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 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.
Genetic Evaluation of Stillbirths and Neonatal Deaths
ACOG

Committee on Genetics

Committee Opinion

Number 298, August 2004

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

Number 212, November 1998

Screening for Canavan Disease
ACOG Committee on Genetics

Committee Opinion

Number 230, January 2000

Maternal Phenylketonuria
ACOG Committee on Genetics

Committee Opinion

Number 287, October 2003

Newborn Screening
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.

Newborn Screening. ACOG Committee Opinion Number 287; October 2003.
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 ($$)

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

Preconception Counseling

Pregnancy (early v. late)

Postpartum

Gynecology Care

Recurrent Early Age

Motivated Attentive

Motivated Attentive

Motivated Attentive

Remote

Limited Patients

Distractions

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

The American College of Obstetricians and Gynecologists
Women's Health Care Physicians
400 12th Street, SW
PO Box 98920
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**