National survey: Genetic Knowledge of Danish Nurses - Needs and Reality

Christiansen, Karin; Mikkelsen, Thomas Raundahl; Nissen, Kari Konstantin

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Join Us

On behalf of the 2017 International Society of Nurses in Genetics (ISONG) World Congress Planning Committee and the ISONG Board of Directors, we are delighted to invite you to be part of this year's Congress, an exciting opportunity to network with both new and old colleagues in Reston, Virginia. The venue is located near Washington DC, affording attendees the opportunity to visit the nation's capital while expanding their knowledge of precision genetic health care.

In keeping with the mission of ISONG to foster scientific discovery and professional growth in nursing and human genetics and genomics worldwide, the focus of the 2017 ISONG World Congress is "Precision Nursing: Through Research, Education and Practice". Presentations by Keynote, Plenary, Invited speakers and abstract presentations have been selected to meet the following program objectives:

- To describe the concept of personalized nursing, and its translation into nursing research, education and practice.
- To understand the unique, and important role of the professional nurse in the education of patients regarding personalized medicine.
- To recognize bioethical issues surrounding personalized nursing and their application in research, education and practice.
- To apply the concepts gained through this conference to further integrate personalized nursing in their own clinical specialty.

We couldn't have our meeting without the support of our Congress sponsors. Please stop by each booth, hear what is new and thank them for coming to Virginia!

Sincerely,

Susan W. Wesmiller, PhD, RN
Congress Co-chair

Deborah Tamura, MS, RN
Congress Co-chair

In Recognition of the Dedication in the Planning of the ISONG World Congress

2017 Congress Committee

Tara Albrecht, PhD, ACNP-BC
Katherine Beutner, MS, CNS-BC, NP-BC
Cheryl Brubaker, BSN, MSN, DNP, FNP-BC
Dennis J. Cheek, RN, PhD, FAHA
Sylvia S. Estrada, DNP, WHNP-BC, CBCN
Jane Garvin, PhD, APRN, FNP-BC
Jessica M. Gill, PhD, RN
Mary Quinn Griffin, PhD, RN, FAAN, ANEF
Michael Groves, PhD, RN, CNE
Lynnette Howington, DNP, RNC, WHNP-BC, CNL
Kathi Huddleston, PhD, RN, CCRC
Elisabeth Klein, DNP, CCRP, CNS, RNC
Theresa Koleck, PhD, BSN, RN
Stephanie Nikbakht, DNP, PPCNP-BC
Mandy Schmella, PhD, RN
Memnun Seven, RN, PhD
Kim Walker, MSN, RN, CPNP
Mckenzie Wallace, BSN, BA, RN
Conference Venue
We are delighted to announce that the 2017 ISONG World Congress on Nursing and Genomics will be held in Reston, Virginia USA.

Reston, Virginia is conveniently located approximately 35 minutes outside of Washington D.C. This allows for an ideal starting point for exploring Washington DC and fascinating Virginia, as well. Discover history, enjoy shows at Wolf Trap or Patriot Center, tour the wine country, shop, walk or bike on the Old Dominion Trails or wander through the newest Smithsonian Museum, The Udvar-Hazy Center in Chantilly, Virginia. The Udvar-Hazy Center is the companion facility to the Smithsonian Museum on the National Mall in Washington, DC and lists some of the World's most significant objects in aviation and space history. The Center also offers the Donald D. Engen Observation Tower, which gives you a 360-degree bird's-eye view of Washington Dulles International Airport and the surrounding area.

Hotel and Travel Details
The Hyatt Regency Reston Hotel will serve as the host hotel for the 2017 ISONG Congress. Conde Nast Traveler Magazine has named this Four-Diamond Reston hotel a Readers Choice Top 100 Hotel in the United States. This luxury hotel offers a full range of services and amenities, a heated indoor pool, a sun deck and oversized elegantly appointed guestrooms.

The hotel is located in Reston Town Center. Reston Town Center is a lovely community destination, offering an acclaimed outdoor venue, more than 50 shops, 35 restaurants and an 11-screen cinema all within walking distance of the hotel. The center’s hub features the 20-foot Mercury Fountain designed by the sculptor Saint Clair Cemin and the Pavilion hosts festivals throughout the year. Reston Town Center is home to The Northern Virginia Fine Arts Festival, Taste of Reston. From the hotel, guests can access the Old Dominion Trails by walking across the street.

**Host Hotel**  
Hyatt Regency Reston  
1800 Presidents Street  
Reston, Virginia 20190 USA  
Phone: +1 703-709-1234

All room reservations must be made by October 11, 2017 to ensure that you get the discounted group room rate. It is recommended that you make your reservation as soon as possible.

Check in 3PM / Check out 11AM

**Hotel Parking**  
The Hyatt Regency Reston offers valet parking or self parking options.  
Valet Parking Cost:  
Daily - $20.00 / Overnight - $25.00  
Self-Parking Cost:  
Daily - $18.00 / Overnight - $15.00

The ISONG Congress group room rates are as follows:  
$179 Single/ Double plus taxes

The hotel offers a complimentary shuttle to/from the Dulles Airport. (see airport travel for the details.)

**Airport Travel Options**

**Dulles International Airport (IAD)**  
Located 6.7 miles from Hyatt Regency Reston. The Hyatt Regency Reston offers a complimentary shuttle that arrives at Dulles Airport at the top of each hour between 6am-10pm Monday through Friday and 7am-10pm on Saturday & Sunday. The pick-up and drop-off point will be at curbs 2A and 2H, adjacent to the lower level baggage claim level. Return shuttle transportation from the hotel departs on the :45 beginning at 5:45am Monday-Friday and 6:45am Saturday & Sunday. For more information please contact the hotel concierge at 1 (703) 709-1234 x51.

