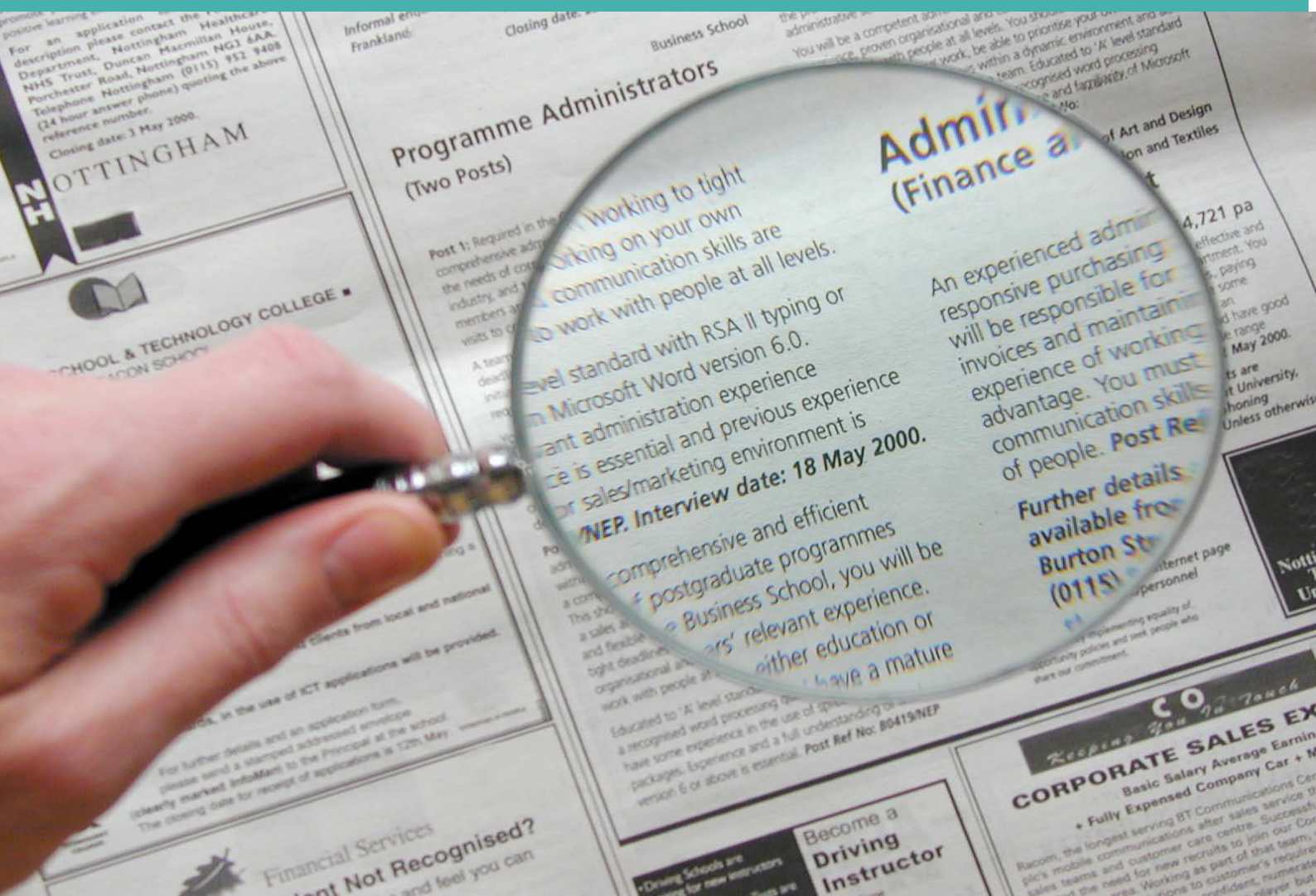




International Society of Nurses in Genetics 2012 Organizational Overview



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RESTATING OUR MISSION



ISONG Mission

Vision Statement

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

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

Mission Statement

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

The goals of ISONG are:

