



2009 ISONG ORGANIZATIONAL OVERVIEW



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RESTATING OUR MISSION

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.

PRESIDENT'S UPDATES PRESENTED AT THE FOR THE 2009 ISONG BOD & BUSINESS MEETINGS

*Submitted by
Agatha Gallo*

- The American Nurses Association and ISONG have co-published a book, *Genetics and Ethics in Health Care: New Questions in the Age of Genomic Health*, Rita Black Monsen, DSN, MPH, RN, FAAN, Editor. Several ISONG members were authors, editors and contributors to the project.
- ISONG and ANA are delighted that Japanese Society of Genetic Nurses translated ISONG's *Genetics/Genomics Nursing: Scope & Standards of Practice* into Japanese. Thanks to Drs. Karen Greco and Michiko Mizoguchi for their participation in overseeing this project.
- ISONG has collaborated with several organization and groups:
 - ▶ National Society of Genetic Counselors
 - Agatha Gallo participated in the NSGC Strategic planning meeting in Chicago.
 - Steve Kieles, the President of NSGC presented at the annual conference on genetic counseling and nursing and moderated a panel discussion on patients and caregivers.
 - The 2010 ISONG and NSGC conferences in Dallas will have an overlap of one day.
 - ISONG provided a support letter to support and partner with the Genetic Counseling Foundation (GCF) and the National Society of Genetic Counselors (NSGC) in its application to the Agency on Healthcare Research and Quality to host Phase I of the Collaborative Genetic Services Summit.

The two-phased summit is designed to bring together primary care providers and genetics specialists for the purpose of developing a collaborative model for integrating genomics into healthcare.

▶ Genetic Alliance

- ISONG is a member of the Genetic Alliance and receives their online materials that are reviewed and sent on to the membership if appropriate.

• Endorsements

▶ Nursing Community (American Association of College of Nursing) and the ANSR (Americans for Nursing Shortage Relief) Alliance (National League for Nursing and the Emergency Room Nurses): Although these groups are not specifically related to genetics/genomics in nursing, it is important that ISONG be visible in the Education Appropriations bills and the health care reform discussions.

▶ ISONG completed and submitted a comprehensive survey request for SACGHS (The Secretary's Advisory Committee on Genetics, Health, and Society) that focused on ISONG's its genetics education and training activities. Thanks to Marcia Van Riper, Karen Greco, and Sue Tinley for their input.

▶ Master's Essentials Regional meetings: AACN is having 4 regional meeting to get input into the draft end-of-program outcomes document for master's nursing education. The process will be similar to the Essentials of Baccalaureate Education for Professional Nursing Practice in which representation at each meeting followed by written commentary was ultimately successful in integrating genetic/genomics into those essentials. I thank Karen Greco, Sue Tinley and Diane Seibert for their continued work on the Master's genetic/genomic competencies and review of the Master's Essentials draft in preparation of these meetings. Several of our member will be attending these regional

meeting – thanks to them in advance for their dedication and participation in this very important project.

- Meetings ISONG Representative attended:

