

Genetic Counselors and Genomics Education

Amy Cronister, MS, CGC

Genetic Counselors on ISCC

- Emily Edelman – Educational Products Working Group
- Kate Reed – Innovative Approaches Working Group
- Liz Varga - Innovative Approaches Working Group
- Toni Pollin- Payer Education Working Group
- Becki Hullinsky- Case Studies Working Group
- Karen Lewis- Insurer Staff Education Working Group

Agenda

- Provide some background regarding the genetic counseling profession
- Review NSGC initiatives and educational accomplishments
 - > Are some adaptable or useful in supporting ISCC efforts?
- Highlight GC specific core skills and training curriculum
 - > How might this guide ISCC's curriculum development or educational products for other providers
- Describe how genetic counseling and genetic counselors must adapt to a technology driven genomics world
 - > Does this influence ISCC educational approaches and content?
- Discuss the critical partnership that must exist between Genetic Counselors and other Health Care Providers
 - > How best to leverage our complementary competencies to improve clinical care in a changing genomics world

A stylized, light blue DNA double helix structure is centered in the background, rendered in a semi-transparent, artistic style. The helix is composed of several overlapping, curved segments that create a sense of depth and movement. The overall color palette is light blue and white, with a dark blue horizontal bar at the top and bottom of the slide.

GENETIC COUNSELING PROFESSION AND NSGC INITIATIVES

Genetic Counselors

- Master's trained healthcare professionals
 - > Interpret and provide clear and comprehensive information about genetic conditions, risks and testing options
- Training guided by practice-based competencies developed by the accrediting body (Accreditation Council for Genetic Counseling-ACGC)
 - > Curriculum
 - Genetics expertise and analysis
 - Interpersonal, psychosocial and counseling skills
 - Education
 - Professional development and practice
 - > Clinical internships - Variety of settings including cancer, reproductive, pediatric genetics, labs
- Certification examination administered American Board of Genetic Counseling (ABGC)
 - > Today over 3500 genetic counselor are certified in the US and Canada

What Is Genetic Counseling

- Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease
- This process integrates:
 - > *Interpretation* of family and medical histories to assess the chance of disease occurrence or recurrence
 - > *Education* about inheritance, testing, management, prevention, resources and research
 - > *Counseling* to promote informed choices and adaptation to the risk or condition
- Supports physician's role in directing patient medical management and treatment

