





2017 Annual Report International Society of Nurses in Genetics

Table of Contents

2016-2017 BOARD OF DIRECTORS	2
RESTATING OUR MISSION	2
PRESIDENT’S FINAL REPORT	3
COMMITTEE REPORTS.....	4
Bylaws and Awards Committee.....	4
Communications Committee.....	5
Congress Planning Committee	6
Development Committee	6
Education Committee.....	6
Ethics and Public Policy Committee	9
Membership Global Committee	11
Nominations Committee	12
Professional Practice Committee	13
Research Committee	15
EXECUTIVE DIRECTOR’S REPORT	17
TREASURER’S REPORT	18
SECRETARY’S REPORT	19
STUDENT REPRESENTATIVE’S REPORT.....	19

2016-2017 BOARD OF DIRECTORS

PRESIDENT

Beth L. Pestka MS, PMHCNS-BC, AGN-BC

PRESIDENT – ELECT

Mindy Tinkle, PhD, RN, WHNP-BC, FAAN

PAST PRESIDENT

Sandra Daack-Hirsch, PhD, RN

TREASURER

Rebecca Kronk PhD, MSN, CRNP

SECRETARY

Cathy Read PhD, RN

MEMBERS AT LARGE

Gia Mudd Martin, RN, MPH, PhD

Sivia Barnoy RN, PhD

STUDENT REPRESENTATIVE

Lacey Wright, BSN, RN

EXECUTIVE DIRECTOR

Beth Kassalen, MBA

ISONG ASSOCIATION MANAGER

Linda Mason

RESTATING OUR MISSION

Vision

Caring for people's genetic and genomic health throughout the lifespan and across the continuum of health and disease.

Mission

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

Elizabeth (Beth) Pestka



Thank you to the members of ISONG for electing me to serve as president of this prestigious organization. It has been a wonderful opportunity and this report highlights activities from the past year. A top priority was to increase the visibility of ISONG so that we are able to be of benefit to more healthcare providers and individuals with genetic/genomic issues. Although we are a small international group, we are the premier organization of genetic nursing experts, and continue to have a tremendous impact on the use of genetics/genomics in nursing practice and collaboration with multidisciplinary colleagues.

As the President of ISONG I was able to encourage and support the extensive work of all of the committee co-chairs and members. Over half of the members of ISONG are involved in at least one committee. I am proud to report that all committees were very active and increased the visibility of the organization in many ways. Important work occurred with developing resources for our beautifully enhanced website, communication information about the organization, interaction on social media, educational programs, online mentoring, professional presentations, publications, research grants, position statements, and numerous collaborations. The committee summaries in this annual report are testimony to the extensive work of our organization. We are fortunate to continue having Kassalen Services as our headquarters and the work of Linda Mason and Beth Kassalen are vital to the ongoing success of our organization as well as the tremendous commitment of time and effort from each member of the ISONG Board of Directors.

In January, I was able to represent ISONG at the Global Genetics Nursing Alliance workgroup in the UK where a roadmap for integrating genetics/genomics into nursing practice around the world was developed. As president of ISONG, I participated in collaborative discussions with individuals from a number of organizations interested in advancing the use of genomics in healthcare. ISONG and the American Society of Human Genetics are proceeding with a collaborative effort to provide education at nursing conferences focused on non-genetics specialist practice. I believe that by partnering with other professional and consumer groups, we will be able to have a greater impact on achieving our mission of caring for people's genetic and genomic health throughout the lifespan and across the continuum of health and disease.

It is very important that we recognize and support student nurses who value the inclusion of genetics/genomics in nursing education, practice, and research. These nurses represent the future of our organization. I was pleased that members of ISONG requested recognition and support for the nursing students who passionately promoted a resolution at the USA Student Nurses Association conference to increase the focus of genetics/genomics in nursing education and competencies. The resolution did not pass in 2017 but there is interest in bringing it forward another time. With support of the ISONG Board of Directors, I wrote letters and provided certificates of accomplishment to each of the nursing student proponents. I strongly encourage ISONG to acknowledge nursing student interest in genomics in all of the countries involved in our organization.

Being the president of ISONG has been a great honor. I am grateful to every member of ISONG for all that you do to make this an amazing organization.

Respectfully Yours,

Elizabeth (Beth) Pestka, MS, PMHCNS-BC, AGN-BC

COMMITTEE REPORTS

Bylaws and Awards Committee

Sandra Daack-Hirsch

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

Committee Members: Sandra Daack-Hirsch (Chair), Sheila Alexander, Elizabeth Pestka, and Sivia Barnoy

The Bylaws Committee serves to review and update bylaws as needed. The Bylaws had no review or revisions this fiscal year.

This committee also serves to manage the ISONG Founders Awards process. The Call was reviewed in early April and no changes were made. The committee solicited nominees for the ISONG Founders Awards in Education, Practice and Research for the 2016-2017 year.

