

Quality of Life

QUARTERLY

IN THIS ISSUE...

- PAGE 1** President's Message
- PAGE 2** SAVE THE DATE!
- PAGE 3** From the Editor's Desk
- PAGE 4** Apply for ISOQOL 2015 Travel Scholarship Opportunities
- PAGE 4** Let us know what you think...because ISOQOListens
- PAGE 5** ISOQOL Annual Conference – Vancouver 2015
- PAGE 5** Call for Volunteers: Oral and Poster Abstract Reviewers
- PAGE 6** ISOQOL Awards
- PAGE 6** 22nd Annual Conference Submission Deadline is this Friday!
- PAGE 7** Mixin' It Up: ISOQOL's Newest Special Interest Group Takes Form
- PAGE 7** Call For Associate Editors
- PAGE 8** The Child Health Special Interest Group – A Brief Update from the Co-Chairs
- PAGE 9** What Does Your Member Profile Look Like On The ISOQOL Website?
- PAGE 9** Welcome to our Newest ISOQOL Members

VOLUME 21 ISSUE 2

Newsletter for
ISOQOL Members
SPRING 2015



PRESIDENT'S MESSAGE

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



Dear ISOQOL Members,

For those of us in the Northern hemisphere the spring is finally coming where we can enjoy the warmth and the longer daylight. This is a busy time for ISOQOL as we prepare for the next conference. Please submit your abstract for review and presentation at the 2015 Annual Conference. The poster and oral abstracts are due Friday, April 24, 2015. The abstract review process will begin in May and I encourage all members to volunteer to serve as an abstract reviewer this year. Having a diverse group of peer reviewers will increase the quality of our reviews across all disciplines. Even if you are a relatively junior researcher, please come forward. There is no better way of learning than looking at how other colleagues are performing and reporting their work. All reviews are done online. If you

are interested in volunteering, please send an e-mail to info@isoqol.org.

I would like to thank Carolyn Gotay and Ida Korfage for their relentless and imaginative hard work. They have put together an outstanding conference themed as *The Matrix: Quality of Life in Social Context*. The influential list of plenary speakers can be found here: <http://www.isoqol.org/2015conference/plenary>.

As an ISOQOL member, I ask that you **serve as our ISOQOL ambassador** 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>. Please post the information and share the email communications with those in your department or research area. The dynamic and energizing 2015 Annual Conference program continues to develop. I invite you to join us in beautiful Vancouver, British Columbia, Canada for a cutting edge and thought-provoking program.

Continued on page 2.



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

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Ana Popielnicki, BA, USA

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

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President's Message, Continued from page 1.

ISOQOL would also like to thank Maria-José Santana for her wonderful service and dedication over the past three years as the Board liaison to the Special Interest Groups (SIG). She has been a wonderful advisor to the SIGs. Thank you so much for your service.

I also would like to welcome our new board SIG liaison! Sandra Nolte has graciously accepted to serve as the Board liaison to our ever growing and industrious SIGs. As a Board and SIG member, she will be an excellent mentor and a source of support.

May is also the deadline for nominating someone for the ISOQOL Emerging Leader Award and the President's Award. All nominations must be received by 29 May. Nomination information can be found on our website: <http://www.isoqol.org/membership/awards>.

ISOQOLists is a new online opportunity to post questions and

share ideas about the society. I wish to thank Claire Snyder, our President-Elect, who came up with the idea and developed it to fruition. Many thanks to Colleen and the ISOQOL staff for their support developing the web form. Please forward your suggestions using ISOQOLists: <http://www.isoqol.org/forms/isoqol-listens.php>.

The coming months provide you with many different opportunities for engagement with ISOQOL. I hope you take advantage of these to both share your knowledge and learn from 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 ISOQOLers:

Welcome to the Spring (or Fall, as the case may be where you are) issue of our Quality

of Life Quarterly! Our members and Special Interest Groups have been busy with exciting projects and initiatives around the world.

In her President's Message, Dr. Velikova calls our attention to the research abstract submissions for our Annual Conference, and emphasizes the learning benefits of acting as peer reviewer, while giving us all the opportunity to get involved and serve our Society. Her (and our) thanks go to Drs. Gotay and Korfage, the Scientific Chairs, who have worked enthusiastically to put together a wonderful program for the upcoming AC – please check out their article on the conference in this issue.