Genetic Counselor Patient Centered Approach

Components of the GC Session

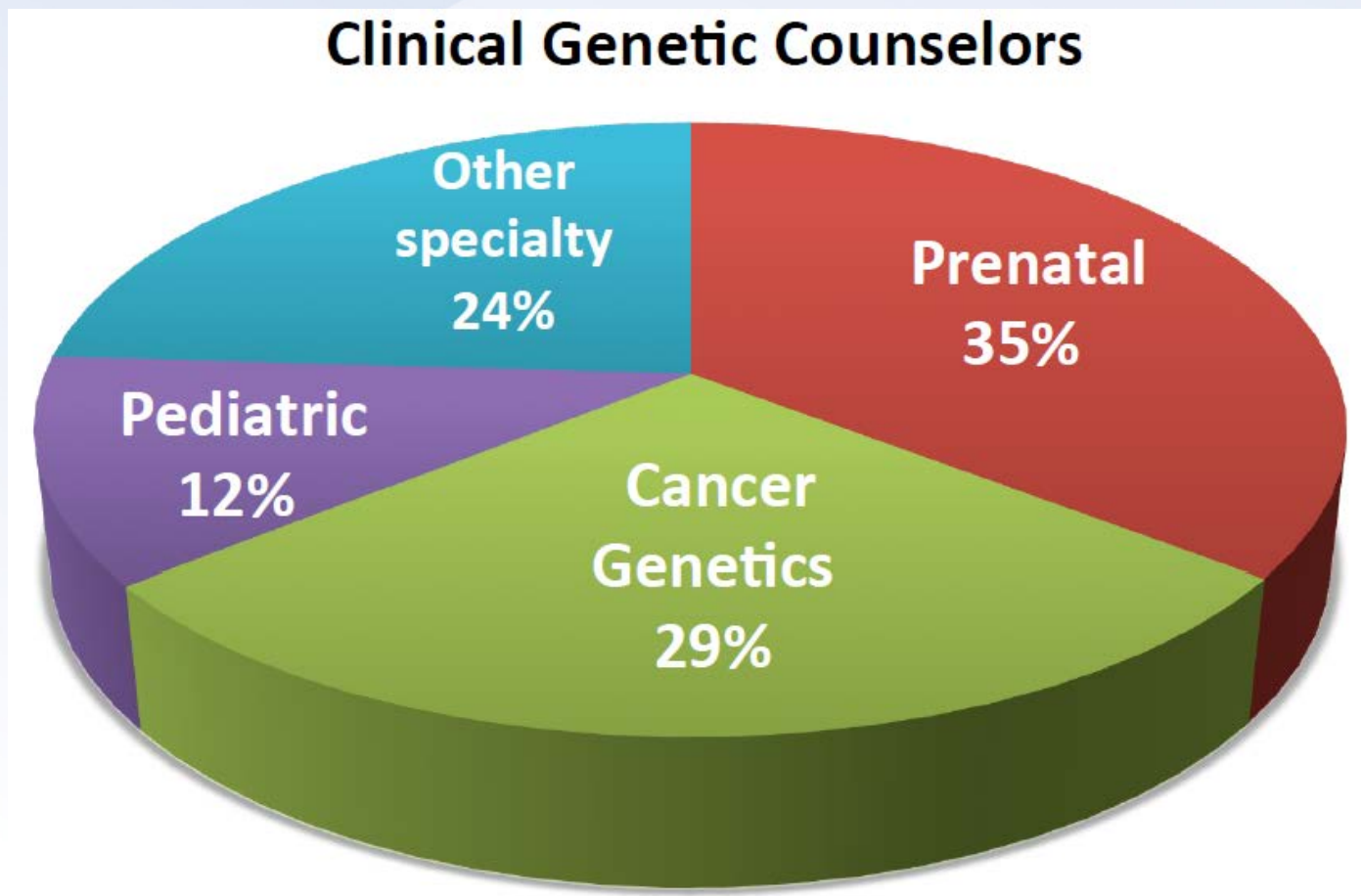
- Construct comprehensive personal and family histories
 - > Utilize a range of counseling skills to pursue a relevant path of inquiry
 - > Elicit, extract and assess pertinent information
- Identify appropriate testing options
 - > Based on patient specific risk factors, genetic risk assessment and existing practice guidelines
- Educate patients regarding the inheritance, testing options, management, prevention, etc.
 - Effectively educate patients based on patient's needs and circumstances of the encounter
 - Target information to patient's level of understanding, questions, concerns
 - Assess patient understanding and educational needs throughout the process

Components of the GC Session (cont.)

- Provide tailored psychosocial assessment and support
- Facilitate informed consent
 - > Identify, assess and integrate patient's knowledge, understanding and cultural beliefs and values
 - > Use a range of genetic counseling skills to facilitate informed decision making and adaption to genetic risks or conditions
 - > Communicate risks benefits and limitations of testing, management or treatment in a way that is meaningful for the patient
- Aid patient in choosing a course of action that is personally appropriate
- Throughout balance roles as educator, communicator, counselor, facilitator

Clinical Genetic Counselor Work Setting

From NSGC 2014 Professional Status Survey



Work Setting- Expanding Roles

- Hospital/ Medical Center or Facility
- Physician Private Practice
- Research Development
- Diagnostic Laboratory
- Government Organization or Agency
- Health Advocacy Organization
- Non-Profit Organization
- Biotechnology Company
- Health Maintenance Organization
- Professional Organization
- Marketing/ Advertising Company
- Pharmaceutical Company
- Bioinformatics Company
- Internet website company

Genetic counselors work in multiple specialty areas, including prenatal, cardiovascular disease, cancer, metabolic disease, neurology, pediatrics, infertility, pharmacogenetics and genomic medicine.

Genetic Counselors as Educators

- NSGC Profession Status Survey 2014 data
 - > 90% of genetic counselors report involvement in teaching and education
 - Genetic counselors/ students (68%)
 - Physicians/medical students/residents/fellows (64%)
 - Nurses/ nursing students (23%)
 - Other health professionals (21%)
 - Community organizations/lay public (15%)
 - Advocacy/support groups (13%)
 - Physician Assistants/students (10%)

National Society of Genetic Counselors (NSGC)

NSGC is the leading voice, authority and advocate for the genetic counseling profession

Mission: The National Society of Genetic Counselors advances the various roles of genetic counselors in health care by fostering education, research, and public policy to ensure the availability of quality genetic services

