



2007 ISONG ORGANIZATIONAL OVERVIEW



2007 ISONG
Organizational Overview

CONTRIBUTORS

Ann Cashion

Ann Dylis

Beth Kassalen

Cecelia Roscigno

Dale Halsey Lea

Heather Skirton

Ida Spruill

Janet Williams

Lorraine Frazier

Karen Greco

Marcia Van Riper

Martha Driessnack

Rebekah Hamilton

Sandy Daack-Hirsch

Sharon McGraw

Sivia Barnoy

Susan Tinley

EDITOR

Erika M M Santos

PROOFREADER

Beth Kassalen

1	MESSAGE FROM OUTGOING PRESIDENT
3	MESSAGE FROM INCOMING PRESIDENT
5	RESTATING OUR MISSION
6	COMMITTEE INFO
7	AWARDS COMMITTEE
10	BY-LAWS COMMITTEE
11	CONFERENCE COMMITTEE
13	EDUCATIONAL COMMITTEE
15	ETHICAL ISSUES AND PUBLIC POLICY COMMITTEE
16	GLOBAL MEMBERSHIP COMMITTEE
17	NEWSLETTER
19	NOMINATING COMMITTEE
19	PROFESSIONAL PRACTICE COMMITTEE
20	RESEARCH COMMITTEE
21	FINANCIAL STATEMENTS/PARTNERSHIPS/BOARD OF DIRECTORS
22	TREASURER 'S REPORT
22	PARTNERSHIPS
23	BOARD OF DIRECTORS

ORGANIZATIONAL UPDATE — PRESIDENT'S REPORT

The ISONG Organizational Overview was prepared by the ISONG Board of Directors and Committee Chairs to inform the ISONG membership of our organizational activities, our key accomplishments, our upcoming initiatives, and our financial status for the year. ISONG's annual membership meeting is typically held in the fall in conjunction with our Annual Conference. However, this year our Annual Conference was held in May; therefore, the Board decided to provide ISONG's organizational information to its membership in the form of a printed organizational report in place of the traditional oral reports given at the annual membership meeting. Several Board members have already commented that possibly ISONG should continue using the written report format in the future as those members who can not attend the Annual Conference can still be informed regarding ISONG's overall activities and financial status. The new board will be considering this option. In addition, any questions/concerns that the membership may have regarding our activities or financial status will be responded to by the Board and Executive Director. The process will be for members to submit questions to me at acashion@utm.edu. The Board will then respond to the questions in a timely manner.

As outgoing President, it is my responsibility to provide an overview of our key goals and accomplishments for the year. ISONG has focused on four objectives over the last year. The objectives have been to:

- 1) Leverage our ability to impact patients' health by collaboration with other organizations,

specifically the Genetic Alliance & National Society of Genetic Counselors;

- 2) Increase global membership participation by developing ISONG's website in foreign languages and identifying key ISONG members in various countries to define and address global genetic/genomic issues;

- 3) Engage our membership in leadership development and mentoring activities and also encourage student participation; and

- 4) Define and articulate nursing's role in the emerging genomic health care system, particularly where it applies to common disorders of adulthood.

We have made significant progress on our objectives as demonstrated by collaborative efforts with both the Genetic Alliance and the National Society of Genetic Counselors, and ongoing testimony before the Secretary Advisory Committee on Genetics, Health and Society (a key policy advisory committee within the US). Dr. Heather Skirton was instrumental in building on key relationships with genetic organizations in countries outside the US including the Association of Genetics Nurses and Counsellors (UK) and the European Society of Human Genetics (Sub-committee for education of genetic nurses and counsellors). We have also begun the process of identifying key individuals in countries outside the US who will actively participate to bring an increasingly global perspective to our position statements and white papers. We have engaged a genetic nurse from Brazil, Erika Santos, as our Newsletter Editor and she will also oversee content on the website. Our first annual conference outside

the US was a success with productive dialogue among genetic nurses and counselors from over 15 countries. Because ISONG members are recognized as experts in incorporating genetic/genomics content into nursing curriculum, we have been actively involved in the US effort to revise the Essentials of Baccalaureate Nursing Education. Our incoming President, Sue Tinley, has been leading this effort along with Dr. Van Riper, chair of the ISONG Education committee.

Overall, ISONG has been active this year and we should be proud of our organization and its members. While our membership may not be large (averaging

around 220), we are very outspoken and passionate about our vision “to be a global nursing specialty organization dedicated to fostering the scientific and professional growth of nurses in human genetics and genomics worldwide.”

I have learned a lot about leadership, nursing, and genetics during my years as President-elect and President. Thank you to all my board members and committee chairs who have been engaged throughout the year and responsive to our organizational needs.

Ann Cashion
President

TO ALL MEMBERS OF ISONG

Thank you for the opportunity to assume the role of President of ISONG for 2007-2008! It is with great pleasure that I anticipate a year in which I will be able to give back to an organization that has given so much to me over the years. From the days before the organization existed to the present, you the nurses of ISONG, have been a source of support, encouragement, education and example in my career as a genetics nurse.

In my 25 years in genetics, I can safely say the field has never been stagnant or boring. In fact, at times, it has been like riding with my nephew who is a race car driver in his spare time. Just as speeding down the road is a thrill for him; genetics has been a thrill for me. So much has happened and there does not seem to be any indication that the ride will slow down. It is a challenge to keep up, but a challenge that holds so much promise for the future. And what better way to take such a challenging ride than with a group of highly intelligent and truly dedicated nurses!

As we all know, advances in genetics/genomics are changing the practice of nursing not just for those of us who love the field but for all nurses. Some are resistant to the change, but that resistance often comes from fear. The fear may be from one's self-perceived inadequacy in understanding and applying genetics/genomics to one's practice or it may be about where the advances are going to take all of us. The bright and talented members of ISONG have already expended great time and effort to prepare nurses and nursing educators for this future that has the potential to hold tremendous promise for

all. These efforts have been many and varied such as vital networking with nursing leaders at local, national and international levels, development of curricula, written and oral presentations targeted to generalists and all types of specialty groups, teaching in schools of nursing and teaching nursing educators, conducting research at the bench or with the individuals and families we serve, etc.

