

Training Needs in Genomics Panel
An Overview of NCHPEG

**House of Lords Inquiry on Genomic
Medicine**

Holly L. Peay, MS, CGC



What NCHPEG Does

Mission: To promote health professional education and access to information about advances in human genetics to improve the health care of the nation.

- Provide a central educational resource for all health professionals
- Develop tools to educate health professionals and incorporate genetics into practice

History and Structure

- **Founded in 1996 by AMA, ANA, and NHGRI**
- **501(c)(3) non-profit, incorporated in Maryland in 2001**
- **Governance provided by a 15-person elected board of directors**
- **Located in the Baltimore area**
- **Supported by public and private sector**

Eclectic Membership

83 dues-paying members:

- Commercial entities
- Professional societies, government agencies, foundations/granting agencies, educational/academic institutions, medical/health-care institutions
- Consumer groups
- Individuals
- Patrons
- Benefactors

More Structure

- Staff = 5
 - 1 Executive Director
 - 2 Project Directors
 - 1 Administrative Assistant
 - 1 Intern
- Working groups
 - Content & Instruction
 - Family History
 - Membership & Diversity

Educational Development Process

- Person-intensive, iterative process
 - advisory and writing committees come to consensus, develop the conceptual framework, and outline major content areas
 - formative evaluation with multiple rounds of review and revision
 - maximizes input from content experts and end-users

Educational Content

- Four principles: our content must be
 - 1) scientifically accurate,
 - 2) clinically relevant,
 - 3) educationally effective, and
 - 4) not significantly duplicative of other efforts.
- Products
 - Web-based
 - Print
 - Face-to-face instruction
 - Video
 - Simulated patient encounters
 - Point-of-care/decision support tools

Educational Resources

- **General guidance, e.g.,**
 - Core competencies in genetics
 - Core principles in genetics
 - Framework for genetics and common disease
- **Resources on specific topics, e.g.,**
 - Genetics, race, and health care
 - Genetics and psychiatric disorders
 - Genetics and common disease
 - Discipline-specific programs

Core Competencies

What do health-care providers need to know and do?

- Knowledge
- Skills
- Attitudes

- Core principles of genetics

www.nchpeg.org

**Core Competencies in Genetics
Essential for All
Health-Care Professionals**



Specific Audiences

- Nurses
- Dentists and dental hygienists
- Family physicians
- Speech-language pathologists and audiologists
- Physician assistants
- Dietitians (Fall 2008)

Target Audiences: Dietitians

Nutrition & Genetics: Key Concepts and Clinical Scenarios for Dietetic Educators and Practitioners in the US & UK

This site is designed to help dietitian faculty and practitioners incorporate genetics in the nutrition care process.

[Home](#) [About](#) [Glossary](#)

- Getting Started
- How Genes and Nutrition Interact
- Tools for Integrating Genetics into Practice
- Clinical Scenarios
- CPE/CPD Credits
- Resources and Links



 **American Dietetic Association**
Your link to nutrition and health™

 **NCHPEG**
National Coalition
for Health Professional
Education in Genetics

 **BRITISH DIETETIC ASSOCIATION**
Dietitians
• Nutritionists

 **NHS**
National Genetics Education and
Development Centre

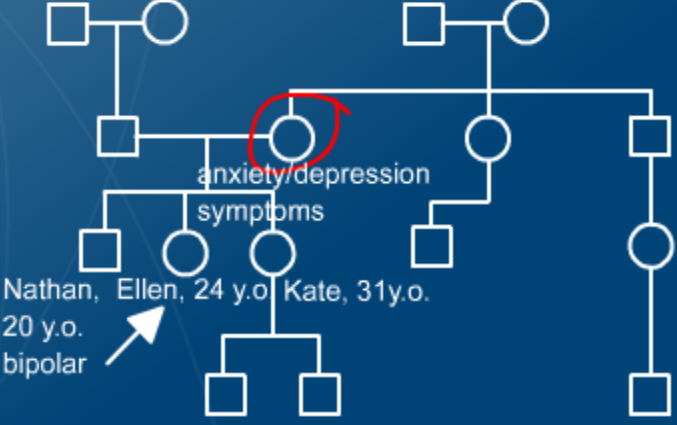
Target Audiences: Family Practice

http://www.aafp.org - intro - Microsoft Internet Explorer

ACF Bipolar Disorder :: Family History



Streaming video player controls: STREAMING, 0:00:15.359, play/pause, previous/next, volume, and navigation buttons.



anxiety/depression symptoms

Nathan, 20 y.o. bipolar

Ellen, 24 y.o.