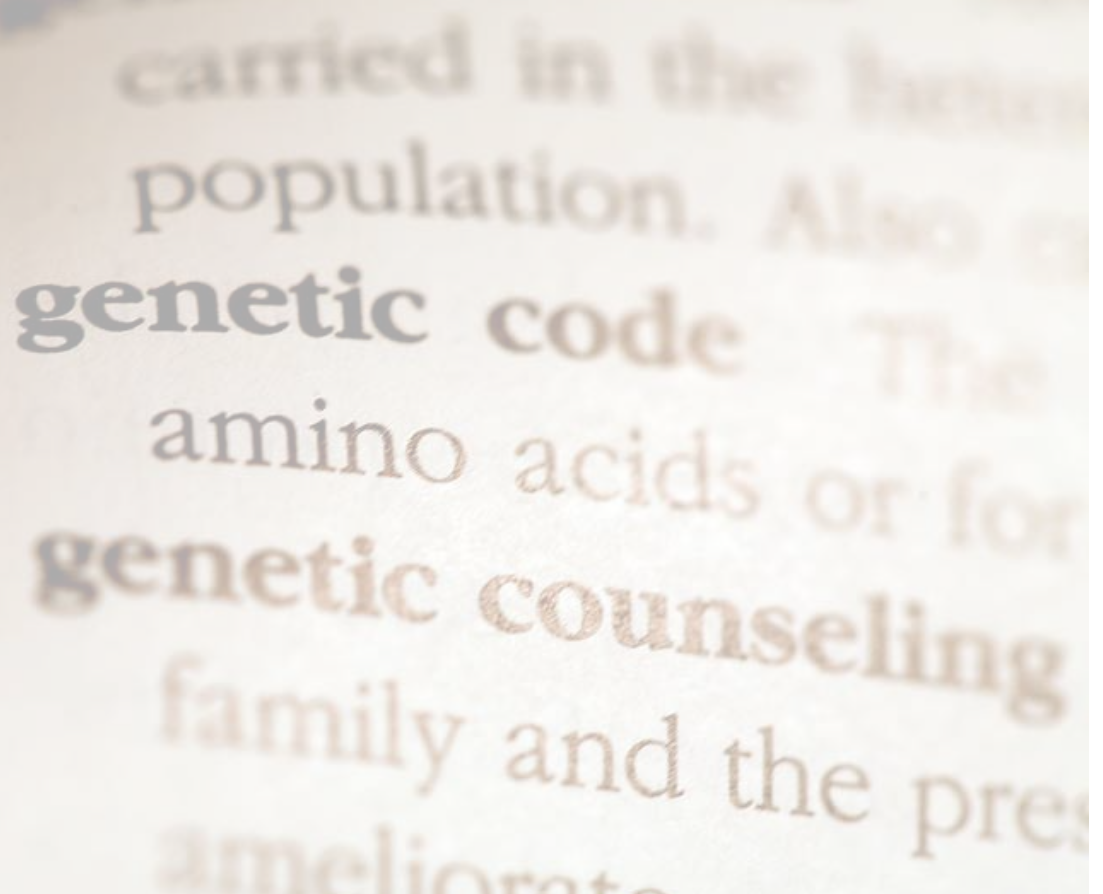
- ▶ Karen Greco attended the NCHPEG (National Coalition for Health Professions Education in Genetics) meeting in Bethesda, MD.

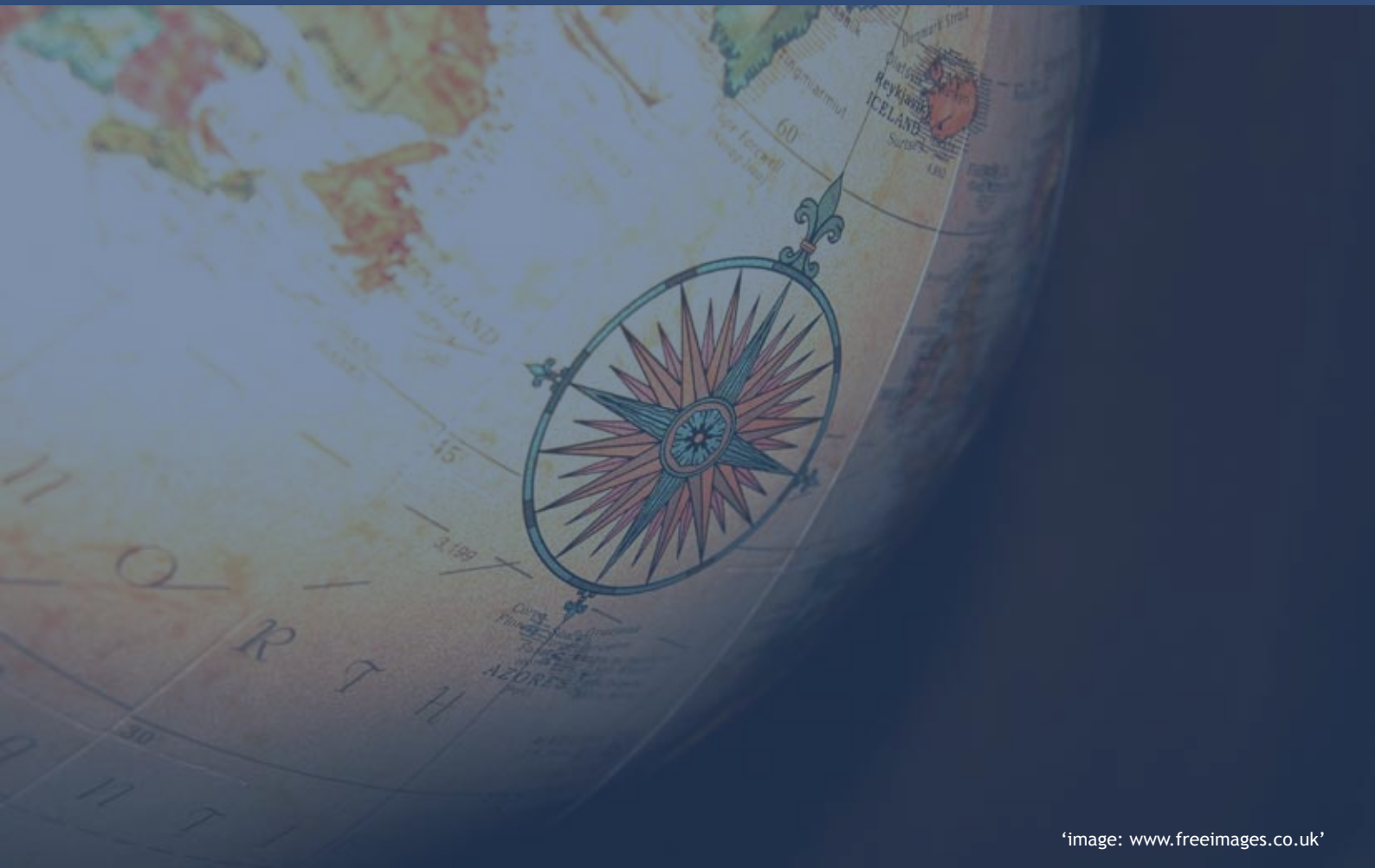
- ▶ Ann Cashion attended the Nursing Quality and Alliance meeting at George Washington University.

