International Society of Nurses in Genetics

newsletter

Caring for People´s Genetic and Genomic Health

January-March 2010

Contents

President´s Message

Karen Greco
ISONG President

Greetings to our ISONG membership!

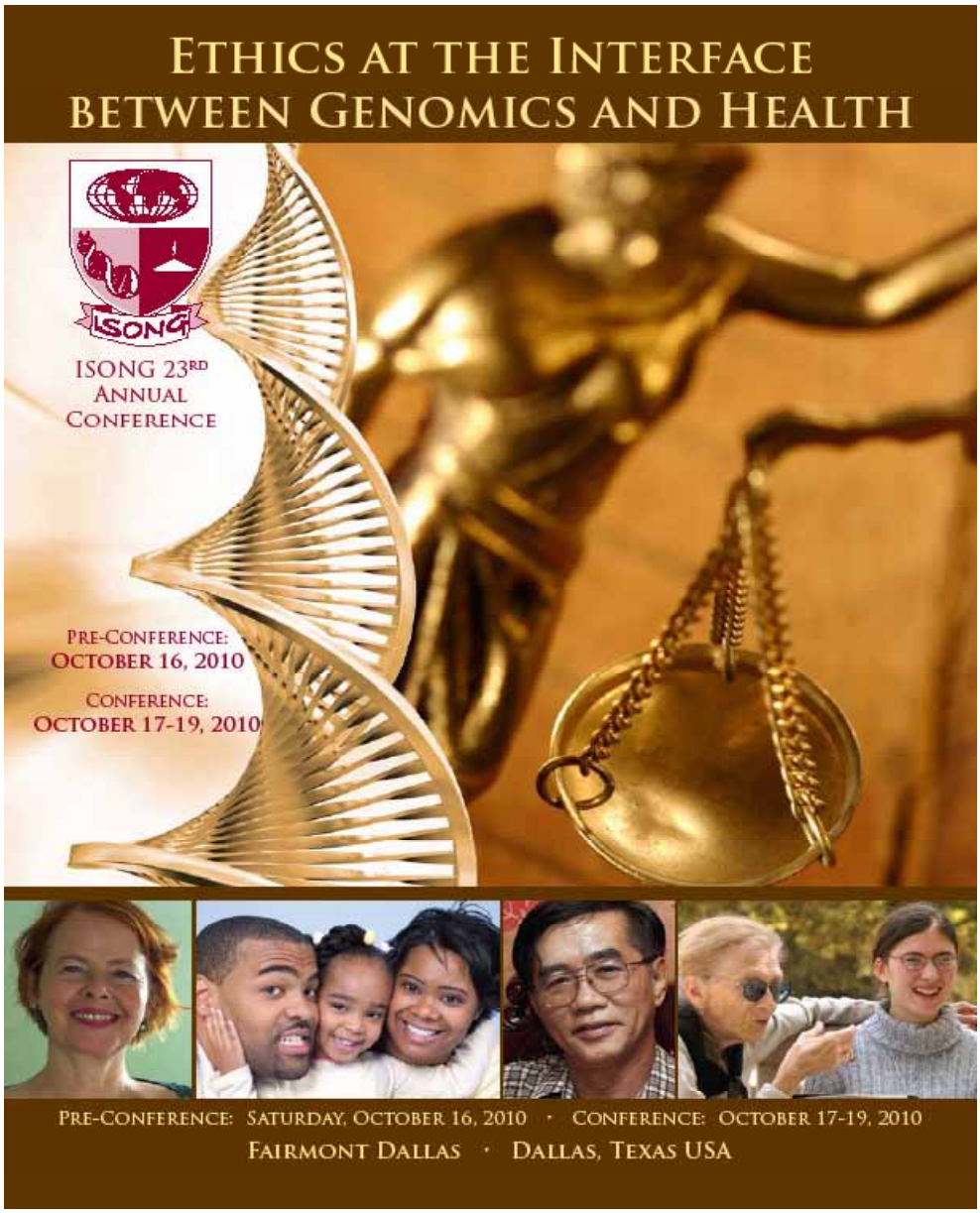
The ISONG conference in San Diego seems like yesterday and yet our conference committee already has a call for abstracts for the upcoming ISONG conference in Dallas. The abstract deadline is April 15th so now is the time to submit if you haven't already. It is not too soon to start making plans for the ISONG Dallas pre-conference on October 16th, 2010 followed by the conference October 17th to the 19th. Our conference committee has an exciting program planned and we have a lot of local support so plan to join the fun. The National Society of Genetic Counselors will have their conference October 14-17, 2010 at the Hyatt Regency Dallas which will be convenient for those interested in attending both conferences.

Be sure and check out the updated ISONG website. Our dynamic website team, Lynnette Howington and Julie Eggert, are busy evaluating and updating the ISONG website. They have updated the information, creating new links so information is easier to find, and fixed non working links. There is now a link on the home page for Board of Directors with ISONG's current officers and a description of each position. Plans are in progress for a future website re-design and new look so stay tuned and keep checking the website for the latest changes. Lynnette and Julie are looking for ISONG members to help them give the ISONG website a new look and expand the information available, please contact Lynnette Howington (l.l.howington@tcu.edu) and Julia A. Eggert (JAEGGER@clemson.edu)

President´s Message

ISONG elections are just around the corner. This is an opportunity for you to run for office or nominate someone you think would be wonderful addition to our leadership team. We welcome new members and new ideas so consider running for office. It is a great opportunity to help shape ISONG's future and be part of great international network of genetics nurse leaders. Check out the newsletter article about upcoming leadership opportunities. Contact ISONG's nomination committee co-chairs, Carolyn Farrell at carolyn.farrell@roswellpark.org or Emma Tonkin at etonkin@glam.ac.uk if you would like more information.