Kate, 31 y.o.

8 of 15


Target Audiences: Speech-Language Pathology and Audiology

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Genetics in the Practice of Speech-Language Pathology and Audiology


[About this site](#) [Genetics Primer](#) [Case Studies](#) [Teaching Tools](#) [Resources & Links](#) [Glossary](#)

Taking a Family History





Research continues to uncover genetic contributions to more and more conditions, and knowing how to take a family history has never been more important. This segment will explain how a genetic family history can improve your practice, teach you the basic symbols needed to draw a pedigree, and help you recognize red flags signaling a genetic contribution to anomalies in speech, hearing, and language development.



Syndrome Identification




Sometimes a change in a single gene can affect a wide range of body systems, and many seemingly unrelated symptoms results. That constellation of traits and symptoms is called a syndrome. Syndrome identification does not require you to be an expert on each of several hundred conditions that may cause speech, language, or hearing impairments. Instead, this segment will help you recognize when a syndrome may be present, help you ask appropriate follow-up questions, and make referrals that can lead to an accurate diagnosis.

CEU

[AAA CEUs](#)  

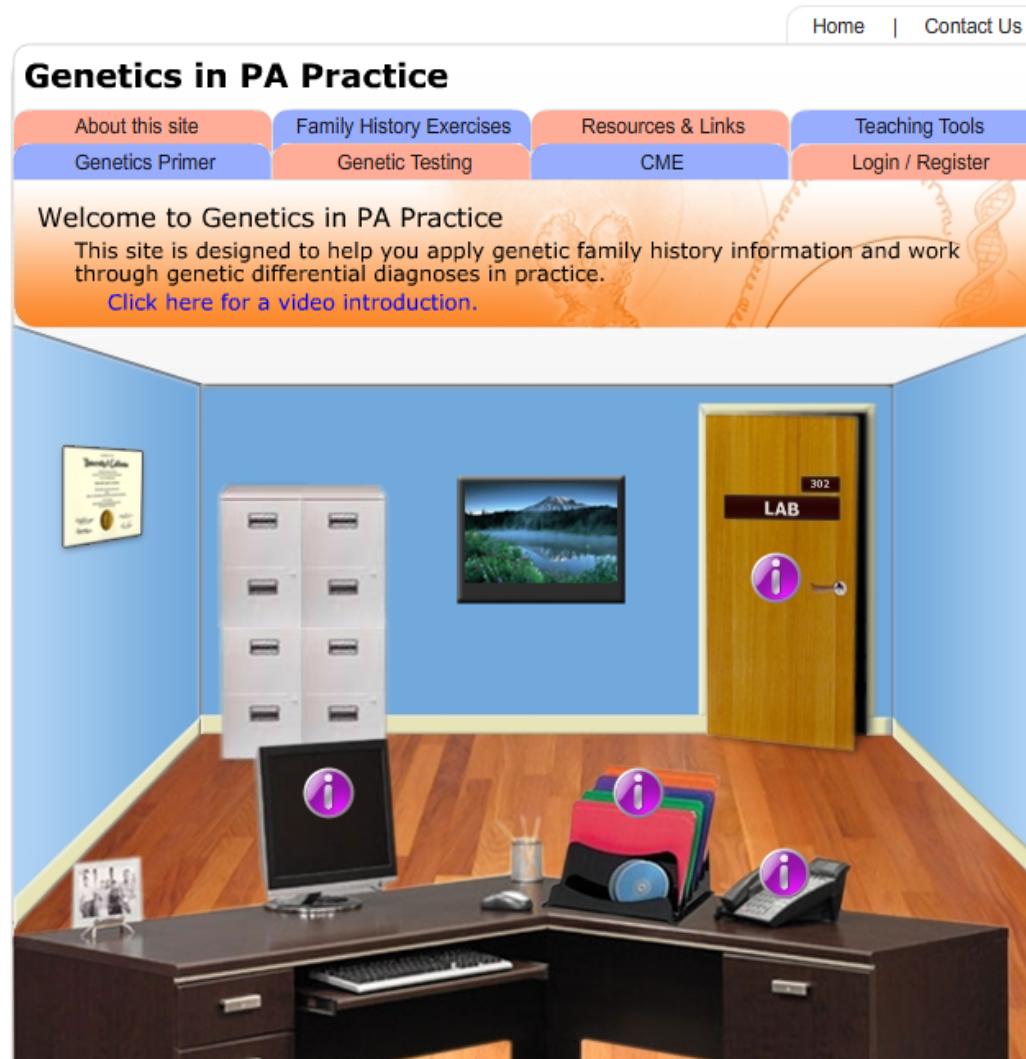
[ASHA CEUs](#)  

