

Quality of Life

QUARTERLY

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Newsletter for
ISOQOL Members
WINTER 2016



PRESIDENT'S MESSAGE

Claire Snyder, PhD, Johns Hopkins School of Medicine



to look forward to in the coming year.

Something new this year that we're very excited about is the "**Measuring What Matters**" symposium, which will be held July 25-26, 2016, outside of Washington, DC. This symposium is the first in what may become a series focused on this important topic. This year's meeting addresses "Bridging industry regulatory needs with what matters to patients and clinicians." The symposium will cover both regulatory issues and stakeholder engagement practices for designing and implementing a PRO measurement strategy. In addition to podium presentations, there will be an interactive component with participation by attendees. Many thanks to Sara Ahmed and Steven Blum for co-chairing this meeting, to their

Hello and Happy New Year! I hope that everyone's 2016 is off to a good start. At ISOQOL, there is much

committee members, and to Board Liaison Susan Bartlett. I'm personally looking forward to this symposium and hope to see many of you there.

And while October may seem more distant, plans for our **23rd Annual Meeting** in Copenhagen, Denmark, are well underway. Workshop and symposia proposals have already been submitted. Oral & Poster Abstract submission will open next month. The Annual Meeting provides a valuable opportunity to share your research findings and to learn about our colleagues' studies. Outside of the meeting, Copenhagen and Denmark have much to offer. It's my first trip to this region, and I'm eager to explore Scandinavia.

Finally, a couple of quick updates on the strategic priorities I outlined in November. We are well on our way in re-organizing and re-energizing ISOQOL's structure. We have developed definitions for committees, task forces, and judging panels; reviewed the current committees; and developed and refined the profiles for

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.

existing committees, including the committee's charge, activities, membership, and terms of service. Stay tuned for a call for committee volunteers in late 2016.

At our upcoming board meeting in April, we will continue discussions of the ISOQOL governance structure and dedicate significant time to discussing what ISOQOL can do to work towards our 2015-2017 themes: "Measuring What Matters" and "Making Measurement Meaningful." This summer's symposium is just the beginning, and we welcome any thoughts or ideas regarding initia-

tives ISOQOL should consider in these areas. At the core of everything we do is the desire to support our mission and serve the needs of our membership. Please share any suggestions and ideas on these and other topics at ISOQOListsens.

Sincerely,

Claire Snyder, PhD, ISOQOL President



SUBMIT AN ARTICLE TO THE QUALITY OF LIFE QUARTERLY!

Quality of Life Quarterly is an excellent opportunity to network, share ideas and disseminate information about important industry happenings, article reviews, keynotes, and special events. Although we cannot guarantee that all submissions will be published, we invite you to submit short articles and topic suggestions, achievement announcements, calendar of events, or comments.

Send your submission to **info@isoqol.org** with the subject line "Newsletter Submission". Please include a completed copy of the copy-right release form, both for original and reprinted material.

For more information on the Quality of Life Quarterly, including submission deadlines, advertising opportunities, and more, visit: <http://www.isoqol.org/research-publications/quality-of-life-quarterly>



FROM THE EDITOR'S DESK

By: Ana Popielnicki, BA, TransPerfect



Dear
ISOQOLers:

Hope 2016
has started
auspiciously
for you all –
Happy New
Year! I am
pleased to

present to you our Winter issue of *Quality of Life Quarterly*. We have plenty of activities and initiatives to share with you for these coming months.

In her President's Message, Dr. Snyder touches on the educational opportunities ISOQOL has in store for this year, starting with the "Measuring What Matters" Symposium scheduled for July in Washington, DC (see the article with the symposium details in this issue as well). She also mentions our Annual Conference, reminding us of the deadline for abstract submission (April 18th). Lastly, Claire informs

us of new and exciting changes in ISOQOL structure, so check out her piece to find out and get involved!

This issue brings us an enthusiastic update on the Child Health Special Interest Group – check out their article to hear about the productive and exciting activities at the last Annual Conference in Vancouver. Speaking of the Annual Conference – make sure to see the article on scholarships. ISOQOL offers travel scholarships to students/new investigators, members from developing countries, and patient engagement scholars. Links for the applications are included here.

