

# Quality of Life

QUARTERLY

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## PRESIDENT'S MESSAGE

*Claire Snyder, PhD, Johns Hopkins School of Medicine*



Dear Colleagues,

As I write this column, I'm a bit groggy after a rough night of sleep. I was awakened by

a nightmare about the Copenhagen meeting – something about my iPhone melting and my being really late (and unshowered) for my symposium presentation. But as soon as I woke up and reconnected with reality, I was reminded that there's nothing to worry about. Our Annual Meeting co-chairs Mogens Grønvold and Jakob Bjørner, along with their fantastic program committee, have planned an intellectually stimulating conference with the theme **"Successful Strategies for Dealing with the Challenges in Quality of Life Research."** Plus, our management group, EDI, always has everything organized and under control. So I went back to sleep, reassured by the promise of a great conference

and looking forward to a fun time in Denmark.

Speaking of great conferences, this summer we held our inaugural symposium **"Measuring What Matters."** Under the leadership of Sara Ahmed and Steven Blum, along with a great organizing committee, a group of about 85 of us gathered outside of Washington, DC, to discuss "Bridging industry regulatory needs with what matters to patients and clinicians." The plenary presentations were complemented by case study breakouts, which enabled everyone to actively engage with the topic. Notably, a number of the discussions and take-home points from the sessions emphasized the importance of ISOQOL's initiatives.

For example, there was much discussion of the need for education, and ISOQOL offers a suite of educational resources ranging from the **Annual Conference Workshops**, the **webinars** occurring throughout the year, and the recently released **Dictionary of Quality of Life and**

*Continued on page 2.*

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ISOQOL Members*  
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Ana Popielnicki, BA, USA

Send articles with subject line addressed "Newsletter Submission" to: [info@isoqol.org](mailto:info@isoqol.org)

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President's Message, Continued from page 1.

#### Health Outcomes Measurement

(ED: Nancy Mayo). We have also just launched an **Introductory Education Course**: This one-day course covers the "why" and "how" of using patient-reported outcomes (PROs) in research. It will be offered on Wednesday, October 19, in Copenhagen, but ISOQOL can also bring the course to you. All it takes is a minimum of 25 registrants, and ISOQOL can partner with your group to organize a session at your location. For more information, contact the ISOQOL office at [info@isoqol.org](mailto:info@isoqol.org).

Another hot topic that emerged from the "Measuring What Matters" symposium is the need for guidance on best practices. This is also an area in which ISOQOL has been active – and will be doing even more. In terms of the clinical trial context, which was the major focus of this year's "Measuring What Matters," an ISOQOL Task Force has developed ISOQOL recommendations for publishing PRO results from randomized controlled trials, in addition to partnering with the Consolidated Standards of Reporting Trials (CONSORT) group to develop an extension specific to PROs. The Task Force is currently working on recommendations for the PRO sections of protocols, to provide assistance upfront on how to conduct PRO studies successfully. ISOQOL will be participating in a survey to inform their work, so be on the lookout for a survey coming to you this fall. Of course, ISOQOL focuses on more than just clinical trials, and I encourage you to check out the website and explore the range of resources available to assist you in your work: <http://www.isoqol.org/research-publications/isoqol-publications>.

To further focus ISOQOL's efforts on meeting the needs of our members, and the field as a whole, we have recently formed the **"Standards & Best Practices Committee."** Under the able leadership of Susan Bartlett, Melanie Calvert, and Lena Ring, this newly initiated committee will start by developing an inventory of ISOQOL's previous and ongoing standard-setting efforts, and in collaboration with the Board, prioritize topics for future work. Beyond just writing guidance documents, the aim is to develop tools that will facilitate implementation in practice.

Finally, a key aspect of what we do in this field is publish our findings. *Quality of Life Research* is our long-standing publication, and we are pleased to announce the launch of the new *Journal of Patient-Reported Outcomes (JPRO)*. *JPRO* will build on and complement the success of *Quality of Life Research*. David Feeny and Dennis Revicki have agreed to serve as the inaugural *JPRO* editors, and along with Carolyn Schwartz and Frans Oort who edit *Quality of Life Research*, will provide our field high-quality publishing resources.

I look forward to discussing all of this in more detail with you during the annual meeting in Copenhagen; hopefully with a non-melted iPhone in-hand and a shower in my recent past. In the meantime, please feel free to send feedback to [ISOQOL@listens](mailto:ISOQOL@listens).

