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
Congress Co-chair

Deborah Tamura
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
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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

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.)

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

**Airline 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 through 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.

<table>
<thead>
<tr>
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<th>Before September 5</th>
<th>After September 5</th>
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<tbody>
<tr>
<td>ISONG active dues member</td>
<td>$495.00</td>
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<td>Podium / Abstract Presenter</td>
<td>$495.00</td>
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<tr>
<td>*Non-member</td>
<td>$645.00</td>
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<tr>
<td>Full-time students</td>
<td>$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.
Thursday, November 2, 2017

4:00PM – 8:00PM  Congress Registration

7:00PM – 9:00PM  Welcome Reception

Friday, November 3, 2017

7:30AM – 5:00PM  Congress Registration

7:30AM – 8:30AM  Coffee, Tea / Visit Exhibits, Posters and Raffle

8:30AM – 8:45AM  President’s Welcome and Opening Remarks
  Elizabeth L. Pestka, MS, PMHCNS-BC, AGN-BC
  ISONG President
  Clinical Nurse Specialist
  Pain Rehab Center
  Assistant Professor of Nursing
  Mayo Clinic
  Rochester, Minnesota USA

8:45AM – 9:45AM  Opening Keynote Presentation - Prenatal Genome Sequencing
  Benjamin E. Berkman, JD, MPH
  Deputy Director
  NHGRI (National Human Genome Research Institute)
  National Institutes of Health
  Bethesda, Maryland USA

  Benjamin D. Solomon, MD, FACMG
  Managing Director
  GeneDx
  Gathersburg, Maryland USA

