## Needs for Genetic/Genomic Literacy Among Obstetricians and Gynecologists

Nancy C Rose, MD
Chair, Committee on Genetics
American College of Obstetrics and Gynecology
January, 2013



## **ACOG Membership**

- Total active members and fellows: 55, 858
- Total fellows: 30, 067
- Junior fellows in practice: 4,965
- Fellowship training: 246



#### **ACOG**

- Goal: to give basic tools for patient management
  - OB-GYNs are overwhelmed
  - Worried about litigation
    - Rely on ACOG statements
  - Strong issues from corporate marketing
    - Example: Non-invasive prenatal testing
      - Counsyl, Arisosa, Verinata, Natera,Sequenom



#### **ACOG**

- For the busy practitioner:
  - Genetics/genomics is viewed as a complex nuisance that interferes with clinical management
  - Little time to focus on issues
  - Family histories: inaccurate and may violate privacy of other family members
  - Limited genetic counseling support nationally
    - Abysmal GC reimbursement
  - Commercial laboratories (with financial interest)
     often provide genetics support



- ACOG staff
- Chair
- Vice Chair
- Young Member (usually non geneticist)
- 7 members
- Genetic Counselor
- Liaisons: SMFM, ASRM, CDC, NSGC, AAP, ACMG, Committee on Ob Practice.



- Internal collaboration with
  - Committee on Obstetric Practice
  - Committee on Gynecologic Practice
    - Example "Assisted Reproductive Technology and Genetic Disease"
  - Ethics Committee
    - Microarray issues



- Collaborative Relationships with:
  - American College of Medical Genetics
  - Centers for Disease Control (SACHDNC)
  - American Society of Reproductive Medicine
  - American Academy of Pediatrics (COG)
  - Society for Maternal Fetal Medicine
  - National Society of Genetic Counselors
  - March of Dimes
  - National Coalition of Health Professionals in Genetics (NCHPEG)

- External collaborations:
  - to develop documents with other national organizations for uniformity of recommendations
  - Example: ACMG supports SMA screening in pregnancy
    - –ACOG does not
  - Example: Non Invasive Prenatal Testing
    - –ACOG SMFM joint document



#### **Educational Activities: ACOG COG**

- Education:
  - Committee Opinions that are educational and practical
    - Websites for information
  - Technology Assessment Document:
    - Genetics and Molecular Diagnostic Testing
  - Incorporation of Genetics at Annual Clinical Meeting
  - Continued collaboration with the ABMG, and ABOG
    - Example: Genetics as part of PART II ABOG Literature Review
  - Continued work toward timely publication of clinical documents with "how to" sections
    - Ex: "How to Discuss Cystic Fibrosis Screening"

## Information on Cystic Fibrosis to Share with Your Patients

 Cystic fibrosis (CF) is a genetic disorder that causes breathing and digestive problems. Intelligence is not affected by CF. Individuals with CF have a current life expectancy of approximately 37 years, and the cause of death usually is lung damage. Approximately 15% of individuals with CF have a milder form of the disease course and live an average of 56 years. Common symptoms of CF include coughing, wheezing, failure to thrive, loose stools, abdominal pain, and, in men, infertility. Treatment involves medication to aid digestion, proper nutrition, and lung therapy.

ACOG Committee Opinion #486



# American College of Obstetricians and Gynecologists

- Guideline development:
  - Committee generates ideas
  - Guidelines written by assigned member
  - Vetted by entire committee
    - Secondary review by other national organizations as appropriate
  - Clinical document review panel
  - Executive Board review
  - Published in Obstetrics and Gynecology
    - Timeline



#### ACOG

- Goal: for Increasing Joint Collaborative Documents
  - Decrease duplication of effort
  - Develop consistent policies:
    - Non invasive prenatal testing (CO 545)
       December, 2012
    - Microarray in Prenatal Diagnosis



#### Genetic Documents in the Last 5 Years

- CO#527, "Personalized Genomic Testing for Disease Risk"
- CO#488, "Pharmacogenetics"
- CO#486, "Update on Carrier Screening for CF"
- CO#481, "Newborn Screening"
- CO#478, "Family History as a Risk Assessment Tool"
- CO#469, "Carrier Screening for Fragile X Syndrome"
- CO#449, "Maternal PKU"