Connexin 26 Genes and Hearing Loss

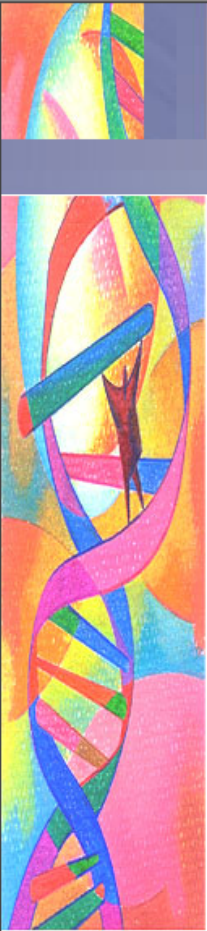


Genetic changes that alter the connexin 26 protein, called CX26 mutations, account for up to 50% of cases of nonsyndromic, sensorineural hearing loss in some populations. One reason for this is the high prevalence of people who carry a deafness-causing mutation, even though they themselves are not hearing impaired. For example, approximately 1 in 33 Caucasians is a "carrier" of a CX26 mutation. This segment will walk you through more in-depth pedigree analyses to help you recognize when CX26 may be playing a causative role in hearing loss in a patient and family.

Target Audiences: Physician Assistants





Target Audiences: Nurses



Genetics is Relevant Now

[FAQ/Help](#) | [Logout](#)

 Cincinnati Children's
Hospital Medical Center

 NCHPEG
National Coalition
for Health Professional
Education in Genetics


Thank you for accessing the Genetics is Relevant Now: Nurses' Views and Patient Stories Module

developed by

Carol Hetteberg, MSN, CNS
Jean F. Jenkins, PhD., RN, FAAN
Erin K. Harvey, MS, CGC
Cynthia A. Prows, MSN, CNS

[Register to Process Contact Hours](#) - To obtain 1.5 Nursing Contact Hours you must **register with the above link**. You will receive a printable certificate for 1.5 Nursing Contact Hours at the end of the registration process.

No processing fee is required.

 genetics
EDUCATION PROGRAM

Target Subject: Genetics, Race, and Healthcare



Newsletters

a newsletter for health care professionals

The Genetic Family History

Family history and ethnicity alter interpretation of cystic fibrosis carrier test

Elmer Langfelder-Schwind, MS

As is the case for many genetic conditions, family history and ethnicity figure prominently in decisions about whether to offer cystic fibrosis carrier testing and in the interpretation of test results.

In 2001, the American College of Obstetricians and Gynecologists (ACOG) and screening should be offered to patients considered to be at highest risk (i.e., Caucasians). Although there are more than 1,000 known mutations in the CF gene (most are extremely rare), the screening panel will detect only a limited number of the most common mutations.

The sensitivity of this test, therefore, is dependent on the ethnicity of the patient.

a newsletter for health care professionals

The Genetic Family History

Ancestry Testing: Where Genealogy meets Genetics

By Charal Waport, MS, CGC, PA-C
Center for Human Genetics, Duke University Medical Center

Opah Wintley announced recently that she had her DNA tested and the results showed that she was a descendant of the Zulu tribe in South Africa. Opah stated she was thrilled about having this information, but wasn't all that surprised by information about genetic ancestry recently available. What is your ancestry? Where did your grandparents come from? Where did your great-grandparents come from? What was their ancestry? If you don't know your genetic

a newsletter for health care professionals

The Genetic Family History

Not Just for Geneticists

Why Family History?

Why Family History?

