



# INTERNATIONAL SOCIETY OF NURSES IN GENETICS, Inc.



**2004 Conference**

## **GENOMIC NURSING IN THE 21ST CENTURY**

October 23-26, 2004  
Metropolitan Hotel Toronto  
Toronto, Ontario, Canada



Co-Sponsored with the National Institute of Nursing Research,  
National Institutes of Health,  
Department of Health and Human Services

# Genomic Nursing in the 21st Century

## Information About ISONG:

The vision of the International Society of Nurses in Genetics:  
Caring for people's genetic health.

The mission of the International Society of Nurses in Genetics:  
To foster the scientific, professional and personal development  
of members in the management of genetic information.

## PROGRAM INFORMATION

**Program Purpose:** This program is intended to provide the international nursing community in genetics with cutting edge information on the impact of genomics on nursing practice across the health continuum.

**Objectives:** Upon completion of this program, the participant will be able to:

1. Critically examine key issues in genetic nursing practice in the genomic era.
2. Examine best practices and current research findings to evaluate the state of the knowledge in clinical genetic nursing for clients across the lifespan and encountered in different practice settings.
3. Network with national and international colleagues and experts in genetic healthcare.
4. Prioritize strategies for the advancement of genomic nursing practice.

**Target Audience:** This program is targeted to members of ISONG, nurse practitioners, clinical specialists, nursing faculty, nurse scientists, staff/office nurses, educators, genetic counselors, leaders of nursing organizations, other interested health care providers and students.

**Meeting Location:** Metropolitan Hotel Toronto  
108 Chestnut Street, Toronto, Ontario, Canada M5G1R3  
Telephone – 416-977-5000  
Guest Fax – 416-977-9513  
<http://www.metropolitan.com/toronto>

**Housing:** The Metropolitan Hotel Toronto is in the heart of Toronto with access to all Toronto Ontario attractions including the financial district, internationally renowned art galleries and museums, Eaton's Centre and the world-class shopping of Bloor Street as well as being conveniently located near the Metro Toronto Convention Centre, site of the American Society of Human Genetics Meeting. The hotel features:

- Les Clefs d'or Concierge
- Complimentary use of fitness center
- Heated indoor swimming pool
- Award-winning restaurants—Hemispheres, and Lai Wah Heen

## Reservations:

To receive discounted hotel room rates, reservations must be received by September 22, 2004. All rooms will be released after this date.

Single (1 person, 1 bed) \$189\*

Double (2 people, 2 beds) \$189\*

\*All room rates are in Canadian funds and subject to a Hotel Tax, which is currently 15%.

## For reservations please call:

**Direct Dial:** 416-599-0555  
Toll free 800-668-6600  
Fax 416-597-6351  
Email: [reservations@metropolitan.com](mailto:reservations@metropolitan.com)

**YOU MUST INDICATE YOUR GROUP AFFILIATION (ISONG) WHEN MAKING RESERVATIONS!**

**Cancellations:** All cancellations must be made 24 hours prior to date of arrival.

## Continuing Education Units:

Application for contact hours has been made to CNE-Net, the education division of the North Dakota Nurses Association, an accredited approver of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. Please contact Jean Anderson at [janderson@ISONG.US](mailto:janderson@ISONG.US) for more information about contact hours. Application has been made for up to 28.5 contact hours.

## Special Accommodations:

All ISONG education sessions are presented in English.  
All ISONG sessions are handicapped accessible.

## Program Registration and Cancellation Policies:

Registration fee includes syllabus materials, breaks, continental breakfasts on Sunday, Monday and Tuesday, lunch on Tuesday and a reception on Monday evening. A full refund of the registration fee, less a \$50 administrative fee, will be granted if cancellation is made on or before October 1, 2004. Email confirmation notices will be sent if valid email address is provided. If you have questions regarding the conference or your registration, contact Jean Anderson at 641-831-9230, visit the ISONG Web site, or email at [janderson@isong.us](mailto:janderson@isong.us).

## Conference Sponsors:

National Institute of Nursing Research  
North Dakota Nurses Association

## Registration Hours:

The Registration Desk will be open during the following hours:

- Saturday, October 23, 2004 7:30 AM – 5:00 PM
- Sunday, October 24, 2004 8:00 AM – 1:00 PM
- Monday, October 25, 2004 8:00 AM – 9:00 AM
- Tuesday, October 26, 2004 8:00 AM – 9:00 AM

## FEATURED SESSIONS

### *Keynote Address:*

## **Visioning Nursing in the Genomic Era**

**Jean Jenkins, PhD, RN, FAAN**

Senior Clinical Advisor

Contractor, National Human Genome Research Institute,  
National Institutes of Health



**Description:** Information will be provided about how completion of the human genome project has implications for understanding the biology of human health and disease. This knowledge will increasingly permeate the clinical approach to individuals and families requiring an informed clinical workforce. Examples of how this expanding perspective of the influence of genomics on complex disease diagnosis, management, screening, and intervention influences genetic nursing will be provided. Social issues influencing the successful integration of genomic information into practice will be highlighted. An overview of the implications of future genomic research and visioning the research opportunities for genetic nursing will be introduced.