23rd Annual ISONG Conference



Members Accomplishments

American Psychosocial Oncology Society Fellow

Submitted by
Deborah J. MacDonald, PhD, APNG

Deborah J. MacDonald, PhD, APNG, Assistant Professor, Division of Clinical Cancer Genetics, City of Hope Comprehensive Cancer Center attended the American Psychosocial Oncology Society (APOS) meeting in mid-February in New Orleans, Louisiana were she was recognized as a 2010 APOS Fellow. Ten oncology professionals were awarded the fellowship. At this meeting she presented a poster describing the perceived experience of genetic cancer risk assessment for underserved Latinas and their post-counseling needs. The APOS meeting is an opportunity for anyone interested in psychosocial oncology to learn about current research and clinical care in this important area of cancer prevention and control and to network with others in the field.

Recent Publications:

MacDonald DJ. "Establishing a Cancer Genetics Service," Chapter 7, pp.73-79, *Kuerer's Breast Surgical Oncology*. McGraw-Hill, NY, 2010.

MacDonald DJ, Sarna L, Weitzel JN, Ferrell B. Women's perceptions of the personal and family impact of genetic cancer risk assessment: Focus group findings. *Journal of Genetic Counseling*. 2009 (on-line; in print 2010).

43rd Annual Western Institute of Nursing Communicating Nursing Research – Selected Studies

Submitted by
Diane Von Ah; Cindy M. Anderson;
Jacquelyn Taylor and Joachim G Voss

The following studies from ISONG members were selected for presentation at 43rd Annual Western Institute of Nursing Communicating Nursing Research that will be held at Glendale, Arizona, April 14-17:

- Voss J, Taylor J, Anderson C, Von Ah D. Symposium Titled, "Nursing Genetics: Translating Science From Population to Patient"
- Von Ah D, Skaar T, Unverzagt F, & Carpenter JS. "Candidate Gene Approach to Enhance Breast Cancer Symptom Management."
- Anderson CM & Uthus E. "Epigenetic Patterns in Placental Programming of Preeclampsia"
- Taylor JY, Sun Y, Hunt S, & Kardia SL. "Gene-Environment Interaction for Hypertension Among African American Women Across the Lifespan"
- Voss JG, Goo YA, Morse C, Kovacs J, Adams L, & Goodlett DR. "Identifying Mitochondrial Proteins in Plasma of Fatigue Hiv-Patients and Controls"

News and Announcements

DNA Day

Submitted by
Virginia Minichiello, MS, RN, C

It is only a short time to April 23rd when the National Human Genome Research Institute (NHGRI) is celebrating DNA Day with its annual Chatroom. NHGRI is looking for teachers and students from schools across the U.S. to sign up for the Chatroom. If you have not had a chance to share this information with your local teachers that you know, please do so. I hope to hear from you that you are planning to do something in your area to acknowledge DNA DAY. Any small piece (article for local paper, talk to a youth group, sharing the web info www.genome.gov) helps to promote the focus on NHGRI and ISONG.

2010 NIH Summer Institute on Transdisciplinary Research: Integrating Genetic and Social Work Research

Submitted by
Agatha Gallo

Deadline to submit applications: MAY 5, 2010

The Office of Behavioral and Social Sciences Research in collaboration with participating NIH Institutes and Centers will sponsor an intensive, week long summer research institute on the applications of genetic research techniques and methods relevant to social work problems. The summer institute is intended for junior faculty in schools of social work or related disciplines who want to improve their research skills regarding studies of genetics and gene and environment interactions as they relat to the social determinants of health. The summer institute will be held on Sunday August 8 through Friday August 13, 2010 at the Bethesda NorthMarriott Hotel & Conference Center in Bethesda, Maryland. The intense program will cover several topic areas including reviews of genetic studies related to both physical and mental health; an overview of genetic epidemiology (focusing on behavior genetic studies); basic genetic technologies; study designs; developing and assessing clinical, social and behavioral-phenotypes; assessment of different social environments; and data analytic strategies using genetic information. The session on study design will focus on the interplay between genes and environment. Since social work researchers who become involved in genetic research are likely to collaborate with scientists in several other disciplines, a portion of the workshop will be devoted to strategies for building transdisciplinary research teams. Prospective participants will be required to submit a brief description of a research proposal in their area of interest for consideration. For detail information on eligibility and the application process, please visit the 2010 Summer Institute website: http://conferences.thehillgroup.com/obssr/SI2010/index.html The Institute will be led by an experienced team of researchers under the leadership of the institute co-chairs: Victor M. Hesselbrock, Ph.D., M.S.W. (Professor and Interim Chair Department of Psychiatry Physicians Health Services; Professor of Addiction Studies and Director, Alcohol Research Center University of Connecticut) and Michie N. Hesselbrock, Ph.D., M.S.W (Professor Department of Psychiatry University of Connecticut School of Medicine).

