


# **American College of Obstetricians and Gynecologists (ACOG)- Newborn Screening “Policy”**



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# ACOG

## Group Unified by a Commitment to the Health Care of Women

**Fellows** (National and International)

Board Certification

**Junior Fellows**

ABOG Approved Residency Training in OB/GYN

**Associate Member**

Provide valuable service in OB/GYN and are not eligible to be a Fellow (National and International)

**Educational Affiliate**

Hold non-M.D. degrees and are active in some facet of OB/GYN (National and International)

**Medical Students**

# ACOG

## ACOG Works Primarily in Four Areas

To serve as a **strong advocate for quality health care for women.**

Maintaining the highest standards of clinical practice and **continuing education** for its members.

Promoting **patient education** and stimulating patient understanding of and involvement in medical care.

Increasing awareness among its members and the public of the **changing issues** facing women's health care.

# ACOG Committee on Genetics

The Committee on Genetics considers all aspects of genetics as it relates to reproduction and develops appropriate recommendations regarding clinical management, **education**, and research issues.

It has a formal liaison with other groups, such as the American Academy of Pediatrics, the American College of Medical Genetics, and the Teratology Society, and interacts with the Centers for Disease Control and Prevention, the National Institutes of Health, and other federal agencies as appropriate.

The committee develops written opinions on newly emerging or rapidly changing issues in the field and responds to matters referred by other College groups.

ACOG

Committee on  
Genetics

# Committee Opinion



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Number 257, May 2001

*(Replaces No. 178, November 1996)*

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**Genetic Evaluation of Stillbirths  
and Neonatal Deaths**



ACOG

Committee on  
Genetics

# Committee Opinion



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Number 298, August 2004

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Prenatal and Preconceptional Carrier  
Screening for Genetic Diseases in  
Individuals of Eastern European  
Jewish Descent

ACOG

Committee  
on Genetics

# Committee Opinion



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Number 212, November 1998

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## Screening for Canavan Disease

ACOG

Committee on  
Genetics

# Committee Opinion



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Number 230, January 2000

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## Maternal Phenylketonuria



ACOG

Committee on  
Genetics

# Committee Opinion



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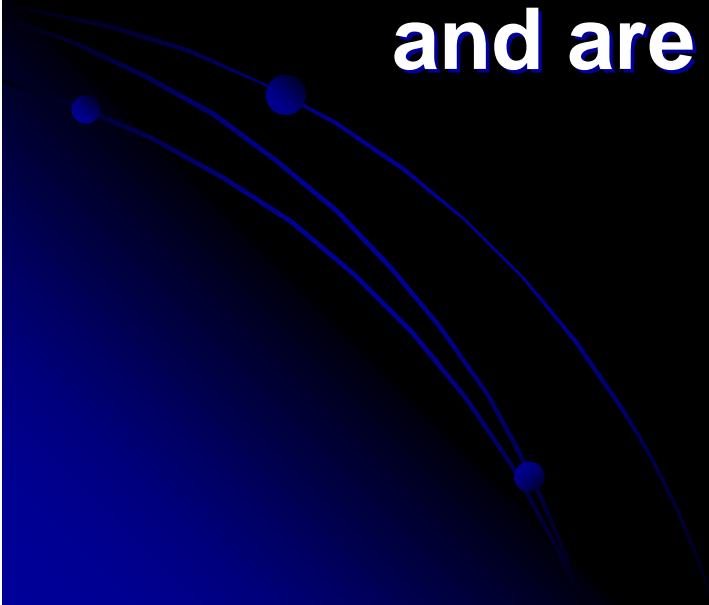
Number 287, October 2003

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## Newborn Screening

# Committee Opinion

**ACOG Committee Opinions represent an ACOG committee's assessment of emerging issues in obstetric and gynecologic practice and are reviewed regularly for accuracy.**



# **ACOG recognizes that Technology Drives Change**

**Newborn screening dates to 1963**

**With technology such as MS/MS  
expansion of Newborn Screening  
Programs must be considered**

Newborn Screening. ACOG Committee Opinion Number 287; October 2003.

