International Society of Nurses in Genetics

Newsletter

Caring for People´s Genetic and Genomic Health

Oct-Dec 2011

Contents

President's Message

POSITION AND MOMENTUM : The quantum mechanics of genetic nursing

Ellen Giarelli

Once again we thank you for being a member of ISONG and it will be my privilege to serve you this next year as President.

Over the past decade, nurses have made great strides in designing genetics educational curricula for undergraduates and advanced practice nurses and have approved core competencies that are being integrated with professional training. The mandate for educating nurses in genetics/genomics is clear and in five years, we expect to see genetics and genomics instruction in all nursing programs. However, the goals for genetic nursing research and the clinical application of core competencies across practice settings remain less clear.

The nursing profession stands at the threshold of the future of genetic and genomic health care. With a clearly marked path, nursing can be proactive and directive. We are the largest group of health care providers and will be responsible increasingly for interfacing with the public on issues of genetic and gain more legitimate influence over genomic health care·· It is most important to not wait to be told what we will be and what we should do. Rather, nurses must create their roles as researchers and clinicians in the genomics era.

In quantum mechanics there are two principles: the principle complementarity and the Heisenberg principle. Complementarity states that some objects have multiple properties that appear to be contradictory. It is possible to switch back and forth between different views to observe these properties --- but it is impossible to view both at the same time despite their simultaneous co-existence in reality.

The Heisenberg principle states there is a fundamental limit on the accuracy with which physical properties of a particle can be simultaneously known. In other words, the more precisely one property is measured , the less precisely the other can be controlled, determined or known.

So, if we closely examine the position of our organization, we cannot be sure where we are going and how fast (momentum). And, conversely the more we focus on change –movement, the less sure we are of where we stand. Accelerating changes in genetics and genomics is like the \perpetual uncertainty explained by quantum mechanics and is therefore a reality that we have to deal with.

President´s Message

ISONG is the organization of *particular* people with common ideas and shared interests in caring for people's genetic and genomic health. Our mission (position) is to foster the scientific, professional and personal development of members in the management of genomic information. Our momentum is our goals: to provide a forum for education and support for nurses providing genetic healthcare, promote the integration of the nursing process into the delivery of genetic healthcare services, advance nursing research in human, and promote the development of standards of practice for nurses in human genetics genetics.

We have a new **taskforce to create online educational programs for nurses.** We have a **Genetic Nursing Essential Taskforce** that is planning a series or bundle of instructional sessions on HOW to integrate essentials within curricula. The **Global Membership Committee** is envisioning membership drive by taking a systematic approach to recruiting members, target students, SGI fellows, and faculty.

Genetic nursing is a science and an art and there is creative genius in the work you do

With your creativity, direction and momentum, we (ISONG) will become bigger, better, finer, more complex, and more global.

Reach out to your colleagues, share your knowledge and demonstrate through your good work why they should join you as a member of ISONG.

News and Announcements

EBMG report

Submitted by Sandra Daack-Hirsch PhD, RN

For the purposes of this document , registration is used as the term to define the assessment and recording of competence of an individual practitioner. In some countries the terms credentialing or licensure may be used, but for ease of reading we have used one consistent term.

The European Society of Human Genetics is establishing a Board, EBMG, to oversee registration of Medics, Lab scientists, genetic nurses and genetic counselors in Europe. Many countries are too small to have their own registration systems and this board will cover all European countries. They are gathering information on existing registration systems.

To that end the EBMG working group met on the November 13, 2011 during the 12th International Congress of Human Genetics in Montreal. Dr. Joerg Schmidtke, Chairperson of the working group asked representatives from American Board of Genetic Counselors (ABGC) and American Board of Medical Genetics (ABMG), and ISONG/Genetic Nursing Credentialing Commission (GNCC) to attend their meeting and give a presentation on their respective registration systems to include information on the structure of the board, how often the board met and where meetings take place, and a summary of the registration process. In addition, members of ISONG (Kathy Sparbel, Heather Skirton, and Sandy Daack-Hirsch) and GNCC (Jeanine Seguin Santelli and Jane M. DeLuca) collaborated to provide an overview of ISONG and GNCC's missions, scope and standards of nursing practice in genetics in the USA, and a brief history of the registration process of genetic health care providers in the USA, the effect these events had on nurses providing genetic health care and how that lead to the GNCC's credentialing process.

This was a fantastic opportunity to share with our European colleagues our experience in developing a rigorous registration system for nurses, and to talk about an alternative method for registering health care professionals in the delivery of genetics information other than an exam based system. Europe has mixture of non-physician healthcare providers delivering genetic counseling. In some European countries all genetic counselors are nurse, in others both genetics counselors and genetic nurses provide genetic counseling, while in other countries only genetic counselors provide genetic counseling. As genetics permeates heath care, the ESHG may find a need to encourage nurses who are not genetic counselors to specialize in genetics. We provided an example of one way to formally recognize and register these nurses.

Japanese Society of Genetic Nursing 10th Anniversary Celebration and Conference September 2011 in Tokyo, Japan

Submitted by Karen Greco, PhD, RN, ANP-BC,FAAN and Michiko Mizoguchi, PhD, RN, PHN

The Japanese Society of Genetic Nursing (JSGN) held their 10th Anniversary celebration and educational conference, in Tokyo, Japan September 23-24, 2011. One hundred and twenty attendees from Japan, Korea, and Taiwan attended this conference on "Genetic Nursing and Culture" to discuss cultural issues influencing genetic nursing research, education, practice and policy. Dr. Michiko Mizoguchi served as chair for this memorable conference.

Hironao Numabe, MD, DG, PhD from Kyoto University in Japan gave the keynote address on the influence of culture in Asia on genetic counseling of decision making for genetic testing. "Nurses' Roles in Counseling Patients on Genetic Testing and Cultural Influences on the Process" was presented by Mei-Chih Huang, Ph.D, RN from Taiwan and Nyungheee Jun, Ph.D., RN from Korea. JSGN President, Naoko Arimori, RN, CNM, Ph.D. gave a JSGN activity progress report. ISONG was officially represented by Dr. Kathleen Sparbel from the USA who was ISONG President at the time of the conference and Dr. Heather Skirton from the UK who both presented video conference. JSGN appreciates ISONG's support in providing these video presentations. ISONG was also well represented by many JSGN members attending the conference who are also ISONG members.