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

Specific goal was to have two or more nominees for each Founders Award: Education, Practice and Research. The committee members and the BoD encouraged individuals to self-nominate and/or nominate others. New this year as an initiative to increase the number of nominees, we encouraged the Research, Education and Practice Committee chairs to send messages to their committee members encouraging them to nominate individuals for awards that represented their respective committees. The committee achieved this goal. The following members were nominated for each award:

Education: S Wesmiller, J. Dungan, and A. Maradiegue

Practice: B. Coleman, K. Beutner, and J. Eggert

Research: M. Kirk, S. Alexander, and A. Vorderstrasse

Each nomination was reviewed and scored separately by each member of the committee. The committee met by conference call on July 24, 2017, discussed each candidate and voted. The Founders Award recipients were:

Education: Ann H. Maradiegue

Practice: Julie Eggert

Research: Allison Amend Vorderstrasse

Names were forwarded to L. Mason on July 24th so plaques could be made for presentation of the awards at the ISONG annual congress in November 2017.

Other Comments

The committee leadership rotates such that the Immediate Past President takes over as chair of the Bylaws and Awards committee in November. Ms. Elizabeth Pestka will step into this position at the end of the November BoD meeting. As such, she will have the ability to select and invite committee members.

Communications Committee

Jamie Newland & Paule Joseph

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

Working with office staff on e-Updates newsletter, redesign of website, coordination of social media posts. Co-chair or representative from committee reported at all assigned Board calls. Committee's last phone meeting was October 2016. Use email predominately to communicate.

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

1. Contribute content to e-Updates, either written or acquisitioned - J. Newland sent email to all committee co-chairs asking them to contribute an article about their committee or other relevant information. Had positive response, at least 3 submitted.
2. Partner with other committees to meet common goals for Society – L. Wright contacted/attended meetings with Membership and P. Joseph with Research and Education. No measurable outcomes yet but generated ideas.
3. Provide input to redesign of website – Co- chairs frequently reviewed progress with staff's work with web designer. New site created but will launch after Congress.
4. Increase social media presence and member engagement – There are more posts to FB and Twitter account – 124 Twitter and 384 Facebook followers. Would like to see more engagement from members.

Budget/Financial Issues:

Board approved \$250 for consultant for web redesign and work was started. Project turned out to be much more and was continued through negotiations with consultant.

Committee Members:

Jamesetta A. Newland	New York University Rory Meyers College of Nursing
Paule V. Joseph	National Institutes of Health, NINR
Carolyn Allen	George Washington University Hospital
Stacy Hines-Dowell	St. Jude's Children's Research Hospital
Caitlin Driesbach	University of Virginia Health System
Lacey Joan Wright	University of Pittsburgh, doctoral student

Future Goals:

1. Complete web redesign, monitor and maintain its currency
2. Institute more targeted strategies to increase social media presence, e.g., direct/personal appeal to ISONG members individually via email
3. Establish content for Members Only section of website
4. Strengthen collaboration with other committees to advance common Society goals
5. Increase content for e-Updates from committees to lessen need to write by staff
6. Increase ISONG's visibility through outside communication sources

Other comments:

The bulk of the work of the Communications Committee is done by office staff. Linda Mason has been invaluable in moving the web redesign project along as well as the production of the newsletter. Paule Joseph and Lacey Wright have done an excellent job in promoting Social Media. Committee Co-Chairs were responsive to the members in working on standardizing content on the web.

Congress Planning Committee

Susan Wesmiller and Deborah Tamura

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

Overall 2017 Goal: A successful World Congress that meets the needs of all members: educators, researchers and clinicians as measured by the final program evaluation.

To achieve this goal:

1. We recruited an excellent, hardworking and dedicated committee assigned to subcommittees with monthly full committee meetings.
2. Co-chairs took responsibility for the keynote speakers.
3. Abstract committee set time frame, communicated to all potential authors for submission and organized breakout sessions.
4. Poster Blitz Committee planned the poster blitz and reception.
5. Development Committee found new sponsors!
6. Hospitality Committee planned reception of new members and speakers, coordinating plans to reach out to new members, first time attendees and speakers in advance of the congress.
7. Moderator Committee formalized the role of the ISONG Congress Moderating process
8. Raffle Committee solicited contributions for this fun and money making event.
9. Continuing Education Committee completed the entire CE document and submitted on time for all members to receive CEU's for the 2017 program.

Budget/Financial Comments:

The financial challenges for this committee are largely balancing the desire to offer our membership the “niceties” with the number of vendors we are able to attract. It is crucial to have good speakers so that the congress attendees will continue to increase in number, so in some respect we must spend money to make money.

Development Committee

Chairperson needed.

Education Committee

Jennifer Sanner and Jennifer Dungan

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

1. Meetings 2017:
 - Full Committee: November 21, 2016, January 23, 2017, March 27, 2017, May 30, 2017, September 25, 2017
 - Education Products Subcommittee (including ISONG/ASHG partnership mtgs): May 25, 2017, May 26, 2017, June 14, 2017, September 20, 2017
 - Marketing Subcommittee: June 20, 2017
2. Webinars 2017:
 - April: “Genetics and Implications of Metabolic Newborn Screening for Nurses”

- May: “Women at Increased Risk for Breast Cancer”
3. Initiatives: Proposal for Marketing & Advertising ISONG Webinars submitted to BoD

