





# 2016 Annual Report International Society of Nurses in Genetics

## Table of Contents

RESTATING OUR MISSION .....	2
PRESIDENT’S FINAL REPORT.....	3
IMMEDIATE PAST PRESIDENT’S UPDATE .....	4
COMMITTEE REPORTS .....	4
Bylaws and Awards Committee .....	4
Communications Committee .....	5
Congress Planning Committee.....	6
Development Committee .....	7
Education Committee .....	8
Ethics and Public Policy Committee.....	9
Membership Global Committee .....	12
Nominations and Awards Committee.....	13
Professional Practice Committee.....	15
Research Committee.....	17
BOARD OF DIRECTOR’S REPORT .....	18
EXECUTIVE DIRECTOR’S REPORT.....	18
TREASURER’S REPORT .....	20

## RESTATING OUR MISSION

### **Vision**

The vision of ISONG is: Caring for people's genetic and genomic health throughout the lifespan and across the continuum of health and disease.

### **Mission**

The mission of ISONG is to serve both the nursing profession and the public. ISONG fosters and advocates for the scientific and professional development of its members and the nursing community, in the discovery, interpretation, application, and management of genomic information, for the promotion of the public's health and wellbeing. ISONG advocates for public understanding of genomic health and use of genomic information.

### **Goals**

#### **Global community**

Build and sustain a vibrant international community for the development of nurses in genetics and genomics in relation to education, research and professional practice that enhances social capital by:

- fostering effective communication and networking with nursing organizations and other genetics specialty groups;
- promoting interprofessional collaboration in the care of people, families, and communities at risk for genetic conditions;
- providing a forum for education and support for nurses providing genetic- and genomics-based healthcare.

#### **Integration**

Promote the integration of genetics and genomics across nursing education, research and care at all levels of professional practice, through:

- promoting engagement of nurses with genetics and genomics;
- sharing expertise and best practice in education, research and care delivery;
- offering practical support for continuing professional development.

#### **Leadership**

Demonstrate and promote leadership in the development and implementation of standards of healthcare practice in genetics and genomics for the benefit of patients and families, through:

- leading and influencing public policies;
- articulating standards of practice in nursing professional education and clinical care;
- generating and disseminating evidence for high quality nursing practice; maintaining an outward-facing approach to collaborative working with other relevant public and professional groups.

## PRESIDENT'S FINAL REPORT

by Sandra Daack-Hirsch



It is my pleasure to provide a summary of my work in ISONG as your president. One of my priorities was to focus on clinical practice because it had been a long time since we've highlighted nursing practice in genetics/genomics. This is important to me because we, as an organization, want to lead the way in demonstrating how omics-based research findings can and do change nursing practice. Across the world, we have an important role to play in the promotion of nurses being certified and recognized as experts in clinical genetics. This goal was supported by the membership during the 2015 World Congress where I engaged with you in a Fish-Bowl exercise to discuss how we will promote practice. I am still so pleased that ISONG's 2016 World Congress was centered on practice, and enjoyed an amazing congress with many of you in Dublin, Ireland.

Many of our committees put practice and practice issues front and center this past year. I have highlighted just a few here. The Education Committee had several webinars focused on practice, and I enjoyed being the nurse planner for the "Family History in Clinical Practice" webinar. The Ethics and Public Policy Committee also addressed issues that impact practice, and they promoted ISONG through collaborative publications. The Global Membership Committee networked with several practice and consumer partners to promote ISONG. The Professional Practice Committee completed and published the *Scope and Standards* with the ANA, and they collaborated with the Education Committee and ANCC on an educational webinar on Advanced Genetics Nurse (AGN-BC) certification. Please read, with pleasure and awe, each committee's full report. I am immensely proud of all our committee members and chairs and their significant contributions to ISONG.

I also wanted to be a good steward for ISONG. To that end, I negotiated two collaborations between ISONG and BRN (Biological Research for Nursing). The first is to publish a set of papers (2-4 per issue) on "the basics of genomics research". This is underway, and Dr. Shelia Alexander is the guest editor for this series. The second is to publish an annual issue devoted to genetics/genomics research. I am pleased to say that the first issue is in the works and two ISONG members, Gia Mudd-Martin and Wendy Henderson, will be guest editors for the inaugural issue.

I also worked with CIGNA to revise their policies and forms to recognize nurses certified as a Genetic Clinical Nurse (GCN), Advanced Practice Nurse in Genetics (APNG), or Advance Genetics Nurse (AGN-BC) as "covered" providers in the act of genetic counseling. As I leave the office of president, I hope to continue to work with the education committee to offer webinars in non-English speaking countries where our ISONG members reside. These webinars will be delivered in the home country's native language (or English if they prefer) directed toward nurses in that country. I am working with ANA and the Japanese Genetics Nursing Society to facilitate the translation (English to Japanese) of ANA's *Scope and Standards of Practice Genetics/Genomics Nursing 2<sup>nd</sup>*.

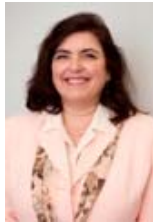
It has truly been my honor and privilege to serve as ISONG's president this past year.