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>Clinical Practice</th>
<th>Research</th>
<th>Research</th>
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<tbody>
<tr>
<td>9:45AM – 10:45AM</td>
<td>Family Health History In Primary Care: A Critical Analysis Of Available Tools</td>
<td>Suffering In The Midst Of Technology: Routine Prenatal Ultrasound Screening to Turbulent Congenital, Chromosome or Genetic Disorder Results</td>
<td>A Novel Hypomethylator Phenotype Unique to Basal-like Breast Cancer: Implications for Epigenetically Based Interventions</td>
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<td></td>
<td>Karen J Whitt¹, Ann Maradiegue², Gaye Ray³, Lauren Bretzing³, ¹George Washington University, Washington, DC, USA, ²James Madison University, Harrisonburg, VA, USA, ³Brigham Young University, Provo, UT, USA</td>
<td>Jeanne Gottlieb¹, ¹University of Southern Maine, Portland, ME, USA</td>
<td>Theresa Swift-Scanlan¹, Mikhail Dozmorov¹, ¹Virginia Commonwealth University, Richmond VA, USA</td>
</tr>
<tr>
<td>10:00AM – 10:15AM</td>
<td>Standards of Practice: Living in the Real World</td>
<td>Antibiotic Exposure During Pregnancy Effects Offspring Microbial Colonization: Bad Bugs Bloom</td>
<td>Genetic Characterization of Families from a Hereditary Cancer Registry in Brazil</td>
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<td>Alice Kerber¹, Nancy Ledbetter², Suzanne Mahon³, ²Georgia Center for Oncology Research and Education, Atlanta, Georgia, USA, ²Portland Wellness Center, Portland, Oregon, USA, ³Saint Louis University, St. Louis, MO, USA</td>
<td>Stephanie Prescott¹, Ernesto Perez-Chanona², Wendy Henderson¹, Giorgio Trinchieri³, ¹National Institute of Nursing Research, Bethesda, MD, USA, ²National Cancer Institute, Cancer and Inflammation Program, Bethesda, MD, USA, ³University of Virginia, Charlottesville, Virginia, USA, ¹Fairfax Neonatal Associates, Falls Church, VA, USA</td>
<td>Erika Santos¹, Caroline Sá1, Bernardo Garicochea¹, Maria Del Pilar Díz¹, Renata Coudry¹, Edite Oliveira¹, Benedito Rossi¹, ¹Hospital Sirio-Libanes, Sao Paulo, Brazil</td>
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<td>Mary Beth Steck¹, ¹Clemson University, Clemson, SC, USA</td>
<td>Kelley Baumgartel¹, Michael Morowitz², ¹University of Pittsburgh, School of Nursing, Pittsburgh, PA, USA, ²University of Pittsburgh, School of Medicine, Pittsburgh, PA, USA</td>
<td>Rieko Sotojima¹, Joelle Fenger¹, William Kisseberth¹, Jennie Rowell¹, ¹The Ohio State University College of Nursing, Columbus, OH, USA, ¹The Ohio State University College of Veterinary Medicine, Columbus, OH, USA, ¹The Ohio State University Comprehensive Cancer Center, Columbus, OH, USA</td>
</tr>
<tr>
<td>10:30AM – 11:15AM</td>
<td>An Initiative to Mentor Nurses</td>
<td>Primary Care Nurse Practitioners’ Knowledge and Experience Regarding the Management of Presumptive Positive Results of the Kentucky Mandated Newborn Screening Program</td>
<td>Development Of An Interactive Pharmacogenomic Education Module: Comparison Of Oncology Nurses’ Knowledge And Attitudes Within Teaching And Community Hospitals.</td>
</tr>
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<td>Susan Montgomery¹, Tammy McKamie¹, ¹Fox Chase Cancer Center, Philadelphia, PA, USA, ²W. Temple Webber Cancer Center, Texarkana, TX, USA</td>