NHGRI Launches Online Genomics Center For Educators of Nurses, Physician Assistants

Submitted by
Jean Jenkins, R.N., Ph.D

An online tool to help educators teach the next generation of nurses and physician assistants about genetics and genomics was launched today by the National Human Genome Research Institute (NHGRI), part of the National Institutes of Health. The tool is part of NHGRI's effort to address the growing need among health care professionals for knowledge in this area, which is paving the way for more individualized approaches to detect, treat and prevent many diseases.

The Genetics/Genomics Competency Center (G2C2), developed by the University of Virginia in Charlottesville through a contract with NHGRI, is a free, Web-based collection of materials on genetics and genomics designed for educators who train nurses and physician assistants. To access this resource, visit http://www.g-2-c-2.org.

"As we enter the era of personalized medicine, establishing genetic and genomic literacy is an urgent concern for those who educate health professionals. This online resource will provide a valuable new tool for meeting that challenge," said Jean Jenkins, R.N., Ph.D., NHGRI senior clinical advisor to the director. "In the future, we hope to expand this tool to include other health care professions, such as pharmacists and physicians."

Dr. Jenkins announced the new resource at the 2010 American Association of Colleges of Nursing (AACN) Master's Education Conference in New Orleans.

Nursing and physician assistant educators can use the Genetics/Genomics Competency Center to find and download materials for use in their classrooms. They also can share their favorite genomic and genetic teaching resources and materials with other educators by uploading material, which is regularly reviewed by the center's editorial board to ensure quality control.

The Genetics/Genomics Competency Center was created under the guidance of an advisory group made up of representatives from a wide range of research and professional organizations. In addition to AACN, participating organizations included the American Academy of Physician Assistants, National Cancer Institute, National Coalition for Health Professional Education in Genetics, National League for Nursing, National Society of Genetic Counselors, Physician Assistant Education Association and Sigma Theta Tau International, the honor society of nursing.

"We're very excited that physician assistants were included in this pioneering effort. Our profession has been at the vanguard of realizing the importance of genetics and genomics in the future of medicine, and encouraging efforts to incorporate more of these key concepts into education and training," said physician assistant Michael Rackover, M.S., an advisory group member who directs the physician assistant program at Philadelphia University.

To encourage sharing and reduce duplication across health care disciplines, the Genetics/Genomics Competency Center helps to match existing educational resources with educational competencies for health

professionals. The online center accomplishes this through sophisticated, cross-mapping of learning activities and assessments, outcome indicators and professional competencies, such as Genomics Nursing: Competencies, Curricula Guidelines and Outcome Indicators, http://www.genome.gov/Pages/Careers/HealthProfessionalEducation/geneticscompetency.pdf, and similar guidelines for physician assistant education, http://www.paeaonline.org/index.php?ht=d/ContentDetails/i/60083.

Additional Information

NHGRI's Genomic Healthcare Branch will host a webinar this spring to provide educators with a tutorial on using the tool and answer questions about the resource.

NHGRI supports the development of resources and technology that will accelerate genome research and its application to human health. For more about NHGRI, visit www.genome.gov.

The National Institutes of Health — "The Nation's Medical Research Agency" — includes 27 institutes and centers, and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments and cures for both common and rare diseases. For more, visit www.nih.gov.

Call For Abstracts - 23rd ISONG Conference, 2010

Submitted by
Heather Skirton and Rebekah Hamilton
Chairs of the Abstract Committee

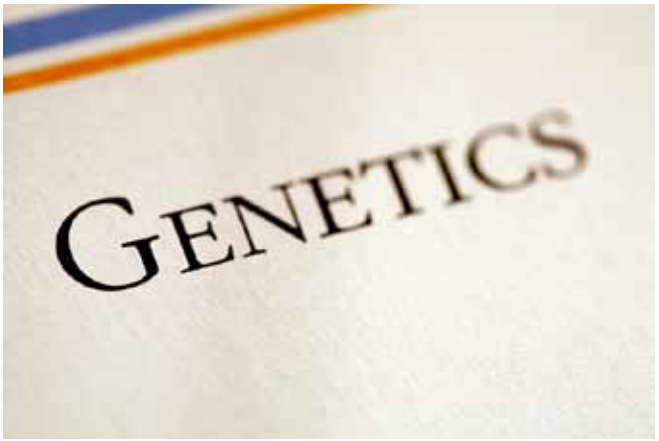
We'd like to remind everyone that we are seeking abstracts for presentations or posters for the ISONG Conference in Dallas in October.

If you have interesting work in clinical practice, education or research, please consider sharing it with genetic nurses from across the globe.

This opportunity to share good practice and new insights into care and education is an important aspect of the conference.

To submit an abstract, simply go to http://www.isong.org/ and click on the abstract submission link on the ISONG homepage. Rebekah and I will be pleased to assist anyone who has any questions or difficulties when submitting.

The call for abstracts will close on 16 April, so don't leave it to the last minute!



Position Statement Revised

Submitted by
Ellen Giarelli

One responsibility of the Ethics and Public Policy Committee (EPPC) of ISONG is to systematically review and update related Position Statements. The Committee has revised the following Position Statement : Genetic Counseling for Vulnerable Populations: The Role of Nursing. It has been approved by the Board of Directors and is posted on the ISONG website (http://www.isong.org/about/position.cfm). The committee is presently reviewing 'Position Statement: Access to Genomic Healthcare: The role of the nurse and Position Statement' and 'Position Statement: Privacy and confidentiality of genetic information: The role of the Nurse.' Visit the ISONG Website over the next few months to access the approved revisions. If you would like to be involved in the work of the EPPC contact Ellen Giarelli (Giarelli@nursing.upenn.edu)or Marie Twal (metwal@iup.edu).