- ▶ Agatha Gallo attended the GAPPNet (Genomic Applications in Practice and Prevention Network) meeting (National Collaboration for Realizing the Promise of Genomics in Health Care and Disease) in Ann Arbor, MI. The meeting is a partnership of several Federal Agencies and organized by the University of Michigan Center for Public Health and Community Genetics.

- Diane Siebert, Janet Williams, Kathy Calzone, Cindy Prows, Jean Jenkins, and Agatha Gallo were highlighted in an article, “A perfect match, Nurses take on genetics, genomics and make a difference” in the October issue of the American Nurses Association publication, the *American Nurse-TAN*. We thank Martha Turner, the Assistant Director of ANA’s Center for Ethics and Human Rights for this opportunity.

- Watch for the upcoming Needs Assessment Survey. We need to hear from our members about their interests and what programs, products, and other ideas that ISONG should focus.





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COMMITTEES AND MEMBER AT LARGE

AWARDS AND BY-LAWS

*Submitted by
Susan Tinley*

In my role as Chair of the By-Laws and Awards Committees for ISONG, I have established the following goals for my position and or committee. They include:

1. Respond to requests for change in By-Laws as needed
2. Recruit members of awards committee
3. Request nominations for awards
4. Identify the nominees
5. Order plaques

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

Respond to requests for change in By-Laws as needed

Action taken: NA at this time.

Recruit members of awards committee

Action taken: Requested volunteers in last newsletter.

Status Report: Heather Skirton and Ida Spruill graciously agreed.

Request nominations for awards

Action Taken: Nominations were requested from the membership.

Status Report: The following were received: Two for service, three for education and one for research

Identify the nominees

Action taken: Recipients have been identified.

Status Report: Recipients will be announced at the annual meeting.

Order plaques

Action taken: The names have been given to Janet Williams to order the plaques.

Status Report: Janet will bring plaques to the meeting.

FOLLOW-UP PLANS:

1. Announce awardees.
2. Provide next chair with timeline.

COMMUNICATIONS - NEWSLETTER

*Submitted by
Erika Santos*

The goals of Communications Committee are:

1. Producing a regular newsletter for members
2. Updating, maintaining and editing information posted on the ISONG website.
3. Encouraging the Board and other committees to share information for the newsletter or website.
4. Providing information on topics or issues that may have an impact on members in the newsletter or on the website.



5. Presenting a world perspective news or insights on issues for nurses in genetics worldwide
6. Communicating with members in ways that are appropriate, as directed by the Board

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

Producing a regular newsletter for members

Action taken: Three newsletters has been published from October 2008 to October 2009

Status report: The next newsletter is published in November 2009

Updating, maintaining and editing information posted on the ISONG website

Action taken: The Newsletter is available to members in the member only section.