<td>Delwin Jacobs⁴, Angela Crutcher⁵, ¹Spalding University, Louisville, KY, USA, ²University of Kentucky, Lexington, KY, USA</td>
<td>Crissy Dodson¹, ¹University 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.
<table>
<thead>
<tr>
<th>Time</th>
<th>Clinical Practice</th>
<th>Research</th>
<th>Education</th>
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</thead>
<tbody>
<tr>
<td>11:15AM – 12:15PM</td>
<td><strong>Abstract Sessions</strong></td>
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<tr>
<td>11:15AM – 12:15PM</td>
<td><strong>Clinical Utility Of Rapid Genomic Sequencing In The Neonatal And Pediatric Intensive Care Units: What Nurses Need To Know</strong> Julie Cakici¹, Stephen Kingsmore¹, David Dimmock², Sara Caylor³, ¹Rady Children's Institute for Genomic Medicine, San Diego, CA, USA</td>
<td>A Novel Approach to Genotype-phenotype Profiling for Ryanodine Receptor 1-related Myopathies Katherine Meilleur¹, Monique Shelton¹, Jessica Witherspoon¹, Carolyn Allen¹, M. Sonia Razaqyar¹, Michaela Cortes¹, Irene Chrismer¹, ¹National Institute of Nursing Research, Bethesda, MD, USA</td>
<td>A Review of the Literature on the Relationships Between Genetic Polymorphisms and Chemotherapy–Induced Nausea and Vomiting Komal Singh¹, Elena Flowers¹, Kord Kober¹, Anand Dhruba¹, Christine Miaskowski¹, ¹University of California San Francisco, San Francisco, CA, USA</td>
</tr>
<tr>
<td>11:30AM – 12:00PM</td>
<td><strong>Educational Needs of Nurses to Provide Genetic Services in Prenatal Care: A Cross Sectional Study from Turkey</strong> Memnun Seven¹, Kafiye Eroglu¹, Aygül Akyüz¹, Charlotte Ingvalstad², ¹Koç University, İstanbul, Turkey, ²Karolinska Institute, Stockholm, Sweden</td>
<td>Fatigue In Elderly Latino Home Care Patients With Chronic Conditions Jinglei Shang¹, Mary Byrne¹, Kathleen Hickey¹, Suzanne Bakken¹, ¹Columbia University, New York, NY, USA</td>
<td>XRAY: Unconfuse The News For Young Breast Cancer Survivors and Those At High Risk Of Breast Cancer Lisa Schlager¹, Lisa Rezende¹, Sue Friedman¹, Julie Huynh¹, Robin Pugh-Yi¹, ¹FORCE: Facing Our Risk of Cancer Empowered, Tampa, FL, USA</td>
</tr>
<tr>
<td>12:00PM – 12:15PM</td>
<td><strong>Utilization of and Women Educational Needs for Prenatal Screening tests: A Turkish study</strong> Memnun Seven¹, Aygül Akyüz¹, Kafiye Eroglu¹, Sandra Daack-Hirsch², Heather Skirton³, ¹Koç University, Istanbul, Turkey, ²The University of Iowa College of Nursing, Iowa, USA, ³Plymouth University, Plymouth, UK</td>
<td>Factors Associated With Family Communication About Genetic Risk for Inherited Cardiac Conditions Lisa Shah¹, ¹University of Iowa, Iowa City, IA, USA</td>
<td>Incidence and Perception of Nursing Students’ Academic Incivility in Oman Jansirani Natarajan¹, Joshua Kanaabi Muliria¹, Jacoba Vandercolff¹, ²Sultan Qaboos University, Muscat, Oman</td>
</tr>
<tr>
<td>12:15PM – 1:45PM</td>
<td><strong>Lunch / Networking and ISONG Committee Meetings</strong></td>
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<tr>
<td>1:45PM – 2:30PM</td>
<td><strong>Keynote Presentation - The Ethics in Research</strong></td>
<td></td>
<td>David S. Wendler, MA, PhD Head, Section on Research Ethics Department of Bioethics Clinical Center National Institutes of Health Bethesda, Maryland USA</td>
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## Friday, November 3, 2017 (continued)

