



# ISONG

25TH ANNIVERSARY CONFERENCE

## 25 Years of Leadership in Genetics Nursing

DoubleTree Hotel Bethesda  
Bethesda, Maryland USA

October 4-6, 2013





## Invitation

Twenty five years ago a small group of forward thinking nurses working in the field of genetics founded the Genetic Nurse Network. This organization has evolved into The International Society of Nurses in Genetics (ISONG). This year, we are celebrating the Silver Anniversary. It is with great pride that the Conference Committee and the Board of Directors, invites nurses and healthcare professionals interested in genetics and genomics to ISONG's Silver Anniversary conference in, Bethesda, Maryland, USA.

ISONG is a global specialty organization dedicated to fostering the scientific discovery and professional growth in human genetics and genomics. The conference provides an educational forum for nurses and other healthcare professionals dedicated to all aspects of human genetics and genomics including basic science and clinical research, clinical practice and education for professionals and the public.

The conference theme is "Twenty-Five Years of Genetics Nursing Leadership" and will have a special presentation on the history of ISONG to honor and thank the founding members for their vision and leadership for Genetic Nursing.

Participants will have opportunities to share their work in research, education, and practice that advance the knowledge, science, and practice of genetics and genomics nursing. This three-day conference is designed to provide a lively discourse on genetics and genomics in healthcare and an opportunity for professional networking. The first day will feature a three-part pre-conference for nurses interested in learning more about clinical genetics, genetic nursing research or genetic education issues.

The 2013 Silver Anniversary conference will help attendees to:

- Gain insight into the history of ISONG and get to know its founding members.
- Appreciate applications of genetic advances to guide diagnosis, therapeutic intervention, clinical efficacy, and decision-making processes.
- Envision the future of genetic nursing for the next 25 years.

You are eagerly invited to our Silver Anniversary Conference on October 4-6, 2013 and we look forward to welcoming you to Bethesda, Maryland USA.

Sincerely,

**Deb Tamura**

Deborah Tamura, MS, RN  
Conference Co-Chair

**Erica Yu**

Erica Tengan Yu, PhD, RN, ANP  
Conference Co-Chair

### REGISTRATION

Register early! It helps us plan better and keeps your costs down. Take advantage of the early registration discount by registering by August 16, 2013. The discounted rates are made available in order to facilitate administrative planning which is required prior to the Conference.

**Early registration deadline:  
August 16, 2013**

On line registration and payment  
is available at  
<http://isong.wildapricot.org/events>.

[Click Here](#)

Once you register, you will receive a confirmation letter from ISONG. If you do not receive a letter confirming receipt of your registration, please call us at +1 412-344-1414 to check your registration status, or contact us via email at: [ISONGHQ@msn.com](mailto:ISONGHQ@msn.com).

# TWENTY-FIVE YEARS OF LEADERSHIP IN GENETICS NURSING

## HOST HOTEL

Doubletree by Hilton Bethesda  
Bethesda, Maryland 20814 USA  
Phone: +1 301-652-2000 (main) or +1 800-955-3759

**Direct link for ISONG Conference hotel reservations:**

[Click Here  
Hotel Reservations](#)

**Cut-off date for ISONG Conference room rate: September 4, 2013**

The hotel room rate is \$149.00 (USD) plus tax per night for Single/Double. Reserve your room early! The special conference rate and room availability cannot be guaranteed after the September 3<sup>rd</sup> cut-off date.

Attendees of the ISONG Conference will be delighted with the Doubletree by Hilton Hotel Bethesda. This hotel is a top choice to make the best of your time in and around the capital of the USA. This stylish hotel welcomes you with friendly service and ultra comfortable guest rooms with free WiFi. Who can resist the famous Doubletree warm chocolate chip cookies? The hotel features a fully equipped fitness center and a hotel restaurant that offers a comfortable communal atmosphere to catch up with friends and colleagues.

Check in: 3 PM  
Check out: 12 PM

### Hotel Parking

Valet Parking is available at \$22/per 24 hours (with in and out privileges)

## Conference Venue

Bethesda is a unique venue with an exciting surrounding area and nearby to the nation's capital and Georgetown. There are more than 100 lively shops, restaurants and entertainment in Bethesda within walking distance or with the complimentary bus.

Experience Washington DC, with a short one-stop Metro shuttle ride. The White House, famous monuments, impressive museums and the incredible Smithsonian Institutions are a must-see and don't forget your camera! This may be the nation's capital but it's also an international metropolis home to diplomats and embassies from around the world. An array of exotic cuisine makes DC an adventurous eater's paradise.

Historic Georgetown is less than 7 miles away and is one of the oldest neighborhoods in Washington DC. Georgetown served as a major port and center during colonial times because of its prime location on the Potomac River. Today, Georgetown is a vibrant community with upscale shops and restaurants along the cobblestone streets. The tree-lined streets feature restored row houses with beautiful gardens.

## Travel Details

Distance from the airports and airport transportation options are as follows:

Washington Dulles International Airport  
Approximately 35 minutes travel time  
Super Shuttle \$29  
Limo \$60  
Taxi \$56

Washington National Airport  
Approximately 30 minutes travel time  
Taxi \$46  
Subway/Rail \$5  
Limo \$50

Baltimore Washington International  
Approximately 40 minutes drive time  
Super Shuttle \$39  
Taxi \$75  
Limo \$75

Airline transportation is available near the baggage claim area. Rates are quoted in USD and are subject to change.

