



# **The Medical Genetics Workforce: Getting to Where We Need to Be From Here**

**Judith Benkendorf, MS, CGC  
Project Manager  
American College of Medical Genetics**

**November 20, 2007**



# Today's Medical Genetics Workforce

- ◆ **As of November 2007:**
  - 2,341 individuals hold 2,772 certificates from AMBG
    - In 2003, 13% represented minority populations
  - 2,513 genetic counseling certificates issued; with an estimated 2437 genetic counselors actively practicing (ABGC, 2007)
    - Certification by ABMG until 1990; ABGC after 1993
  - Not all of these ~4700 individuals are alive, and a portion live and work outside the USA
- ◆ **Genetic counselors are the fastest growing cohort, BUT only:**
  - 6% are men
  - 9% represent minority populations (2006 NSGC PSS)
- ◆ **Assuming GCs all are alive and practicing in the USA**
  - 1 GC for every 123,600 population
    - Based on US population of 301,140,000

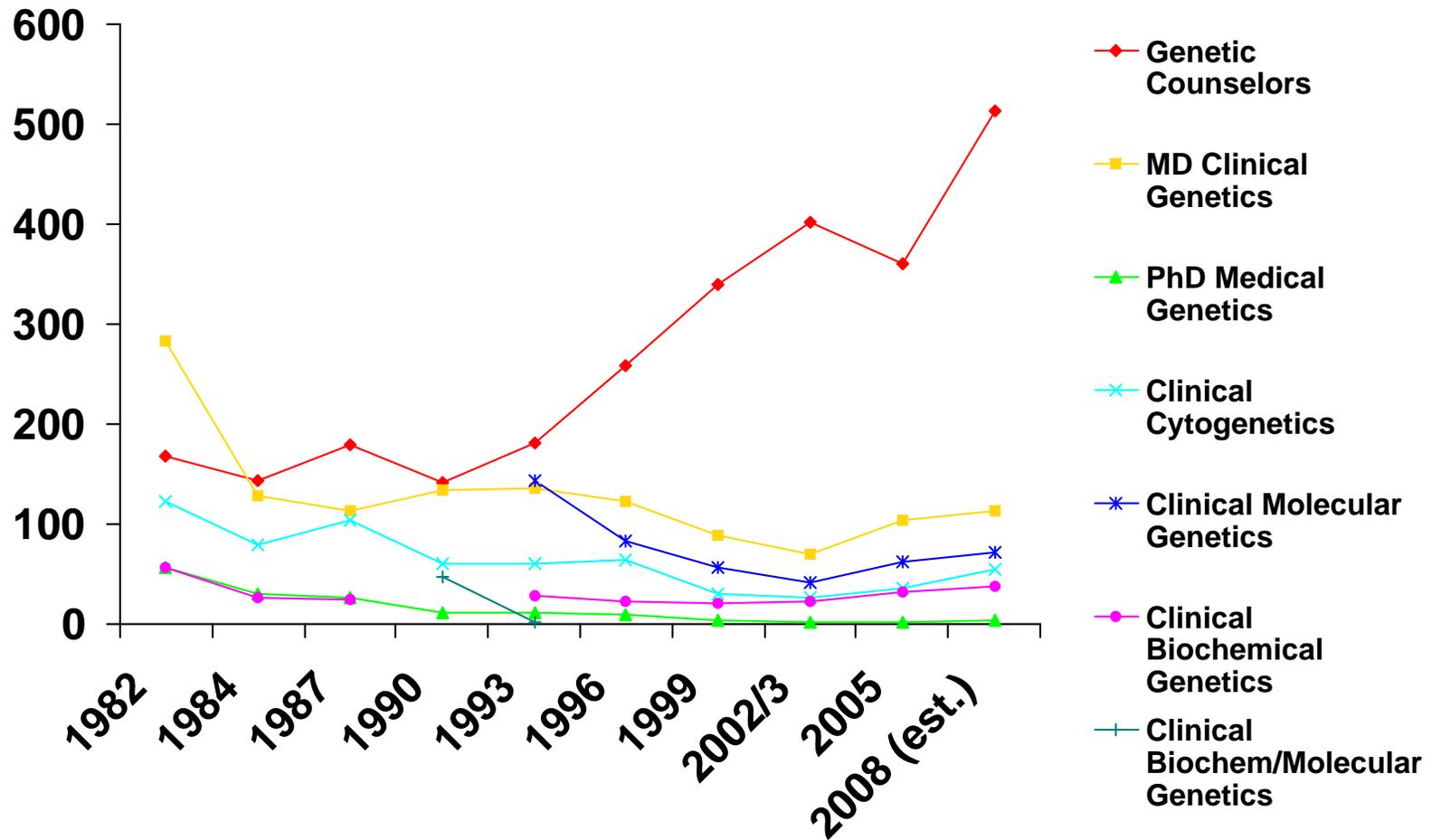


# The Clinical Geneticist Workforce

- ◆ **1,253 ABMG certified clinical geneticists (November 2007)**
  - This represents 0.18% of the 700,000 physicians in the US
- ◆ **~1,100 active in the US (estimated) spend ~45% of their time seeing genetics patients (ACMG, 2007)**
  - ~1 FTE certified MD geneticist per ~560,000 people; or ~1.8 clinical geneticists per million population
- ◆ **Royal College of Physicians estimates 1 FTE per 250,000 population as ideal**
  - Based on current population of roughly 301,140,000 the US needs 1200 FTE MDs.
  - **We are only half way there!**



