UNC HEALTH CARE
WOMEN'S WELLNESS AND SPECIALTY SERVICES

CYSTIC FIBROSIS CARRIER TESTING - MIM# 508

WHAT IS CYSTIC FIBROSIS?

- Cystic Fibrosis (CF) is an inherited lung and digestive disease. More than 25,000 American children and young adults have CF. About 850 CF cases are diagnosed every year.
- Symptoms of CF vary but include lung congestion, pneumonia, diarrhea and poor growth. Many people with CF have severe medical problems and die at a young age. Others have few symptoms and are unaware they have CF.
- CF does not affect a persons learning ability or physical appearance.

Currently there is no known cure for CF. However scientists are making progress in the treatment of CF. Although the average person with CF lives to the age of 30, a baby born today with CF today may live longer.

IS THERE A CHANCE MY BABY COULD HAVE CYSTIC FIBROSIS?

Approximate risk that a couple with no family history of CF will have a child with CF:

ETHNIC BACKGROUND	CHANCES YOU ARE A CARRIER	RISK OF A BABY WITH CF	DETECTION RATE*
Caucasian Couple	1 in 25	1 in 2,500	90%
Ashkenazi Jewish Couple	1 in 25	1 in 2,500	97%
Hispanic Couple	1 in 46	1 in 8,000	57%
African American Couple	1 in 65	1 in 15,300	69%
Asian Couple	1 in 90	1 in 32,100	Unknown

**based on UNC laboratory data*

- Most people have two working copies of the CF gene.
- Carriers of CF have one working copy and one non-working copy of the CF gene.
- If both parents are carriers there is a 1 in 4 chance pregnancy will produce a child with CF.
- People with CF have two non-working copies of the CF gene.

WHAT TESTING IS AVAILABLE?

- ✓ There is a voluntary blood test available to determine if you or your partner might carry the CF gene.
- ✓ It is important to understand that carrier testing does not detect all CF carriers.
- ✓ If test results determine you both are carriers, your unborn baby can voluntarily be tested for CF.

HOW MUCH DOES IT COST TO HAVE CYSTIC FIBROSIS CARRIER TESTING?

- **$** Cost and insurance coverage for CF carrier testing depends upon your insurance policy. Please ask to speak to a financial counselor if you would like information regarding CF carrier testing.

Your doctor or genetic counselor can provide information about CF carrier testing and answer any questions. They can also give you a detailed brochure about CF and testing options.

☐ Yes I am interested in CF carrier testing. *Date test ordered*_____

☐ No I am **NOT** interested in CF carrier testing.

Patient Signature_____ Date_____

Reviewed By_____ Date_____

UNC HEALTH CARE
WOMEN'S WELLNESS AND SPECIALTY SERVICES

UNC Prenatal Diagnostic Center
Screening Questionnaire – MIM# 302

_____
Appointment Date

Referring Provider_____ Clinic Location_____

LMP_____ EDC_____

Patient's Occupation_____ Patient's Education:

Patient's Religion_____

- ☐ No formal education
- ☐ 1-4 years of school
- ☐ 5-8 years of school
- ☐ 9-12 years of school
- ☐ Completed high school
- ☐ Some college
- ☐ College degree
- ☐ Postgraduate education
- ☐ Technical degree

Partner's Name_____ Partner's Age_____

Partner's Occupation_____ Partner's Education:

Partner's Religion_____

- ☐ No formal education
- ☐ 1-4 years of school
- ☐ 5-8 years of school
- ☐ 9-12 years of school
- ☐ Completed high school
- ☐ Some college
- ☐ College degree
- ☐ Postgraduate education
- ☐ Technical degree

Have you or your partner ever received any form of Genetic Counseling before? ☐ Yes ☐ No

If yes, when & where?_____

Primary language spoken in the home?