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>2:30PM – 3:00PM</td>
<td>Refreshment Break / Visit Exhibits, Posters and Raffle</td>
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<tr>
<td>3:00PM – 4:00PM</td>
<td>Invited Speakers</td>
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<tr>
<td></td>
<td><strong>Global Genetics Nursing Alliance –</strong></td>
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<td></td>
<td><strong>Creating a Roadmap</strong></td>
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<tr>
<td></td>
<td>Kathleen Calzone, PhD, RN, APNG, FAAN</td>
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<td></td>
<td>Research Geneticist</td>
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<td>National Cancer Institute</td>
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<td></td>
<td>Bethesda, Maryland USA</td>
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<td></td>
<td><code>Maggie Kirk, PhD, BSc Hons, DipN, RGN, FRCN, SFHEA</code></td>
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<tr>
<td></td>
<td>Professor of Genetics Education</td>
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<td></td>
<td>University of South Wales</td>
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<td>Glyntaff, Wales, UK</td>
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<tr>
<td>3:00PM – 3:30PM</td>
<td>Genetic Testing for Hereditary Cancer Syndromes: A Foreign Language or The Way of the Future?</td>
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<tr>
<td></td>
<td>Tammy McKamie, RN, MSN, OCN, GCN</td>
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<td></td>
<td>Genetic Clinical Nurse/ Educator</td>
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<td>Christus St. Michael Cancer Treatment Center</td>
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<td></td>
<td>Texarkana, Texas USA</td>
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<tr>
<td>3:30PM – 4:00PM</td>
<td>Promise Strategies for Genomic Nursing Education</td>
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<td></td>
<td>Linda D Ward, PhD, ARNP</td>
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<tr>
<td></td>
<td>Assistant Professor</td>
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<td>College of Nursing</td>
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<td>Washington State University</td>
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<td>Spokane, Washington USA</td>
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<tr>
<td>3:30PM – 4:00PM</td>
<td>Epigenomic Biomarkers in Preeclampsia</td>
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<td></td>
<td>Cindy Anderson, PhD, CRNP, WHNP-BC, FNAP, FAHA, FAAN</td>
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<td></td>
<td>Associate Dean for Academic Affairs and Educational Innovation</td>
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<td>College of Nursing</td>
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<td>The Ohio State University</td>
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<td>Columbus, Ohio USA</td>
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<tr>
<td>4:00PM – 5:00PM</td>
<td>Poster Blitz Oral Presentations</td>
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<tr>
<td>4:45PM – 5:45PM</td>
<td>Poster Reception</td>
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<tr>
<td>5:45PM – 6:30PM</td>
<td>Fireside Chat</td>
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### 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.
### Saturday, November 4, 2017