Some of that effort has resulted in the identification of competencies for nurses at multiple levels from the new RN to the advanced practice nurse in genetics. Within the United States, that effort has influenced the draft revision of the Essential Competencies for the BSN as defined by the American Association of Colleges of Nursing (AACN). Although the AACN has expanded their inclusion of genetics/genomics in the revisions, it will not be sufficient to prepare new BSN graduates to meet the needs of their current let alone future patients. One of my goals for this year is for ISONG to leverage its resources to urge even greater inclusion of genetics among nursing competencies such as the AACN's. We have developed talking points and recommendations for presentation at the five regional AACN meetings for interested nurses and educators to provide input on the competencies. We have identified at least two members who will be attending most of these meetings and other, non-member but interested, nurses who are willing to support our message also. By the time this goes out to all of you, the second meeting will be just around the corner. For the sake of nurses who will be practicing well into the future, let us hope that AACN is receptive to the

message. It is my goal that ISONG will be responsive to the needs of members in other countries related to identifying genetic competencies for their nursing workforce.

My second goal for this year is to continue to focus and build on the international character of our organization. Great progress has been made by previous presidents and members to make our society of nurses in genetics truly international. Those of us in the United States are dependent on members of other countries to assume the lead for each of their countries. I will do all that I can as president to be supportive of those efforts and be responsive to that lead. Our annual meeting in Bristol this year brought in so many new members, with representation from over 20 countries. I encourage each new member to recruit at least one of your colleagues to join ISONG. I then challenge you and your colleague(s) to identify what ISONG can do for the nurses in your country and what you can bring to ISONG in terms of your knowledge and experiences. It is only with this essential assistance that ISONG can hope to be of service to you and other nurses in your country

My third goal is to update and expand the ISONG website to provide a resource of current and accurate genetic information that can be utilized by all nurses. This does not mean developing new information but pulling together the best resources appropriate for nurses in the form of links to other sites that are already available. There is a multitude of genetics web resources for various purposes with links to other sites. What I am suggesting is the development of a resource of links that will be especially suited for nurses so that they do not have to sort through the resources that are more suited for the scientist or the clinical specialist. These resources would be targeted to nurses and other professionals who are not geneticists. Each of the ISONG committees will be responsible for a section of the website related to the focus of the committee and the chairs and co-chairs are asked to organize that effort.

This goal ties in with the second in that it includes bringing a truly international focus to our web site. It will be essential for those of you in other countries to identify the resources that are appropriate and most useful for nurses in your countries. I encourage each of you to identify what is available in terms of web resources for genetic information in your country with which ISONG can link. It will require that all areas of the website be continually kept up to date, with a rotation of individuals being responsible to check the reliability of the links on an ongoing basis. If there are enough of us to take this on, it should not be too onerous for any one individual and we could provide an essential service for nursing education and practicing nurses around the world.

Since we do not have an annual meeting this fall, when traditionally committees have met and planned activities for the year, we need to approach committee recruitment and activity a little differently. A survey will be coming out on the listserv with a request that you sign up for the committee(s) with which you would like to be involved. Once the committee memberships are identified, the chairs will contact their respective membership via e-mail to plan the activities of the year.

It has been said many times before, but it is so true that an organization can only be as strong as its members. I know there is a wealth of strength within our organization, and I encourage each of you to continue your efforts on behalf of ISONG and consider expanding them if you can. As this year proceeds, I sincerely hope that you will call or send me an e-mail if you have any suggestions or concerns about the course of the organization.

I thank you again for this marvelous opportunity!

Susan Tinley

ISONG MISSION



VISION STATEMENT

ISONG, the International Society of Nurses in Genetics, is a global nursing specialty organization dedicated to fostering the scientific and professional growth of nurses in human genetics and genomics worldwide.

The ISONG vision is: Caring for people's genetic and genomic health.

MISSION STATEMENT

To foster the scientific, professional, and personal development of members in the management of genomic information.

The goals of ISONG are:

- 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.
- Encourage the incorporation of the principles of human genetics into all levels of nursing education.
- Promote the development of standards of practice for nurses in human genetics.
- Advance nursing research in human genetics.
- Provide a forum for dialogue with others.



'image: www.freeimages.co.uk'

COMMITTEE INFO

AWARDS COMMITTEE

The main focus of the work of the Awards Committee is to solicit and judge the nominations for the Founder's Awards. These were established in 1996. The purpose of these awards is to honor individual ISONG members who demonstrate excellence in research, education, and service. One of the highest forms of recognition one can receive is a tribute from one's peers and each year the members of ISONG have the opportunity to nominate those whom they believe have fulfilled the criteria for the education, research and service awards.

This year, the ISONG 2007 Founder's awards were made at the Bristol conference. The Awards committee then makes a decision about the final recipients. The decision was very difficult as we had a cadre of excellent nominees. My thanks to the members of the Awards Committee, Joie Davis, Christina Trout, Hiroko Ando, Carolyn Farrell.

It was a great pleasure to make the announcement of the awards and we present here the names of the recipients and the information we received from those who nominated them. Unfortunately, Cindy Prows was not able to get her flight due to the weather so was unable to receive it in person. The photo shows the other happy recipients, Agatha Gallo and Naoko Arimori.

*Heather Skirton,
Chair*

EDUCATION

Ms. Cynthia Prows, Children's Hospital Medical Center, Cincinnati

The nomination received for Ms. Prows was as follows:

Cynthia Prows has made significant contributions in strengthening nursing and healthcare workforce knowledge in genetics and genomics. She is a superb visionary scholar and innovator who sixteen years ago recognized the need for dissemination of nursing knowledge to enhance the translation of genetics and genomics into clinical practice. Through her program of research, she is one of the first in the United States (US) to document the status of genetics nursing education in academia, design genetic educational programs to train nursing faculty and measure the effectiveness of these initiatives. Her track record for successful research funding indicates respect and recognition of her program of research with expectations of continuing success for future research projects. Ms. Prows has been instrumental in applying creative methodologies to reach out to nursing faculty to develop a strong cadre of experts. She pursued a certificate in distance education so as to be prepared to offer cutting edge methodologies to reach as many nurses as possible, often free of charge. Specifically she developed and directed the Genetics Program for Nursing Faculty (GPNF). The GPNF produced seven Genetics Summer Institutes (GSIs) and eight Web-Based Genetics Institutes (WBGIs). The 18 week WBGi has been self sustaining since 2003 and is currently in its ninth session. She also created the



Dr. Naoko Arimori and Dr. Agatha Gallo, recipients of ISONG 2007 Founder's Award

Genetics Education Program for Nurses (GEPN) and directed the development and production of six self-paced, web-based genetics education modules. Her multimedia continuing education programs including online programs have prepared nursing leaders for change, resulted in curricula modifications, and informed practice standards and policy. GPNF and GEPN programs have provided genomics education and instructional resources to nearly 900 nursing faculty, nurse clinicians and nurse researchers from nearly 400 different nursing schools and health care organizations.