## Airline Reservation

### Assistance

Sue Ryan at Travel By Design can assist interested parties in making their air transportation arrangements. Sue can be reached at: +1 847-395-2772 or e-mail: [tbdesign@ameritech.net](mailto:tbdesign@ameritech.net). Note that a standard travel agency fee applies when using this service to book your flight.

# TWENTY-FIVE YEARS OF LEADERSHIP IN GENETICS NURSING

*Celebrate Silver!*

## CONTINUING EDUCATION CREDITS

This provider-directed activity will be submitted to the University of Pittsburgh for approval to award contact hours.

The University of Pittsburgh is accredited as an approver of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

## EXHIBITS

There will be an exhibit hall at the ISONG conference. Each participating company will have a table top display area and be able to interact personally with our attendees. Visit University Row this year, a reserved section in the exhibit area which will highlight genetic nursing programs.

## ISONG Raffle

Registrants will be given an opportunity to participate in an exciting raffle. All proceeds from the raffle will directly benefit the on-going goals and objectives of ISONG. Items will range in value and payment can be accepted as follows: cash (USD) checks drawn on US Bank or credit card payment (USD only) using Visa or Mastercard.

## DONATE A RAFFLE ITEM

Please consider making a special anniversary donation to the ISONG raffle. **Think silver – and help celebrate this historic anniversary.** Our members hail from all over the world and we usually have an array of unique items. Bring something to celebrate the silver anniversary or from your hometown, country or your hospital or academic institution. Make sure that your item will travel well – meaning it is compact, lightweight, and can be easily transported in a suitcase. Pictures, books, jewelry, music CDs, t-shirts, sweaters, chocolates, gift certificates, handmade items, autographed items and cultural items are just a few popular suggestions. Contact [isongHQ@msn.com](mailto:isongHQ@msn.com) with any questions regarding the raffle. We prefer that you carry the item with you to the conference, but we will need a description of the item and its value in advance. Please send the description and value to ISONG headquarters via email to [isongHQ@msn.com](mailto:isongHQ@msn.com). All funds raised by the ISONG raffle will directly benefit our organization.

## NATIONAL INSTITUTES OF HEALTH CLINICAL CENTER TOUR

ISONG is honored to announce a special invitation to tour the clinical center at NIH on Friday, October 4, 2013. *This is the world's premier research hospital and a rare opportunity to tour the facility.* There are a limited number of spots available and tour registrants **must sign up in advance and complete all clearance requirements.** The tour sign-up option is listed on the conference registration form. Contact ISONG headquarters with any questions.

## ISONG RESEARCH AWARDS

The purpose of the annual ISONG Nursing Research Grant award is to support research related to genetic nursing practice or that which contributes to the development of genetic nursing science.

The Research Grant applications are available to ISONG members via the ISONG webpage and listerv approximately 2-3 months prior to the grant deadline. All grant submissions undergo rigorous peer review by a committee of Research Committee members and the annual awards will range from \$1,500 - \$2,000 (for each award). Grant information and an application form can be found at [www.ISONG.org](http://www.ISONG.org).

## SCIENTIFIC POSTERS

All posters will be available for review on October 4-6, 2013. Posters must be removed during the morning break on Sunday, October 6. Authors will be available for small group discussions about their posters during the poster reception on Saturday evening.