ISONG 2011 - Montreal, Quebec Canada

Submitted by
Beth A. Kassalen, MBA
Executive Director
International Society of Nurses in Genetics

As our members requested, ISONG will meet up again with ASHG/ICHG in 2011. The ISONGConference will immediately precede the International Congress of Human Genetics (ICHG) which is hosted by the American Society of Human Genetics (ASHG) and organized on behalf of the International Federation of Human Genetic Societies. It is expected that many ISONGmembers may take the opportunity to attend both meetings, or at least also attend part of the ICHG meeting in 2011.

ISONG conference dates are October 8-11, 2011, with the pre-conferences being held on Saturday, October 8. The full ISONG conference will continuing, October 9-11 with its regular 2.5 day educational program. ICHG begins at Noon on October 11 to allow for optimal timing and possible consolidation of accommodation expenses for ISONG attendees.

ISONG's host hotel will be the Hilton Montreal Bonaventure Hotel, a rooftop hotel rising high above the downtown area. The hotel is directly atop a subway station and directly across the street from a Canadian Rail station. The ICHG will be held at the Montreal Convention Center. Those interested in staying on to attend ICHG should investigate, on their own, the Montreal area and decide whether to continue on at the Hilton or move to a different hotel for ICHG. Please note that ISONG has only blocked rooms for its own

conference over the dates of October 6-11, as allowed. Should an ISONG member wish to continue on at the Hilton, it is suggested that they book as far in advance as possible and communicate with the Hilton reservations staff that they wish to extend their stay further than the ISONG Conference dates. ISONG has no control over the rooms at the Hilton outside of the rooms reserved forISONG over our conference dates. Check the ICHG website for more accommodation information during the ICHG conference dates.

ISONG is currently seeking two co-chairs to oversee and orchestrate the 2011 Conference in Montreal. If anyone is interested, please contact Kathy Sparbel, currently ISONG President-Elect, at KSparbel@uic.edu

GNCC Report

Submitted by
Jeanine Seguin Santelli, PhD, ANP-BC/GNP-BC
GNCC Executive Director

Credentialing Class of 2005, its time to start putting the pieces together for your renewal! Renewals are due September 1, 2010. The guidelines can be found on our website www.geneticnurse.org (.) Just click on either the APNG or GCN button to access the file.

ISONG Website

If you have website ideas, changes or additions that you would like to see please send us an e-mail.

We are planning on sending a survey regarding changes/additions to the website in the near future. And while we are renovating the site, if anyone notices any "bad" links to please notify us.

Lynnette Howington (l.l.howington@tcu.edu)

and Julia A. Eggert (JAEGGER@clemson.edu)

ISONG Needs You

Submitted by
Carolyn Farrell and Emma Tonkin

It's that time of year again when ISONG is looking to its membership to fill posts on the Board of Directors. As Karen has said in the President's address, this is a great opportunity to bring fresh ideas and views to the organisation and help to shape ISONG's future.

We are currently looking for candidates to three posts: President Elect, Treasurer and Member-at-Large (summary descriptions of each are below). Please consider running for office or nominating a colleague.

Involvement on the Board lasts for two years for the Treasure and Member-at-Large, and three in total for the Presidency (one year in each of the following positions: President Elect, President and Immediate past-President). Meetings during the year take place by conference call so geographical location is not a restriction.

For further information, or to propose yourself or another ISONG member please contact ISONG's nomination committee co-chairs, Carolyn Farrell at carolyn.farrell@roswellpark.org or Emma Tonkin at etonkin@glam.ac.uk . For those of you who completed the online survey in December your contact information was not captured so we need you to get in touch.

We will be sending out a reminder via the Listserve, but why wait? Please take a moment to consider all the great things that you could bring to ISONG and get in touch.Voting will take place online in the summer.

2010 vacancies:

• The President-elect period provides a period in which you become familiar with the duties of the President. The post automatically succeeds to the presidency at the conclusion of the President's term of office. The President-elect performs the duties of the President in the absence of the President or in the case of inability to act and performs duties as assigned by the Board of Directors. Once in post as President you would be the principal executive officer of the Society and shall, in general, supervise and control all of the administrative matters and business affairs of the organization. For the year immediately following your Presidency you will provide assistance to the President and Board of Directors in order to support, facilitate and effect administrative business and other affairs of the Society. The Immediate Past-President is chair of the Bylaws committee and the Awards committee.

• The Treasurer is responsible for all funds and securities of the Society, including all authorized monies due and payable to the Society from any source. The post-holder accounts for and records all financial transactions; prepares the annual report and performs additional duties as may be assigned by the Board of Directors.

• The Members-at-Large provide to the Board of Directors a perspective of the general membership and perform such duties as may be assigned by the Board of Directors.

News from the National Human Genome Research Institute (NHGRI)

Submitted by
Dale Halsey Lea, MPH, RN, CGC, FAAN

Advances in Genomics to Biology

Newly Identified Genes Influence Insulin and Glucose Regulation

An international research consortium has found13 new genetic variants that influence blood glucose regulation, insulin resistance and the function of insulin-secreting beta cells in populations of European descent. Five of the newly discovered variants increase the risk of developing type 2 diabetes, the most common form of diabetes in the United States and worldwide. The results of two studies, conducted by the Meta-Analyses of Glucose and Insulin Related Traits Consortium (MAGIC), provide important clues about the role of beta cells in the development of type 2 diabetes. The studies were funded in part by the National Institutes of Health http://www.genome.gov/27537482.