Ms. Prows made a significant landmark international contribution to nursing when in 1994 she lead the initiative that culminated in the 1998 publication of the International Society of Nurses in Genetics (ISONG) Scope & Standards of Genetics Clinical Nursing Practice. She co-authored the US document Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics which was then approved by Consensus Panel September 21-22, 2005 which establishes the minimum basis by which to prepare the nursing workforce to deliver competent genetic and genomic focused nursing care.

In summary, Cynthia Prows is a respected international leader in genetic/genomic nursing education and research. She has a sustained program of research and demonstrated accomplishments in the arena

of genetic/genomic practicing nursing and nursing faculty education. She consistently demonstrates the use of novel and innovative education strategies and has trained the first generation of US nursing faculty in genetics and genomics which has already resulted in curricula modifications.

RESEARCH

Dr. Agatha Gallo, Professor, Dept of Maternal Child Nursing, The University of Illinois.

The nomination received for Dr. Gallo was as follows:

Dr. Gallo has a sustained record of research that integrates areas of family and genetics. She is the PI on the ELSI funded R01, Parents' interpretation and use of genetic information (HG02036), a Co-Investigator on the NINR funded R01, "Assessing family management of childhood chronic illness" (NR008058, K. Knafl, PI). She was the PI on an R15 award (NR03062) to study "Well sibling adjustment to childhood chronic illness", as well as PI or Co-PI on four other funded family health research projects.

Dr. Gallo is a prolific scholar whose publications from her research appear in journals targeted at pediatric and family nursing audiences. She has

authored over 27 referred papers, 6 chapters, and 14 manuscripts in nonrefereed publications, including two letters on child health topics, to the editor of the Chicago Tribune. She has shared results of her research at professional meetings in the US, Canada, Jamaica focused on genetics, qualitative research, genetic nursing, and family health. This year, she will present results of her research at ISONG in Bristol, at the Family Nursing conference in Thailand, and at the Sigma Theta Tau, Int. meeting in Vienna.

Dr. Gallo is a generous mentor of new researchers. As the leader of a research team, she has mentored pediatric nursing colleagues, graduate students and a postdoctoral fellow. Dr. Gallo has a national reputation as a nursing scholar whose focus spans pediatrics, families, and genetics. She represents the National Association of Pediatric Nurse Practitioners Association on the National Coalition for Health Professional Education in Genetics. She was a consultant on the March of Dimes and Robert Wood Johnson Foundation production of the CDROM, *Genetics & Your Practice*, and she has been an invited grant reviewer at the NIH.

SERVICE

Dr. Naoko Arimori St. Luke's College of Nursing, Tokyo, Japan

The nomination received for Dr. Arimori was as follows:

Dr. Naoko Arimori has been a member of ISONG for many years and has regularly attended and contributed to the annual conference. She is a member of the Faculty at St Luke's College

of Nursing in Tokyo, where she is involved in both teaching and research. Dr. Arimori has been an active leader in the move to establish genetics nursing as a specialty in Japan and to raise the profile of genetic healthcare in that country and it is for this service that she is being nominated for the Founder's award.

With a strong background in both nursing and midwifery, it is not surprising that her teaching and research interest has focused on genetics and childbearing. The main area of her recent research has been decision-making processes in couples who have had a prenatal genetic diagnosis. However, she has also been involved in work to establish the genetic nursing skills for clinical practice and published work on genetic counseling from a nursing viewpoint and the potential for nurses to develop a role in genetics healthcare in Japan. As project leader of the Genetic Nursing in Japan Project on the Kango Net (website connecting the community and nursing), she is raising the profile of genetics nursing in Japan through publication of the relevant research and documents related to this topic. One project that has been publicized on the site is the use of the calendar created by the Down's Syndrome Association in Japan to enhance the view of those who are affected with a genetic condition in Japanese society.

Dr. Arimori's research work was recognized in Japan when she was awarded the Encouragement Award by the Japan Academy of Nursing Science in 2005. She has contributed to ISONG activities over many years and is on the Scientific program committee for the 2007 conference. In addition, she has encouraged other Japanese nurses to be involved in ISONG. I believe she is a worthy recipient of the Founder's Award.

BY-LAWS COMMITTEE

As ISONG develops and expands, the by-laws require revision to reflect the changes in our organization. Each year, the past President chairs the By-laws Committee for this purpose. This year we suggested several changes to enable ISONG business to be carried out effectively in an era when the annual meeting may not be at the same time each year and when much of our business can be conducted electronically. In addition, we are aware of the significant input into ISONG by some members without a nursing qualification. The membership was asked to vote online on each of the suggested changes. I am pleased to report that the majority of those voting were in favour of the changes and that the by-laws have therefore been altered accordingly

CHANGES TO BY-LAWS.

The new text is in italics.

Section 3.1

A. Full Membership. Full membership shall be extended to any professional nurse, licensed to practice nursing, who is interested in fostering the goals of the Society and who has paid dues in full to the Society. Full members may attend all meetings of members, vote, hold office, serve on the Board of Directors or as Chairperson of a committee, be a committee member, and receive privileges of membership.

In exceptional circumstances, members who do not hold a nursing qualification but who have contributed to the development of genetic nursing may be awarded full membership. These individuals must be nominated by

two full ISONG members and the membership must be approved by the ISONG Board.