<table>
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<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:45AM – 5:00PM</td>
<td>Congress Registration</td>
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<tr>
<td>7:45AM – 8:45AM</td>
<td>Coffee, Tea / Visit Exhibits, Posters and Raffle</td>
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<tr>
<td>8:45AM – 9:00AM</td>
<td>Announcements</td>
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<tr>
<td>9:00AM – 9:45AM</td>
<td><strong>Keynote Presentation – State of the Science in Genomic Nursing</strong></td>
</tr>
<tr>
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<td><em>Patricia A. Grady, PhD, RN, FAAN</em></td>
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<td></td>
<td>Director</td>
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<td>National Institute of Nursing Research</td>
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<td>National Institutes of Health</td>
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<td>Bethesda, Maryland USA</td>
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<tr>
<td>9:45AM – 10:30AM</td>
<td><strong>P30 Grant Panel</strong></td>
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<td><strong>Precision in Symptom Self-Management (PriSSM): Looking Through a Nursing Lens for the Future</strong></td>
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<td><em>Kathleen T. Hickey, EdD, FNP, ANP, FAHA, FAAN</em></td>
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<td></td>
<td>Associate Professor</td>
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<td>School of Nursing</td>
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<td>Columbia University</td>
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<td>Nurse Practitioner</td>
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<td>Division of Cardiology</td>
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<td>Columbia University</td>
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<td></td>
<td>New York, New York USA</td>
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<tr>
<td>10:30AM – 11:00AM</td>
<td>Refreshment Break / Visit Exhibits, Posters and Raffle</td>
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**Towards Oncology Precision Symptom Science: Phenotype-Omics Association Studies in Clinically Relevant Animal Models**

*Susan G. Dorsey, PhD, RN, FAAN*

Professor of Nursing
Chair, Department of Pain and Translational Symptom Science
Co-Director
UM Center to Advance Chronic Pain Research
University of Maryland Baltimore
Baltimore, Maryland USA