- *Provide a forum for education and support for nurses providing genetic healthcare.*
- *Promote the integration of the nursing process into the delivery of genetic healthcare services.*
- *Encourage the incorporation of the principles of human genetics into all levels of nursing education.*
- *Promote the development of standards of practice for nurses in human genetics.*
- *Advance nursing research in human genetics.*
- *Provide a forum for dialogue with others.*

PRESIDENT'S UPDATE

PRESIDENT'S UPDATE



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COMMITTEES AND MEMBER AT LARGE

COMMITTEES AND MEMBER AT LARGE

Education Committee

Co-Chairs: Cathy Read, Sheila Alexander

Committee purpose, roles and responsibilities: the ISONG by-laws description of the Education Committee was revised this year and the following proposed draft is awaiting approval by the Board of Directors:

Education Committee: This committee shall facilitate the education goals of the Society by promoting and supporting genetic/genomic education of all professional nurses. The committee shall assemble and maintain educational resources to support the integration of genetics and genomics into nursing practice and nursing education. Such resources shall be available for Society members as well as other individuals and groups. The committee shall promote opportunities for discourse among nurses regarding evidence-based genomic health care and encourage sharing of best practices in education. The Education committee shall coordinate with the Information and Public Relations, Research, Program and other such committees as designated by the Board of Directors.

Meeting dates:

- *October 9, 2011 – Montreal*
- *November 4, 2011 – via email to all members (see report in DropBox)*
- *February 3, 2012 - via email to all members (see report in DropBox)*
- *April 30, 2012 - via email to all members (see report in DropBox)*
- *May 29, 2012 - via email to all members (see report in DropBox)*
- *July 11, 2012 - via email to all members (see report in DropBox)*
- *Several virtual meetings (phone or email) also took place that included members of the Education Committee webinar interest group.*

Membership- updated throughout the year. Members as of September 2012:

Alexander, Sheila
Andrews, Tracy
Bowers, Nancy
Cheek, Dennis
Choi, Hyunkyung
Davies, Marilyn
Haase Uhler, Judith
Kirk, Maggie
McKamie, Tammy
Murphey, Christina
Muto, Lisa
Pestka, Elizabeth L.
Read, Cathy
Seguin Santelli, Jeanine
Sheets Cook, Sarah
Sparbel, Kathy
Steinbart, Stephanie
Tinley, Susan
VanRiper, Marcia
Ward, Linda
Whitt, Karen
Joseph, Paule
Krau, Stephen
Vick, Lori

COMMITTEES AND MEMBER AT LARGE

Education Committee Goals/Accomplishments/Ideas for 2013:

2012 goals	Progress toward goals	Ideas for 2013
1. Respond to education-related queries generated from visitors to ISONG website	Beth Pestka responded to several queries forwarded to her by the ISONG administration.	renew goal, reassign task as necessary
2. Review Education Committee responsibilities from ISONG bylaws and submit suggested revisions to Kathy Sparbel by September 1, 2012.	This goal was met (see above)	N/A
3. Update education-related items on the ISONG website on an ongoing basis.	Several updates were forwarded to Julie Eggert and changes were made	Continue to review and update. Web management under new direction in 2013.
4. Work with other ISONG groups and ISONG administration to develop and offer genomic-related webinars	<p>After reviewing multiple options for providing continuing education credit (CE) for ISONG online webinars, it was determined that the University of Pittsburgh would serve in that role.</p> <p>A “trial” webinar, using the Go-to-Meeting platform, was presented by Rebekah Hamilton on November 15, 2011. The topic was “Young Women’s (18-39 y/o) Screening and Surgical Choices After Testing Positive for a BRCA Mutation.”</p> <p>The first webinar (“for profit”) was held on March 22, 2012 and is archived and available for viewing on the ISONG website. The title was “Incorporating Genetic/ Genomic Content into MSN Curriculum: MSN Essential I: Background for Practice from Sciences and Humanities.” It was well-received and profitable.</p> <p>The second (“for Profit”) webinar was held on June 6, 2012 and is archived and available for viewing on the ISONG website. The title was “Master’s Essential 2: Organizational and Systems Leadership”. It was well-received and profitable.</p> <p>These webinars and four more to follow were/will be organized and presented by an ISONG webinar subcommittee dedicated to disseminating information about the AACN Master’s essentials. The Education Committee will help to publicize these.</p> <p>Future webinars: The Education Committee needs to assume the responsibility for webinars once the “Essentials” webinars are complete. The ISONG membership was asked to send ideas for future topics. C. Read has this list.</p>	Discuss future webinar topics and develop a plan at meeting in Philadelphia in October 2012.
5. Update ISONG membership list and submit timely reports to ISONG Board	This goal was met and all report and membership lists are up-to-date in DropBox.	Renew goal.

