

# Promoting Effective Communication and Decision Support- Genetic Counselors' Roles

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## Scope of genetic counseling services - Genetic counselor perspective

- 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

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

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# What is the role of healthcare professionals without specialty training in genetics?

- Moving target
- Hayflick's definition appropriate for genetic services in 1998 - still applicable for many scenarios
- In 2007, a need for roles that extend beyond identification and referral
- Gap: When to refer to genetics and when to manage in primary care

## Role of primary care professionals\*

- Identification
- Recognition of features
- Monitoring of health
- Provision of basic information
- Coordination of care
- Recognition of special psychosocial issues
- Knowledge of available genetics services
- Referral of patients
- Facilitation of use of genetics services

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\*Hayflick SJ et al (1998). *Genetics in Medicine* 1(1):13-18.

# Factors that effect roles of non-genetics professionals in service provision

## **Provider**

- Competencies in genetics: professional guidelines, adherence
- Practice setting and time constraints
- Interest

## **Community**

- Availability of genetics services
- Community's willingness to utilize genetics services
- Community's access to information about genetic risk
- Insurance reimbursement

## **Disease**

- Indication for risk assessment or testing
- Complexities of disease genetics
- Complexities of testing
- Complexities of management
- Psychosocial impact
- Complexity of decision making
- Quality of available data (ambiguity?)

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# Services provided by PCP versus genetic counselor for cystic fibrosis carrier screening

	Population Screening by PCP	Family History of CF Genetic Counselor
Identify and introduce	✓	✓
Contract	✓	✓
Limited family history	✓	
Detailed family history		✓
Limited risk assessment	✓	
Detailed risk assessment		✓
Education (limited)	✓	
Education (extensive)		✓
Informed consent for testing	✓	✓
Psychosocial Counseling		✓
Follow-up	✓	✓

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# What is required for PCP's to effectively provide genetic counseling for CF population carrier screening?

- PCP's who know:
  - To whom to offer the test
  - How to take a (limited) family history
  - Basic information about symptoms of CF
  - Patient's baseline risk
  - How to accurately interpret test results
  - How to refer for genetics services when needed
  - Importance of complying with laboratory's request for patient information
- Laboratories that provide interpretable test results and have professionals available to answer questions
- Accessible educational resources for PCP's and patients

*Genetic counselors can help with all of these factors.*

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# Genetic counselors' two-pronged approach to integrating genetics into primary care

## **Training & Continuing Education of Genetic Counselors**

- Increase number of programs and certified providers (increase workforce)
- Increase & diversify applicant pool
- Promote and validate the quality of the credential
- Pursue licensure and federal recognition
- Provide opportunities for continuing education

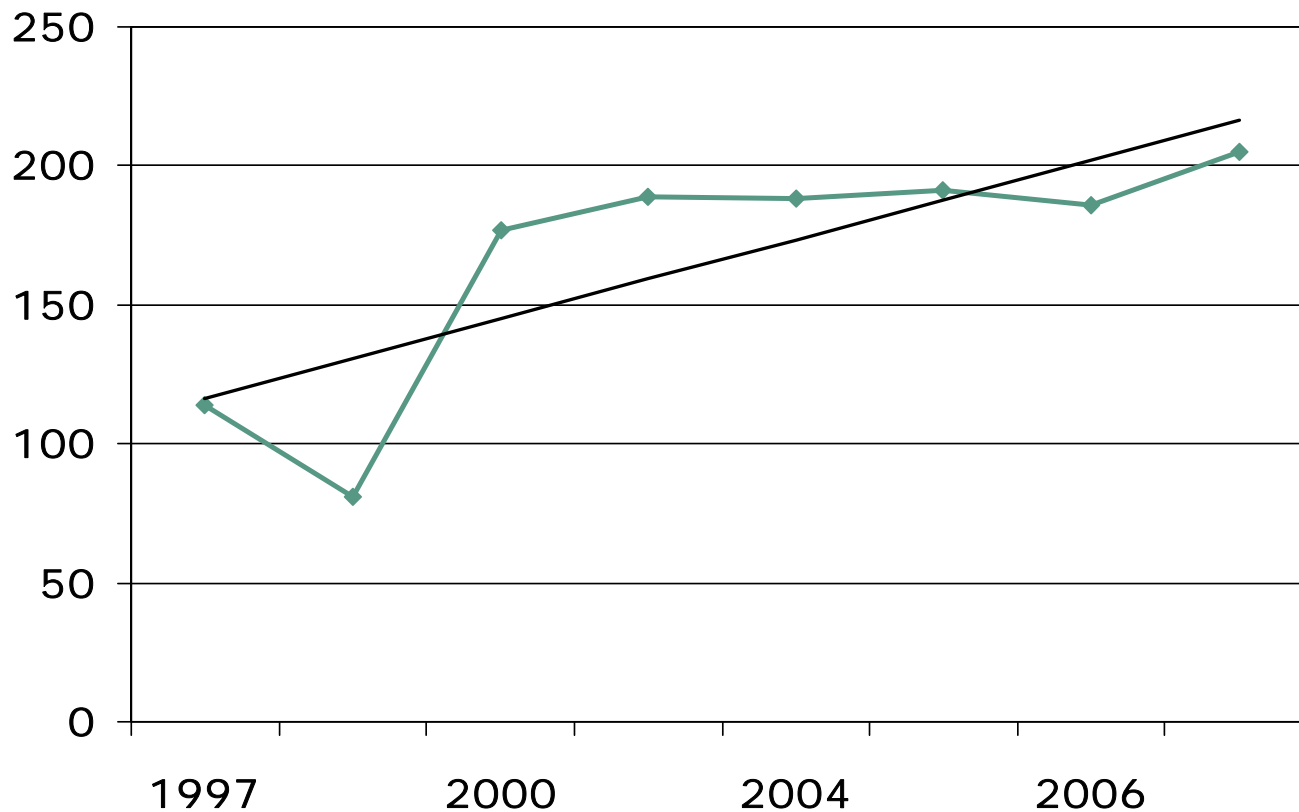
## **Improve Genetics Knowledge of Healthcare Providers & Public**