In honor of Dr. Masato Tsukahara, who passed away earlier this year, a memorial service was held during the conference in his honor. Dr. Tsukahara's wife attend the memorial service and conference and JSGN President Naoko Arimori presented a thank you message to her honoring Dr. Tsukahara's service to JSGN and genetic nursing. Dr. Tsukahara was a long time member and supporter of both JSGN and ISONG.

This exciting conference was the first time genetic nurses from Japan had the opportunity to discuss genetic issues with other Asian nurses from Korea and Taiwan. They were able to dialog about genetic nursing in Asian cultures and create a network to continue this discussion and work together on common issues in the future. JSGN created a beautiful slide show of photos from the conference that was available for viewing during the ISONG conference in Montreal.

Japanese Society of Genetic Nursing 10th Celebration and Conference

Dr. Jun and Dr. Huang at the Conference

Dr. Mizoguchi JSGN conference chair

Tribute to Dr. Masato Tsukahara

Submitted by Karen Greco

It is with deep sadness that ISONG recognizes the passing of Dr. Masato Tsukahara, a long time ISONG member and supporter of genetic nursing. Although his background is in pediatrics and medical genetics, he fought for a decade to support genetic nursing in Japan and worldwide. His own research career in genetics includes the identification of a syndrome which bears his name, Tsukahara's syndrome, characterized by radio-ulnar synostosis, short stature, microcephaly, scoliosis, and mental retardation.

Dr. Tsukahara has a long history of being an international leader in genetic nursing. In 2005 he received an honorary

membership award from Sigma Theta Tau International for his exceptional leadership and contribution to nursing worldwide. He has worked collaboratively with top nursing leaders in Japan conducting innovative research related to genetic education in nursing programs in Japan, published and presented these research findings. Dr. Tsukahara's work has been instrumental in developing genetic nursing competencies in Japan, increasing genetic and genomic content in Japanese nursing programs, and preparing nursing faculty to teach this content in nursing education programs in Japan.

Through his role as Editor-in-Chief of the journal *Nursing & Health Sciences*, Dr. Tsukahara made it possible for ISONG abstracts to be published in this journal for several years. These published ISONG abstracts are now indexed in CINAHL and other databases increasing ISONG's visibility and impact worldwide. In 2009 he received the ISONG Research Award.

He has consistently attended the ISONG annual conferences and participated in oral and poster presentations related to this work. Dr. Tsukahara has also brought with him to ISONG conferences other nursing leaders from Yamaguchi University where he was a Professor and Vice President of Academic and Student Affairs. As a physician and one of ISONG's few non nurse members, his outstanding long term contributions to genetics nursing are especially note worthy. Although his presence will long be missed, Dr. Tsukahara, his legacy to genetic nursing is enduring.

Dr. Tsukahara at 2008 JSGN.

JSGN President Dr. Arimori giving Dr. Tsukahara's wife a thank you message.

GNCC Report

Submitted by Jeanine Seguin Santelli

Order forms for the APNG and GCN Portfolio Application are available on our website homepage http://www.geneticnurse.org/ (.) The next portfolio deadline is March 1, 2012.

Credentialing Class of 2007 renewals will be due September 1, 2012. The guidelines can be found on our websitewww.geneticnurse.org (.) Just click on either the APNG or GCN button to access the file.

Jeanine Seguin Santelli, PhD, ANP-BC/GNP-BC

GNCC Executive Director

112 Central Ave.

Keuka Park, NY 14478

ANA Genetics Competencies

Submitted by Alice Kerber

Alice and Nancy Ledbetter, are currently working for ANA genetics competencies, also ONS competencies. Alice is co-chair of the professional practice committee and with Nancy they are working on developing an ISONG resource/ referral service.

Virtual Pharmacogenomics Update

Submitted by Patricia Newcomb PhD, RN CPNP

Save the date. On April 14, 2012, the Genomics Translational Research Lab (University of Texas at Arlington, College of Nursing), will host a virtual pharmacogenomics update for nurses and a panel discussion of current ethical, social, or legal issues in healthcare related to genetics/genomics.

ISONG members, Patty Newcomb, Barbara Raudonis, and Denise Cauble are planning this virtual meeting for the Second Life environment and invite other ISONG members to attend. Nurses may register for CEs ($25 per session), but anyone may attend for free if CEs are not requested.

We are interested in the Second Life platform and other virtual environments as potential teaching venues and currently organize journal clubs and class presentations there successfully. This will be a new adventure. If you are interested, e-mail Patty Newcomb at pnewcomb@uta.edu for further information regarding how to access the program.

2012 USA National Cancer Institute Summer Curriculum in Cancer Prevention

Submitted by Kathleen Calzone

The USA National Cancer Institute (NCI) Cancer Prevention Fellowship Program will host the NCI Summer Curriculum in Cancer Prevention in 2012. This educational opportunity has long been recognized as an opportunity for scientists, clinicians, and persons from other disciplines to learn the latest information about preventing cancer.

The summer program consists of two separate courses:

The Principles and Practice of Cancer Prevention and Control Course is a 4 week course designed to give participants a broad-based perspective on the current state-of-the-science in the field of cancer prevention. Experts representing disciplines from across the entire spectrum of cancer prevention research will present lectures on timely topics. It will be held from July 9 - August 3, 2012 in Rockville, Maryland, USA, with lectures from 8:30 am to 2:30 pm on most days.