☐ Arabic ☐ Chinese ☐ French ☐ Spanish
☐ Burmese ☐ English ☐ Japanese ☐ Other_____

What is your ethnic background: *(please check all that apply)*

☐ African American ☐ Asian ☐ Filipino ☐ Hispanic ☐ Middle Eastern
☐ Alaskan ☐ Cajun / Creole ☐ French Canadian ☐ Italian
☐ American Indian ☐ Caucasian ☐ Greek ☐ Jewish
☐ Other_____

From which country and/or countries in particular does your family originate?_____

_____

please continue ➔

What is your partner's ethnic background: *(please check all that apply)*

☐ African American ☐ Asian ☐ Filipino ☐ Hispanic ☐ Middle Eastern
☐ Alaskan ☐ Cajun / Creole ☐ French Canadian ☐ Italian
☐ American Indian ☐ Caucasian ☐ Greek ☐ Jewish
☐ Other_____

From which country and/or countries in particular does your family originate?_____

_____

Please answer the following questions carefully. Your answers may help identify problems that could affect your health or the health of your baby. Your answers may also indicate special tests that may be important to perform during your pregnancy. All information will be kept confidential. Thank you.

01. ☐ Yes ☐ No Will you be 35 or older when you expect to deliver?

02. Have you, the father of your baby, or anyone in either of your families ever had:

a. ☐ Yes ☐ No Down syndrome
b. ☐ Yes ☐ No Other chromosome problems
c. ☐ Yes ☐ No Mental Retardation
d. ☐ Yes ☐ No Fragile X-syndrome
e. ☐ Yes ☐ No Spina Bifida *(open spine)* or Anencephaly *(open skull)*
f. ☐ Yes ☐ No Hydrocephalus *(water on the brain)*
g. ☐ Yes ☐ No Muscular Dystrophy
h. ☐ Yes ☐ No Hemophilia *(easy bleeding, free bleeder, or problems clotting)*
i. ☐ Yes ☐ No Cystic Fibrosis
j. ☐ Yes ☐ No Stillbirth *(baby died prior to birth)*
k. ☐ Yes ☐ No Blindness or Deafness
l. ☐ Yes ☐ No Heart Defect *(hole in heart or leaky valve)*
m. ☐ Yes ☐ No Kidney Disease
n. ☐ Yes ☐ No Cleft Lip *(hare lip)* and / or Cleft Palate

03. ☐ Yes ☐ No Have you or the father of your baby had a child born dead or alive with a birth defect not listed above? If yes, please describe:_____

_____

04. ☐ Yes ☐ No Do you, the father of your baby, or a relative in either of your families have an inherited disease or problem not listed above? If yes, please describe:_____

_____

05. ☐ Yes ☐ No Have you had a blood test during this pregnancy that screens for Down syndrome or spine defects? If yes, what were the results:_____

_____

please continue ➔

06. Have you taken or been exposed to any of the following during this pregnancy? If yes, please state approximate amount.

a. ☐ Yes ☐ No Alcohol_____

b. ☐ Yes ☐ No Tobacco / Cigarettes_____

c. ☐ Yes ☐ No Medications *(prescribed or purchased over the counter)*_____

d. ☐ Yes ☐ No Street Drugs_____

e. ☐ Yes ☐ No Radiation *(X-Ray)* Exposure_____

f. ☐ Yes ☐ No Herbal Medications / Large Dose Vitamins_____

07. ☐ Yes ☐ No Did you take any fertility medications or have special fertility procedures to become pregnant?
If yes, please describe:_____

_____

08. Do you have:

a. ☐ Yes ☐ No Diabetes *(sugar in your blood)*

b. ☐ Yes ☐ No Cancer

c. ☐ Yes ☐ No Premature Deliveries or Stillbirths

d. ☐ Yes ☐ No Two or more Miscarriages

e. ☐ Yes ☐ No A known Vaginal Infection

f. ☐ Yes ☐ No Hepatitis or HIV

g. ☐ Yes ☐ No Other medical problems_____

09. ☐ Yes ☐ No Are you and the father of your baby related to one another by blood?

_____ _____

Patient Signature Date

_____ _____

Genetic Counselor Signature Date