# Medical Genetics Certification Trends 1982 - 2008 (estimated based on 2007 boards)





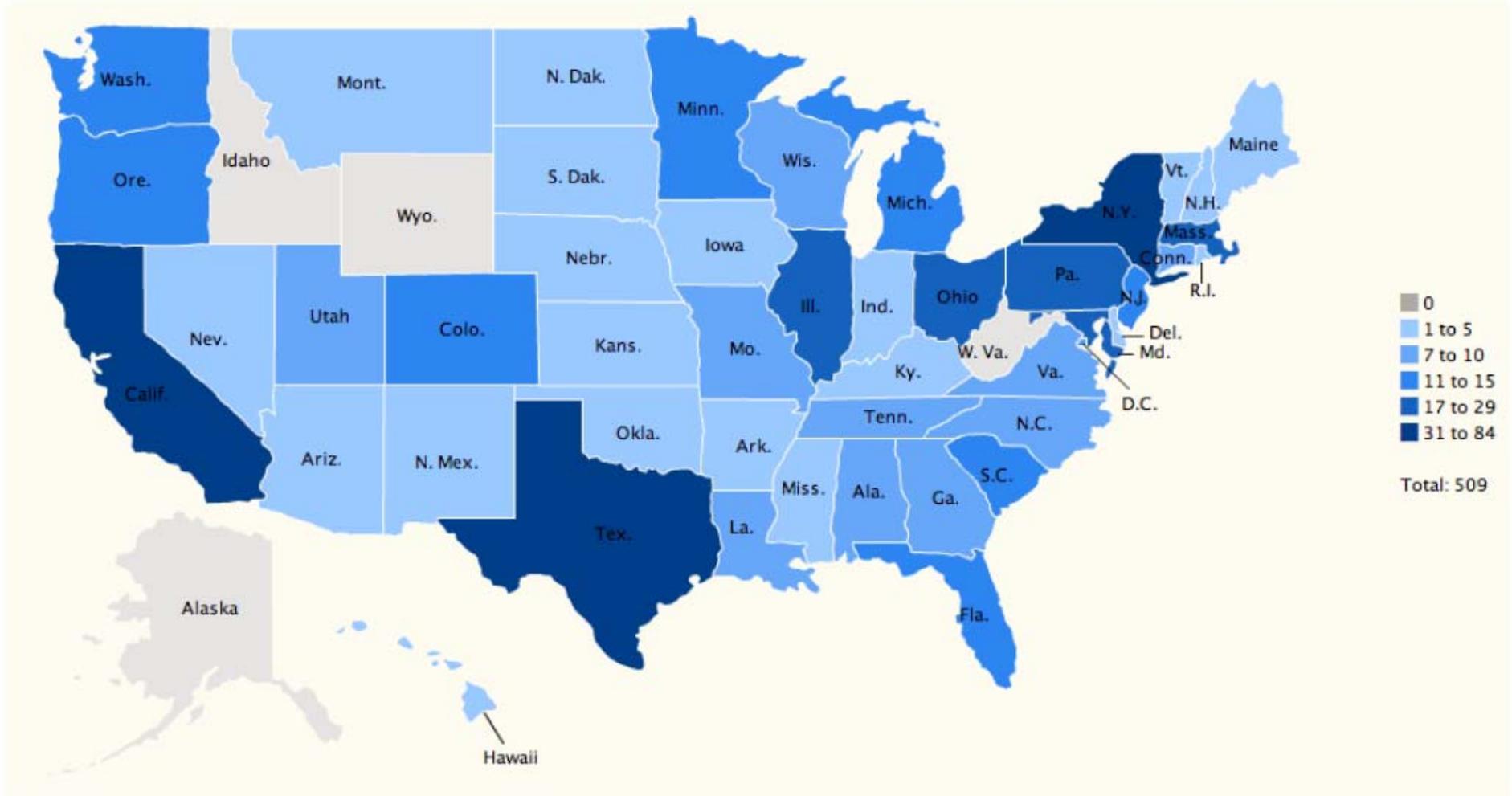
# Genetics Workforce Study: Conclusions (1)

## **The medical genetics workforce situation is critical!**

- ◆ **Current clinical services workforce not expected to meet patient care needs in next 5-15 years**
- ◆ **Serious mismatch exists between expansion of knowledge and workforce size**
- ◆ **Young physicians not entering field**
  - Competition expected to increase with emerging national physician shortage
- ◆ **Many states ( $\geq 17$ ) and parts of US have inadequate supply of MD clinical geneticists to meet demand**
  - Metabolic genetics physicians are the most critical need
- ◆ **Issues of how MD geneticists work also a factor**
  - Banbury Conferences II and III addressing this