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

1. Offer at least 4-5 webinars from January 2017 to December 2017
 - a. Internal review and update of Webinar Moderator Script.
 - b. 2 webinars completed (see above), both with strong positive evaluations.
 - c. 4 webinars in active development for end of year 2017 and early 2018:
 - i. Ethical Issues in Personalized Medicine: Father Kevin Fitzgerald [Karen Whitt ISONG Nurse Planner] scheduled for Dec. 2017
 - ii. Personalized Medicine/Diabetes: Maggie Shepard [Caitlin Dreisbach, ISONG Nurse Planner) CEU paperwork completed, date TBD, waiting to hear back from Maggie as of September 25 meeting]
 - iii. Genetic Risk App [Jennifer Dungan (ISONG) working on a 2-part webinar series on genetic risk app and looking at sponsorship for both, planning to launch both in the same month]
 - iv. ASHG co-sponsored webinar on Epigenetics/Methylation for next year; seeking nurse planner.
 - d. Progress on an International Webinar: Jennifer Sanner worked for 6 months with one of the international members from Japan to try to facilitate a webinar in their time zone, in Japanese language. The member was reluctant to develop their own content, so consideration was taken for having her to translate an existing webinar into Japanese and host it, with permission of the original presenter. The member was provided the list of topics from previous webinars and decided not to pursue the opportunity.
 - e. Our plan to identify some Congress speakers from 2016 to develop webinars from their topics/talks has ~50% success rate (2 out of 4 who initially agreed are in actual planning phase). Education Committee members attending Congress this year will be observing talks and reaching out to some speakers for potential webinar development for 2018.
 - f. Successfully on-boarded 4 new Nurse Planners. Continue to seek additional nurse planners; will ask about any languages they speak and make sure they have access to all Education Committee resources to assist them with the role.
2. Secure webinar sponsors for at least 2 webinars
 - a. Identified need to match sponsor’s goals to the webinar’s content; as part of this effort it was decided to keep a list of webinars under consideration for development for sponsors to consider. Templates for inquiries/communications developed and used. UT Knoxville sponsorship fell through with change in their leadership. Color Genomics is interested in next year. Education Committee leadership will be reaching out to Congress sponsors (Industry and Academic) to try to secure webinar sponsors for next year.
 - b. Also identified a need to reach out to potential sponsors earlier, because budgetary decisions are often made out to a year in advance; this will also be facilitated by more long-term webinar planning for next year.
3. Develop a formal marketing and business plan for webinars
 - a. Refer also to Item 7; The Committee sought out a member that had marketing skills to help lead a subcommittee. A member initially stepped forward but later stepped off the Ed Comm due to competing priorities. Jennifer Dungan has been leading this work, and identified the potential to partner with students from the UNC Student Chapter of National Public Relations Society of America to develop a formal marketing plan, as these students seek out pro-bono opportunities to build their portfolios. A request to reach out to this group and possibly donate a small amount to

- their chapter in return was incorporated into our proposal to the BoD for advertising funds request (item 7). Pending further consideration.
4. Discuss potential for ISONG to expand our educational ‘products’ beyond webinar platform
 - a. Nicole Osier leading the subcommittee formed to explore new educational products beyond the webinar platform (first meeting was on May 25, 2017).
 - b. Subcommittee initially focused on collaboration with ASHG (meetings May 26, 2017, June 14, 2017, and September 20, 2017) to develop webinar content and pre-conference workshops. Needs assessment survey developed & implemented; results informed direction of education platforms and targets. Beth Pestka is leading application for APNA pre-conference workshop; a memorandum of understanding is being developed. Ed Comm leadership seeking members to form “task force” for this initiative to work with leadership/HQ and help expand possible target nursing conferences.
 5. Update website for 2016-2017
 - a. Carolyn Allen is leading the subcommittee making progress on this goal; a need for additional organization and user-friendliness was identified, especially the educational resources tab. HQ received feedback and indicated much of these concerns will be addressed with the new website format that is in progress.
 6. Secure ISONG webinar information on the G2C2 landing page
 - a. In 2017, the committee has followed up on the original 2016 submission for G2C2 Landing Page and the response continues to be slow, as described below:
 - i. In May additional information was requested and followed up on.
 - ii. As of September, all the materials have been submitted and they are continuing to review them; it is taking a while because they need to be reviewed individually by separate people. Jennifer Dungan continues to be in contact with Donna Messersmith at NHGRI regarding our application review.
 7. Submit formal proposal with business plan to BoD requesting a % webinar revenue back to Education Committee to support future webinar marketing.
 - a. Submitted a proposal to BoD on May 1 to access funds donated in Elizabeth Thompson’s name for webinar marketing/advertising with a comprehensive and cost-effective set of strategies and metrics-based request for reinvestment to promote sustainable marketing over time.
 - b. Implemented a pilot social media advertisement for BRCA webinar (10 day span prior to May webinar: reached 358,281 people in our international target demographics, had 15,502 clicks on the registration link). Unfortunately, this did not return an increase in registration for the event. Price point, overhead costs, and live scheduling were discussed. BoD approved a 1-time “Free webinar special” for upcoming webinar (Dec) with another social media ad. Data from this free webinar will be reported to BoD for consideration of additional funds for 2018.
 - c. Other paid and unpaid marketing and advertising strategies and demographic targets have been discussed in the committee, with the BoD, and HQ.
 - d. *These activities involved student representatives and social media liaison (Lacey Heinsberg) from the Membership/Communications Committee.
 - e. Also, developed “in kind” collaboration with Hereditary Colorectal Cancer Foundation President to cross-list our webinars to our memberships. Discussed potential to reach out to other organizations and foundations to do the same. Deemed lower priority at this time.

