

International Society of Nurses in Genetics

**ISONG**



**International Society of Nurses in Genetics, Inc.  
461 Cochran Road, Box 246, Pittsburgh, PA 15228 USA  
+1 412-344-1414 Fax: +1 412-344-0599**

**INTERNATIONAL SOCIETY OF NURSES IN GENETICS (ISONG)**

**ANNUAL REPORT**

**Report Period: February 1, 2011-January 31, 2012**

**Prepared for the**

**National Advisory Council for Human Genome Research**

**National Human Genome Research Institute**

**Submitted by:**

**Ellen Giarelli, EdD, RN, CRNP, ISONG President**

**January 18, 2012**

**ISONG is a nursing specialty organization dedicated to fostering the scientific and professional growth of nurses in human genetics and genomics worldwide. ISONG is a leading authority on genetic/genomic nursing and education.**

The mission of ISONG is to foster the scientific, professional, and personal development of members in the management of genomic information.

The goals of ISONG are to: (1) provide a forum for education and support for nurses providing genomics-based health-care; (2) promote the integration of the nursing process into the delivery of genomics-based healthcare services; (3) encourage the incorporation of the principles of human genetics into all levels of nursing education; (4) promote the development of standards of practice for nurses in human genetics; (5) advance nursing research in human genetics; and (6) provide a forum for dialogue, communication, and networking with others.

Organizational priorities for 2011 were to: build ISONG presence as the premier international genetic nursing organization; strengthen ISONG infrastructure to facilitate organizational mission and continuity; promote genetic nursing roles in practice, education, and research; and promote nursing in global genetic/genomic strategic and policy planning.

## **MEMBERSHIP**

### **Global Membership**

The society consists of approximately 320 genetics nurses from 9 countries, Membership includes non-nurse affiliates have included physicians, bench scientists, and genetic counselors. Since November 2011, ISONG has been actively recruiting new members using a variety of incentives designed to appeal to nurses, students, non-nurses affiliates, and corporations/organizations. The Society is exploring ways to engage the public as members of the society. ISONG has created several documents that highlight the benefits of joining including the following Fact sheets and brochures: *What is a Genetics Nurse*, *Why join ISONG*, and *Contributing to ISONG*. The Global Membership Committee is actively recruiting members from international nursing organizations and from nursing schools in the US. The goal is to increase membership by 25% in 2012. [Pei-Ying Chuang, Milena Floria-Santos, Yolanda Powell-Young, Ida Spruill]

## **BOARD OF DIRECTORS**

The Board of Directors meets monthly by teleconference along with the co-chairs of committees and task forces. Committees prepare quarterly reports and elections are held annually. [Martha Driessnack, Debra Schutte]

The members of the executive board are:

President - Ellen Giarelli - <a href="mailto:eg446@drexel.edu">eg446@drexel.edu</a>
President -Elect - Kathleen Hickey - <a href="mailto:kth6@columbia.edu">kth6@columbia.edu</a>
President - Ex - Kathy Sparbel - <a href="mailto:ksparbel@uic.edu">ksparbel@uic.edu</a>
Secretary - Patricia Newcomb - <a href="mailto:pnewcomb@uta.edu">pnewcomb@uta.edu</a>
Treasurer - <a href="mailto:metwal@auxmail.iup.edu">metwal@auxmail.iup.edu</a>
Member at Large - Mary Quinn Griffin - <a href="mailto:mary.quinngriffin@case.edu">mary.quinngriffin@case.edu</a>
Member at Large - Sarah Sheets Cook - <a href="mailto:ssc3@columbia.edu">ssc3@columbia.edu</a>

Kassalen Management Company is employed to manage our database, membership renewals conference planning and legal and accounting responsibilities. [Beth Kassalen, Pam Vogel, Linda Mason, Debra Zapparoni]

## COMMUNICATIONS

### **ISONG Website** <http://www.isong.org>

The ISONG website is updated continually with information on educational programs and resources for nurses and other health care professionals. [Julia Eggert, Lynn Howinton]  
ISONG has a Facebook Page- <http://www.facebook.com/pages/International-Society-of-Nurses-in-Genetics/200618556695861>; a Twitter address, [https://twitter.com/#!/ISONG\\_news](https://twitter.com/#!/ISONG_news); and an email to post news and updates, [isong.news@gmail.com](mailto:isong.news@gmail.com)<<mailto:isong.news@gmail.com>>