**Ronald Reagan Washington National Airport (DCA)**  
Located 23.8 Miles from Hyatt Regency Reston. Super Shuttle service is available for approx $27 each way. For information or reservations call 800-BLUE-VAN or book online. Taxi fare is approx $50 to $60 depending on traffic. Additional options include the METRO’s Blue or Yellow Line to Silver Line.
Welcome Reception
We would like to invite all ISONG Congress to the Welcome Reception on Thursday evening, November 2 from 7-9PM. It is a great way to kick off our annual meeting and to connect with new and old friends!

Invited Speakers Session
The Invited Speakers listed in the program were recognized by members of the ISONG Congress Planning Committee as experts in their field of research and genetics and were invited to share their knowledge with the attendees.

Donate A Raffle Item
Please consider making a donation to the ISONG raffle. The ISONG raffle is always a highly anticipated event at the annual Congress! Our members hail from all over the world and we usually have an array of unique items. Bring something from your hometown, country, hospital/academic institution or a cultural item. Make sure that your item will travel well – meaning it is compact, lightweight, and can be easily transported in a suitcase. If you prefer, you can support the raffle though a monetary donation (the Congress Committee will purchase items with the donations for the raffle.) Click here to make a monetary donation. Please direct any questions to ISONG Raffle Committee chair Sylvia Estrada at estradas@cshs.org. Be a part of the raffle prize drawing on Friday at 5PM - it will be lively!

ISONG Awards and Grants
Fostering scientific research in genetics is an important part of ISONG’s mission. The support received from our sponsors will provide for ISONG Nursing Research Grant Awards. With the contributions from ISONG members who donated to the Nursing Research Donations Campaign to support their fellow members, an additional grant will be offered this year. These grants as well as the Founders Awards and President’s Award will be presented during the lunch program on Saturday.

Abstract Sessions/Scientific Posters/Poster Blitz Session
The 2017 Abstract Sessions reflect a focus on the titles as listed and offer current and late breaking information in Genetics/Genomics. Abstracts that were accepted for poster presentations will have their posters displayed throughout the Congress and due to popular demand the “Poster Blitz” session is once again featured in the program. This session provides select poster presenters with the opportunity to orally present their work to Congress attendees with a brief overview of their work in addition to presenting at the traditional poster session. The Poster Session and Reception will immediately follow the Poster Blitz to provide the attendees dedicated time to meet with the poster authors.

Congress Registration
Register early to secure your spot and to take advantage of the early registration discounted rate.

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<thead>
<tr>
<th></th>
<th align="right">Before September 5</th>
<th align="right">After September 5</th>
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<tbody>
<tr>
<td>ISONG active dues member</td>
<td align="right">$495.00</td>
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<td>Podium / Abstract Presenter</td>
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<td>*Non-member</td>
<td align="right">$645.00</td>
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<td>Full-time students</td>
<td align="right">$395.00</td>
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(With copy of University/Program ID card)

*Non-members – Join now for membership benefits and take advantage of the reduced Congress registration fees. Click here to join ISONG.

For payment by check – after you register online, please print the registration form or invoice and mail the payment to: ISONG, 461 Cochran Road, Box 246, Pittsburgh, PA 15228 USA.

You will receive a confirmation from ISONG after you have registered. If you have any questions, please call us at +1 412-344-1414, or contact us via email at: linda@isong.org. All cancellations must be received in writing. A $50.00 USD administrative fee will be deducted from cancellations received up to 14 days in advance. After that time, no refunds can be made.
## Congress Program Agenda

### Thursday, November 2, 2017

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>4:00PM – 8:00PM</td>
<td>Congress Registration</td>
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<tr>
<td>7:00PM – 9:00PM</td>
<td>Welcome Reception</td>
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### Friday, November 3, 2017

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:30AM – 5:00PM</td>
<td>Congress Registration</td>
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<tr>
<td>7:30AM – 8:30AM</td>
<td>Coffee, Tea / Visit Exhibits, Posters and Raffle</td>
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<tr>
<td>8:30AM – 8:45AM</td>
<td>President’s Welcome and Opening Remarks</td>
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<tr>
<td></td>
<td><em>Elizabeth L. Pestka, MS, PMHCNS-BC, AGN-BC</em></td>
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<td><em>ISONG President</em></td>
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<td>Clinical Nurse Specialist</td>
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<td>Pain Rehab Center</td>
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<td></td>
<td>Assistant Professor of Nursing</td>
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<td>Mayo Clinic</td>
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<td>Rochester, Minnesota USA</td>
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<tr>
<td>8:45AM – 9:45AM</td>
<td>Opening Keynote Presentation - Prenatal Genome Sequencing</td>
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<td><em>Benjamin E. Berkman, JD, MPH</em></td>
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<td></td>
<td>Deputy Director</td>
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<td></td>
<td>NHGRI (National Human Genome Research Institute)</td>
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<td>National Institutes of Health</td>
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<td>Bethesda, Maryland USA</td>
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<td><em>Benjamin D. Solomon, MD, FACMG</em></td>
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<td>Managing Director</td>
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<td>GeneDx</td>
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<td></td>
<td>Gathersburg, Maryland USA</td>
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## Continuing Education Credits

