

# Quality of Life

QUARTERLY

## IN THIS ISSUE...

- PAGE 1** President's Message
- PAGE 3** From the Editor's Desk
- PAGE 3** 24<sup>th</sup> Annual Conference - Submissions
- PAGE 4** 2016 Annual Conference in Review
- PAGE 4** Call For Reviewers
- PAGE 5** New Investigators Special Interest Group
- PAGE 6** Renew your 2017 Membership Dues
- PAGE 7** Members' Corner

## PRESIDENT'S MESSAGE

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



Dear Colleagues,  
Those of you who read my Fall column might recall that I was suffering from a stress nightmare prior to our annual conference. I am so pleased to report that the actual meeting exceeded my wildest dreams. As a result of the expert planning of our Annual Meeting co-chairs, Mogens Groenvold and Jakob Bjørner, the 2016's meeting's focus on **"Successful Strategies for Dealing with the Challenges in Quality of Life Research"** was truly a success. We had 610 registrations – the most in recent history – and everyone was engaged in the plenary sessions, oral abstract presentations, and poster displays. Plus, the collegiality and "hygge" was evident during the coffee breaks and social events. Putting the conference together was a team effort, and I'd also like to thank the program committee, including Jordi Alonso who chaired the symposia;

Cindy Gross, María Santana, and Juliana Bredemeier, for coordinating the mentor/mentee session; and Nancy Mayo and Skye Barbic for organizing the workshops. I also want to recognize all who served as judges for the awards and scholarships. Last, but certainly not least, our management team at EDI kept everything on track – special thanks to Colleen Pedersen, Michelle Holm, and Marjorie Struck.

The Annual Meeting was an opportunity for us to reflect back on all of our activities over the past year and to plan for the future. In the President's Address, I had the opportunity to review our efforts to **Measure What Matters, Make Measurement Meaningful, and Make Sense of Methods**, topics which have also been discussed in these newsletter columns. During the Members Business Meeting, we reviewed some of our organizational and governance initiatives, including unveiling ISOQOL's refined governance structure. This refined organizational structure, the culmination of a two-year effort, involved multiple steps, including defining Committees, Task Forces,  
*Continued on page 2.*

VOLUME 22 ISSUE 4  
*Newsletter for*  
*ISOQOL Members*  
DECEMBER 2016





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

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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.*

and Special Interest Groups (SIGs), as well as organizing these various entities into different Councils based on topic area. Specifically, each Committee, Task Force, and SIG now have a Board Liaison, and those Board Liaisons operate as part of a Council. The four councils are Executive, Education, Methods & Standards, and Regional Networks. The hope is that this refined governance structure will improve coordination between Committees/Task Forces/SIGs and the Board, as well as coordination across Committees/Task Forces/SIGs.

In addition, each entity now has a profile on the ISOQOL website that outlines its charge, membership, and terms. Moving forward, each year there will be a call for volunteers for opening Committee positions, and we hope that this will be just one way for members to become more involved. As I summed up in my comments at the meeting, getting involved in ISOQOL is a simple two-step process: (1) volunteer to do something and (2) do it.

There were also several important new initiatives at this year's Annual Meeting. We had the inaugural presentation of our **Introductory Education Course**, which covers the "why" and "how" of using patient-reported outcomes (PROs) in research. As a reminder, this course is a "traveling show" and can be conducted onsite for groups of 25 or more. For more information, contact the ISOQOL office at [info@isoqol.org](mailto:info@isoqol.org). We also were excited to launch our new **Journal of Patient-Reported Outcomes** and to introduce membership categories for our **Patient Research Partners**.

Looking ahead, we plan to build on these efforts. ISOQOL's current strategic plan is nearing the end of its

lifecycle, and the Board has embarked on a process to develop a Strategic Plan for the next 5 years. You likely have seen the survey that has been circulated to get your input on the role of ISOQOL for its members and the field as a whole. This is just one part of a multi-stage effort that we are undertaking as part of this process. The Strategic Planning Committee (comprised of the Board, a New Investigator representative, a Past President representative, and key staff) will be meeting in April 2017 to review the input received from members, key opinion leaders, and the Board/staff to chart ISOQOL's course for the coming years. There will be an opportunity for member review and comment, and we look forward to discussing the plan more at next year's annual meeting.