Sincerely,

Claire Snyder, PhD, ISOQOL President





# 30+ years experience in clinical outcomes assessment (COA) to support labeling and promotional claims



<b>70+</b> Scientific staff, 80% with advanced degrees	<b>800+</b> Peer-reviewed publications since 2000	<b>100+</b> Number of novel PRO instruments designed and implemented
<b>EXPERTISE</b> invited experts for advisory boards; task force/committee participation; regulatory expert presence at FDA	<b>100+</b> PRO evidence dossiers prepared and submitted to support PRO endpoint use	<b>INNOVATION</b> Created the first PRO consortium (exactproinitiative.com); first FDA and EMA qualified PRO

## Evidera Presentations During ISOQOL

### Short Course

Introduction to Quality of Life and Other Patient Reported Outcomes: Theory, Measurement and Applications  
*Valderas JC, Lenderking WR*

### Workshops

An Introduction to Health-Related Quality of Life Assessment  
*Gelhorn H, Wyrwich K*

Clinical Outcomes Assessment in a Multi-Cultural Context: Measurement Challenges and Solutions - A Collaborative Workshop by the Psychometric and Translation & Cultural Adaptation Special Interest Groups  
*Hudgens S, Regnault A, McLoud L, Martin M, Eremenco S*

Concept Elicitation for the Development of Clinical Outcome Assessments (COAs) - Qualitative Methodological Approaches for Data Collection, Analyses and Reporting  
*Skalicky A, Hareendran A, Magasi S*

### Oral Presentations

Evaluating Options for Presenting Health States from PROMIS Item Banks  
*Hanmer J, Feeny D, Fischhoff B, Hays R, Hess R, Pilkonis P, Revicki D, Roberts M, Tsevat J, Yu L*

Psychometric Properties of the Migraine Physical Function Impact Diary (MPFID)  
*Kawata AK, Hsieh R, Hareendran A, Bender R, Shaffer S, Sapra S, Desai P, Widnell K, Bayliss M, Buse DC, Revicki D*

Translation and Linguistic Validation of the Migraine Physical Function Impact Diary (MPFID) for Use in 25 Countries  
*Oko-osi H, Arnold B, Savic L, Desai P, Hareendran A, Mannix S, Sapra S, Eremenco S*

### Posters

A New Symptom-Specific Patient-Reported Outcome Measure for Patients with Soft Tissue Sarcoma  
*Rentz A, Skalicky A, Ghate S, Chawla SP, Conley AP, Villalobos VM, Perez JR*

An Adaptation of the Profile of Mood States (POMS) for Use in Adults with Phenylketonuria (PKU): Development of the PKU-POMS  
*Bacci ED, Wyrwich KW, Bender R, Gries K, Chen Y, Jain R, Konkol L, Merilainen MJ, Weng H*

Assessing the Content Validity of the Investigator-Rated ADHD Rating Scale Version IV (I-ADHD RS-IV) Instrument for Use in Adults with Phenylketonuria (PKU)  
*Wyrwich KW, Gries K, Al-Jassar G, Bacci ED, Chen Y, Jain R, Konkol L, Merilainen MJ, Weng H*

Psychometric Evaluation of the ANMS Gastroparesis Cardinal Symptom Index-Daily Diary  
*Revicki D, Parkman H*

Psychometric Properties of the FAACT Additional Concerns Subscale (A/CS) for Measurement of Anorexia in Patients with Non-Small Cell Lung Cancer  
*Gelhorn HL, Gries KS, Duus EM, Bourne RK, Friend JE, Speck RM, Leidy NK, Cella D*

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## FROM THE EDITOR'S DESK

By: Ana Popielnicki, BA, TransPerfect



Dear ISOQOL family:

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

our wonderful Annual Conference is quickly approaching, our Executive Office and leadership are dedicating their energy to enthusiastic preparations and finalizing details, to ensure we all enjoy and benefit from the fantastic program scheduled for this conference. In that regard, we figured we'd bring to you a short and sweet issue, with pertinent information about the AC.

In her President's Message, Dr. Snyder shares with us (besides an alarming, totally unlikely nightmare

situation) her usual enthusiasm and optimism for the conference and all planned activities. She also touches on the recently held inaugural symposium, "**Measuring What Matters**", and the various educational resources the Society makes available to its members – take advantage of the open channels of communication, and make sure to send questions or feedback to [ISOQOListens](#).

In this issue you will also get to meet the new members of the Board of Directors, and our congratulations to Dr. Carolyn Schwartz, recipient of the 2016 President's Award!

The rest of the issue has important information on the registration and logistics for the Annual Conference, as well as the different events our Scientific Committee has planned for us during the meeting. Please check out the helpful information

about Copenhagen that can also be found here.

Please send any questions, comments, or submissions for the 2016 Fall issue to [info@isoqol.org](mailto:info@isoqol.org) with "Newsletter" on your subject line. We will be publishing our last issue of the year after the conference. I look forward to see old friends and meet new ones next month – safe travels and see you in Copenhagen!