# TWENTY-FIVE YEARS OF LEADERSHIP IN GENETICS NURSING

Thursday, October 3, 2013

6:00PM - 8:00PM Conference Registration

Pre-Conference - Friday, October 4, 2013

7:00AM - 8:00AM Continental Breakfast/ Visit Exhibits/ Silent Auction

8:00AM - 12:00PM Pre-Conference Concurrent Sessions

## Genetics 101 Workshop

8:00AM - 9:00AM

### Introduction to the Genome

*Melissa Merideth, MD, MPH, FACOG, FACMG*

Investigator

National Institutes of Health

Bethesda, Maryland USA

9:00AM - 10:00AM

### Pedigrees - Assessments from the Genetics Perspective

*Deborah Tamura, MS, RN*

NCI/CCR/Dermatology

National Institutes of Health

Bethesda, Maryland USA

## Education Workshop

8:00AM - 9:00AM

### Developing Genetic Education

*Erica Tengan Yu, PhD, RN, ANP*

Assistant Professor

The University of Texas Health Science Center at Houston

Houston, Texas USA

9:00AM - 10:00AM

### Outreach to the Community

*Susan Fernbach, RN, BSN*

Director of Genetic Outreach

Baylor College of Medicine

Houston, Texas USA

10:00AM - 10:30AM Refreshment Break/ Visit Exhibits/ Silent Auction

## Genetics 101 Workshop (continued)

10:30AM - 11:15AM

### Tree Hugging 101 -

#### The Role of the Nurse in Cancer Genetics

*Alice S. Kerber, MN, APRN, ACNS-BC, AOCN, APNG*

Oncology Clinical Nurse Specialist

Georgia CORE

Center for Oncology Research and Education

Atlanta, Georgia USA

11:15AM - 12:00PM

### Family Responses to a Change of Plans: Birth of a Child with a Genetic Condition

*Marcia Van Riper, PhD, RN, FAAN*

Professor

University of North Carolina - Chapel Hill

Chapel Hill, North Carolina USA

## Education Workshop (continued)

10:30AM - 11:15AM

### Incorporating Genetics/Genomics into the MSN Curriculum to Meet the Essentials

*Sheila A. Alexander, PhD, RN*

Assistant Professor

School of Nursing

School of Medicine

University of Pittsburgh

Pittsburgh, Pennsylvania USA

11:15AM - 12:00PM

### MINC Project: Expanding RN Scope of Practice: A Method for Introducing a New Competency into Nursing Practice

*Kathleen Calzone, PhD, RN, APNG, FAAN*

Senior Nurse Specialist Research

National Institutes of Health,

National Cancer Institute

Bethesda, Maryland USA

*Jean Jenkins, PhD, RN, FAAN*

Clinical Advisor

Genomic Healthcare Branch

National Human Genome Research Institute

Bethesda, Maryland USA

# TWENTY-FIVE YEARS OF LEADERSHIP IN GENETICS NURSING

## Pre-Conference - Friday October 4, 2013 (continued)

12:00PM – 1:00PM Lunch (on your own)

1:00PM - 1:30PM Refreshment Break/ Visit Exhibits/ Silent Auction

### Genetics 101 Workshop

1:30PM – 2:30PM

#### **Genetics Testing**

*Sherri Bale, PhD*

Managing Director

GeneDx

Gaithersburg, Maryland USA

2:30PM – 3:30PM

#### **Cardiogenetics**

*Kathleen T. Hickey, EdD, FNP, ANP, FAHA, FAAN*

Assistant Professor of Nursing

Columbia University School of Nursing

Nurse Practitioner Cardiac Electrophysiology

Robert Wood Johnson Nurse Faculty Alumna

Columbia University Medical Center

New York, New York USA

### Research Workshop

1:30PM – 2:30PM

#### **NINR Update**

*Yvonne Bryant, PhD*

Special Assistant to the Director

National Institute of Nursing Research

Bethesda, Maryland USA

2:30PM – 3:30PM

#### **Unique Program Research Development: Starting a Lab**

*Wendy Henderson, CRNP, MSN, PhD*

Investigator

Chief, Digestive Disorders Unit

Biobehavioral Branch

Division of Intramural Research

National Institute of Nursing Research

National Institutes of Health

Department of Health and Human Services

Bethesda, Maryland USA

3:30PM – 4:00PM Refreshment Break/ Visit Exhibits/ Silent Auction

### Genetics 101 Workshop (continued)

4:00PM – 5:00PM

#### **Ophthalmologic Genetics**

*Wadhi Zein, MD*

Principal Investigator

National Institutes of Health

National Eye Institute

Bethesda, Maryland USA

### Research Workshop (continued)

4:00PM – 5:00PM

#### **Submitting for Research Funds**

*Lois Tully, PhD*

Program Director

National Institute of Nursing Research

Bethesda, Maryland USA

# TWENTY-FIVE YEARS OF LEADERSHIP IN GENETICS NURSING

## ISONG Conference - Saturday, October 5, 2013

7AM – 5:00PM **Conference Registration**

7:00AM – 8:00AM

**Continental Breakfast/ Visit Exhibits/  
Silent Auction**

7:00AM – 8:00AM

**Sunrise SIG Meetings:  
Metabolic, Oncology and  
Preconception/Prenatal**

8:00AM – 8:15AM

**Meeting/President Welcome**

*Kathleen T. Hickey, EdD, FNP, ANP,  
FAHA, FAAN*

Assistant Professor of Nursing  
Columbia University School of Nursing  
Nurse Practitioner Cardiac  
Electrophysiology  
Robert Wood Johnson Nurse Faculty  
Alumna  
Columbia University Medical Center  
New York, New York USA

8:15AM – 9:15AM **Keynote Presenter**

**The Evolution of Genetics Nursing  
Research**

*Janet Williams, PhD, RN, FAAN*  
Kelting Professor of Nursing, University  
of Iowa  
Genetics Nurse Specialist  
Director of the Clinical Genetics  
Nursing Research  
Postdoctoral Fellowship Program  
National Institute of Nursing Research  
Iowa City, Iowa USA

9:15AM – 9:45AM **Refreshment Break/  
Visit Exhibits/ Silent Auction**

9:45AM – 10:30AM **National**

**Perspective on Nursing Research**

*Patricia A. Grady, PhD, RN, FAAN*  
Director  
National Institute of Nursing Research  
Bethesda, Maryland USA

10:30AM – 11:30AM **International  
Panel – Genetics Nursing in the World**

*Lian-Hua Huang, RN, EMBA, PhD*  
Professor & Dean, School of Nursing  
National Taiwan University  
Director, Department of Nursing  
National Taiwan University Hospital  
President, Taiwan Association of Genetic  
Counseling

