



Women's Medical Group

15151 National Avenue, Los Gatos, CA 95032
PHONE: (408) 356-0431 - FAX: (408) 356-8569
www.lowmg.com

Consent for Cystic Fibrosis Carrier Testing

What is Cystic Fibrosis?

Cystic Fibrosis (CF) is a genetic condition affecting the ability to secrete mucous fluids normally. Individuals with CF commonly have problems with the lungs, digestive, and reproductive systems. They often suffer from pulmonary infections and organ damage due to difficulty in clearing secretions. The severity of CF varies from person to person.

The condition does not affect intelligence, appearance, or development. There is no cure for CF currently. The average life expectancy is 30 years, but children born today with CF may live longer as treatments improve. Currently, CF is diagnosed by blood testing when a pediatrician suspects the condition during childhood.

How common is CF?

European Caucasian:	1/3,000	African American:	1/15,300
Ashkenazi Jewish:	1/3,300	Asian:	1/32,000
Hispanic:	1/8,500		

Could I have a child with CF? How do I know if I carry the gene?

CF is a recessive condition, therefore IF BOTH PARENTS ARE CARRIERS; there would be a 25% chance of the child having the disease. Carrier frequency varies by ethnic background:

European/Caucasian:	1/25	African American:	1/62
Ashkenazi Jewish:	1/29	Asian:	1/90
Hispanic:	1/46		

A blood test can be performed to detect if you are a carrier, but accuracy also varies by ethnic background. The test will detect the following percentage of carriers:

European/Caucasian:	80%	African American:	69%
Ashkenazi Jewish:	97%	Asian:	30%
Hispanic:	57%		

How much does the testing cost?

As of January 2002, ACOG recommends discussing CF testing with all couples. However, this recommendation does not imply that insurance will necessarily cover the cost of the screen. Coverage varies, and patients need to contact their insurer directly.

What if my spouse and I are carriers? Can the baby be tested?

Fetal testing can be done via amniocentesis. Results may take several weeks to complete.

- Yes, I wish to have my blood drawn for cystic fibrosis carrier testing.
- It is my responsibility to check with my insurance regarding coverage.
- No, I do not want to have my blood drawn for cystic fibrosis carrier testing.

Signature: _____ Date: _____

To learn more about Cystic Fibrosis, contact

1. Cystic Fibrosis Foundation 1-800-FIGHT CF (1-800-344-4823) www.cff.org E-mail: info@cff.org
2. National Society of Genetic Counselors 1-610-872-7608 Press 7 www.nsgc.org Click on Resource Link
3. Genetic Alliance 1-800-336-4363 www.geneticalliance.org E-mail: info@geneticalliance.org



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AFP Consent

- 1. I have read the information about the California Expanded AFP screening Program which is contained in the booklet given to me by my physician.
2. I have been informed that:
a. The purposed of the California Expanded AFP Screening Program is to detect most fetuses with open neural tube defects, abdominal wall defects, Down syndrome, and trisomy 18. However, not all such defects can be detected by the Program.
b. There are other birth defects that cannot be detected by this Program
c. If the result is "screen positive," I will need to make a decision regarding follow-up testing. Authorized follow-up tests are covered by the Program and will be discussed with me in more detail.
d. If the result is "screen negative," the Program will not pay for any follow-up testing.
e. If the fetus is found to have a birth defect, the decision to continue or terminate the pregnancy will be entirely mine.
f. Participation in the California Expanded AFP Screening Program is voluntary. I can refuse any tests at any time.
3. I have read the detection rates for certain birth defects as they are described in this booklet.
4. I have been informed that a blood specimen for the California #Expanded AFP Screening Program is only reliable between 15 and 20 weeks of pregnancy.
5. I have had my questions answered to my satisfaction.

Yes, I request that blood be drawn for the Expanded AFP Screening Program.
Signed _____ Date _____
I should have my blood drawn between: _____ and _____
No, I request that blood not be drawn for the Expanded AFP Screening Program.
Signed _____ Date _____

I understand that the blood specimen and information obtained during the testing process become the property of the California Department of Health Services. They may be used for program evaluation or research by the Department or Department-approved scientific researchers without identifying the person or persons from whom these results were obtained, unless I specifically prohibit such use in writing. All information procured by the Department of Health Services, or by any other person, agency or organization acting jointly with the Department in connection with such special studies, shall be confidential. I may obtain additional information about the study or prohibit the use of my specimen by writing George Cunningham, MD, MPH, Genetic Disease Branch, 2151 Berkeley Way, Annex 4, Berkeley, CA 94704.

If new information becomes available about a birth defect detected during this pregnancy, the information may be sent to me unless I specifically prohibit it by writing to George Cunningham, MD, MPH at the above address.



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Ultrasound Scanning in Pregnancy

What is ultrasound scanning?

Ultrasound scanning is a procedure that uses sound waves to create pictures of the uterus, placenta, and fetus. There is no exposure to radiation and no known risk. Early pregnancy scans are done using a vaginal transducer covered with a clean, disposable sheath. There is no discomfort, risk of infection or harm to the pregnancy using this technique. Scanning in later pregnancy is done with a large transducer, which is placed on your abdomen.

Ultrasound scanning may be used:

- to make sure the baby is developing in the uterus and not inside a fallopian tube (ectopic pregnancy)
- to determine how far along you are in your pregnancy (due date)
- to check that the baby is growing normally
- to estimate the weight of the baby
- to check the position of the baby and the placenta
- to check the amount of fluid around the baby
- to see how many babies are in the uterus
- to look for fetal movement and breathing

Ultrasound scanning cannot detect all birth defects. Ultrasound examinations performed at Los Olivos are related to the above purposes only. A normal ultrasound in this office does not assure the absence of birth defects or abnormalities. If you are at high risk for having a baby with a congenital anomaly, you should see a perinatologist for a Level II ultrasound. A Level II ultrasound is usually performed for women over 35 with or without an amniocentesis. Additional screening tests such as Nuchal Thickness Screening, AFP triple marker screening and amniocentesis can help to detect some birth defects, but NO screening test, including amniocentesis or ultrasound, can detect all birth defects.

When is it used in pregnancy?

Not all pregnancies require routine ultrasound exams and the American College of Obstetrics and Gynecology does not consider it necessary for all pregnancies. Some insurance carriers do not reimburse for elective ultrasound screening of a normal pregnancy. If any other reason for ultrasound scanning arises, the ultrasound is more likely to be covered according to the details of your health insurance policy.

I understand the indication for my ultrasound today. I understand the limitations of ultrasound screening and wish to continue with the test. I have had all my questions answered.

Patient: _____ Date: _____