**Achieving Precision Pain Management Through Nursing Research: A Trajectory to the Bull’s-Eye**

*Angela Starkweather, PhD, ACNP-BC, CNRN, FAAN*

Director
Center for Advancement in Managing Pain
Professor
University of Connecticut
Storrs, Connecticut USA
<table>
<thead>
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<td>11:00AM – 12:00PM</td>
<td><strong>Abstract Sessions</strong></td>
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| 11:00AM – 12:00PM | Next-Generation Sequencing: Implications Surrounding Usefulness for Newborn Screening | Testing Safety and Efficacy: The Randomized Controlled Exploratory Study of Exercise Training in Hypertrophic Cardiomyopathy  
(RESET-HCM)  
Heidi Salisbury1, Euan Ashley2, Sharlene Day3, Sara Saberi4, Adam Helms2, John Meyers3, John Herrera3, Suwen Kumar2, Yael Schmargad2, Annika Dries1, Matthew Wheeler1, Maryann Concannon2, Anil Attili1, Prachi Agarwal2, Whitney Hornsby2, Jennifer Bragg-Gresham2, “Stanford Health Care, Palo Alto, CA, USA, 2University of Michigan, Ann Arbor, MI, USA | Revision Of The Genomic Nursing Concept Inventory  
Linda D. Ward3, 1Washington State University, Spokane, WA, USA |
| 11:00AM – 12:00PM | Genetic Counselling Outcome Scale (GCOS-24): Cultural Adaptation And Validation For Use In Measuring Patient-Reported Outcomes From Genetic Counselling In Brazil | Learning From Patients With Rare Diseases: Clinical Challenges Faced By Two Patients With Different Forms Of Methylmalonic Acidemia (MMA)  
Carol Van Ryzin1, Susan Ferry1, NIH/NHGRI, Bethesda, MD, USA | Precision Nursing Thru Undergraduate Education For Nurses In The Future  
Anecita Gigi Lim1, 1University of Auckland, Auckland, New Zealand |
| 11:00AM – 12:00PM | A Transition Program for Adolescents with Down Syndrome: Three Year Review | Pharmacogenetics: A Valuable Resource For Patients Participating In Care Coordination With Depression | Measuring Genomic Literacy Among Lebanese Nurses  
Kathi C. Huddleston1, Linda D. Ward3, Maya Nizam2, Iman Kouatly3, Alik Sarian1, Lina Kurdaibi Badr1, 1Inova Translational Medicine Institute, Falls Church, VA, USA, 2Washington State University, Spokane, WA, USA, 3American University of Beirut Medical Center, Beirut, Lebanon |
| 11:00AM – 12:00PM | Outcomes of Newborn Screening for Lysosomal Storage Disorders in Illinois | Evaluating the Practicality of Clinic-Wide Utilization of a Psychotropic Assay | Innovotive Online Teaching Strategies for Graduate Students  
Leighsa Sharoff1, 1Hunter College, New York, NY, USA |
| 11:00AM – 12:00PM | Lunch/Awards Presentations/Business Meeting |                                                                                 |                                                                           |

**Lunch/Awards Presentations/Business Meeting**

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**

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<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></td>
<td><strong>Measuring Meaningful Learning Through Longitudinal Tracking Of Genomic Knowledge</strong></td>
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<td>Sheila Alexander1, Bryan McVerry1, Scott Gunn1, Yvette Conley1, Dianxu Ren1, University of Pittsburgh, Pittsburgh, PA, USA</td>
<td>Kathi Huddleston1, Elisabeth Klein1, Varsha Deopujari1, Suchitra Hourigan1, Inova Translational Medicine Institute, Falls Church, VA, USA, Pediatric Specialists of Virginia, Fairfax, VA, USA</td>
<td>Linda D. Ward1, Lynn Jinishian1, Washington 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></td>
<td><strong>Understanding Parental Refusal To Enroll Their Children In A Genomic Sequencing Research Study</strong></td>
<td><strong>Up to Date: Ankyloglossia and Maxillary Lip-ties</strong></td>
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<td>Jennie Rowell1, Judy Tate1, Michele Balas1, Matthew Exline1, Linda Chlan1, Pearly Yan1, Jackson Killian1, Mary Beth Happ1, Chi Song1, Guy Brock1, Ralf Bundschuh1, The Ohio State University, Columbus, OH, USA</td>
<td>Annastasia Ouma1, Stacy Hines-Dowell1, Kayla Hamilton1, Lynn Harrison1, Elsie Gerhardt1, Victoria Liddle1, Rose McGee1, Regina Nuccio1, Emily Quinn1, Jessica Valdez1, Chimene Kesserwan1, Kim Nichols1, St. Jude Childrens Research Hospital, Memphis TN, USA</td>
<td>Emily Hopkins1, Chatham University, Pittsburgh, PA, USA</td>
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<td><strong>DNA Methylation Associated with Early Neurodevelopment in Preterm Infants</strong></td>
<td><strong>Factors Affecting Recruitment And Consent To Biological Specimen Banking In An Observational Cohort Study Of Pregnant Women</strong></td>
<td><strong>Gene Expression Patterns and Measurement of Gene Expression Changes</strong></td>
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<td>Rita Pickler2, Cindy Anderson2, Maciej Pietrzak2, Joyce Ohm1, Roswell Park Cancer Institute, Rochester, NY, USA, The Ohio State University, Columbus, OH, USA</td>
<td>Shannon Gillespie1, Cindy Anderson1, The Ohio State University, Columbus, OH, USA</td>
<td>Komal Singh1, Christine Miaskowski1, Elena Flowers1, Anand Dhruva1, Kord Kober1, University 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></td>
<td><strong>Relationship Between Psychosocial Distress In Pregnancy And Two Genes Associated With Human Social Interaction</strong></td>
<td><strong>Keeping Pace With Genetics: An Educational Program on Prenatal Cell-free DNA Screening for Obstetricians.</strong></td>
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<td>Allison Rietze1, Yvette Conley1, Carl Hubel1, Arun Jayabal1, James Roberts1, Mandy Schmella1, University of Pittsburgh, Pittsburgh, PA, USA, Magee-Womens Research Institute and Foundation, Pittsburgh, PA, USA</td>
<td>Sarah Dewell1, Donna Slater1, Karen Benzie1, Sheila McDonald1, Suzanne Tough1, University of Calgary, Calgary, AB, Canada</td>
<td>Karen Hanson1, Joseph D. McInerney1, Michael Dougherty1, American 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></td>
<td><strong>The Gut Microbiome in Necrotizing Enterocolitis: A Case Study of Twins</strong></td>
<td><strong>Pairing Pedagogical and Genomic Advances to Prepare APNs for the Era of Precision Health</strong></td>
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<td>Cindy Anderson1, Shannon Gillespie1, Danielle Perley1, Joyce Ohm1, The Ohio State University, Columbus, OH, USA, University of North Dakota, Grand Forks, ND, USA, Roswell Park Cancer Institute, Buffalo, NY, USA</td>
<td>Elisabeth Klein1, Kathi Huddleston1, Varsha Deopujari1, Suchitra Hourigan1, Inova Translational Medicine Institute, Falls Church, VA, USA, Pediatric Specialists of Virginia, Fairfax, VA, USA</td>
<td>Elena Flowers1, Hamza Abid1, Sasha Binford1, Meg Martin1, Lynda Mackin1, University of California, San Francisco, CA, USA</td>
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**3:00PM – 3:15PM**

