

2007 PAEA Annual Educational Forum (Tucson)

Abstract

The explosion of information in the field of medical genetics holds immediate and future implications for healthcare. Many PAs are beginning to feel the impact of genetics in practice, but lack adequate training to effectively apply genetic information and technologies, or to answer patient questions. In 2006, a group of PA educators was awarded a grant from National Coalition for Health Professions Education in Genetics (NCHPEG) to develop an interactive, case-driven, genetics educational website to be used and accessed by PAs, PA educators, and PA students. This presentation will introduce and demonstrate the recently launched website in the context of newly proposed PA genetic competencies and a nationwide needs assessment of genetics curricula in PA programs.

Educational Goals and Objectives

At the conclusion of this session, participants will be able to:

1. discuss results of a nationwide needs assessment for PA genetics education and how the online program may be useful;
2. navigate through interactive cases as well as their complementary educational tools on the new NCHPEG web site: "Genetics in the Physician Assistant's Practice" (<http://pa.nchpeg.org/>)
3. recognize segments of the NCHPEG website that relate to proposed PA genetic competencies and propose how they can serve as educational resources;
4. appreciate the importance of teaching PA students how to incorporate genetic thinking into their daily practice.

Presentation Outline

- I. Introduction of presenting faculty and topic
 - A. Faculty introduction
 - B. Discussion of relationship of topic to individuals in attendance and the profession
- II. Start with the salient questions:
 - What will PAs be doing re genetics?
 - What do we need to know (and, as PA educators, teach)?
 - A. Reference to proposed PA clinical genetic competencies
 - B. Overview of highlighted results of genetics survey of PA educators
 1. What we may be doing right
 - a. Integration
 - b. Variety of teaching methods
 2. Current gaps identified by faculty
 - a. Specific concepts/content
 - i. Pharmacogenetics

- ii. Molecular biology
 - iii. Mendelian and non-Mendelian inheritance
 - iv. Pedigree structure
 - v. Genetic diagnostic testing
3. Curricular needs
- a. Time
 - b. Case histories including ethical issues
 - c. Web resources (maintained and updated)
 - d. Self instructional materials
 - e. Assessment tools

III. Introduction to the NCHPEG Website

A. Objectives for site

B. Tour of site

- 1. Desk cartoon with 3 interactive cases
 - a. Demo case approach
 - b. Demo exercises
 - c. Demo links, learn more
- 2. Separate modules
 - a. Family History Exercises
 - b. Genetics Primer
 - c. Genetic Testing
 - d. Genetics Links
 - e. Teaching Tools

C. How site may be used

- 1. As pedagogical tool
 - a. Use to model case construction
 - b. Integration
 - c. Gaps covered:
 - i. Molecular biology,
 - ii. Mendelian and non-Mendelian inheritance,
 - iii. Pedigree structure,
 - iv. Genetic diagnostic testing
- 2. Curricular needs addressed
 - a. Case histories including ethical issues
 - b. Web resources
 - c. Self instructional materials/time
- 3. Supplement to classroom
- 4. Self-directed learning
- 5. Second year activity
- 6. Continuing medical education
- 7. Your ideas!

References:

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2. Rackover M, Goldgar C, Wolpert C, Healy K, Feiger J. Establishing essential physician assistant clinical competencies guidelines for genetics and genomics. *Journal of Physician Assistant Education*. 2007; 18 (2); 48-49.
3. Engstrom, J, Sefton, M, Matheson, J, Healy, K, Genetic competencies essential for health care professionals in primary care, *Journal of Midwifery & Women's Health*, 2005: 50(3):177-183.
4. Rackover M, Peay H, Wolpert C. The need for genetic literacy in physician assistants. *Perspective on Physician Assistant Education*. 2001; 12(2):113-6.
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Establishing Essential Physician Assistant Clinical Competencies Guidelines for Genetics and Genomics

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The translation of genetic and genomic science to clinical care has significant implications for the physician assistant (PA) profession. Similar to other health care professionals, PAs will need to develop strategies for applying new knowledge in genetics. In response to this need, the authors have undertaken to define the essential genetic and genomic competencies for all PAs, regardless of academic preparation, role, or clinical specialty. The authors' intention in developing these genetics/genomics competencies is to encourage PA educators to seek out academic curriculum content/learning activities based on the most current genetic and evidence-based information. They are proposed to complement the Competencies for the Physician Assistant Profession. Practicing PAs can also use these to chart a course for advancing their own practice.