Section 4.9 Election of Officers

The Officers shall be elected by electronic or written vote of all members with voting privileges. Elections each year shall include the President-elect and a Member-at-Large. Election of the Secretary shall occur in odd years and the Treasurer in even years. The President and the Past-President positions shall be an automatic sequence following the conclusion of the President-elect and President positions, respectively.

The election of officers shall be completed prior to the completion of the term of office of the previous incumbent and shall be installed on the date that the previous incumbent's term of office is completed.

Section 4.11 Ballot Preparation

The Nominating committee shall prepare a ballot listing the nominees for each position, together with a provision for write-in votes for each position. The names of the members of the Nominating Committee shall be included with the ballot. The Nominating Committee shall submit its ballot to the Board of Directors before members are invited to vote. Members will be mailed information about the process for voting. The ballot will be posted on the ISONG website, with access to the ballot limited to members who have voting privileges. Security measures will be in place to ensure that no member can vote more than once.

Section 4.12 Ballots: Count of Votes

The tally of ballots will be the responsibility of the Nominating Committee. The President, or other members of the Board of Directors, shall announce the results to the members not more than two weeks after the close of the ballot via the ISONG website and member listserv. The list of officers and committee chairpersons will also be listed in the subsequent newsletter.

Section 5.3 Quorum

At any meeting, a vote in the affirmative by a clear majority of those voting shall constitute acceptance of any motion for purposes of transaction of business by the Board.

Section 7.5. Global Membership Committee

The aim of the Global Membership Committee (GCC) is to make ISONG a viable international organization that makes a significant contribution to genetic nursing worldwide.

The Committee will:

1. Review all membership applications and determine eligibility
2. Encourage qualified applicants to apply for membership
3. Formulate and undertake strategies for increasing and maintaining membership .
4. Work to raise the profile of ISONG in the international forum.

*Heather Skirton
Chair*

CONFERENCE COMMITTEE

In 2004, the ISONG Board took the immense step of approving a proposal to hold the 2007 conference outside North America. As the proposer, I became the Program Chair for the conference, held in Bristol, UK from 19-21 May, 2007. The other members of the Committee, all of whom played an enormous role, were Christine Patch, Mary Quinn Griffin, Naoko Arimori, Maggie Kirk, Susan Berends, Heather Keizman and Cindy Prows.

The conference was titled 'Global Issues in Genomic Healthcare' and the aim was to address issues of relevance to genetic healthcare professionals worldwide. As ISONG believes that many issues in genetic healthcare transcend disciplinary and national barriers, we adopted an inclusive approach

and attracted many professionals from countries all over Europe and Asia, as well as those who crossed the Atlantic from the States.

We had a record 103 abstracts submitted, and the program included some 48 posters as well as 36 spoken presentations based on those abstracts. A number of the abstracts have now been published in Nursing and Health Sciences. Our invited speakers from UK, US, Italy, Japan and the Netherlands were all very well-evaluated by participants, but by far the most common comment on the evaluation forms was the positive experience of hearing and talking about practice in many corners of the globe. For the first time we included a debate on the first evening, just before the reception. I am pleased to say that the room was absolutely full!



Conference Chair Dr. Heather Skirton, ISONG President Dr. Ann Cashion, Conference Committee member Dr. Christine Patch and Session Chairman Professor Masato Tsukahara



Japanese members of ISONG with the ISONG quilt at the 2007 conference.

Despite two years of planning, you can't account for everything. The weather off the east coast of the US resulted in a couple of members who were presenting papers being stranded at the airport stateside, but our resourceful members stepped into the breach. I am very grateful to them for producing presentations with a few hours notice.

With a record attendance, this was a great opportunity

to spread the word about ISONG and I have had so many non-members write to say how impressed they were by our organisation. I look forward to the next meeting that will be outside the US, probably in 2011, especially as I won't be organising it!

*Heather Skirton
Chair*

EDUCATION COMMITTEE

ISONG has developed a response to the American Association of Colleges of Nursing (AACN) regarding their draft revision of the Essentials for Baccalaureate Nursing. We will have ISONG representatives at their regional meetings to promote a greater emphasis on genetics within the Essentials. We would like to have an organized response from as many ISONG representatives as possible request that you contact Marcia Van Riper if you plan to attend one of the meetings.

Below is the announcement from the AACN website followed by the ISONG response:

Stakeholders will be provided the opportunity to review and provide feedback regarding the draft Baccalaureate Essentials document including the end-of-program competencies for baccalaureate nursing education. AACN members, faculty, students, practicing nurses, and representatives of other healthcare and education organizations are invited to attend. The draft document has been posted on the AACN website: <http://www.aacn.nche.edu/BACEssentMtg.htm>.

Baccalaureate Essentials Regional Meeting Dates and Hotel Meeting Locations:

San Diego, CA- September 27-28, 2007

– Westin Horton Plaza San Diego

Savannah, GA- November 2-3, 2007

– Hilton Savannah DeSoto

Tucson, AZ- January 15-16, 2008

– Sheraton Tucson

Nashville, TN- March 13-14, 2008

– Hilton Nashville Downtown

Boston, MA- April 24-25, 2008

– Royal Sonesta Boston (Cambridge)

ISONG RESPONSE TO AACN DRAFT

In recognition of the role that AACN plays in providing the leadership for the future of nursing, we encourage you to consider that:

1. Genetic and genomic science is redefining the understanding of the continuum of human health and illness and thereby will change health promotion, disease prevention and disease management. Nurses are at the interface of this translation and will increasingly care for individuals and families who have a genetic condition or a genetic component to their health and disease. Genetics/genomics needs to be integrated throughout BSN curricula to be able to provide care at this interface.

2. Nurses provide quality care for persons/families/communities and populations throughout the lifespan. Therefore, genetics/genomic education needs to include discussion of ethical dilemmas as well as the relevance of cultural sensitivity. This information is of personal significance and will endow nurses with the skills and resources to provide quality genomic based healthcare.