- Plan educational programs
- Conduct presentations for practicing professionals and trainees
- Develop resource materials
- Participate in state and federal efforts towards integration
- Develop practice guidelines

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## Increasing the workforce: Trainees entering genetic counseling graduate programs



Since the inception of American Board of Genetic Counseling (1992), # of programs has increased from 18 to 31

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*\*Data courtesy of Association of Genetic Counseling Program Directors*



## Increasing the workforce: Certification trends

- Number of certified genetic counselors has increased from 495 to 2437 since the inception of ABGC (~400% change)
- Since the 2004 Resolution, almost 1100 have become certified
- In 2006, first cycle of recertification resulted in 316 recertifying. 122 voluntarily recertified.
- Certification exam is now offered on a two year cycle (as of 2005)

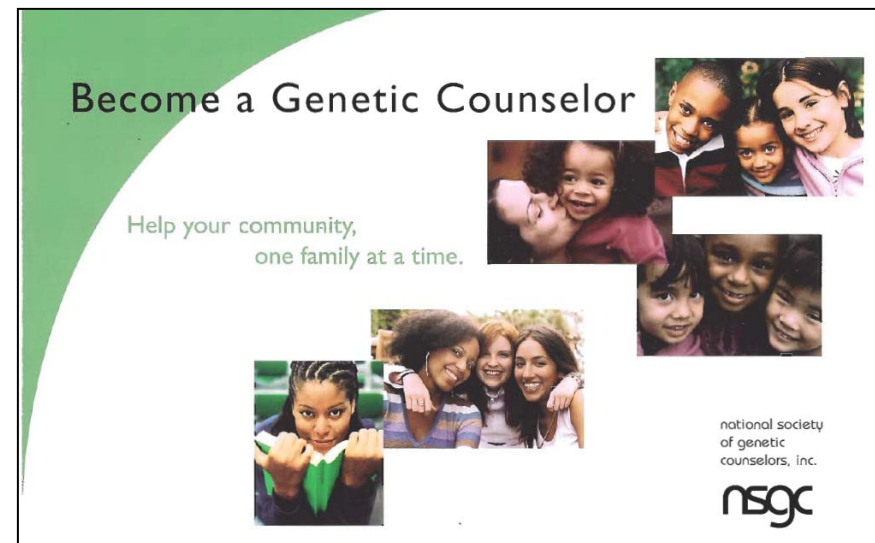
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*Data courtesy of the American Board of Genetic Counseling*

# Promoting diversity and cultural competence in the genetic counseling profession

- 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*

# Improving quality and access: Credentialing, licensure and federal recognition

- ABGC will conduct a practice analysis in 2008
  - Defines performance domains and tasks performed by professionals, and associated knowledge and skills
  - Information used to develop a relevant and valid certification exam
- State licensure
  - 7 have passed licensure bills (one with active license)
  - 5 have introduced bills, 13 have begun process
  - NSGC has developed guiding principles and language
- Federal recognition of genetic counselors
  - NSGC drafting legislation that would amend the Social Security Act so CMS recognizes genetic counselors

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# Enhancing education of practicing 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 is working towards becoming the authorized provider of genetic counselor CEU's through IACET - May result in new CEU opportunities
- NSGC short courses provide comprehensive information on emerging topics (public health, cardiovascular genetics)

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## Genetic counselors as educators: Current practices\*