### **Newsletter**

The Society distributes a quarterly Newsletter to the membership with vital information on educational programs, position statements and policies, upcoming activities and networking opportunities.[Erica Santos]

## COLLABORATIVE ACTIVITIES

### ***Nursing Community***

ISONG is a member of the *Nursing Community*, a forum of professional nursing organizations. The Nursing Community represents the interests of the registered nurses who practice in all roles and settings. The members also include Advanced Practice Registered Nurses (APRNs) such as nurse practitioners (NPs), clinical nurse specialists (CNSs), certified nurse-midwives (CNMs), and certified registered nurse anesthetists (CRNAs). Given our interest in promoting the role of all nurses in American's health, we call on HHS and its many agencies to use provider-neutral language to acknowledge the significant contributions of the wide array of professionals who meet the health needs of our nation. The organization represents over 850,000 Registered Nurses (RNs) and Advanced Practice Registered Nurses (APRNs), the 47 undersigned organizations. Among its advocacy activities, the collaboration has been appealing to legislators for *at least level funding* for the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.) [Ellen Giarelli]

### ***Genetics Alliance***

ISONG is an active member of the Genetic Alliance. At least one ISONG representative attends the annual meeting.

***Lynch Syndrome Screening Network (LSSN).*** ISONG has a member actively participating in LSSN. The purpose of the LSSN is to enable ongoing cooperative efforts to collect key data in order to promote research and surveillance activities among institutions currently performing routine screening; and, to share existing protocols/educational materials and create new resources to facilitate other institutions initiating universal Lynch syndrome screening protocols. [Karen Greco]

### ***ISONG and the Japanese Society of Genetic Nursing***

***Genetics and Genomics Nursing: Scope and Standards of Practice*** has been translated into Japanese and published in Japan. This is a collaborative effort between ISONG, The American Nurses Association and The Japanese Society of Genetic Nursing. ISONG planned to attend the 10<sup>th</sup> Annual Conference of the Japanese Society of Genetic Nursing in September 2011 but cancelled due to the earthquake damage. [Kathleen Sparbel]

### ***Essential Genetics and Genomics Competencies for Nurses***

The Steering committee Co-Chairs of the American Nurses Association/ISONG collaborated on the publication of an important document that describes the basic expectations for nursing advanced practice in genetics. The publication called “Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees” has been formal endorsed by both organizations who will co-publish the Essentials with ANA (*with 50% copyright and no monetary cost*). The publication has been in the works for over 2 years and is represents a consensus of memberships.

The document identifies essential genetic and genomic competencies for all nurses with graduate nurses, including advanced practice registered nurses, regardless of role or practice setting. These competencies build on the *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines and Outcome Indicators* (2009) currently posted at <http://www.genome.gov/Pages/Careers/HealthProfessionalEducation/geneticscompetency.pdf>. An Advisory Board and Consensus Panel with broad representation of nursing leaders from key nursing organizations was created to develop, refine, and validate the competencies. In September 2010 the draft competencies were posted for public comment on the American Nurses Association website. [Alice Kerber, Nancy Ledbetter, Karen Greco, Mary Quinn Griffin, Gia Mudd, Ken Wysocki]

#### ***European Society of Human Genetics (EBMG)***

Representative from ISONG met with member of the EBMG working group met in November 2011 during the 12<sup>th</sup> 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. Members of ISONG and GNCC provided 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. [Sandra Daack-Hirsch]

#### ***Genetic Nurses Credentialing Center (GNCC)***

ISONG continues to network with the GNCC to assure that the highest standards are applied to the review of applications and credentialing of Genetic Nurses. [Karen Greco]

### **ONGOING PROFESSIONAL INITIATIVES**

#### **ISONG Participation in the at the Advisory Council of the NHGRI**

Dr. Sharon J Olsen, PhD, RN, AOCN, Assistant Professor, Emerita, Johns Hopkins University School of Nursing has been the ISONG liaison to the National Advisory Council For Human Genome Research at NHGRI since 2001. She has retired from this important position. Ellen Giarelli, Current president of ISONG will be taking her place.

