



# 2010 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.

### CONFERENCE

Our attendance here in Dallas is just under 150, which I think is great. We did have an issue with people booking outside of the hotel block, getting credited for rooms in our contract and people staying elsewhere. I think this is a sign of the economy and a sign of the times.

- Discuss a 'room block'
- Discuss the issues of over/under booking
- Thank Pam Williams and Sandy Founds for their oversight of the conference.
- Thank others
- 1/3 of attendees indicate this is their 1<sup>st</sup> ISONG meeting.

### MEMBERSHIP NUMBERS

### FINANCIALS

- The availability of grant monies is down, in general, but ISONG is at a major disadvantage because it is not recognized as a 501 c3 charitable non-profit organization. When it was established, it was set up as a non-profit 501 c6 organization, with the difference being that there is no tax benefit (charitable) for companies, foundations or individuals to give us money.
- We are restricted in the grant we can apply for such as Genetech (old Roche USA) and even NIH. Often, the first question on a grant application is "Is your organization at 501 c3 charitable organization?"
- I strongly recommend that ISONG begin

setting aside some money to retain a law firm who specializes in tax law to investigate whether ISONG has the possibility of gaining 501 c3 status. The process takes about two years and costs in the area of \$8,000. If approved, we would make this money back within the first year, and then some.

- Ideas for setting aside funds could be: using silent auction funds, cashing in a CD, doing an online fundraiser, a web cast on some hot topic where people pay money to view.

### ISONG WEBSITE

- Our big project this year was redesign and revitalization of [www.isong.org](http://www.isong.org). It was in serious need to attention and thanks to Julie Eggerton and Lynette Howington, we have a brand new website. This redesign included the hiring of a Web-Makeovers, Inc. out of Pittsburgh, PA. Julie, Lynette, some of the board and some of the office staff worked heartily during June, July and August to get pages of the old site reviewed and revised and the new site up and running. I am sure they will report more on developments and a revision schedule during their time at this meeting.

### ISONG IN MONTREAL IN 2011

- The co-chairs for 2011 are Carmen Paniagua and Marlena Kern.
- The theme will be "**Genomic Health World-**

### *wide: Nurses Leading the Way”*

- We are preceding ICHG, with ASGH, in Montreal, Quebec

- The host hotel will be the Hilton Montreal Bonaventure

- Things needing consideration in Montreal:
- Reimbursement guidelines
- Budget
- Considerations for President and/or conference co-chairs
- Marketing of the conference
- Abstracts

### GENERAL OFFICE ACTIVITIES:

- Book sales, template sales, renewals, dues, accounting, membership cards, website updates, coordination of committee chairs and so on.

### FUTURE IDEAS:

- Hold a web cast on some hot topic
  - ▶ Oncology genetics
  - ▶ It could be live, from Pittsburgh, and

attendees receive special invitations to join the webcast for a nominal fee \$30? Attendees would need Flash graphics on their computers and speakers. We would need a grant to accomplish something like this

- Do something to benefit ‘the public’
  - ▶ Write a patient education booklet on some genetic disorder or something like ‘tips for caring for yourself with ...’ This will apply toward our 501 c3 status for the application.
- Money-Saving adventures:
  - ▶ Kassalen has been employed by ISONG since 2005, so for the last 5 years. The average annual fee had always been just around \$50,000. With the incorporation of new staff, billed at a lower rate, we came in about \$47,000 last year and perhaps we will see even more of a reduction this year. We have never raised our rates in 5 years.
  - ▶ I would like to suggest an annual flat fee to ISONG for next year, being paid by the bank automatically, every two weeks.
  - ▶ This saves on paperwork for us, check-writing, postage and so on.
  - ▶ We have 5 years of history to based our flat fee on and I would like to ask the board to consider this, when it comes up, in late December for a possible start of January 1.
  - ▶ We share a mailbox and phone lines to reduce annual costs of this service.



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# COMMITTEES

## COMMITTEES

### BYLAWS AND AWARDS COMMITTEE

*Submitted by Agatha Gallo*

- Bylaws:
  - ▶ No requests or actions for change were considered or recommended this year.
- Founder Awards:
  - ▶ Committee member: Agatha Gallo (Immediate Past President and Chair; Ida Spruill (Membership Committee representative) and Sue Tinley.
  - ▶ Request for nominations were sent to the membership by listserv email and through the *ISONG Newsletter*.
  - ▶ Two nominations were received for each of the Founder Awards categories (Education, Research and Service).
  - ▶ The Committee selected the Award recipients by consensus.
  - ▶ Plaques were ordered by Dr. Janet Williams.
  - ▶ Award recipients were announced at the October 2010 annual meeting in Dallas, TX.