Budget/Financial Issues:

\$ 1,300.00 (Revenue as of 10/1/17*)
 - 615.00 (Continuing Education Expenses as of 10/1/17)
 = 685.00 (Net revenue**)

*Planned December 2017 webinar may impact final numbers.

**Does not include Social Media Advertising Expense from E. Thompson Memorial Acct): \$150.00 (May BRCA webinar)

Approved Social Media Advertising Expense for Dec webinar: \$150.00 (not yet withdrawn from funds)

Ethics and Public Policy Committee

Laura Beamer

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

1. On September 6, 2016; we held a transitional EPP Committee meeting. The committee leadership typically changes after the annual congress.
2. The 2016 ISONG Congress was held early (i.e., in August) since the location was in Dublin, Ireland.
3. On February 14, 2017; the EPP Committee met to establish/re-establish progress and team memberships to review and revise all the position statements.
4. We did not meet in the summer of 2017 because we focused our effort on the position statements.
5. The EPP Committee met on October 11, 2017 to discuss our progress on the review and revision of the position statements and to make plans for Congress.
6. We plan to meet again on November 3rd the 2017 Congress. Further, we hope to include a teleconference at Congress so that every EPP Committee member has a voice. We tentatively plan to meet in February 2018.

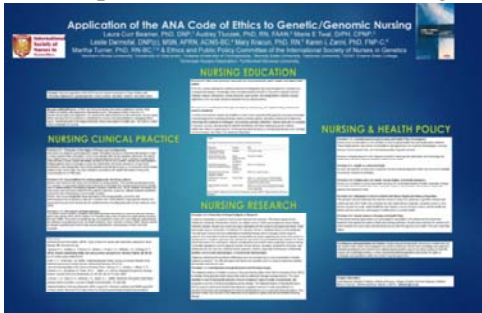
Specific Goals set at Start of year and progress report on the goals:

1. Begin/continue the revision of all position statements.

Title	Status
<i>Direct-to-Consumer Marketing of Genetic Tests</i>	Completed and approved by the ISONG Board (10/03/2017).
<i>Privacy and Confidentiality of Genetic Information: The Role of the Nurse</i>	Completed. Sent to EPP Committee members for comment.
<i>Provision of Quality Genetic Services and Care: Building a Multidisciplinary, Collaborative Approach among Genetic Nurses and Genetic Counselors</i>	L Beamer spoke with NSGC representative. They are not interested in collaborating with ISONG on this position statement (PS). EPP Committee members believe PS scope should expand to include other healthcare providers (e.g., physicians, PAs, etc.). Under revision.
<i>Access to Genomic Healthcare: The Role of the Nurse</i>	Under revision
<i>Genetic Counseling for Vulnerable Populations: The Role of Nursing</i>	Under revision
<i>Informed Decision-Making and Consent: The Role of Nursing</i>	Under revision
<i>Newborn Screening: The Role of the Nurse</i>	Under revision
<i>Genetic Biobanking for Research</i>	Under revision
<i>Gene Editing (therapy)</i>	New position statement under development.

2. Submit manuscript for publication.
 - Submitted to Nursing Outlook {11/05/2016}
 - Submitted to Journal of Advanced Nursing (04/11/2017)
 - Submitted to Nursing Ethics (06/26/2017)

3. Present poster at the National Nursing Ethics Conference in Los Angeles, CA



Committee Members

Aiello, Lisa	Drexel University
Anderson, Jennifer	Invision Sally Jobe
Arabadjian, Milla	NYU School of Medicine
Beamer, Laura	Northern Illinois University
Blair, Lisa	The Ohio State University
Cakici, Julie	Rady Children's Institute for Genomic Medicine
Connors, Laurie	Vanderbilt University
Darmofal, Leslie	Bemidji State University
Dickey, Susan B.	Temple University
Dreisbach, Caitlin	University of Virginia Health System
Earl, Dawn	Seattle Children's
Farrell, Carolyn	Professional Genetic Interactions
Giarelli, Ellen	Drexel University
Groves, Michael	Shepherd University
Hersperger, Cheryl	Worcester State University
Hickey, Kathleen	Columbia University
Hose, Kristy	Meritus Center for Breast health
Jaja, Cheedy	University of Cincinnati
Joseph, Paule	Div. of Intramural Research NINR, NIH, DHHS
Kracun, Mary	National University
Markum, Catherine	CHI Memorial Cancer Risk & Survivorship Center
Mazzola, Patricia	Englewood Hospital & Medical Center
Molle, Elizabeth	Catholic University of America
Moyer, Julie	St. Louis Fetal Care Institute
Musser, Denise	University of Minnesota
Muto, Lisa	Edwards Comprehensive Cancer Center
Nastasi, Gail	Orange Regional Medical Center
Ouma, Anastasia	St. Jude Children's Research Hospital
Reed, Cathy	Boston College Wm. F. Connell SON
Robinson, Kathryn	Northeastern University
Sadlon, Penni	Rhode Island College
Siqveland, Elisabeth	Children's MN
Steck, Mary Beth	Clemson University
Stokes, Liz	American Nurses Association
Tluczek, Audrey	University of Wisconsin
Turner, Martha	American Nurses Association
Twal, Marie	Indiana University of Pennsylvania

Twomey, John	Hasbro Children's Hospital
Voights, Kaitlin	University of Kentucky
Wade, Christopher	University of Washington Bothell
Wangi, Karolus Yosef Woitila	Tarumanagara Institute of Health Science
Willis, Valerie	University of San Diego
Yu, Erica	University of TX Health Science Center at Houston

Proposals for the ISONG Board:

Some members of the EPP Committee mentioned an interest in creating an EPP and genetics/genomics educational webinar.