# **ACOG recognizes the Importance of Statistical Considerations in Adopting National/Statewide Newborn Screening Policies**

**Maximum Sensitivity and specificity**

**There is a tradeoff between the false  
negative rate and false positive rate**

**Confirmatory testing is required.**



# ACOG recognizes:

**Absence of constitutional or federal mandate for newborn screening**

**State autonomy**

**State statutes or regulations determine specifics related to newborn screening**

**Consent required: Maryland, Wyoming**

**Tests performed, Fees, Fee source**

**Systems must be in place for adequate communication and treatment (\$\$)**

# **ACOG recognizes:**

**Technology is driving change**

**Costs may prevent families from  
universal access to technologic  
advances being considered**

Newborn Screening. ACOG Committee Opinion Number 287; October 2003.

# **ACOG is concerned:**

**MS/MS may result in identification of diseases for which there are no effective treatments.**

**Identification of more disease entities will result in the need for greater follow-up.**

***Added cost without benefit***

**Fate of stored blood spots**

Newborn Screening. ACOG Committee Opinion Number 287; October 2003.

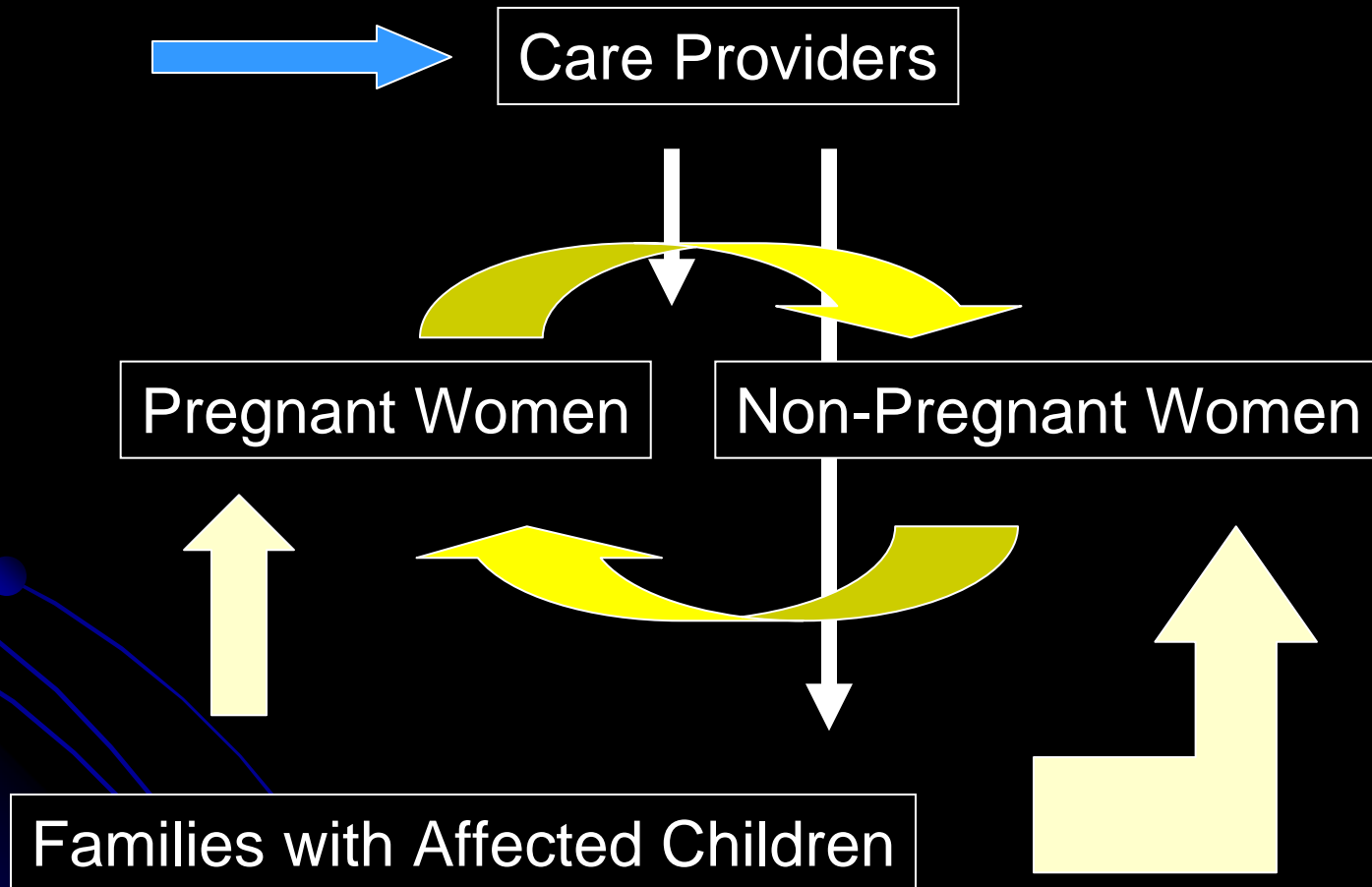
# Obstetrician's Role

**“Prenatal education** about newborn screening not only provides parents with an understanding of the reasons for obtaining their newborn's blood specimen, but also informs them that an initial positive test result does not necessarily mean that their child will be affected... Many patients will turn to their obstetrician for additional information regarding newborn testing...”

Newborn Screening. ACOG Committee Opinion Number 287; October 2003.