Nature Genetics 42, 105 - 116 (2010) http://www.nature.com/ng/journal/v42/n2/full/ng.520.html

Nature Genetics 42, 142 - 148 (2010) http://www.nature.com/ng/journal/v42/n2/full/ng.521.html

The Cancer Genome Atlas Identifies Distinct Subtypes of Deadly Brain Cancer That May Lead to New Treatment Strategies

The most common form of malignant brain cancer in adults, glioblastoma multiforme (GBM), is not a single disease but appears to be four distinct molecular subtypes, according to a study by The Cancer Genome Atlas (TCGA) Research Network. The researchers of this study also found that response to aggressive chemotherapy and radiation differed by subtype. The study, published Jan. 19, 2010 in *Cancer Cell*, provides a solid framework for investigation of targeted therapies that may improve the near uniformly fatal prognosis of this cancer. The research team for TCGA is a collaborative effort funded by the National Cancer Institute (NCI) and the National Human Genome Research Institute (NHGRI), both parts of the National Institutes of Health http://www.genome.gov/27537489.

Cancer Cell, Volume 17, Issue 1, 98-110, 19 January 2010

A common variant of the latrophilin 3 gene, LPHN3, confers susceptibility to ADHD and predicts effectiveness of stimulant medication

The Journal of Molecular Psychiatry recently published an article about the discovery of a novel gene that contributes to Attention-Deficit/Hyperactivity Disorder (ADHD), which has a high heritability of 0.8. The linkage study discovered that a common variant of the

latrophilin 3 gene (LPHN3) confers susceptibility to ADHD and can predict the effectiveness of stimulant medication. This study provides new insights into the genetics, neurobiology, and treatment of ADHD http://www.nature.com/mp/journal/vaop/ncurrent/full/mp20106a.html

Researchers Discover the First Gene for Stuttering

A study in the February 10 Online First issue of the New England Journal of Medicine reports that stuttering may be caused by a problem in the day-to-day process by which cellular components in key regions of the brain are broken down and recycled. The study, led by researchers at the National Institute on Deafness and Other Communication Disorders (NIDCD), part of the National Institutes of Health, has identified three genes as a cause of stuttering in volunteers in Pakistan, the United States, and England. Mutations in two of the genes have already been implicated in other rare metabolic disorders also involved in cell recycling, while mutations in a third, closely related, gene have now been shown to be associated for the first time with a disorder in humans http://www.genome.gov/27537901.

New England Journal of Medicine, 362 (8):677-685 (2010)

http://content.nejm.org/cgi/content/full/362/8/677

Genetic Variant Greatly Increases Lung Cancer Risk for Light, Non-Smokers

Researchers and collaborators at the National Institutes of Health, conducting a major, genetic epidemiology research study of lung cancer, have identified a genetic variant that greatly increases the risk of this disease for individuals who inherit it, even if they have never smoked or are light smokers. The finding suggests that any level of tobacco exposure increases susceptibility for lung cancer in this group, underscoring the dangers from any type of cigarette smoke exposure. The study was published by *Cancer Research* on March 15th, 2010. http://www.genome.gov/27538326

Advances in Genomics to Health

NHGRI Uses Recovery Act Funds to Accelerate Genome Research to Improve Human Health

The National Human Genome Research Institute (NHGRI) has awarded more than $113 million provided by the American Recovery and Reinvestment Act. The new awards will stimulate ground-breaking research

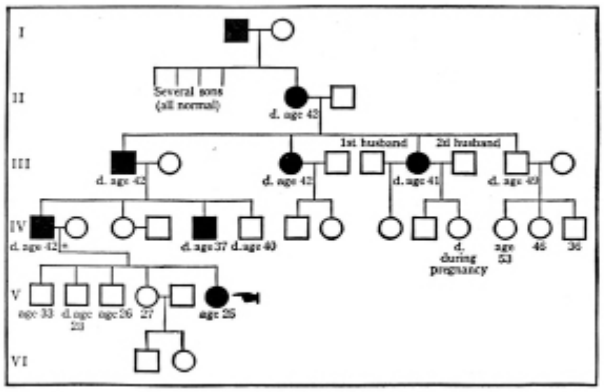
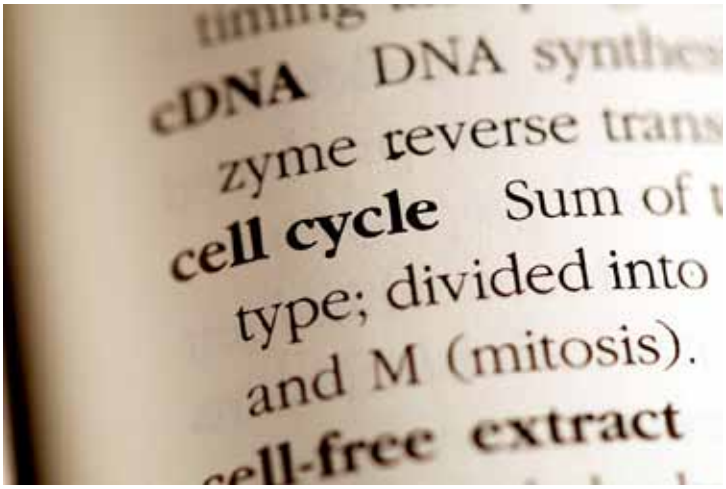


