Genetics Education Pipeline and Workforce

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Overview

- Describe
  - Genetic healthcare providers
    - Genetic Counselors
    - MD, PhD Geneticists
    - Genetics Nurses
  - Education pipeline
  - Status of current workforce
  - Challenges and Initiatives

Data compiled from ACMG, NSGC, ABGC, ABMG, ISONG

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Genetic Counselors

- Identify and introduce possibility of genetic risk
- Contract: determine patient's knowledge and motivations
- Ascertain personal and family medical histories via three-four generation, targeted pedigree
- Provide risk assessment for patient and family
- Educate about condition(s), inheritance pattern, risk, availability of genetic testing, management, and prevention
- Facilitate informed decision making
- Obtain informed consent for genetic testing
- Counseling to assess psychosocial impact and provide support
- Resource identification
- Follow up including guidance about informing key relatives

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Adapted from NSGC Scope of Practice, ABGC Practice-Based Competencies, NSGC's Definition of Genetic Counseling

Genetic Counselors: Education

- Master's in Genetic Counseling: two year accredited program
  - **Coursework: Counseling techniques/theories, molecular biology, human and medical genetics, ethics, healthcare delivery systems, public health, teaching techniques, research methods**
  - **Clinical Training: exposure to broad range of genetic conditions in variety of clinical settings, documents expected competencies**
  - **Research Component**
- Association of Genetic Counseling Program Directors (AGCPD)
  - Established to increase communication and collaboration between graduate programs
  - Address training issues and challenges

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Credentialing: American Board of Genetic Counseling (ABGC)

- Genetic Counselors were credentialed by the American Board of Medical Genetics (ABMG) before 1993
- ABGC: incorporated in 1993 as the credentialing body for the genetic counseling profession
- Accreditation sets academic standards for institution
  - Currently 32 graduate programs in genetic counseling

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American Board of Genetic Counseling (ABGC)

- Certification establishes the standards individual practitioners must have to provide competent genetic counseling services
  - Graduate from an ABGC accredited program
  - Logbook of 50 clinical cases (shifting this to programs)
  - Successfully complete a general genetics and genetic counseling specialty exam
  - 1996 and beyond: required to recertify every 10 yrs (exam or continuing education)

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Genetic Counselors: Licensure

- State Licensure
  - Licensure usually based on passage of ABGC examination
  - 7 states have passed licensure bills (two with active license)
  - 5 states have introduced bills, 13 have begun process
  - NSGC has developed guiding principles and language

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Genetic Counselors: Workforce

- 2448 certified GCs (~400% increase since the inception of ABGC: 495 to 2448)
- 3000 genetic counselors estimated to be in the United States
- Assuming GCs all are alive and practicing in the USA
  - 1 GC for every 100,380 population (using 3000)
  - 1 GC for every 123,015 (using 2448)
    - Based on US population of 301,140,000

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Genetic Counselors: Workforce

Percent by Region (2006 NSGC PSS)