The proposed essential competencies were developed by a panel of physicians and PA leaders from clinical, research, and academic settings, whose goal was to establish the minimum basis by which to prepare the PA workforce to deliver competent genetic/genomic clinical care. This is an ad hoc group of academicians interested in promoting competency and has no official affiliation or sponsorship by any professional association.

The Proposed Core Competencies

Knowledge

All physician assistants should:

- 1.1 Understand basic human genetics terminology
- 1.2 Recognize the four basic Mendelian patterns of inheritance
- 1.3 Define types of non-Mendelian inheritance (eg, multifactorial, mitochondrial, trinucleotide repeat expansion, imprinting)
- 1.3 Be able to list a "genetic" disease in the differential diagnosis of common medical disorders, (eg, including alpha-1-antitrypsin deficiency in the differential diagnosis of patients with emphysema)
- 1.4 Utilize family history (pedigree analysis of a minimum of three generations) in assessing potential genetic or familial predisposition to disease
- 1.5 Recognize the genetic and environmental contribution to multi-factorial conditions (eg, congenital heart disease, cancer, hypertension, diabetes, psychiatric illness)
- 1.6 Be able to distinguish between genetic screening, presymptomatic testing, and diagnostic testing, and apply each appropriately
- 1.7 Distinguish between clinical diagnosis of disease and identification of genetic pre-

Feature Editor's Note:

Genomic science has extraordinary implications for health workers, and the legal, social, and financial issues related to genetic testing and recording of genomic information are important policy issues. Explaining basic concepts of probability and genetic risk are formidable tasks to add to an increasing body of knowledge for the busy clinician — but they will have to be mastered as information about genetics races forth. These draft core competencies in genetics for PAs, developed by knowledgeable leaders in this area, may prove a helpful starting point for all PA education institutions.

— Roderick S. Hooker

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The Abstracts and Brief Reports section publishes short, focused communications on a research endeavor relevant to PA education or behavior. Submissions should be limited to approximately 1,500 words and one or two exhibits (tables or illustrations). The intent of this feature is to promulgate new information and provide a platform for additional research. Authors desiring to contribute to Abstracts and Brief Reports should forward submissions (with a copy to journal staff at jpae@PAEAonline.org) to:

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- disposition to disease and testing strategies employed
- 1.8 Discuss current genetic and biochemical laboratory studies and their validity and reliability
 - 1.9 Understand the principles of carrier screening, with attention to ethnic groups that may exhibit founder effects, and common disorders that may particularly benefit from screening
 - 1.10 Describe current population genetic screening programs and guidelines for the introduction of such programs
 - 1.11 Describe procedures available for prenatal genetic screening and diagnosis, kinds of diseases that can be detected prenatally and/or antenatally, and the risks and benefits of these procedures.
 - 1.12 Be aware of newborn screening programs, with attention to the disorders that are tested for in the state in which the PA practices
 - 1.13 Understand the principles of pharmacogenetics and their applications
 - 1.14 Delineate the role of genetics in pathogenesis of neoplasms and predispositions to malignancies
 - 1.15 Identify family history characteristics associated with increased cancer risk (eg, inherited breast, ovarian, or colorectal cancer syndromes).
 - 1.16 Discuss the range of genetic approaches to treatment of disease (prevention, pharmacogenomics/prescription of drugs to match individual genetic profiles, gene-based drugs, gene therapy)
 - 1.17 Discuss the role of genetic counseling in primary care and be able to develop a strategy for making appropriate referrals for genetic counseling, genetic diagnosis, and screening
 - 1.18 Describe the contribution of genetic professionals, geneticists, genetic counselors, and others within primary and specialty care settings

Skills

All physician assistants should be able to:

- 2.1 Gather genetic family history information, including an appropriate multigenerational pedigree
- 2.2 Identify and appropriately determine referral of patients who would benefit from genetic services, eg, recognition of dysmorphic features, genetic “red flags” in family histories
- 2.3 Use information technology to obtain credible current information about genetics
- 2.4 Communicate the concept of risk in a manner that can be understood by the patient or assure that patient receives appropriate information from reliable and valid sources
- 2.5 Assure that patient receives appropriate informed-consent process to facilitate decision making related to genetic testing
- 2.6 Assess the potential clinical and psychosocial benefits, limitations, and risks of genetic information for individuals, family members, and communities
- 2.7 Identify resources available to assist patients seeking genetic information or services, including the types of genetics professionals available and the range of responsibilities

Attitudes

All physician assistants should:

- 3.1 Seek coordination and collaboration with interdisciplinary team of health professionals
- 3.2 Recognize their own professional role in the referral to genetics services, or provision, follow-up, and quality review of genetic services
- 3.3 Promote informed decision making for patients, and when indicated, provide nondirective genetic counseling, appreciating the history of misuse of human genetic information
- 3.4 Examine their competence of practice on a regular basis, identifying areas of strength and areas where professional development related to genetics and genomics would be beneficial
- 3.5 Be aware of the sensitivity of genetic information and the need to maintain privacy and confidentiality
- 3.6 Consider the influence of ethnicity, culture, related health beliefs, economics, and health literacy in the patient’s ability to use genetic information and services
- 3.7 Appreciate the ethical, legal and social issues related to genetic testing and recording of genetic information (eg, privacy, duty to warn, awareness of state and federal regulations regarding protection from genetic discrimination)

Genetics Resources on the Web for Students and Clinicians

CATEGORY	DESCRIPTION	AFFILIATION/ COST
EDUCATIONAL RESOURCES		
Basic Genetics		
Genetics and Molecular Medicine http://www.ama-assn.org/ama/pub/category/1799.html	Designed to help clinicians stay abreast of genetic developments. Potpourri of resources, both educational and clinical.	Free. AMA sponsored.
*Genetics & Your Practice http://www.marchofdimes.com/gyponline/index.bm2	Customized for those working with the following patient types: preconception/prenatal, infant/children, and adolescent/adult. Gives practical information/resources to assist in integrating genetics into patient care. Users can earn CME Credits by completing the interactive case study at the end of each module.	Free. Requires registration. March of Dimes sponsored. Grant supported Robert Wood Johnson Foundation.
CDC National Office of Public Health Genomics: Genomics in Your Practice http://www.cdc.gov/genomics/phpractice.htm	Provides current information on the impact of human genetic research and gene discoveries on disease prevention and health promotion. Includes weekly updates of news stories, scientific literature, announcements, events, and public health perspectives on advances in human genetics.	Free. Center for Disease Control (CDC).
GeneTests Illustrated Genetics Glossary http://www.genetests.org/servlet/access?qry=ALLTERMS&db=genestar&fcn=term&gtreport2=true&id=888891&key=IXMXGL2eKQUle	Context-sensitive illustrated glossary defining > 225 medical genetics terms (>70 terms are illustrated); linked to relevant cases in GeneTests educational materials.	Free online. NIH funded