COMMITTEES AND MEMBER AT LARGE

Ethics and Public Policy Committee

Chair: Marie Twal

Co-chair: Lynn Rew (resigned July 12, 2012)

GOALS:

1. Review website EPP committee statement annually and all other aspects of website monthly to assure accuracy of all information pertaining to EPP committee.
2. . Work with website committee to increase accuracy of Position Statement Postings
3. Complete Position Statement on Newborn Metabolic Screening
4. Complete Position Statement on Biobanking
5. Review position statement Provision of Quality Genetic Services and Care: Building a Multidisciplinary, Collaborative Approach among Genetic Nurses and Genetic Counselors
6. Review issues relevant to populations not protected by the GINA legislation. Consider developing an issue paper to be posted on our website. Consider expanding

investigation to consider international protections and vulnerabilities

7. Find out if there are any past issue papers
8. Revise membership list
9. Revise policy on writing position statements and issue papers

Follow-up plans:

1. Continuing goal
2. Finalize changes Jan, 2012
3. Completed
4. Reform committee
5. Moved to Professional Practice Committee
6. Revisit this with 2012-2013 EPP Committee
7. Completed
8. New list will be provided in Oct.
9. Continue the process with incoming Board

List of Committee Members

Arbique	Debbie	Murphey	Christina
Beamer	Laura	Muto	Lisa
Berger	Susan	Perry	Cynthia E.
Bowman	Katherine	Pierce	Peggy
Brennan	Patricia	Pullum	Cherese
Cashion	Ann	Sandhaus	Leah
Damato-Kubiet	Leslee	Sanner	Jennifer
Darmofal	Leslie	Springstead	Laura
Giarelli	Ellen	Steck	Mary Beth
Gonzales	Bonnie	Thomson	Sue
Harney	Laura	Tluczek	Audrey
He	Ran	Tscharner	Nancy
Hershberger	Patricia	Turner	Martha
Jaja	Cheedy	Twal	Marie
Johnson	Vanessa Althea	Tymkow	Catherine
Kerber	Alice	Underhill	Meghan
Lagerwey	Mary	VanOnselen	Christina
Mazzola	Patricia	Wade	Christopher
Miklush	Lisa	Williams	Pamela
		Zambelas	Rita

COMMITTEES AND MEMBER AT LARGE

EPPC Committee Goals/Accomplishments/Ideas for 2013:

Goal/Task	Action taken	Status Report-Outcome	Next Steps
Review website EPP committee statement annually and all other aspects of website monthly to assure accuracy of all information pertaining to EPP committee.	Reviewed New Committee Description written	Website; 1.Under Education tab: information on GINA with links to US sources 2. Under About Us tab: Committee Description not consistent with by-laws description.	1. Explore other items of member interest and provide appropriate links 2. Present new committee description to Board for approval and inclusion in the revised by-laws
Work with website committee to increase accuracy of Position Statement Postings		1. Under Professional Practice tab: list of Position statements should include both date of initial approval and all revision dates 2. Position Statement on Informed Decision -Making title wrong on statement itself	1. Work with HQ to include both initial date of PS and dates of revisions 2. work with HQ to correct this - need to delete the word "consent" from the title document.
Complete Position Statement on Newborn Metabolic Screening	Subcommittee: Audrey Tluczek (Chair), Dale Lea, John Twomey, Leslie Darmofal, Marie Twal and Chris Wade formed July, 2011. Numerous conference calls Draft sent to full committee and selected international members for review April, 2012 Revised draft presented to Board July, 2012 Draft sent to membership Sept, 2012	All responses considered. Changes made to document as sub-committee deemed appropriate.	Present to Board via email for vote prior to the Oct. meeting Distribute Position Statement at annual conference in Oct.