FIG. 498. *Inheritance of Huntington's Chorea*

ranging from studies aimed at understanding the human genome to those intended to lead to improvements in the prevention, diagnosis and treatment of human diseases. http://www.genome.gov/27534233

Surgeon General with Microsoft HealthVault Expands Consumer Benefits for the My Family Health Portrait Offering

The U.S. Surgeon General recently announced a collaboration with Microsoft HealthVault that will provide new features and expand access to *My Family Health Portrait*, a free Internet-based resource. This resource will help consumers to easily record their family health history and integrate the information stored in their *My Family Health Portrait* profile into a personal HealthVault account. It will also allow users to share that information with a variety of health care providers and services that connect to HealthVault, helping them to make more informed decisions around their current and future healthcare needs. In the coming months, My Family Health Portrait will expand its offering to other third-party health solutions. http://www.hhs.gov/news/press/2010pres/02/20100224a.html



Events/Resources

The National Human Genome Research Institute (NHGRI) has launched a new, redesigned Web site at http://www.genome.gov/.

The newly redesigned web site provides specific sections and information of relevance to the general public, healthcare professionals, students and teachers. It also provides updated information about the institute's research programs, which includes research funded by NHGRI at academic institutions, and research conducted by NHGRI scientists on the campus of the National Institutes of Health (NIH). In addition, genome.gov offers a wide range of information about grants and other funding opportunities; educational resources and programs; careers and training; genetics and genomics in health care; ethical, social and legal issues; and many other subjects.

Opportunities

Investigator Recruitment in Genetic Disease Research

Application Period: December 15, 2009 until filled

The Genetic Disease Research Branch (GDRB) of the National Human Genome Research Institute provides unparalleled opportunities for investigators to develop

News from the National Human Genome Research Institute (NHGRI)

world-class research programs in genetics and genomics. The branch is pleased to announce that it is seeking to recruit a new tenure-track investigator to pursue innovative, independent research as part of this group of highly interactive and supportive investigators. (more) http://www.genome.gov/27533282

Investigator Recruitment in Social and Behavioral Research

The Social and Behavioral Research Branch (SBRB) of the National Human Genome Research Institute (NHGRI) is seeking to recruit one or two outstanding tenure-track or tenured investigators to pursue innovative, independent research in support of SBRB's goal to become one of the nation's premier research programs at the intersection of social and behavioral science and genomics.

Application Period: November 23, 2009 Until Filled. http://www.genome.gov/27533283

Current Postdoctoral Positions

Postdoctoral Fellowship: Social and Behavioral Research in Genomics

The Social and Behavioral Research Branch (SBRB) in the National Human Genome Research Institute at the National Institutes of Health is seeking applicants for their postdoctoral training program to join an interdisciplinary team of faculty and research fellows. SBRB is one of the nation's premier research programs in social and behavioral science and genomics. Researchers in the SBRB investigate a broad array of research questions related to public health, health communication, health behavior change, clinical genetic counseling, health disparities, and community-based research http://www.genome.gov/27527644.

For more information about Career and Training opportunities at the National Human Genome Research Branch, go to http://www.genome.gov/10000005

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 accomplishments
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

Learning Hereditary Cancer Risk Assessment in Three Part Harmony: The City of Hope Intensive Genetics Course

Submitted by
Patricia Kelly, MS, RN, CNS, AOCN®

When I first saw the City of Hope "Intensive Course in Clinical Cancer Genetics" on the website, I was intrigued. I noted that City of Hope, located in Duarte, California, was an NCI designated cancer center (one of only a handful in the nation) and knew of their excellent reputation in clinical cancer genetics education and research. The web page described a three part/phase course involving a year long multi-modal, interprofessional NCI grant-funded approach to cancer genetics education. Ideal candidates were described as individuals who had at least two years of experience in oncology or genetics with a target audience of physicians, physician assistants, genetic counselors, oncology advanced practice nurses (APNs), and Master's or PhD genetics nurses. The course description:

> "*This course combines multidisciplinary didactics, interactive case conferencing, molecular genetics, wet-lab and training in the use of informatics resources. The program is flexible to accommodate the needs of participants with varied training background and practice setting." The course goal is to improve knowledge, efficacy and range of management options concerning the identification and management of individuals at high-risk for hereditary cancer syndromes."*

I thought the objectives were on target for my personal learning needs, and I was attracted to the interprofessional educational component. I was familiar with the 2003 Institute of Medicine (IOM) report, *Health Professions Education: A Bridge to Quality* (IOM Committee on the Health Professions Education Summit, 2003). The IOM report emphasized working together as an interprofessional team as one of the five core competencies for healthcare providers. I had heard reports of how interprofessional education facilitated team building and improved patient outcomes, but I had never participated in a true interprofessional based education program. Most programs would target one professional group and "include" other professionals, almost as an afterthought. The City of Hope program seemed to be the real McCoy concerning interprofessional education and training, and the course directors and faculty reflected this commitment: Jeffrey Weitzel, MD, course director, Kathleen Blazer, CGC, course co-director, and Deborah MacDonald, PhD, RN, MS, APNG, course faculty. There did appear to be "harmony" and equality within the City of Hope team.