Now to our Special Interest Groups – we have quite a variety of activities and news! Take a look at the announcement of our newest SIG, Mixed Methods, with an introduction by co-Chairs Tom Willgoss and Antoine Regnault – make sure to attend their first official meeting at the AC in Vancouver, and to become a member if you are interested in learning and sharing experiences on mixed methods research approach.

The new co-Chairs of the Child Health SIG – Jeanne Landgraf, Nancy Young, and Anne-Catherine Haller – bring us a very informative update on the SIG's activities and ongoing initiatives. We welcome them and extend our thanks to the departing co-Chairs, Anne Riley and Katherine Bevans, for all their hard work during their tenure.

I'd like to introduce our new online tool for our members to communicate their ideas/suggestions/ comments: ISOQOLists! Many thanks to our President Elect Claire Snyder

for her enthusiastic outreach in leading this project – read all about it in this issue!

Please check out our call for Associate Editors for the Society's scientific journal, *Quality of Life Research*. Drs. Schwartz and Revicki, co-Editors-In-Chief, will be reviewing applications – you can learn the specifics in their article here. We are also asking for your nominations for the Emerging Leader and the President's Award, as well as applications for any of our Scholarship opportunities (details in this issue).

We look forward to your questions, comments, or submissions for the summer issue! Please send your queries/comments to your Communications Committee at info@isoqol.org with "Newsletter" on your subject line. Enjoy your reading!



Ana Popielnicki
Editor



APPLY FOR ISOQOL 2015 TRAVEL SCHOLARSHIP OPPORTUNITIES

The ISOQOL Scholarship Program has been developed to increase the opportunity for members in the early stages of their careers, members from developing countries, and patient partners to attend the annual conference by providing funds to help defray the expenses associated with travel to the annual conference.

All scholarship application deadlines are **Friday, May 29, 2015**. Applications will be reviewed by the ISOQOL Scholarship Committee and decisions will be made in June.

2015 SCHOLARSHIP OPPORTUNITIES

Developing Country Scholarship

Eligible applicants must be current ISOQOL members, and hold their primary residence in one of the eligible emerging and developing countries.

Developing Country Scholarship Application

Student and New Investigator Scholarships

Eligible applicants must be current ISOQOL members, and either a current student or new investigator (within 5 years of completing terminal degree or medical residency).

Student & New Investigator Scholarship Application

Patient Engagement Scholarship

To contribute to the advancement of patient engagement in outcomes research, ISOQOL is able to provide funding options to selected patient partners with relevant experience to attend the 22nd Annual Conference in Vancouver.

Patient Engagement Scholarship Description and Application

Applications should be e-mailed to info@isoqol.org. Please use "Patient Engagement Scholarship Application – Surname" for the subject of the message.



LET US KNOW WHAT YOU THINK... BECAUSE ISOQOListens

By: Claire Snyder PhD, President-Elect

Do you have an idea for how to help ISOQOL serve its mission to advance the scientific study of health-related quality of life and other patient-centered outcomes? Or maybe you have an administrative issue that you would like to share with the leadership (such as suggestions for improving our communication strategies). While ISOQOL and its leadership have always encouraged input, until now there was no formal mechanism to make suggestions. People who knew the leaders tended to reach out to them directly; people who didn't know the leaders were unlikely to send an email to the general info@isoqol.org address. ISOQOListens is an online suggestion box that will allow everyone the same access to submit their input to help ISOQOL. At the same time, it provides a systematic mechanism for the leadership to evaluate and prioritize issues.

ISOQOListens is available via the website (<http://www.isoqol.org/forms/isoqol-listens.php>). It is a simple, online form that asks (1) whether the issue is mission/substance driven or administrative; (2) whether the submitter would be willing to participate on a team to address the issue, if one were formed; and (3) for a brief summary of the topic the submitter wants to bring to leadership's attention. Both members and potential members are welcome to submit ideas to ISOQOListens. The goal is to give equal access to everyone to provide input and to enable systematic evaluation of needs and priorities.

Let us know what you think... because ISOQOListens.