The Molecular Prevention Course is a 1 week course that helps participants gain a stronger background in the molecular biology and genetics of cancer. It provides a thorough overview of cutting-edge research in molecular epidemiology, chemoprevention, biomarkers, and translational research. This course will be held from August 6 - August 10, 2012, also in Rockville, Maryland, USA with lectures from 8:30 am to 2:30 pm on most days. Please visit this website for more information and to view syllabus samples from the 2011 Summer Curriculum in Cancer Prevention at https://cpfp.cancer.gov/summer/summer.php

Registration for both courses is free but all registration materials need to be submitted by close of business on March 15, 2012 because space is limited. For Additional Information contact:

NIH, NCI, CCT, Cancer Prevention Fellowship Program (301) 496-8640

DNA DAY 2012

Submitted by Virginia Minichiello, M.S., R.N.,C.

Do you know some high school students? Or even children of neighbors, or your relatives that might be interested in DNA DAY? Would you like to be a resource to those students? There are a number of wonderful things going on through NIH for students to participate in and to be aware of! What better way to foster interest and stimulate ideas for genetics. There is a wonderful essay contest sponsored by the ASHG group with awards and honors to essay winner;

2012 DNA Essay Contest Question Now Available http://www.ashg.org

Also, there is an exceptional opportunity for high school students to do some exciting experiments and at the same time be exposed to the incredible resources available to them through NIH at the following website, http://challenge.gov/challenges/184. ISONG again this year is represented on the NIH DNA DAY Committee and we are hoping that you will find a way to promote this DAY and its many activities.

DNA Day is actually celebrated worldwide as you may know, and of course being an international organization, we have members from all over the world. It is wonderful to think that there are so many countries involved and thus provides other resources and ideas for youngsters to participate. For example this is a piece taken from a Chinese website from last years' program. http://www.dnaday.com/

2011.4.25, the 58th Anniversary of the publication of DNA Double Helix Structure on Nature, Dalian hosted the 2nd World DNA and Genome Day on this day. 9 Nobel Laureates and 2500+ participants from 50 countries and areas attend the conference. The officials of Dalian Government and the Directors of Hosting Organizations delivered the welcome speech at the opening ceremony. The conference came to a successful conclusion finally. As the operating organization, BIT Congress Inc. cordially invites you to join the event in 2012.

As you are aware, we are not alone in our quest to inspire, inform and initiate interest in genetics. Please do consider doing something as a representative of ISONG in your local community, other nursing organizations and with colleagues. Give us credit by reporting back through our website of activities you are undertaking. Our organizational link will be on the website for NIH DNA DAY -

www.genome.gov/Education/ - 30k04-20-2011 -

GENETIC NURSING Online Courses at

The University of Iowa

Genetics Nursing Research 96:415

3 credit hours

Spring 2012

This graduate course addresses concepts in human genetics and genomics regarding implications of gene discoveries for understanding of causes of and human responses to conditions with a genetic component. Relevant genetic, nursing, and biologic and behavioral theories and concepts will be evaluated for their integration into genetic nursing research. Students analyze current research on selected genetic topics of concern to nursing.

Information:

janet-williams@uiowa.edu,

jennifer-clougherty@uiowa.edu

introduction to human genetics 96:116

3 credit hours

Fall 2012

This course provides an introduction to the organization of the human genome and basic principles of inheritance and variation in humans. Space is limited.

Information: wilene-larpenteur@uiowa.edu

Articles Published by ISONG Members

Submitted by Susan Miller-Samuel

Variants of Uncertain Significance in Breast Cancer–Related Genes: Real-World Implications for a Clinical Conundrum. Part One: Clinical Genetics Recommendations. Seminars in Oncology Vol. 38, Issue 4, Pages 469-480.

Susan Miller-Samuel, Deborah J. McDonald, Jeffrey N. Weitzel, Ferdy Santiago, Martin A. Martino, Tara Namey, AnnMarie Augustyn, Rebecca Mueller, Andrea Forman, Angela R. Bradbury, Gloria J. Morris

http://www.seminoncol.org/article/S0093-7754(11)00123-0/fulltext

BRCA1 and BRCA2 Variants of Uncertain Significance. Part Two: Medical Management.

Susan Miller-Samuel, Anne Rosenberg, Adam Berger, Leonard Gomella, David Loren, Gloria J. Morris. BRCA1 and BRCA2 Variants of Uncertain Significance. Part Two: Medical Management. Seminars in Oncology Vol. 38, Issue 5, Pages 605-611

http://www.seminoncol.org/article/S0093-7754(11)00124-2/fulltext

Award-winning genetics website publishes landmark 100th story!

Submitted by Emma Tonkin PhD

We are delighted to report that the 100th story is being published on the Telling Stories Understanding Real Life Genetics website (www.tellingstories.nhs.uk) in December! Launched in 2007, the project, led by Professor Maggie Kirk (of the Genomics Policy Unit, University of Glamorgan and lead Professional Specialist, Nursing Professions, at the NHS National Genetics Education & Development Centre), was developed to help health professionals understand the impact genetics has on people's lives by using real-life stories from individuals with, or at risk of, a genetic condition, their family members, carers and healthcare professionals.

The stories cover a range of genetic conditions from cystic fibrosis and Down syndrome to diabetes and breast cancer. The freely-available stories are linked to educational frameworks for nurses, midwives, GPs and medical students and include a toolkit of learning activities. As well as some of the more recognised genetic conditions, the stories also cover some rare - and less well-known - conditions such as Niemann-Pick disease, Costello syndrome and Brugada syndrome.

Hundredth story

The 100th story describes Siobhan's experiences of living with two complex genetic conditions, type 2-diabetes and the inflammatory condition ankylosing spondylitis, which are caused by a combination of genetic and environmental factors. On her experience of being a storyteller, Siobhan says:

"I was really pleased to be able to tell my story; it's a good way to raise awareness of people like me trying to live a full life while dealing with complex problems (in my case ankylosing spondylitis and type-two diabetes). Too often I find that health professionals only see/deal with the part of you that interests them and not a whole person. The Telling Stories resource is a good way for us ordinary people to be ourselves and hopefully that is what the health professionals will see as well as understanding more about genetics."