3. All of us have clinical experiences that highlight the essential need to have genetics/genomic content incorporated into practice today and for the future. (ISONG representatives: share your stories)

Specific Recommendations for Revision of Essentials as Drafted

Essential 1. Integration of liberal education

Line 161. No change

Essential 2. Leadership

No recommendation

Essential 3. Evidence-based practice

Line 480. Add genomics, ie: The unique issues related to genetics and genomics research (as a content area)

Essential 4. Informatics

Line 688. Add: Utilizes accurate, appropriate and current genetic/genomic information, resources, services and technologies in the provision of care. (as an integrative strategy for learning)

Essential 5. Policy

No recommendation

Essential 6. Inter-professional

Line 912. Add: 7. Facilitates referrals for specialized services such as genetics (as a competency)

Essential 7. Public health

Line 1012. Keep genetics in rationale

Line 1058-60 Keep competency

Line 1106. Add genomics (as a curricular thread)

Line 1137. Add genomics (The study of all genes in the human genome together, including their interaction with each other, the environment and the influence of other psychosocial and cultural factors)[as a content area]

Line 1157-8..change the phrase to: identifying and referring high risk individuals to genetic services. (as an integrative learning strategy)

Essential 8. Professional values

Line 1258-9. Delete phrase: genetic technologies

and treatments. Add: Nurses should recognize when one's own attitudes and values related to genetic/genomic science may affect care provided to clients. (under rationale)

Line 1388. Add: Genetics/genomics (as content)

Line 1396. Add: Discussion of cultural diversity issues related to genetic/genomic information and technologies. (as an integrative strategy)

Essential 9. Generalist

Line 1543. Add: Develops a plan of care that incorporates genetic/genomic assessment information (as a competency)

Line 1564. Add: Genetics/genomics (as curricular thread)

Line 1573. Add: Genetics/genomics (as content)

Potential references to add to the document:

Consensus Panel (2006). Essential nursing competencies and curricula guideline for genetics and genomics. Silver Spring, MD: American Nurses Association.

Giger, J., Davidhizar, R., Purnell, L., Harden, T., Phillips, J., & Strickland, O. (2007). Understanding cultural language to enhance cultural competence. *Nursing Outlook*, 55(4) 212-214.

Jenkins, J. (Ed.). (2007). *Genomics in Nursing and Healthcare*. Nurse Advance Collection. Indiana: Sigma Theta Tau International

Jenkins, J., & Calzone, K. (2007) *Genomics to Health: Establishing the Essential Nursing Competencies for Genetics and Genomics*. *Journal of Nursing Scholarship*, 39(1), 10-16.

Ida Spruill

Marcia Van Riper

Co-chairs

ETHICS AND PUBLIC POLICY COMMITTEE

In our role as Co-Chairs for ISONG Ethics and Public Policy Committee, we have established the following goals for our position. They include:

1. When writing or revising Position Statements, make all attempts to include an international focus.
2. Draft a joint ISONG/NSGC Position statement on provision of quality genetic services.
3. Collaborate with the Education and Practice Committee to draft a new ISONG Position Statement – Essential Nursing Competencies: Guidelines for

Genetics and Genomics.

4. After discussion with ISONG President, Ann Cashion, move forward and develop 3 new Position Statements: Genetic Discrimination, Genetic Testing Regulation, and the importance of family history in collaboration with the Genetic Alliance.

5. Draft ISONG Commentary and Testimony for SACGHS.

Since the last board meeting, I am reporting on the following:

Goal	Action taken	Status Report BOD Meeting MM, YYYY
1. International Focus to Position Statements	Discussed with President that EPP will draft up requested Position Statements that can then be tailored by international Members to reflect their country's perspective.	Reporting at October, 2007 BOD meeting.
2. Collaboration with NSGC on position statement	Position Statement – Provision of Quality Genetic Services and Care: Building a Multidisciplinary, Collaborative Approach among Genetic Nurses and Genetic Counselors	Drafted and approved by ISONG BOD at the 2006 Annual Meeting. Approved by NSGC shortly thereafter.
3. Collaborate with Education and Practice Committee on Essential Nursing Competencies Position Statement	Has not yet come to EPP for review	Reported to BOD in January 2007 meeting.
4. Three new position statements	Position statements on genetic discrimination and a collaborative statement on family history with the Genetic Alliance have been approved by EPP and submitted to the BOD for review	Reporting to BOD at May Meeting, 2007
5. SACGHS testimony and commentary	EPP drafted Testimony for the March 26 – 27, 2007 SACGHS meeting and President, Ann Cashion presented the testimony. EPP has drafted commentary on the Report on pharmacogenomics in response to SACGHS request	Reporting to BOD at May Meeting, 2007. Delivered to President for submission to SACGHS.

Follow-up plans:

1. With direction from the BOD, continue to draft up Position Statements and include an international focus.
2. When opportunities arise to collaborate with NSGC on Position Statements, EPP will move forward with drafting the statements.

3. Follow-up with the Education and Practice Committee on the status of the Essential Nursing Competencies position statement.

4. Work on additional policy statements as directed by the BOD.

Dale Halsey Lea
Co-chair

GLOBAL MEMBERSHIP COMMITTEE

This report highlights the activities of the Membership Committee over the past year:

1) *We explored the role & goals for a new global membership committee.*

Status: The Global Connection and Membership Committees have joined to form the Global Membership Committee.

The aim of the Global Membership Committee is to make ISONG a viable international organization that makes a significant contribution to genetic nursing worldwide. The Committee will:

1. Review all membership applications and determine eligibility
2. Encourage qualified applicants to apply for membership
3. Formulate and undertake strategies for increasing and maintaining membership .
4. Work to raise the profile of ISONG in the international forum.

2) *We explored an option for full membership for non-nurses.*

Status: A recent change to the ISONG by-laws now allows members who do not hold a nursing qualification, but who have contributed to the development of genetic nursing to be awarded full membership. These individuals must be nominated by two full ISONG members and the membership must be approved by the ISONG Board.

3) *We discussed strategies to expand the number of members from non-US countries*

Status ongoing: One suggestion made at the committee meeting in Bristol was to offer a membership to nursing specialty groups which includes registration to our annual meeting for one person. The membership would be given to the organization and the specialty group could send a delegate to ISONG's annual conference.

4) *We have maintained the buddy system initiated by the global connections committee, linking members in different countries.*

Status: The buddy system is activated, but has not received any requests.