## **Pre-Conference Workshops:**

### ***ATCG's of Genetics***

Coordinator: Dale Halsey Lea, MPH, RN, APNG, FAAN

Description: This workshop is for nurses new to genetics and for those wanting an update of basic genetic principles, family history assessment, ethical issues, and the impact of genetics and genomics across the health care continuum.

### ***Emerging Technologies in Genetics: Science, Technology and Practical Issues***

Chair: Carolyn Farrell, MS, RN, CNP, CGC

Co-Chairs: Lorraine Frazier, DSN, RN, NP-C; Jennifer Loud, MSN, RN, CRNP

Description: This session will include an overview of some of the latest cutting edge genetic technologies and their clinical as well as research applications. The workshop also includes on a panel discussion focused on both practical issues and clinical dilemmas arising from these technologies.

## **Panel Discussion:**

### ***International Collaborative Research Initiatives***

Coordinator: Lorraine Frazier, DSN, RN, NP-C

Description: This panel will present a variety of international collaborative research initiatives. The panel will also provide an overview of the 2002 International Symposium on Genetic Nursing held in Ube, Japan.

## **Poster Session:**

Monday, October 25, 2004 5:00 PM – 6:30 PM

## **Vendor Exhibits:**

Exhibitor displays will be available:

Sunday, October 24, 2004 8:30 AM – 3:00 PM

Monday, October 25, 2004 8:00 AM – 6:30 PM

Tuesday, October 26, 2004 8:00 AM – 5:00 PM

## **2004 ISONG Annual Business Meeting:**

The annual business meeting, held during lunch, announces election results, highlights annual committee reports, and features important issues for ISONG members.

## **SOCIAL ACTIVITY**

### **Dinner Cruise with Lecture**

Sponsored by Genzyme

Sunday, October 24, 2004 6PM – till

**NO CHARGE but registration required**

### ***Interventional Genetics for LSD: Model for Collaborative Practice for Nursing and Genetic Counseling***

Description: This presentation will review and discuss the collaborative efforts of nurses and genetic counselors in the care and management of patients with lysosomal storage disease with particular emphasis on enzyme replacement therapy (ERT). Special attention will be paid to the team approach to patient care; the communication process with families and other medical staff; and the paradigm shift in genetics from teaching/information giving to medical intervention. The integration of each profession's unique skills into patient care and management will be highlighted.

# Conference Agenda

## Saturday October 23, 2004

7:30 AM – 5:00 PM	Early Registration
8:00 AM – 12:00 Noon	<b>Pre-Conference Workshop</b> ATCG's of Genetics Coordinator: Dale Halsey Lea, MPH, RN, APNG, FAAN
1:00 PM – 5:00 PM	<b>Pre-Conference Workshop</b> Emerging Genetic Technologies: Applications for Research and Practice Chair: Carolyn Farrell, MS, RN, CNP, CGC, Co-Chairs: Lorraine Frazier, DSN, RN, NP-C; Jennifer Loud, MSN, RN, CRNP

## Sunday October 24, 2004

8:00 AM – 1:00 PM	Registration
8:00 AM – 9:00 AM	Continental Breakfast
8:00 AM – 12:00 Noon	Board Meeting

### CONCURRENT SESSIONS

8:30 AM – 10:00 AM	<b>Special Interest Group Meetings</b>
8:30 AM – 10:00 AM	<b>Summer Genetics Institute Breakfast Network</b>
10:00 AM – 10:20 AM	Break
10:20 AM – 11:30 AM	<b>Committee Meetings</b>
11:30 AM – 1:00 PM	Lunch on your own
1:00 PM – 1:10 PM	<b>Conference Introduction:</b> 2004 Program Committee
1:10 PM – 1:30 PM	<b>Welcome Address:</b> Judith Lewis, PhD, RN, FAAN
1:30 PM – 2:30 PM	<b>Keynote Address:</b> Visioning Nursing in the Genomic Era Jean Jenkins, PhD, RN, FAAN
2:30 PM – 3:00 PM	Break
3:00 PM – 4:00 PM	<b>Plenary Session:</b> Religion and Genetics in the Clinical Encounter Judith Lewis, PhD, RN, FAAN
4:00 PM – 5:30 PM	<b>Plenary Session:</b> Systems of Genetic Healthcare Delivery Coordinator: Dale Halsey Lea, MPH, RN, APNG, FAAN
6:00 PM til....	<b>Dinner Cruise with Lecture</b>

## Monday October 25, 2004

7:30 AM – 8:00 AM	Registration and Continental Breakfast
8:00 AM – 8:15 AM	Announcements