COMMITTEES AND MEMBER AT LARGE

EPPC Committee Goals/Accomplishments/Ideas for 2013 (Continued):

Complete Position Statement on Biobanking	<p>Subcommittee: Lynn Rew (Chair), Catharine Tymkow, Alice Kerber, Meghan Underhill, Jennifer Sanner</p> <p>Draft sent to EPP committee chair March, 2012</p>	<p>Lynn Rew resigns from committee July, 2012. She reports no activity on the rough draft.</p> <p>Appoint new chair of the subcommittee</p> <p>Prepare draft for review by international members and EPP committee members.</p> <p>Revise and send to board for initial approval. Send final draft to membership for comment. Submit to Board for final approval</p>
Review position statement Provision of Quality Genetic Services and Care: Building a Multidisciplinary, Collaborative Approach among Genetic Nurses and Genetic Counselors	<p>Laura Beamer, Janet Williams, Deborah MacDonald, Kathleen Calzone, and Dale Lea agreed to serve on the subcommittee. They questioned origin of document and felt it should be addressed by the Professional Practice committee</p>	<p>Nancy Ledbetter and Alice Kerber, Co-chairs of the Professional Practice Committee have agreed to address this issue</p> <p>This goal has moved from the EPP committee to the Professional Practice Committee.</p>
Review issues relevant to populations not protected by the GINA legislation. Consider developing an issue paper to be posted on our website. Consider expanding investigation to consider international protections and vulnerabilities	<p>Mary Beth Steck attempted to form a committee to address this. Was unable to do so.</p>	<p>Mary Beth Steck has resigned from the committee with regret for health reasons.</p> <p>Bring this issue forth at the Oct meeting</p>
Find out if there are any past issue papers	<p>Investigated</p>	<p>No issue papers have been written</p>
Revise membership list		<p>1 HQ adds names to listserv as new members join;</p> <p>2 HQ sends names of new members to committee chair</p> <p>3 Committee chair not aware when members fail to rejoin or become uninterested in the committee.</p> <p>1 Current list will be provided at the Oct meeting by HQ;</p> <p>2 After Oct meeting email will be sent to all members inquiring about continued interest</p>

COMMITTEES AND MEMBER AT LARGE

EPPC Committee Goals/Accomplishments/Ideas for 2013 (Continue):

Revise policy on writing position statements and issue papers	Discussions with board regarding policy	Two documents exist Dated Oct, 2001 Revised policy prepared by committee April, 2004. May have been approved by the Board Sept, 2009??? Need determination of responsibility.	Continue this process with the incoming Board.
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Nominating Committee

Debra L. Schutte, PhD RN, Chair;

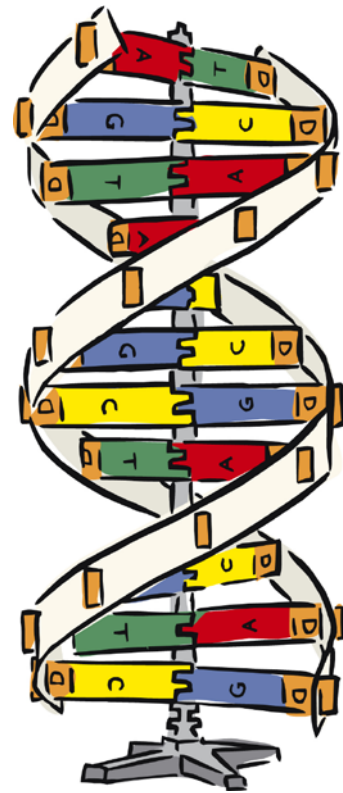
Martha Driessnack, PhD, PNP Co-Chair

Goals/Activities: Previous Year Goals:

- Identify needed nominations
- Secure nominations from membership
- Create ballot
- Conduct election
- Share results with membership

Committee Accomplishments for 2012

- Reviewed bylaws (related to Nominating Committee) and developed timeline and processes for 2012 election.
- Conducted a formal call for nominations using online mechanisms.
- Created 2012 ballot according to bylaws.
- Conducted 2012 election.
- Announced election results to ISONG membership.
- Will forward suggestions for modifications to process prior to 2013 election process.