Future Goals:

1. Finish revising all the existing position statement.
2. Publish our manuscript focusing on the ANA Code of Ethics with Interpretive Statements.
3. Update the white paper on GINA.
4. Make recommendations to the Board of Directors as the political and healthcare environment continues to evolve.

Membership Global Committee

Susan Fernbach

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

1. Manual “listserv” for ISONG outreach compiled from publicly available contacts, including 36 Deans of Schools of Nursing, leaders of nursing organizations, and societies within the US plus 7 countries
2. A letter introduction of ISONG signed by Beth Petska was sent to all contacts via email with positive responses. The letter has been translated to Spanish and will be to Portuguese next.
3. A slide set was developed for use at presentations given by members
4. A brochure was created and translated to 3 additional languages: French, Hebrew, Spanish, and are all now available on the website
5. Business cards and brochures have been given out at local and international conferences
6. Increased social media/Facebook presence to encourage member engagement

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

Increase membership by 10% - While there were 73 new members, an equal number did not renew.

Budget/Financial Issues:

No budget issues to report, mailing list compiled by committee as purchasing a mailing list was cost prohibitive, letters sent by email to 36 Deans and various nursing organizations.

Committee Members:

Pilar Amaya-Rey	University of Columbia
Jessica Anderson	Invision Sally Jobe
Milla Arabadjian	NYU School of Medicine
Naoko Arimori	St. Luke's International University
Sivia Barnoy	Tel-Aviv University
Caroline Benjamin	School of Health, University of Central Lancashire (UCLan)
Dennis Cheek	Texas Christian University
Beth Chiatti	Drexel University

Sarah Cook	Columbia University
Caitlin Dreisbach	University of Virginia Health System, University of VA
Andrew Dwyer	University of Lausanne/Centre Hospitalier Universitaire Vaudois
Susan Fernbach	Baylor College of Medicine
Juana Mercedes Gutierrez Valverde	Universidad Autonoma de Nuevo Leon
Wendy Henderson	NIH, NINR, DHHS
Simbarashe Kamba	Crown Agents Zimbabwe
Amanda King	Marquette University
Anecita Gigi Lim	School of Nursing FMHS University of Auckland
Erika Maria Monteiro Santos	Hospital Sirio-Libanés
Scott Moore	Frances Payne Bolton School of Nursing, Case Western Reserve Univ.
Jansirani Natarajan	Sultan Qaboos University
Memnum Seven	Koc University School of Nursing, Istanbul, Turkey
Komal Singh	University of California San Francisco
Elizabeth Siqueland	Children's – MN
Emma Tonkin	University of South Wales
Marcia Van Riper	UNC Chapel Hill
Karolus Yosef Woitila Wangi	Tarumanagara Institute of Health Science (Preparation of Establishment)
Lacey Wright Heinsberg	University of Pittsburgh School of Nursing
Erica Yu	University of TX Health Science Center at Houston

Future Goals:

1. Increase membership and retention of members over the next year
2. Increase engagement/participation in Facebook and social media
3. Identify additional strategies to attract and retain members
4. Increase international presence

Other comments

We, as a committee, appreciate the opportunity to contribute to this organization. We truly believe in the mission of ISONG, and hope to continue to contribute to the goals and vision of this organization.

Nominations Committee

Sandra Daack-Hirsch

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

The Nominations Committee solicited nominees for the ISONG Board of Directors positions open for the 2017-2018 year. Open positions include: President-Elect, Secretary, Member-at-large, and Student Representative. Table 1 summarizes the committee’s activities.

Task/Activity	Date/Start	Date/End
Call for Nominations	4-24-2017	5-26-2017
Vetting by committee	5-27-2017	6-6-2017
Present Slate to the BoD	6-6-2017	
Post on Website	6-7-2017	
Voting open	6-7-2017	7-10-2017
Report to Board/Winners and non-winners notified	7-11-2107	7-13-17
Announcements to membership and on the website	7-17-2017	
Announcement at the Congress		November

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

Specific goals were to have two or more nominees in each position on the ballot. The goal was achieved for all positions. Elected BOD names are *italicized*.

President - *Cathy Read*, Kim Subasic

Secretary - *Jennifer Dungan*, Erika Santos

Member at Large - Lisa Aiello, Allison Vorderstrasse, *Sue Wesmiller*

Student Rep - *Caitlin Dreisbach*, Maura McCall

Committee Members

Sandra Daack-Hirsch (Chair), Sheila Alexander, Elizabeth Pestka, and Sivia Bar-Noy

Other Comments

The committee leadership rotates such that the Immediate Past President takes over as chair of the Bylaws and Awards committee in November. Ms. Elizabeth Pestka will step into this position at the end of the November BoD meeting. As such, she will have the ability to select and invite committee members.

In addition, S. Daack-Hirsch reached out to the Japanese Society of Genetic Nurses to nominate someone for BOD. This year they decided not to nominate someone but will consider in the future. There are logistic barriers—language and time difference that make serving on the BOD difficult for non-US members. We need to address these issues in order to be more inclusive.