ISONG and the University of Pittsburgh School of Nursing are collaborating to provide this learning activity. Contact hours are being determined and will be posted prior to the learning activity. The University of Pittsburgh School of Nursing is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center’s Commission on Accreditation.
<table>
<thead>
<tr>
<th>Time</th>
<th>Abstract Sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:45AM – 10:45AM</td>
<td><strong>Clinical Practice</strong></td>
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<td><strong>Research</strong></td>
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<td></td>
<td><strong>Research</strong></td>
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<tr>
<td>9:45AM – 10:00AM</td>
<td><strong>Family Health History In Primary Care: A Critical Analysis Of Available Tools</strong></td>
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<tr>
<td></td>
<td>Karen J Whitt¹, Ann Maradiegue², Gaye Ray³, Lauren Bretzing³, George Washington University, Washington, DC, USA, James Madison University, Harrisonburg, VA, USA, Brigham Young University, Provo, UT, USA</td>
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<td><strong>Suffering In The Midst Of Technology: Routine Prenatal Ultrasound Screening to Turbulent Congenital, Chromosome or Genetic Disorder Results</strong></td>
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<td>Jeannie Gottlieb¹, University of Southern Maine, Portland, ME, USA</td>
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<tr>
<td>9:45AM – 10:00AM</td>
<td><strong>Antibiotic Exposure During Pregnancy Effects Offspring Microbial Colonization: Bad Bugs Bloom</strong></td>
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<td>Stephanie Prescott¹, Ernesto Perez-Chanona², Wendy Henderson¹, Giorgio Trinchieri³, National Institute of Nursing Research, Bethesda, MD, USA, National Cancer Institute, Cancer and Inflammation Program, Bethesda, MD, USA, University of Virginia, Charlottesville, Virginia, USA, Fairfax Neonatal Associates, Falls Church, VA, USA</td>
</tr>
<tr>
<td>10:00AM – 10:15AM</td>
<td><strong>Standards of Practice: Living in the Real World</strong></td>
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<td>Alice Kerber¹, Nancy Ledbetter², Suzanne Mahon³, Georgia Center for Oncology Research and Education, Atlanta, Georgia, USA, Portland Wellness Center, Portland, Oregon, USA, Saint Louis University, St. Louis, MO, USA</td>
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<tr>
<td>10:00AM – 10:15AM</td>
<td><strong>Genetic Characterization of Families from a Hereditary Cancer Registry in Brazil</strong></td>
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<td>Erika Santos¹, Caroline Sá¹, Bernardo Garicochea¹, Maria Del Pilar Diz², Renata Coudry³, Edite Oliveira¹, Benedito Rossi¹, Hospital Sirio-Libanes, Sao Paulo, Brazil</td>
</tr>
<tr>
<td>10:15AM – 10:30AM</td>
<td><strong>A Toolbox Approach to Guide Ethical Decision-Making in Genetics and Genomic Nursing</strong></td>
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<td>Mary Beth Steck¹, Clemson University, Clemson, SC, USA</td>
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<tr>
<td>10:15AM – 10:30AM</td>
<td><strong>Breast Milk Microbiota Profiles Among Mothers With Preterm Infants: A Review of the Literature</strong></td>
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<td>Kelley Baumgartel¹, Michael Morowitz², University of Pittsburgh, School of Nursing, Pittsburgh, PA, USA, University of Pittsburgh, School of Medicine, Pittsburgh, PA, USA</td>
</tr>
<tr>
<td>10:30AM – 10:45AM</td>
<td><strong>A Model Of The Childhood Lymphoma Implicates Important Prognostic Genes In Cancer Survival</strong></td>
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<td>Rieko Sotojima¹, Joelle Fenger², William Kisseberth³, Jennie Rowell³, The Ohio State University College of Nursing, Columbus, OH, USA, The Ohio State University College of Veterinary Medicine, Columbus, OH, USA, The Ohio State University Comprehensive Cancer Center, Columbus, OH, USA</td>
</tr>
<tr>
<td>10:45AM – 11:15AM</td>
<td><strong>Primary Care Nurse Practitioners’ Knowledge and Experience Regarding the Management of Presumptive Positive Results of the Kentucky Mandated Newborn Screening Program</strong></td>
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<td>Delwin Jacoby¹, Angela Crutcher¹, Spalding University, Louisville, KY, USA, University of Kentucky, Lexington, KY, USA</td>
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<td><strong>Development Of An Interactive Pharmacogenomic Education Module: Comparison Of Oncology Nurses’ Knowledge And Attitudes Within Teaching And Community Hospitals.</strong></td>
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<td>Crissy Dodson¹, University of North Carolina at Wilmington, Wilmington, NC, USA</td>
</tr>
</tbody>
</table>

10:45AM – 11:15AM **Refreshment Break/ Visit Exhibits, Posters and Raffle**

**ISONG Genetic Nursing Research Grant Award Recipients**

Look for the ribbons throughout the congress program denoting the authors who are past recipients of this award.
### Friday, November 3, 2017 (continued)