COMMITTEES AND MEMBER AT LARGE

Professional Practice

Nancy Ledbetter, Alice Kerber Co-Chairs

Professional Practice Committee/SIG Goals/Activities/Outcomes for Previous Month

Previous Month Goals	Prev. Mo. Activities	Prev. Mo. Outcomes
Update scope and standards for genetics nurses with ANA		Committee formed (Nancy Ledbetter, Alice Kerber, Gia Mudd, Mary Quinn Griffen, Maggie Kirk, Karen Greco) assignments made, work is underway

Professional Practice Committee/SIG Goals/Activities/Outcomes for This Month

Current Month Goals	Current. Mo. Activities	Current. Mo. Outcomes (anticipated)
Update Position Statement: Provision of Quality Genetic Services and Care: Building a Multidisciplinary, Collaborative Approach among Genetic Nurses and Genetic Counselors	Have agreed to spearhead this.	Will discuss at Philadelphia meeting.



COMMITTEES AND MEMBER AT LARGE

Research Committee

Co-Chairs Dr. Gia Mudd; Dr. Sandy Founds In-coming Co-chair

Goals/Activities/Outcomes for 2012

Goals	Activities	Outcomes
RC listserv operational	Listserv was updated Tested and functional	Members responded to calls for Research Award applications and Task Force for policy/guideline work
Assess status of 4 policy and guidelines	Worked with EB to update status of 4 pending policy/guideline requests for RC consideration	Two items resolved. Phone meeting 9/25/12 to discuss draft Guideline and Policy; these 2 items are in progress **
Research Award	Verified one \$1500 award from the University of Pittsburgh School of Nursing. Conducted process	Six applications reviewed; 9 reviewers volunteered. Meeting 9/18/12; notification letters sent Michelle Wright, PhD student UND awardee
Suggestion to improve accessibility of RC work	Identified issues in locating needed documents for RC work	Please add a tab to the ISONG Website for "Research"
Foster genomics nursing networking	S. Founds working on JOGNN Editorial Board and 2012 Conference Hot Topics panel	New ISONG Perinatal SIG
New Co-chair for 2013		Nicole Hoh, PhD University of Pittsburgh

** Status of policy and guideline work by the RC

071212 Regarding GUIDE: ISONG Letters of Support for Research Proposal Submissions, it was decided by the Board in 2011 that no Letters of Support are to be provided. This document can be posted for member and public access.

081312 The GUIDE: Response to requests to recruit study participants during ISONG Conferences was approved by the EB. This document can be posted for member and public access.

Task Force drafts in progress to be forwarded to the EB by Annual Conference:

Guideline: For a For-Profit Organization to Sponsor Research

POLICY UPDATE: Recruitment for Studies Using ISONG website and listserv

COMMITTEES AND MEMBER AT LARGE

Member-at-Large

Sarah Sheets Cook, DNP, RN-CS

In this role, I have provided mostly consultation services for various organization activities and concerns : present at most Board conference calls, assisted with planning of October 2012 'anniversary' meetings in Philadelphia, offered opinions about organization direction re : membership and fund raising [eg. provided contact listing for all WHO CCs and US schools of nursing], participated in poster and presentation submissions, etc.

It has been a pleasure to serve in this role and to see that the organization is now re-vitalized and strong.

Auction Task Force

Chairs: Lori Farmer, Dale Lea

After exhaustive research and attempts to garner support for an online ISONG auction, the current two-person committee feels compelled to inform the ISONG Board that the undertaking is simply too great a task at the current time (for such a small committee), and without ISONG member buy-in, to recruit auction package components appropriate for an endeavor such as this one.

In lieu of this, a new fundraising initiative was suggested: getting a nice piece of jewelry donated, and then doing a «ring raffle» with an International theme. Using Chinese Take-out boxes, we will sell each one for \$20, and at the annual ISONG event in October, members who purchase a box or boxes will open their boxes at a designated time, to find either a «toy» ring and one winner will find a very nice real ring they win.