### CONCURRENT SPECIAL SYMPOSIA

8:15 AM – 10:30 AM	<b>State of the Knowledge Symposium:</b> Oncology and Genetics Coordinator: Jennifer Loud, MSN, RN, CRNP
	<b>State of the Knowledge Symposium:</b> Neurogenetics Coordinator: Janet Williams, PhD, RN, FAAN
	<b>State of the Knowledge Symposium:</b> Genetics and Reproductive Health Coordinator: Lori Farmer, MS, RN, APNG, ARNP
10:30 AM – 11:00 AM	Break

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## CONCURRENT ABSTRACT SESSIONS

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11:00 AM – 12:00 PM      **Abstract Session I**  
**Abstract Session II**  
**Abstract Session III**

12:00 PM – 1:30 PM      Lunch on your own

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## CONCURRENT SPECIAL SYMPOSIA

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1:30 PM – 3:30 PM      **State of the Knowledge Symposium:** Neonatal and  
Pediatric Genetics  
Coordinator: Carolyn Graff, PhD, RN  
**State of the Knowledge Symposium:** Genetics of Complex  
Disorders in Adults

3:30 PM – 4:00 PM      Coordinator: Lorraine Frazier, DSN, RN, NP-C  
Break

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## CONCURRENT ABSTRACT SYMPOSIA

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4:00 PM – 5:00 PM      **Abstract Session IV**  
**Abstract Session V**

5:00 PM – 6:30 PM      **Poster Session**

6:30 PM – 8:00 PM      **ISONG Reception/Awards**

### Tuesday October 26, 2004

7:30 AM – 8:00 AM      Registration and Continental Breakfast

8:00 AM – 8:15 AM      Announcements

8:15 AM – 10:15 AM      **Plenary Session:** Genetics and Public Policy  
Coordinator: Judith Lewis, PhD, RN, FAAN

10:15 AM – 10:45 AM      Break

10:45 AM – 12:45 PM      **Plenary Session:** Evidence Based Practice  
Coordinator: Cindy Munro, PhD, RN

1:00 PM – 3:00 PM      **2004 ISONG Annual Business Meeting**  
Lunch provided

3:00 PM – 4:00 PM      **Incoming Presidential Address:**  
Kathleen Calzone, MSN, RN, APNG  
**Panel Discussion:** International Collaborative Research  
Initiatives  
Coordinator: Lorraine Frazier, RN, DSN, NP-C

4:00 PM – 5:00 PM      **Harnessing Novel Genetic Technologies for Research and  
Clinical Applications**  
Yvette Conley, PhD

5:00 PM – 5:15 PM      **Closing Remarks:** Judith Lewis, PhD, RN

5:00 PM – 5:30 PM      Evaluation of Meeting

5:30 PM – 6:00 PM      Distribution of Contact Hours

6:00 PM – 9:00 PM      Board Meeting

### Wednesday October 27, 2004

8:00 AM – 5:00 PM      **ASHG Joint Sessions** with valid ISONG Name Badge

# Conference Registration

**Please mail completed form to:**

Jean Anderson, MA, RN, CPNP—ISONG Executive Director  
 2593 West 15th Street South  
 Newton, IA 50208-8500.  
 Credit card payments may be faxed to 641-792-0265.

Name: \_\_\_\_\_  
 (As you would like this information printed on your name tag)

Mailing Address: \_\_\_\_\_

Telephone Numbers: Work \_\_\_\_\_ Home \_\_\_\_\_

Meal Restrictions:  None  Vegetarian

RN License Number: \_\_\_\_\_ State Licensed In: \_\_\_\_\_

Please Check One	Category	Registration Received by September 15, 2004	Registration Received After September 15, 2004
<input type="checkbox"/>	<i>Current ISONG Member</i>	\$230	\$255
<input type="checkbox"/>	<i>Non ISONG Member</i>	\$300	\$325
<input type="checkbox"/>	<i>Student*</i> <small>Enclose letter from faculty confirming full-time enrollment in nursing program</small>	\$150	\$175

## PRE-CONFERENCE WORKSHOP

Please Check If Attending	Pre-Conference Workshop	Registration Received by September 15, 2004	Registration Received After September 15, 2004
<input type="checkbox"/>	<i>The ATCG's of Genetics</i>	\$125	\$150
<input type="checkbox"/>	<i>Emerging Genetic Technologies: Applications for Research and Practice</i>	\$125	\$150

## SOCIAL ACTIVITY REGISTRATION

Please Check If Attending	Dinner Cruise With Lecture	Registration Received by September 15, 2004	Registration Received After September 15, 2004
<input type="checkbox"/>	<i>Sunday, October 23, 2004</i>	Free	Free

### Method of payment:

- Check - Please make payable to ISONG (U.S. dollars)
- Credit Card - If paying by credit card, please complete the following:
  - Visa  MasterCard      Expiration Date: \_\_\_\_\_
  - Card Number: \_\_\_\_\_
  - Signature: \_\_\_\_\_