In closing, I want to recognize the incredible Board that is serving ISOQOL. Our organization is fortunate to have such a dedicated, thoughtful, and engaged group of leaders, and I am so honored to be a part of this group. Special thanks to retiring Board members Melanie Calvert and Rick Sawatzky, and particular recognition for Past-President Galina Velikova, who just completed her 4-year term. We look forward to working with new Board members Ida Korfage, Zoe Winters, and President-Elect Chema Valderas. As always, comments and feedback are welcome at [ISOQOLists](mailto:ISOQOLists@isoqol.org)

Sincerely,

Claire Snyder, PhD, ISOQOL President



## FROM THE EDITOR'S DESK

By: Ana Popielnicki, BA, TransPerfect



Dear ISOQOLers:  
Greetings from the frozen dunes of Cape Cod,

Massachusetts! And by frozen, I mean literally – the Northeast of the US has gone directly from nice 50 degrees to Arctic blast mode in just one day. But I digress! I am pleased to bring to you the last issue of the year for our *Quality of Life Quarterly*. It was great seeing you all and making new friends during our Annual Conference in Copenhagen – read our staff and President's recap of the conference in this issue.

The year 2016 has been one of many challenges, but also of great growth for our Society. Dr. Snyder touches upon the exciting educational opportunities, projects, and initiatives in her traditional message.

Check out the news on our staff changes, the call for reviewers for next year's conference, and important information on membership and SIGs – renew your membership and get involved!

We also have our always enthusiastic New Investigators SIG article – learn about their activities during the conference, and consider signing up for future Mentor/Mentee relationships. Last but not least, we extend a warm welcome to our new members, a list of which you will find in the Members' Corner.

Please send any questions, comments, or submissions for the first 2017 issue to [info@isoqol.org](mailto:info@isoqol.org) with "Newsletter" on your subject line. In the meantime, stay warm (or cool, if it's summer where you are), and have a wonderful holiday!



Ana Popielnicki  
Editor



### 24<sup>TH</sup> ANNUAL CONFERENCE - SUBMISSIONS

18-21 October 2017 • Philadelphia, Pennsylvania, United States

#### Submission Deadlines:

Workshop & Symposium Abstracts - 30 January

Oral & Poster Abstracts - 17 April\*

\*Oral & Poster Abstract submission opens in March 2017

[Submit Workshop/Symposium Proposals Today!](#)

### ISOQOL STAFF CHANGES

Marjorie Struck leaves ISOQOL to pursue a career in teaching. We wish her the best in her new role and know she will make a true difference in her students' lives. Jorie will truly be missed for her dedication, enthusiasm, and warmth. We thank her for her diligence and support of ISOQOL.

We are pleased to announce that Samantha Machart will move into the open position. Samantha is currently working at EDI in a communications and marketing role. We are excited to welcome Samantha to the ISOQOL team.

## 2016 ANNUAL CONFERENCE IN REVIEW

ISOQOL Staff



*Copenhagen offered attendees beautiful views, unique architecture, and delicious cuisine.*

Copenhagen, capital of the happiest country in the world, recently served as the host city for the 24th Annual ISOQOL Conference! The Conference took place from 19-22 October 2016, at the Radisson Blu Scandinavia Hotel, Copenhagen. Situated on the river, the hotel boasted a stunning view and was just minutes away from the Strøget pedestrian area, Tivoli Gardens, and the Nyhavn waterfront area.

Scientific Committee Co-Chairs, Mogens Groenvold, MD PhD and Jakob B. Bjørner, MD PhD, are to be commended for their passionate work and dedication in coordinating an excellent program centered around the theme “Successful strate-

gies for dealing with the challenges in quality of life research.”

While the weather was cool, the conference kicked-off with a warm welcome on Wednesday night and was full of networking opportunities, throughout the week. The Conference ended with just as much style as it began, as the Closing Dinner was held at the Tivoli Gardens, a must-see Copenhagen amusement park, decorated for Halloween.

The Friday night “Dine-Arounds,” were another very successful feature of the 2016 Annual Conference. Several restaurants around the city hosted groups of seven or more conference attendees, as they dined together, networked, and enjoyed an evening of socializing and good company.

Final conference registration was at an all-time high with 598 registra-

tions and 228 first time ISOQOL attendees. To date, this has been one of our most well-attended conferences!