**3:15PM – 3:45PM  Refreshment Break / Visit Exhibits, Posters and Raffle**
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<td>3:45 PM – 5:00 PM</td>
<td><strong>Abstract Sessions</strong></td>
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| 4:00 PM – 4:15 PM | Moderate Blast Exposure Alters Peripheral Concentrations of Proteins Related to Neurodegeneration  
Nicole Osier², Jessica Gill¹, Katie Edwards¹, Kristine C. Dell¹, Walter Carr¹, Peter Walker¹, Steven Ahlers⁴, Matthew LoPresti², Angela Yarnell², ¹National 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 |
| 4:15 PM – 4:30 PM | OMICS Nursing Science and Education Network (ONSEN)  
Kathleen Calzone¹, Ann Cashion¹, Lois Tully¹, Jean Jenkins², ¹National Institutes of Health, National Cancer Institute, Bethesda, MD, USA, ²National Institutes of Health, National Institute of Nursing Research, Bethesda, MD, USA, ³National Institutes of Health, National Human Genome Research Institute, Bethesda, MD, USA |
| 4:30 PM – 4:45 PM | Genetic Risk Factors of the Transition from Acute to Chronic Pain  
Angela Starkweather¹, Divya Ramesh¹, Mallory Perry¹, Thomas Julian¹, Katherine Bernier¹, Debra Lyon¹, Susan Dorsey², Kyle Baumbauer¹, Erin Young¹, ¹University of Connecticut, Storrs, CT, USA, ²University of Maryland, Baltimore, MD, USA, ³University of Florida, Gainesville, FL, USA |
| 4:45 PM – 5:00 PM | Neurobiological Mechanisms Of Chemobrain: A Feasibility Study Using An Animal Model  
Grace Lawrence², Kyeung Mi Oh¹, Margaret Rodan¹, Theodore Dumas¹, Virginia Espina¹, ¹George Mason University, Fairfax, VA, USA, ²INOVA, Falls Church, VA, USA |
| 5:00 PM – 5:15 PM | Clinical Documentation Of Genetic Counseling-related Emotional Distress In Electronic Health Record Narratives  
Theresa Koleck¹, Suzanne Bakken¹, Kathleen Hickey¹, Nicholas Tatonetti¹, ¹Columbia University, New York, NY, USA |
| 5:15 PM – 5:30 PM | HLA-Matched Adult Sibling Donor Allogeneic Hematopoietic Stem Cell Transplantation (AlloHSCT) Experience and Health-related Quality of Life in Sickle Cell Disease (SCD)  
Agatha Gallo¹, Derrick McCoy¹, Crystal Patil¹, Lewis Hsu¹, Molly McGown², ¹University of Illinois at Chicago, Chicago IL, USA, ²Northwestern University, Chicago, IL, USA |
| 5:30 PM – 5:45 PM | Oxytocin Receptor (OXTR) and Vasopressin Receptor (AVP1RA) Genes as Candidate Genes for Apathy in Persons with Alzheimer Disease  
Emilie Goris¹, Jamie Johnson¹, Sarah Melby¹, Alexandra Vroom¹, Debra Schutte¹, ¹Hope College, Holland, MI, USA, ²Wayne State University, Detroit, MI, USA |
| 5:45 PM – 5:50 PM | Assessing Awareness and Integration of the Genetic Information Nondiscrimination Act of 2008 (GINA) Among Nurse Practitioner Faculty  
Mary Steck¹, ¹Clemson University, Clemson, SC, USA |
| 5:50 PM – 5:55 PM | Identifying Gene Variants Associated With The Poor Absorption Of A Key Anti-inflammatory Nutrient Betacarotene: Implications For Healthcare  
Bobbi Laing¹, Nishi Karunasinghe¹, Lynnette Ferguson¹, ¹University of Auckland, Auckland, New Zealand |
| 5:55 PM – 6:00 PM | Altered Gene Expression Following Blast-Induced Traumatic Brain Injury in a Military Population  
Katie Edwards¹, Nicole Osier¹, Vida Motamed², Jessica Gill¹, ¹National Institute of Nursing Research, National Institutes of Health, Bethesda, MD, USA, ²University of Pittsburgh School of Nursing, Pittsburgh, PA, USA |
| 6:00 PM – 6:05 PM | Diabetes Education Is Associated with Improved Sleep Quality and Changes in Gene Methylation  
Evelyn G. Bigini¹, Eileen R. Chasens¹, Yvette P. Conley¹, Christopher C.imes¹, ¹University of Pittsburgh School of Nursing, Pittsburgh, PA, USA |
| 6:05 PM – 6:10 PM | Lysozyme Association With Extracellular Vesicles And Circulating RNA  
Sarah Abey¹, Yuana Yuana¹, Paule Joseph¹, Natnael Kene¹, Nicolaas Fourie¹, LeeAnne Sherwin¹, Gregory Gonye¹, Paul Smyser¹, Erin Stempski¹, Christina Boulineaux¹, Kristen Weaver¹, Christopher Bleck¹, Wendy Henderson¹, ¹Digestive Disorders Unit, Division of Intramural Research, National Institutes of Health, Department of Health and Human Services, Bethesda, MD, USA, ²Image Sciences Institute, Division of Imaging, University Medical Centre, Utrecht, Netherlands, Germany, ³NanoString Technologies, Seattle, WA, USA, ⁴The Pennsylvania State University, College of Medicine, Hershey, PA, USA, ⁵Electron Microscopy Core Facility, National Heart Lung Blood Institute, National Institutes of Health, Department of Health and Human Services, Bethesda, MD, USA |
| 6:10 PM – 6:15 PM | Family Communication About Familial Risk Of Stroke Promotes Perceived Risk In Adult Offspring of Stroke Patients  
Masakazu Nishigaki¹, Mana Kawaguchi¹, Maimi Fukumori¹, Miyako Minoda¹, Akiko Ota¹, ¹Kyoto University, Kyoto, Japan, ²Brain Attack Center Ota Memorial Hospital, Fukuyama, Japan |
| 6:15 PM – 6:20 PM | Developing A Pre-appointment Video To Prepare New Families For Genetics Clinic Visit  
Andrea Hartgraves¹, Tammy Fairbanks¹, ¹Seattle Children’s Hospital, Seattle, WA, USA |
| 6:20 PM – 6:25 PM | A Complex Genetic Variant with Distinct Phenotype as a Model for Understanding Common-Complex Diseases  
Elizabeth McNamara¹, Jacob Bailey¹, Carlos Alvarez¹, Jennie Rowell¹, ¹The Ohio State University College of Nursing, Columbus, OH, USA, ²The Ohio State University College of Medicine, Columbus, OH, USA |
Sunday, November 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 Niendorf1, Mary Ahrens1, Olivia Michel1, Sarah Mets1, 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 Barnov1, 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 Tsujii2, Reiko Yokomakura2, Mitsue Simizu2, Yukiko Osanai1, Kazumi Takahashi1, Michiko Mizoguchi1, Syunichi Izumi1, Kiwamu Akagi1, 1Saitama Cancer Center, Division of Molecular Diagnosis and Cancer Prevention, Kitadachi-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, Isehara City, Kanagawa, Japan, 5Saitama Cancer Center, Department of Nursing, Kitadachi-gun, Saitama, Japan