*Erika Monteiro Santos, RN, PhD*

Nursing Research / Educator  
Hospital SÍrio-Libanês  
São Paulo, Brazil

11:30AM – 12:00PM **Business Meeting**

12:00PM – 1:00PM **ISONG Networking  
Luncheon (included)**

### 1:00PM – 2:20PM Abstract Breakout Sessions

|               | <b>Breakout A<br/>Research 1<br/>Cardiovascular and Diabetes</b>  | <b>Breakout B<br/>Clinical Practice 1<br/>Genomics in Clinical Nursing Practice</b>   | <b>Breakout C<br/>Education 1<br/>Global Genomic Education</b>  |
|---------------|---|---|---|
| 1:00pm-1:20pm | <b>Family History and Perceptions of Genetic Testing among African Americans with Hypertension</b><br><i>Christina Pettey, MNsc</i><br>University of Arkansas for Medical Sciences<br>North Little Rock, Arkansas USA                 | <b>Prioritising The Evidence Base For Genomics In Nursing (PrEGEN)</b><br><i>Emma Tonkin, PhD, BSc(Hons)</i><br>University of Glamorgan<br>Pontypridd, United Kingdom   | <b>From Base Pairs to Bedside: Expanding RN Genomics Scope of Practice</b><br><i>Patricia Kelly, DNP, APRN, CNS, AOCN</i><br>Texas Health Presbyterian Hospital Dallas<br>Dallas, Texas USA                     |
| 1:20pm-1:40pm | <b>Genetic Predictors For Depressive Symptoms And Future Cardiac Events In Patients With Acute Coronary Syndrome</b><br><i>Jennifer Sanner, PhD</i><br>The University of Texas Health Science Center at Houston<br>Houston, Texas USA | <b>Xeroderma Pigmentosum: Developing The Role Of The Clinical Nurse Specialist In The UK</b><br><i>Sally Turner, RGN, RSCN, Cert District Nursing, BSc</i><br>Guys and St. Thomas' NHS Foundation Trust<br>London, United Kingdom | <b>Benchmark Evaluation Of The Integration Of Genetics And Genomics In Nursing Practice</b><br><i>Jean Jenkins, PhD, RN, FAAN</i><br>NHGRI, NIH<br>Bethesda, Maryland USA                                       |
| 1:40pm-2:00pm | <b>T2D Genetic Risk Counselling &amp; Testing In Primary Care</b><br><i>Allison Vorderstrasse, DNSc, APRN</i><br>Duke University<br>Durham, North Carolina USA  | <b>Fragile X</b><br><i>Rebecca Kronk, PhD, MSN, CRNP</i><br>Duquesne University<br>Pittsburgh, Pennsylvania USA   | <b>Genetic Knowledge and Attitudes toward Genetic Testing among Baccalaureate Nursing Students in China</b><br><i>Mary Quinn Griffin, PhD</i><br>Case Western Reserve University<br>Cleveland Heights, Ohio USA |
| 2:00pm-2:20pm | <b>Personalizing Familial Risk for Type 2 Diabetes Mellitus: From the Patient's Point of View</b><br><i>Sandra Daack-Hirsch, PhD, BSN</i><br>The University of Iowa<br>Iowa City, Iowa USA  | <b>Exploring Noninvasive Prenatal Testing: A Case-Based Approach</b><br><i>Mindy Tinkle, PhD, RN, WHNP-BC</i><br><i>Amy J. Levi, CNM, WHNP-BC, PhD, FACNM, FAAN</i><br>University of New Mexico<br>Albuquerque, New Mexico USA    | <b>Survey about Teaching of Genetics and Genomics into Undergraduate Nursing Programs in a Developing Country</b><br><i>Milena Flória-Santos, PhD, MS, RN</i><br>Ribeirão Preto, São Paulo Brazil               |