### COMMUNICATIONS COMMITTEE

*Submitted by Co-Chairs:*

*Lynette Howell and Julie Eggert*

#### **Goal: New website**

- Actions and Status
  - ▶ Review & revision by team of ISONG members: Completed 8/2010
  - ▶ Monitoring: We have been receiving feedback and great ideas for additions/modifications.
  - ▶ Direction/policy for continued development and funding: Awaiting BoD input

#### **Goal: Updates to website**

- Actions and Status
  - ▶ Monthly: Co-chairs alternating months for collecting information from others and browsing the site for improvements that we

have the capabilities to make.

- ▶ Making a list and will compile changes at the end of the month and send forward for implementation. (Not certain could meet a twice monthly update deadline.)
- ▶ Keep website access to a minimum but need help with monitoring needs.

#### **Goal: Committee Chair Involvement**

- Actions and Status
  - ▶ As to the inquiries that are received about ISONG: We propose that committee chairs draft potential response letters to the types of responses that they might receive: Awaiting BoD input.
  - ▶ When email inquiries come through, they can be routed to the appropriate committee chair and the chair can send a response letter to the inquiry (Co-chairs not qualified to answer all types of question.). President should not have to answer all questions.

#### **Goal: BoD Minutes**

- Actions and Status:
  - ▶ Suggest posting in Members Only section: Awaiting BoD input.

#### **Goal: Book Posting Policy**

- We ask the board to consider the book posting policy as we are continuing to get inquiries. We



like posting book reviews in the newsletter but don't remember what the policy is for offering books for purchase. Another web page for this purpose would be an extra cost to us so adding a section to a pre-existing page is a less expensive idea: Awaiting BoD input.

## ETHICS AND PUBLIC POLICY COMMITTEE (EPPC)

*Submitted by: Ellen Giarelli and Marie Twal*

### ETHICS AND PUBLIC POLICY COMMITTEE GOALS

- To monitor the emergence of ethical issues related to genetic health care;
- To evaluate ethical and policy issues related to scientific advances and political changes;
- To weigh the need to for an ISONG response to policy changes or issues that relate to the vision, mission and goals of the Society;
- To identify the need for formal position statements and commentaries from ISONG on ethical or policy issues.

## ETHICS AND PUBLIC POLICY COMMITTEE

### ACTIVITIES 2009-2010

- Began a list of contact information on international organizations that address ethical, social and policy issues related to genetics in general and genetic nursing in particular.
- Prepared and submitted for Board approval a position statement on the issue of *Direct to Consumer Marketing of Genetic tests*.
- Reviewed, updated, and posted on the website three position statements:

- ▶ Genetic Counseling for Vulnerable Populations
- ▶ Access to Genomic Healthcare: the role of the Nurse
- ▶ Privacy and confidentiality of Genetic Info: the role of the nurse

## UPDATE ON COMMITTEE GOALS

### ACHIEVEMENT

**Goal:** *Update membership and explore formation of subgroups.*

- Action: No action

**Goal:** *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: No activity

**Goal:** *Systematically review existing position statement for timeliness and relevance (as per ISONG POLICY: Definitions, Process and Format of Position Statement )*

- Actions and Status:
  - ▶ The position statement on DTC marketing of Genetic tests was approved in the Summer was posted on the website.
  - ▶ Three position statements went through multiple edits and revisions. According to the Policy, position statements should be reviewed by the board every two years for relevance and timeliness. At this time all position statement are past due for review. We examined those that were developed by the EPPC.
- Genetic Counseling for Vulnerable Populations (10/10/02, EPPC) – Approved
- Access to Genomic Healthcare (10/6/03, EPPC) – Approved
- Privacy and confidentiality of Genetic Info (8/8/05, EPPC) – Approved

**Goal: Hold at least 2 teleconferences**

- Action and Status:
  - ▶ Core group and subcommittees met multiple times by call and on-line over the last three months. Active reviewers and contributors were: Becky Althaus; Ann Cashion; Cheedy Jaja; Heather Keizman; Alice Kerber; Dale Lea; Lynn Rew; John Twomey; Pam Williams; Lynette Wright.
  - ▶ Held 4 teleconferences and multiple meetings among small groups working on position statements



**GLOBAL MEMBERSHIP COMMITTEE**

*Co-Chairs: Ida Spruill (Domestic) and Pei-Ying (International)*

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

- Recruitment of new members,
- Retention of members,
  - Activate ISONG BUDDY SYSTEM,
  - Respond to needs of membership in timely manner and
  - Diversify the membership (International and Domestic)

Since the last board meeting, we are reporting on the following:

**Goal: Recruitment**

- Actions and Status:
  - ▶ Develop a conference invitation letter for international and national nursing organizations: No mailing list of Nursing organizations
  - ▶ Decide on list of nursing organizations at 2010 committee meeting: Will refine list and present to ED. Recommend mailing to nursing Organizations for 2011 conference

**Goal: Retention**

- Action and Status:
  - ▶ Monthly e-mail reminders will be sent for

membership renewal: Ongoing

**Goal: BUDDY System**

- Actions and Status:
  - ▶ Logo designed by (Erika): August, 2008
  - ▶ Develop information on Buddy System for ISONG newsletter: September, 2008
  - ▶ Sent request for Buddies to membership: October, 2008
  - ▶ E-Mail sent to membership re Buddy System: Ongoing
  - ▶ Will have Information Table at annual conference

**Goal: Members needs**

- Actions:
  - ▶ Will have quarterly contact with Beth/Debbie for membership needs and updates
  - ▶ Will send quarterly e-mail to membership: Ongoing
  - ▶ Survey Monkey
  - ▶ Global committee to meet and recruit at Annual meeting: October 17-19<sup>th</sup>, 2010

**Goal: Diversity**

- ▶ Comments regarding Web page sent to communication committee: New web -page design

## NOMINATIONS COMMITTEE REPORT

*Co-chairs: Emma Tonkin & Carolyn Farrell*

*Additional member: Maxine Adegbola*

During 2009/2010 the committee has completed its tasks to:

- Identify an up-to-date description of each post for use during nominations/election process [Descriptions are as set out in ISONG By-Laws 2007]
- Work with HQ to offer an online nominations process

The online nomination process which also allowed individuals to self-nominate or to contact the committee for further information (prior to putting themselves forward) worked well (see table below).

- Provide a slate of candidates (including personal statements) for posts available in 2010 [President-elect, Treasurer and Member at large]
- Work with HQ to undertake the election and to notify membership regarding the outcome.
- Keep records of all correspondence sent out to potential candidates, nominees and successful / unsuccessful individuals along with a timeline

Table 1 - Outcome of voting

Position	Nomination/self nomination	Final number of candidates (max of 3 permitted)	Outcome
President-Elect	7	2	Ellen Giarelli
Treasurer	2	1	Marie Twal
Member-at Large	6	3	Mary Quinn-Griffin

of activities that can be used by future committee members

## ACTIVITIES FOR 2010/2011

- To identify candidates for the posts of President-Elect, Secretary and Member-at-Large
- When working on the 2010/2011 slate the committee must:
  - ▶ In addition to soliciting new candidates, re-approach individuals identified during 2009/2010.
  - ▶ At least 4 of the individuals, who after consideration choose not to run, remain interested in standing for office next year or in the future after becoming more involved with ISONG through a committee.
  - ▶ 2) Make clear during the nomination phase the eligibility criteria for candidates – Only those with Full ISONG membership are eligible to stand for Board positions

## RESEARCH COMMITTEE

*Submitted by: Gia Mudd and Maggie Kirk*

During the 2009-2010 time period, the co-chairs of the ISONG Research Committee agreed to maintain focus on the previous year's committee goals, as attainment of the goals was identified as integral to accomplishing the mission of committee and meriting continued development. The goals were to:

1. Raise awareness of the role of research within ISONG's core 'business'.

2. Alert members to research opportunities (funding; collaboration).
3. Facilitate the research activities of ISONG members.
4. Disseminate news of research to key stakeholders.
5. Administer the ISONG Annual Grant award through an equitable and efficient process.

Over this year, We are reporting on the following:

### **Goals: 1 to 4**

Actions and status:

- ▶ Moodle site for sharing ISONG research-related information is in-progress: M. Kirk has been leading the efforts on this. A template site has been developed and permission received from the University of Glamorgan to host and manage/monitor the Moodle resource, which could be accessed via a link from the ISONG website.

### **Goal: 3**

- Actions and Status
  - ▶ Research Committee activities, news, and information updated for the new ISONG

website: M. Kirk and G. Mudd submitted updated information for the newly developed ISONG website to provide enhanced information available for organization members.

- ▶ Committee membership update: G. Mudd sent an email to ISONG members to identify interest in participation on the Research Committee. A new membership list was developed based on responses and updated to include information on members' areas of research interest and expertise. This information will provide a foundation for future use in research networking endeavors as well as to support identification of potential proposal review team members.

### **Goal 5**

- Actions and Status:
  - ▶ Funding sufficient to support two research proposals was sought via a request for continued additional support from the University of Pittsburgh School of Nursing: Reflecting past years' support of two research proposals, the University of Pittsburgh School of Nursing was invited to again contribute resources to facilitate funding of a ISONG second grant for the 2010-2011 period. The University's generous response to this request resulted in the availability of two \$1500 research grants, one provided through ISONG and the second by the University of Pittsburgh.



