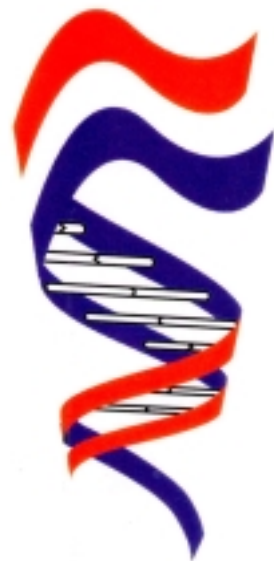


Genetics Education

Addressing (some of) the Gaps

Joseph D. McInerney
Director, NCHPEG



NCHPEG
National Coalition
for Health Professional
Education in Genetics



NCHPEG

National Coalition
for Health Professional
Education in Genetics

OUR GOALS ARE:

- To develop tools and resources that help integrate genetics content into the knowledge base of practicing health professionals.
- To strengthen and expand a coordinated, national genetics education effort for health professionals.

127 member organizations

The challenge is to meld the practical and the conceptual:

“Primary care providers are asking for instruction on **specific content**, and there is no debate about this need. However, with the rapid pace of change in genetic medicine, specific content will fall short of what PCPs really need....A thoughtful, deliberate, and informed refinement of the **‘usual’ cognitive strategies** will have the greatest impact on integrating genetics into all of health care.”

Hayflick & Eiff. 2002. *Genetics in Medicine*. 4(2): 43-44.

NCHPEG's Core Competencies

- Knowledge
- Skills
- Attitudes

- Core principles of genetics

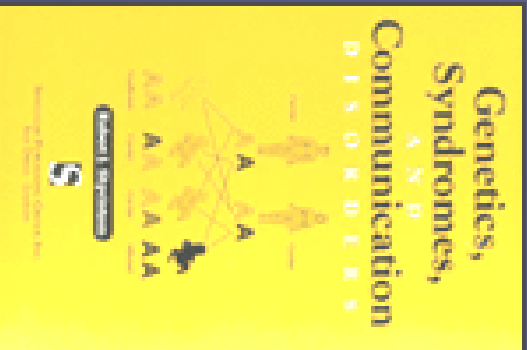
- www.nchpeg.org

Core Competencies in Genetics
Essential for All
Health-Care Professionals



Educational Efforts By

- Professional societies
- Consumer/advocacy groups
- Commercial entities
- Colleges, universities, medical schools
- Individuals



GENETICS

Challenges and Opportunities
for Health Care Professionals

Jennie Q. Lou, MD, MSc, OTR/L

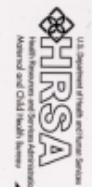
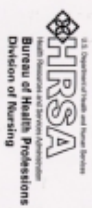
AOTA
PRESS
The American
Occupational Therapy
Association, Inc.



REPORT OF THE EXPERT PANEL ON GENETICS AND NURSING:

IMPLICATIONS FOR EDUCATION AND PRACTICE

September 28-29, 2000
Washington, DC



THE AMERICAN ASSOCIATION FOR RESEARCH AND FAMILY THERAPY

Family Therapy

M A G A Z I N E

May
June
2003

Genomics:
Changing the
Future of
Families



8. Explain why you believe about genetic medicine.
- 12. CBAQ Special Report: Breakdown and the respondent's responses
 - 13. Special you start receiving (SPR)
 - 14. Journal Plus
 - 15. Our Clinical treatment protocols for their sites
 - 16. Health insurance options: Comparison to physician assistants
 - 17. Still Learning to think globally in clinical practice
 - 18. Specialty (Special) changing the industry with the improvement
 - 19. The emergence of lower life
 - 20. The impact