#### 11:15AM – 12:15PM

##### Abstract Sessions

<table>
<thead>
<tr>
<th>Clinical Practice</th>
<th>Research</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical Utility Of Rapid Genomic Sequencing In The Neonatal And Pediatric Intensive Care Units: What Nurses Need To Know</strong>&lt;br&gt;Julie Cakici¹, Stephen Kingsmore¹, David Dimmock², Sara Caylor³&lt;br&gt;¹Rady Children's Institute for Genomic Medicine, San Diego, CA, USA</td>
<td><strong>A Novel Approach to Genotype-phenotype Profiling for Ryanodine Receptor 1-related Myopathies</strong>&lt;br&gt;Katherine Meilleur¹, Monique Shelton¹, Jessica Witherspoon¹, Carolyn Allen¹, M. Sonia Razazyar¹, Michaela Cortes¹, Irene Chismer¹&lt;br&gt;²National Institute of Nursing Research, Bethesda, MD, USA</td>
<td><strong>A Review of the Literature on the Relationships Between Genetic Polymorphisms and Chemotherapy-Induced Nausea and Vomiting</strong>&lt;br&gt;Komal Singh¹, Elena Flowers¹, Kord Kober¹, Anand Dhruva¹, Christine Miaskowski¹&lt;br&gt;³University of California San Francisco, San Francisco, CA, USA</td>
</tr>
<tr>
<td><strong>Educational Needs of Nurses to Provide Genetic Services in Prenatal Care: A Cross Sectional Study from Turkey</strong>&lt;br&gt;Memnun Seven¹, Kafiye Eroğlu¹, Aysüler Akyüz¹, Charlotte Ingoldstad²&lt;br&gt;¹Koç University, Istanbul, Turkey, ²Karolinska Institute, Stockholm, Sweden</td>
<td><strong>Factors Associated With Family Communication About Genetic Risk for Inherited Cardiac Conditions</strong>&lt;br&gt;Li莎1&lt;br&gt;¹University of Iowa, Iowa City, IA, USA</td>
<td><strong>XRAYS: Unconfuse The News For Young Breast Cancer Survivors and Those At High Risk Of Breast Cancer</strong>&lt;br&gt;Lisa Schlager¹, Lisa Rezende¹, Sue Friedman¹, Julie Huynh¹, Robin Pugh-Yi¹&lt;br&gt;³FORCE: Facing Our Risk of Cancer Empowered, Tampa, FL, USA</td>
</tr>
<tr>
<td><strong>Utilization of and Women Educational Needs for Prenatal Screening tests: A Turkish study</strong>&lt;br&gt;Memnun Seven¹, Aysüler Akyüz¹, Kafiye Eroğlu¹, Sandra Daack-Hirsch², Heather Skirton³&lt;br&gt;¹Koç University, Istanbul, Turkey, ²The University of Iowa College of Nursing, Iowa, USA, ³Plymouth University, Plymouth, UK</td>
<td><strong>The Importance of Coronary Heart Disease Family History for Triage Evaluation of Patients With ST Elevation Myocardial Infarction in the Emergency Department</strong>&lt;br&gt;Efrat Dagan¹, Mor Saban¹, Rabia Salame²&lt;br&gt;¹University of Haifa, Haifa, Israel, ²Rambam Health Care Campus, Haifa, Israel</td>
<td><strong>Incidence and Perception of Nursing Students’ Academic Incivility in Oman</strong>&lt;br&gt;Jansirani Natarajan¹, Joshua Kanaabi Mulira¹, Jacoba Vandercolff¹&lt;br&gt;³Sultan Qaboos University, Muscat, Oman</td>
</tr>
<tr>
<td><strong>Genetic Variation And Drug Phenotype Data For 3372 Newborns That Completed Pharmacogenetic Testing</strong>&lt;br&gt;Grace N Lawrence¹, Julie A Muskett¹, Allison G Mitchell¹, Grace Jo¹, Kathleen Brown¹&lt;br&gt;¹Inova, Falls Church, VA, USA</td>
<td><strong>Assessment Of Genomic Knowledge Among Nurses In An Online RN To BSN Completion Program</strong>&lt;br&gt;Li莎1, ²Drexel University, Philadelphia, PA, USA, ³Villanova University, Villanova, PA, USA</td>
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#### 12:15PM – 1:45PM

**Lunch / Networking and ISONG Committee Meetings**

Enjoy lunch with ISONG Members during the committee meetings (optional) or with your fellow Congress attendees. This is an opportunity to network early in the program!

#### 1:45PM – 2:30PM

**Keynote Presentation - The Ethics in Research**

*David S. Wendler, MA, PhD*

Head, Section on Research Ethics
Department of Bioethics
Clinical Center
National Institutes of Health
Bethesda, Maryland USA
Friday, November 3, 2017 (continued)

2:30PM – 3:00PM  
Refreshment Break / Visit Exhibits, Posters and Raffle

3:00PM – 4:00PM  
Invited Speakers

| Global Genetics Nursing Alliance –  
Creating a Roadmap  
Kathleen Calzone, PhD, RN, APNG, FAAN  
Research Geneticist  
National Cancer Institute  
Bethesda, Maryland USA  
Maggie Kirk, PhD, BSc Hons, DipN, RGN, FRCN, SFHEA  
Professor of Genetics Education  
University of South Wales  
Glyntaff, Wales, UK | Genetic Testing for Hereditary Cancer Syndromes: A Foreign Language or The Way of the Future?  
Tammy McKamie, RN, MSN, OCN, GCN  
Genetic Clinical Nurse/ Educator  
Christus St. Michael Cancer Treatment Center  
Texarkana, Texas USA |

3:00PM – 3:30PM  
Genetic Testing for Hereditary Cancer Syndromes: A Foreign Language or The Way of the Future?  
Tammy McKamie, RN, MSN, OCN, GCN  
Genetic Clinical Nurse/ Educator  
Christus St. Michael Cancer Treatment Center  
Texarkana, Texas USA

3:00PM – 3:30PM  
Promising Strategies for Genomic Nursing Education  
Linda D Ward, PhD, ARNP  
Assistant Professor  
College of Nursing  
Washington State University  
Spokane, Washington USA

3:30PM – 4:00PM  
Epigenomic Biomarkers in Preeclampsia  
Cindy Anderson, PhD, CRNP, WHNP-BC, FNAP, FAHA, FAAN  
Associate Dean for Academic Affairs and Educational Innovation  
College of Nursing  
The Ohio State University  
Columbus, Ohio USA