Professional Practice Committee

Tammy McKamie and Sue Montgomery

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

1. Ongoing telephone and online communication between Tammy McKamie and Sue Montgomery – no official meetings other than one at Congress 2016.
2. 2016-2017 goals were set at World Congress 2016 with the new members of the professional practice committee (PPC). 13 members joined this committee while at congress.
3. Susan Montgomery RN BSN GCN accepted the position as co-chair of professional practice committee and to serve along with Tammy McKamie.

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

1. 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
 - a. 14 inquiries from Oct 2016 to present related to:
 - i. Requirements for certification/genetic counselor
 - ii. Billing & coding
 - iii. Requirements for nurse providing genetic counseling
 - iv. AGN-BC portfolio requirements
 - b. Website updated to reflect information re: mentoring
2. 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.
 - a. Abstracts for 2017 World Congress:
 - i. “Evaluating the Practicality of a Psychotropic Assay.” Katie Halbmaier

- ii. “An Initiative to Mentor Nurses in Genetics” Susan Montgomery & Tammy McKamie
 - iii. “Hereditary Cancer Knowledge of Honduran Healthcare Providers” Sylvia Estrada
 - iv. “Genetic Testing for Hereditary Cancer Syndromes: A Foreign Language or The Way of the Future?” Tammy McKamie
 - v. “Evaluating the Practicality of Clinic-Wide Utilization of a Psychotropic Assay, Katie Halbmaier”, Virginia Conley, University of Iowa College of Nursing
- b. Posters for 2017 world congress:
- i. An Innovative Interdisciplinary Doctoral Program for Nurses Focusing on Genetics and Genomics, Mary Beth Steck, Julia Eggert, Clemson University, Clemson, SC, USA
 - ii. Hereditary Cancer Knowledge of Honduran Healthcare Providers, Sylvia S. Estrada, Cedars-Sinai Medical Center, Los Angeles, CA, USA
 - iii. Patient Perceptions and Behavior Changes Associated with Nurse Led Education and Discussion Related to a Reported Family History of Substance Abuse, Elizabeth Pestka, Mayo Clinic, Rochester, MN USA
3. 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).
- a. Articles submitted in 2017:
- i. Brouwer, W., Everett, P., Hassen, E, Lowe, T., McGreal, S., Montgomery, S. & Eggert, J. (Accepted for publication, October, 2017) Genetics in the clinical setting: What nurses need to know. American Nurse Today. (This was collaboration among seven members of the Clinical Practice Committee, International Society of Nurses in Genetics [ISONG]) The above article will offer CEUs & be available online.
 - ii. Halbmaier, K. Beutner, K., Daniels, C., & Eggert, J. (Scheduled for Publication) October, 2017). Genetics in the Cardiovascular ICU. Nursing2017 Critical Care. (This was a collaboration among four members of the Clinical Practice Committee, International Society of Nurses in Genetics [ISONG])

Committee Members

Tammy Mckamie	tammy.mckamie@christushealth.org	Oncology	CHRISTUS St. Michael
Susan Montgomery	susan.montgomery@fcc.edu	Oncology	Fox Chase Cancer Ctr
Julie Eggert	jaegger@clemson.edu	Oncology	Clemson University
Sylvia Estrada	sylvia.estrada@cshs.org	Oncology	Cedars-Sinai Med Ctr
Elizabeth Pestka	pestka.elizabeth@mayo.edu	Pharmacogenomics	Mayo Clinic
Hiroko Susaka	11mn021t6n-ts@slcn.ac.jp	Neuro	University of Tokyo
Cathleen Goetsch	cathleen.goetsch@vmc.org	Oncology	
Katie Halbmaier	katie-halbmaier@uiowa.edu	Cytogenetics	University of Iowa
Cheryl Brubaker	brubaker@iglide.net	epigenetics	NIH NINR
Phyllis Everett	hemoncnp@gmail.com	Oncology	
Katherine Beutner	KatherineBeutner@stanfordhealthcare.org	Cardiology	Stanford Center In CA
Wendy Brouwer	tomandwendybrouwer@hotmail.com	Oncology	MDA Ca Center
Shelia Bridget McGreal	Sheilamcgreall@hotmail.com		

Future Goals:

1. To be a part of identifying a way to re-instate credentialing in genetics for the GCN and the Advanced practice nurse in genetics (AGN-BC).
2. To continue the current goals

Other Comments:

I would like to thank Sue Montgomery for working so hard to ensure this committee not only met but exceeding the goals set forth at the 2016 congress she along with the rest of the committee members have gone above and beyond their expected request.

Research Committee

Allison Vorderstrasse & Wendy Henderson

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

1. Many members of ISONG/Research Committee participated in the editorial and review process for the first BRN genomics issue.
2. Co-chairs met approximately monthly by phone to plan for grant review and any other activities. Discussion was focused on trying to standardize grant review procedures, following closely to standard study section or review protocols. Another priority was to standardize some review procedures in order to include those on the committee who had not participated as a reviewer in the past but to provide an overview orientation to all reviewers and assign grants to an experienced reviewer as one of two reviewers along with anyone new to review.
3. Meetings were held for purposes of the following activities and included those from the Research Committee who volunteered for this work:
 - a. June 2017- Committee member review and discussion of the procedures for grant review process for 2017 applications.
 - b. August 2017- Review meeting for 2017 ISONG grants. 12 grant applications were reviewed by committee. Discussion and committee voting resulted in 4 awarded grants as listed in section C below.