# TWENTY-FIVE YEARS OF LEADERSHIP IN GENETICS NURSING

## ISONG Conference - Saturday, October 5, 2013

2:20PM – 2:45PM Refreshment Break/ Visit Exhibits/ Silent Auction

### 2:45PM – 4:05PM Abstract Breakout Sessions

|               | <b>Breakout A<br/>Research 2<br/>Reproductive Health</b>  | <b>Breakout B<br/>Education 2<br/>Genomic Curricula Approaches</b>   | <b>Breakout C<br/>Research 3<br/>Behavioral Genomics</b>  |
|---------------|---|--|---|
| 2:45pm-3:05pm | <p><b>Encoded Follistatin-like3 Across Gestation in Preeclampsia and Normal Pregnancies of Lean and Obese Women</b><br/> <i>Sandra Founds, PhD</i><br/>                     University of Pittsburgh School of Nursing<br/>                     Pittsburgh, Pennsylvania USA</p>                | <p><b>Further Development of the Global Genetics and Genomics Community (G3C): Online Unfolding Genomic Case Study Simulations</b><br/> <i>Kathleen Calzone, PhD, RN, APNG, FAAN</i><br/>                     National Institutes of Health, National Cancer Institute<br/>                     Bethesda, Maryland USA</p> | <p><b>Gene Expression Profiling in Post-traumatic Stress Disorder and Depression among Military Personnel</b><br/> <i>Hyunhwa Lee, PhD</i><br/>                     National Institutes of Health, National Institute of Nursing Research<br/>                     Bethesda, Maryland USA</p> |
| 3:05pm-3:25pm | <p><b>CHOICES Intervention Effects on Sickle Cell Reproductive Health Knowledge</b><br/> <i>Agatha Gallo, PhD, RN, FAAN</i><br/>                     University of Illinois at Chicago<br/>                     Chicago, Illinois USA</p>   | <p><b>Visualizing the Curriculum Mapping Process of Genetic and Genomic Content to Impact Learning Outcomes in Healthcare Education</b><br/> <i>Patricia Brennan, PhD, MS, BSN</i><br/>                     Samuel Merritt Univeristy<br/>                     Oakland, California USA</p>                                 | <p><b>Genetic Variations Of Fatty Acid Amide Hydrolyase (FAAH) Gene And The Personality Trait Of Persistence</b><br/> <i>Jeongok Logan, PhD, RN</i><br/>                     National Institutes of Health<br/>                     Bethesda, Maryland USA</p>                                |
| 3:25pm-3:45pm | <p><b>The Role of Estrogen Receptor 1 and Vitamin D Receptor Gene Polymorphisms in Postmenopausal Bone Loss: A Systematic Review</b><br/> <i>Yamnia Cortes, MS, FNP-BC, MPH</i><br/>                     Columbia University School of Nursing<br/>                     Bronx, New York USA</p> | <p><b>A Model For Evaluating Genomic Nursing Education</b><br/> <i>Linda Ward, PhD, ARNP</i><br/>                     Washington State University<br/>                     Spokane, Washington USA</p>   | <p><b>The Effects of Cigarette Smoking on Motor and Cognitive Symptoms in Huntington Disease</b><br/> <i>Nancy Downing, PhD</i><br/>                     University of Iowa<br/>                     Iowa City, Iowa USA</p>  |
| 3:45pm-4:05pm | <p><b>The effect of culture on the intention to undergo an abortion in case of a fetal abnormality</b><br/> <i>Sivia Barnoy, RN, PhD</i><br/>                     Tel-Aviv University<br/>                     Tel-Aviv, Israel</p>   | <p><b>Development &amp; Implementation of an Interdisciplinary Elective in Genomics and Personalized Medicine with a Personal Genome Testing Option</b><br/> <i>Jennifer Dungan, PhD, RN</i><br/>                     Duke University<br/>                     Durham, North Carolina USA</p>                              | <p><b>OXTR As A Candidate Gene for Apathy Among Persons with Alzheimer Disease</b><br/> <i>Emilie Goris, BSN</i><br/>                     Michigan State University<br/>                     Grand Rapids, Michigan USA</p>   |

4:15PM – 5:30PM **Poster Session and Reception** (Posters are listed on page 11-13)

6:30PM – 10:00PM **Gala Dinner Social Event**

Celebrate this historic Silver Anniversary for ISONG at Positano's Restaurant (included with full-registration conference fee)



# TWENTY-FIVE YEARS OF LEADERSHIP IN GENETICS NURSING

## ISONG Conference - Sunday October 6, 2013

7:00AM - 8:00AM

**Continental Breakfast /  
Visit Exhibits / Silent Auction**

8:00AM - 8:45AM

**Meeting / Incoming President Address**  
*Maggie Kirk, PhD, BSc (Hons), DipN, RGN*  
Professor of Genetics Educations  
University of Glamorgan  
Pontryppidd, Wales UK

8:45AM - 9:30AM

**Evolution of Genetic Nursing -  
Founding Mothers Forum**  
*Shirley Jones, PhD, RNC, FAAN*  
SLJ Healthcare Consultant  
SLJ Healthcare Management Consulting  
Somerset, Pennsylvania USA

*Lynette Wright, MN, CNS, CGC*  
Associate Professor (Retired)  
Emory University  
Decatur, Georgia USA

9:30AM - 10:15AM

**Genetics in the Next 25 Years**  
*Thomas Markello, MD, PhD*  
Principal Investigator  
National Institutes of Health  
National Human Genome Research Institute  
Bethesda, Maryland USA