Our Executive Office as usual has provided several ways that you can explore in order to get involved and network: There is the call for nominations to the Board of Directors, a link to renew your membership, ISOQOL's Career Center for both employers and candidates, and a call to join one or more of our Special

Interest Groups. We are also asking for contributions to the newsletter, so do take a look at the links and contact us with your news!

Our Save the Date piece for our 2016 Annual Conference in Copenhagen is included here as well, and make sure to check out amazing and helpful links to things to do and see in Denmark while we are there for our meeting!

As always, we are at your service for any questions, comments, or submissions for the 2016 Spring issue. Please send your queries/comments to your Communications Committee at info@isoqol.org with "Newsletter" on your subject line. Happy reading!



Ana Popielnicki
Editor



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MEASURING WHAT MATTERS

Bridging industry regulatory needs with what matters to patients and clinicians
25-26 July 2016
Washington, DC, United States

REGISTER HERE

Learning Objectives:

1. To learn about the evolution of PRO measurement in the regulatory approval process in the US and Europe.
2. To understand the meaning of patient-centered outcomes research and patient engagement in the context of developing a PRO measurement strategy for regulatory approval of medical products and devices.
3. To learn how to develop a PRO measurement strategy in partnership with patients and clinicians that meets regulatory requirements.

Intended audience: industry, clinicians, patients, patient advocacy groups, government agencies, academia



ISOQOL Online Education

ISOQOL offers opportunities for learning at your convenience. Our expert presenters address industry trends and best practices, engage the audience through pertinent questions, and ensure that everybody that participates will leave the session having learned something new.

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 is 100% electronic and all rankings will be submitted online.

Contact the ISOQOL Office at info@isoqol.org for more information or to volunteer as an oral and poster abstract reviewers for the dates listed below:

- **Oral and Poster Presentation Abstract Review:** May 5 – May 18, 2015

As a reminder, you must be a current ISOQOL Member (paid through 12/31/2016) to participate as a reviewer.



CHILD HEALTH SIG UPDATE

The members of the Child Health SIG (CH-SIG) look back on an exciting ISOQOL Annual Conference in Vancouver! As of October 2015, there were 105 CH-SIG members.

The conference commenced with a preconference dinner on Tuesday, October 19th, graciously hosted by Anne Junker and Christine Oriel of the Child and Family Research Institute Vancouver (CFRI), part of the Maternal Infant Child & Youth Research Network. The attendees were warmly welcomed by Anne Junker, her colleagues, Jean-Paul Collet and Lori Tucker, as well as by the CH-SIG co-chairs Jeanne Landgraf, Nancy Young and Anne-Catherine Haller.

The networking buffet dinner was preceded by a round table/café table format with CH-SIG members and Vancouver colleagues discussing common child focused topics submitted by members such as Integration of Technology into QoL Research, The Developing Child, and Patient Engagement & Integration of QoL into Clinical Practice. The evening allowed CH-SIG members to become more acquainted with each other, to meet new colleagues, and to exchange knowledge and expertise. The response from all attendees was overwhelmingly positive and CH-SIG members have asked for a preconference dinner at the next ISOQOL Annual Conference in Copenhagen in October 2016. Plans are underway so save the date Tuesday October 18th. Further details to follow.

The preconference dinner was followed by four exciting conference days. Child health contributions included more than 50 posters and presentations spanning from the

development of measures of QoL for specific populations and the assessment of outcomes across an array of conditions including: asthma, ADHD, cochlear implants, epilepsy. Other topics included brain tumor survivors and aboriginal children, as well as prevalence rates of QoL and use of QoL measures to predict healthcare utilization.