4:00PM – 5:00PM  
Poster Blitz Oral Presentations

4:45PM – 5:45PM  
Poster Reception

5:45PM – 6:30PM  
Fireside Chat

Exhibits

Please visit and support our sponsors and exhibitors in the exhibit hall during the Congress. Sponsorship of the annual Congress helps to support this premier educational opportunity and the ISONG Research Grants awarded for nurses in genetics/genomics worldwide.
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<thead>
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<th>Time</th>
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<td>7:45AM – 8:45AM</td>
<td>Coffee, Tea / Visit Exhibits, Posters and Raffle</td>
</tr>
<tr>
<td>8:45AM – 9:00AM</td>
<td>Announcements</td>
</tr>
</tbody>
</table>
| 9:00AM – 9:45AM | **Keynote Presentation – State of the Science in Genomic Nursing**  
*Patricia A. Grady, PhD, RN, FAAN*  
Director  
National Institute of Nursing Research  
National Institutes of Health  
Bethesda, Maryland USA |
| 9:45AM – 10:30AM| **P30 Grant Panel**  
**Precision in Symptom Self-Management (PriSSM): Looking Through a Nursing Lens for the Future**  
*Kathleen T. Hickey, EdD, FNP, ANP, FAHA, FAAN*  
Associate Professor  
School of Nursing  
Columbia University  
Nurse Practitioner  
Division of Cardiology  
Columbia University  
New York, New York USA |
<p>| 10:30AM – 11:00AM| Refreshment Break / Visit Exhibits, Posters and Raffle      |</p>
<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Presenters</th>
<th>Institutions</th>
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<tbody>
<tr>
<td>11:00AM – 12:00PM</td>
<td>Abstract Sessions</td>
<td></td>
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<tr>
<td>11:00AM – 11:15AM</td>
<td>Next-Generation Sequencing: Implications Surrounding Usefulness for Newborn Screening</td>
<td>Satishkumar Ranganathan Ganakammal1, 1Clemson University, Clemson, SC, USA</td>
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<tr>
<td>11:15AM – 11:30AM</td>
<td>Genetic Counselling Outcome Scale (GCOS-24): Cultural Adaptation And Validation For Use In Measuring Patient-Reported Outcomes From Genetic Counselling In Brazil</td>
<td>Milena Flória-Santos1, Marion McAllister2, Mayara Segundo Ribeiro1, Bruna Tavares Bacalá1, Ana Paula Torres1, Alan Assunção1, Jennifer Thalita Targino dos Santos1, 1University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, São Paulo, Brazil, 2Cardiff University School of Medicine, Cardiff, Wales, UK</td>
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<tr>
<td>11:30AM – 11:45AM</td>
<td>A Transition Program for Adolescents with Down Syndrome: Three Year Review</td>
<td>Joanna Spahis1, Debbie Clark1, 1Children's Health Dallas, Dallas, TX, USA</td>
<td></td>
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<tr>
<td>11:45AM – 12:00PM</td>
<td>Outcomes of Newborn Screening for Lysosomal Storage Disorders in Illinois</td>
<td>Erika Vucko1, Lauren Hitchins1, 1Ann &amp; Robert H. Lurie Children's Hospital, Chicago, IL, USA</td>
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<tr>
<td>11:50AM – 12:00PM</td>
<td>Pharmacogenetics: A Valuable Resource For Patients Participating In Care Coordination With Depression</td>
<td>Julie Kittelsrud1, Lisa Weisser2, Neil Matthiesen3, Trisha Lauterbach1, Melissa Black1, Noah Kallsen1, Sandy Crisp1, David Basal5, Krista Bohlen1, 1Avera Institute for Human Genetics, Sioux Falls, USA, 2University of South Dakota, Sanford School of Medicine, Department of Psychiatry, Sioux Falls, SD, USA, 3Avera Health, Care Coordination program, Sioux Falls, SD, USA</td>
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<tr>
<td>11:55AM – 12:00PM</td>
<td>Learning From Patients With Rare Diseases: Clinical Challenges Faced By Two Patients With Different Forms Of Methylmalonic Acidemia (MMA)</td>
<td>Carol Van Ryzin1, Susan Ferry1, 1NIH/NHGRI, Bethesda, MD, USA</td>
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<tr>
<td>12:00PM – 2:00PM</td>
<td>Lunch/Awards Presentations/Business Meeting</td>
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Enjoy lunch and networking while honoring ISONG members as the awards for Nursing Research Grants, Founders' and President's awards are presented. Also, this is an exciting time to hear updates about our organization, committee reports and the goals of ISONG for the coming year - please join us!
# Saturday, November 4, 2017 (continued)