# Education



# Education

**Recurrent  
Early Age**

**Gynecology Care**

**Remote**

**Motivated  
Attentive**

**Preconception Counseling**

**Limited  
Patients**

**Motivated  
Attentive**

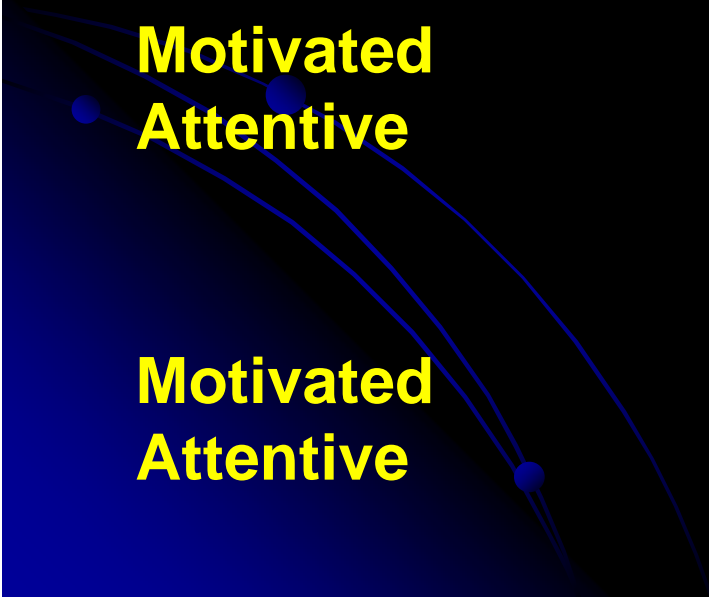
**Pregnancy  
(early v. late)**

**Distractions**

**Motivated  
Attentive**

**Postpartum**

**Vulnerable  
Distracted**



# **ACOG recognizes an important omission in the ACMG Report**

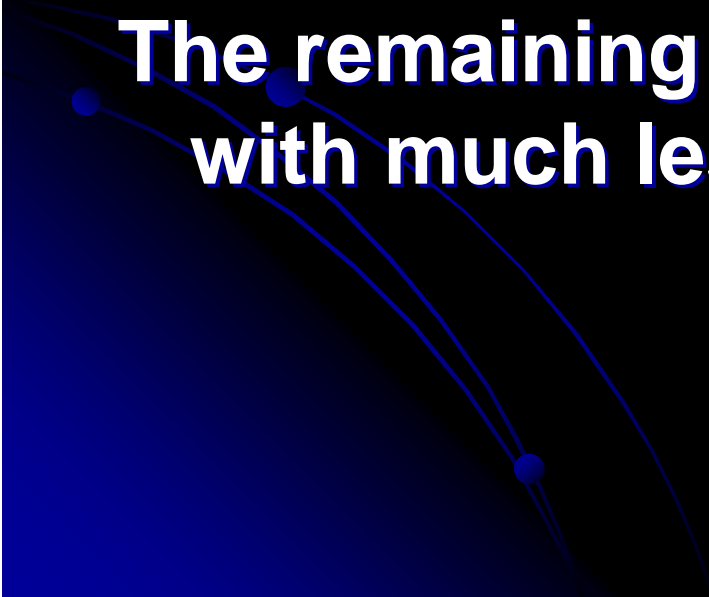
**Failure to include obstetrician representation on the expert panel**

**Uncertain that obstetrician representation was integral in the survey of health care providers and consumers related to the importance of various features of the data collection instrument**

# **ACOG notes that**

**Five major areas were to be considered by ACMG however one of these was discussed extensively – A uniform condition panel.**

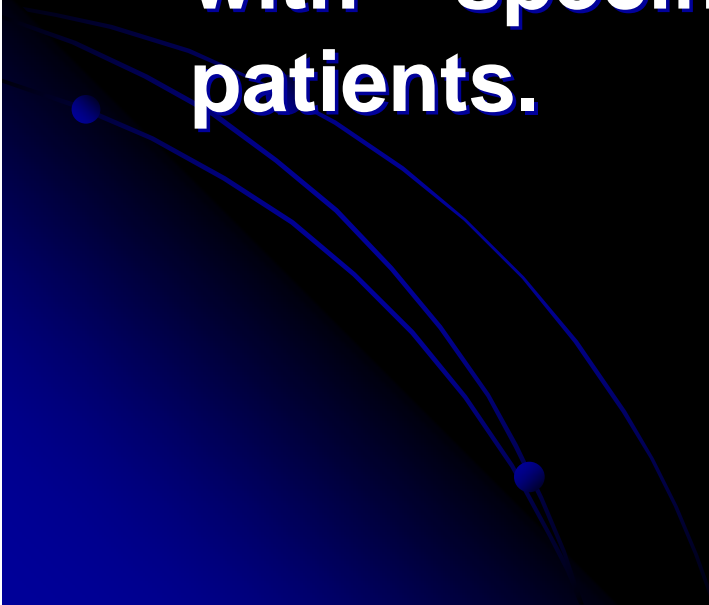
**The remaining four areas were discussed with much less focus and vigor.**





# **ACOG recognizes in the ACMG report:**

**The Fact Sheets could be used to provide  
a rapid resource for obstetricians faced  
with specific questions posed by  
patients.**