10:15AM - 10:45AM

**Refreshment Break /  
Visit Exhibits / Raffle Drawing**

10:45AM - 11:30AM

**Committee Meetings: Research, Practice,  
Global Membership, Education, EPP and  
Communications**

11:30AM - 12:30PM

**Networking Luncheon (included)**

12:30PM - 1:50PM

**Abstract Breakout Sessions**



# TWENTY-FIVE YEARS OF LEADERSHIP IN GENETICS NURSING

## ISONG Conference - Sunday October 6, 2013

### 12:30PM – 1:50PM Abstract Breakout Sessions

|                 | <b>Research<br/>Research 4<br/>Neonatal and Pediatrics</b>   | <b>Education<br/>Clinical Practice 2<br/>Genomic Risk Assessment</b>  | <b>Practice<br/>Research 5<br/>Oncology and Research Study Issues</b>  |
|-----------------|--|---|--|
| 12:30pm-12:50pm | <b>Maternal Knowledge and Attitudes about Newborn Screening and Dried Bloodspot Retention in Texas</b><br><i>Patricia Newcomb, PhD, MSN, BSN, BA</i><br>Texas Health Resources<br>Fort Worth, Texas USA      | <b>Genetic Predisposition: A Concept Analysis with Implication for Nurse Clinicians and Scientists</b><br><i>Dru Riddle, DNP, CRNA</i><br>Texas Christian University<br>Fort Worth, Texas USA | <b>Lynch Syndrome and Hereditary Colorectal Cancer Type X: Phenotypic Differences</b><br><i>Erika Santos, PhD, MSc, RN</i><br>Hospital A.C. Camargo<br>São Paulo, SP Brazil  |
| 12:50pm-1:10pm  | <b>Validation of the Pediatric Quality of Life Scales in Patients with Congenital Muscular Dystrophy</b><br><i>Katherine Meilleur, PhD, PNP-BC</i><br>NIH<br>Bethesda, Maryland USA                          | <b>Is the Family History of Type 2 Diabetes a Practical Screening Tool?</b><br><i>Katie Curran</i><br>University of Iowa<br>Iowa City, Iowa USA   | <b>Epigenetic Regulation and Obesity Impact Prostate Cancer</b><br><i>Jody Ralph, PhD, RN</i><br>University of North Dakota<br>Grand Forks, North Dakota USA   |
| 1:10pm-1:30pm   | <b>“Something Is Missing”: Mother’s Appreciation Of Genetic Testing For Autism Spectrum Disorder</b><br><i>Ellen Giarelli, EdD, RN, CRNP</i><br>Drexel University<br>Philadelphia, Pennsylvania USA          | <b>Family History Information Related to Substance Abuse Helps Inform Chronic Pain Treatment</b><br><i>Elizabeth Pestka, MS, PMHCNS-BC, APNG</i><br>Mayo Clinic<br>Rochester, Minnesota USA   | <b>Recruiting Healthy Infants Into Genetic Research-Oil and Water?</b><br><i>Linda Hatfield, PhD</i><br>University of Pennsylvania<br>Philadelphia, Pennsylvania USA   |
| 1:30pm-1:50pm   | <b>Impact Of Breast Milk On Obesity: A Possible Epigenetic Mechanism Influencing Metabolic Programming</b><br><i>Heide Temples, PhD(c), RN, PNP, BC</i><br>Clemson University<br>Clemson, South Carolina USA | <b>Epigenomic Biomarker Identification and Application in Complex Disease</b><br><i>Cindy Anderson, PhD, WHNP-BC, FAAN</i><br>University of North Dakota<br>Grand Forks, North Dakota USA     | <b>ACMG Recommendations For Reporting Clinical Genomic Incidental Results: Implications for Returning Children’s Genomic Incidental Research Results</b><br><i>Cynthia Prows, MSN, CNS, FAAN</i><br>Children’s Hospital Medical Center<br>Cincinnati, Ohio USA |

1:50PM – 2:05PM

### Refreshment Break

2:05PM – 3:05PM

### Closing Keynote

Jean F. Jenkins, PhD, RN, FAAN  
 Senior Clinical Advisor  
 National Institutes of Health  
 National Human Genome Research Institute  
 Bethesda, Maryland USA

### Conference Concludes

## Posters

### **Identification of Candidate Genes for Investigation of Symptom Variability in Women with and Receiving Treatment for Breast Cancer**

*Theresa Timcheck-Koleck, BSN, RN*  
University of Pittsburgh  
Pittsburgh, Pennsylvania USA

### **Nitric Oxide Synthase Gene Expression In Patients With Nonalcoholic Fatty Liver Disease**

*Wendy Henderson, PhD, BSN, RN*  
National Institutes of Health  
Bethesda, Maryland USA

### **The distribution and range of risk predicted by a coronary heart disease genetic risk score in Caucasian, African, Chinese, Japanese relative to a genotyped Filipino-American women population**

*Irma Ancheta, PhD, RN*  
University of North Florida  
Jacksonville, Florida USA

### **The 719Arg allele of the KIF6 SNP rs20455, a putative predictor of coronary heart disease, in association with the lipid profile and statin usage of Filipino women residing in the United States**

*Irma Ancheta, PhD, RN*  
University of North Florida  
Jacksonville, Florida USA

### **Knowledge Level and Learning Needs for Prenatal Genetic Tests among Pregnant and Postpartum Women in South Korea**

*Gyeyoung Shin, PhD*  
Shinheung College  
Uijeongbu, Gyeonggi-do Republic of Korea

### **Unique Gene- and Disease-Specific Survival Effects in Two Case-Control Studies of Coronary Artery Disease**

*Jennifer Dungan, PhD, RN*  
Duke University  
Durham, North Carolina USA

### **Pediatric Traumatic Brain Injury: Creating a Sample Repository for Future Genetic Study**

*Karin Reuter-Rice, PhD*  
Duke University  
Durham, North Carolina USA

### **Communication of Genetic Risk Of Hypertrophic Cardiomyopathy And Long QT Syndrome In Families**

*Lisa Shah, BSN*  
University of Iowa  
Iowa City, Iowa USA

### **Shared Genomic Variation Across Three Phenotypes**

*Anne Ersig, PhD, RN*  
University of Iowa  
Iowa City, Iowa USA

### **Defining the Pediatric Procedural Anxiety Phenotype Across a Two Phase Study**

*Anne Ersig, PhD, RN*  
University of Iowa  
Iowa City, Iowa USA

### **Analysis Of Gene Polymorphism CYP2C19 In The Lebanese Population Who Reside In Colombia.**

*Mostapha Ahmad, Magister*  
Universidad del Norte  
Barranquilla, Colombia

### **The MINI Study: Metabolism, Infection And Immunity in Inborn Errors of Metabolism**

*Janet Shiffer, BSN, MSN*  
National Institutes of Health  
Silver Spring, Maryland USA