Vision: Integrating genetics and genomics to improve health for all

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NSGC Initiatives

- Licensure
 - > Outlines qualifications, Continuing Ed requirements, title protection, scope of practice, etc.
 - > Issuing licenses: CA, DE, ID, IL, IN, MA, NE, NJ, NM, OH, OK, PA, SD, TN, UT, WA
 - > Passed bills/in rulemaking: HI, NH, ND, VA
- Awareness of GCs as independent providers
 - > Actively pursuing legislation that will recognize genetic counselors as Medicare providers
 - > Collaborative model with physicians to provide specific service to their patients
 - GCs as physician partners in the delivery of personalized medicine
 - > Lack of recognition for the profession under the Social Security Act
 - Limits physician referrals for genetic counselor services
 - > Significant budget impact

NSGC Initiatives

- Billing and Reimbursement
 - > 96040, Medical Genetics and Genetic Counseling, available for use by “trained genetic counselors ”
 - > Advocate for coverage and reimbursement from third party payers
 - > Development of Model Payer Policy on genetic counseling
 - > Encourage research and publication of data demonstrating value and cost savings with involvement of genetic counselors
 - NSGC is developing quality measures for standard of care
- Access
 - > Consistent growth (70% increase in CGCs from 2006)
 - > Innovative service delivery models

NSGC Education Efforts

- NSGC offers a variety of high quality and diverse genetics education opportunities for members and other healthcare providers to continue their education and enhance their knowledge in genetic counseling, genetics and genomics
 - > NSGC Education Committee
 - > Annual Education Conference
 - > Library of online courses
 - > Topical webinars
 - > Journal-based CEU
 - > Special Interest Group (SIG) projects
 - > Sharing of member-contributed resources
 - > Funding opportunities
 - Jane Engleberg Memorial Fellowship
 - Audrey Heimler Special Project Award

NSGC Education Efforts: Online Courses

- 2015 Online Course: Personalized and Precision Medicine
 - > Precision medicine in oncology, cardiology, neurology, and psychiatry
 - > Current and emerging technologies for precision diagnostics
 - > Building a new precision medicine program
 - > Educating clinicians re: personalized and precision medicine
 - > DTC and ELSI
- Business Foundations
 - > Insurance and Credentialing Course
 - Insurance coverage for genetic counseling services
 - Credentialing process for genetic counselors
 - > Billing and Coding Course
 - Service delivery models
 - Coding and documentation for maximum reimbursement
 - > Access to discussion forum
 - > Follow-up webinars

NSGC Education Efforts: Webinars

- 6 webinars per year
 - Current issues in the field
 - Topics applicable to broad ranges of GCs and/or
 - General updates for the non-specialist
- January 2014: *Deciphering FDA, CLIA, DTC, LDT and IVD: Making Sense of Genetic Testing Regulation*
- November 2014: *What GCs need to know: Basics of DNA Ancestry and Genetic Genealogy Testing*
- January 2015: *Lesbian, Gay, Bisexual, Transgender, Queer/Questioning (LGBTQ) Clients in Genetic Counseling: Awkward Questions? Complex Answers? Let's Start the Discussion.*
- March 2015: *Who? What? When? Why? Overview of Genetic Testing for Congenital Heart Defects*