Respectfully Yours,



## IMMEDIATE PAST PRESIDENT'S UPDATE

by Sheila A. Alexander



### **Summary of Activities, Initiatives, Meetings, and/or Events:**

As the Immediate Past President I attended all Board of Directors meetings (except one) and a majority of Executive Committee meetings.

I served as chair of the Nominations and Awards Committee and the Bylaws Committee. Please see those Annual Reports for a review of activities.

I additionally served as chair of the Development Committee. Please see that Annual Report for a review of activities.

### **Specific Goals set at start of year and progress report on the goals:**

- Solicit new members for the Development Committee. A call was sent out to the general ISONG members and specific individuals were encouraged to join this committee by myself and other board members. One individual joined the committee.
- Support current President in all initiatives and transitioning into the role. Achieved.

## COMMITTEE REPORTS

### Bylaws and Awards Committee

by Sheila Alexander

#### **Summary of Activities, Initiatives, Meetings, and/or Events:**

The Bylaws committee serves to review and update bylaws as needed. The Bylaws went through a substantial review and revision over the previous 18 months (April, 2014-November, 2015). Given that, the bylaws were not reviewed since November 2015.

#### **Specific Goals set at start of year and progress report on the goals:**

None as the Bylaws underwent a major overhaul in late 2015.

For the 2016-2017 year, the incoming chair may want to consider reviewing the bylaws, but also making recommendations for elimination of some sections of the bylaws that are outdated or repetitive. For instance, the 'Nominations Committee' and the 'Awards Committee' were merged into the 'Nominations and Awards Committee' last year yet the 'Nominating Committee' still appears as a separate and repetitive entry in the bylaws (section 7.5a and 7.5i).

#### **Committee Members**

For the 2016-2017 year, I recommend the incoming chair determine if there is a need for full bylaws revision and solicit committee members accordingly.

#### **Other Comments**

The Bylaws Committee does not have a large workload every year. It is my opinion that this committee should be disbanded and removed from the bylaws, with a change in bylaws (and process) that ensures bylaws are reviewed every few years by the Board of Directors rather than maintaining a committee with low workload.

## Communications Committee

by Jamie Newland & Paule Joseph

### **Summary of Activities, Initiatives, Meetings, and/or Events:**

1. Communication through email, face-to-face during annual meeting on 8/05/2016, and one conference call on 10/25/2016.
2. Jamie and/or Paule either attended or sent verbal/written report for Board calls in January, March, May, August (annual meeting), and October.
3. Instituted limited communication via social media on Twitter and Facebook.
4. Links to ISONG social media accounts were prominently placed on ISONG home page.
5. Linda Mason sent outside requests for information to be placed on ISONG website to Jamie for review and approval, including where to place on website.

### **Specific Goals set at start of year and progress report on the goals:**

1. Conduct a survey of members (and larger nursing population?) for comments on website to identify areas on which to work.
  - Was not feasible for committee during this year.
2. Contribute content regularly to the e-Updates, either written or acquisitioned (e.g. announcement of publication) by (rotating) committee members.
  - Wrote a blurb about social media but had no regular contributions. Linda Mason assembles content and creates monthly e-Updates.
3. Identify ways to become more involved in recruitment of new members; work with Membership.
  - Collaboration pending.
4. Place (promote) content in the Members Only section, such as past webinars, to create tangible benefits to membership.
  - Link to Section is more visible on home page with benefits of membership better highlighted. Access to webinars and associated fee accessible to anyone from home page.
5. Highlight research grant recipients and member activities on website.
  - Two members at a time highlighted on Members Only login page so visible to anyone.
6. Partner with Education Committee to identify areas for collaboration to market ISONG products, such as webinars.
  - Paule has had conversations with Education co-chairs; no action yet.
7. Increase member (and others') participation in ISONG social media connections – Twitter, Facebook, LinkedIn, Pinterest, etc. (and track numbers).
  - Paule and Linda sent messages of events or news, but long spaces of no activity on site. To date, Facebook has had 243 likes and Twitter has 68 followers. ISONG follows 79 people/companies.
  - Committee members listed below:

Fifteen members from the past 2 years were queried. Most because of other obligations (work, family, school) indicated they were not able to continue participation on committee. A few never responded. After the annual meeting in August, there are 6 active members:

Jamie Newland, co-chair	New York University
Paule Joseph, co-chair	National Institutes of Health-NINR
Carolyn Allen	Georgetown University
Stacy Hines-Dowell	St. Jude's Children's Research Hospital
Caitlin Dreisbach	University of Virginia Health System
Lacey Joan Wright	University of Pittsburgh – doctoral student

Maggie Kirk agreed to review content for international tab on website on an as needed basis. The website is primarily maintained by staff in the office.

#### **Other comments:**

Communications are managed effectively through office staff. With the growing committee numbers now, we plan to make assignments and move forward with goals:

1. Improve appearance and usability of ISONG website.
2. Increase member engagement with ISONG through social media.
3. Attract new members through social media and the ISONG website.
4. Work closely with other committee chairs to publicize their work and to update the website.

## Congress Planning Committee

by Kim Subasic, Tina Mladenka, Susan Wesmiller

#### **Summary of Activities, Initiatives, Meetings, and/or Events:**

This committee has taken charge to develop the 2016 Annual ISONG Congress. The theme for this year's event is "Integrating Genetics across Nursing Practice".