Grants Awarded in 2017:

1. Lacey Wright Heinsberg - 'Epigenetic variation of the iron homeostasis pathway in patient outcome following aneurysmal subarachnoid hemorrhage' (University of Pittsburgh- PhD student)
2. Mitchell Knisely - 'Identification of associations between inflammatory pathway candidate genes and health-related quality of life in individuals with inflammatory bowel disease' (University of Pittsburgh – Postdoctoral fellow)
3. Michelle Wright - 'Characterization of allele specific DNA methylation of PABPN1' (Emory University – Faculty)
4. Nancy Dubois – 'Identification of health and 16S microbiome characteristics of ideal stool donors for fecal microbiota transplantation' (Boston College - PhD student)

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

1. One of the major goals was to extend the foundation established by the prior year's committee to form the detailed protocols, procedures and materials for the yearly grant review process as sustainable resources for the process and committee work.
2. A second goal was related to the involvement of ISONG members/Research Committee as editors/reviewers for the BRN issues on genomics. This will greatly enhance the visibility and dissemination of genomic nursing science and keep our members at the forefront of that process and work.

We made significant progress in terms of work to standardize grant review process and procedures and align with NIH or other scientific review group procedures. The following were created and will be uploaded to ISONG document folders: procedural review slide presentation used on conference call with reviewers to orient all to the

process; scoring criteria review form; agenda for the review meeting; letters of notification of award; sample notification emails to those not awarded.

Budget/Financial Issues

1. ISONG received 2 sponsorships for research grants in addition to 2 grants in the budgeted ISONG funds.
2. Sponsorships and funding are an annual concern because they allow ISONG to support investigators to the highest degree possible. The research committee members are willing to actively help find sponsorship of the grants from their home institutions or other entities.

Committee Members

LAST NAME	FIRST NAME	E-MAIL
Adamian	Maria	adamian66@aol.com
Anderson	Cindy	cindy.anderson@email.und.edu
Barr	Taura	tlbarr@hsc.wvu.edu
Bell	Mandy	mjb111@pitt.edu
Cashion	Ann	ann.cashion@nih.gov
Charles	Bashira A.	charlesba@mail.nih.gov
Cheek	Dennis	d.cheek@tcu.edu
Conley	Yvette	yconley@pitt.edu
Doswell	Willa	wdo100@pitt.edu
Dylis	Ann M.	crest68882@aol.com
Founds	Sandra	safounds@comcast.net
Giarelli	Ellen	eg446@drexel.edu
Henderson	Wendy	wendy.henderson@nih.gov
Hickey	Kathleen	kth6@columbia.edu
Holman	Alison	aholman@uci.edu
Houfek	Julia F.	jhoufek@unmc.edu
Imes	Christopher	imesc@pitt.edu
Kirk	Maggie	mkirk@glam.ac.uk
Kronk	Rebecca	kronkr@duq.edu
Linder	Lauri	lauri.linder@nurs.utah.edu
Mudd	Gia	gia.mudd@uky.edu
Nealis	Rose	nealirm@ufl.edu
Newcomb	Patricia	pnewcomb@uta.edu
Raudonis	Barbara	raudonis@uta.edu
Stanfill	Ansley	astanfi4@uthsc.edu
Tully	Lois	lois.tully@nih.gov
Umberger	Reba	rumberge@uthsc.edu
Von Ah	Diane	dvonah@iupui.edu
Vorderstrasse	Allison	allison.vorderstrasse@duke.edu
Wesmiller	Susan	swe100@pitt.edu
Williams	Janet K.	janet-williams@uiowa.edu
Flowers	Elena	elena.flowers@ucsf.edu

Proposals for the ISONG Board:

Clarifications to grant applications may be helpful moving forward:

1. add 'faculty', 'student', 'postdoctoral fellow' indication to application
2. Should we consider limiting the number of submissions put forward from each institution in each category of applicant in order to keep the available funding spread out across institutions? Also, should we designate the grant awards by these categories to distribute the funding across levels of research programs?
3. At any point should we consider awarding fewer but larger grants? This year we decided to use the prior limit per grant and award more grants but there are pros and cons to this.

Future Goals:

Increase Research Committee activity, productivity, and visibility through some of the following potential means:

1. Networking and researcher postings on new ONSEN site.
2. Follow up regarding committee discussion at last congress regarding networking and other opportunities we are not currently actively using in our committee. An example may be research collaborations and networking session at subsequent ISONG meetings. Alternatively, we could try web conference calls for peer review and networking.
3. Brainstorm with research Committee at ISONG meeting re: other potential interests.

EXECUTIVE DIRECTOR'S REPORT

Beth Kassalen



ISONG Showing Steady Growth in Many Areas

Under the direction of Elizabeth Pestka as ISONG President 2016-2017, ISONG moved along smoothly and strategically with its mission and goals. Membership stands around 345 active participants, with some additional members due to renew this month. Each committee has prepared its own annual report and the projects and tasks they've accomplished are a testament to their diligent and non-stop hard work throughout the year.

ISONG Headquarters, Linda Mason in particular, led the charge with securing a record number of sponsors for the 2017 ISONG Congress. We gratefully acknowledge the financial support of our sponsors and exhibitors and encourage continued collaboration between our members and these universities and companies. Linda has expertly moved into a role managing not only the ISONG Congress, but participating on committee calls, board calls, and updating and maintaining the ISONG website.