Genetic cases		
Genetics in the Physician Assistant's Practice http://pa.nchpeg.org/	Case-based on-line interactive continuing medical education (CME) designed by and for PAs. Approved by the American Academy of Physician Assistants. June 2007.	National Coalition for Professional Education in Genetics (NCHPEG)
Genetics Case Studies for Medical Students http://cim.usuhs.mil/genetics/cases.html	This web page is designed to provide an educational experience in Medical Genetics using 12 Case Studies. A self quiz follows.	Uniformed Services University.
Genetics Through a Primary Care Lens http://www.genetests.org/servlet/access?id=INSERTID&key=INSERTKEY&fcn=y&filename=/tools/index.html	Genetics Through a Primary Care Lens; Materials for teaching genetics in primary care settings from GeneTests. Developed for physicians, other healthcare providers, and researchers.	Free online. NIH funded
Genetics & Your Practice http://www.marchofdimes.com/gyponline/index.bm2		Free. MOD sponsored. User must register.
National Office of Public Health Genomics's HuGENet™ Case Studies Series http://www.cdc.gov/genomics/hugenet/casestudies.htm#case	Cases (7) provided to train health professionals in practical application of human genome epidemiology (HuGE), which translates gene discoveries to disease prevention by integrating population-based data on gene-disease relationships and interventions.	Free. Sponsored by National Office of Public Health Genomics (NOPHG)
Pedigree-related		
US Surgeon General's Family History Initiative http://www.hhs.gov/familyhistory/respacehealth.html	Provides resource packet developed to help Health Professionals educate the public about the importance of family health history, includes forms, a couple of case studies and resources in English and Spanish.	US Dept. of Health & Human Services. Free online.
American Medical Association—Family History Tools http://www.ama-assn.org/ama/pub/category/2380.html	Contains: Prenatal, Pediatric, and Adult Family History Questionnaires, (pdf downloadable). Also provides a pdf pocket guide that provides instructions and examples for patients on how to generate a simple pedigree.	Free. AMA sponsored.

Genetics & Your Practice http://www.marchofdimes.com/gyponline/index.bm2	Contains: adult, pediatric, and prenatal family history questionnaires. Also contains toolkits that include pdf or PDA downloadable format, pedigree drawing, pedigree analysis, inheritance patterns, red flags, and risk assessment examples	Free. MOD sponsored. User must register.
Pedigree Drawing Programs		
U.S. Surgeon General's Family History Initiative http://www.hhs.gov/familyhistory/	A web-enabled tool (newly updated) that organizes family history information for patients to bring to their clinicians (and save on their own computers).	Free.
Smart Draw http://www.smartdraw.com/specials/genealogy.asp?id=24226	A program for drawing organizational charts but can be used to organize a pedigree.	Free 30-day trial \$198
Misbach Enterprises http://misbach.org/pdfcharts/	Has free charts that can be downloaded and printed off. It also offers a free program that can be used to organize a pedigree on a web site.	Free. Misbach Enterprises
PowerPoint	Has chart-drawing capability.	Software program.
Genetics and Ethics		
http://www.genethics.ca/ http://www.ethicsweb.ca	A Canadian site that is part of a large website on ethical issues. Might be useful for a couple of courses	Free.
Genetic Testing, Discrimination and Privacy http://www.gene-watch.org/programs/privacy.html	Fosters public debate about the social, ethical and environmental implications of genetic technologies.	Free. Council for Responsible Genetics (CRG)

<p>Genetics & Your Practice http://www.marchofdimes.com/gyponline/index.bm2</p>	<p>Financial, Ethical, Legal and Social Issues (FELSI) issues are integrated into Genetic & Your Practice Online. WHO guidelines were used to develop an index of FELSI information on the site.</p>	<p>Free. MOD sponsored. User must register.</p>
<p>Genetics Through a Primary Care Lens http://www.genetests.org/servlet/access?id=8888892&key=NSCfIO0grmDxM&fcn=y&fw=mMcz&filena me=/tools/elsi/ELSI.html</p>	<p>Resource containing descriptions of ethical obligations of health care providers as well as case materials for illustrating these issues.</p>	<p>Free online. NIH funded</p>
<p>Genetic Testing</p>		
<p>Genetics Through a Primary Care Lens http://www.genetests.org/servlet/access?id=8888892&key=NSCfIO0grmDxM&fcn=y&fw=LDKS&filena me=/tools/concepts/usingTests.html</p>	<p>Provides examples of different types of genetic tests (both diagnostic and screening) linked to cases illustrating the tests.</p>	<p>Free online. NIH funded.</p>
<p>Genetics & Your Practice http://www.marchofdimes.com/gyponline/index.bm2</p>	<p>Contains toolkits that include pdf or PDA downloadable format for algorithms for genetic testing, checklists for information to collect, analysis and interpretation of common genetic tests and much more.</p>	<p>Free. MOD sponsored. User must register.</p>
<p>Human Genome Project—Genetic Testing http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetest.shtml</p>	<p>Module on genetic testing including pros and cons of gene testing, diseases for which gene tests are available, insurance coverage, testing recommendations, and further genetic testing resources.</p>	<p>U.S. Dept of Energy and the National Institutes of Health.</p>
<p>National Cancer Institute Understanding Cancer Series: Gene Testing http://www.cancer.gov/cancertopics/UnderstandingCancer/genetesting</p>	<p>Tutorial that illustrates what genes are, explains how mutations occur and are identified within genes, and discusses the benefits and limitations of gene testing for cancer and other disorders.</p>	<p>Free. National Cancer Institute.</p>