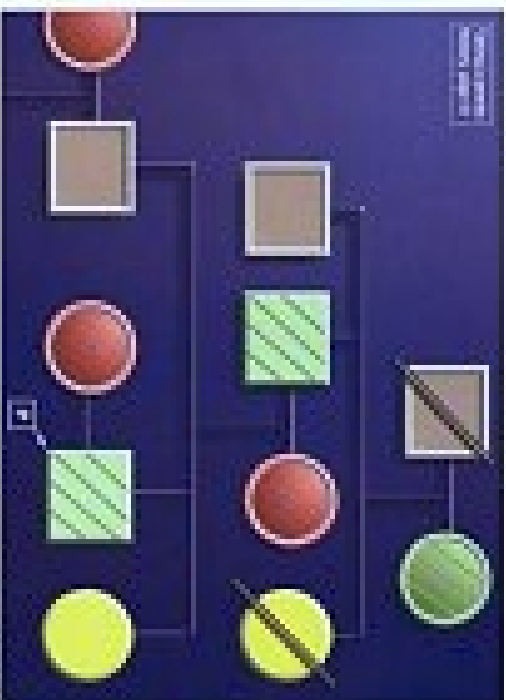


Figure 1. Specialty (Special) changing the industry with the improvement

Commitment from the Top

“The American Physical Therapy Association supports...genetics literacy and its importance and implications for patient/client management by physical therapists. This...encompasses the emerging importance, benefits, and risks of genetic information and gene-based therapies, as well as the associated ethical, legal, psychological, and social implications.”

APTA House of Delegates, 2001

American Society of Radiological Technologists

Curriculum Guidelines – Ethics and Law

- Objective 12. Analyze the ethical issues of genetic screening
- Objective 13. Explain the genetic counseling responsibility of health care providers

Nursing

In 1998, The International Society of Nurses in Genetics and the American Nurses Association developed:

Statement on the Scope and Standards of Genetics Clinical Nursing Practice

Nursing

● Genetics-specific credentials

- Advanced Practice Nurse in Genetics (APNG), for those trained at the masters level
- Genetics Clinical Nurse (GCN), for those trained at the bachelors level

Provided by: Genetic Nursing Credentialing Commission, Inc., a subsidiary of the International Society of Nurses in Genetics

From: Josh Carlson, for GeneTests, University of Washington ©
2003

Nursing

- Certification in a nursing specialty, with a genetics component in the certification test or core competencies
 - 11 separate credentials, including Advanced Oncology Nurse, Clinical Nurse Specialist in acute and critical care, and Certified Nurse-midwifery

Provided by: individual professional societies

From: Josh Carlson, for GeneTests, University of Washington ©
2003

Nursing

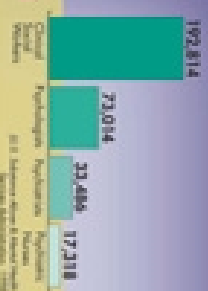
- 11 graduate programs or graduate certificate programs that emphasize genetics
- 16 short courses or web-based programs on genetics

From: Josh Carlson, for GeneTests, University of Washington ©
2003

THE DNA OF SOCIAL WORK:

The Genetic Standards as Building Blocks

Social Workers are the Largest Providers of Mental Health Services



COMMITTEE MEMBERS

- CHAIR:** Jean O. Weiss, ACSW
 Rhonda N. Block, DSW
 Ann M. Johnson, PhD, ACSW
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The National Association of Social Workers (NASW) recognizes the need to integrate knowledge of genetics into social work practice in the context of the NASW Code of Ethics (NASW, 2009). The standards that are delineated in this brochure represent a foundation for introducing genetics into social work practice.

A Advocacy

- policy
- institutional
- community
- with clients

G Genetics Standards in Social Work Practice

- ethics & values
- genetics knowledge
- practice skills
- collaborative practice model
- interdisciplinary practice
- self-awareness
- research
- genetics & cross-cultural knowledge
- advocacy

C Community Settings

- adoption agencies
- nursing homes
- individual & family counseling
- schools
- prison practice
- legal settings
- community agencies
- hospitals & clinics

T Training Opportunities

- educational programs
- web-based programs
- structured dissemination
- continuing education



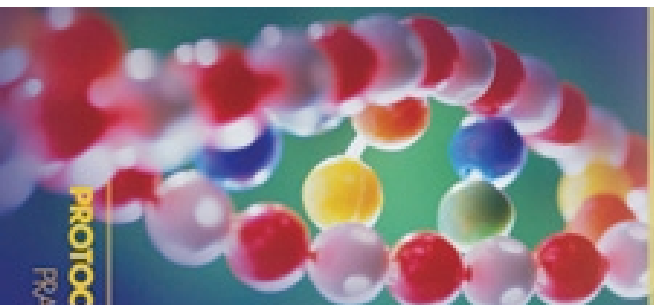
NEW RELEASE
 The National Association of Social Workers (NASW) has published 'Code of Ethics for Social Workers' (2009), the 10th edition of professional social workers' code of ethics. Approximately 1,500,000 workers from 30 chapters in the United States and abroad, the association provides standards and practices for ethical social work and the well-being of individuals, families, and communities through its work and advocacy.