#### **Specific Goals set at start of year and progress report on the goals:**

1. To obtain an international presence for the Congress with regard to presenters and attendees.
  - Meetings - The guest speakers were from Ireland, the United Kingdom, and the United States. In addition to podium and poster presenters from around the world, an International Panel will address issues specific challenges to integrate genomics into nursing.
  - Activity(ies) - Invitations to guest speakers (congress co-chairs)  
Abstract committee  
International Panel Committee
  - Budget/Finance issues related to the goal - need to pay or support speaker-related costs
2. To acquire speakers who represent a broad spectrum in the application of genetics and genomics.
  - Meetings - LOTS of meetings and calls to identify potential speakers
  - Activity(ies)- Invitations to potential speakers
  - Budget/Finance issues related to the goal- need to pay speakers
3. To develop a Congress that will serve the varied interests of ISONG members.
  - Meetings - Monthly meetings with the ISONG Congress Planning Committee.

- Activity (ies) - Sub-committees of the Congress Planning Committee worked feverishly to respond to the charges for their committee and to report their activity (or plans) during the monthly conference call.
- Budget/Finance issues related to the goal - General finances needed to support the overall production of the Congress.

4. To build on the nursing and genetic knowledge of the ISONG members.

**Budget/Financial Comments:**

The financial challenges for this committee are largely related to the need to pay for speakers. It is also crucial to have good speakers so that the congress attendees will continue to increase.

## Development Committee

by Sheila Alexander

**Summary of Activities, Initiatives, Meetings, and/or Events:**

The first several months of the year were spent identifying and soliciting new members. One individual volunteered.

**Specific Goals set at start of year and progress report on the goals:**

The Development Committee serves to facilitate outreach to community organizations, educational institutions, associations and businesses to advocate for ISONG’s mission. This includes building relationships with schools of nursing, collaborating with agencies to foster new initiatives, and promoting sponsorship of professional and public education related to genetics and genomics.

This committee had not been an active committee for a few years. As such, goals were focused on:

1. Identifying committee members - A call for members was sent out to the membership and board members were encouraged to reach out to appropriate individuals to encourage volunteers.
  - One member, R. Koszalinski responded and played a vital role in the revitalization of the committee
2. Developing an ‘elevator speech’ or set of talking points for use by Development Committee members and the ISONG membership.
  - A document was developed by B. Kassalen and S. Alexander and sent out to relevant individuals (K. Hickey, T. Mladenka, T. McKamie and A. Kerber) and the BoD for review. The document was finalized in late March, 2016 and is available for members.
3. Seeking out new sponsors and collaborating agencies.
  - Through the tireless work of Linda Mason and the 2 committee members, we established or improved relationships with a few new groups including:
    - Ariosa Diagnostics who advertised a job listing with ISONG and we are working to obtain sponsorship of future events.
    - Leadership-Knoxville- ISONG materials distributed.
    - University of Tennessee-Knoxville (ongoing webinar, congress or other support).

For the 2016-2017 year, the goals of the Development Committee will be to 1) continue to solicit new members and 2) continue to solicit new sponsors and collaborating entities.



## **Committee Members**

For 2016-2017 members include S. Alexander and R. Koszalinski.

## **Other Comments:**

The Development Committee has an important role within ISONG. It would be beneficial to have a larger pool of committee members to increase productivity of this group. Please continue to try to solicit new members for this committee.

## Education Committee

by Jennifer Sanner

### **Summary of Activities, Initiatives, Meetings, and/or Events:**

1. Meetings:
  - August 3rd, 2016 (full committee)
  - September 23rd, 2016 (partial committee)
  - scheduled for November 21st, 2016 (full committee)
  
2. Webinars 2016:
  - February: ANCC/ISONG Co-sponsored: “Advanced Genetics Nursing Certification: Informational Webinar & Certified Provider Panel”
  - March: “Family History in Clinical Practice”
  - April: “Pharmacogenomics and Your Clinical Practice”

### **Specific Goals set at start of year and progress report on the goals:**

1. Offer at least 4-5 webinars from January 2016 to December 2016.
  - Three webinars completed (see above)
  - Three webinar topics in development
    - Genetic Apps & Integration with Clinical Setting [Alice Kerber (ISONG) & Lori Orlando, MD – Duke, contacted for interest]
    - Emerging Trends in Pediatric & Prenatal Genetics [Stacy Hines-Dowell, DNP, APNG, FNP-BC [(St. Jude’s) contacted for topic fit]
    - Clinical Exome Sequencing [Jennifer Loud, RN, CRNP, DNP (NIH/NCI), contacted for interest]
  
2. Secure webinar sponsors for at least 2 webinars.
  - Subgroup will be established during November 21 meeting and will lead
  - Dr. Pestka: Obtained a lead with UT-Knoxville for sponsorship r/t Informatics and genetics webinar
  
3. Develop a marketing plan for webinars.
  - Discussions & investigations continuing; anticipate difficulties with marketing itself no budget
  - Will identify a lead for the development of a marketing plan at the November 21 meeting