# Areas Examined by ABMG for Certification in Clinical Genetics

## Basic Principles

Genetic Mechanisms

Pedigree Analysis/Risk Assessment

## **Biochemical Genetics**

Cytogenetics

Molecular Genetics

## **Screening**

## Clinical Diagnosis

### **Metabolic Disease**

Dysmorphology

Cytogenetics Disorders

Genetic Disease Recognition

Prenatal Diagnosis

## Patient

## Management

Legal/Ethical Issues

### **Counseling**

Anticipatory Guidance

Treatment

# **American Board of Obstetricians and Gynecologists\***

**33,026 Active Diplomats**

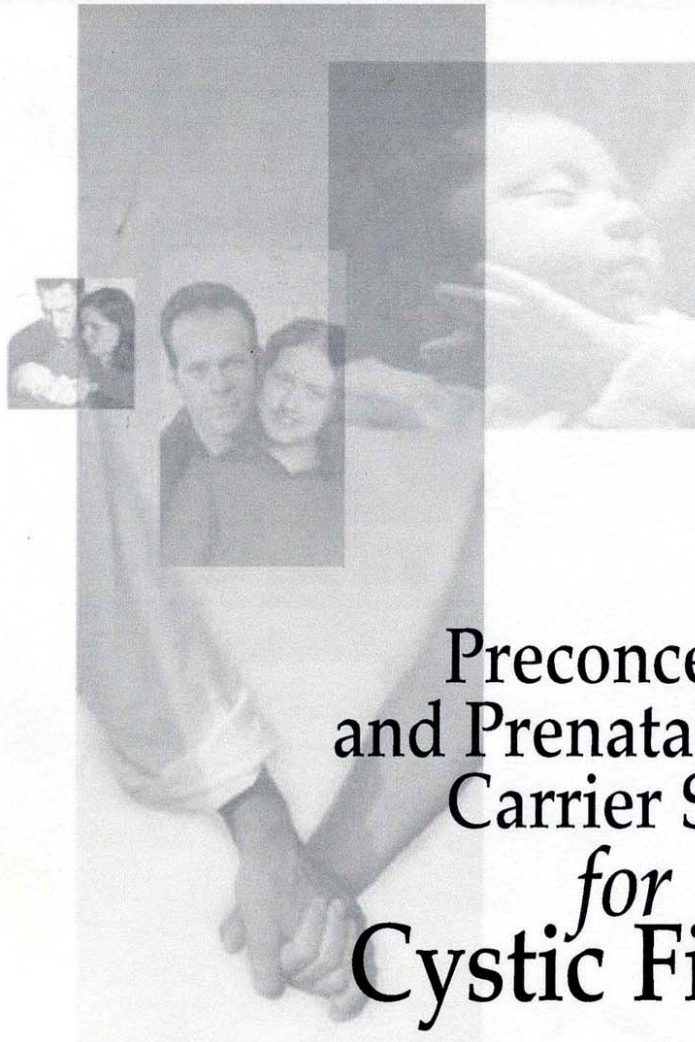
**1,419 also certified in Maternal Fetal Medicine (4%)**

# **American Board of Medical Genetics\***

**1,006 Clinical Genetics Certificates**

**112 Of above also ABOG certified (11%)**

**\* March 2002**



# Preconception and Prenatal Carrier Screening *for* Cystic Fibrosis

Clinical and Laboratory Guidelines

October 2001



The American College of Obstetricians  
and Gynecologists  
*Women's Health Care Physicians*  
409 12th Street, SW  
PO Box 96920  
Washington, DC 20090-6920



American College of Medical Genetics

October 2001

# Preconception and Prenatal Carrier Screening for Cystic Fibrosis

- **Introduction**
- **Background**
  - Incidence
  - Inheritance
  - Pathophysiology and Clinical Presentation
- **Clinical Implementation of Carrier Screening**
  - Timing of Carrier Screening
  - Screening Strategies
  - Screening Process
- **Laboratory Testing for Carrier Screening**
  - The Panel of Mutations for Screening
  - Laboratory Reports and Interpretation
  - Laboratory Standards and Quality Assurance
- **Counseling for Screening**
  - Counseling Before Screening
  - Limitations and Pitfalls of Screening
- **Interpretation of Results and Posttest Counseling**
  - Counseling and Screening of Family Members of Cystic Fibrosis Carriers
- **Prenatal Diagnosis**
- **Conclusion**
- **Bibliography**
- **Appendix A. Report on Cystic Fibrosis Screening**
  - Example of a Negative Report
  - Example of a Positive Report
- **Appendix B. Sample Patient Letters Reporting Results**
  - Both Partners Tested, Both Negative
  - Both Partners Tested, One Positive, One Negative
  - One Partner Tested Positive, One Not Tested
  - One Partner Tested Negative, One Not Tested
- **Appendix C. Sample Letter for Family Members of a Cystic Fibrosis Carrier**