On Friday October 23rd, the annual CH-SIG business meeting took place, with 18% of the membership being present and another 19 non-members attending the meeting. The co-chairs reported on the 2014/2015 CH-SIG activities. In addition to creating a CH-SIG website in the Spring 2015, in response to a direct request from members, the co-chairs undertook a project to survey CH-SIG members' areas of expertise and training, research interests, and learning objectives. The goal was to create a CH-SIG specific "matrix" that would enhance communication and networking by linking members with their areas of interest and expertise. Survey response rate was 47% of the total CH-SIG membership. A formal summary of findings was presented during the business meeting. A PDF of the slide presentation and the matrix will be posted for CH-SIG members in late winter using Teamworks, an ISOQOL online project management program that will further facilitate collaboration within our special interest group.

During the coming year we will be working with CH-SIG members to identify activities of interest including the facilitation of a child-specific webinar.

A special thank you on behalf of all CH-SIG members is due to col-



Anne Junker from the CFRI Vancouver with ISOQOL CH-SIG co-chairs Anne-Catherine Haller, Jeanne Landgraf and Nancy Young at the CH-SIG preconference event on October 19th, 2015 (left to right)



Members of ISOQOL CH-SIG and Vancouver colleagues enjoying lively discussions

leagues Nora Fayed, Anne Klassen, Hein Raat, Karen Kuhlthau and Nalin Payakachat for their incredible hard work in preparing a planning grant for submission to CIHR with a very quick turn-around time. Although the grant was not funded, their collective efforts are to be commended!

We wish everyone a happy and productive 2016 and hope to welcome new attendees to the preconference get-together to launch yet another successful ISOQOL Annual Conference in Copenhagen.



2016 ANNUAL CONFERENCE TRAVEL SCHOLARSHIP OPPORTUNITIES

DEVELOPING COUNTRY & STUDENT AND NEW INVESTIGATOR SCHOLARSHIP

APPLY HERE

Eligible applicants for the Developing Country Scholarship must be current ISOQOL members, and hold their primary residence in one of the eligible emerging and developing countries. List of [Eligible Countries](#).

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

PATIENT ENGAGEMENT SCHOLARSHIP

APPLY HERE

In order to contribute to the advancement of patient engagement in outcomes research, ISOQOL has funding for selected patient partners with relevant experience to attend the ISOQOL 23rd Annual Conference. The primary objectives for this participation are to:

- Collaborate with the Patient Engagement Special Interest Group (SIG) to develop educational programs and tools suitable for patient partners and researchers.
- Support the development and implementation of activities related to the active engagement of patient partners in research of relevance to the ISOQOL community.

Patient partners will be selected based upon their experience as active partners in research programs (particularly those of relevance to the ISOQOL community), and their potential to contribute to the development of the ISOQOL patient engagement initiative both during this conference and in the future. In this context, we are defining patient partners as patients who have actively contributed to the design, development, delivery and/or evaluation of research projects and not solely as patients who have participated as research participants.

This application is not complete without a letter of reference from an ISOQOL member who is nominating you & will accompany you to this meeting. Please address the letter to the Scholarship Committee and e-mail or mail it to the ISOQOL office. If sent via email, please use "Patient Engagement Scholarship Application – Surname" for the subject of the message and send to info@isoqol.org. If mailed, send to the office address is 555 East Wells Street, Suite 1100, Milwaukee, WI USA 53202.

Scholarship Application Deadlines:

Applications must be completed online by **Tuesday, 31 May 2016 at 11:59 pm CDT**. Applications will be reviewed by the ISOQOL Scholarship Committee. Decisions will be made in June. Scholarship funds will be provided following the conference. Advance funds will not be available.

Please direct any inquiries for the scholarship application process to info@isoqol.org.

Visit the [scholarship page](#) of the annual conference website for more information.