I: Northeast

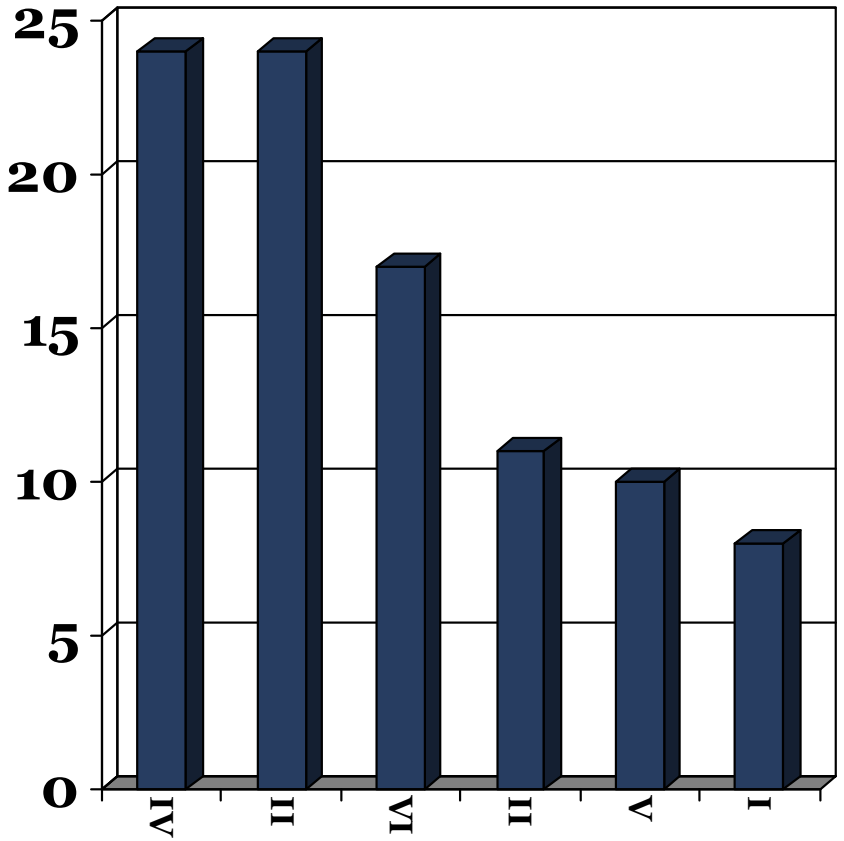
II: Mid Atlantic, NY, PA

III: Southeast

IV: Midwest

V: Mountain States, TX

VI: West



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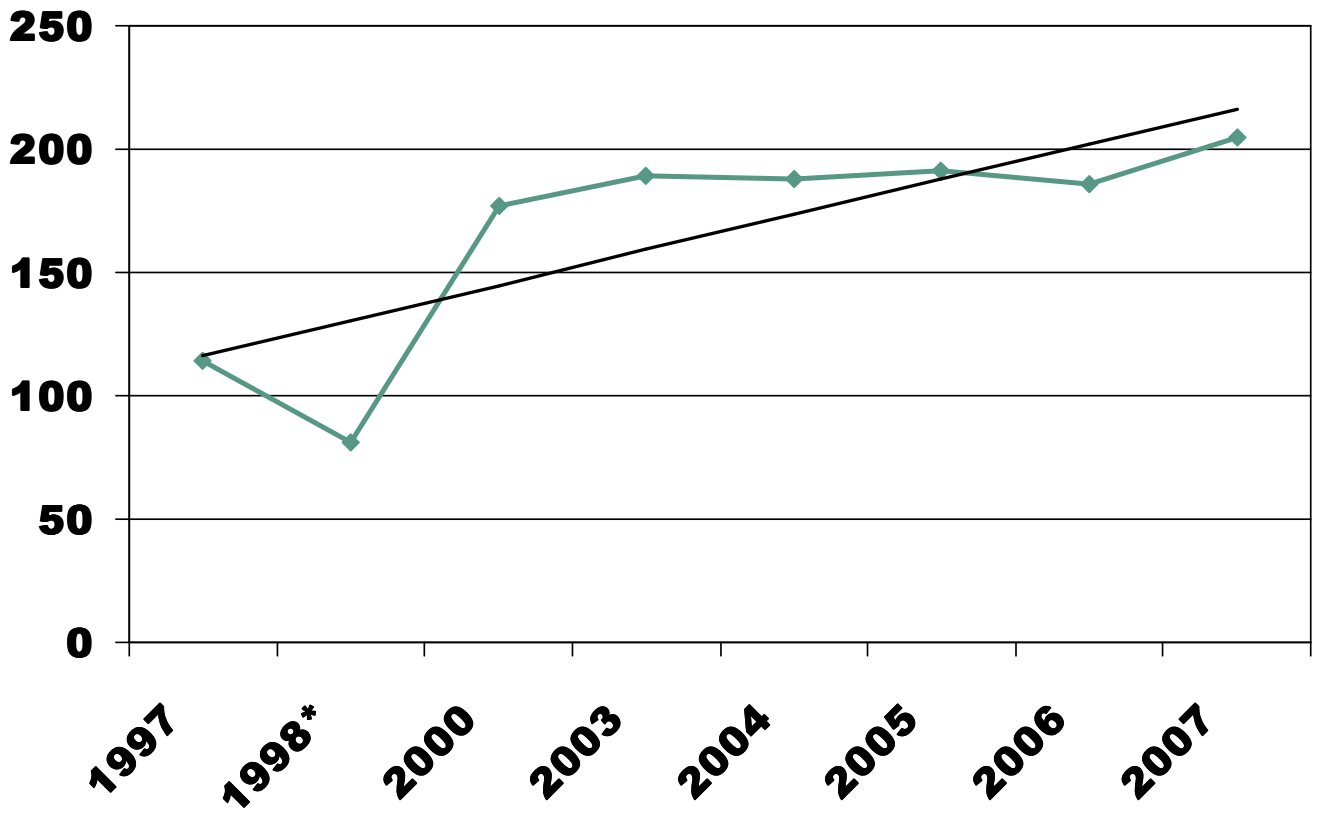
Trainees entering genetic counseling graduate programs