ISOQOL ANNUAL CONFERENCE – VANCOUVER 2015

By: Ida Korfage and Carolyn Gotay, 14th of April 2015



As scientific chairs, we very much look forward to welcoming you at the ISOQOL Annual Conference in October 2015! The location is beautiful Vancouver, Canada, and our 2015 theme is 'The Matrix – Quality of Life in Social Context'. The focus of the plenaries is on the social dimension of HRQoL – the theory, the way we measure it and use it in research, practice, and in our interactions with one another. We are proud to present to you the plenary topics, and we're happy that so many inspiring speakers have accepted our invitation to share their thoughts with you.

The plenary sessions will focus on three aspects of social issues. *"Not the Usual Suspects"* will address social determinants – particularly socioeconomic factors - as they affect health and quality of life. *"The Theory of Everything - New Models and Measures"* will present new approaches in conceptualizing and as-

sessing the social dimension, while *"The Social Network"* will provide examples of how to use social media in research and knowledge translation.

The fourth plenary will feature *"Cutting Edge Research"* based on selected submitted abstracts.

We have introduced some new features to enhance the ISOQOL meeting's innovativeness and expose attendees to exciting new ways to extend their research and applications. One innovation is the option of a digital audience response system during plenaries to increase audience participation in the discussion – so bring your smartphone (Wi-Fi will be available in the room).

Those of you who have been to ISOQOL conferences before know its friendly atmosphere. It is very inspiring to meet so many others who are interested in quality of life research, including authors of famous papers, and to exchange ideas and experiences. Elements such as the Mentor/Mentee Program encourage this exchange and add to the benefits of attending a conference. As chairs of the conference, we are a living example of what such a meeting may bring: we met when participating in the Mentor/Mentee Program in 2005,

we've kept in touch during the intervening years, and now we co-chair this meeting. You will note that the plenaries include both established experts and rising stars, to reflect and inspire ISOQOL's multigenerational membership.

At the 2015 conference, we will also offer a 'Dine-Around' on Friday evening. Enjoy an evening of inspiring discussion with your fellow attendees and experts in quality of life, while experiencing the local Vancouver scene! You will be offered a range of discussion topics and nearby restaurants. We recommend that you check the website (www.isoqol.org) regularly to stay updated about the program and speakers. As well, we hope that when you're in Vancouver, you'll have a chance to visit the city and environs, to take advantage of the incredible cultural and natural attractions of this vibrant part of the world!

We encourage you to register and join us in making the 2015 Conference one of the best yet!

Carolyn Gotay and Ida Korfage



CALL FOR VOLUNTEERS: ORAL AND POSTER ABSTRACT REVIEWERS

Abstract reviewers serve a vital role in the scientific program planning by ensuring the quality of the educational content presented at the Annual Conference. Serving as an abstract reviewer provides an excellent way to support ISOQOL. Time commitment is low, but the impact is high!

Abstract review will take place from May 1 – May 22, 2015. Abstract review is 100% electronic and all rankings will be submitted online. Contact the ISOQOL Office at info@isoqol.org for more information or to volunteer to serve. Abstract reviewers must be current ISOQOL members.

ISOQOL AWARDS

By: Colleen Pedersen, Executive Director, ISOQOL

EMERGING LEADER AWARD IN HONOR OF DONNA LAMPING, PHD

With the passing of Past President Donna Lamping, PhD in 2011, the Board of Directors agreed to establish an award for emerging leaders within ISOQOL and the field of health-related quality of life research. Donna spent much of her career mentoring young researchers, and by creating this award, ISOQOL hopes to honor her legacy. Special recognition goes to Neil Aaronson and Madeleine King for leading the process of designing this award.

The award nominee must be a current member of ISOQOL and have been active on an ISOQOL committee, SIG or working group for at least 2 years, having shown exceptional leadership skills and potential. Individuals must be within 10 years of completing a PhD (or equivalent), MD or Masters Degree. Current and

past ISOQOL board members are ineligible. Self-nominations are accepted. Full information regarding the application process can be found at www.isoqol.org/membership/awards.

PRESIDENT'S AWARD

The goal of this award is to recognize outstanding contributions (by an individual or group) to the advancement of the quality of life field in one or more of the following areas: "education of professionals, patients or lay individuals about the value of quality of life assessment as related to health"; "promotion or execution of quality of life research or other scholarly activities"; and "facilitating or furthering policy initiatives that impact upon health-related quality of life." The winner may be given the opportunity to give a 20-minute plenary during the Annual Meeting.

Please submit your nomination package consisting of a letter from the nominator specifying the nominee's contributions, the curriculum vitae of the nominee, and an external support letter.