5) *Current ISONG membership*

As of 8/31/2007 ISONG has 352 members. The following 2 figures show the membership according global distribution and type of membership

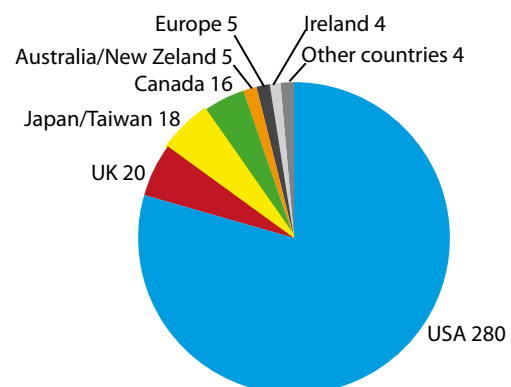


Figure 1 - ISONG Membership by Global Distribution

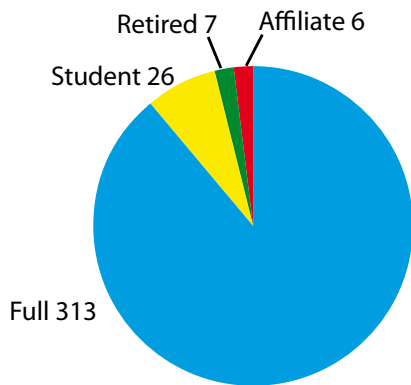


Figure 2 - ISONG Membership by Membership Type

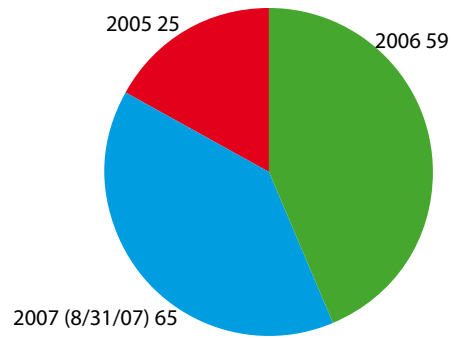


Figure 3 - New Members by Year

6) New Members

Since 2005 ISONG has had 149 new members join. Each year we have seen an increase in the number of people joining ISONG for the first time. The following figures show our total new members for years 2005, 2006 and 2007 and the number of new members who renewed after their first year. Retention and recruitment of new members continue to be areas for the Global Membership Committee to work on.

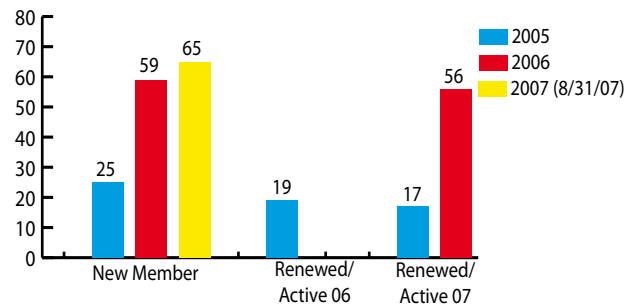


Figure 4 - New Members Who Renewed After Their First Year

Sandy Daack-Hirsch
Sivia Barnoy
Co-chairs

NEWSLETTER

NEWSLETTER COMMITTEE COMPOSITION:

The final newsletter with Cecelia Roscigno as editor was put out to membership in August 2007. This year our committee has dropped down to Virginia Minichiello, John Twomey, and Erika Santos who took over as new editor. Judy Lewis is continuing to act as our proof reader and a resource person. Cecelia provided Erika with a report that summarizes the editor's role and various tasks across the annual calendar year. She also gave Erika contact information for relevant persons who are continuing to contribute to the newsletter during her term.

NEWSLETTER CONTENT GOALS

The Newsletter is a means by which:

- ISONG Board and committee members can apprise members of their on-going work efforts.
- Members can apprise other members of their individual accomplishments
- Committees can apprise members of avenues for more membership involvement
- Leaders can apprise members of current issues in practice, research or education in nursing and healthcare.

Overall, our goal continues to be focusing the newsletter content to reach the broad membership of this organization (clinical practice at various levels, research, and education). For each newsletter issue we try to have an article that addresses each of these areas.

More involvement from persons living in locations outside the United States would help the content to be relevant to all members and educate members of the broader issues, which those of us living in more developed and industrialized countries may not always be aware of.

REGULAR NEWSLETTER CONTRIBUTORS FOR 2007

Virginia Minichiello: Practice/Research issues

John Twomey: Ethical issues in any of these areas.

Jean Jenkins: NHGRI Overview Report

Barbara Burns McGrath: Secretary's Advisory Committee Report

President: President's Message

FUTURE GOAL:

Expansion of the newsletter committee members, so that the burden of meeting content goals for each newsletter is not overwhelming to each committee member. Possible ideas to expand involvement and content covered are:

- encouraging more student involvement.
- recruiting representatives from various countries to report on issues.
- encouraging all ISONG representatives to outside professional organizations/committees

to regularly provide reports to the newsletter.

- encouraging members of the practice, education, and research committees to provide articles addressing these areas for at least 2 of the quarterly newsletters and plan this out ahead of time so that the editor can plan accordingly. Then newsletter committee could supplement the areas not covered in each newsletter.
- printing abstracts or brief summaries of presentations from yearly conference. Asking nursing researchers to submit abstracts they have presented elsewhere too (the newsletter is not copy-write protected, so it would not prevent them from submitting elsewhere).

Increasing contributions from the various ISONG committees to maintain ISONG's goal of being informative to the membership. Ideas include but are not limited to:

- explanations of any initiatives undertaken by each of the committees and their plans to achieve their goals.
- any committee accomplishments.
- reports of events, which occurred at the annual meeting (e.g. if research or awards committee would send a list of any awardees (and any pictures taken) then they could be printed in the newsletter as well after the meeting). Any other events worth highlighting from the annual meeting.

More contributions from and/or about areas of the world outside the United States.

Cecelia Roscigno
Newsletter Editor 2005-2007

NOMINATING COMMITTEE

Goals of the Committee were to:

- 1) Recruit at least 2, but no more than 3 nominees for each office - President-Elect, Secretary, Member at Large.
- 2) Maintain communication with members and the board regarding nomination opportunities.

