

# Quality of Life

QUARTERLY

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VOLUME 21 ISSUE 3  
Newsletter for  
ISOQOL Members  
SUMMER 2015



## PRESIDENT'S MESSAGE

*Galina Velikova, MD, PhD, FRCP; University of Leeds*



It is very exciting to hear of the great plans for the 22<sup>nd</sup> ISOQOL Annual Conference in Vancouver, British Columbia,

Canada. You will not want to miss this exhilarating event that will focus on the social dimension of health-related quality of life (HRQOL) - theory, assessment, and applications. The scientific program committee (led by co-chairs Carolyn Gotay, PhD, and Ida Korfage, PhD) has brought together an incredible set of speakers that will cover a broad range of highly informative and cutting edge topics in HRQOL research.

On Wednesday, 21<sup>st</sup> October prior to the conference, you can expand your knowledge and skills by attending the highly acclaimed workshops offered. Space is limited so please make sure to register early to ensure a spot at the various workshops.

Our conferences always end in a wonderful dinner and party to celebrate a successful meeting and to enjoy time with friends. Come see the city lights on The Roof at The Fairmont Vancouver. Please join us for a welcome from the First Nations, a wonderful dinner with entertainment from a jazz singer, and then dance the night away.

The Annual Conference is a wonderful opportunity to learn about fellow ISOQOL members' research findings during oral presentations and poster sessions, to meet old friends and make new friends. Registration for the conference is open and I ask that you serve as our ISOQOL ambassadors and *spread the word* to your colleagues about our conference. There are PDF documents available for download on our website (<http://www.isoqol.org/2015conference>) to display in your institutions and promote our conference.

It has been an eventful and productive year, and I would like to take this opportunity to thank the leadership

*Continued on page 2.*



**The ISOQOL Newsletter is published four times a year by the International Society for Quality of Life Research.**

*Newsletter Editor*

**Ana Popielnicki, BA, USA**

Send articles with subject line addressed "Newsletter Submission" to:  
**info@isoqol.org**

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United Kingdom**

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#### **ADVERTISING INFORMATION**

Contact Executive Director,  
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**cpedersen@isoqol.org**

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**info@isoqol.org • www.isoqol.org**

*President's Message, Continued from page 1.*

of our task forces, committees and SIGs for their ongoing dedication to the society. Special thanks goes out to Carolyn Gotay and Ida Korfage for their relentless and yet imaginative hard work. I am excited about the many ISOQOL initiatives yet to come in 2015 and hope you will consider joining us by engaging in new ways to share your knowledge with your colleagues.

Sincerely,

*G Velikova*

Galina Velikova, MD PhD FRCP  
ISOQOL President



## **SAVE THE DATE!**

The International Society for Quality of Life Research  
will hold their 23rd Annual Conference

**19 - 22 OCTOBER 2016 COPENHAGEN, DENMARK**

**PLEASE MARK YOUR CALENDARS!**



## FROM THE EDITOR'S DESK

By: Ana Popielnicki



Dear ISOQOL Friends:

I am pleased to present to you the Summer issue of our *Quality of Life Quarterly!*

As we all prepare for our favorite event of the year, you can find detailed information about the Annual Conference and its various activities and sessions in this issue.

Dr. Galina Velikova enthusiastically gives us an overview of the exciting program that the Scientific Chairs, Drs. Carolyn Gotay and Ida Korfage, have put together for the conference, and asks us to spread the word about the AC to our colleagues and friends – please check out several informative articles on the conference in this issue.

We welcome the new members of the Board of Directors, as well as the new Co-Editor-In-Chief of the *Quality of Life Research Journal* – many thanks to the past members and editor for their valuable contributions. Please also find inside the announcements for the recipients of the prestigious President's and Emerging Leader Awards. Congratulations to both our deserving colleagues!

Our Executive Office brings us a treasure of information on the upcoming Annual Conference – Registration procedures, hotel and travel information, a description of the excellent workshops being offered this year, and of course the pure fun part: Vancouver tourism, our popular closing dinner, and other highlighted events planned by several of our Special Interest Groups that you don't want to miss. I look forward to the Conference and to seeing old friends and colleagues, plus meeting new ones – hope to see you all then!

As always, we welcome your questions, comments, or submissions for the fall issue! This is our final issue before the conference, and our Fall issue will be published in November, so we particularly invite you to send your thoughts on the conference and your experiences there. Please send your queries/comments to your Communications Committee at [info@isoqol.org](mailto:info@isoqol.org) with "Newsletter" on your subject line. Happy reading!