4. Discuss potential for ISONG to expand our educational ‘products’ beyond webinar platform (perhaps as a pilot).
  - BoD has approved the committee to ‘pilot’ inviting some of this years’ Congress speakers (Dublin) to develop their Congress presentations into full-scale webinars. Cathy Read is leading this initiative. Goal is to get 1 speaker from each of the three categories (Research, Education, and Practice) to develop webinars for next year that expands on their Congress presentation. We have confirmation that this is feasible and allowable from a CEU perspective. Update: Congress speakers evaluated by Educ. Committee members and list generated with 5-6 strong speakers (who stated interest in developing talk for webinar); confirmations/planning in progress.
  - Additional ideas for educational platform expansion will be discussed at November 21 meeting.
5. Update website for 2016-2017.  
Subgroup will be established during the November 21 meeting and will lead.
6. Secure place for ISONG webinar information on the G2C2 landing page.  
J. Dungan submitted application request for ISONG to have a G2C2 Landing Page (to Donna Messersmith); has been assigned reviewer, and HQ asked to provide reviewer webinar access for review.
7. Submit formal proposal with business plan to BoD requesting a % webinar revenue back to Education committee to support future webinar marketing.  
We would like to have the BoD consider allocating a small percentage of webinar revenue back to the committee to help support future our webinar marketing endeavors. Committee members agreed that an initial request of 10% of registration and sponsorship (calculated after HQ overhead) is a reasonable start, with the potential to increase this percentage if board-approved metrics are met.

**Budget/Financial Issues:**

2016 Webinar Revenue: \$1725, minus HQ operating/support costs for webinars of \$630 = \$1,095 total.

## Ethics and Public Policy Committee

by Dr. Marie E. Twal

**Summary of Activities, Initiatives, Meetings, and/or Events thus far:**

1. Development of White Paper entitled *The Genetic Information Nondiscrimination Act of 2008 and Discordance with the Patient Protection and Affordable Care Act of 2010*.
2. Completion of Manuscript to be submitted for publication entitled *Application of the Code of Ethics for Nurses to Genetic/Genomic Nursing*.
3. Significant work on the revision of the position statement addressing Direct to Consumer Genetic Testing.

**Specific Goals set at Start of year and progress report on the goals:**

**Website:**

1. Position Statement on bio-banking is not formatted correctly, lacks identification of contributors, and has a different-appearing link than the other statements.
  - Formatting corrected.
2. Would like to make tab for the position statements on home page so they are easily accessible. Not all position statements relate to ethics and public policy and are not appropriately placed under that tab.
  - Discussed among committee members, Linda Mason, and co-chairs of Communications Committee. No resolution.
3. The only item under the Ethical Issues tab is HIPPA of 1996.
  - Needs addressed in 2017.
4. There is no information under the Public Policy Information tab.
  - The White Paper on GINA is now placed there.
5. Determine if current website has ability to track # of hits on specific position statements.
  - ISONG cannot track # of hits on specific position statements.
6. Determine complexity and cost of making changes in website.
  - Did not determine cost since we have not yet determined best solution.
7. Investigate possibility of including links to selected articles pertaining to genetic nursing and ethics.
  - Beginning conversations. Needs to be addressed in 2017.

**Position Statements:** There are currently 8 position statements.

1. Direct-to-consumer marketing of Genetic Tests was approved in 2009 and now requires a review.
  - Subcommittee of JaJa Cheedy, Carolyn Farrell, Heather Skirton, Chris Wade & Marie Twal. Held 3 meetings. Expect completion by January 2017.
2. Last revised in 2010 – to be completed in 2017.
  - Access to Genomic Healthcare: The Role of the Nurse – Headed by Michael Groves.
  - Privacy & confidentiality of Genetic Information: The Role of the Nurse – Susan Dickey, Mary Beth Steck, Leslie Darmofal
  - Genetic counseling for Vulnerable Populations: The Role of Nursing – Laura Beamer, Mary Kracun, Paule Joseph, Cheedy Jaja and Laurie Connors.
3. Provision of Quality Genetic Services and Care: Building a Multidisciplinary Collaboration Approach among Genetic Nurses & Genetic Counselors was last reviewed in 2006.
  - See this as a practice issue rather than ethical. Referred to Practice Committee.

**Manuscript:**

1. Integrating genetic nursing with the revised ANA Code of Ethics. Application of the Code of Ethics for Nurses to Genetic/Genomic Nursing.

- Group began meeting Spring of 2015. Stalled a bit but moved forward with monthly meetings. Reviewed by entire EPP Committee. Sent to Board Oct. 17, 2016. Audrey Tluczek, Marie Twal, Laura Beamer, Candace Burton, Leslie Darmofal, Mary Kracun, Martha Turner, Karen Zanni

**White Paper:**

1. Mary Beth Steck and Susan Dickey have produced a white paper on the scope and limitations of GINA.
  - Sent to EPP committee for review and comment.
  - Approved by Board in March.
  - Placed in Public Policy tab of EPP Committee on Website.

**Communication:**

1. Committee meetings to be held as needed.
  - In person meetings Nov 8, 2015 and Aug 4, 2016.
  - Conference Calls Jan 12, 2016 and Sept 29, 2016.
2. Committee report will be sent quarterly to committee members.
  - Minutes of meetings sent to all members.
3. The ISONG monthly e-update is sent to all members of ISONG and is a good vehicle to alert members to ethical and policy issues.
  - Need investigation into feasibility and discussion regarding topics and format.
  - Some conversation about this but have not yet developed plan.
4. Offer services of this committee to other ISONG committees  
Not done.