NSGC Publications

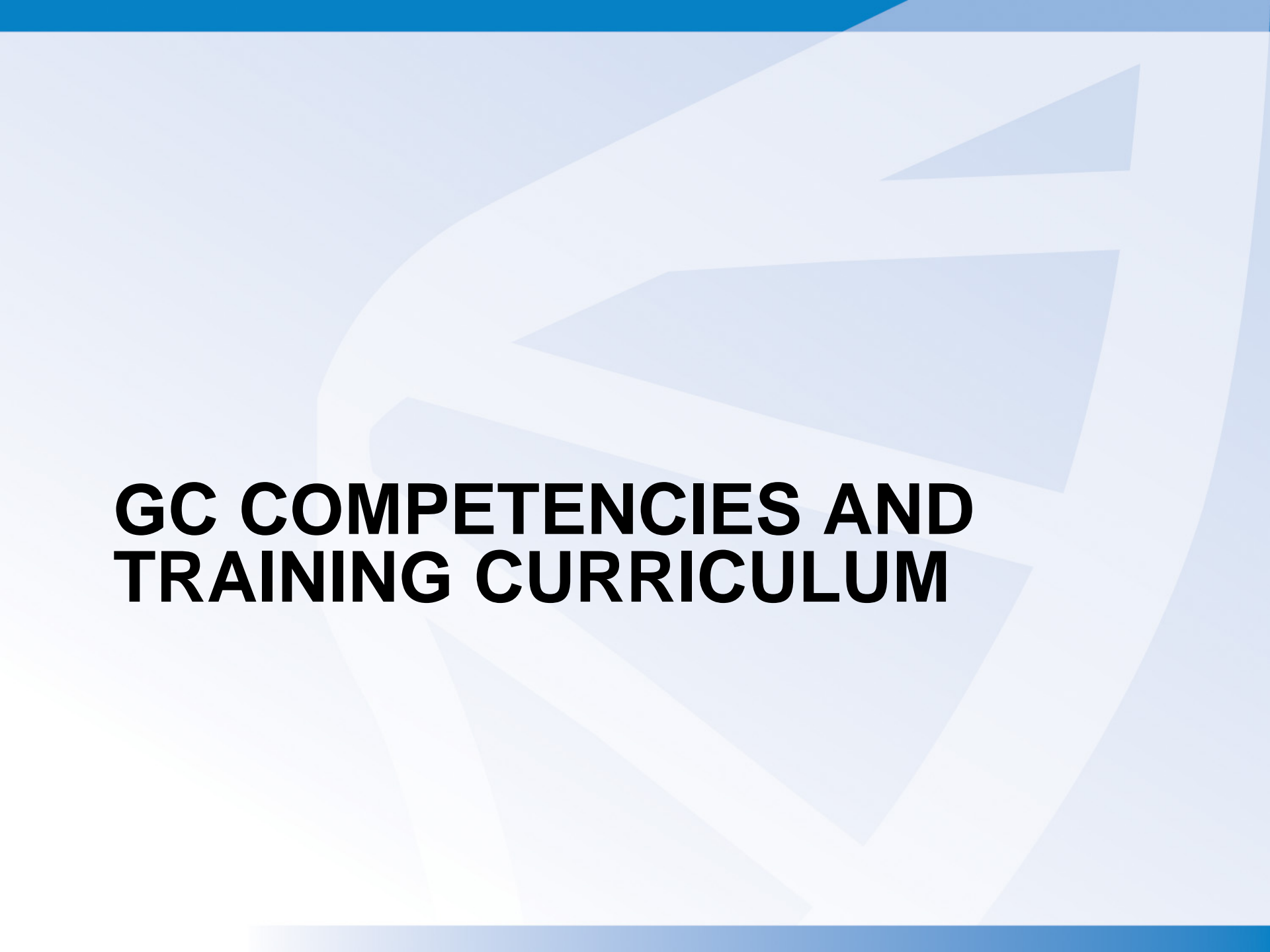
- *Journal of Genetic Counseling*
- *Perspectives in Genetic Counseling*
- Professional Status Survey
- Practice Guidelines
 - > Useful tools for GCs and others in healthcare
 - > All new and updated NSGC practice guidelines submitted to the National Guideline Clearinghouse to enhance visibility and accessibility to other healthcare providers
- Position Statements
 - > Present views on policy issues from the unique perspective of genetic counselors
- Consumer focused blog addresses current topics in genetic testing



[2015 Genetic Testing Trends: Precision Medicine, Breast & Ovarian Cancer, and Home DNA Tests](#)

Blog: [NSGC Blog](#) | By: Joy Larsen Haidle | Released: February 18, 2015, 2:42 pm

The year ahead promises to be an exciting one in the field of genetics, and to officially kick it off I'd like to highlight a few trends the National Society of Genetic Counselors is watching. Precision Medicine: During his State of the Union address this year, President Obama announced his precis



GC COMPETENCIES AND TRAINING CURRICULUM

Core Skills* & Competencies of Genetic Counselors

ACGC Practice-based competencies

- Genetics expertise and analysis
 - > Genetic risk assessment
 - > Identify and integrate genetic testing option
- Interpersonal, psychosocial and counseling skills
 - > Facilitate and promote patient centered informed decision making
 - > Apply genetic counseling skills in a culturally responsive and respectful manner
- Education
 - > Patient and physician education tailored to patient or physician needs
- Professional development and practice

Core Skills of GC
Deep and broad knowledge of genetics
Ability to tailor and communicate complex information in a simple, relevant way for a broad range of audiences
Strong interpersonal skills, emotional awareness, and self-awareness
Ability to dissect and analyze a complex problem
Research skills (Self education)
In-depth knowledge of healthcare delivery