Why Family History?

a newsletter for health care professionals

The Genetic Family History

Misattributed Paternity in the Genetic Age

Dawn Gardner, MS, CGC

Five to 10 people out of every 100 are fathered by someone other than the man listed on their birth certificate. Misattributed paternity, also called nonpaternity, crosses all racial and socioeconomic groups. In addition to obvious social implications, nonpaternity has clinical relevance: it can challenge your ability to take an accurate genetic family history, and it can significantly alter genetic risk assessment and case management.

How do you recognize misattributed paternity?

When the details of a case don't add up, keep in mind that nonpaternity may be an explanation. You will typically uncover cases of nonpaternity when a patient's genetic findings are inconsistent with clinical history or the test results of other family members.

Consider the following scenario:

Ms. Thompson, age 40, is 18 weeks pregnant and nurses a routine amniocentesis for advanced maternal age. Results show a balanced chromosome translocation.

The interpretation of the amniocentesis result depends on the maternal karyotype. Either the translocation occurred for the first time in this conception, in which case there is an increased chance for an abnormal outcome, or it is parental in origin, in which case the finding is not likely to be of clinical significance because the parent (with the same translocation) is healthy.

On the web

Announcing a new online resource from the March of Dimes!

Genetics & Your Practice Online is a practical,

Genetic Applications

inpractice

bridging the GAP from bench to bedside
A Newsletter for Health Professionals Courtesy of NCHPEG

Spring/Summer 2008

In this issue:

- From the provider to the lab and back to the patient, a look at genetic testing in practice.
- Doctor, what do you mean my genetic test came back positive? pages 2 & 3
- Case 1: When is a mutation associated with disease? page 4
- Case 2: Communicating with the lab: Is the staff on board? page 5
- Case 3: You've got the right result, but does the patient really "get it"? page 6
- Family history in the broader context of genetic testing: From single-gene disorders to complex disease page 7
- Tying it all together: Challenges and opportunities for genetic testing in primary care page 8

NCHPEG news:

- From the Editor: page 2
- Expanding our scope of the NCHPEG's Family, Race, Genetics, and Healthcare: An Online NCHPEG CME Program page 9
- Scotti Award Recipient 2008 page 10
- NCHPEG's Newest Staff Member page 10
- Genetics Education Website for Physician Assistants page 11
- NCHPEG's 10th Annual Meeting page 12

