

Educating Health-Care Professionals about Genetics

SACGHS Education Roundtable

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I hope to accomplish the following:

- Review some challenges to improving genetics education for non-genetics health professionals and to integrating genetics into mainstream practice
- Review some data about genetics education and genetics knowledge among health professionals
- Review one NCHPEG program

Should they be able to diagnose, treat, and counsel about all genetic

diseases? Will it suffice for them to check the literature or consult a

geneticist whenever a genetic problem arises? Optimal knowledge

must lie between these extremes, because a primary physician must

have enough knowledge to recognize a problem as genetic and

should have enough familiarity with genetic principles to be able to

use the literature wisely, or to consult with a geneticist intelligently.”

Hsia YE, Bucholz KE, and Austein CA. 1979. Genetic knowledge of pediatricians and obstetricians (Connecticut, 1975, 1977): Implications for continuing education, In, Porter IH and Hook EB (eds.), *Service and Education in Medical Genetics*. New York: Academic Press.

Challenges to Genetics Education for Health Professionals (not limited to physicians)

- 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, Porteous M, McInerney JD. *Nat Rev Genet*, Feb 2007

Some Challenges to the Integration of Genetics into Primary Care

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

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

Genetic Literacy for Health Professionals

The response we hear most often:

“What should I do differently now, and how will that improve outcomes for my patients?”

Genetics is a cognitive discipline, and genetic information has intrinsic value, but...

“Thinking is not highly valued in the healthcare reimbursement system.”

Epstein CJ. 2004. Genetic testing: Hope or hype. *Genetics in Medicine* 6(4): 165-172.

REALIZING THE PROMISE OF Personalized MEDICINE

Aspinall, Mara G., Hamermesh, Richard G.,

Harvard Business Review, Oct 2007, Vol. 85, Issue 10

“Breakthrough targeted therapies could save many lives and a great deal of money. Obsolete business models, regulations, reimbursement systems, and **physician behavior** stand in the way but can be overcome .”

“...most medical schools have yet to fully incorporate genetics and genomics into their curricula.”



◆ Preceded by: Journal of Medical Education (ISSN: 0022-2577)

Association of American Medical Colleges
Volume 82(5), May 2007, pp 441-445

The Current Status of Medical Genetics Instruction in U.S. and Canadian Medical Schools

Thurston, Virginia Carol PhD; Wales, Paula Sue EdD; Bell, Mary Alice MS; Torbeck,
Laura PhD; Brokaw, James Joseph PhD, MPH

Data from the paper by Thurston et al.

- 149 U.S. and Canadian course directors in medical genetics or curricular deans in accredited medical schools
- Response rate = 75.2%, as of June 2005
- 77% = medical genetics in 1st year
- 47% = incorporated into 3rd or 4th year

Data from the paper by Thurston et al. (cont'd.)

- 62% = 20-40 hrs of instruction
 - 86% = general concepts
 - 11% = practical applications
- 46% = stand-alone course
- 54% = integrate med genet into another course

Data from the paper by Thurston et al. (cont'd.)

Most commonly taught topics

- Cancer genetics = 92%
- Multifactorial inheritance = 91.3%
- Mendelian disorders = 90.3%
- Clinical cytogenetics = 89.3%
- Patterns of inheritance = 87.4%

Providers' knowledge of genetics: A survey of 5915 individuals and families with genetic conditions

Harvey, Erin K. ScM, CGC¹; Fogel, Chana E. MGC²; Peyrot, Mark PhD³; Christensen, Kurt D. MPH⁴; Terry, Sharon F. MA⁴; McInerney, Joseph D. MA, MS¹

Volume 9(5), May 2007, pp 259-267

Central Questions & Challenges

- Which content is appropriate for whom?
 - Accurate vs. complete
- Which clinical behaviors and attitudes do we want to change, and can we?
- How do we get educational programs to the people who need them – and get them used?
- How do we define and measure success?

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

NCHPEG's Core Competencies
Third Edition, fall 2007

- Knowledge
- Skills
- Attitudes

- Core principles of genetics

www.nchpeg.org

Core Competencies in Genetics
Essential for All
Health-Care Professionals



GeneFacts



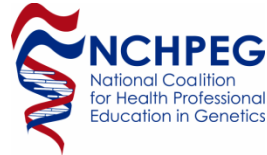
Open Genetics Databases

- Freely accessible
- Genetics and clinical content highly reliable and detailed
- Content often presented inappropriately for clinicians

Subscription Databases

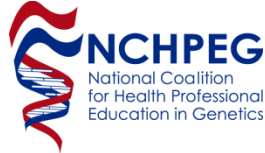
- Fee for access (or through institution)
- Genetics and clinical content not always accurate
- Content generally presented appropriately for clinicians

GeneFacts



- Point-of-care decision-support system in genetics for non-geneticists
- A middle ground between genetics databases and subscription databases
- Written by PCPs and geneticists
- Content abstracted from *GeneReviews* and created *de novo*

GeneFacts



Partial List of Criteria for Selection of First 50 Entries

- Most hits on GeneReviews and other resources
- Prevalence of the condition [using CDC data]
- Disorders where early detection and treatment can improve outcomes
- Prevalence in primary care practices [based on ICD9 reports]
- Morbidity and mortality [as modifiers for prevalence]
- Utility in testing the template
- Availability of genetic testing, and clinical utility
- Disorders that geneticists see commonly and want PCPs to know more about
- Common/complex diseases

A Modest Proposal To Help Integrate Genetics into Mainstream Health Care

Stop using the terms “genetic disorder”
and “genetic disease.”