The application was due in a just a few weeks, and I was concerned I might not be able to complete the course requirements and continue my Doctorate of Nursing Practice courses at the same time. Concentrating on the "flexibility" verbiage in the course description, I took a leap of faith and e-mailed my completed application. In November, City of Hope notified me that my application was accepted. I would be part of the

Learning Hereditary Cancer Risk Assesment

January 2009 course.

I was thrilled and a little nervous. With the web-based orientation, I connected with the other 26 course participants including 8 genetic counselors, 10 physicians, and 9 advanced practice nurses. Course participants who came from all over the United States and world included a medical oncologist from Spain, a PhD genetics nurse from Brazil, and a genetic counselor from Nova Scotia.

The mailman delivered the Phase I notebook which included eight CD-ROM distance learning modules and written course notes. I wasn't sure I could lift the notebook (it actually weighed nine pounds) let alone work my way through it, but I found the content to be manageable. I spent about three to four hours per week on the lecture, writing my postings, and participating in the web-based discussion. The City of Hope staff welcomed questions, and the weekly web-based audio conferences were fun. It was a challenge to connect both nationally and internationally via the web-conferencing technology, but it was worth it.

Phase II was a five-day interactive cancer genetics workshop on campus at City of Hope, and yes we had another full notebook of materials. Interactive is the operative word as the course faculty used principles of adult education and focused on a case-based approach to learning about hereditary cancer syndromes. Working in teams on case studies, each professional contributed from his/her bank of knowledge and experience. We often worked through a catered lunch as there was a full agenda each day. In addition to case reviews, course faculty shared valuable and practical information about establishing a hereditary cancer clinic, billing and reimbursement, and incorporating research protocols into a hereditary cancer program. The course faculty put in an amazing amount of time coordinating course activities, and the course evaluation component included pre and post tests, case studies and questionnaires. To make sure participants were not neglecting their physical health, Dr. Weitzel extended an open invitation to join him for a 6 AM spin class (and some did).

I am currently in Phase III of "continuous learning" via Web Board and Web conferences. Once a week (Wednesdays), participants and/or faculty present interesting and challenging hereditary cancer cases via web-conferencing with opportunities for discussion and consultation. For the Friday web-based conferences, course participants present scholarly articles or topics of interest concerning hereditary cancers and risk assessment. As a 2009 participant, I am expected to present one case presentation and one topic of interest via the web-based format. Although the City of Hope course is described as a year long event, participants can benefit from the web-based and web-board consultations and continuing education on an on-going basis.

Eight months into the year program I am grateful I was selected, and I have a new appreciation for the "intensive" component of the course description. I will use the course information and skills in oncology nursing education and clinical practice. Even though it was

Learning Hereditary Cancer Risk Assesment

additional work, the Intensive Course helped me with my DNP program requirements, and I would definitely recommend this model of interprofessional education.

In summary, I encourage advanced practice oncology nurses to check out the City of Hope web site, http://www.infosci.coh.org/ccgp/ic/course09.aspx ,

and look for the Fall 2010 application. In the 2009 class, a portion of the participants received grant-funded scholarships covering tuition and some expenses. With the rapid advances in cancer and genetics, nurses need to stay current with familial and hereditary cancers. The ONS position statement on the oncology nurse in cancer genetic counseling reflects the important role that APNs can play *if* APNs have specialized education in cancer genetics and hereditary cancer predisposition syndromes (ONS, 2009). Nurses must keep pace with the genetics race. A starting point is to advance your education with the three-part, interprofessional City of Hope Intensive Course in Clinical Cancer Genetics.

**For more information about the City of Hope Intensive Course in Clinical Cancer Genetics go to: http://www.infosci.coh.org/ccgp/ic/course09.aspx

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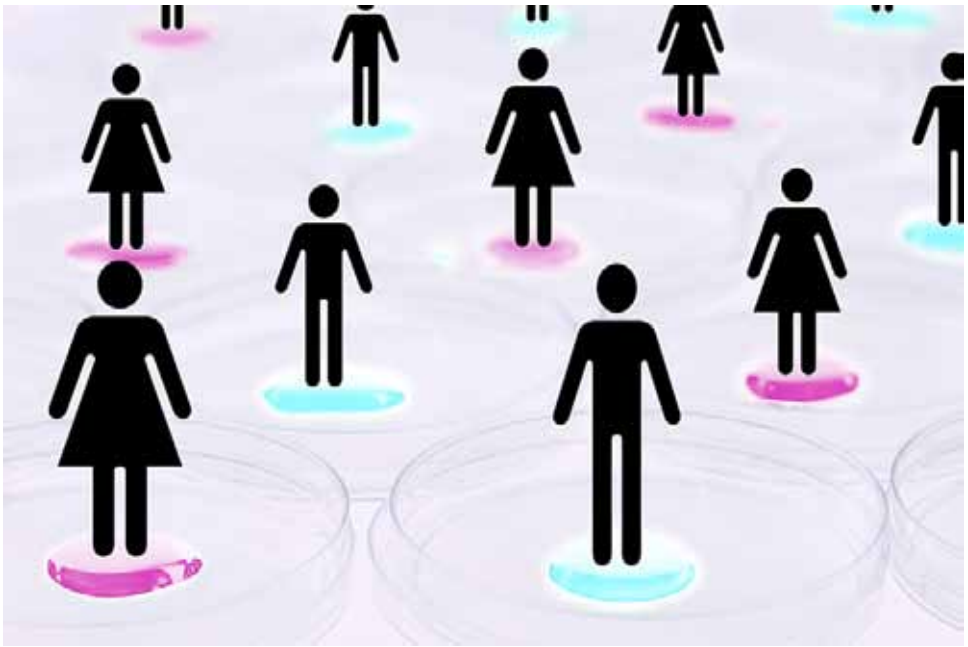
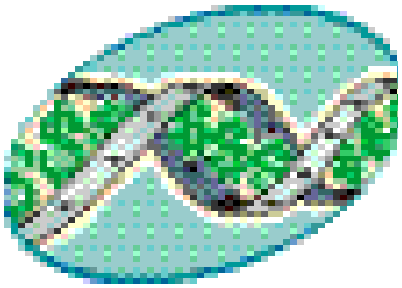