### **CYP2D6, CYP2C9 and CYP2C19 Allelic Variants in a Pediatric Sickle Cell Disease Patient Cohort: Opportunities and Challenges for Pharmacogenetic Profiling**

*Cheedy Jaja, PhD, MPH, MN, RN*  
Georgia Regents University  
Augusta, Georgia USA

### **Leptin, Leptin Receptor, and Ghrelin Genes and Their Association with Protein Levels and Body Mass Index (BMI) in a Sample of Weight Cyclers**

*Christopher C. Imes, BSN, PhD*  
University of Pittsburgh  
Pittsburgh, Pennsylvania USA

### **Nurse's Self-Assessment of Genetic Related Activities in Hospice and Palliative Nursing in the United States**

*Denise Cauble, PhD*  
University of Texas at Arlington  
Arlington, Texas USA

### **Dopaminergic Genetic Contributions to Food Addiction and Obesity**

*Ansley Stanfill, PhD(c), RN*  
University of Tennessee Health Science Center  
Arlington, Tennessee USA

### **Exploring The Relationship Between vWF Polymorphisms And Depressive Symptoms On Cardiac Outcomes Among Patients With Acute Coronary Syndrome**

*Erica Yu, PhD, RN, ANP*  
The University of Texas Health Science Center at Houston  
Houston, Texas USA

# 25 TWENTY-FIVE YEARS OF LEADERSHIP IN GENETICS NURSING

## Posters

### **Experiences And Attitudes Toward Prenatal Testing Among Women Of Advanced Maternal Age In Japan**

*Kyoko Murakami,*  
Ube, Yamaguchi Japan

### **Using a State Cancer Registry to Recruit Young Breast Cancer Survivors and their High-risk Relatives to a Randomized Trial to Increase Use of Genetic Services and Screening**

*Maria Katapodi, PhD, RN, FAAN*  
University of Michigan School of Nursing  
Ann Arbor, Michigan USA

### **Cardiovascular Disease and Type 2 Diabetes Risk Reduction Among Latinos: Integrating Genomic And Family History Education Into A Healthy Lifestyle Intervention**

*Gia Mudd-Martin, MSN, MPH, PhD*  
University of Kentucky  
Lexington, Kentucky USA

### **Cystic Fibrosis Newborn Screening Web Pages Evaluation**

*Audrey Tluczek, PhD*  
University of Wisconsin, School of Nursing  
Madison, Wisconsin USA

### **Association Between Cardiogenetics, Arrhythmias, and Quality of Life**

*Kathleen Hickey, EdD, FNP-BC, ANP-BC, FAHA, FAAN*  
Columbia University  
New York, New York USA

### **The Effect of Genetic Education Program for the Hereditary Colorectal Cancer in Korean Nurses**

*Kyung Sook Choi, PhD*  
Chung-Ang University  
Seoul, Republic of Korea

### **The Intention to integrate Down Syndrome children in society: a study of attitudes and beliefs of Jewish and Muslim mothers**

*Sivia Barnoy, RN, PhD*  
Tel-Aviv University  
Tel-Aviv, Israel

### **The Role Of Leadership In The Uptake Of Genetics In Nursing Practice: Identifying The Characteristics Of Genetic Nurse Adopters And Opinion Leaders**

*Verity Andrews, PhD, BSc(Hons)*  
University of Bristol  
Bristol, United Kingdom

### **Prenatal Genetic Screening: A Qualitative Study Of Provider-Patient Discussion During The Prenatal Visit**

*Gwen Latendresse, PhD CNM*  
University of Utah  
Salt Lake City, Utah USA

### **Population With Shared Genetic Condition Functions as Community Sharing Healthcare Disparities: Nursing Research and Practice Implications**

*Pamela Holtzclaw Williams, JD, PhD, MSN*  
Medical University of South Carolina  
Charleston, South Carolina USA

### **Designing a Computerized Genomic Information System for Nurses: What essential areas of genetic information should be integrated?**

*Jeeyae Choi, DNS*  
University of Wisconsin Milwaukee  
Milwaukee, Wisconsin USA

### **Knowledge of Genetics and Attitude for Terminating Pregnancy among Nursing Students in South Korea**

*Sun Ae Lee, MSN*  
Freseneus Medical Care  
Thiensville, Wisconsin USA

### **Providing Personalized Health Care: Nursing Assessment and Education of the Patient with a Hereditary Kidney Cancer Syndrome.**

*Geri Hawks, BSN*  
National Cancer Institute  
Bethesda, Maryland USA

### **Achieving Genetic/Genomic Competency in Advanced Practice Nurses: Lessons from Pre-licensure Students/Faculty Inquiry**

*Kathleen Sparbel, PhD, FNP-BC*  
University of Illinois at Chicago  
Chicago, Illinois USA

### **Development of a Prenatal Genetic Nursing Education Program**

*Myunghee Jun, PhD*  
University of Wisconsin-Milwaukee  
Milwaukee, Wisconsin USA