**Miscellaneous:**

1. Received and responded to inquiry from Association of Women's Health, Obstetric and Neonatal Nursing regarding our process for reviewing position statements.
2. Agreed to improve communications with the Board by including Cathy Read in all committee updates

**Budget/Financial Issues:**

The committee is grateful to Kassalen Meetings & Events for providing conference calling for our general meetings, as well as for meetings of subgroups working on the White Paper, Position Statements, and the Manuscript. Linda Mason and other staff are very accommodating and helpful with an array of questions.

**Committee Members**

Linda Mason has been notified of a change in the committee list. We continue to work with her as we become aware of resignations and additions.

**Other Comments**

The committee thanks the Board for its flexibility in working to forward our agenda in a timely manner.

## Membership Global Committee

by Susan Fernbach and Gigi Lim

### **Summary of Activities, Initiatives, Meetings, and/or Events:**

#### **Initiatives:**

1. Raising ISONG awareness through seminars, letters and face to face contact where possible.
2. University of Auckland School of Nursing has not adopted curricular thread relating to genetics and genomics. Another ten hours added to 15 hours of teaching genetics in the undergraduate level. Four students doing genetic research in their honors year starting 2017.
3. Susan has made contact genetic nurses in Guatemala. Informing them of ISONG conference for 2016. Unfortunately, they were not able to attend due to lack of funding.
4. Gigi has one master's student who is currently seeking funding to attend the conference. This student is currently doing targeted therapy research under clinical pharmacology and nursing.

#### **Meetings:**

1. ISONG was promoted in the 2016 February meeting on Rare Disease condition in Texas.
2. ISONG was promoted in a seminar of Filipino Nurses organization in Texas.
3. ISONG was promoted in the Curriculum Meeting of the Board of Studies University of Auckland.
4. ISONG was promoted in a letter to three Schools of Nursing in New Zealand and three nursing schools in Australia.
5. A flyer about the ISONG conference will be advertised in the First Interprofessional Symposium for safe and quality prescribing. A focus on pharmacogenomics will be use as the participants will be doctors, nurses, midwives and pharmacists.

### **Specific Goals set at start of year and progress report on the goals:**

#### **Meetings:**

1. Collect information from all Global Committee members re their research activities and commitment to ISONG.
  - Done – Need to finalize LIST
2. Increasing awareness – promoting ISONG in six schools of nursing in New Zealand.
  - Achieved
3. Increasing awareness – promoting ISONG in ten Australian Schools of Nursing.
  - To date only three Australian universities.

## Other comments

Susan and I feel that schools of nursing outside of United States (e.g. New Zealand and Australia) do not have a good understanding of ISONG and what it does. They can relate to genetics, however many cannot relate to genomics and epigenetics. I have been informed that every time the Head of Schools of nursing receive notifications and letters from ISONG, the letter is forwarded to Molecular and Biochemistry Departments. This is because very few nurses are involved in genetics and genomic research and if they are, their role in the project is minimal and not in a lead role.

Genetics and genomics research and education is still very new in Australia and New Zealand. Therefore, there may be opportunities in the future to promote ISONG in the nursing schools. However, face to face may be the best way to go forward. This is my goal for the rest of 2016 for recruiting more international members for ISONG.

## Nominations and Awards Committee

by Sheila Alexander

### Summary of Activities, Initiatives, Meetings, and/or Events:

1. The Nominations Committee solicited nominees for the ISONG Board of Directors positions open for the 2016-2017 year. Open positions include: President-Elect, Treasurer, Member-at-large, and the newly formed Student Representative. The Call for Nominations was revised in 2014-2015. The Call was reviewed in early April and two changes were made: 1) the Student Representative position and its' description was added and 2) contact information was changed (updated). The Call was sent to full ISONG membership on April 12<sup>th</sup>, 2016 with a deadline of May 27<sup>th</sup>, 2016. Committee members encouraged individuals to self-nominate and encouraged current BoD's to nominate peers. As of May 27<sup>th</sup> the following individuals self-nominated:

President-Elect: No nominees.

Treasurer: L. Howington, R. Kronk

Member-at-large: S. Barnoy, L. Beamer, D. Cheek, M. Groves

Student Representative: L. Wright

2. Slate of nominees were presented to the BoD at the June meetings. After much discussion, it was determined that some board members might consider self-nominating and/or changing their nomination from one position to the President-Elect position. If no one self-nominated in the next few days, we would re-open the call. D. Cheek changed his nomination from MAL to President-Elect and M. Tinkle self-nominated. The remaining board members approved the slate of nominees and the following ballot was distributed to ISONG membership on June 17<sup>th</sup>, 2016:

President-Elect: D. Cheek, M. Tinkle

Treasurer: L. Howington, R. Kronk

Member-at-large: S. Barnoy, L. Beamer, M. Groves

Student Representative: L. Wright

3. Voting closed on July 15<sup>th</sup>, 2016 with new BoD announced at the ISONG conference (August 4-8, 2016) and positions taking effect at the November board meeting. New BoD members include:

President-Elect: M. Tinkle  
Treasurer: R. Kronk  
Member-at-large: S. Barnoy  
Student Representative: L. Wright