## 2:00PM – 3:15PM  Abstract Sessions

<table>
<thead>
<tr>
<th>Research</th>
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<tr>
<td><strong>ICU Delirium And Changes In IL6ST Methylation.</strong> &lt;br&gt;Sheila Alexander¹, Bryan McVerry¹, Scott Gunn¹, Yvette Conley¹, Dianxu Ren¹, ¹University of Pittsburgh, Pittsburgh, PA, USA</td>
<td><strong>Differences in the Stool and Skin Microbiome and in Antimicrobial Resistance Genes in a Private Room Versus Open-bay Neonatal Intensive Care Unit</strong>&lt;br&gt;Kathi Huddleston¹, Elisabeth Klein¹, Varsha Deopujari¹, Suchitra Hourigan¹, ¹Inova Translational Medicine Institute, Falls Church, VA, USA, ¹Pediatric Specialists of Virginia, Fairfax, VA, USA</td>
<td><strong>Measuring Meaningful Learning Through Longitudinal Tracking Of Genomic Knowledge</strong>&lt;br&gt;Linda D. Ward¹, Lynn Jinishian¹, ¹Washington State University, Spokane, WA, USA</td>
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<td><strong>DNA Methylation Hints at Biological Mechanisms in the Critically Ill Patient: A Pilot Study</strong>&lt;br&gt;Jennie Rowell¹, Judy Tate¹, Michele Balas¹, Matthew Exline¹, Linda Chlan¹, Pearlyn Yan¹, Jackson Killian¹, Mary Beth Happ¹, Chi Song¹, Guy Brock¹, Ralf Bundschuh¹, ¹The Ohio State University, Columbus, OH, USA</td>
<td><strong>Understanding Parental Refusal To Enroll Their Children In A Genomic Sequencing Research Study</strong>&lt;br&gt;Anastasia Ouma¹, Stacy Hines-Dowell¹, Kayla Hamilton¹, Lynn Harrison¹, Elsie Gerhardt¹, Victoria Liddle¹, Rose McGee¹, Regina Nuccio¹, Emily Quinn¹, Jessica Valdez¹, Chimene Kesserwan¹, Kim Nichols¹, ¹St. Jude Childrens Research Hospital, Memphis TN, USA</td>
<td><strong>Up to Date: Ankyloglossia and Maxillary Lip-ties</strong>&lt;br&gt;Emily Hopkings¹, ¹Chatham University, Pittsburgh, PA, USA</td>
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<td><strong>DNA Methylation Associated with Early Neurodevelopment in Preterm Infants</strong>&lt;br&gt;Rita Pickler², Cindy Anderson², Maciej Pietrzak², Joyce Ohm², ¹Roswell Park Cancer Institute, Rochester, NY, USA, ²The Ohio State University, Columbus, OH, USA</td>
<td><strong>Factors Affecting Recruitment And Consent To Biological Specimen Banking In An Observational Cohort Study Of Pregnant Women</strong>&lt;br&gt;Shannon Gillespie¹, Cindy Anderson¹, ¹The Ohio State University, Columbus, OH, USA</td>
<td><strong>Gene Expression Patterns and Measurement of Gene Expression Changes</strong>&lt;br&gt;Komal Singh¹, Christine Miaskowski¹, Elena Flowers¹, Anand Dhruva¹, Kord Kober¹, ¹University of California San Francisco, San Francisco, CA, USA</td>
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<td><strong>Blood-Based DNA Methylation Levels Of Endoglin Pathway Candidate Genes: Do They Differ In Women With And Without Clinically-Overt Preeclampsia?</strong>&lt;br&gt;Alison Rietze¹, Yvette Conley¹, Carl Hubei¹, Arun Jeyabalani¹, James Roberts¹, Mandy Schmella¹, ¹University of Pittsburgh, Pittsburgh, PA, USA, ²Magee-Womens Research Institute and Foundation, Pittsburgh, PA, USA</td>
<td><strong>Relationship Between Psychosocial Distress In Pregnancy And Two Genes Associated With Human Social Interaction</strong>&lt;br&gt;Sarah Dewell¹, Donna Slater¹, Karen Benzies¹, Sheila McDonald¹, Suzanne Tough¹, ¹University of Calgary, Calgary, AB, Canada</td>
<td><strong>Keeping Pace With Genetics: An Educational Program on Prenatal Cell-free DNA Screening for Obstetricians.</strong>&lt;br&gt;Karen Hanson¹, Joseph D. McInerney¹, Michael Dougherty¹, ¹American Society of Human Genetics, Bethesda, MD, USA</td>
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<td><strong>Dietary Status and DNA Methylation in Endothelial Dysfunction: A Pilot Study</strong>&lt;br&gt;Cindy Anderson¹, Shannon Gillespie¹, Danielle Perley¹, Joyce Ohm¹, ¹The Ohio State University, Columbus, OH, USA, ²University of North Dakota, Grand Forks, ND, USA, ³Roswell Park Cancer Institute, Buffalo, NY, USA</td>
<td><strong>The Gut Microbiome in Necrotizing Enterocolitis: A Case Study of Twins</strong>&lt;br&gt;Elisabeth Klein¹, Kathi Huddleston¹, Varsha Deopujari¹, Suchitra Hourigan¹, ¹Inova Translational Medicine Institute, Falls Church, VA, USA, ²Pediatric Specialists of Virginia, Fairfax, VA, USA</td>
<td><strong>Pairing Pedagogical and Genomic Advances to Prepare APNs for the Era of Precision Health</strong>&lt;br&gt;Elena Flowers¹, Hamza Abid¹, Sasha Binford¹, Meg Martin¹, Lynda Mackin¹, ¹University of California, San Francisco, CA, USA</td>
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## 3:15PM – 3:45PM  Refreshment Break / Visit Exhibits, Posters and Raffle
### Saturday, November 4, 2017 (continued)

#### 3:45PM – 5:00PM

<table>
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<td><strong>Research</strong></td>
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| Moderate Blast Exposure Alters Peripheral Concentrations of Proteins Related to Neurodegeneration | OMICS Nursing Science and Education Network (ONSEN)  
Kathleen Calzone², Ann Cashion¹, Lois Tully³, Jean Jenkins², 'National Institutes of Health, National Institute of Nursing Research, Bethesda, MD, USA, ²Walter Reed Army Institute of Research, Silver Spring, MD, USA, ³USARMY MEDCOM USAMRMC, Fort Detrick, MD, USA, ⁴Naval Medical Research Center, Silver Spring, MD, USA |
| Neurobiological Mechanisms Of Chemobrain: A Feasibility Study Using An Animal Model | Clinical Documentation Of Genetic Counseling-related Emotional Distress In Electronic Health Record Narratives  
Theresa Kolecık, Suzanne Bakken¹, Kathleen Hickey¹, Nicholas Tatonetti¹, 'Columbia University, New York, NY, USA |
| Oxytocin Receptor (OXTR) and Vasopressin Receptor (AVPR1A) Genes as Candidate Genes for Apathy in Persons with Alzheimer Disease | Assessing Awareness and Integration of the Genetic Information Nondiscrimination Act of 2008 (GINA) Among Nurse Practitioner Faculty  
Mary Steck¹, 'Clemson University, Clemson, SC, USA |
| Altered Gene Expression Following Blast-Induced Traumatic Brain Injury in a Military Population | Diabetes Education Is Associated with Improved Sleep Quality and Changes in Gene Methylation  
Evelyn G. Bign integration with B. J. Chasens³, Yvette P. Conley⁴, Christopher C. Ims⁵, 'University of Pittsburgh School of Nursing, Pittsburgh, PA, USA |
| Family Communication About Familial Risk Of Stroke Promotes Perceived Risk In Adult Offspring of Stroke Patients | Developing A Pre-appointment Video To Prepare New Families For Genetics Clinic Visit  
Andrea Hartgraves¹, Tammy Fairbanks¹, 'Seattle Children's Hospital, Seattle, WA, USA |

#### 5:00PM – 5:30PM

| **Raffle Drawing in General Session Room** |

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**Schedule for November 3-5, 2017**

- **November 3, 2017**
  - 12:00PM – 12:30PM: Abstract Sessions
  - 12:30PM – 1:00PM: Lunch Break
  - 1:00PM – 1:30PM: Abstract Sessions

- **November 4, 2017**
  - 10:00AM – 10:30AM: Abstract Sessions
  - 10:30AM – 11:00AM: Abstract Sessions
  - 11:00AM – 11:30AM: Abstract Sessions
  - 11:30AM – 12:00PM: Abstract Sessions
  - 12:00PM – 12:30PM: Lunch Break
  - 1:00PM – 1:30PM: Abstract Sessions