Status Report: ISONG Newsletter January – March is in the website. The newsletter April-June will be updated.

Encouraging the Board and other committees to share information for the newsletter or website

Action taken: E-mail reminders to members one month prior the newsletter publication.

Status report: The next e-mail was sent in October 2009

FOLLOW UP PLANS

To publish three newsletters in 2010, including the annual report.

We would like to thank all colleagues that send us articles this year and special thanks to Judith Lewis for proofreading the newsletter.

- Agatha Gallo
- Ann Cashion
- Carmen Paniagua

- Cindy Prows
- Dale Halsey Lea
- Deborah MacDonald
- Ellen Giarelli
- Emma Tonkin
- Heather Skirton
- Ida Spruill
- Janet Williams
- Jean Jenkins
- Jeanine Seguin Santelli
- John Twomey
- Judith Lewis
- Karen Greco
- Lorraine Frazier
- Maggie Kirk
- Marcia Van Riper
- Sharon Olsen
- Silvana Ioannou
- Sivia Barnoy
- Susan Tinley
- Virginia Minichiello



ETHICS AND PUBLIC POLICY COMMITTEE (EPPC)

*Submitted by
Ellen Giarelli*



Committee Purpose: This Committee evaluates ethical and policy issues related to scientific advances and political changes. The committee weighs the need to prepare a response on behalf of the Society. Members recommend and establish criteria, with approval by the Board of Directors, for such evaluations that reflects the Vision, Mission and goals of the Society. Specifically, the committee writes position statements and commentaries.

The Ethics and Public Policy Committee has established the following goals for the committee.

1. Update membership and explore formation of subgroups.
2. Identify and get contact information for International organizations that address ethical, social and policy issues related to genetics in general and genetic nursing in particular.
3. Prepare a POSITION STATEMENT on the issue of Direct to Consumer Marketing of Genetic tests.
4. Identify issues for which ISONG may wish to prepare statements of position.
5. The committee will hold at least two teleconferences.

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

Update membership and explore formation of subgroups

Action Taken: Two names added to EPPC membership – Howard A. Fuchsia (fuchsiahoward@

mac.com); and Kim Subasic (subasick2@scranton.edu).

Status Report: Reviewed and updated members list, twice.

Identify and get contact information for International organizations that address ethical, social and policy issues related to genetics in general and genetic nursing in particular

Action Taken: Martha received responses from Iceland and Cyprus. She recommends:

1. The next contact be made when there is something specific to be done. Perhaps answering a question or providing info about a genetics issue.
2. Cross checking the ISONG membership list with the ICN list to identify countries where we have no representation to focus this effort so the next contact is only to those who are not already affiliated with ISONG.
3. Discuss in more detail at annual conference.

Status Report: Martha Turner worked on this goal and prepared a letter sent to the list she compiled. She collected information from the orgs as it arrived. The response was low.

No more action needed on this goal until a specific question is raised that would benefit from the input of international organizations.

Prepare a POSITION STATEMENT on the issue of Direct to Consumer Marketing of Genetic tests

Action taken: The subcommittee developed a draft of a position statement. The subcommittee is composed of Cheedy, Pam, and Marie. Later, Lynn Rew joined.

- The subcommittee defined the relevant constructs of consumer, genetic testing, marketing, etc.
- Prepared PS and distributed to members of EPPC on several occasions.
- Board reviewed the draft in July and suggestions made by board members were reviewed and incorporated into the draft.

Status Report: Final PS was presented to the Board for vote on September 3. The motion to approve was passed. Final PS will be adjusted to conform to the formatting specified in the policy and posted on the website.

Identify issues for which ISONG may wish to prepare statements of position

Action Taken: The existing ISONG POLICY: Definitions, Process and Format of Position Statement needs review and/or revision and approval.

Status Report: ISONG created a policy for writing position statements which was originally approved in October 2001. This policy was later reviewed/revised by EPPC. The revision, however, was never approved by the board. The revised policy was reviewed at the September 3rd board meeting. Motion to approve was passed.