Audience: Health professionals without formal genetics training

Purpose: Introduce genetics issues from different perspectives

Genetic Applications

inpractice

bridging the GAP from bench to bedside
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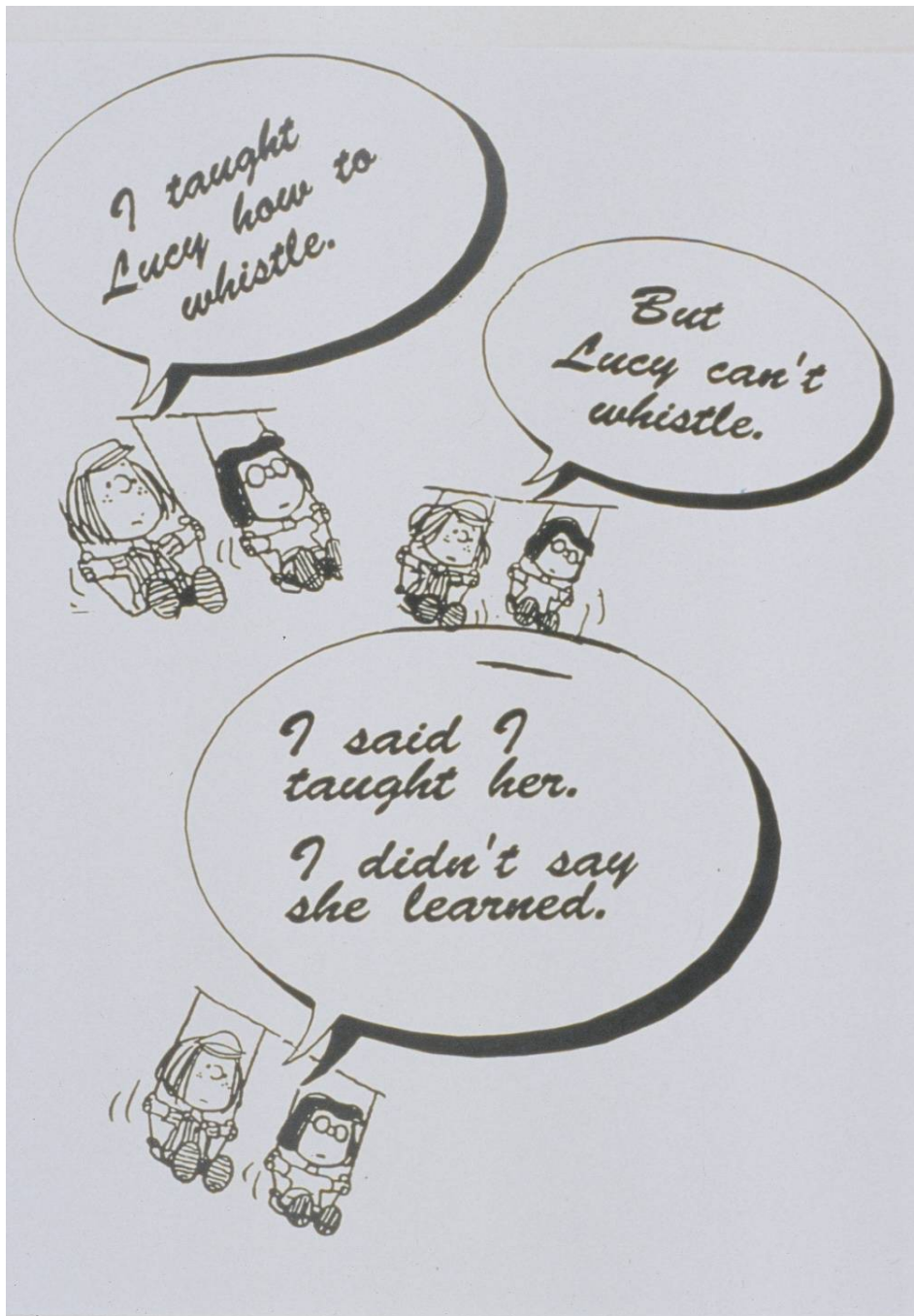
Spring/Summer 2007

In this issue:

- Contributors to this issue explore the promise and pitfalls of pharmacogenetics in the clinic and the classroom.
- Why personalize medicine? pages 1 & 2
- Battle of the Genomes: A Biologic Perspective of Pharmacogenetics in HIV/AIDS Therapies page 3
- On the Web: Nurses' Role in Pharmacogenetics: HIV Pharmacogenetics: NCHPEG's new site for PAs page 5
- The Clinical Utility and Teaching Implications of Pharmacogenetics page 6
- NCHPEG news: Highlights from NCHPEG's 10th Annual Meeting pages 7-9
- The 2007 Scotti Award Winner page 10
- April 25th is DNA Day: NCHPEG's Mission & Staff page 11

phar-ma-co-ge-no-mics: n, a science that combines the techniques of medicine, pharmacology, and genomics and is concerned with developing drug therapies to compensate for genetic differences in patients which cause varied responses to a single therapeutic regimen. Medicine Plus

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Barriers to Genetics Education for Health Professionals

- Crowded curriculum
- Misconceptions about genetics
- Lack of knowledgeable faculty
- Disconnect between basic sciences and clinical experiences during training
- Failure to integrate genetics across the curriculum
- Inadequate representation of genetics on certifying exams

Guttmacher AE, Porteus ME, McInerney JD. 2007. Nature Reviews Genetics 8:151-157.

Some Barriers to the Integration of Genetics into Primary Care

- Dearth of genetics professionals
- Lack of knowledge about genetics among primary-care providers
- Lack of confidence
- Inadequate family histories (time is an issue)
- Lack of practice and referral guidelines

Suther, S. and Goodson, P. Barriers to the provision of genetic services by primary care physicians: A systematic review of the literature. *Genetics in Medicine* 5(2): 70-76, 2003.

Challenges

- Which clinical behaviors and attitudes do we want to change, and can we?
- Which content is appropriate for whom?
- What is the appropriate level of detail?
- What is the appropriate scope?
- How do we define and measure success?

Some Programs in Planning

- Genetics and colorectal cancer for VHA providers
- GeneFacts – point-of-care electronic decision support for PCPs
- Genomic applications related to breast cancer for the U.S. Air Force
- Genetics for social and behavioral scientists