▶ Seven applications were received and reviewed by a team of seven research team members: G. Mudd facilitated review team efforts. All applications were well-written; two proposals were of superior quality and the PIs were named by the review team as recipients of the ISONG 2010–2011 funding.

***Follow-up plans:***

- M. Kirk will continue to work on development of the Moodle site with projected initiation of the site during the 2010–2011 period.

- G. Mudd will work with the in-coming co-chair to address proposal submission process for 2010–2011 including development of:

- ▶ Development of an on-line submission process to facilitate accurate and timely reception of all proposal documents;
- ▶ Development of an annual announcement deadline;
- ▶ Identification of rotating members of the

proposal review team.

The Research Committee has also been asked by the ISONG Board to develop policies on (1) use of ISONG listserv for research surveys, and (2) response to requests for ISONG letters of support for funding proposals. This request will be addressed during the 2010–2011 rotation.





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# FINANCIAL STATEMENTS SECRETARY REPORT BOARD OF DIRECTORS

**TREASURER'S REPORT**

*Submitted by Marie Tival*

Financial summary of the year October 1, 1009 to September 30, 2010

Beginning Balance:		71,861.53
Income:		84,576.77
Expenditures:		121,772.24
Itemized expenses:		
Kassalan Meetings and Events	51,629.06	
Nancy Marshall, CPA	1,966.50	
Website	7,805.00	
Grants/Awards		
J. Rowell	1,500.00	
Ending balance:		34,716.06
CD #1		10,389.97
CD #2		10,335.93
Total Assets		55,441.96

**SECRETARY'S SUMMARY OF  
ACTIVITIES FROM  
OCTOBER 2009-OCTOBER 2010**

*Submitted by Rebekah Hamilton, Secretary*

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.
5. 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:** Meetings of the Board and Committee Chairs

- Executive Board Meetings: 3/3/09 & 09/21/1010

• Executive Board and Committee Chairs Meetings: 12/08/2009, 04/19/2010, 08/04/2010, 10/16/2010

- No business meeting was convened at the annual meeting in 2010

***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 2010-2011

President: Kathy Sparbel [ksparbel@uic.edu](mailto:ksparbel@uic.edu)

Past President: Karen Greco [k.greco4@frontier.com](mailto:k.greco4@frontier.com)

President-Elect: Ellen Giarelligiarelli [ellengiarelli@nursing.upenn.edu](mailto:ellengiarelli@nursing.upenn.edu)

Secretary: Becky Hamilton [rebekah\\_hamilton@rush.edu](mailto:rebekah_hamilton@rush.edu)

Treasurer: Marie E Twal [metwal@auxmail.iup.edu](mailto:metwal@auxmail.iup.edu)

Members at Large:

Sheila Alexander [salexand@pitt.edu](mailto:salexand@pitt.edu)

Mary Quinn Griffin [mary.quinngriffin@case.edu](mailto:mary.quinngriffin@case.edu)

ISONG Office:

Pam Vogel [Pam.Vogel@msn.com](mailto:Pam.Vogel@msn.com)

Beth Kassalen [isonghq@msn.com](mailto:isonghq@msn.com)

## ISONG COMMITTEE CO-CHAIRS 2010-2011

Committee	Co-Chair	Email
2011 Conference Committee	Marlena Kern	<a href="mailto:MKern@nshs.edu">MKern@nshs.edu</a>
	Carmen Paniagua	<a href="mailto:PaniaguaCarmen@uams.edu">PaniaguaCarmen@uams.edu</a>
Education	Rose Nealis Cathy Reed	<a href="mailto:nealirm@ufl.edu">nealirm@ufl.edu</a> <a href="mailto:readca@ucol.ac.nz">readca@ucol.ac.nz</a>
Global Membership	Ida Spruill Pei Ying Chuang	<a href="mailto:ispruill@yahoo.com">ispruill@yahoo.com</a> <a href="mailto:peiyding@yahoo.com">peiyding@yahoo.com</a>
Nominating	Emma Tonkin	<a href="mailto:etonkin@glam.ac.uk">etonkin@glam.ac.uk</a>
Professional Practice	Audrey Tluczek Lori Farmer	<a href="mailto:atluczek@wisc.edu">atluczek@wisc.edu</a> <a href="mailto:lori.farmer@uncp.edu">lori.farmer@uncp.edu</a>
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Ethics & Public Policy	Marie Twal Lynn Rew	<a href="mailto:metwal@auxmail.iup.edu">metwal@auxmail.iup.edu</a> <a href="mailto:ellerew@mail.utexas.edu">ellerew@mail.utexas.edu</a>
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**INTERNATIONAL SOCIETY OF NURSES IN GENETICS, 2010**