Decision-Making Regarding Prenatal Genetic Screening Among Pregnant Korean-American Women
Myunghee Jun1, Vipavee Thongpriwan2, Jeeyae Choi1, Kyung Sook Choi1, Gwen Anderson2, 1UW-Green Bay, Green Bay, WI, USA, 2UW-Milwaukee, Milwauke, 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 Gariocchea1, Edite Oliveira1, Maria Del Pilar Diz1, Renata Coudry1, Benedito Rossi1, 1Hospital Sirio-Libanos, Sao Paulo, Brazil

National Survey: Genetic Knowledge Of Danish Nurses – Needs And Reality
Kari Konstantin Nissen1, Karin Christiansen2, Thomas Raundahl Mikkelsen1, 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
Posters

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 Tsujii1, Reiko Yokomakura1, Mitsue Simizu1, Yukiko Osanai1, Kazumi Takahashi1, Michiko Mizoguchi1, Syunichiro Izumi1, Kiwamu Akagi1, 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, Isehara 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

Heredity Cancer Knowledge of Honduran Healthcare Providers
Sylvia S. Estrada1, 1Cedars-Sinai Medical Center, Los Angeles, CA, USA

Exploring A Biobehavioral Self-Management Intervention On Epigenetic Alterations In Adults With Acute Myeloid Leukemia: A Pilot Study
Tara Albrecht1, Mikhail Dozorov1, Danielle Shafer1, Theresa Swift-Scanlan1, Adam Sima1, Angela Starkweather1, 1Virginia Commonwealth University, Richmond, VA, USA, 2University of Connecticut, Storrs, CT, USA

Challenges To Precision Nursing And Whole Exome Sequencing
Katherine Burbank1, 1Mayo Clinic, Rochester, MN, 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 Hickey1, Mary Bryne1, Niurka Suarez-Tejeda2, Suzanne Bakken1, 1Columbia University, New York, NY, USA

Acculturation of Mexican Immigrants and the Prevalence of NAFLD: A Review
Claudia Rivera-Salas1, Lori Houghton-Rahrig1, 1Grand Valley State University, Grand Rapids, MI, 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 Kolecz2, John Merriman1, Susan Sereika1, Catherine Bender1, 1University of Pittsburgh School of Nursing, Pittsburgh, PA, USA, 2Columbia University School of Nursing, New York, NY, USA
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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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