinued from the care of Dr.______________________________________and Capital OB/GYN.

Ô **PATIENT SIGNATURE** ____________________ **DATE** __________
MM/DD/YYYY

WITNESS NAME : ______________________________
Please print

Ô **WITNESS SIGNATURE** ____________________ **DATE** __________
MM/DD/YYYY

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VERIFICATION OF CONSENT FOR HIV ANTIBODY TESTING

This is to acknowledge that ____ will be tested to ascertain the possible presence in the bloodstream of antibodies to the probable causative agent of Acquired Immune Deficiency Syndrome (AIDS), the HIV Virus.

I have been informed that the accuracy and reliability of the test is uncertain and that the test results may, in some cases, falsely indicate the presence of antibodies to the virus (false positive) or may fail to detect the presence of antibodies to the virus (false negative). I have also been informed that other blood tests must be used in conjunction with the HIV Antibody Test in order to diagnose AIDS.

Furthermore, I realize that, even if a test is positive (indicating presence of antibodies to the AIDS virus), the person being tested may not necessarily develop AIDS.

I understand that I may ask the responsible physician any questions that I may have concerning the nature of the blood test, its expected benefits, its limitations, and its alternatives before I consent to the blood test.

I understand that the results of this test will only be released to those healthcare practitioners directly responsible for my care and treatment. I further understand that no additional release of the results will be made without my written authorization.

By my signature below, I acknowledge that I have been given all of the information I desire concerning the blood test and release of results and have had all of my questions answered. Further, I acknowledge that I have given consent for the blood test to detect antibodies to the HIV virus, the probably causative agent of AIDS.

Ô **PATIENT SIGNATURE** _______________ **DATE** _______________ **TIME:** _______________

(Patient/Parent/Legal Guardian) *MM/DD/YYYY*

RELATIONSHIP : ______________________________

(if signed by individual other than parent)

WITNESS : ______________________________