

► Genetics/Genomics Toolkit for Faculty:
ENDORING ORGANIZATIONS RESPOND!
JEAN JENKINS, PHD, RN, FAAN 1 AND 3

○ ISSUE 3 | ○ VOLUME 2 | ○ YEAR 2008

► STAKEHOLDERS IN EVALUATION OF GENOMIC
APPLICATIONS IN PRACTICE AND PREVENTION
(EGAPP)
MARTHA TURNER AND ANN CASHION 2

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Competency *focus*

UPDATING THE NURSING COMMUNITY ON THE IMPLEMENTATION OF
THE ESSENTIAL NURSING COMPETENCIES AND CURRICULA
GUIDELINES IN GENETICS AND GENOMICS.

Fourteen participants assembled at the National Institutes of Health for a two day meeting to develop a toolkit for faculty to integrate the Essential Competencies into the nursing curricula. LOTS of work remains to be done, but progress has been made towards achieving this goal.

Genetics/Genomics Toolkit for Faculty: June 24-25, 2008

This was a two day working meeting that focused on a review of available genetics/genomics (g/g) educational materials and prioritizing those of most value to include as part of a toolkit for nursing faculty.

Introduction and Purpose of the Meeting:

The purpose of the meeting was to develop a resource that assists nursing faculty to prepare ALL levels of nurses to competently integrate genetics/genomics advances into nursing practice.

Action Items included:

- Identify and vet nursing education genetic/genomic resources
 - Utilize the Competency Outcome Indicators to facilitate identification and inclusion of Toolkit items that advance competency
- Identify gaps in existing resources
 - Prioritize gaps to be addressed
 - Identify funding mechanisms to fill the gaps
- Begin discussion about mechanisms for a network analysis to identify Opinion Leaders/Faculty Champions
- Establish a Marketing and Dissemination Plan

Attendees proposed that we utilize learning outcome practice indicators to select what to include.

- The toolkit content must illustrate
 - Relevancy of g/g for nurses;
 - Identify the right skills;
 - Be realistic in the expected outcomes;

- Offer Champions for consultation; and
- Consider varied methodologies to offer valuable g/g resources

At this toolkit meeting we heard about several options - learning from experiences of others (UK), and saw what other disciplines are offering (CoGE).

Achieving Competency Today (ACT) from

University of Virginia: Kathy Calzone and Jean Jenkins provided a summary of the finalized Competency Outcome Indicators and the ACT online tool built on the moodle platform from the University of Virginia as a framework for organizing the tool kit resources. To view the UVA resource site go to: <http://act.med.virginia.edu:16080> It is in the Beta testing mode only.

Background Presentations:

National Genetics Education and Development Centre, United Kingdom: Maggie Kirk, PhD, RGN Dr. Kirk provided a summary of progress with the UK healthcare professional education initiative and website including Telling Stories: www.geneticeducation.nhs.uk/tellingstories

Community of Genetic Educators (COGE): Jeff Witherly, MA Providing a social learning environment that is searchable and a resource for communities of learning. People learn from reflection and interaction. This NHGRI site provides resources for science teachers-events, news, discussion board, potential for evaluations. See <http://www.coge.nih.gov>

Building the Tool Kit

Attendees divided into working groups which were assigned identified core knowledge themes emerging

from the Outcome Practice Indicators. The spreadsheet summary of stratified educational resources was reviewed by working groups for currency, accuracy, relevancy, completeness and appropriateness of identified resource for inclusion in the toolkit for g/g education.

Tool Kit Gap Analysis:

Discussion of missing items occurred; items that with modification could be of value to nursing were identified; items recommended for development/modification were prioritized; and opportunities for collaborative development of materials to fill the gaps determined.