Storytellers as partners

The storytellers, who represent a variety of ages and backgrounds, are at the heart of *Telling Stories*, and the project team is passionate about working in partnership with them to ensure that their voices are heard. Paula, whose son has a rare chromosomal condition, says "I am glad I have told my story and I really hope people will understand how hard it can be when faced with the news your child has a disability."

Geraint died suddenly at the age of 24 from an inherited heart condition (Brugada syndrome). On telling their family's story, Geraint's mother said "I feel the more people that read about experiences such as mine, the more understanding and help is likely to become available… this is what I set out to do, tell the people who are able to help people such as myself."

Storyteller Siobhan looks at her family tree.

Impact

Since January 2009, the website has received almost 41,000 visits and more than 193,000 page views from users in over 150 countries and was 'Best Use of New Media' winner at the 2009 Association of Healthcare Communicators awards. Dr Rhian Morgan, Telling Stories Project Officer, said "I am very pleased that we are now publishing the 100th story. Working with the storytellers is inspiring and their stories are powerful, engaging and memorable. Hearing their experiences is key in helping to improve our understanding of the relevance of genetics to healthcare practice and the impact genetic conditions can have on those affected. The feedback we receive from the storytellers who participate in the project, and from those using the website, is overwhelmingly positive. That the 100th story is about to be published is a testimony to the commitment of the storytellers and all those involved with the project".

Working together

The Telling Stories project team represents a collaborative effort between the Genomics Policy Unit at the University of Glamorgan, Genetic Alliance UK, Plymouth University and the NHS National Genetics Education and Development Centre, which hosts the website.

Professor Kirk said "I'm delighted that Telling Stories is now celebrating its 100th story. As a health professional educator, I find the site to be an enormously valuable resource and the stories never fail to stimulate discussion amongst students. This is so important when we are trying to get health professionals to understand how genetics impacts on the lives of individuals and families.

The resource has been developed by working in partnership with storytellers. Siobhan has worked closely with Project Officer Dr Rhian Morgan to help promote the resource for our 100th story celebration. Of course, all of our storytellers are important to us and we do regard them very much as the 'senior partners' – we certainly couldn't do it without them!"

If you are interested in finding our more about the project or participating as a storyteller, you can contact the team by email: tellingstories@glam.ac.uk or go to www.tellingstories.nhs.uk.

Greetings from the

Global Membership Committee

Dear members; we would like to share our vision and goals for 2012.

Although slightly different from all of the details listed in our Working documents, below are specific measurable goals that we would like to share in hope that all of ISONG members see themselves as "Ambassadors for the organization. We are soliciting new members, so please let us hear from you.

1.Goal: Engage in and create activities that will allow for growth of our membership by 25% base while also ensuring member retention.

A. Objective: Each One Bring

Activities: We are appealing to our members to identify a total of 5 members by 6-12. We encourage you to seek out students, organizations, and fellow colleagues to join ISONG by 9-12.

B. Create a campaign by 1-5-12 to "Reach Out to like organizations

C. Work with Communication Committee to Create organizational reciprocal links on ISONG web page

E. Offer reduce membership fees for three or more years.

2. Goal: Increase retention and satisfaction of ISONG members over 12 months to reflect an increase in retention by 90%

A. Objective: Create a "You Me & ISONG Corner on the web-page for member's Testimonials, (What ISONG membership means to me?)

B. Initiate "Members Speaks" at the Annual conference

C. Embrace new members at the conference, with incentives

D. Capture fun events at annual conference on put on web site

E. Consult and Provide detail information and fees for membership categories

F. Bank expertise of our members and put on Web page

G. Expand offerings to members, conference presenters to attract new members

H. Work with Education and Policy Committee to provide certified educational offering

I. Investigate the merit of standard versus rotating membership renewal

3.Goal: Revisit and Redefine the "Buddy System by 7-12

ISONG Newsletter

All ISONG Members are wellcome to contribute in our newsletter:

Please consider sharing reports of your research projects and results

Send us your acoomplishments

Exchange your experience among different cultures by sharing your practice, ethical, social, and legal perspectives

Please contact

Erika M M Santos

at

erikammsantos@gmail.com

Congratulations to ISONG's 2011 Founders Award Recipients

ISONG Founders Service Recipient:

Jeanine Seguin Santelli, PhD, ANP-BC/GNP-BC
GNCC Executive Director
Nazareth College School of Health, chair of nursing
Rochester, New York, USA

ISONG Founders Education Recipient:

Suzanne Mahon RN DNSc AOCN APNG
Assistant Professor, Division of Hematology/Oncology,
Department of Internal Medicine, Saint Louis University, USA

ISONG Founders Research Recipient:

Jacquelyn Taylor, PhD, PNP-BC, RN
Yale School of Nursing, Associate Professor
New Haven, Connecticut, USA

The purpose of the ISONG Founders awards, established in 1996, is to honor individual ISONG members who have demonstrated excellence in genomic nursing education, research or service. ISONG members have the opportunity each year to nominate another ISONG member for a Founders Award. One of the highest forms of recognition one can receive is a tribute from one's peers. The ISONG Founders' Awards make it possible for ISONG as a professional organization to recognize members who have served ISONG and are leaders in genetic/genomic nursing and health care.

Dr. Jeanine Seguin Santelli has been a pioneer in facilitating the development and evolution of the credentialing of genetics nurses. Since its inception, she has been associated with the Genetic Nursing Credentialing Commission (GNCC) and since 2005 has led the credentialing process for nurses in genetics serving as the volunteer GNCC Executive Director. The GNCC webpage currently lists 48 nurses in 26 states with the Advanced Practice Nurse in Genetics or APNG credential and 15 nurses in 10 states with the Genetics Clinical Nurse or GCN credential. She began working with GNCC before she completed her dissertation, and her work for that centered around developing a valid and reliable comprehensive multiple choice exam to assess knowledge of pertinent genetic content for nurses seeking the certification credential. Options for operationalizing this tool will are being considered. She is a long time ISONG member and has also served as a liaison between ISONG and GNCC attending the annual conference, board meetings, conference calls, and providing written reports of GNCC activities.