# Geographic Maldistribution of MD Geneticists



Acknowledgement: Jason Bobe, Harvard University (November 2010)



# The State of Our Metabolic Specialists

- ◆ **At a time when expanded NBS is expected to detect 10,000 affected infants annually needing chronic disease management...**
  - **There are 200 metabolic physicians in USA**
    - Some conditions so rare, only a handful of experts exist
  - **This group is least able to expand services (2003 data)**
    - 3/4 report practices “nearly full”
    - 20% expect to retire in next 5 years
  - **States unable to expand NBS panels due to this shortage**
    - (E.g., Michigan and West Virginia)
- ◆ **Solutions need to take many approaches**
  - **Funding for training in S. 1858 (NBS legislation)**
  - **1 ACMGF/Industry-sponsored MD fellowship position annually**
  - **Creation of Medical Biochemical Genetics ABMG certification**
    - **First of many Clinical Geneticist subspecialties**



# Banbury Conference on the Evolving Role of the Clinical Geneticist (2006)

- ◆ **Banbury I (October 2004):**
  - **Sponsored by ACMG to discuss training of medical genetics physicians and recruitment strategies**
- ◆ **Banbury II (February 2006):**
  - **Convened by ACMG, with broad representation, to define the domain of medical genetics practice and develop principles that underpin this practice**
  - **Report with principles and recommendations forthcoming in *Genetics in Medicine***
    - **Sets foundation for “Banbury III” (2008) to develop core competencies and curriculum for medical genetics training**



# Banbury II: Principles

- 1. Medical genetics is a primary medical specialty dedicated to the use and interpretation of genetic information to maintain and improve the health of individuals, their families, and their communities.**
- 2. The primary medical specialty, as recognized by the American Board of Medical Specialties (ABMS), is comprised of board certified physician geneticists and clinical laboratory geneticists.**
- 3. The purview of medical genetics services includes all of the following:**
  - a. Clinical and laboratory diagnosis, risk assessment, pedigree analysis, counseling, provision of therapy and longitudinal medical care**
  - b. Care to patients across the age spectrum and for conditions involving any organ system**
  - c. Patients and their families**
  - d. Practices and policies pertaining to public health and disease prevention**
- 4. The rapid pace of discovery in medical genetics necessitates a dynamic approach to training and implementation of new paradigms of care.**



## **Banbury II: Points to Consider** **To facilitate quality care, optimize geneticists' skills and position field for the future (1)**

- 1. Medical genetics services are best provided by a physician geneticist working together with a team of professionals, including clinical laboratory geneticists, genetic counselors and/or genetics nurses.**
- 2. The realization of an integrated model is best achieved through establishment of a consolidated administrative unit that has equal status in the academic institution and/or health system with other primary medical specialties.**
- 3. Medical geneticists should provide leadership in the responsible introduction of new technologies, their integration into medical care, and monitoring of outcomes. Current examples include:**
  - a. Prenatal and newborn screening for an expanding range of genetic conditions**
  - b. Application of genomic technologies to high throughput diagnostic testing**
  - c. Development and application of informatic approaches to incorporate genetic and genomic data into patient care**
  - d. Predictive testing to assess genetic risk of common disorders and to guide prevention and management**
  - e. Clinical applications of pharmacogenetics**
  - f. New approaches to therapy of inherited disorders**



## **Banbury II: Points to Consider** **To facilitate quality care, optimize geneticists' skills and position field for the future (2)**

- 4. Genetics training and certification should recognize the competencies expected of medical geneticists as well as the rapid pace of change of the discipline.**
- 5. The medical genetics community should actively promote its services and educate colleagues in other specialties and should facilitate the integration of genetics into medical and public health policy and practice.**
- 6. Medical genetic services must be made accessible to the entire population.**
- 7. The medical genetics workforce must be increased to meet current and anticipated needs.**
- 8. To prepare for the future practice of medical genetics, training and continuing education programs should include substantial exposure to molecular and population genetics, epidemiology, and bioinformatics.**
- 9. The pool of trainees who enter the field of medical genetics must be increased and broadened, and training pathways and the certification process must be aligned with this goal.**



# In Conclusion: Getting to Where We Need to Be From Here

- ◆ **Opening the medical geneticist tent to expand workforce**
  - Increasing joint training programs and clinical genetics subspecialties
  - Re-aligning medical genetics training to reflect emphasis on common traits and genetic healthcare over the lifespan
- ◆ **Being aware of how genetic services will be distributed in healthcare, based on complexity**
  - Roles of primary care and specialty care
  - Roles of consumer genetics and personalized medicine movements
- ◆ **Positioning the profession to:**
  - Provide adequate clinical support in a range of service settings
  - Adapt medical student education to future genetics needs
  - Welcome new practice and training modalities and paradigms
  - Anticipate future needs and develop tools to address these