Gap Funding:

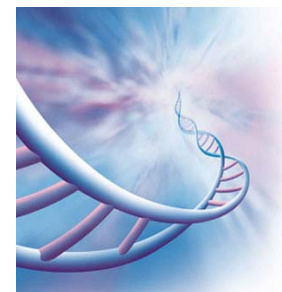
The group recommended development of Talking Points to be able to explore opportunities with potential funding resources. Options to consider:

- Gates Foundation (Global Health);
- HRSA (Nurse retention gaps);
- Practice Partners (i.e., AONE-practice partners); Pharmaceutical companies (i.e., Genelex; Glaxo-Smith-Kline);
- NCHPEG (previously offered \$20,000 to develop educational programs),
- AARP;
- March of Dimes;
- Met Life;
- Johnson & Johnson;
- Cerner;
- Annie Casey foundation.
- Develop a School of Nursing G/G Consortium
- Guide Star for list of non-profit opportunities
- Workshop Grants
- Package Faculty Development for the Essentials as a strategy

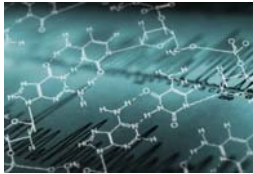
Marketing/Dissmination

1. Consider Education immersion at the grass roots

Continued on Page 3



SPOTLIGHT



Stakeholders in Evaluation of Genomic Applications in Practice and Prevention (EGAPP)

By Martha Turner and Ann Cashion

Report from the Nursing EGAPP Representatives

Are your patients coming to you with printouts from Internet websites and asking for information on the newest genetic screening tests? Is a genetic screening test the next step for your patients with diabetes or cardiovascular disease? How will you know if the genetic screen is clinically useful? Are you looking for a reliable resource for answers to these questions? EGAPP is a new group that will provide these answers. EGAPP is building the capacity to provide recommendations on genomic applications for clinical practice.

What is EGAPP's goal? To establish and evaluate a systematic, evidence-based process for assessing genetic tests and other applications of genomic technology in transition from research to clinical and public health practice. EGAPP is sponsored by the Centers for Disease Control National Office of Public Health Genomics.

This Fall EGAPP will publish its second recommendation which is on testing for polymorphisms (UGT1A1)

when determining treatment for colorectal cancer. This will be followed quickly by recommendations on the use of genetic testing for early detection and management of Lynch Syndrome and breast cancer. Other reviews in progress include those on cardiovascular disease risk profile and type 2 diabetes risk profile.

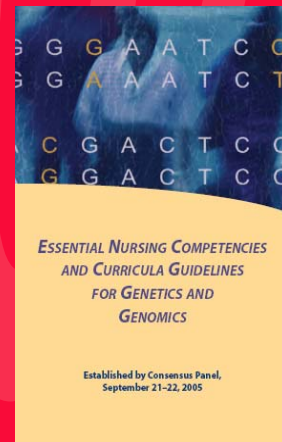
Nurses' voices have been heard. Two nurses, Ann Cashion PhD, RN, past president of International Society of Nurses in Genetics (ISONG), and Martha Turner PhD, RN from The American Nurses Association (ANA) Center for Ethics and Human Rights, are among the 35 members of the EGAPP Stakeholders Group (ESG). The ESG was established to formally engage stakeholders in such activities as recommendations for the use of genetic tests. There are five activities for ESG members and they include but are not limited to assisting EGAPP in identifying the central points from evidence reports and helping to frame and deliver the key messages in ways that are useful to the stakeholder

groups.

The first report published examined the evidence for using the cytochrome P450 genetic test to determine polymorphisms in adults with nonpsychotic depression treated with selective serotonin reuptake inhibitors. The recommendations were published in Genetic Medicine (2007, Dec;9(12):819-25). Other reports will be addressed as they are published. Watch for future updates at the EGAPP website (<http://www.egappreviews.org/default.htm>). For more information about the EGAPP Stakeholders group go to http://www.cdc.gov/genomics/gte/sting/egapp_esg.htm.



DO YOU NEED A COPY OF THE COMPETENCIES?



Download Today at:

<http://www.genome.gov/Pages/Careers/HealthProfessionalEducation/geneticscompetency.pdf>

Publication Update

Paniagua, C.T., Taylor, R.E. (2008). The Cultural Lens of Genomics. OJIN: The Online Journal of Issues in Nursing, 13(1). Available: www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/vol132008/No1Jan08/CulturalLens.aspx

Accepted for publication:

Paniagua, C.T., Taylor, R.E. (2008, in press). Hispanic/Latino perspectives on genetic tests and ethics. In Monsen, R.B. (Ed.) Genetics and ethics in health care: New questions in the age of genomic health. Silver Spring, MD: Nursesbooks.org.