Dr. Suzanne Mahon has been a leader in cancer genetics education and practice for the past 20 years with over 90 journal articles. several books and book chapters related to cancer risk assessment, genomics education, genetics nursing, and hereditary cancer syndromes. Her contributions include development and dissemination of genetics/genomics case studies, continuing education modules, and other educational materials currently available through nursing education websites and Amazon. She has received several grants to provide genetic/genomic education to individuals, families, health care providers and the public. She was among the first advanced practice nurses to establish a cancer genetics program and provide cancer risk assessment, genetic counseling and testing and in 2001 was one of the first 13 advanced practice nurses to be credentialed through the Genetic Nursing Credentialing Commission. She holds dual appointments with the School of Medicine and School of Nursing and has primary responsibility for developing and teaching the genetics/genomics courses and curricula where she holds appointments. She has been teaching nurses, medical students and other health professionals for the past 20 years in addition to providing extensive mentorship through the cancer genetics program she developed and manages.

Dr. Jacquelyn Taylor has focused her nursing research on the identification of genomic and environmental factors that trigger the onset, severity, and development of hypertension among African Americans. She has identified genes in African Americans that are risk factors for development of hypertension in normotensive offspring in addition to genes that act as protective mechanisms against increases in blood pressure. Her current study, funded by the Robert Wood Johnson Foundation Nurse Faculty Scholars Program, examines the interaction between genome-wide association and social environmental factors related to blood pressure among African American hypertensive parents and early risks for high blood pressure among their untreated children. Her work in hypertension genetics has crossed national borders and has spread to her replicating the work in Africa and to others replicating her study in Asia. She also serves as an advocate for genetics nursing through her efforts to recruit minority nurses into genetics research. Her long-term goals include developing nursing interventions to prevent and reduce gene-environment risks associated with hypertension.

The Essential Genetic and Genomic Competencies for Nurses With Graduate Degrees

Submitted by Karen Greco, PhD, RN, APN-BC, FAAN,
Susan Tinley, PhD, RN, CGC, and Diane Seibert, PhD, CRNP, FAANP

The Essential Genetic and Genomic Competencies for Nurses With Graduate Degrees are now in final form and are in the process of being published on the American Nurses Association's NursingWorld website under the Ethics, Genetics & Genomics section at

http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Genetics-1

The primary purpose of these graduate level competencies is to establish essential genetic and genomic competencies for individuals prepared at the graduate level in nursing. The overarching goal is to improve the genetic/genomic competence of nurses in advanced clinical, educational, academic and research leadership roles. These competencies apply to all individuals functioning at the graduate level in nursing, including but not limited to advanced practice registered nurses (APRNs), clinical nurse leaders, nurse educators, nurse administrators, and nurse scientists.

These graduate level competencies build upon and are complimentary to the 2009 *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines and Outcome Indicators (2nd Ed)* and assume that nurses functioning at the graduate level have already acquired those competencies. In 2008, these essential genomic nursing competencies served as a foundation for facilitating the integration of genetics/genomics into the Association of Colleges of Nursing (AACN) "Essentials of Baccalaureate Education for Professional Nursing Practice." In early 2009 AACN was preparing for the revision of *The Essentials of Masters Education for Advanced Nursing Practice.* It became evident that graduate level genetic/genomic competencies that build on the essential genetic/genomic competencies were needed to facilitate integration of genetics/genomics into the revised masters essentials and to better inform the education and practice of nurses with graduate degrees.

In the spring of 2009 a Steering Committee comprised of Karen Greco, Sue Tinley, and Diane Seibert was formed to develop these graduate level competencies. Development of the initial draft competencies included review and analysis of the following:

- *published genetic/genomic competencies for similar graduate level health professionals*
- *published literature concerning what nurses prepared at the graduate level need to know about genetics/genomics*
- *genetic/genomic content on eleven APRN credentialing exam materials*
- *other key nursing documents*

An advisory board of nursing leaders and genetics experts was created to review and revise the draft document. Representatives from a diverse number of nursing and advanced practice nursing organizations were later added to create a Consensus Panel, consisting of 31 leaders and genetics experts representing diverse nursing communities and APRN organizations. The draft competencies document was posted on the American Nurses Association website for public comment in the Fall of 2010. The competencies were revised based on the feedback received and sent out to the Consensus Panel for validation using Survey Monkey. Ultimately, the consensus process resulted in 38 competencies organized under the following categories: Risk Assessment and Interpretation, Genetic Education, Counseling, Testing, and Results, Interpretation, Clinical Management, Ethical, Legal and Social (ELSI) Issues, Professional Role, Leadership and Research.

Although achieving consensus on these graduate level genetic/genomic competencies is an important milestone, endorsement, dissemination and implementation of these competencies are necessary next steps to help assure nurses with graduate degrees are prepared to deliver competent genomic care. The endorsement process is currently underway. Next steps include developing performance indicators and genomic educational resources for each competency to assist educators with teaching these competencies. This process will be modeled after the one used for the *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines and Outcome Indicators* (2009). Long term plans also include dissemination of the competency document, outcome indicators, and genomic resources through the Genetics/Genomics Competency Center (G2C2) website. If your organization or institution is interested in endorsing these competencies, please contact Karen Greco at karen.greco@nih.gov for more information.

ISONG Facilitates Incorporation of Genetics and Genomics into the 2011 *The Essentials of Masters Education in Nursing*

Submitted by Karen Greco, PhD, RN, APN-BC, FAAN

In 2009, the American Association of Colleges of Nursing (AACN) began the process of updating their 1996 *Essentials Masters Education in Advanced Practice Nursing*, which does not include genetics/genomics content. The Commission on Collegiate Nursing Education (CCNE), the accredition arm of AACN, requires that masters nursing programs seeking their accreditation implement the AACN masters essentials. As a result, the AACN masters essentials significantly impact curricula in US masters nursing programs. As of June 2008, 76% of baccalaureate degree programs and 86% of master's degree nursing programs in the US had selected CCNE as their accrediting agency (CCNE, 2008). Consequently, the integration of genetics and genomics into the AACN masters essentials is a critical step towards increasing genetics and genomics in US masters nursing programs.