Lori got Bere Jewelers in Gulf Breeze, Florida to donate a 18 k and solid sterling silver, white agate stone ring, by jeweler Andrea Candela, retail value \$450-- for this auction.

Further, it is suggested by this committee that going forward, a new Fundraising committee for ISONG be created, and sub committees created for the annual silent auction, for educational endeavors that are fundraisers, and any other fundraisers be put under this overall umbrella. We strongly feel that having an overall larger fundraising committee would help ISONG raise more funds than keeping these fundraising initiatives as «separate» entities.

Annual Committee Report

Sponsorship Task force

Kathleen Hickey EdD, FNP, ANP, FAAN Chair

Key Committee Activities – accomplishments and status of work in progress: **Raised \$17,000 over 2012.**

Raising awareness of ISONG's mission with potential sponsors this includes schools of nursing, industry, volunteer organizations, patient support groups, the media etc.

Board Action: No board action required



COMMITTEES AND MEMBER AT LARGE

SPECIAL INTEREST GROUP (SIG)

PRENATAL SCREENING/GENETIC COUNSELING

Christine (Tina) Mladenka Chair

Proposed Startup Activities:

1. Create listserv
2. Networking meeting
3. Purpose and plans and policy ideas
4. Meeting at Annual Conference
5. Comment/review Positions Statement on Prenatal Testing
6. Webinar series. #1: ELSI of Prenatal Screening