Ana Popielnicki  
Editor



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## QUALITY OF LIFE RESEARCH JOURNAL

### THANK YOU!



**Dennis Revicki, PhD**

ISOQOL would like to thank Dennis Revicki for his dedication to the Quality of Life Research Journal.

### WELCOME!



**Frans Jeroen Oort**

ISOQOL welcomes Frans Jeroen Oort as the new Co-Editor-in-Chief of the Quality of Life Research Journal.



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ISOQOL 22<sup>ND</sup> Annual Conference | **Visit Us At Table 5**



ISOQOL  
22<sup>nd</sup> Annual Conference  
VANCOUVER  
British Columbia, Canada  
OCTOBER 21-24, 2015



VANCOUVER

Presenter Registration Deadline - August 21  
Advanced Registration Deadline - September 25  
ISOQOL Hotel Room Block Closes - September 25



## 22<sup>ND</sup> ANNUAL CONFERENCE REGISTRATION INFORMATION

Register today for the 22<sup>nd</sup> Annual Conference and receive the advance registration discount. Advance registration is available through **September 25**.

Visit the [Registration page](#) for details and to access the registration form.

Registration fees not only provide access to the Scientific Program of plenary sessions, oral and poster presentations, and symposia; but there are several exciting highlighted events that are included in registration fees. These highlighted events can be attended at no additional fee, but pre-registration is required.

### 22<sup>ND</sup> ANNUAL CONFERENCE HIGHLIGHTED EVENTS

Highlighted events can be attended free of charge for all registered conference attendees.

#### **Industry Advisory Committee (IAC) Symposium**

Wednesday, October 21, 4:30 pm – 6:00 pm

*Symposium organized by: , United Kingdom; , United States; United States, , United Kingdom*

#### **Welcome Reception**

Wednesday, October 21, 6:00 pm – 7:30 pm

Begin your time at the conference by visiting with old friends and networking with new friends and colleagues.

#### **Tricks of the Trade Presentation**

Thursday, October 22, 6:00 pm – 6:30 pm

The New Investigator SIG will present the *Tricks of the Trade* series. If you would like to attend the *Tricks of the Trade* presentation, but not participate in the mentoring program, please indicate this on the registration form.

#### **Mentor/Mentee Reception**

Thursday, October 22, 6:30 pm – 7:30 pm

The ISOQOL mentoring program promotes career development and provides networking opportunities for students and new investigators within the society. Individuals interested in serving as a Mentor will be paired up with students and new investigators that have signed up for the program. This reception provides a forum for the exchange of knowledge in a relaxed atmosphere. Refreshments will be provided.

Pre-registration is required for the mentoring program, as participants will be matched prior to the conference. Sign up on the registration form, or e-mail the ISOQOL Office at [info@isoqol.org](mailto:info@isoqol.org).

**Registration for the mentoring program closes Friday, August 21.**

### CLOSING DINNER

Join us for the Closing Dinner on the last night of the Annual Conference. The Closing Dinner will be held at **The Roof** at the top of the Fairmont Vancouver hotel. The view of the city lights and mountains is breathtaking. Come and listen to the First Nations' Welcome, enjoy a wonderful dinner with entertainment from a jazz singer, and then dance the night away.

**The Closing Dinner will be held on Saturday, 24 October; from 7:00 to 10:00 pm.** Tickets are required for this event and can be purchased through the registration form. Space is limited, so be sure to register for the Closing Dinner early.



## WORKSHOPS

All 22<sup>nd</sup> Annual Conference attendees are invited to register for the workshops presented on Wednesday, October 21. A ticket is required for each workshop, and can be purchased through the 22<sup>nd</sup> Annual Conference registration form. Space in each workshop is limited, so please register early.

Workshops provide an in-depth, and often hands-on approach to a wide range of focus areas in health-related quality of life and outcomes research.

If you have already registered for the Annual Conference and would like to add workshops to your registration, please contact the ISOQOL Business Office.

Visit the Workshop page of the website for session descriptions and instructor information.  
(<http://www.isoqol.org/2015conference/workshops>)

### MORNING WORKSHOPS

Wednesday, October 21, 9:00 am – 12:00 pm

(WK01) An Introduction to Health Related Quality of Life Assessment

(WK02) Death and Missing Data

(WK03) Best Practice for Qualitative Methods for Patient Reported Outcomes Research

(WK04) Using innovative methods to inform instrument development and understand patient preferences: how Group Concept Mapping and other creative approaches can be used to capture the experiences and priorities of patients

(WK05) Implementation of Routine Patient Reported Outcome Measurement in Clinical Practice