In the Fall of 2009 and Winter of 2010 AACN held four regional meetings at different US locations to allow discussion and input into the revised masters essentials document. As President of ISONG during that time, I coordinated the effort to assure that ISONG presented written and verbal testimony with specific recommendations concerning the integration of genetics/genomics content into the revised masters essentials. These recommendations contained key elements based on the "The Essential Genetic and Genomic Competencies for Nurses With Graduate Degrees" draft document. This testimony was revised and re-submitted with each draft version of the revised masters essentials. ISONG was also officially represented at the regional meetings by Kathy Sparbel, Marie Twal, Agatha Gallo, and myself. ISONG's presence was noticed and our efforts were successful. The 2011 *Essentials of Masters Education in Nursing* contains seven references to genetics/genomics distributed across three of the nine essentials, Essentials I, VIII, and IX (AACN, 2011). For example, Essential VIII: Clinical Prevention and Population Health for Improving Health states "The master's-degree program prepares the graduate to: Synthesize broad ecological, global and social determinants of health; principles of genetics and genomics; and epidemiologic data to design and deliver evidence-based culturally relevant clinical prevention interventions and strategies." (AACN, 2011, p. 23).

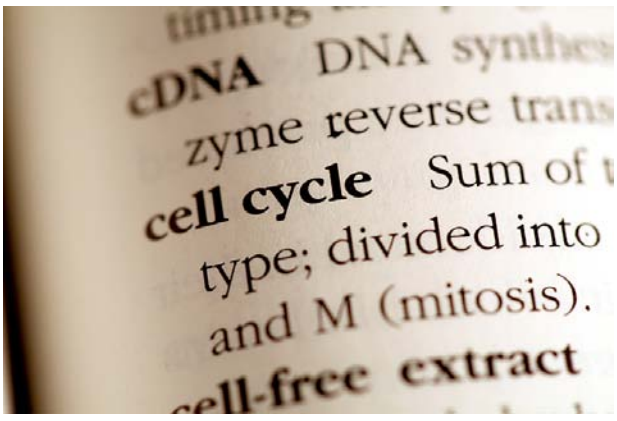
ISONG is currently planning a webinar to provide nursing faculty with the tools they need to incorporate the genetics/genomics content into masters programs in order to address these new accreditation requirements. Information will be provided on the ISONG website and through the listserve.

American Association of Colleges of Nursing. (1996). The essentials of masters education for advanced nursing practice. Retrieved from http://www.aacn.nche.edu/Education/pdf/MasEssentials96.pdf.

American Association of Colleges of Nursing. (2011). The essentials of masters education in nursing. Retrieved frombhttp://www.aacn.nche.edu/education-resources/MastersEssentials11.pdf

Commission on Collegiate Nursing Education (CCNE). 2009. Achieving Excellence in Accreditation: The First 10 Years of CCNE Retrieved from http://www.aacn.nche.edu/ccne-accreditation/CCNEHistory.pdf

Commission on Collegiate Nursing Education (CCNE). (2009). Standards of accreditation of baccalaureate and graduate degree programs. Retrieved from http://www.aacn.nche.edu/ccne-accreditation/standards09.pdf



Submitted by Jean Jenkins PhD, RN, FAAN

Highlights

JNS Series of Genetic/Genomic Articles for Nursing Educators

Congratulations to all the series authors for creating valuable resources for educators!

- *Genetics/Genomics Competencies and Nursing Regulation*
- *Strategies to Prepare Faculty to Integrate Genomics into Nursing Education Programs*
- *Integrating Genomics into Undergraduate Nursing Education*
- *Genomic Education Resources for Nursing Faculty*

(all articles in the series posted at http://www.genome.gov/27543639)

The Genetics/Genomics Competency Center (www.g-2-c-2.org), an article about the free Web-based repository of peer reviewed curricular materials on genetics and genomics was just published. Establishment of the Genetic/Genomic Competency Center for Education (also posted at http://www.genome.gov/27543639)

New England Journal of Medicine Series on Genomic Medicine Continues http://www.genome.gov/27541912 Latest articles include:

- *Genomics, Health Care, and Society*
- *Genomics and the Multifactorial Nature of Human Autoimmune Disease*
- *Genomics of Cardiovascular Disease*

Genetic and Genomic Research News

NHGRI broadens sequencing program focus on inherited diseases, medical applications (http://www.genome.gov/27546261) In addition to continuing on-going studies, a four-year, $416 million plan launches new efforts to find causes of rare inherited diseases and accelerate the use of genome sequence information in the medical care of patients. The largest share of the program will go to the large genome sequencing centers at the Broad Institute, Washington University, and Baylor College of Medicine. Additionally, NHGRI will partner with the National Heart, Lung and Blood Institute (NHLBI) to invest $48 million over the next four years to rapidly and systematically find the genetic underpinnings of Mendelian disorders funding the Center for Mendelian Genomics, University of Washington, Seattle, the Center for Mendelian Disorders, Yale University, New Haven, Conn., and Baylor-Johns Hopkins Center for Mendelian Genetics. To help speed up the application of genomic science to medical care, NHGRI will also invest $40 million over four years to support five Clinical Sequencing Exploratory Research Projects, in which new multi-disciplinary research teams will explore the ways in which healthcare professionals may use genome sequencing information in a medical care setting.

The Cancer Genome Atlas Research Network Symposium Meeting In November 2011, The Cancer Genome Atlas (TCGA) Research Network held its first open scientific symposium in Washington, D.C. TCGA researchers and outside investigators from around the world presented results on the use of TCGA data to make biological discoveries about cancer. The two-day meeting included lectures, collaborative workshops and poster sessions. The lectures are freely available at http://www.genome.gov/27546242

NIH Undiagnosed Diseases Program resumes new applications review

Each application to the NIH Undiagnosed Diseases Program (UDP) is given careful consideration by medical experts who are also NIH clinical researchers engaged in studying the disorders affecting participants in the program.