*NSGC Task Force 2008-2009

Curriculum Highlights and Approaches

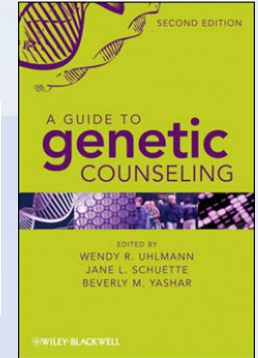
- Medical genetics course work – lecture format
- Medical communication course work
 - > Active-learning approach to the basic skills of communication
 - > Focus on interviewing concepts and techniques including active listening
- Case based approach to learning genetic counseling skills
 - > Clinical and case management practicum- Case presentation, role playing, audio/ video tape
 - > Skills evaluated include
 - Assessment of patient knowledge
 - Genetic risk assessment and communication
 - Psychosocial management including messaging related to cultural diversity
- Emphasis on available genetic resources and web-based tools.
Examples include:
 - > GeneTests / GeneReviews
 - > Cancer risk assessment tools (BRCAPRO, Boadicea, etc.)
 - > Databases like OMIM, ClinVar

Genetic Counseling Key References

<http://g-2-c-2.org/>

🔗 A Guide to Genetic Counseling, 2nd Edition. Chapter 6: Patient Education

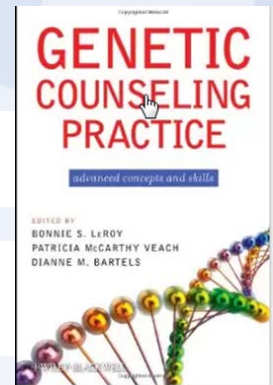
This chapter provides detailed analysis of how best to share information with patients. It covers models of patient learning, application of instructional aids for patient education, and applying the tenets of health education and promotion to genetic counseling. Includes bullet points for improving patient-clinician communication and other practical pointers.



🔗 Facilitating the Genetic Counseling Process. Chapter 5: Gathering Information: Asking Questions and Taking Client Genetic History

🔗 Genetic Counseling Practice: Advanced Concepts and Skills. Chapter 3: Actively Engaging with Patients in Decision Making

🔗 Genetic Counseling Practice: Advanced Concepts and Skills. Chapter 9: Honoring Diversity: Cultural Competence in Genetic Counseling



🔗 Counseling about Cancer: Strategies for Genetic Counselors, 3rd edition

Authoritative book on cancer genetics and providing cancer genetic counseling that includes information on cancer biology, epidemiology, detection and treatment, hereditary cancer syndromes, collecting and interpre...

Includes a chapter on cancer risk communication.

The Shift To Genomic Counseling*

- Increased number of conditions included in testing
 - > A move from testing based on a specific clinical indication / targeted risk assessment to broader testing which casts a wider net
 - > A move away from the traditional comprehensive educational model to a broader discussion of the test indications, the range of possible results and the benefits and limitations
- Increased number of “positive” and uncertain results, and overall increase in the number of disclosed results
 - > Increased uncertainty
 - > Variable and changing clinical validity and utility of genomic results
 - > Requires greater proficiency in variant interpretation

* Kelly Ormond, Invited commentary Molecular Genetics and Genomic Med
doi:10.1002/mggg3.45 2013

The Shift To Genomic Counseling*

- Increased time spent with the clinician discussing
 - > Incidental and VUS findings and limitations of testing
 - > High penetrant condition with limited or poorly understood medical actionability
- A more health promotional counseling approach
 - > A move from a diagnosis focused approach toward a preventive approach
 - Genomics brings in aspects of healthcare that emphasize behavior change
 - A more directive counseling approach
- The need for innovative and efficient service delivery models that include collaborative partnerships with other healthcare providers

* Kelly Ormond, Invited commentary Molecular Genetics and Genomic Med
doi:10.1002/mggg3.45 2013

Genetic Counselors: Part of the Healthcare Team

- Integral role in providing information that serves as a foundation for patients and their physicians
 - > Genetic counseling for patients, a time-intensive service
 - > Support with genetic test selection and interpretation of results
 - > Commitment to professional education



www.nsgc.org

[Find a Genetic Counselor](#)

Interested in contacting a genetic counselor in your area?



Find a Genetic Counselor

Questions and Discussion