4. For the 2016-2017 year, open positions on the BoD include President-Elect, Secretary, one Member-at-large and Student Representative. Up to 3 nominees may appear on the ballot for each position.
5. This committee also serves to manage the ISONG Founders Awards process. The committee solicited nominees for the ISONG Founders awards in Education, Practice and Research for the 2015-2016 year. The Call for Nominations was revised in 2014-2015. The Call was reviewed in early April and no changes were made. The Call was sent to full ISONG membership on May 2nd, 2016 with a deadline of June 25th, 2016. Committee members encouraged individuals to self-nominate and encouraged current BoD's to nominate peers. The following members were nominated for each award:

Education: L. Ward, L. Badzek, J. Taylor  
Practice: T. McKamie  
Research: L. Badzek

6. The committee reviewed and scored all nominations separately. Drs Cheek and Hickey sent scores to Dr. Alexander who combined them with her own scores. Scores were in excellent alignment with the 'top score' in each category matching for all reviewers. Due to this strong match, there was no need for a conference call meeting. The Founders Award winners were:

Education: Linda Ward  
Practice: Tammy McKamie  
Research: Laurie Badzek

Names were forwarded to L. Mason on July 11th so plaques could be made for presentation of the awards at the ISONG annual congress in August, 2016.

**Specific Goals set at start of year and progress report on the goals:**

1. Specific goals were to have more than one nominee in each position on the ballot and one or more nominees for each of the Founders awards: Education, Practice and Research.
  - The committee members and the BoD encouraged individuals to self-nominate and/or nominate others for both BoD election and Founders Awards. Two board members not on the Nominations and Awards Committee did nominate other individuals for awards.
  - The committee achieved this goal as there were more than one nominee for each BoD position except Student Representative (a new position) and at least one nominee for each award, and 3 nominees for the Education award.
  - For the 2016-2017 year, I recommend maintaining this goal and identifying new ways to solicit additional nominations for the BoD and the Founders Awards.

**Budget/Financial Issues:** None.

## **Committee Members**

I did not receive a 'committee list in advance of the Congress. For the Nomination process, committee members were S. Alexander (chair), D. Cheek (until he was nominated) and K. Zanni. This was a variance from the bylaws as the chair did not realize the bylaws stated there should be 3 committee members in addition to the chair. For the Founders Award process, committee members were S. Alexander (chair), D. Cheek and K. Hickey.

For the 2016-2017 year, the Immediate Past President (SDH) serves as chair of the committee and will select committee members. The ISONG bylaws state there should be 3 committee members in addition to the chair. Nomination and Awards committee members serve for one year. The chair may serve a second year to maintain continuity and, if Dr. Daack-Hirsch prefers I serve an additional year I am willing to do so. Committee members should be individuals with full membership for 3 years preceding the committee appointment. Nomination and Awards committee members cannot be on the ballot.

## **Other Comments**

The committee leadership rotates such that the Immediate Past President takes over as chair of the Nominations and Awards committee in November. Dr. Sandy Daack-Hirsch will step into this position at the end of the November BoD meeting. Dr. Alexander (current chair) will reach out to Dr. Daack-Hirsch in early November and provide discussion and orientation to the position.

## **Professional Practice Committee**

by Alice Kerber and Tammy McKamie

### **Summary of Activities, Initiatives, Meetings, and/or Events thus far:**

1. Completed update of *Scope and Standards* with ANA.
  - Published 4/1/16
2. Collaborated on and presented in educational webinar in collaboration with ANCC and Education committee re: advanced genetics certification (Alice Kerber, Nancy Ledbetter, and Suzanne Mahon).
3. Initiated communication with GCN (Tammy McKamie) to evaluate interest in generalist certification continuance through ANCC. Discussed the pros and cons of GCN certification as well as testing options vs portfolio for Advanced Genetics Nursing-Board Certified (AGN-BC).
4. Initiated Chat room on ISONG website for GCN (Tammy McKamie).
5. Collaborating with Marie Twal on updating position statements.
6. Ongoing telephone and online communication between Tammy McKamie and Alice Kerber – no official meetings other than one at Congress 2015 (Tammy McKamie).
7. Tammy McKamie along with Susan Montgomery and Yvonne Hanhauser gave a presentation on “Exploring Diversity Across Cancer Genetic Clinical Practices”.



8. 2016-2017 goals were set at World Congress 2016 with the new members of the professional practice committee (ppc).
  - Ten members joined this committee while at congress.
9. Susan Montgomery RN BSN OCN GCN accepted the position as co-chair of professional practice committee and serve along with Tammy McKamie.