Starting Dec. 1, 2011, the UDP will reopen their application process. The process for consideration and the UDP information line are available at http://www.genome.gov/27544402 UDP researchers have published the program's first retrospective analysis in the Sept. 26, 2011 issue of Genetics in Medicine (http://www.genome.gov/27545778)

International genome consortium discovers new genes that control blood pressure

A study reports identification of 29 genetic variations across 28 regions of the human genome that influence blood pressure. The results appear in the Sept. 11, 2011 edition of Nature. Individually, the genetic variations increased the risk of hypertension (high blood pressure) by only a tiny amount. For people with multiple variants, however, the effects were more significant. More details at http://www.genome.gov/27545346

NIH Therapeutics for Rare and Neglected Diseases Program announces next round of drug development projects (http://www.genome.gov/27546023)

Researchers will begin drug development projects for rare and neglected diseases that include potential treatments for a musculoskeletal disorder, a cognitive dysfunction disorder, a virus that affects the central nervous system of newborns, a parasitic worm infection, a form of muscular dystrophy and a rare lung disease. The six new projects are part of the National Institutes of Health's Therapeutics for Rare and Neglected Diseases (TRND) program.

U.S. Tox21 to begin screening 10,000 chemicals. *NIH, EPA, and FDA collaborate to move science forward* (http://www.genome.gov/27546291)

A high-speed robotic screening system, aimed at protecting human health by improving how chemicals are tested in the United States, begins today to test 10,000 compounds for potential toxicity. The compounds cover a wide variety of classifications, and include consumer products, food additives, chemicals found in industrial processes, and human and veterinary drugs. A complete list of the compounds is publicly available at www.epa.gov/ncct/dsstox. The goal of the testing is to provide results that will be useful for evaluating if these chemicals have the potential to disrupt processes in the human body to an extent that leads to adverse health effects.

International Congress of Human Genetics (ICHG) 2011: 1000 Genomes Project Tutorial

A tutorial for how to use the 1000 Genomes Project data was held at the 2011 International Congress of Human Genetics (ICHG) annual convention, October 11-15, 2011 in Montreal. The Powerpoint slides for the tutorial describe 1000 Genomes Project data, how to access it and how to use it. Each of the speakers and their topics are listed below along with their topics and PowerPoint slides at http://www.genome.gov/27545968

Career Opportunities

http://www.genome.gov/Careers/

Postdoctoral Fellowships

Bioinformatics and Evolutionary Genomics (http://www.genome.gov/27545268) Candidates should have or be close to obtaining a Ph.D. or equivalent degree in bioinformatics, computational biology, computer science, molecular biology, or a closely related field.

The Social and Behavioral Research Branch (SBRB) in the National Human Genome Research Institute at the National Institutes of Health is seeking applicants for our postdoctoral training program to join an interdisciplinary team of faculty and research fellows. http://www.genome.gov/27527644

Cancer Genetics. Fully funded postdoctoral positions are available immediately in the Cancer Genetics Branch of the National Human Genome Research Institute to work on the recently discovered oncogene, PI3Kα, which is one of the most mutated oncogenes in human cancer. http://www.genome.gov/19517957

What are the Meanings of Confidentiality in Daily Practice?

Submitted by John Twomey

Privacy and confidentiality. Two terms that get thrown around quite a bit in any bioethical discussions. What do they mean and why are we so concerned about them? The second question tends to be more emphasized in the first. The accepted mean is that confidentiality is highly valued and should always be preserved, though in reality we know that is not always the case. The first question is a bit simpler but still meaningful (Kipnis, 2006). Simply put, privacy usually means the ability of individual make decisions about what they want known about themselves. Therefore, when a person becomes a Facebook member, they can limit what type of pictures and descriptions go up on their wall. If they wish to keep something private, they can choose not to put it on their Facebook page.

Confidentiality refers to an agreement between parties about how much protection will be given and individuals shared information. To refer back to our example from social media, the entity that maintains Facebook has a responsibility to make sure that once material has been posted, only those who have access to it through prior agreement, can see such material. Of course the parameters for access in Facebook tend to be much more wide then the parameters that we in healthcare generally are used to regarding the protected information of our patients and clients.

In essence, any discussion regarding the concepts of privacy and confidentiality in healthcare addresses the issue of protection. It is considered impossible for us to provide healthcare to people who do not share some of the most intimate details of their life. In fact, probably one of the salient developmental tasks that any individual in the society must complete is to learn how much information should be shared and in what context. Learning such boundaries are crucial and anyone who is privy to other individual's information be it financial, psychological, or simply demographic also must learn what the boundaries of protection are. So

Another poorly defined concept in any discussion of confidentiality is its overall value. When one examines the overall phenomenon of how individuals share information, it must be recognized that information sharing is the basis of human interaction. Again, the issue of boundaries is crucial, but it is apparent that different people have varying comfort levels about how much information about themselves to share. There are some people whom you meet in professional or social circles and within 10 minutes you have their whole life story. And there are anecdotes about family members who live together lifetimes and only learn details about their intimate partners from third parties who knew the partner or family member in their youth. In most relationships, levels of information sharing probably lies someone within the middle. Though I may complain to my barber about my boss, I certainly am much more reticent about sharing my financial information with him beyond the fact that I have enough in my pocket to pay for his services.

The confounding aspect of confidentiality the challenges us is the widely diverse worth of one's private information. Frankly, when one hears that information is being shared about you that you consider private the greatest harm that most people incur is the feeling of embarrassment. Not that embarrassment is a trivial emotion – we're seeing the power of having one's persona open to ridicule the great masses of people through our social media only compounds the effects of things such as bullying beyond the small group. But most of us tolerate being embarrassed without any permanent damage. Many of us in nursing put up with malicious embarrassment in our past, such as when our skills were belittled in front of patients. As our professional skills grew and our egos strengthened, we shook off the pain of such experiences and moved on. That is the normal reaction.