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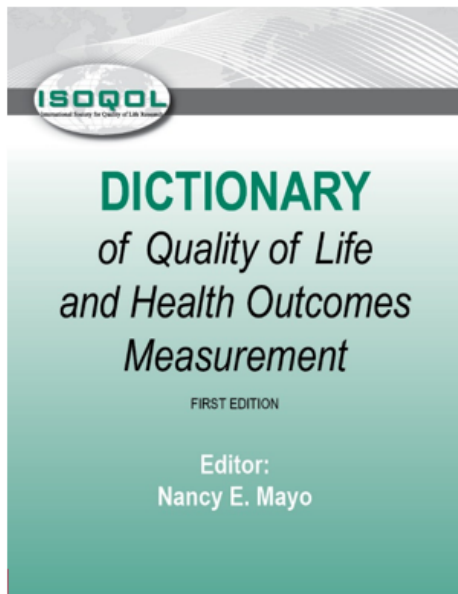
Embrace a world of fairytales at
the Little Mermaid statue

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Castle

Bring home souvenirs from
Strøget shopping street



ISOQOL
23rd Annual Conference
19-22 October 2016
COPENHAGEN
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BE ON THE LOOKOUT

FDA REQUEST FOR COMMENT ON CLINICAL OUTCOME ASSESSMENT COMPENDIUM

With the hard work and perseverance of our Writing Task Force, ISOQOL is completing the first draft comment in response to the Department of Health and Human Services, Clinical Outcome Assessment Compendium's notice of request for comments. The Writing Task Force will soon be presenting this ISOQOL Comment to the membership and calling on the ISOQOL membership to review and submit input/comments on the draft document.

Links regarding the FDA Request for Comment and the Clinical Outcome Assessment Compendium are below for your information. This gives an overview of the FDA request.

[FDA Request for Comment](#)

[Clinical Outcome Assessment Compendium](#)

The comment period will be open Tuesday, 23 February and close Monday, 29 February 2016. More information will be sent out via email in the coming week.

As an ISOQOL member, your contribution will enhance and strengthen the societies input and advance the scientific study of health-related quality of life and other patient-centered outcomes.

ISOQOL THANKS YOU FOR YOUR INPUT AND INSIGHT!

Many thanks to the members of the writing group:

Co-Chair Diana Rofail, PhD CPsychol, UK

Co-Chair Dennis Revicki, PhD, USA

Alexandra I. Barsdorf, PhD, USA

Ethan Basch, MD MSc, USA

David Cella, PhD, USA

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MEMBERS IN THE NEWS

Congratulations to ISOQOL member Ethan Basch and ISOQOL President Claire Snyder for their recent feature in Reuters. The article, titled "Online symptom monitoring benefits cancer patients," by Andrew M. Seaman, was published in December. [Read the article here.](#)

If you or a fellow ISOQOL member are featured in a media news outlet for the work you are doing in Quality of Life and Outcomes Research, please email info@isoqol.org to be featured in our "Members in the News" section of the QOL Newsletter.



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CALL FOR NOMINATIONS FOR THE ISOQOL BOARD OF DIRECTORS

The Nominations Committee welcomes recommendations from ISOQOL members for candidates to fill two (2) opening Board Member positions and the President-Elect position. Please consider nominating yourself or another ISOQOL member for one of these important roles.

If you are nominating someone else, please provide a very brief statement supporting your nomination, and the ISOQOL office will follow-up with the nominee to obtain the additional information.

For self-nominations, please submit:

1. A five-page bio sketch
2. One-page summary of contributions to ISOQOL
3. A five-hundred word vision for ISOQOL

Please send all nomination information to info@isoqol.org.

Final nominations are due 31 March 2016.

In addition to the duties listed below, all board members are expected to attend two face-to-face meetings; one just prior to the Annual Conference and a second mid-year meeting. Expenses to travel to the Board meeting not coinciding with the Annual Conference are covered by ISOQOL. Two conference calls are also required, along with any agreed upon project work.

PRESIDENT-ELECT

The President-Elect will serve a one-year term (2016-2017). The President-Elect will assume the Presidency at the 2017 Annual Conference and will serve a two-year term as President (2017-2019). Upon completion of the term as President, a one-year term as Past-President will be served (2019-2020). This position is a four (4) year commitment.

President-Elect/Past President

- Serve on the Executive Committee and attend monthly calls.
- Serve in the absence of the president.
- Perform such duties as identified in the bylaws or assigned by the president.
- Serve as Chair of the Nominating Committee.