Ana Popielnicki  
Editor



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### PRESIDENT-ELECT



**Jose M Valderas, MD PhD MPH**  
University of Exeter  
Exeter, United Kingdom

### INCOMING BOARD MEMBERS



**Ida J. Korfage, PhD**  
Erasmus MC  
Delft, Netherlands



**Zoe Winters, PhD FRCS FCS**  
University of Bristol  
Bristol, United Kingdom



### CONGRATULATIONS!

### 2016 PRESIDENT'S AWARD RECIPIENT

**Carolyn E. Schwartz, ScD**  
President and Chief Scientist  
DeltaQuest Foundation, Inc.  
Massachusetts, United States



## 23<sup>RD</sup> ANNUAL CONFERENCE REGISTRATION INFORMATION

**REGISTER HERE:** [HTTP://WWW.ISOQOL.ORG/2016CONFERENCE/REGISTRATION](http://www.isoqol.org/2016conference/registration)



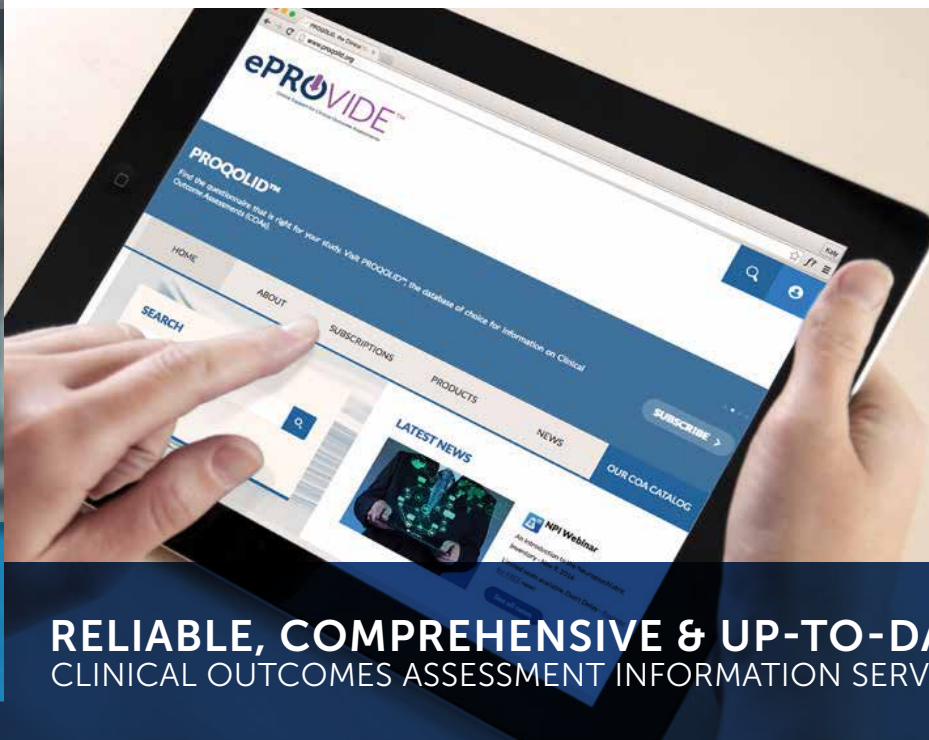
Registration fees not only provide access to the Scientific Program of plenary sessions, oral and poster presentations, and symposia; but there are several exciting highlighted events that are included. These highlighted events can be attended at no additional fee, but pre-registration is required.

### 23RD ANNUAL CONFERENCE HIGHLIGHTED EVENTS

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

- **Industry SIG Symposium** (Formerly Industry Advisory Committee - IAC)  
Wednesday, 19 October, 4:30 PM - 6:00 PM  
*Incorporating the patient voice in benefit risk assessment and regulatory/HTA decision-making*
- **Welcome Reception**  
Wednesday, 19 October, 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, 20 October, 6:00 PM - 6:30 PM  
*Advice for New Investigators in Quality of Life Research*  
*Successful strategies for dealing with challenges in research and career paths*  
Speakers:
  - Nancy E. Mayo, PhD, McGill University Health Centre, Montreal, QC, Canada
  - John E. Ware, PhD, University of Massachusetts Medical School, Worcester, MA, United States





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# Network & Explore Copenhagen

## Join the ISOQOL Dine-Arounds



*A 2015 Annual Conference Dine-Around group enjoying seafood in Vancouver.*



*A classic take on a Scandinavian dish, one of the many options available at several of our 2016 Dine-Around locations.*

**FRIDAY, 21 OCTOBER 7:00 PM**

**VARIOUS LOCATIONS AROUND COPENHAGEN**

Individuals that participate in the ISOQOL Dine-Arounds will be placed in a group of eight people. Tables will be reserved for all groups at unique restaurants around Copenhagen.

If you choose to participate in the optional Dine-Around event, you will be placed in a group based on personal preference and availability. On Friday evening, 21 October, after conference sessions conclude, you will meet with your designated group and walk or take a taxicab together to your specific dining location. All dine-around participants are responsible for paying for their own meal.

This is a great opportunity to visit with fellow members of the ISOQOL and Health Related Quality of Life Research community, as well as experience one of the wonderful restaurants Copenhagen has to offer!

If you are interested in being a part of this year's dine-around event, please fill out the survey below! Space is limited and on a first-come, first-served basis. Sign-up for a Dine-Around group via this survey: <https://www.surveymonkey.com/r/S8T9K6K>





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24<sup>TH</sup> ANNUAL CONFERENCE

18–21 October 2017  
*Philadelphia, Pennsylvania*

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# SAVE THE DATE



## *Abstract Submission Deadlines:*

WORKSHOP & SYMPOSIUM SUBMISSION — 30 JANUARY  
ORAL & POSTER ABSTRACT SUBMISSION — 17 APRIL