Since the inception of ABGC (1993), # of programs has increased from 18 to 32

Approximately 225 new graduates each year (600 applicants)

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Data courtesy of Association of Genetic Counseling Program Directors

Challenges: Increasing Diversity

- Status of the profession: 91% self identify as Caucasian
  - 1% African American
  - 4.9% Asian
  - 2% Hispanic
- Midwest Program Directors Retreat on Increasing Diversity*
  - Improve understanding and address barriers
  - Implement recruiting strategies
  - Increase cultural competence

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Convened by Nancy Warren, University of Cincinnati

Challenges: Increasing the Workforce

- Genetic counselors and their services are typically not directly reimbursed limiting revenue generation
  - Leads to inadequate number of genetic counselors
  - Limits access to genetic counseling services
  - Ultimately, prevents full integration into healthcare system

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Challenges: Increasing the Workforce

- Limited number of genetic counseling graduate programs due to limited/lack of funding
  - Need other revenue streams besides tuition: government
  - Loan forgiveness programs
  - Providing scholarships to support the matriculation of under-represented applicants
  - Example: Nurse Reinvestment Act of 2002
- Limited number of positions available in each program due to availability of clinical internships
  - Need more genetic counselors to train more students
  - Workload and nature of supervision limit number able to take trainees

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Addressing the Challenges to Access- NSGC's Strategic Plan

- Expand access to genetic counseling services by actively pursuing reimbursement for certified genetic counselors
  - Pursue federal legislation that recognizes genetic counselors as healthcare providers
  - Support states in the efforts to pursue licensure to provide consumers with Certified genetic counselors
  - Develop and grow relationships with third party payers

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Other NSGC Initiatives

- Pursuing research to demonstrate the financial value/impact of genetic counseling
- Monitoring trends in healthcare to determine how we will respond moving forward
- Exploring alternative service delivery models
- Pursuing partnerships and activities that support integration efforts, e.g.,
  - Working with PCPs and PAs on genetics education
  - Working with ABGC and Association of Genetic Counseling Program Directors to address workforce issues

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Recent ABGC Certification Changes

- One exam format (used to be two part exam: one general administered by ABMG and one genetic counseling administered by ABGC)
  - Practice Analysis: one test psychometrically sound, redundancy eliminated
  - Frequency: offered annually (licensure, clinical training issues)
  - 30 day window to take exam

Data courtesy of the American Board of Genetic Counseling

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Continuing Education of Genetic Counselors

- NSGC Educational Summit (Summer 2007): Goals were to identify and address emerging educational needs of membership and other professionals, to explore alternative methods of education, and enhance quality
- NSGC: became the authorized provider of genetic counselor CEU's through IACET: May result in new CEU opportunities
- NSGC short courses/symposium provide comprehensive information on emerging topics (public health, cardiovascular genetics, common complex disease)

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Medical Geneticists

- Since 1981 the American Board of Medical Genetics (ABMG) has offered certification to MD clinical geneticists and clinical laboratory geneticists (MD or PhD)
  - Clinical Geneticists also referred to as “MD geneticists” or “physician geneticists”
  - Laboratory Geneticist certifications:
    - Clinical Cytogeneticist
    - Clinical Molecular Geneticist
    - Clinical Biochemical Geneticist
    - This group not discussed further today

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Credentialing: A Bit of History

- American Board of Medical Genetics (ABMG)
  - Recognized as the 24th primary medical specialty board by the American Board of Medical Specialties (ABMS) in 1991
  - Required separate groups to certify nurses and genetic counselors
  - Eligibility to sit for the examination: successfully complete a minimum of two years in an ABMG accredited training program
  - Eligibility to sit for clinical genetics and a laboratory specialty: complete a minimum of three years in an ABMG or ACGME accredited training program
  - Catalyst for establishing the American College of Medical Genetics (ACMG)

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Scope of Medical Genetics Practice

- Challenges to establishing Scope of Practice exist (Korf, et al, *GIM 10(7)*:502, July 2008)
  - Genetic issues apply to all organ systems, periods of life, disease entities, etc.
  - Broad territory and roles of medical geneticist may differ from condition to condition and/or institution to institution
  - Various kinds of genetics professionals involved
  - New approaches for risk assessment and management of common disorders on the horizon
- Medical Genetics Scope of Practice recently approved by ACMG Board of Directors