### AFTERNOON WORKSHOPS

Wednesday, October 21, 1:00 pm – 4:00 pm

(WK06) Introducing the Concept of Response Shift - An Overview of Theory and Methods

(WK07) Place Bookmark Here: How to Conceive, Develop, Conduct and Evaluate a Bookmarking Workshop for Identifying Clinically Meaningful Levels of PROs

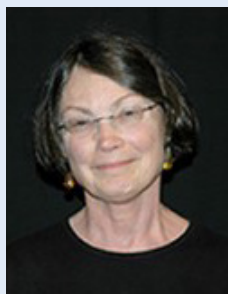
(WK08) Improving the Design of Clinical Trials with Patient Reported Outcomes: Guidance for Protocol Writers

(WK09) Clinical Outcomes Assessment (COA) in Rare Disease (RD) - New Perspective on Traditional Methods

(WK10) Caring about Caregivers: Definitions, Methods and Importance of Evaluation Caregivers' Burden

## AWARDS

### 2015 PRESIDENT'S AWARD RECIPIENT



**Carol M. Moinpour, PhD**

Fred Hutchinson Cancer Research Center  
Seattle, Washington

### 2015 EMERGING LEADER AWARD RECIPIENT



**Bellinda L. King-Kallimanis, PhD**

Pharmerit International  
Boston, United States



## TRAVEL LOGISTICS

### RESERVE A ROOM AT THE ANNUAL CONFERENCE VENUE – THE FAIRMONT HOTEL VANCOUVER

The Scientific Program of the 22<sup>nd</sup> Annual Conference will take place at The Fairmont Hotel Vancouver. Known as the “Castle in the City”, the Fairmont Hotel Vancouver is in walking distance from the city’s best shopping, entertainment and various restaurants. Public transportation is also easily accessed from The Fairmont Hotel Vancouver to explore local attractions in the city.

#### The Fairmont Hotel Vancouver

900 West Georgia Street

Vancouver, British Columbia, V6C 2W6, Canada

Phone: +1 (604) 684-3131

Reservations: +1 (604) 684-3131

Website: <http://www.fairmont.com/hotel-vancouver/>

### ROOM RESERVATIONS

**Conference attendees have been offered reduced sleeping room rates** at The Fairmont Hotel Vancouver. Please reserve your room online today using the ISOQOL reservation link below:

**Reservation Link:** <https://aws.passkey.com/event/11233517/owner/2071/home>. If you prefer to book by telephone, mention **ISOQOL** for the reduced room rate.

Room rates range from \$192 – \$299 CAD for single occupancy. *Please Note: Sales tax not included in nightly rate.*

The discounted room rate will be available until the room block reaches capacity, or through **September 25, 2015**. Reduced room rates cannot be guaranteed after this date. **The hotel is starting to sell out, so reserve a room as soon as possible to guarantee a sleeping room at the headquarter hotel.**

### TRAVEL INFORMATION

The Fairmont Hotel Vancouver is centrally located and about a 30 minute taxi or Canada Line Skytrain ride from the Vancouver International Airport (YRD).

#### Pricing

Taxi: Approximately \$35 CAD

Canada Line Skytrain (*recommended for those with little luggage*): \$8.75 CAD/person

Parking is available at the hotel. Please contact the hotel directly for parking details and pricing.

### ARE YOU PLANNING TO EXPLORE VANCOUVER BEFORE OR AFTER THE ANNUAL CONFERENCE?

Tourism Vancouver, the convention and visitors bureau of the city has a great list of sites and attractions in Vancouver.

<http://www.tourismvancouver.com/do/>



## INTRODUCING THE NEW MEMBERS OF THE ISOQOL BOARD OF DIRECTORS



**Susan J. Bartlett, PhD**

McGill University  
Montreal, QB, Canada



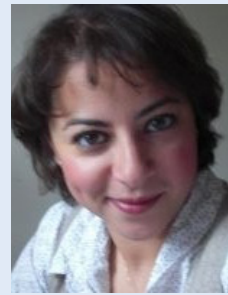
**Mogens Groenvold, MD, PhD**

University of Copenhagen  
Copenhagen, Denmark



**Anne Klassen, D Phil**

McMaster University  
Hamilton, ON Canada



**Diana Rofail, PhD CPsychol**

Roche Products Limited  
Welwyn Garden City, United Kingdom

## UNITED KINGDOM (UK) AND IRELAND: ISOQOL'S NEWEST SPECIAL INTEREST GROUP TAKES FORM

*By: John Brazier and Elizabeth Gibbons, Co-Chairs*

We are delighted to announce the beginning of a new Special Interest Group (SIG) for ISOQOL members: the UK and Ireland SIG. The overall aim of the group would be to promote research into use of PROMS in the UK and Ireland. We would hope to address important methodological issues, discuss PROM developments across the four countries as they arise. This will be an opportunity to encourage and facilitate networking, and support engagement with users (policy, clinical and patients). Support could also be provided for research students and fellows, new UK and Irish investigators and first time attendees at ISOQOL. Our first meeting will be to develop a shared vision for the group and plan future activity.