APPLYING STANDARDS

- Evaluate social engineering, genetic engineering, cloning, and human genetic modification.
- Promote and encourage the development of genetic engineering, gene therapy, and related technologies that benefit and improve human health and well-being.
- Conduct research to determine the ethical implications of genetic engineering, gene therapy, and related technologies that benefit and improve human health and well-being.
- Educate the public about the ethical implications of genetic engineering, gene therapy, and related technologies that benefit and improve human health and well-being.
- Advocate for policies that protect the privacy and confidentiality of genetic information.
- Promote the right of individuals to know their genetic information.

PROTOCOL FOR DEVELOPING PRACTICE STANDARDS

- expert workgroup drafts standards
- internal and external review
- 60 day web voting and final review
- adopting final standards by NASW board



NASW Standards for Integrating Genetics into Social Work Practice

- Ethics and values
- Genetics knowledge
- Practice skills in working with individual, families, groups and communities
- Client/practitioner collaborative practice model
- Interdisciplinary practice
- Self-awareness
- Genetics and cross-cultural knowledge
- Research

Some Professional Groups Asking for Help

- Clinical pharmacists
- Dental professionals
- Dietitians and nutritionists
- International groups
- Nurses
- Physical and occupational therapists
- Physician assistants
- Physicians
- Radiation technologists
- Social workers
- Speech, language, hearing specialists

What do they request?

- Curriculum guidelines
- New content for courses (lectures, slides, chapters)
- Workshops
- New courses
- Recommendations for CME and CEU
- Programs at regional and national meetings
- Organizational assistance

Some Practical Constraints

- Preparation at different levels: AA, BS, MS, MD, PhD
- State-by-state regulation of practice and CEUs
- Licensing
- Certification
- Testing

Some New NCHPEG Programs

- Psychiatric genetics (DOE/ELSI)
 - Genetic counselors
 - Psychiatric nurses, psychiatric social workers, psychiatrists
- Genetics and common chronic disease (DOE/ELSI)
 - Primary-care providers
 - Public-health professionals
- CF screening
 - AWHONN

Genetics and Public Health

Epidemiologists assert, “This (behavior, drug, dietary variable) is a risk factor.”

Geneticists ask, “For whom?”

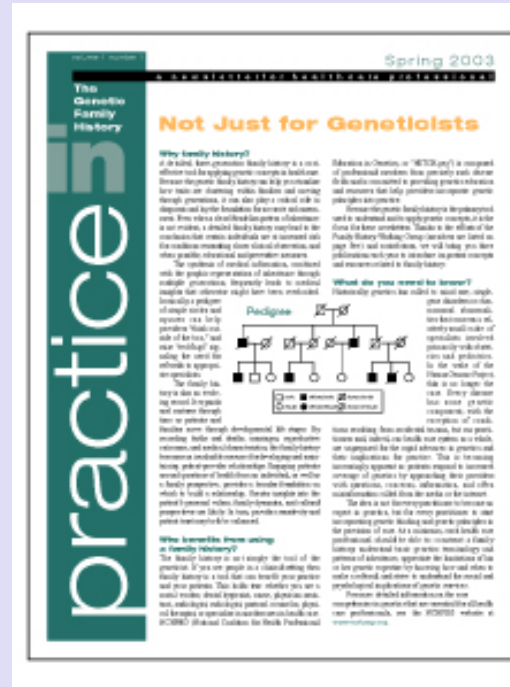
Genetics helps to build the bridge between populations and individuals.