The award will be selected by the ISOQOL Executive Committee and approved by the Board of Directors. The award will consist of a plaque, a \$1,000 US honorarium and up to \$1,000 US in travel expenses if the recipient plans to attend the Annual Conference.

Make sure to read the full description and criteria for the awards at www.isoqol.org/membership/awards.

Nominations are due by Friday, May 29, 2015. Please send your nomination package for either award to info@isoqol.org.



22ND ANNUAL CONFERENCE SUBMISSION DEADLINE IS THIS FRIDAY!



ISOQOL
22nd Annual Conference
VANCOUVER
British Columbia, Canada
OCTOBER 21-24, 2015

Abstract submission closes **Friday, April 24** at 11:59 pm CDT.

The 22nd Annual Conference Scientific Program Committee is now accepting abstracts for oral and poster presentations at the 2015 Annual Conference. Visit the [Submission Guidelines](#) page of the ISOQOL website for submission instructions and a link to the online abstract submission system.

The speakers for the *Cutting Edge Research* plenary session will be selected during oral and poster abstract evaluation. This plenary will feature some of the highly ranked, innovative research from ISOQOL abstract submissions. All oral and poster abstract submissions are eligible for selection, but you will be able to opt out of selection during submission.

All abstracts will be peer reviewed and notifications will be e-mailed to all submitting authors in June.

CALL FOR ASSOCIATE EDITORS

The journal *Quality of Life Research* is seeking to recruit two new Associate Editors to begin a three-year term in early 2015. Eligible persons will have published scientific works in *Quality of Life Research*, will have served as a reviewer in good standing for the journal, and will be committed to working on our editorial board team to improve the quality and efficiency of manuscript processing as well as the impact of the journal. If interested, please send to the Co-Editors-in-Chief at your earliest convenience: your updated curriculum vitae and a cover letter stating your background in quality of life research, your areas of expertise, and your reasons for seeking the role of Associate Editor for the journal. We are in particular seeking Associate Editors with generalist expertise (i.e., expertise in multiple domains/applications) as well as specialists with expertise in geriatrics and utilities.

Thank you.

Carolyn Schwartz, Sc.D., and Dennis Revicki, Ph.D.

carolyn.schwartz@deltaquest.org and dennis.revicki@evidera.com

MIXIN' IT UP: ISOQOL'S NEWEST SPECIAL INTEREST GROUP TAKES FORM

By: Tom Willgoss and Antoine Regnault, Mixed Methods SIG Co-Chairs

We are delighted to announce the initiation of a new Special Interest Group (SIG) for ISOQOL members: the Mixed Methods SIG. The purpose of the Mixed Methods SIG is to promote the use of mixed methods research in the field of QoL research by exploring the challenges and methodological solutions offered by this research paradigm, identifying opportunities for application of mixed methods research in the field, and defining good practice.

Our ultimate aim is to share and learn best-practice methodologies which can be utilized to enhance the patient centeredness of outcomes research. Therefore, one of our first actions will be to identify examples of mixed methods approaches being utilized by ISOQOL members. Our aim is to explore the current role of mixed methods research in outcomes research and showcase some of the cutting-edge methodologies being used by ISOQOL members. We'd love to hear about your experiences, so please get in touch.

We look forward to growing our membership during 2015, and are excited about our first official meeting in Vancouver. So if, like us, the thought of a 'third paradigm' in patient-centered research excites you, then come and join us!



THE CHILD HEALTH SPECIAL INTEREST GROUP – A BRIEF UPDATE FROM THE CO-CHAIRS

By: Jeanne Landgraf, Nancy Young and Anne-Catherine Haller

At the conclusion of the Child Health Special Interest Group (CH-SIG) business meeting in Berlin Germany 2014, Anne Riley and Katherine Bevans announced they were vacating their positions as Chairs.

We want to publically acknowledge the tremendous efforts and leadership of both Anne and Katherine during their many years serving as chairs. The well-attended child-focused symposium at last year's meeting was a direct result of the initiative launched in 2011 to identify the top priorities for child reported outcomes research using an international consensus process. The symposium was stimulating and included wonderful presentations by long-time CH-SIG members across an array of cutting edge topics. Work on the top research priorities manuscript is ongoing and the paper will be distributed to CH-SIG members for comment soon.