Small Project: to evaluate the availability of audio-visual instructional materials related to ethical issues in genetics/genomics for nurses

Action Taken: Pam Williams plans to initiate identification process for audio visual materials as education tools for nurses and nursing students. She

plans to conduct this process in conjunction with her 2010 Annual conference co-chair responsibilities to plan the 2010 annual conference, which has as its theme ethical issues for genetic healthcare. Once these resources are identified she intends to include a screening of these materials as part of the 2010 conference schedule.

Status Report: No action on this goal.

The committee will hold at least 2 teleconferences.

Action taken: The DTC subcommittee has met by conference call on several occasions over the last three months. Next meeting will be in San Diego.

Status Report: The DTC subcommittee and the EPPC met by conference call on several occasions over the year. Conference calls and email follow-up communication continues to be a productive venue for committee work.

AGENDA ITEMS FOR ANNUAL MEETING:

1. Identify ELSI for EPPC consideration: Pam Williams to Co-Chair 2011 Conference committee.
2. Continue expanding list of International organizations.
3. Identify goals and objectives for 2009-2010.

GLOBAL MEMBERSHIP

Submitted by

Co-Chairs: Ida Spruill (Domestic)

Sivia Barnoy (International)

In our role as Co-Chairs of the Global Membership Committee for ISONG, we have established the following goals for the committee.

1. Recruitment of new members.
2. Retention of members.

3. Activate ISONG BUDDY SYSTEM.
4. Respond to needs of membership in timely manner.
5. Diversify the membership (International and Domestic).

Over this year, we are reporting on the following:

Recruitment

Action Taken: Welcome letter sent to new members; Designed new Membership Application.

Status Report: List of ISONG current members
- Total 337.

Retention

Action Taken: Membership renewal sent to members.

Status Report: 2005-2007 - 125 did not renew membership.

October 8-April 09 - 40 members did not renew.

BUDDY System

Action Taken: Sent request for Buddies to membership; Still need BUDDIES; Information Table at 2008 annual conference.

Status Report: 30 members or 30% of membership have been matched.

Members Needs

Status Report: Review of Survey Monkey Results: 135 members received survey.

- 35 responded: 69.2% - Did not feel ISONG helped professionally; 83.3% - never received a renewal notice; 55% - would like a renewal notice; 47.6% - desire to apply online.

FOLLOW-UP PLANS:

1. Maintain close working relationship quarterly with ISONG administration (Beth, Debbie)
2. Develop a plan to increase the diversity and visibility of the organization.



RECOMMENDATIONS:

Continue to:

- 1) Send renewal reminders/letters to members not renewed from October 8-April 09.
- 2) Send e-mails to members not renewing 2005-2007.
- 3) Send welcome letters to new members.
- 4) Investigate feasibility of on-line application.
- 5) Investigate feasibility of a Standard Membership Renewal Date.

NOMINATING

Submitted by

Ann Cashion

In my role as Chair for the Nominations Committee for ISONG, my committee established the following goals for the year:

1. Establishing a 3-4 member Nominations Committee.
2. Providing a slate of officers to include president-elect, secretary and member at large, for the 2009 ISONG Elections.
3. Overseeing an electronic voting process.

4. Communicate voting results to candidates and membership via listserve and newsletter.

Over this year, I am reporting on the following:

Established a 3-4 member Nominations Committee

Action taken: The committee consisted of Mary Quinn Griffin, Janet Williams, Ellen Giarelli, and was co-chaired by Heather Skirton and Ann Cashion

Status Report: Committee members participated in all activities of the nominations committee.

Provided a slate of officers to include president-elect, secretary and member at large, for the 2009 ISONG

Elections

Action taken: A slate was prepared by the nominations committee and approved by the executive board.

Status Report: We had two candidates for each position. Tentative TimeLine for Nominating/Voting Process:

- April 18-June 15, 2009 —confirm those willing to run for office and get biosketches from them.
- July 1-14, 2009 —open polls for voting (administered by ISONG HQ).
- July late, 2009 —share voting results with ISONG Exec Committee.
- August, 2009 —announce results to ISONG membership.
- October 16, 2009—ISONG conference (San Diego).

Oversee an e-voting process

Action taken: With input and oversight from the nominations committee, ISONG HQ conducted the survey monkey e-voting process. All ISONG members eligible to vote were emailed a link to the survey. Voting was open from July 6-July 26 initially, and was extended for 2 days (until July 28). At least 2 reminders were sent to encourage voting. Members

could submit a paper ballot.