**Specific Goals set at start of year and progress report on the goals:**

1. Complete scope and standards update - Completed (as above).
2. Promote involvement of both advanced practice and generalist genetics nurses through webinar and online activities (as above).
3. Mentoring/Shadowing: Our committee consists of individuals who are experts in a variety of areas such as: Neuro, Psych, Oncology, Cardio, Primary Care, Gerontology etc. The first step is to identify ourselves in detail to allow others to know which individual is appropriate to increase their knowledge in clinical genetic practice.
  - Progress: A brief overview of our mentoring opportunity was posted on the ISONG website as well as all ISONG social media platforms
  - Opportunity for Learning from Nurses in Genetics/Genomics Clinical Practice
  - Members of the International Society of Nurses in Genetics (ISONG) Professional Practice Committee are eager to share their expertise with individuals interested in learning more about genetics/genomics nursing. We are prepared to respond to questions and provide brief mentoring experiences. Please respond to the following e-mail [linda@isong.org](mailto:linda@isong.org) and provide your name, contact information, and specific questions or request for mentoring in a specialty clinical area.
  - Linda Mason monitors requests and forwards them to Tammy for assignment to the appropriate committee member.
  - Tammy has collected demographic information using a form titled “*Clinical Genetic Champions*” from all ppc members that include their specialties in nursing genetics and professional background.
  - To date we have had 4 inquiries that have been successfully answered ranging from how to further their interest in genetics to how to charge for genetic counseling.
4. Increase the number of abstracts submitted to conference regarding clinical practice: Each of the committee members submit an abstract on clinical practice for the 2017 Congress and try to get at least one other person to do the same.
5. Increase the knowledge of genetic information in a particular practice via articles: Julie Eggert agreed to take the lead and write the first article “What You Need to Know about Genetics in Your Practice” (i.e. listing the main “Red flags” for each area etc).
  - Progress: Julie received a positive response from Cindy, Editorial Director of *American Nurse Today* and she will be talking with her via phone conference November 7<sup>th</sup> to discuss the details. She provided a link to the author guidelines: <https://www.americannursetoday.com/author-guidelines/>

## **Committee Members**

At the 2016 World Congress 12 volunteers come forward to join the PPC.

### **Feel free to provide other comments for the Board of Directors.**

I have been honored to serve for the past several years and am happy to continue in the capacity of resource. I hope fresh leadership will promote participation. I am also glad to have completed the Scope and Standards! Alice Kerber

I am honored to serve as Co-chair of the ppc along with Susan Montgomery. I want to thank Alice Kerber for asking me to serve as Co-chair with her for 2015-2016. She not only encouraged me to become a member of ISONG but also brought out the best in me professionally by encouraging me to become credentialed as a GCN and helping others to do the same. I would also like to thank Beth Pestka for nominating me for the Founder's Award *Excellence in Genomic Nursing Practice*. What an honor. I look forward to this next year and all the exciting things our committee can provide to other nurses interested in the field of genetics. -Tammy McKamie

## Research Committee

by Rebecca Kronk

### **Summary of Activities, Initiatives, Meetings, and/or Events thus far:**

1. Updated the research grant web-page with current information.
2. Help to solicit grant donors.
3. Solicited 12 grant letters of intent.
4. 13 committee members served as reviewers for 8 full applications; newer committee members were involved; 48% of committee dedicated their time and expertise to this process.
5. Awarded two \$2500 grants.
6. Had initial meeting with board to discuss role of Research committee with BRN Special Issues.

### **Specific Goals set at start of year and progress report on the goals:**

1. Continued to refine and protocolled grant review process – completed.
2. Provided reviewer feedback to grant applicants—completed.
3. Updated membership list—completed.

### **Budget/Financial Issues**

Discussed with Board Liaison monies designated to research funds; will continue to grow this year possibly to support future grant awardee

### **Committee Members**

There are currently 31 members on this committee. List provide to headquarters.

## Other Comments

At the Committee meeting held at Congress 2016 with discussed the opportunity and obligation to orient grant reviewers to the peer review process and to pair “new” reviewers with more experienced reviewers. Allison Vorderstrasse provided these two resources to help with peer review training:

1. Peer review meeting video  
<http://public.csr.nih.gov/aboutcsr/contactcsr/pages/contactorvisitscrpages/nih-grant-review-process-youtube-videos.aspx>
2. Slide show tutorial on reviewing:  
<http://internet.csr.nih.gov/reviewerorientation/OrientationtoPeerReviewFinaltoPostCAK.pdf>

## BOARD OF DIRECTOR’S REPORT

### Biological Research in Nursing (BRN) journal

- Working with Carolyn Yucha and Marnie Wiss on two projects to promote ISONG and biological nursing research in genetics
- The BoD and Research Committee chairs working on the logistics of creating a special genetics/genomics issue and a series of articles on basic genetics in collaboration with BRN

### SLACK Journal of personalized Healthcare

- Tom Moore has talked with several ISONG members – exploring ideas for new journal

### Thanks to:

- KME
- Board of Directors
- Committee co-chairs
- Committee members
- Individual members

## EXECUTIVE DIRECTOR’S REPORT

by Beth Kassalen



### ISONG Celebrates its Global Reach

ISONG reaffirmed its commitment to our global members this year by holding the 2016 World Congress on Genetics and Genomics in Dublin, Ireland. To facilitate travel to Europe and secure accommodations for the Congress and our attendees, ISONG moved the Congress to August 1-4 instead of its typical first week of November timeframe.

Registrations peaked around 143 and ISONG enjoyed a healthy representation of exhibitors and vendors. The Royal Marine Hotel was our host venue for the week and the location, with a view of the harbor just outside of the front door, added to the enjoyment of the event as ISONG members and attendees brought their family members, friends, or colleagues to share in the event.

Sandra Daack-Hirsh presided over ISONG Congress this year and made stellar contributions in leading the ISONG Board and the many ISONG committees. Special recognition and thanks goes out to all Board members this year, our committee chairpersons and all members are willing to donate their time serving on our many committees.