We look forward to our first official meeting in Vancouver. So if you wish to share your expertise and experiences of PROMs research in the UK and Ireland, then come and join us!

### WELCOME TO OUR NEWEST ISOQOL MEMBERS

Abdulhameed A. Alharbi, MD, MPH, JBCM; *Ministry of Health*

Faraz M. Ali; *Cardiff University*

John P. Barile, PhD; *University of Hawaii at Manoa*

Philip Batterham, PhD; *The Australian National University*

Temitope Kayode T. Bello; *University of Pretoria*

Victor B. Boesen; *Gentofte Hospital*

Vanessa Bouchard; *McGill University*

Majken M. Bronserud, MD, PhD student; *University of Southern Denmark*

Julia Elisa Cabezas Arteaga, MD; *Centro de la Piel - CEPI*

Cristina Nataly Cadena Palacios; *University of Santiago de Compostela*

Jesse Cambon; *Humana, Inc.*

Andrea C. Cueva; *Centro de la Piel*

Selena Daniels; *FDA*

Neha Dewan; *McMaster University*

Ngadiman Djaja, PhD student; *Queensland University of Technology*

Heidi S. Donovan, PhD, RN; *University of Pittsburgh School of Nursing*

Nidup Dorji, PhD Candidate; *Faculty of Nursing and Public Health, KGUMSB, Bhutan*

Sabrina M. Figueiredo; *McGill University*

Kathrin Fischer; *Charité Universitätsmedizin Berlin*

Ingrid H. Flight, PhD; *Flinders University of South Australia*

David Flum, MD MPH; *University of Washington*

Jason M. Fowler; *University of Sydney*

Dan Froggatt; *Roche*

Amanuel T. Gebremedhin, MPH; *Jimma University*

Christelle GirouDET; *Mapi Language Services*

Sabine Goldhahn; *AO Foundation*

Ana L. Gonzalez-Celis, PhD; *National Autonomous University of Mexico (UNAM)*

Carrie Howell; *St. Jude Children's Research Hospital*

Venkata Jaggumantri; *University of British Columbia*

Karen N. Keating, RPT, MBA; *Bayer Healthcare*

JaeYung Kwon; *University of British Columbia*

Danielle Lavalley; *University of Washington*

Karen B. Leyton; *ForeignExchange Translations*

Jialing Li; *Sun Yat-sen University*

Gregor Liegl, Mag. rer. nat.; *Charité Universitätsmedizin Berlin*

Nandini Maharaj; *University of British Columbia*

Ayesha Mahmud; *University of Birmingham*

Jessica T. Markowitz, PhD; *Mapi*

Yvonne A. Michel; *Univeristy of Oslo*

Kathi Mooney; *University of Utah*

Andrea L. Najera;

Carlos Eduardo Paiva, MD, PhD; *Barretos Cancer Hospital*

Nuria Pastor, BSW (Psychology); *University Of Barcelona. Psychology*

Ranjan Pattnaik; *Indian Institute of Technology Kharagpur*

Michele Peters, PhD; *University of Oxford*

Roxanne Morin Potgieter, PhD; *University of Bristol*

Chris G. Richardson, PhD; *University of British Columbia*

Beverly M. Romero, MA; *ICON*

Lara Russell; *University of Victoria*

Shinya Saito, MD, PhD; *Okayama University*

Koonal Shah; *Office of Health Economics*

Selina A. Smith, Ph.D; *Georgia Regents University*

Purnima Sundaresan, MBBS, FRANZCR; *The University of Sydney*

Konrad M. Szymanski; *Riley Hospital for Children*

Bik Wai Tai, PharmD, AE-C; *Khoo Teck Puat Hospital*

Danielle Thiel; *University of Alberta*

Elena Tsangaris; *McMaster University*

Zia Ul Haq, PhD MPH MBBS; *Institute of Public Health & Social Sciences*

Lionne DF Venderbos; *Erasmus University Medical Center*

Bella Vivat; *UCL*

Lorraine Warrington; *University of Leeds*

Hayley S. Whitford, PhD; *The University of Adelaide*

Justin G. Wilford; *University of California Irvine*

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Magdalena A. Zemojtel-Piotrowska; *University of Gdansk*