GENOME-WIDE ASSOCIATION STUDIES

Submitted by
Erika Santos, PhD, RN

Sequencing of the human genome provided the initial foundation for GWAS (Genome-wide association studies). GWAS use high-throughput genotyping technologies to assay hundreds of thousands of single-nucleotide polymorphisms (SNPs) and relate them to clinical conditions and traits.

Although GWA provide valuable insights into genomic function, there are many issues that should be considered before clinical application.



A GWAS has 4 aspects: selection of a large sample of cases and adequate control group; DNA isolation, genotyping and data review; statistical tests for association between the SNPs and the disease or trait; and replication of identified associations in independent population sample or experiments to evaluate functional implications.

Most of GWAS published were planned to identify associations between SNPs and common diseases. However the technique has several applications: to identify genetic variants related to quantitative traits; to rank the importance of previously identified susceptibility genes; to demonstrate gene-gene interactions, or modifications of the association of one genetic variant by another; to detect high-risk haplotypes or combinations of multiple SNPs within a single gene; to identify SNPs associated with gene expression.

There are three approaches to GWAS: case-control, cohort and trio design. The most frequently design has been the case-control, in which allele frequencies in disease cases are compared to those in control group (disease-free). Case-control designs have the advantages of short time frame, the possibility of a large number of cases and control participants and the optimal epidemiologic design for studying rare diseases. This type of design, however, has the disadvantage of overestimate the relative risk for common disease. The sample size required to detect modest associations (e.g, odds ratios (1.5) is thousands of subjects. Initially, the need for large samples and the cost of genotyping have motivated the development of multi-stage GWAS. In multistage designs genome wide scans are conducted in a smaller group of cases and controls, and then the replication is performed in larger groups. With cost of genotyping reduction, studies of multistage are less essential.

Cohort studies, although more expensive and complex than case-control studies often include participants who are more representative than the clinical series of case-control studies. For this reason, strategies for genotyping are being added to cohort studies like the Framingham Heart Study.

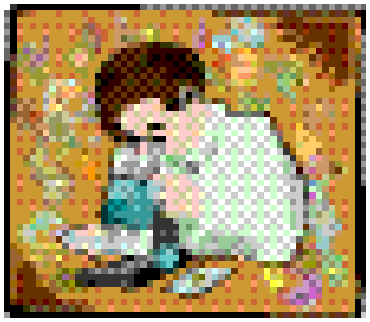
The trio design includes an affected individual and his or her parents. Genotyping is performed in three individuals, and the frequency in which each allele is transmitted is calculated. This type of design has the advantages of controlling for population structure, and is

logistically easier for childhood diseases.

The results of the GWAS are available in the "Catalog of Published Genome-Wide Association Studies" from the National Human Genome Research Institute in which at least 100,000 SNPs were evaluated. In June 2009 350 studies were included with more than 1,600 SNPs associated with more than 200 phenotypes.

The effect size is modest in studies with median odds ratio of 1.28. In about 70% of the studies, SNPs are in genes or gene regions whose loci have not been previously associated with any disease.

Wite (2010) in his article published in Annual Review of Public Health has identified three projects: the Wellcome Trust Case Control Consortion (WTCCC), the decoder / Polish studies, and the Cancer Genetic Markers of Susceptibility (CGEMS).



The WTCCC was conducted in the United Kingdom and includes groups of 2,000 cases of the following conditions: bipolar disorder, hypertension, rheumatoid arthritis, Crohn's disease, coronary artery disease, and diabetes type 1 and type 2. The control group was composed of 3,000 individuals. The platform used was Affymetrix GeneChip 500K array. This initiative has identified a new association between the *FTO* gene and type 2 diabetes and a locus on chromosome 9 associated with coronary artery disease.

The deCODE GWAS was carried out in Iceland and included more than 40,000 individuals. They have found associations with various phenotypes (cancer, heart disease, obesity, glaucoma, among others).

The GCMS is a multi-stage GWAS of breast cancer and prostate cancer. In relation to prostate cancer, several loci were located on chromosome 8q24 and one risk SNP in the gene MSMB.

The results of GWAS may help understand the biological basis of the disease, providing explanations about the mechanisms of the terget disease. Although most of SNPs provide moderate risk for developing the disease (with low penetrance), it is possible to consider the development of genetic tests from a panel of SNPs.

But the GWAS have limitations. The first limitation involved determining the causal factors associated with a GWAS, which limit the implementation of preventive measures. The results of GWAS account for a small fraction of the heritability of the disease. Furthermore, the results of GWAS cannot yet distinguish between individuals with low risk and high risk for developing a specific disease, which limits its application in clinical settings.

It is believed that the next generation of GWAS will overcome these limitations and improve our understanding of the disease process, risk and response to therapy. The results of GWAS may also have an impact on public health and on individual decisions.

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