The following people responded with interest in joining a SIG

Sandra Founds

Ruth T. Mielke, PhD, RN, CNM
Stanley Grant RN, MSN, APNG, CGD

Irma B. Ancheta, PhD, RN, FPCNA
Reena Haymond

Shirley Karr, BSN, RN, MSN

Stacy Hines-Dowell, DNP, APNG

Lori Farmer

Myunghee, RN, PhD

Judy Rokeach

Karen Zanni, PhD(c), RN-C, ARNP-BC

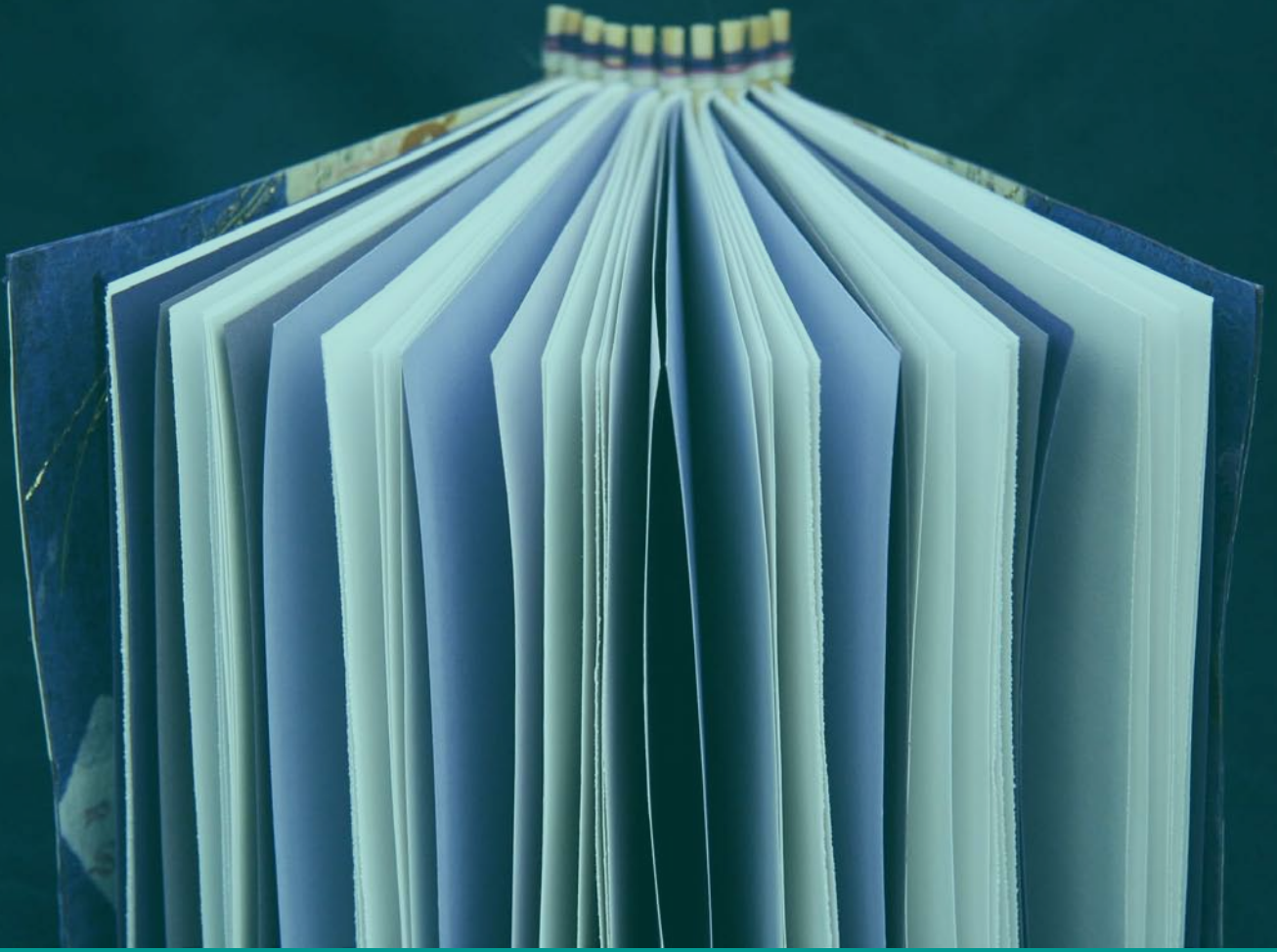
Elizabeth Barnby

Dr. Emily E. Stevens, PhD, RN, WHNP, FNP-BC
Willa Marlene Doswell

Laura Springstead, RNc, BSN

Patricia E. Hershberger, PhD, APRN, FNP-BC





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ISONG BOARD OF DIRECTORS AND COMMITTEES

ISONG BOARD OF DIRECTORS AND COMMITTEES

ISONG Board of Directors

President

Ellen Giarelli, ED, RN, CRNP
E-mail: eg446@drexel.edu

President-Elect

Kathleen Hickey, EdD, FNP-BC, ANP-BC, FAAN
Email: kth6@columbia.edu

Past President

Kathleen Sparbel, PhD, APRN-BC, FNP
Email: ksparbel@uic.edu

Treasurer

Marie Twal, PhD, RN
Email: metwal@auxmail.iup.edu

Secretary

Patricia Newcomb, PhD, RN CPNP
Email: pnewcomb@uta.edu

Member-at-Large

Mary Quinn Griffin, PhD, RN
Email: mary.quinngriffin@case.edu

Sarah Sheets Cook, DNP, RN-CS

Email: ssc3@columbia.edu

Executive Director

Beth Kassalen, MBA
Email: isonghq@msn.com

Committees

Bylaws / Awards Committee

Chair: Kathy Sparbel (ksparbel@uic.edu)

Communications Committees

Web Development Co-Chairs:

Julia Eggert (jaegger@clemsun.edu)
Lynnette Howington (l.l.howington@tcu.edu)

Newsletter Chair: Erika Santos

(erikammsantos@gmail.com)

Education Committee

Co-chairs

Sheila Alexander (salexand@pitt.edu)
Cathy Read (readca@bc.edu)

Ethical Issues and Public Policy Committee

Co-Chairs

Lynn Rew (ellerew@mail.utexas.edu)
Marie Twal (metwal@iup.edu)

Global Membership Committee

Co-Chairs

Milena Floria-Santos (milena@usp.br)
Pei-Ying Chuang (peiyug@yahoo.com)

Nominating

Co-Chairs

Debra Schutte (Debra.Schutte@hc.msu.edu)
Martha Driessnack (Martha-driessnack@uiowa.edu)

Professional Practice Committee

Alice Kerber (akerber@sjha.org)
Nancy Ledbetter (Nancy.ledbetter@providence.org)

Research Committee

Co-chairs

Gia Mudd (gia.mudd@uky.edu)
Nick Nichols (n.nicol@ucol.ac.nz)