COMPETENCY WATCH

Fall is soon to be upon us and as you know, we have been carefully nurturing the nursing genetic/genomic landscape by working closely with the American Association of Colleges of Nursing (AACN) on the revised **Baccalaureate Essentials**.

Many of you have contributed input to the work of the Essentials Task Force revising the American Association of Colleges of Nursing (AACN) Baccalaureate Essentials. Their work is almost done! At their July meeting, the AACN Board of Directors unanimously approved the draft posted at <http://www.aacn.nche.edu>. This draft will be voted on by the membership at the AACN Fall Meeting. AACN will be hosting three teleconferences to provide information about this work: September 10 from 1:00-2:30 p.m. EDT; September 18 from 4:00-5:30 p.m. EDT; and September 23 from 1:30-3:00 p.m. EDT. Details about call-in information will be sent to the membership soon. Please contact Kathy McGuinn at kmcguinn@aacn.nche.edu with any questions. (Dr Patricia Martin's slides see <http://www.aacn.nche.edu/Education/teleconf.htm>). It's appropriate that indeed genetics/genomics is recognized as an important component of nursing education as reflected in this document.

AAN 2008 ANNUAL MEETING AND CONFERENCE: HEALTH AS A BRIDGE FOR GLOBAL PEACE

The November 6-8, 2008, American Academy of Nursing's 35th Annual Meeting and Conference, will focus on Global Health. As a kick-off to this conference, the AAN Expert Panel on Genetic Healthcare has planned a pre-conference day.

AAN PRE-CONFERENCE: GENETICS AND GENOMICS THE GLOBAL BRIDGE TO HEALTH SPEAKERS INCLUDE

Maggie Kirk, PhD, RGN, Professor of Genetics Education, Leader Genomics Policy Unit, University of Glamorgan, Glyn Taf, Wales, United Kingdom

Tesfamichael Ghebrehwet, PhD, RN, Consultant in Nursing and Health Policy, International Council of Nurses, Geneva, Switzerland

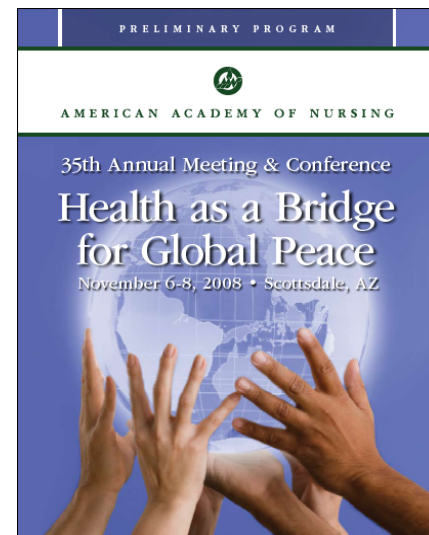
LOGISTICS

Thursday, November 6, 2008 1:00 PM – 4:00 PM

Cost \$60 for Fellows, \$85 for Non-Fellows, \$25 for students. Pre-Registration is required.

FOR MORE INFORMATION

<http://www.aannet.org/i4a/pages/index.cfm?pageid=3577>



Toolkit for Faculty: Continued from Page 1

presenting at Sigma Theta Tau International (STTI), AACN, American Academy of Nursing, National League for Nursing (NLN), American Nurses Association, American Organization of Nurse Executives, National Coalition of Ethnic Minority Nursing Association meetings about the g/g competencies, outcome indicators, and toolkit.