Status report: Candidate bios were posted on the ISONG website. Voting ran smoothly with almost 50% voter turnout (137 of 292 members voted). This was better than in previous years. We had a handful (~3-5) faxed votes. There were no complaints on the voting process communicated to the Nominations committee.

Communicate voting results to candidates and membership.

Action taken: Once the votes were tallied, the results were confirmed by the nominations committee and then reported to the exec committee. Once candidates were notified, results were posted for all members to read via the listserve.

Status report: Those who received the highest vote agreed to accept their position. Candidates were notified of results on 8/7/09. Results were posted on the Listserve on 8/20/09. Results will be placed in the upcoming newsletter.

Election Results:

President-Elect: Kathleen Sparbel

Secretary: Rebecca Hamilton

Member at Large: Sheila Alexander

FOLLOW-UP PLANS:

1. Place election results in upcoming newsletter.
2. Ensure that the procedures used by this committee as posted on the ISONG “procedures” website.
3. Assist incoming chair, when needed.



PROFESSIONAL PRACTICE COMMITTEE

Submitted by

Carmen Paniagua, Co-Chair

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

Integration of scientist/educator-practitioner model

Action taken: Exploring different models.

Status Report: Exploring Phase; Possible initiatives – In Progress; A Listserv that identifies practitioner data sets that is available to academics for research.

Advocate genetic/genomics

Action taken: Developing strategic plan

Status Report: Possible initiatives - Identify specific liaisons with targeted international organizations – Contacted Puerto Rico

Start specific initiatives with each.

Organization of choice

Action taken: Exploring marketing venues

Status report: Possible initiatives – Identify specific liaisons with targeted international organizations – Medical Science Campus, University of Puerto Rico

Professional survey

Action taken: Analyzed survey results

Status report: In Progress – Final Brochure

RESEARCH COMMITTEE

Submitted by

Maggie Kirk

Lorraine Frazier

In our roles as Co-Chair for ISONG, we agreed the following goals for the Research Committee

with the group. They include:

1. To raise awareness of the role of research within ISONG's core 'business'.
2. To alert members to research opportunities (funding; collaboration).
3. To administer the ISONG Annual Grant award through an equitable and efficient process.
4. To facilitate the research activities of ISONG members.
5. To disseminate news of research to key stakeholders.

Over this year, We are reporting on the following:

Goals 1, 2, 4, 5

Action Taken: Possibilities of a closed Moodle site have been explored and a template site has been developed. Director of NHS National Genetics Education & Development Centre has given permission for the Centre to host and manage/monitor the Moodle resource, which could be accessed via a link from the ISONG website.

Status Report: Approval is sought from the Board for the establishment of this interactive web resource, and for the ISONG logo to be displayed on the Moodle site banner heading.

To administer the ISONG Annual Grant award through an equitable and efficient process

Action Taken: Four applications received. Review Panel have reviewed bids.

Status Report: All bids worthy of funding. Two have been selected.

FOLLOW-UP PLANS:

1. Concept of the Moodle site to be presented to Board members and to Research Committee members at ISONG.
2. Moodle site to be established & populated as a closed site for RC members, accessed via ISONG website link.
3. Activity will be monitored over the following 12 months.

MEMBER AT LARGE

*Submitted by
Elizabeth Sparks*

In my role as Member at Large (MAL) for ISONG, I have established the following goals for my position and or committee. They include:

1. Facilitate transition of incoming committee and board members.
2. Clarify and expand the role of Member at Large.
3. Assist with Needs Assessment Tool for ISONG members.
4. Establish communication portal for members to communicate with MAL.

Over this year, I am reporting on the following:

Transition

Action taken: The responsibility for transitioning from outgoing to incoming members lies with each board member, as they prepare to “pass the torch”.

Status Report: No Action for the Member at Large at this time.

Expand MAL role

Action taken: Discussions with the President

Status Report:

- 1) Consider establishing ISONG Ambassadors for each country, to be the point person for that area.
- 2) Needs Assessment Tool for ISONG members.
- 3) Need to establish a MAL communication portal.

Needs Assessment Tool

Action taken: Modified existing needs assessment tool.

Status report: Modified Tool submitted to President, ISONG HQ and other MAL member. Tool may require further modification/fine tuning before distributing to ISONG members.