## Committee Documents in the Last 5 Years, Continued

- CO#446, "Array CGH in Prenatal Diagnosis"
- CO#442, "Preconception and Prenatal Carrier Screening for Genetic Diseases in Individuals of Eastern European Jewish Descent"
- CO#430, "Preimplantation Genetic Screening for Aneuploidy"
- CO#410, "Ethical Issues in Genetic Testing"
- CO#409, "Direct-to-Consumer Marketing of Genetic Testing"
- CO#399, "Umbilical Cord Blood Banking"
- CO#545, "Non Invasive Prenatal Testing"

## ABOG + ABMG Dual-Certified Diplomates

- 153 Ob-Gyn and Genetics
  - 76 General OB-GYN
  - 71 MFM
  - 6 REI
- Genetics Certifications:
  - 153 Clinical Genetics, plus
  - 1 Biochemical
  - 8 Cytogenetics
  - 5 Molecular
  - 1 Sub-molecular Genetic Pathology

## ABMG - ABOG MOC Relationship

#### ABMG:

Three Part II and three Part IV modules per 10 year cycle

#### ABOG:

Yearly Part II modules and 6 Part IV modules per 10 year cycle



## **ABMG - ABOG MOC Training**

- ABMG: Complete cross acceptance of training for Part II literature review modules for maintenance of certification with ABOG
- Acceptance of all genetic-related Part IV ABOG modules
  - Labor intensive for the ABMG.
    - Different ABOG MOC format



### Combined ObGyn-Genetics Residency Programs

- ZERO graduates
- ZERO current trainees

- Difficulty integrating with a surgical specialty?
- Probably not a viable approach

#### American Board of Obstetrics and Gynecology

- Written and oral examinations for original board certification
- Some incorporation of genetics in written and oral board examinations:
  - Examples:
    - BRCA management
    - Genetic screening
      - —Aneuploidy
      - –Cystic fibrosis
      - -Thalassemias

## CREOG: Council on Resident Education in Obstetrics and Gynecology

- Core curriculum 2009, Ninth Edition
  - Genetics as part of:
    - Ambulatory care
    - Obstetrics
    - Heritable disease clinical implications
    - Genetic counseling
    - Gynecology
    - Reproductive Endocrinology
    - Oncology



## Genomic Literary for Obstetricians and Gynecologists

- Planning for the next 10 years :
  - EHR: Meaningful Use and FamilyHealth History
  - -Telehealth
  - Electronic Education tools



### **Electronic Educational Tools**

- Standardized genetic information
  - Extension of genetic counseling.
    - Facebook
    - Office Ipads
- Family history project
- Screening/testing options.



# Health Information Technology for Economic and Clinical Health Act

- "Meaningful Use" of EHRs
  - Electronic information exchange between health systems
  - Quality care assessments of systems
    - EHR vendors must meet national guidelines
      - Office of National Coordinator for Health IT (ONC)
        - Office of Health and Human Services



## Meaningful Use: Family Health History

- Stage 2: 2014
  - Standard for entering family health history must be part of the EHR.
  - Must comply with standard data entry specification
    - SNOMED CT
      - –SNOMED CT (Systematized Nomenclature of Medicine--Clinical Terms)
        - » comprehensive clinical terminology
          - created by the College of American Pathologists (CAP)
    - HL7 Pedigree Standard
      - » international standard setting organization to integrate and exchange healthcare informatics

## Meaningful Use Family Health History 2014

- Will be an option (menu item), not a core requirement
- If chosen for implementation, >20% of all unique patients (ambulatory or inpatient) must have a structured data entry for one or more first degree relatives
- Possible core requirement by 2016

#### **Telehealth Services**

 "For purposes of Medicaid, telemedicine seeks to improve a patient's health by permitting two-way, real time interactive communication between the patient and the physician or practitioner at the distant site. This electronic communication means the use of interactive telecommunications equipment that includes, at a minimum, audio and video equipment."

Source: Medicaid.gov

## **Future Planning**

- Telehealth development to standardize dissemination of information nationally
- Meaningful Use: Family History addition to EHR
- Continued emphasis on educational activities
- More rapid development of ACOG Committee
   Opinions for national dissemination
  - Continued joint statements for national guidelines.