1. Consider utilizing STTI-Nursing Knowledge International
2. Work with publisher to bundle books/g/g information
3. Links to toolkit from organizations websites (i.e., AACN; STTI; NLN)
4. Press release when toolkit available
5. Email Deans announcing toolkit
6. Ad to AACN-newswatch; syllabus
7. Advertise in journals-Journal of Nursing Scholarship, Nursing Perspective, Journal of Professional Nurses
8. Provide to Cindy Prows for list serv
9. International Council of Nurses (ICN)
10. Articles in Nursing Spectrum and Advance
11. Present at National Coalition for Health Professional Education in Genetics
12. Focus on Magnet Hospitals

Gaps to Address

- Develop journal article series on nursing roles modeled after UK series
- Textbooks – Contribute chapters; approach publishers (chip away at this)
- Historical information:
 - Gathering archival information on genetic counseling and nursing

- Pulling together the information with ISONG
- HRSA monograph/J. Williams; ICN
- F/U with International Society of Nurses in Genetics – by year
- Guide for nurses about what to teach patients about genetics and genomics
- Personal Assessment Tool (values & attitudes assessment)
- Unfolding Case Studies (method) – hook up with nursing process; method for education; decision points in caring for patients
- Nursing process:
 - Framework
 - Content associated with assessment
 - Establishing care planning based on what is identified
 - Based on outcome indicators
 - Interprofessional plan of care; nursing path of care
- Access (patients) next steps and what to do
- Pharmacogenomics – slide set for nursing (multiple slides)
- Nursing Roles – link to UK series; divide according to specialty/professional organization articles
- Patient outcomes – what does it look like in practice; what research questions need to be answered; how is it going to benefit patients (e.g., Coumadin)

Resources to Find to fill Gaps

- Basic genomics – look for more resources
- Privacy – create list of resources

- Children and genetics (ethics)– look for resources (check PDQ; position papers, Gallo paper)
- Population Genetics and Public Health – look for resources
- Family components and Concepts – look for resources
- Biorepositories – published literature; find what is relevant to nursing; paper written for nursing (check UK literature and Iceland)
- Culture, Diversity, Minority Health – find resources

Methodologies – match method with GAP

- Create slide bank – method for all areas (UK, NCHPEG slides)
- References for all topics
- Case studies
- Stories
- Article series
- Personal Assessment tool
- Approach continuing education modules (e.g., CE module in a nursing journal on roles)

Prioritizing Gaps (1,2, or 3 with 1=highest priority)

- Patient outcomes – 1
- Nursing roles – 1
- Personal values assessment tool – 1
- Basic genomics – 1 (check NAAN; Genetics in Primary Care)
- Guide to teach patients - 2
- Biorepository – 2
- Access to services – 2 (health disparities; access to use of genetic information and rare diseases)
- Pharmacogenomics – 3
- Children and genetics - 3 (see information on topic)

Conference Update



Resource Highlight

The Genetics Education Program for Nursing

The Genetics Education Program for Nurses created a new 5 week teacher facilitated online offering: Applying Genomics in Nursing Practice (AGNP). The AGNP is designed to meet the needs of clinical nurses – regardless of their area of practice. Nursing contact hours (21.25) are awarded to nurses who participate in an entire course and complete all related assignments and evaluations. Two offerings are scheduled:

- **September 26 - October 31, 2008 - (Orientation begins on September 22nd)**
- **March 20 - April 24, 2009 - (Orientation begins on March 16th)**

Comments from past participants indicate that nurses are able to apply concepts and skills that they learn in the AGNP.

I have already told other colleagues that this course would be helpful to them. This web-based format with interactive self-learning modules/sessions and multiple resources helped to apply concepts to any area of nursing practice.

Helps a lot with pedigrees and how important family histories really are.

The course is very practical and down to earth, meaning that we apply genetic knowledge to everyday cases and also the resources are very useful and accessible.

For more information and to register, visit the GEPN website at <http://gepn.cchmc.org>

For more information please refer to the ISONG website:
<http://www.ISONG.org>

Community of Genetic Educators (COGE)

The COGE website is sponsored by the National Human Genome Research Institute. This website is a place for genetic educators to meet, collaborate, share and learn. Resources on these pages will benefit K-12, collegiate, formal and informal biology, and genetics educators. Plus once registered, there's an interactive component with opportunities to provide input to developing programs or assist in the revision of existing resources like the talking glossary of genetics. Visit: <https://www.coge.nih.gov/Default.aspx> to see what these pages have to offer you.