Communication portal

Action taken: Discussed a procedure for contacting Member At Large or other ISONG members with nursing genetics questions

Status Report: Member At Large communication link on the ISONG website. This link could be the entry for questions related to best practices (alignment with expert nurses in specialty genetics practice), nursing education, and areas of professionalism/policy.

ISONG members that desire, could post/share powerpoint slides/presentations with each other.

FOLLOW-UP PLANS:

1. Continue to discuss the need for and role of ISONG Ambassadors.
2. Incumbent and incoming MALs will continue to develop (and distribute) ISONG Needs Assessment Tool along with ISONG President and HQ.
3. Establish ISONG website link to contact MAL. MAL will work with ISONG HQ, President and others to establish a communication link/portal and develop a triage protocol for answering inquiries. Example: Within ISONG, to whom should patient advocacy and care, education, policy issues be directed? To whom should specific inquiries be directed?



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FINANCIAL STATEMENTS SECRETARY REPORT BOARD OF DIRECTORS

TREASURER'S REPORT

Submitted by

Marie Tival

Financial Summary for the year: 10-1-08 to 10-1-09

Beginning balance:		23,423.34
Income:		165,418.72
Expenditures:		116,980.53
Itemized expenses:		
Kassalan Meetings and Events	48,728.05	
Nancy Marshall, CPA	1,790.03	
Website	4,500.00	
Grants/Awards	4,500.00	
Kathleen Sparbell		
Patricia Underwood		
Jane DeLuca (08)		
		116,980.53
Ending balance:		71,861.53
CD #1		10,278.31
CD #2		10,301.61
Total Assets		92,441.45

SECRETARY'S SUMMARY OF ACTIVITIES FROM OCTOBER 2008 TO OCTOBER 2009

Submitted by
Elizabeth Pestka

In my role as Secretary for ISONG, I have established the following goals for my position. They include:

1. Prepare and distribute a master directory of contact information for members of the ISONG Executive Board and committee chairs.
2. Record and format minutes from the annual ISONG Business and Awards meeting and all of the executive board and committee chairs meetings during the year.
3. Distribute the minutes for review and make any recommended and approved changes.
4. The meeting minutes serve as an official record of ISONG meeting proceedings.

Contribute to Executive Board decisions for ISONG.

Over this year, I have completed the following:

Master Directory of Contact Information

Action Taken: Gathered information, formatted into a table, and distributed.

Status Report: Directory available from the secretary or ISONG's central office

Approved meeting minutes

Action Taken: Minutes were recorded, reviewed and approved for each meeting.

Status Report:

ISONG Annual Business and Award Meetings: 11/9/08 & 10/18/09

Executive Board Meeting: 3/3/09

Executive Board and Committee Chairs Meetings:

11/11/08, 1/6/09, 3/10/09, 5/6/09, 7/8/09, 9/3/09, 10/16/09

Minutes available from the secretary or ISONG's central office

Contribute to decisions

Action Taken: Responded to requests for information, opinions and recommendations

Status Report: Official decisions included in ISONG's meeting minutes

It has been an honor to serve as secretary of ISONG. I look forward to contributing to the organization in other ways in the future.

ISONG BOARD 2009-2010

PRESIDENT

Karen Greco

PRESIDENT-ELECT

Kathleen Sparbel

TREASURER

Marie Twal

SECRETARY

Rebekah Hamilton

PAST PRESIDENT

Agatha Gallo

MEMBER AT LARGE

Milena Floria-Santos
Sheila Alexander

COMMITTEES CHAIRS

AWARDS

Agatha Gallo

BY-LAWS

Agatha Gallo

CONFERENCE

Sandra Founds & Pam Williams

COMMUNICATIONS

Erika Monteiro Santos (newsletter) &
Lynnette Howington (website)
with assistance from Julie Eggert

EDUCATION

Rose Nealis & Beth Pestka

ETHICS AND PUBLIC POLICY

Ellen Giarelli & Marie Twal

NOMINATING

Carolyn Farrell & Emma Tonkin

GLOBAL

Ida Spruill & Pei-Ying Chuang

PROFESSIONAL PRACTICE

Carmen Paniagua & Milena Floria-Santos

RESEARCH

Maggie Kirk & Gia Mudd



INTERNATIONAL SOCIETY OF NURSES IN GENETICS, 2009