- **November 5, 2017**
  - 10:00AM – 10:30AM: Abstract Sessions
  - 10:30AM – 11:00AM: Abstract Sessions
  - 11:00AM – 11:30AM: Abstract Sessions
  - 11:30AM – 12:00PM: Abstract Sessions
  - 12:00PM – 12:30PM: Lunch Break
  - 1:00PM – 1:30PM: Abstract Sessions

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**Location:**

- **2017 ISONG World Congress**
- **Hyatt Regency Reston, Reston, Virginia USA**
- **November 3-5, 2017**
7:15AM – 12:00PM  Congress Registration

7:15AM – 8:00AM  Coffee, Tea / Visit Exhibits

8:00AM – 8:30AM  Incoming President Address
Mindy Tinkle, PhD, RN, WHNP-BC, FAAN
Associate Professor
College of Nursing
University of New Mexico
Albuquerque, New Mexico USA

8:30AM – 9:30AM  International Panel
This panel will be an exciting overview from participant countries on genetic nursing in research, education and practice with the focus on precision nursing. Due to the popularity of this session, the presentation time has been increased for this year's program.

9:30AM – 10:00AM  Invited Speaker
Personalized Nursing
Allison A. Vorderstrasse, DNSc, APRN, FAAN
Associate Professor
School of Nursing
Duke University
Durham, North Carolina USA

10:00AM – 10:30AM  Refreshment Break/Visit Exhibits

10:30AM – 11:00AM  Invited Speaker
Pharmacogenomics Update
Dennis Cheek, RN, PhD, FAHA
Professor
Harris College of Nursing and Health Sciences
Texas Christian University
Fort Worth, Texas USA

11:00AM – 12:00PM  Closing Keynote Speaker – Developing EXPertise; The UK Journey
Sally Turner
CNS in Xeroderma Pigmentosum, Children
St. John’s Institute of Dermatology
St. Thomas’ Hospital
London, United Kingdom

Congress Concludes
Carpenter Syndrome - A Case Report of a Rare Autosomal Recessive Condition
Delwin Jacoby¹, ¹University of Kentucky, Lexington, KY, USA, ²Spalding University, Louisville, KY, USA

Persistent Misconceptions of Graduate Nursing Students About Genome Basics
Jane Garvin¹, Beverly Collins¹, ¹Augusta University, Augusta, GA, USA

Cancer Risk Management Program and Advanced Nurse in Genetics Streamline Comprehensive Surveillance for Patients Most at Risk
Denise Musser¹, Kristin Niendorf², Mary Ahrens¹, Olivia Michel¹, Sarah Merts¹, Alyssa Kne¹, Rob Madoff¹, ¹University of Minnesota, Minneapolis, MN, USA

The Influence of Test Predictive Value and Disease Treatability on Israeli Arabs Intention to Undergo Predictive Genetic Testing and Share Test Results with their Family
Sivia Barnoy¹, Effaf Athamna¹, ¹Tel-Aviv University, Tel-Aviv, Israel

Polymorphism-G308a Gene Tnf-A And Sleep Disturbance In Open Populations Men 25-64 Years Of Siberia: Who Program Monica-Psychosocial
Valery Gafarov¹, Elena Gromova¹, Igor Gagulin¹, Dmitriy Panov¹, Almira Gafarova¹, ¹FSBI Institute of Internal and Preventive Medicine, Novosibirsk, Russia

The Expression-Regulation Model: A Middle-Range Theory
Eric Barbato¹, Rebecca Darrah¹, ¹Case Western Reserve University, Cleveland, OH, USA

Integrating Genetics and Genomics into the Doctor of Nursing Practice Curriculum
Delwin Jacoby¹, ¹Spalding University, Louisville, KY, USA

HAMP Gene Polymorphism and Patient Outcomes Following Aneurysmal Subarachnoid Hemorrhage
Lacey Wright Heinsberg¹, Dianxu Ren¹, Elizabeth Crago¹, Paula Sherwood¹, Samuel Poloyac¹, Yvette Conley¹, ¹University of Pittsburgh School of Nursing, Pittsburgh, PA, USA, ²University of Pittsburgh School of Pharmacy, Pittsburgh, PA, USA

Development Of A Support Program To Assist Hereditary Cancer Patients’ Communication About Genetic Risk Information To Family Members
Miho Kakuta¹, Keiko Tsuji², Reiko Yokomakura³, Mitsue Simizu³, Yukiko Osanai³, Kazumi Takahashi³, Michiko Mizoguchi³, Syunichiro Izumi³, Kiwamu Akagi¹, ¹Saitama Cancer Center, Division of Molecular Diagnosis and Cancer Prevention, Kitaoadachi-gun, Saitama, Japan, ²Keio University, Faculty of Nursing and Medical Care, Fujisawa City, Kanagawa, Japan, ³Aichi Kiwami College of Nursing, Ichinomiya City, Aichi, Japan, ²Tokai University, School of Medicine Department of Obstetrics and Gynecology, Isehara City, Kanagawa, Japan, ³Saitama Cancer Center, Department of Nursing, Kitaoadachi-gun, Saitama, Japan

Decision-Making Regarding Prenatal Genetic Screening Among Pregnant Korean-American Women
Myunghee Jun¹, Vipavee Thongpriwan², Jeeyae Choi¹, Kyung Sook Choi², Gwen Anderson², ¹UW-Green Bay, Green Bay, WI, USA, ²UW-Milwaukee, Milwaukie, WI, USA, ³University of North Carolina Wilmington, Wilmington, NC, USA, ⁴Chung-Ang University, Seoul, Republic of Korea, ⁵Chaminade University of Honolulu, Honolulu, HI, USA

Results of the NGS Analysis in Patients With Suspected Hereditary Colorectal Cancer Due to Family History
Erika Santos¹, Carolina Sá¹, Bernardo Garicochea¹, Edite Oliveira¹, Maria Del Pilar Diz¹, Renata Coudry¹, Benedito Rossi¹, ¹Hospital Sirio-Libanes, Sao Paulo, Brazil