Most proscriptions against sharing patient information are based on worst-case scenarios regarding the harm that can occur to our patients if certain pieces of data fall into the wrong hands. Many civil cases have been settled against healthcare institutions for large settlements when an employee, usually

inadvertently, allows private information to be exposed to unknown third parties. Such cases usually occur because someone has taken computerized data out of authorized spaces and failed to protect it. Even if no harm occurred because of this action, as a warning punishments are usually meted out.

Unfortunately, because of this emphasis on protecting confidentiality we never really get into a dialogue about how formal and informal information sharing about patient information can not only not be a harm actually can provide a benefit. As we attempt to develop better healthcare record-keeping systems, the undiscussed reality is that we are asking patients to provide us with more and more trust in sharing their information with those entities that may help us to coordinate care and therefore provide better outcomes to their families. Even with the best security measures, there are going to be data leaks from time to time that occur with no malice and result in little or no damage to the patients whose information shared inadvertently. I will leave it up to the experts in health care informatics to advise us on the best systems on data management that will promote patient care and be optimally secure. What I am most interested in is discussing how best to think about what are the necessary protections for genetic information.

Let us set aside for the moment the discussion of discrimination based on a genomic health condition. Specifically, I'm referring here to refusals of health or life insurance or even possibly employment discrimination based on genetic data. As we all know there are varying amount of laws not being considered that are addressing these issues. What I like to consider is the ethical issues regarding sharing genetic information when overt discrimination is not the overriding concern.

Let us consider two situations. The first would be when genetic information is being collected as a secondary part of the healthcare encounter. This frequently occurs now in research scenarios where families are seeking information about an ongoing condition or a healthy volunteer joins a research protocol and in either scenario there is a solicitation by an investigator to collect genetic information, deidentify it, and store it for some presently unspecified possible genetic analyses. The second scenario is one in which many of our ISONG members are familiar with-a genetic diagnosis is made within a family in the proband member would prefer to keep the information private, despite the implications for the health of other family members.

Any analysis of the ethics of the situations has to consider where the moral value of privacy derives. Many commentators will center the issue of confidentiality for healthcare professionals under the need to respect the individual and that person's autonomous decision to protect their privacy. Another perspective is under the nurse's duty to protect their patient. This latter perspective makes the autonomy of the patient more tangential and places the nurse in the middle of the decision-making process.

A key concern regarding the autonomy of clients making decisions about genetic information is both their lack of full understanding of the meaningfulness of such information at times and the inability of healthcare professionals to provide to clients clear cut explanations about the significance of genetic information. In the first scenario, how can true informed consent be obtained about biological samples that happen to provide random DNA samples? Can confidentiality be an issue when one cannot even find out which sample longs to its donor? While it is true that there does not seem to be any real risk of direct harm to a research subject who provides a DNA sample, the confidentiality issue can arise later on if they are identified as being a member of a research cohort which shared common health issues which are later found to be linked with specific genes. For example, if parents allow their children to donate genetic material as part of a psychiatric medication monitoring trial in later it is found that there is a predictive genetic marker for the illness but that some variations of the illness cannot be treated, will children who are identified as being part of that diagnostic group face discrimination in school, both in educational placements as well as discipline. In this instance, parents might want to protect their child's privacy by refusing to allow them to be linked in general with a possible genetic cohort that might have a pejorative future.

The second case is probably the most troubling for nurses working in genomic health. There is a large amounts of discussion about the rights and duties of both clients and healthcare professionals to share pertinent information within families. The gamut of harms that can result are predictable. Incidental findings can be embarrassing but they can also be devastating, such as findings of non-paternity. No one from the circumspect perspective would say that sharing such information against a client's wishes was allowable, but what if withholding such information at the request of the client

allowed other family members to await possible information that is not coming about their family's genetic background.

I would like to put forward a curious argument for you, my informed brethren, to consider regarding confidentiality and the duty to protect information. If a client or group of family members request services that result in enough genomic family information being shared with you that your assessment reveals that there is a high likelihood of shared genetic links regarding health issues within the family at large, then there is an argument that there is a duty of the family members to share the generalized information. To create such an ethical model, one needs to look beyond autonomy and protection as primary values into create a model of communal ethics in which the mutual interests of people who are not even involved in the direct encounter are addressed. Part of the transaction would be early in the encounter, that the healthcare professional would discuss openly with the family members in the room the possible outcomes of further investigating the family history and how this information will be shared(McConkie-Rosell & Spiridigliozzi, 2004). If there is a reticence in those individuals to commit to sharing information, then perhaps we need to put limits on continuing the investigation, particularly if it means we wind up discussing people and their health when they are not in the room to represent themselves. Go back to the beginning of this paper what we discussed that one of the harms of others talking about us is embarrassment. Isn't the harm worse when our information is used without our knowledge for the benefit of another and we have no claim to any benefit from sharing that information?

In this essay, I have attempted to show that our rules regarding protecting privacy confidentiality often fail to address the specifics of the interactions that involve the information in simply hold up confidentiality as an end in itself. It is clear that at times that the sharing of one's information without one's knowledge can prove harmful but if you are a third party in such a situation, there may be ways to maximize the benefit that comes out of minimizing privacy and promoting mutual interests(Robertson, 2006).

References

Kipnis, K. (2006). A defense of unqualified medical confidentiality. American Journal of Bioethics, 6(2), 7-18. Retrieved from https://phstwlp1.partners.org:2443/login?url=http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med4&AN=16500838

McConkie-Rosell, A., & Spiridigliozzi, G. A. (2004). "Family matters": A conceptual framework for genetic testing in children. Journal of Genetic Counseling Discusses both Principled and Family Theories of Genetic Ethics, 13(1), 9-29.

Robertson, C. (2006). The consequences of qualified confidentiality. American Journal of Bioethics, 6(2), 31-32. Retrieved from https://phstwlp1.partners.org:2443/login?url=http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med4&AN=16500846