Other Genetic Education Resources		
National Human Genome Research Institute http://www.genome.gov/Education/ http://www.ornl.gov/sci/techresources/Human_Genome/education/education.shtml http://www.ornl.gov/sci/techresources/Human_Genome/links3.shtml	<p>All of these are part of the Human Genome Project</p> <p>Human Genome Project Educational Resources</p> <p>Human Genome Project Information (Links to the Genetic World)</p>	Free. NHGRI, etc.
Genetic Educational Material Data Bank http://www.gemdatabase.org/gemdatabase/DetailedSearch.asp	GEM Database is a searchable listing of public health genetics policy documents and clinical genetics educational materials.	Sponsored by the HRSA, Maternal and Child Health Bureau (MCHB).
CLINICIAN RESOURCES		
GeneTests/GeneReviews http://www.genetests.org/ http://www.genereviews.org	<i>Gene Tests</i> provides worldwide testing laboratory and clinic directories, and teaching tools. <i>GeneReviews</i> provides current, expert-authored, peer-reviewed, disease-specific reviews describing the application of genetic testing to the diagnosis, management, and genetic counseling of patients and families with hereditary disorders.	One-time registration process is required. Free online. NIH funded
Genetic Resources on the Web http://www.geneticsresources.org/	A site and search engine optimizing the use of the web to provide health professionals and the public with high quality information related to human genetics, with a particular focus on genetic medicine and health.	NCHPEG/NHGRI and hosted by RSi Communications. Free online.
Online Mendelian Inheritance in Man™ (OMIM) http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM	OMIM is a catalog of human genes and genetic disorders, with links to literature references, sequence records, maps, and related databases. Search engine parallels PubMed Database.	Developed by National Center for Biotechnology Information.

<p>AMA Risk Assessment for Hereditary Cancer Syndromes-A Physician's Guide to Clinical Genetic Testing and Medical Management http://www.ama-assn.org/cgi-bin/cme/heronc.cgi>http://www.ama-assn.org/cgi-bin/cme/heronc.cgi</p>	<p>A CME monograph (order print copies from the AMA at the link provided). Designed to assist physicians and other health care professionals in the recognition of familial cancer patterns suggestive of an inherited cancer syndrome, utilize genetic risk assessment, counseling, and genetic testing in at risk patients, and utilize the results of testing in determining a patient's risk for hereditary cancer. Note: non-physicians may earn a certificate of completion.</p>	<p>AMA sponsored.</p>
<p>Referral for Genetic Services http://app1.health.state.pa.us/fhc/(q1fv1g5542y4gd45h2om3e55)/ModuleOutline.aspx</p>	<p>Online training module for what patient issues may require genetic referral.</p>	<p>Pennsylvania State Health Department, 2001</p>
<p>National Society of Genetic Counselors (NSGC) http://www.nsgc.org/resourcelink.asp</p>	<p>NSGC website can help locate a genetic counselor in regional areas with search criteria.</p>	<p>Sponsored by NSGC.</p>
<p>Genetic Health http://www.genetichealth.com/</p>	<p>Provides consumers and health care providers with educational information and software tools to help them understand and assess genetic risk of common diseases such as: Alzheimer's, Breast Cancer, Colon Cancer, Diabetes, Heart Disease, Hemochromatosis, and Ovarian Cancer.</p>	<p>Free online. Non-profit.</p>
<p>Foundation for Genetic Education and Counseling (FGEC) http://www.fgcec.org/resources.html</p>	<p>Small site that concentrates on mental illness and the genetic link (bipolar illness, schizophrenia).</p>	<p>Free. Non-profit FGEC sponsored.</p>
<p>American Medical Association—Genetics in Clinical Practice: A Team Approach http://www.ama-assn.org/ama/pub/category/11832.html</p>	<p>This genetics program is intended for health care providers who have an interest in genetic testing. The program focuses on simulated patients who are at risk or have four different diseases (hemochromatosis, cystic fibrosis, colorectal cancer, and Fragile X Syndrome).</p>	<p>The AMA is offering a free CD-ROM. Please email requests to: srt@ama-assn.org</p>