#### **Genetics Nursing Practice**

The Practice Committee has strong leadership and members are monitoring a Breast Cancer Risk Assessment Certification under development proposed by the NCBC for its quality and value (see above). [Alice Kerber, Nancy Ledbetter]

#### **Genetics Nursing Education**

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 [American

Association of Colleges of Nursing. (2011). The essentials of masters education in nursing. Retrieved from <http://www.aacn.nche.edu/education-resources/MastersEssentials11.pdf>. The Education Committee of 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 listserv. [Cathy Read, Sheila Alexander, Kathy Sparbel]

### ***24th Annual ISONG Conference***

“*Genomic Health Worldwide: Nurses Leading the Way*, 24<sup>th</sup> Annual ISONG Conference to be held in Montreal, CA, October 9-11, 2011. The ISONG Conference theme, “Genomic Health Worldwide: Nurses Leading the Way” was planned to provide information on the burgeoning role of nurses in genetics and genomics. This conference was a forum for interdisciplinary collaboration among the global community of nursing and health care providers focused on both genetic/genomic science and clinical practice. Genetic nurses and counselors from around the world attended. The attendees in Montreal were leaders in the field of genetics/genomics and involved in spearheading innovative efforts to incorporate genomics into nursing education, practice, research, and healthcare policy change. These nurses and genetic counselors work in a variety of areas ranging from educational to practice settings. Some are employed within government agencies, while others work in private industry. Most have access to patients, many are administrators and all are committed to fully integrating genomics into healthcare. In addition, ISONG held two preconferences on October 8, 2011. Building Genetic Competency in Clinical Applications and Translational Research: The Clinical Application of Genetics into Nursing Curriculum and Bench to Bedside. [Marlena Kern]

A conference is planned for September/October 2012 with a genetics research theme (see below).

### **Genetics Nursing Research**

The 25<sup>th</sup> Annual Conference of ISONG to be held in Fall 2012 will be titled: *Integrating Genetics with Scholarship: Charting the Course for Transdisciplinary Research and Practice*.

The 25<sup>th</sup> annual conference will take place October 26-27<sup>th</sup> in Philadelphia, PA. This two-day networking conference will be offered to provide a forum for discourse and exploration on integrating genetics/genomics into one’s scholarship. Both days will take a pragmatic approach. During the first day sessions will focus on approaches to the seamless integration of genetics into all levels of nursing education and approaches to evaluating the clinical/practice outcomes. During the second day, sessions will focus on approaches to integrating genetics into one’s research agenda from conceptualization through dissemination. Presentations will address the topics of interdisciplinary, multidisciplinary, and transdisciplinary research and practice including (a) conceptualizing genetics/genomics scholarship; (b) forming collaborations; (c) identifying methodologies; and (d) the “seamless” integration of genetics into ones’ research proposal and clinical practice. Nurse researchers will have the opportunity to participate in discussion groups to strategizing on developing fundable research proposals. [Marlena Kern, Gia Mudd, Lynnette Howington, Ellen Giarelli, Kathy Sparbel, Marie Twal, Ken Wysocki]

### ***Nursing Research Grant Program***

Two ISONG Nursing Research Grants were awarded at the 24<sup>th</sup> ISONG conference in October 2011. One grant award of 1500.00 was sponsored by ISONG, while a second grant was sponsored by the University of Pittsburgh School of Nursing. [Gia Mudd, Ken Wysocki]

### **Ethics and Public Policy**

ISONG will hold a public forum at the 25<sup>th</sup> Annual conference in Philadelphia. The Ethics and Public Policy Committee is presently preparing two Position Statements on the issues of Biobanking and

Newborn Screening. Position statements are posted on the Website and available for review by the public and professionals. [Marie Twal, Ellen Rew]

**ISONG Position Statements**

- Direct to Consumer Marketing of Genetic Tests (September 2009)
- Genetic Counseling for Vulnerable Populations: The Role of Nursing (January 2010)
- Access to Genomic Healthcare: Role of the Nurse (April 2010)
- Privacy and Confidentiality of Genetic Information (April 2010)