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The Clinical Geneticist Workforce

- As of November 2007
  - 1,253 ABMG certified clinical geneticists (ABMG, 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 ~608,000 people; or ~1.6 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
  - Based on ACMG data, there are currently 495 FTE (45% of 1100) in the US workforce
    - This is 41.25% of the 1200 FTE needed

slide from Judith Benkendorf, MS, CGC

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The Clinical Geneticist Workforce

- 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 the USA
    - Some conditions so rare, only a handful of experts exist
  - This group is least able to expand services (2003)
    - ¾ report practices "nearly full"
    - 20% expect to retire in next five 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 a Medical Biochemical Genetics ABMG certification
    - First of many Clinical Geneticist subspecialties

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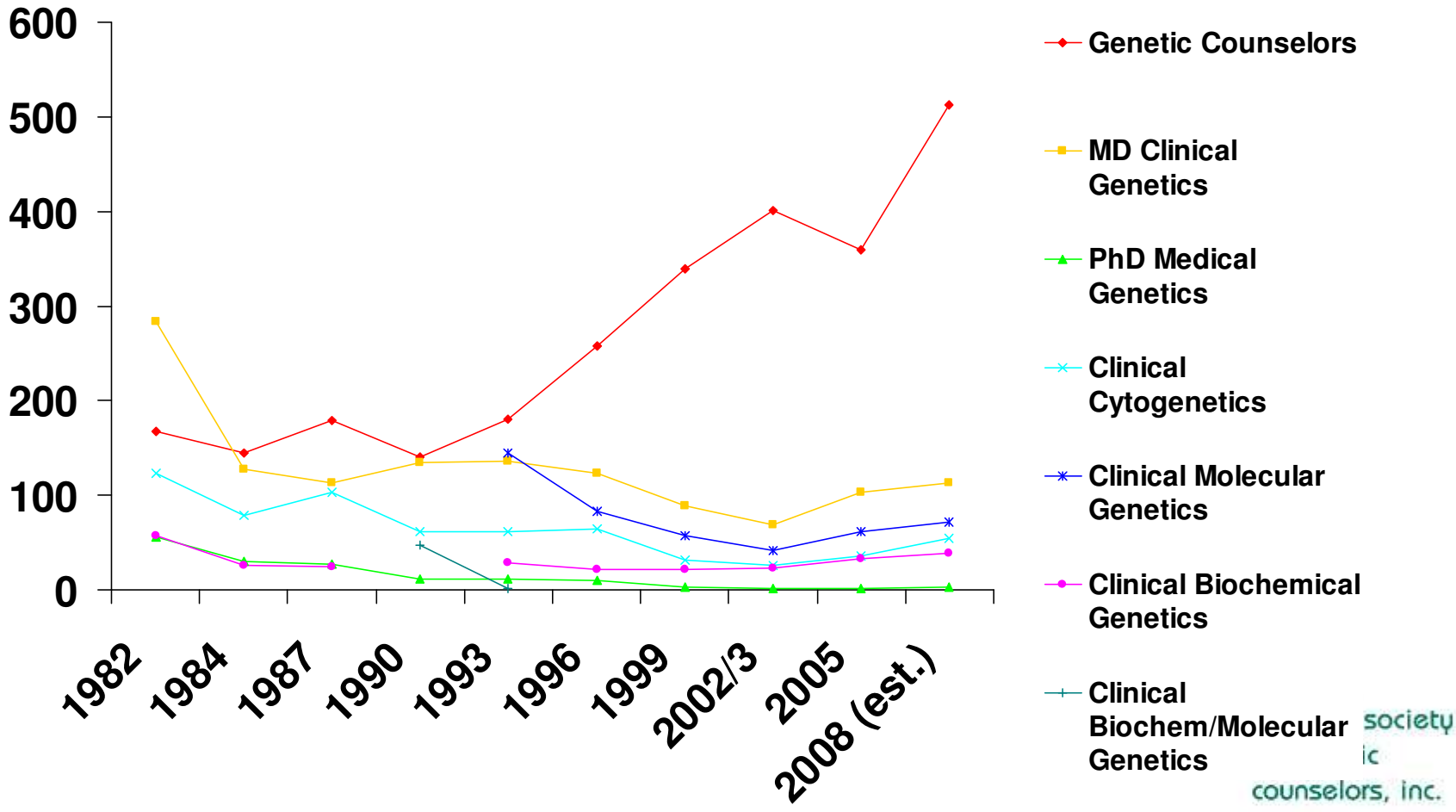
1982 - 2008 (estimated based on 2007 boards)