National Newborn Screening and Genetics Resource Center http://genes-r-us.uthscsa.edu/	This site has information and links about newborn genetic screening tests.	Free. Univ. of Tx Health Science Center (San Antonio) and MCHB.
PATIENT/CONSUMER RESOURCES		
Genetic Alliance http://www.geneticalliance.org	An international coalition comprised of > 600 advocacy, research and healthcare organizations representing millions of individuals with genetic conditions and their interests.	HRSA/Dept of Health and Human Services/Maternal Child Health Administration
Genetics Education Center http://www.kumc.edu/gec/support/index.html	Description of Genetic Conditions, linking with support groups, addresses, and other resources.	Free. University of Kansas Medical Center.
Genetics Home Reference (NLM site) http://www.ghr.nlm.nih.gov/	The National Library of Medicine's web site for consumer information about genetic conditions and the genes or chromosomes responsible for those conditions.	Free. National Library of Medicine.
Compiling your family medical history http://www.mayoclinic.com/invoke.cfm?objectid=385FC65E-F961-49BA-99B799A3A0DAF885	Mayo Clinic provides information on family history and genetic testing plus links for further information for patients.	Free. Mayo Clinic.
Family Voices http://www.familyvoices.org/	Group of families and friends who advocates for health care services and provides information for families with children and youth with special health care needs.	Free online.
Genetic and Rare Diseases Information Center http://rarediseases.info.nih.gov/html/resources/info_ctr.html	Information Center employs experienced information specialists to answer in English or Spanish questions from the general public, including patients and their families, health care professionals, and biomedical researchers.	NHGRI and the Office of Rare Diseases (ORD)

<p>New York Online Access to Health (NOAH) http://www.noahhealth.org/english/illness/genetic_diseases/geneticdis.html</p>	<p>Describes diseases that have a known or suspected genetic origin. Also contains information on basic genetics, genetic disease foundations, and support resources. Also in Spanish.</p>	<p>NY Library Associations, US Dept. of Commerce, March of Dimes-sponsors.</p>
<p>The University of Utah Genetic Science Learning Center http://gslc.genetics.utah.edu/</p>	<p>A Web site created to help people understand how genetics affects their lives and society.</p>	<p>Free online. University of Utah.</p>
<p>Genetics Education Center http://www.kumc.edu/gec/support/index.html</p>	<p>Description of Genetic Conditions, linking with support groups, addresses, and other resources.</p>	<p>Free. University of Kansas Medical Center.</p>
<p>Genetics Home Reference (NLM site) http://www.ghr.nlm.nih.gov/</p>	<p>The National Library of Medicine's web site for consumer information about genetic conditions and the genes or chromosomes responsible for those conditions.</p>	<p>Free. National Library of Medicine.</p>
<p>Compiling your family medical history http://www.mayoclinic.com/invoke.cfm?objectid=385FC65E-F961-49BA-99B799A3A0DAF885</p>	<p>Mayo Clinic provides information on family history and genetic testing plus links for further information for patients.</p>	<p>Free. Mayo Clinic.</p>
<p>Family Voices http://www.familyvoices.org/</p>	<p>Group of families and friends who advocates for health care services and provides information for families with children and youth with special health care needs.</p>	<p>Free online.</p>

Web links verified as of 09/14/07