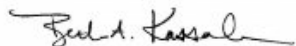
ISONG financials are strong and steady, as Becky Kronk will report at the annual meeting. ISONG has been meeting its budget and making a small profit each year which enables it to keep its reserves ready for future projects and investments back into the association and its members.

The ISONG Board presided over the organization this year with a careful eye, strategically moving toward collaborations with the Journal of Biological Research Nursing, and promoting the portfolio certification managed by the ANCC. Mid-2017, Beth Pestka was approached by the American Society of Human Genetics (ASHG) to explore some joint ventures between our groups. After several calls, board discussions, and a survey to the membership, the ISONG Education Committee is embarking on the development of pre-conference workshops on genetics for presentation at other nursing organization's meetings, thus getting genetics a wider audience. Lacey Wright is successfully completing her first term as Student Representative on the ISONG Board and has been instrumental in positioning the students' view on board deliberations and has contributed to the increased exposure of ISONG through social media channels.

I would like to recognize and congratulate Elizabeth (Beth) Pestka for her steady governance style, appreciation of the clinical aspects of ISONG and its membership needs, and her contributions toward our collaborations with ASHG in preparing several live pre-conference workshops on genetics for other related nursing organizations that should come to fruition in 2018.

Late-breaking news was just reported to ISONG in mid-October that ANCC has not found the genetics certification by portfolio a financially viable product. We are still in the midst of learning more information about the sunseting of the genetics certification by portfolio and evaluating options for providing expert level recognition to our members.

Sincerely,



TREASURER'S REPORT

Fiscal Year 2017

Rebecca Kronk

This ISONG Treasurer's Report covers January 1, 2017 through December 31, 2017.

On December 31, 2017, ISONG's balance sheet reflected assets of \$58,212. This was an increase in net assets by \$420.13 from net assets recorded at the end of 2016.

Total income from ISONG in 2017 was \$161,060.

Major sources of income for ISONG are:

1. Conference Registrations \$83,297 (52% of net income)
2. Membership Dues \$42,875 (27%)
3. Sponsors/Exhibitors \$17,739 (11%)
4. Nursing Research Grants \$ 7,500 (4.6%)

Total operating expenses for ISONG in 2017 were \$160,592.

Major expenses for ISONG operations are:

1. Conference \$81,740 (51% of operating budget)
2. Management Company \$58,483 (36%)

ISONG operates on a very slim margin and counts heavily on the ISONG Congress to be profitable. The Congress profit offsets annual operating expenses of the organization.

ISONG ended Fiscal Year 2017 with a net annual profit of \$467.82.

Looking toward 2018, ISONG will be incurring expenses toward the creation of a new pathway for genetic nursing certification due to the recent elimination of the ANCC genetics certification by portfolio. These are expenses that were not currently part of the ISONG operating budget and the Board will be seeking new sources of income to offset these expenses.

SECRETARY'S REPORT

Catherine Read

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

1. Attended all Board meetings. Prepared minutes and eUpdates for each meeting.
2. Served as liaison to Ethics and Public Policy committee.
3. As a member of the Education Committee I attended their meetings and advocated for funds to market webinars

Future Goals:

1. Orient new secretary (Jennifer Dungan) to role and provide ongoing support
2. serve as president-elect and learn role of president.

STUDENT REPRESENTATIVE'S REPORT

Lacey Wright Heinsberg

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

As the Student Representative of ISONG, I attended a majority of the Board of Directors (BoD) meetings and served as a conduit for communication between student members and the BoD. My work in this role has included heavy involvement with the Membership and Communications Committees (please refer to annual reports from those committees for a review of activities). Specifically, I have worked with Linda Mason and the Membership and Communications Committees to improve member outreach and engagement through an increased ISONG social media presence, bimonthly outreach to our student members highlighting opportunities for success and encouraging communication, and to help to create marketing materials (e.g. ISONG brochure).

Specific Goals and Progress set at start of Year:

1. Act as a conduit for communication between student members and the BoD. This goal was successfully achieved through bimonthly student member outreach via email. These emails summarized BoD meetings, highlighted opportunities for involvement within ISONG, and any external opportunities that may be of interest to student members. These unofficial meetings also encouraged communication from students. I also worked closely with the Communications and Membership Committees based on requests from our student members (e.g. increased social media presence, marketing material).
2. Expand social media to recruit, engage, and retain student members. The social media presence of ISONG was increased substantially, successfully highlighting expertise within the organization and showcasing of our culture and achievement. However, there exists great room for improvement with the social-media-post engagement from our members.
3. Increase member recruitment and engagement through implementation of a "Student Champion" position. With input from several student members, a "Student Champion" position description and call-to-action was drafted. This document includes a summary of attributes and duties for this position. While implementation of the "Student Champion" role was not feasible for this year, substantial progress was made and this idea will be presented to the Membership Committee for further discussion in the coming year.

Future Goals:

1. Continue to act as a voice of the students and encourage communication from members at all levels.
2. Consider working to expand member engagement and recruitment through implementation of "Student Champions."
3. Continue to promote ISONG social media to recruit, engage, and retain members at all levels.

Comments for the Board of Directors.

It has been my pleasure to serve in this role. ISONG is a truly wonderful community and I applaud the work being done by its members. I am honored to be a member of this society.