Essential Competency Outcome Indicators

The Outcome Indicators are an adjunct to the Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics and are intended to define for each competency the knowledge and practice indicators. The knowledge and practice indicators are not intended to be prescriptive but provide a guide to the user of essential knowledge elements and suggested practice indicators. To be consistent with the Competencies, definitions will be identical between the two documents. Genetic and genomic information will be used as the context for defining knowledge and practice indicators for each competency. Look for a revised Competency Monograph with the Competencies AND the Outcome Indicators this Fall.



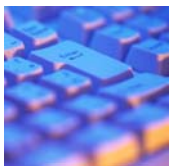
Blending Tradition with Innovation

On August 20, 2008, the National Human Genome Research Institute (NHGRI) awarded more than \$20 million in grants to develop innovative sequencing technologies inexpensive and efficient enough to sequence a person's DNA as a routine part of biomedical research and health care. NHGRI's vision is to cut the cost of whole-genome sequencing to \$1,000 or less, which will enable the sequencing of individual genomes as part of routine medical care. Are you ready??

\$\$ Receipt of Funding \$\$

The GGNCI would like to acknowledge funding obtained from the Division of Nursing, Bureau of Health Professions, Health Resources Services Administration (HRSA). These funds are earmarked for filling a gap identified in the Faculty Tool Kit Gap Analysis. We are very grateful for the ongoing support of the Division of Nursing at HRSA.

New: Health Care Professional Information Now Available on NHGRI Web



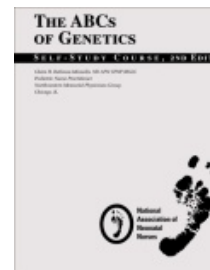
Genetics and Genomics for Health Professionals provides reliable, up-to-date genetics and genomics information related to patient management, curricular resources, new research, and ethical, legal and social issues. Explore everything available for health care providers by visiting: <http://www.genome.gov/27527599>. Dale Lea, Jean Jenkins, Greg Feero, MD, and Judy Wyatt

of NHGRI developed the pages to provide quick links to content relevant to nurses and other care providers. Feedback about the value of these pages is important, so please visit and fill out a questions and feedback form found at: <http://www.genome.gov/10005049>

Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) Update

The SACGHS July 7-8, 2008 meeting focused on Personalized Genome Services. A transcript and webcast of the meeting can be located at: <http://www4.od.nih.gov/oba/SACGHS/meetings/2008Jul/SACGHSJul2008meeting.htm> Also discussed was the SACGHS priority for the upcoming year on genetics education. A Genetics Education and Training Task Force has been formulated and charged with developing a plan to identify the education and training needs of health professionals, the public health work force, and the general public in order to optimize the benefits of genetic and genomic services for all Americans. Barbara Burns McGrath RN, PhD Chair of the Task Force presented their proposed action plan. SACGH has published two reports which may be of interest: <http://www4.od.nih.gov/oba/sacghs.htm>

Report: Realizing the Potential of Pharmacogenomics: Opportunities and Challenges
http://www4.od.nih.gov/oba/sacghs/reports/SACGH_S_PGx_Report.pdf
Report: U.S. System of Oversight of Genetic Testing: A Response to the Charge of the Secretary of Health and Human Services
http://www4.od.nih.gov/oba/sacghs/reports/SACGH_S_oversight_report.pdf



The National Association of Neonatal Nurses developed the *ABCs of Genetics* to outline the basic principles of human genetics. It is intended to help the reader understand inheritance, genetic patterns, and the common

conditions that have genetic underpinnings. The outline format provides the information in a concise, accessible manner, and figures effectively illustrate the material. Practice tests appear throughout to help the reader learn the concepts; answers are provided at the end of the publication. The second edition has been updated with new and revised chapters to encompass advances in the field. Download Today at: <http://www.association-office.com/NANN/etools/products/testproducts.cfm#detail.cfm>
Customer/Nonmember Price: \$40.00
Member Price: \$25.00