The committee placed the announcement for nominations in the ISONG newsletter, communicated with members interested in offices, and received biosketch descriptions from two

candidates for president elect, three candidates for secretary, and two candidates for member at large. The ballot was presented to the ISONG executive board and forwarded to Nancy DuBois for creation of the electronic ballot. The chair recommended bylaws revisions to clarify and simplify the nominations process. The chair thanks the committee members and all ISONG members who placed their names in nomination for the 2007 ballot.

Janet Williams, Chair
Martha Driessnack, Member
Dale Halsey Lea, Member

PROFESSIONAL PRACTICE COMMITTEE

GENETICS AND GENOMICS NURSING: SCOPE AND STANDARDS OF PRACTICE UPDATE

The most significant accomplishment for the past year is the publication of Genetics and Genomics Nursing: Scope and Standards of Practice. ANA Publishing reports that ANA sold 421 copies from October 2006 to August 2007 in addition to the 100 complimentary copies which were available for sale to ISONG members for \$15 each. ANA's sells the document through the following link at <http://nursingworld.org/books/pdescr.cfm?cnum=15#06SSGG> at a cost of \$13.45 for

ANA members and \$16.95 for non members plus shipping and handling. Efforts are underway with ANA to find out the cost and what is involved in having the document translated into Japanese and Portuguese.

WHAT IS A GENETICS NURSE BROCHURE

This brochure is in the process of being revised. A survey has been compiled and is in the process of being sent out to the ISONG membership to determine how the brochure is currently being used and to solicit feedback concerning what revisions ISONG members think would be beneficial.

PROFESSIONAL PRACTICE COMMITTEE FACT SHEET

A Fact Sheet for the Professional Practice Committee has been created and is in the process of being finalized. Content includes contact information for committee chairs, committee goals, and a summary of current activities. The fact sheet will be sent out to new members and periodically updated for current members.

COMMITTEE MEMBERSHIP

The committee currently has 17 members and is co-chaired by Karen Greco and Mei-Chih Huang.

*Karen Greco
Co-chair*

RESEARCH COMMITTEE

The Research Committee activities focused on the Annual Research Grant. Guidelines were updated and sent to the membership via the listserv in July. For the 2007-2008 cycle, ISONG has two \$1500 research awards. In addition to our annual grant, we have a second award, the University of Pittsburgh School of Nursing ISONG Research Grant. ISONG thanks Pittsburgh for their generous funding of this second grant.

Multiple ISONG members submitted the required letter of intent (Sept.1) and full proposal (Sept. 24) by the published deadlines. The awarding of either grant is contingent on the successful peer review of the grant application by the ISONG Research Committee. Award winners will be announced around November 1.

*Ann Dylis
Lorraine Frazier,
Co-Chairs*



'image: www.freeimages.co.uk'

FINANCIAL STATEMENTS PARTNERSHIPS BOARD OF DIRECTORS

TREASURER'S REPORT

As of August 31, 2007, ISONG has recorded \$102,200 in revenues and \$107,400 in expenses.

- Administrative revenues are generated primarily from the membership dues totaling \$25,700, which is 85% of the budgeted membership.
- Additional sources of administrative revenues are Scope & Standards sales, \$2,200, Advertising, \$800, and Royalties of \$900. These revenues are all on budget for the year.
- Administrative expenses relate primarily to the Executive Management Company, \$36,000 which is at 75% of the annual budget.
- Additional administrative expenses related to the organization, such as accounting fees, postage, subscriptions, supplies, and

communication expenses, are all primarily within budget for the year.

- The annual conference generated a net of revenues over expenses totaling \$5,200.
- Registrations totaled \$53,500
- Sponsorships generated an additional \$18,100.

These amounts totaled approximately \$24,000 higher than the 2006 annual conference.

- Expenses for the conference were primarily related to:
 - ▶ The venue costs = \$50,000,
 - ▶ The conference dinner= \$6,400,
 - ▶ Research grants= \$4,500
 - ▶ Speaker expenses = \$2,000.

Rebekah Hamilton, Treasurer

Sharon McGraw, Accountant

PARTNERSHIPS

These are ISONG collaboration from 2007

- Association of Genetics Nurses and Counsellors (UK)
- European Society of Human Genetics (Sub-committee for education of genetic nurses and counsellors)
- Genetic Alliance
- National Society of Genetic Counselors
- American's for Nursing Shortage Relief (ANSR)

- GeneticsNursingCredentialingCommission (GNCC)
- American Association of Colleges of Nursing (AACN)
- American Academy of Nursing
- Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS)
- Nursing Organizational Alliance

Beth Kassalen, MBA

Executive Director

2007-2008 ISONG BOARD OF DIRECTORS

PRESIDENT

Susan Tinley

tinley@creighton.edu

SECRETARY

Beth Pestka

pestka.elizabeth@mayo.edu

PRESIDENT-ELECT

Agatha Gallo

agallo@uic.edu

MEMBER-AT-LARGE

Maggie Kirk

mkirk@glam.ac.uk

PAST PRESIDENT

Ann Cashion

acashion@utm.edu

MEMBER-AT-LARGE

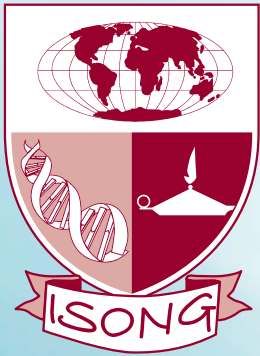
Elizabeth Sparks

sparksl@pediatrics.ohio-state.edu

TREASURER

Rebekkah Hamiton

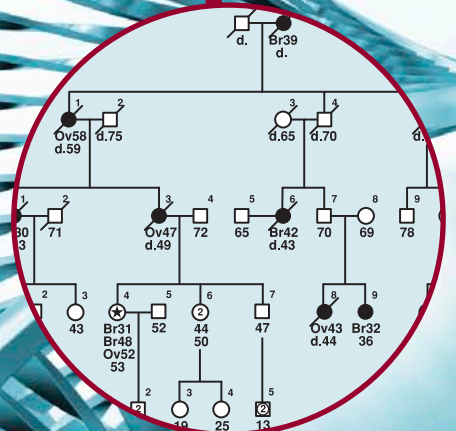
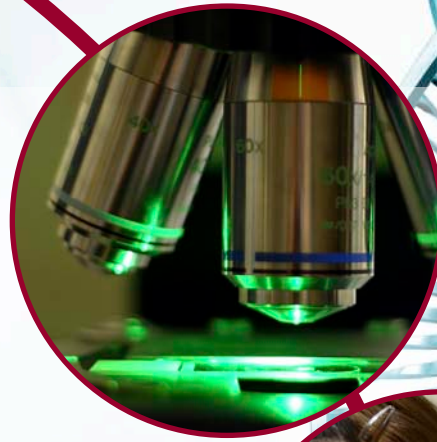
hamilr@pitt.edu