President

- Serve as the chief elected officer over the organization.
- Attend weekly calls with Executive Director.
- Preside over all meetings or identify a designee.
- Interface with the executive director, board of directors, executive committee, and committees.
- Appoint ad hoc committees or task forces.
- Appoint committees in accordance with bylaws.
- Serve as the primary spokesperson for the Board of Directors and the Society.

BOARD MEMBER

Actively promote the mission of ISOQOL and foster ISOQOL's development through strategic planning, policy making, development, and critical evaluation of ISOQOL's activities. Each board member shall participate and lead in the activities of ISOQOL. Board Members shall serve a term of three (3) years and may not succeed themselves.

Duties of a Board member are:

- Understand and promote the organization's mission and bylaws, policies and goals to represent all ISOQOL members.
- Prepare for and attend the full Board meetings for the purpose

of ensuring good governance and strategic overview of ISOQOL.

- Support the President, Board of Directors, and Staff to strengthen programs and services and ensure legal and ethical integrity within the organization.
- Undertake various tasks determined by the Board including service as a board liaison to a committee, task force or program.
- Stay current on issues and trends impacting the organization and contribute to the discussion of documents provided at the Board meetings.
- Treat all information learned or shared at meetings as ISOQOL intellectual property.
- Take an active role in the annual scientific program by volunteering as a reviewer of abstracts, participant as a mentor in the mentor/mentee initiative and other areas where needed.
- Assist the ISOQOL office in activities to raise funds and resources for the Society's activities.

The Nominations Committee will consider these recommendations in developing the slate of candidates. If you have any questions regarding the responsibilities of the positions, please contact Colleen Pedersen, ISOQOL Executive Director at cpedersen@isoqol.org or Galina Velikova, MD PhD Nominations Committee Chair at g.velikova@leeds.ac.uk.



ISOQOL MEMBERSHIP OPPORTUNITIES

Log in to your ISOQOL Member Profile to confirm your membership dues are paid through 2016. Member log-in is available on the menu bar on the top left of the ISOQOL homepage: www.isoqol.org.

RENEW MEMBERSHIP

Renew today to maintain an active membership in the International Society for Quality of Life Research through the end of 2016. Visit the Membership page of the ISOQOL website for dues rates and a link to the online form. (<http://www.isoqol.org/membership>)

BENEFITS OF MEMBERSHIP:

News & Publications

Complimentary online subscription to *Quality of Life Research*
Discounted print subscription to *Quality of Life Research*
ISOQOL's newsletter - *Quality of Life Quarterly*
Discounted access to PRO and QoL Instruments Database

Educational Programs

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Discounted Measuring What Matters registration
Basic Education Course (*Coming Soon*)

Leadership Opportunities

ISOQOL Special Interest Groups
ISOQOL Committees and Initiatives

Networking & Public Awareness

Access to ISOQOL Membership Directory and listserv
Participation in Special Interest Groups (SIGs) with access to Teamwork



JOIN A SPECIAL INTEREST GROUP (SIG) TODAY

Don't forget to update your SIG preferences when you renew your dues. Active participation in Special Interest Groups (SIGs) is open to all ISOQOL members. Update your SIG preferences on your member profile to make sure you are receiving information on special initiatives from the ISOQOL SIGs. You can update your SIG preferences at any time, simply by logging into your account on the ISOQOL website.

Current Special Interest Groups include:

Australia	Patient Engagement
Canada-PRO	Psychometrics
Child Health	QOL in Clinical Practice
Health Preference Research	Response Shift
Ibero America	Translation & Cultural Adaptation
Mixed Methods	United Kingdom & Ireland
New Investigators	

For more information on ISOQOL SIGs, visit the Special Interest Groups page of the website at <http://www.isoqol.org/special-interest-groups> or contact the ISOQOL Office at info@isoqol.org.





ISOQOL
23rd Annual Conference
19-22 October 2016
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**Abstract Submission
Deadlines:**

Workshop & Symposium
Submission—29 January

Oral & Poster Abstract
Submission—18 April

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