# 25 TWENTY-FIVE YEARS OF LEADERSHIP IN GENETICS NURSING

## Posters

### **Genetics And Genomics: A Request And A Response**

*Deborah Peetz, MSN, RN*  
Viterbo University  
Gilman, Wisconsin USA

### **Genetics and Pediatric Nursing Curriculum: Information Technology and Innovation for the Next Generation**

*Tami L. Thomas, PhD, MSN, RN*  
Emory University  
Atlanta, Georgia USA

### **The Genetic and Rare Diseases (GARD) Information Center: Eleven Years Of Improving Access To Hard-To-Find Genetic And Rare Diseases Information And Resources**

*Michelle Snyder, MS, CGC*  
Genetic and Rare Diseases Information Center  
Rockville, Maryland USA

### **Considering of the education programs for midwives about genetic counseling for prenatal diagnosis in Japan**

*Ozasa Yuka, PhD Nursing*  
Tokyo Medical & Dental University  
Tokyo, Japan

### **Nursing Genomics-Its Role in Health Trajectory**

*Pei-Ying Chuang, PhD*  
University of Colorado  
Denver, Colorado USA

### **Dancing in the Dark: Living with Xeroderma Pigmentosum**

*Deborah Tamura, MS, RN, APNG*  
National Institutes of Health  
Bethesda, Maryland USA

### **Moebius-Poland Syndrome: A Case Report**

*Mostapha Ahmad, Magister*  
Universidad del Norte  
Barranquilla, Colombia

### **Cockayne Syndrome: A Case Report.**

*Mostapha Ahmad, Magister*  
Universidad del Norte  
Barranquilla, Colombia

### **Roles Of Genetic Nurses For The Molecular Genetics Predictive Test Of Neurology In Japan**

*Miwa Suzuki, RN, NM, PhD*  
Tokyo Medical and Dental University  
Tokyo, Japan

### **Examining The Relationship Between Microbes And DNA Methylation**

*Michelle Wright, MS, RN*  
University of North Dakota  
Grand Forks, North Dakota USA

### **The lived experiences of families that have attended a Cardiogenetics Clinic**

*Esma Paljevic, EdD, MA, BSN, CPNP*  
Pace University  
Pleasantville, New York USA

### **Development of a Transition Program for Youth with Down Syndrome**

*Joanna Spahis, RN, CNS, APNG, MSN, RN, CNS, APNG*  
Children's Medical Center Dallas  
Dallas, Texas USA

### **Engaging Community Health Care Providers in Genomic Research**

*Kathi Huddleston, DNP, MSN, BSN*  
Inova Health System  
Falls Church, Virginia USA

### **Genetics/Genomics in Oral, Dental, and Craniofacial Health: An Overview for Nurses**

*Christina Murphey, PhD*  
The University of Texas at Austin  
Austin, Texas USA

### **Genetic Counseling Challenges for Rare Inherited Bone Marrow Failure Syndromes**

*Lisa Leathwood, RN, BSN*  
Westat Research Corporation  
Rockville, North Carolina USA

### **A Review of Smith-Lemli-Opitz Syndrome (SLOS)**

*Sandra Conley, MS*  
National Institutes of Health/NICHD  
Bethesda, Maryland USA





# Silver Anniversary Conference October 4-6, 2013

The Doubletree Hotel Bethesda, Bethesda, Maryland

## 25 Years of Leadership in Genetics Nursing

1 800-955-3759 or use the direct hotel reservation link: <http://isong.wildapricot.org/events>

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(please list) \_\_\_\_\_

### NIH Tour: Friday, October 4, 2013 at 1:00PM

I will attend the Clinical Center Tour at NIH.

**Registration is limited to 50 and all registrants must register in advance and complete clearance requirements. There is no charge for this tour.**

I would like to serve as a

session moderator: \_\_\_\_\_  Yes  No

Is this your first ISONG Conference? \_\_\_\_\_  Yes  No

I will attend the Poster Awards Reception

(no additional fee)

Saturday, October 5, 2013 \_\_\_\_\_  Yes  No

I will attend the Gala Dinner (no additional fee

for full-conference attendees) \_\_\_\_\_  Yes  No

Are you a past (current) ISONG President.....  Yes  No

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### International Society of Nurses in Genetics

461 Cochran Road, Box 246, Pittsburgh, PA 15228 USA

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### PRE-CONFERENCE WORKSHOPS:

Genetics 101 ..... Full Day Session...\$150\* / \$125\*\*

Integrating Genetics  
into Curricula ..... AM Session .....\$80\* / \$65\*\*

Genetic Nursing Research ..PM Session.....\$80\* / \$65\*\*

**\*Attending Pre-conference workshop only**

**\*\*Discounted rate with full conference registration**

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Before Aug 16 After Aug 16

ISONG active dues member ..... \$450.00 .....\$495.00

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Non-member (joining now) ..... \$575.00.....\$595.00  
*(Includes membership fee)*

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#### GALA DINNER on Saturday evening October 5

at nearby Bethesda restaurant Positano's.

Dinner is included for all full-conference attendees.

Additional Gala Dinner tickets

available at \$80/person.....\$ \_\_\_\_\_

**Total Fee** *(all funds charged/payable in U.S. Dollars)* \$ \_\_\_\_\_

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The University of Texas Health  
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Houston, Texas USA  
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# ISONG

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