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Genetics Workforce: Challenges

- 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 (≥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

Cooksey, et al, GIM *7(6):439, Aug 2005; slide from Judith Benkendorf, MS, CGC*

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Initiatives: Banbury Conference on the Evolving Role of the Clinical Geneticist

- 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 in *Genetics in Medicine*
    - Sets foundation for "Banbury III" (2008) to develop core competencies and curriculum for medical genetics training

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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.

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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

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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.

4. 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.

5. Medical genetic services must be made accessible to the entire population.

6. The medical genetics workforce must be increased to meet current and anticipated needs.

7. 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.

8. 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.

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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

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Genetic Nurses

- Obtain detailed family history and construct pedigree
- Assess and analyze hereditary and nonhereditary disease risk factors
- Identify potential genetic conditions or genetic predisposition to disease
- Provide genetic information and psychosocial support to individuals and families
- Provide nursing care for patients/families at risk for or affected by diseases with a genetic component
- Provide genetic counseling (Advanced Practice Nurses)
- Facilitate genetic testing and interpret genetic test results and laboratory reports (Advanced Practice Nurses)

International Society of Nurses in Genetics Website

Genetic Nurses: Education and Credentialing

- Several master's or Nursing Doctorate programs available to nurses who wish to specialize in Genetics (5 programs)
- The Genetic Nursing Credentialing Commission (GNCC) provides recognition for clinical nursing practice in healthcare with a genetics component
  - GNCC is a subsidiary of ISONG and grants its credentials based upon a portfolio of evidence
  - Credentialing as an Advanced Practice Nurse in Genetics (APNG) or as a Genetics Clinical Nurse (GCN)

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Genetic Nurses: Advanced Practice Nurse in Genetics (APNG)

- Master's level nurse, proof of RN license in good standing
- 300 hours of Genetic Practicum experiences (greater than 50% genetic practice component)
- Logbook of 50 cases
- 4 written case studies reflecting ISONG standards of clinical genetics nursing practice
- Graduation from an accredited graduate program in nursing
- 50 hours of genetic content in the past 5 years through academic courses or continuing education
- Evidence of patient/family and/or client teaching

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Genetic Nurses: Genetics Clinical Nurse (GCN)

- Proof of RN license in good standing
- 5 years experience as a clinical genetic nurse with greater than 50% genetic practice component
- Log of 50 cases
- Written case studies reflecting ISONG standards
- Graduated from an accredited Baccalaureate program in Nursing
- 45 contact hours of genetic content through academic courses or continuing education
- Evidence of patient/family and/or client teaching and evidence of genetics-related in-service education

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Genetics Nurses Workforce

- Advanced Practice Nurse in Genetics (APNG)
  - 28
- Genetics Clinical Nurse (GCN)
  - 10
- Challenge: Many nurses have certifications or advanced practice licenses in other specialty areas and have not chosen to pursue the APNG

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Data courtesy of ISONG

Initiatives: Nurses

- Initiative launched in 2004 to define essential genetic genomic competencies for all registered nurses (regardless of academic preparation)
- Goal: prepare entire nursing workforce to deliver genetically and genomically competent healthcare
- Part 1: *Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics* established in 2005
- Part 2: 5 year strategic plan for implementation of *Essential Competencies* (2006)
- Part 3: Pilot survey to benchmark baseline nursing knowledge, attitudes, and competency is in process at the NIH

Information courtesy of ISONG

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Initiatives: Nurses

- 1998 Statement on Scope and Standards of Genetics Clinical Practice (defined both basic and advanced specialty practice in genetics) was revised and published in 2007: *Scope and Standards of Genetics/Genomics Nursing* (ISONG and ANA)
- 2007: American Association of Colleges of Nursing released draft of the revision of *The Essentials of Baccalaureate Education for Professional Nursing Practice:* ISONG actively involved in attending meetings and providing feedback to urge inclusion of additional focus on genetics/genomics within competencies, content and learning strategies

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Conclusions

- Various challenges to each genetic service provider
- Challenges include:
  - Interest in profession
  - Funding for training programs
  - Limited billing and reimbursement
  - Rapidly changing technology
  - Defining roles of primary care and specialty care

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