21ST ANNUAL ISONG CONFERENCE

NOVEMBER 8-11, 2008
SHERATON SOCIETY HILL, PHILADELPHIA, PA USA

NURSING REVOLUTION IN GENOMICS: UNITING RESEARCH, EDUCATION & PRACTICE



PRE-CONFERENCE WORKSHOP
SATURDAY, NOVEMBER 8, 2008

**ESSENTIALS OF GENETICS AND GENOMICS:
WHAT'S NEEDED FOR NURSING PRACTICE**

ESSENTIALS OF GENETICS AND GENOMICS: WHAT'S NEEDED FOR NURSING PRACTICE

Host Hotel

Sheraton Society Hill Hotel

Rates - \$199.00 plus taxes Single/Double
One Dock Street (2nd and Walnut Streets)
Philadelphia, PA 19106
(215) 238-6000

Accommodations for the 21st Annual ISONG Conference will be provided at the Sheraton Society Hill Hotel. This colonial style hotel is nestled in Old City, the oldest and significant historic area of Philadelphia. The residents of Society Hill welcome visitors to stroll their cobblestone streets and take in the architecture of the centuries-old homes, churches, and landmarks that make this neighborhood so picturesque. Independence Hall and the Liberty Bell are within a short walking distance of four blocks. Although the city is famous as the birthplace of life, liberty and the pursuit of happiness, Philadelphia offers much more than cobblestone streets and historical landmarks. The one square mile area of Old City District is the home to more than 50 art galleries and over a 100 restaurants and bars. Hotel amenities include an indoor heated swimming pool and whirlpool, fitness center, business center, and 24-hour valet service.

Pre-conference Workshops

The pre-conference workshops are presented as two half-day sessions on November 8, 2008 with tentative times arranged for 8:30 a.m. to noon for the morning session and 1:00 to 4:30 p.m. for the afternoon session. The cost is \$75.00 for one session and \$150.00 for both sessions. The pre-conference offers a practice-oriented focus on genetics and genomics in nursing practice. It is an ideal educational offering for nursing faculty, area nurses, and students to obtain what you need to know about genetics and genomics in today's nursing practice. Both workshops are interactive and ample time is allowed for questions and discussion.

Pre-conference Agenda	
Time	Activity
8:00-8:30	Registration/Continental Breakfast
8:30-12:00	Morning Pre-conference – Implications of Genomics for Nursing Practice
12:00-12:30	Registration/Beverages
1:00-4:30	Afternoon Pre-conference – Genetic & Genomic Curricula Integration

Objectives

At the end of this conference, the participants should be able to:

- Identify the significance of family history to health and risk assessment for disease.
- Discuss the relationship of an individual's genomic profile to drug metabolism, side effects, and efficacy.
- Evaluate patients' experiences of the impact of genetics and genomics of their health and medical management.
- List genetic and genomic resources for nursing curricula.
- Discuss the practical integration of the Essential Nursing Competencies for Genetics and Genomics into nursing practice.
- Evaluate current successful strategies for curricula integration employed by nursing faculty.

Morning Workshop

"Implications of Genomics for Nursing Practice"

\$75

The morning session will focus on the implications of genomics for nursing practice and is geared towards an audience of nursing faculty, practicing nurses, and students. The session will highlight three areas of interest. The first will entail family history with an emphasis on the first genetic test and how it is used in nursing assessment. In addition, the discussion will include how nurses are using pharmacogenomic testing to determine "The right drug, for the right person, at the right dose." Patients will also relay their experiences about the impact of genetic and genomics on their health and medical management.

Afternoon Workshop

"Curriculum Integration"

\$75

The afternoon session's focus will be on curriculum integration and is appropriate for a nursing faculty audience. The discussion will cover genetic and genomic curriculum resources and how essential nursing competencies and curricula guidelines for genetic and genomics are being implemented nationally in the practice of nursing. In addition, a panel of nursing faculty and experts will share their experience on successful strategies for integrating genetics and genomics into the nursing curricula.

Why Attend?

A reported nursing issue with genetics/genomics is that the science is there but genetics/genomics is not yet seen as part of practice. Secondly nursing curricula are already overloaded with requirements. Despite these barriers "Essential Nursing Competencies and Curricula Guidelines for Genetic and Genomics in Nursing Practice" have been endorsed by the American Nurses Association and 46 professional nursing organizations. Within the ISONG membership, nursing faculty have pioneered the integration of genetics and genomics into nursing curricula demonstrating the applicability of genetic/genomics to biologic processes, pathophysiology, diagnosis and treatment. This pre-conference will provide the opportunity to learn the essentials of genetics and genomics for nursing practice directly from nursing experts.

Who Should Attend:

- Area Nurses (Morning session)
- Students (Morning session)
- Nursing Faculty (Both sessions)

Continuing Education Credits

The Columbia University School of Nursing is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. The exact number of CEUs will not be known until approximately four weeks prior to the workshops.

Further Information

Information provided in this flyer is specifically for the pre-conference workshops. For additional information on these workshops, or to provide your input to the planning committee, please contact: Carol Cherry, MSN, RN, C, OCN
Fox Chase Cancer Center
Philadelphia, PA
(215) 728-3672
carol.cherry@fcc.edu

The full ISONG Conference runs from November 8-11, 2008. For a complete brochure and full agenda of the 21st Annual ISONG Conference, contact ISONG at isongHQ@msn.com or by calling ++ 1 412 344 1414.