National Survey: Genetic Knowledge Of Danish Nurses – Needs And Reality
Kari Konstantin Nissen¹, Karin Christiansen², Thomas Raundahl Mikkelsen³, ¹VIA University College, Aarhus School of Nursing, Aarhus, Denmark, ²VIA University College, Holstebro School of Nursing, Holstebro, Denmark, ³VIA University College, Department of Health, Aarhus, Denmark

Racial and Genetic Barriers to Pain Management
Mallory Perry¹, Angela Starkweather¹, ¹University of Connecticut, Storrs, CT, USA

Patient Perceptions and Behavior Changes Associated with Nurse Led Education and Discussion Related to a Reported Family History of Substance Abuse
Elizabeth Pestka¹, ¹Mayo Clinic, Rochester, MN, USA
Identification of DNA Methylation Markers Of Preterm Birth Risk Using Banked Whole Blood Specimens: Methodological Insights
Shannon Gillespie1, Joyce Ohm2, Cindy Anderson1, 1The Ohio State University, Columbus, OH, USA, 2Roswell Park Cancer Institute, Buffalo, NY, USA

Peer Navigation Benefits People Affected By Hereditary Cancers
Lisa Schlager1, Lisa Rezende1, Sue Friedman1, Sandra Cohen1, Diane Rose1, 1FORCE: Facing Our Risk of Cancer Empowered, Tampa, FL, USA

An Innovative Interdisciplinary Doctoral Program for Nurses Focusing on Genetics and Genomics
Mary Beth Steck1, Julia Eggert1, 1Clemson University, Clemson, SC, USA

The National Xeroderma Pigmentosum Service
Sally Turner1, Tanya Henshaw1, 1Guys’ and St Thomas’ NHS Foundation Trust, London, UK

Genetic and Viral Infection Risk Factors for Age-Related Macular Degeneration
Frances Peterson-Burch1, Michael Gorin2, Daniel Weeks1, Yvette P. Conley1, 1University of Pittsburgh, Pittsburgh, PA, USA, 2University of California, Los Angeles, CA, USA

Development Of A Support Program To Determine In Consultation With Nurses Whether Cancer Patients Should Undergo Genetic Testing Or Not
Miho Kakuta1, Keiko Tsuji2, Reiko Yokomakura2, Mitsue Simizu3, Yukiko Osanai4, Kazumi Takahashi4, Michiko Mizoguchi5, Syunichiro Izumi5, Kiwamu Akagi5, 1Saitama Cancer Center, Division of Molecular Diagnosis and Cancer Prevention, Kitaadachi-gun, Saitama, Japan, 2Keio University, Faculty of Nursing and Medical Care, Fujisawa City, Kanagawa, Japan, 3Aichi Kiwami College of Nursing, Ichinomiya City, Aichi, Japan, 4Tokai University, School of Medicine Department of Obstetrics and Gynecology, Ichinomiya City, Kanagawa, Japan, 5Saitama Cancer Center, Department of Nursing, Kitaadachi-gun, Saitama, Japan

Reducing Breast Cancer By Accurately Assessing Risk: Findings of a Community Hospital High Risk Breast Cancer Clinic
Karen Herold1, Ahlam Jadalla1, Allyson Brooks1, 1Hoag Memorial Hospital Presbyterian, Newport Beach, CA, USA

Genetics Education for Health Professionals: Lessons Learned from the American Society of Human Genetics Experience
Karen Hanson1, Joseph D. McNerney1, Michael Dougherty1, 1American Society of Human Genetics, Bethesda, MD, USA

Associations Between Ancestry-informative Markers and Fatigue Self-Management For People Living With HIV/AIDS
Michelle Odlum1, Kathleen Hickey2, Mary Bryne1, Niurka Suero-Tejeda2, Suzanne Bakken1, 1Columbia University, New York, NY, USA

Reducing Breast Cancer By Accurately Assessing Risk: Findings of a Community Hospital High Risk Breast Cancer Clinic
Karen Herold1, Ahlam Jadalla1, Allyson Brooks1, 1Hoag Memorial Hospital Presbyterian, Newport Beach, CA, USA

Connecting The Dots 2 - GeneSteam: Developing An Educational Module To Improve Nurses Knowledge Of Oncogenomics
Stacy Hines-Dowell1, Belinda Mandrell1, Annastasia Ouma1, Leslie Taylor1, Jami Gattuso1, Lynn Harrison1, Kayla Hamilton1, Emily Quinn1, Rose McGee1, Regina Nuccio1, Kim Nichols1, 1St. Jude Children’s Research Hospital, Memphis, TN, USA

Is There A Relationship Between The PNPLA3 (Rs738409)-G Allele And Comorbid Conditions Of NAFLD? Lori Houghton-Rahrig1, 1Grand Valley State University, Grand Rapids, MI, USA

Pre-systemic Treatment Pain Severity And Variant in CYP19A1 rs700519 Genotype Contribute to Worse Pain Severity During Aromatase Inhibitor Treatment For Breast Cancer
Yehui Zhu1, Yvette Conley1, Theresa Koleck2, John Merriman1, Susan Sereika1, Catherine Bender1, 1University of Pittsburgh School of Nursing, Pittsburgh, PA, USA, 2Columbia University School of Nursing, New York, NY, USA
ISONG membership means…

This premier educational event is just one of the many offerings that ISONG provides.

Additional benefits of ISONG membership are:

- Be informed: receive the latest references and updates on genetics.
- Stay connected: connect with your peers through the Forum – a lively area for discussion in the membership system.
- Career and growth opportunities: job postings and educational events are listed in the membership system.
- Year-round education: Webinars and the Annual ISONG Congress offer educational opportunities, and members receive discounted registration fees for these programs. Webinars are available to view at your convenience and include Continuing Education Credits where noted.
- Research grants: ISONG members are eligible to apply for the annual research grant awards.

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