### **Students have Voice on the Board of Directors**

Based on interest, opinion, and an ultimate vote of the membership, ISONG welcomes its first student representative on the Board of Directors, Lacey Wright. The contribution of this student position to the Board is to represent all ISONG members, not just students, but to help the Board retain a pulse and understanding of the needs and views of genetics students in relation to the benefits and offerings provided by ISONG. The position carries a one-year term, and will be on the ballot each year as an opportunity for a qualified nursing student to support ISONG and serve on its Board.

### **Membership numbers**

Membership numbers in 2016 rose about 6% to a total of 367. Historically, ISONG's membership rolls range from 320-350 so we are pleased that new members are finding their way to ISONG and all it has to offer. The Membership Committee has been making strides in reaching genetics nurses in countries outside of North America, and has been collaborating with country liaisons to spread word about ISONG. In 2016, ISONG renewed its commitment of supporting emerging countries, through the World Bank economic identifiers, with discounts on membership dues.

### **ISONG continues its collaboration with ANCC**

The American Nurse Credentialing Council (ANCC) continues its commitment to providing genetics-related credentialing by portfolio for the advanced genetics nurse. Some disappointment ensued when the credential for the basic genetics-level nurse was dropped by ANCC, partly due to not being able to fulfill the commitment to those who were eligible to serve on a 'peer' group for an expert panel or reviewers for portfolio submissions. There were too few eligible people available and/or willing to serve on an expert panel or as reviewers to continue the certification offered to those interested in the basic genetics level. The ISONG professional practice committee is interested in staying abreast of this issue and will continue to monitor interest and progress on this issue.

ISONG Congress 2017 will be held in Reston, Virginia, just outside of Washington, DC, with easy international flight access to Dulles, Reagan National, and Baltimore/Washington airports. Mark your calendar to attend on November 3-5, 2017.

The **Education Committee** offered a robust set of webinars to be offered to both ISONG members and those non-genetics nurses who want to understand more about how genetics impacts their specialty over the year. ISONG members continue to be interested in serving on this committee and lending their time and expertise to being nurse planners for the webinars.

The **Communications Committee** has focused on social media over the last year. We encourage all of you to LIKE the ISONG Facebook page, FOLLOW us on Twitter, Join Us on LinkedIn and start contribution to these social media platforms. Post links to interesting articles relevant to genetics nurses, or post link to your own articles or books. Add pictures, grant information, links to educational opportunities of interest to genetics nurses. Start a conversation on an article, a link, information about the research you are working on, or topics you would like to discuss.

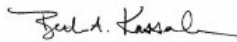
### **Biologic Research for Nursing (BRN) Journal**

ISONG has entered in a collaboration with the BRN to publish a set of papers on the basics of genetics research. Read more about this collaboration under President's Final Report in this annual report. To date, there are several calls available, for ISONG members to contribute to this effort. Visit the website, [isong.org](http://isong.org) for more information.

### **Trip to Cuba**

Beth Pestka headed up an initiative to have a consortium of ISONG members and genetics nurses go to Cuba to explore international nursing relations with nurses in Cuba interested in genetics. Although the trip did not materialize due to lack of travelers and cancellation by the tour operator, this endeavor shows continuation of ISONG mission to reach genetics nurses around the world.

Sincerely,



## **TREASURER'S REPORT**

by Melinda Tickle

1. This report covers financial data from January, 2016 – December, 2016 with some comparison data from 2015.
2. At the end of the 2016 calendar year, our cash balance is \$57,792.82.
3. Annual Income and Expenses: Our total annual income for 2016 is \$144,180.61 and our total expenses are \$143,439.90, leaving our net annual income at \$1,040.71 (compared to \$11,779.84 for 2015). We budgeted a net profit of \$13,998 at the beginning of the year, but our expenses were a bit higher than expected. For 2016, ISONG finished with a small profit, and therefore we did not need to use any of our reserves.
4. Congress: Congress income for 2016 is approximately \$91,224.15 and expenses are \$72,909.23. Our net profit for Congress is \$18,313.92 (compared to the budgeted profit of \$29,822.21), reflecting a variance of -38%. Holding a Congress in Europe (or out of the East coast corridor) is associated with a fairly consistent issue in meeting budget goals (Arizona Congress, 2014= net profit of \$8K; DC Congress in 2015= net profit of \$39K). The Executive Board has expressed its commitment to holding Congress meetings in a variety of venues, but is cognizant of the overall budget implications in terms of the meeting location.
5. Other Items:
  - a. Membership Dues: Our annual membership dues are \$44,735 (on goal with our budgeted projection of 44K) and consistent with our dues history (\$44,805 in 2014 and \$43,125 in 2015).
  - b. Management Fees: Fees for 2016 calendar year are \$59,874.88 (compared to \$58,131.14 in 2015). This reflects a 3% increase (or about \$1,700).

6. Budget for 2017: The new treasurer, Dr. Becky Kronk, the Executive Director and other headquarters staff will be finalizing a projected budget for 2017 to present to the Executive Board. The annual Congress for 2017 will be held in Reston VA and this helps to build confidence in this year's potential Congress earnings which are critical to ISONG's financial health.

Respectfully submitted February 6, 2017