Following the important foundation laid during their tenure, the new CH-SIG co-chairs (Jeanne Landgraf USA; Nancy Young Canada; and Anne-Catherine Haller Germany) hope to further the presence of cutting edge child initiatives both at ISOQOL and beyond, by supporting our global community of members.

Capitalizing on the great energy at the Berlin conference, the Child SIG co-chairs have focused on several key activities identified during the business meeting.

1) Using listserv and the contact list generated at last year's business meeting, a welcome email was sent to CH-SIG members in January 2015. A separate invita-

tion to join ISOQOL and the CH-SIG was also sent to colleagues. If you are a member and did not receive the welcome email, or if you would like to join the CH-SIG, please log in to the Members Only webpage and review your Member Profile. Simply check the Child Health box on the SIG's tab to become a member.

2) We are pleased to announce that we are finalizing the CH-SIG webpage on the ISOQOL website. An email will be forthcoming when the page is "live". We encourage everyone to take a look, provide feedback, and check the webpage periodically as we may use this for updates/postings.

In addition to the CH-SIG website you might find the membership directory of great use. It is searchable by name, geography and interest area. Full contact information is provided including email addresses.

3) In response to members' request, the CH-SIG co-chairs are currently finalizing a CH-SIG specific profile survey. The objective is to obtain more detailed information about members' current areas of research and expertise. An invitation to participate will be forthcoming in the next few weeks.

We encourage all CH-SIG members to participate, as its success in facilitating collaboration and communication depends on your input. Findings will be compiled and presented at this year's business meeting in Vancouver.

4) The co-chairs are making arrangements to organize a CH-SIG specific gathering. The tentative date is **Tuesday October 20th, 2015 in Vancouver**. Please mark your calendars and check the website for further details and updates.

5) The co-chairs hope to submit a Webinar application to the Board later in the year. We will be soliciting topics and potential presenters in the forthcoming profile survey. If you have ideas for webinar topics they are always welcome! Feel free to send along your suggestions. If you have expertise that you would like to share or have a speaker that you wish to recommend let us know and we can work with you to see if a webinar makes sense.

We are actively seeking more members, so please let us know if you would like to join.

If you are already a CH-SIG member, please watch for your email invitation to complete the survey.

As always, please feel free to contact your co-chairs if you have suggestions, comments, concerns or ideas to strengthen the CH-SIG.

Jeanne Landgraf
jml@healthactchq.com
Nancy Young
nyoung@laurentian.ca
Anne-Catherine Haller
a.haller@uke.de



MEMBER'S CORNER

WELCOME TO OUR NEWEST ISOQOL MEMBERS

Gregory A. Abel, MD, MPH; *Dana-Farber Cancer Institute*

Robin Albany

Kristofer M. Charlton-Ouw, MD;
UT Health - University of Texas Health Science Center at Houston

Michael B. Davis; *Provita International Medical Center, LLC*

Alta DeVilliers; *Provita International Medical Center, LLC*

John Fischer, MD; *University of Pennsylvania*

Timothy K. Gardner; *Provita International Medical Center, LLC*

Nicola K. Gartland; *University of Manchester*

Jolijn Hendriks; *London School of Hygiene & Tropical Medicine (LSHTM)*

Jamil Itani; *Provita International Medical Center, LLC*

Tanja Kastien-Hilka; *Swiss Tropical and Public Health Institute*

Dorothy Kessler

Rhonda Knapp-Clevenger, PhD;
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Monika Vance, MBA; *Santium*



WHAT DOES YOUR MEMBER PROFILE LOOK LIKE ON THE ISOQOL WEBSITE?

As part of your ISOQOL Membership Benefits, members can network together using the contact information on the ISOQOL website. You can find members via:

- Geographic area – who is in your city, state/province or country?
- Specialty – who is in your specialty or work environment?
- Quick Search – you can search by name, company, etc.

Your contact information is displayed to all ISOQOL members on the ISOQOL Members Only page. Is your information updated?

MAKE SURE YOUR MEMBER PROFILE IS UP TO DATE!

You are able to log-in to the Members Only page, select Member Profile and update your contact information at any time.

[Click here](#) to access your Member Profile through the ISOQOL Website.

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Abstract Submission Deadlines:

Workshop & Symposium Abstract Submission—February 6, 2015

Oral & Poster Abstract Submission—April 24, 2015

VANCOUVER