<b>Teaching Audiences</b>	<b>%</b>
Genetic counseling students	72.7%
Medical students/physicians	72.6%
Nursing students/nurses	36.3%
Other health professionals, not specified	28.8%
Physician assistants	8.9%
Social workers/students	7.7%
K-12 grades	25.1%
Undergraduates	24.5%

*\*Data from 2006 NSGC Professional Status Survey.*

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# Genetic counselors as educators: Current practices\*

Teaching Activities	%
Spoken to lay/community groups	63%
Develop/organized a conference, workshop or symposium for healthcare professionals	29.7%
Developed/coordinated/served on advisory board or have been a resource for advocacy groups	25.9%
Developed a genetics curriculum for students/teachers	23.6%
Served on committees dealing with delivery of health/genetics services	22.4%
Developed brochures/pamphlets/videos	20.4%

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*\*Data from 2006 NSGC Professional Status Survey.*



## Variety of efforts

- Web-based education - Collaboration between NCHPEG, University of Cincinnati, NSGC, ASHA to develop module for Speech Language Pathologists and Audiologists
- Educational programs -
  - Cancer Genetics Education Program at City of Hope.
  - Family practice residents program with seminars and clinical rotation
- Guest lectures for allied health trainees - OT/PT, audiology, nursing, other allied health students
- Education materials - Tools created for GeneTests website. Subsequently used with family practice physicians.
- Education via standardized patient encounters - With residents, medical students, and practicing physicians.
- Participation in medical student education in genetics – Genetic counselors serve as course directors, lecturers, small group leaders

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## NSGC efforts to promote education of non-genetics healthcare professionals

- Speaker's Bureau
- *Journal of Genetic Counseling* issue devoted to genetics education for healthcare professionals.
- Representation on Secretary Leavitt's Family Health History Multi-Stakeholders Workgroup
- Participation in "Physician Assistant and Genomic Medicine" meeting
- Branding initiative to target physicians/HCP's to help them integrate genetics into their practice
- Position statement with ISONG about promoting collaborative approach to enhance quality of genetic services

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***Genetic counselors have the training, expertise, motivation, and experience to be key providers of education in genetics.***

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# SACGHS 2004 Resolution

## **Report identified urgent needs genetic counseling profession is addressing**

- Greater diversity in workforce and cultural competence
  - Outcome: Better understanding of issues
  - Still much to be done
- Educational models to clarify integration of genetics and genomics
  - Outcome: Majority of genetic counselors provide education to healthcare providers using different models
  - Branding should lead to a more strategic approach to working with physicians
- Growth of faculty appropriately trained in genetics and genomics
  - Outcome: Number of genetic counselors increasing
  - May not be enough to meet future needs

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# SACGHS Resolution - Additional Steps

- Genetics professionals are involved in both providing genetics/genomic services and educating healthcare professionals and the public
- Recommendations - promote and support initiatives to increase the genetics professional workforce, its diversity and cultural competence. This can be achieved by:
  - Supporting development of genetic counseling programs
  - Providing scholarships to support the matriculation of under-represented applicants
  - Supporting initiatives to increase the number of MD geneticists, laboratory geneticists, and genetics nurses

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# SACGHS Draft Report on Oversight of Genetic Testing – Chapter 6

## **Recommendation 1 - Identifying and addressing deficiencies in genetic knowledge and education**

Particularly important to understand why there are deficiencies and which ones may be insurmountable. Important to clearly define to what extent specific provider groups are expected to provide genetic services. Critical to work with professional organizations in addressing these issues.

## **Recommendation 2 - FDA authority over clinical decision making support systems**

Agree that clarification of FDA's role is critical. Also important to assess support and capabilities for utilizing such tools in clinical practice.

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# SACGHS Draft Report on Oversight of Genetic Testing – Chapter 6

## **Recommendation 3 - Need for genetics expertise, access issues**

- Strongly support the recommendation for HHS to act on the 2006 Coverage and Reimbursement of Genetic Tests and Services Report.
- Also recommend that SAGCHS ask the Secretary to promote and support initiatives to increase the genetics professional workforce, its diversity and cultural competence.

## **Recommendation 4- Knowledge gaps about genetic tests and their impact**

There still seem to be substantial gaps in the knowledge necessary to develop valid clinical decision making tools. These gaps will only become greater as multi-gene platforms are increasingly incorporated into clinical care. Recommend that resources are allocated at least equally to these types of studies rather than preferentially to the development of clinical decision support tools.

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# SACGHS Draft Report on Oversight of Genetic Testing – Chapter 6

## **Recommendation 5 – Direct to consumer testing advertising and consumer-initiated genetic testing**

- Agree that it is important to examine these issues
- Recommend that when evaluating these issues, a distinction be made between valid clinical genetic tests versus non-valid tests as the impact on patient outcomes and the cost implications may be very different

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