NCHPEG PRODUCTS AND SERVICES

The Genetic Family History in Practice:

three annual newsletters emphasize important concepts related to family history





NCHPEG PRODUCTS AND SERVICES

GROW Website and Search Engine:

One-stop portal for quality genetics information

www.geneticsresources.org





NCHPEG PRODUCTS AND SERVICES

NCHPEG website
www.nchpeg.org

showcases
NCHPEG
educational
products &
genetics ed.
resources





NCHPEG PRODUCTS AND SERVICES

Collection & Review of Genetics Education Programs:

catalogues
educational
programs and
informs
NCHPEG's
future projects



Genetics Content in Introductory Biology Courses for Non-Science Majors: Theory and Practice

ADAM M. HOTT, CARL A. HUETHER, JOSEPH D. MCINERNEY, CAROL CHRISTIANSON, ROBERT FOWLER, HARVEY BENDER, JOHN JENKINS, ANNETTE WYSOCKI, GLENN MARKLE, AND RICHARD KARP

The increasing importance of genetics in our daily lives requires greater attention to the study of genetics in our educational system. To understand the significance of the rough draft of the human genome, the related benefits and risks of gene therapy, and the increasing complexity of gene-gene and gene-environment interactions, the public must understand basic principles of genetics, including human genetics. The National Science Education Standards, developed by the National Research Council, recommend that the concept of inheritance be introduced in grades kindergarten (K)–4 and the basic principles of heredity and genes in grades 5–8. The standards for grades 9–12 concentrate on the molecular basis of inheritance, including DNA structure and function, genetic change, and variation (NRC 1996).

No similar benchmarks exist for the genetics and human genetics curricula offered at collegiate institutions. Medical schools have received more attention in this regard than have college and university undergraduate courses. Twenty years ago, a noteworthy study of 103 of the 107 medical schools then operating in the United States analyzed the medical genetics courses in terms of content, duration, responsible department, and primary discipline of the instructor (Childs et al. 1981). The authors concluded that human genetics had not found a comfortable niche in medical schools. Shortly thereafter, Goodman (1982) suggested implementation of a core curriculum in genetics and clinical genetics and further proposed establishment of a Genetics Education Task Group to coordinate the process. Much later, in 1995, the Information and Education (I&E) Committee of the American Society of Human Genetics (ASHG) submitted a report outlining a core curriculum in medical genetics for medical school (Friedman et al. 1995).

Studies conducted at the precollege level and in medical schools left the undergraduate years unaddressed. In 1999, ASHG began to address this deficiency by offering a workshop on undergraduate genetics education at its annual meeting (Bender et al. 1999). Catalyzed in part by the positive reception of this workshop, the I&E Committee appointed a subcommittee on undergraduate genetics education to develop a set of content recommendations for institutions of higher education (Paula Gregory, ASHG I&E chairperson, personal communication, 1999). The committee, which comprises the first eight authors of this article, represents a wide variety of educational and professional backgrounds, including undergraduate biology education, clinical genetics, nursing, genetics education, and more than 100 years of cumulative teaching experience.

Adam M. Hott (e-mail: hott@emali.uc.edu) is a graduate student in the Department of Biology at the University of Cincinnati, Cincinnati, OH 45221-0006, and an active member of the American Society of Human Genetics; he also sits on the Human Genetics Education Subcommittee of the Information and Education Committee. Also at the University of Cincinnati are Carl A. Huether and Richard Karp, professors in the Department of Biology; Carol Christenson, who is a genetic counselor and Glenn Markle, professor in the Department of Teacher Education, College of Education. Joseph D. McInerney is executive director of the National Coalition for Health Professional Education in Genetics, Lutherville, MD 21093; Robert Fowler is a professor in the Department of Biological Sciences at San Jose State University, San Jose, CA 95192-0100; Harvey Bender is a professor of biological sciences and director of the Human Genetics Program at the University of Notre Dame, Notre Dame, IN 46556-0360; John Jenkins is a professor in the Department of Biology at Swarthmore College, Swarthmore, PA 19081-1397; Annette Wysocki works at the National Institutes of Health, Bethesda, MD 20892-0967. © 2002 American Institute of Biological Sciences.

Genetics for Undergraduates: Introductory Biology for Non-Majors (ASHG)

- The nature of the genetic material
- Transmission
- Gene expression
- Gene regulation
- Evolution
- Genetics and society

Hott, AM, et al. *BioScience* 52(11): 1024-1035, 2002

A Modest Proposal To Help Integrate Genetics into Mainstream Health Care

We should stop using the terms
“genetic disorder” and “genetic
disease.”