

# **APPENDIX K**

## **Cystic Fibrosis**

## **CYSTIC FIBROSIS (CF)**

Carrier screening for cystic fibrosis is recommended to those seeking preconception or prenatal care. Couples in ethnic or racial groups that are considered to be at a higher risk for carrying the CF gene should be offered screening. A family history of cystic fibrosis suggests that the test be offered to the person seeking medical care. Health care providers offering screening must provide patients and providers education. In addition to a screening test, offer counseling, quality control and monitoring of samples, and follow up on test results.

ACOG's recommendations are the following:

Testing will be made available to all couples, whatever their risk for carrying the CF gene, through information brochures on CD given to couples seeking preconception or prenatal care. These materials explain the relative risks for carrying CF, screening options, and what steps are next should a couple learn that they carry the CF gene.

- For couples in ethnic or racial groups considered at higher risk for carrying the CF gene – Caucasians, particularly those of European or Ashkenazi Jewish descent – physicians will specifically offer screening and will follow up with inquiries about the couple's decision on whether to be screened.
- With regard to couples to whom screening will be offered, it is recommended that this be done when they seek preconceptional counseling or infertility care, or during the first and early second trimester of pregnancy.

### **References :**

ACOG News Release (2001). Ob-Gyns Offering Large-Scale Cystic Fibrosis Screening. 12 December, American College of Obstetricians and Gynecologists, Washington, D.C.

American Medical Association Science (2003). ACOG cystic fibrosis recommendations. 24 February, American Medical Association, Chicago, IL.

Genetics & Public Policy Center (2003). Canary in the Coal Mine? Cystic Fibrosis Genetic Testing Raises Concerns About Use and Regulation of Genetic Tests. 4 April, Genetics & Public Policy Center, Washington, D.C.

### **Resources:**

American College of Obstetricians and Gynecologists  
[www.acog.org](http://www.acog.org)

American Medical Association  
[www.ama-assn.org](http://www.ama-assn.org)

CDC  
[www.cdc.gov](http://www.cdc.gov)

Cystic Fibrosis Foundation  
Bethesda, MD  
[www.cff.org](http://www.cff.org)

Cystic Fibrosis Research, Inc.  
Mountain View, CA  
[www.cfri.org](http://www.cfri.org)

March of Dimes  
[www.marchofdimes.com](http://www.marchofdimes.com)

National Human Genome Research Institute  
[www.genome.gov](http://www.genome.gov)

National Institutes of Health  
[www.nih.gov](http://www.nih.gov)