In total, there were 564 abstracts submitted as either oral, poster, workshop or symposiums. 119 abstract submissions were accepted as Oral Presentations; 361 were accepted as posters.

To view some of the photos, discussions, and insights that were shared by attendees at the conference, search the social media hashtag, #ISOQOL16.

Thank you to all who took the time to complete the post-conference evaluation, and congratulations to Ligia M. Chavez, PhD, the winner of the drawing for the Amazon.com gift card.



*The various plenary sessions at the conference were very well attended and featured top-notch speakers from around the world.*



*Attendees enjoy appetizers, drinks, and good conversation at the Mentor/Mentee Reception.*

### CALL FOR REVIEWERS:

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

To become a reviewer, please sign-up via the ISOQOL 2017 Membership Dues Application or email ISOQOL at [info@isoqol.org](mailto:info@isoqol.org) to participate. View the AC17 Reviewer Webpage for more information.

## NEW INVESTIGATORS SPECIAL INTEREST GROUP

*Manraj Kaur & Kathrin Fischer (Co-chairs) on behalf of the Special Interest Group 'New Investigators'*

The New Investigator SIG welcomed new and returning members at the annual ISOQOL conference on October 20, 2016 for our annual SIG meeting. The agenda of the meeting highlighted the Teamwork platform, and reviewed the academia vs. industry vs consulting career choices with experts. The meeting was well attended by new investigators and the group engaged in a tutorial on "How to use Teamwork" for networking, collaboration, and posting – as well as reviewing – vacancies. The session led by Kathrin Fischer reviewed how to create a profile on Teamwork, how to review SIG updates, view calendar for upcoming activities, and send private and public messages to other SIG members on the platform. The new investigators were highly encouraged to create a profile on Teamwork.

The Teamwork tutorial was followed by a panel, with one representative each from Academia, Consulting and Industry. This session was requested by several members during the 2015 ISOQOL meeting in Vancouver, Canada. Dr. Feng Xie (Academia, McMaster University),



Dr. Catherine Bottomley (Consulting, pH Associates) and Dr. Cicley Kerr (Industry, Janssen UK) provided valuable, first-hand insight on the decision to choose their respective careers, their roles and responsibilities, and the exciting and challenging parts of their current position. On behalf of the NI SIG, we would like to thank all three speakers for sharing their experiences with the New Investigators.

The popular session "Tricks of the Trade", organized by the NI SIG, has become an integral part of the ISOQOL annual conference for new and experienced investigators. This year we were fortunate to have Drs John Ware and Nancy Mayo, who shared their strategies for dealing with challenges in research and career paths in a captivating panel discussion.

The day concluded with the Mentor/Mentee program reception, a unique initiative of ISOQOL where the students or new investigators are paired with Mentors to network, and share experiences and advice over a glass of wine!

We look forward to the upcoming year and seeing everyone in Philadelphia. Keep an eye out on Teamwork for the NI SIG's upcoming events.





# Renew your 2017 Membership Dues

It's dues renewal time, don't let your member benefits lapse.

2017 dues valid through 12/31/2017

We invite you and encourage you to renew your ISOQOL membership for 2017! Renewing ensures that you'll stay connected with the Society and your peers. It also gives you the chance to engage with the cutting edge work being done by our members, and prevents your member benefits from lapsing in 2017.

## MEMBER BENEFITS

As an ISOQOL Member, you will have access to a plethora of resources and member discounts, including:

### Reduced Member Rates for the Following:

- Online Education and Archived Webinars
- Annual Conference Registration
- Measuring What Matters Symposium Registration
- Introductory Education Course Registration
- Member Rate for PRO and QoL Instruments Database
- Member Submission Rate for the Journal of Patient Reported Outcomes (JPRO)
- Member Print Subscription Rate for the Quality of Life Research Journal (QLR)

### Access to the Following Resources & Opportunities:

- All ISOQOL Quality of Life Quarterly Newsletters
- Complimentary Online Subscription to the Quality of Life Research Journal
- Access to the ISOQOL Membership Directory
- Access to the Full Listing of Jobs on the ISOQOL Job Board
- Access to the ISOQOL "Members-Only" Webpage with Various Resources
- Participation in Special Interest Groups (SIGs) and Access to the ISOQOL Teamwork Page.

### An active and engaged membership is the lifeblood of ISOQOL.

We appreciate all that you do to support ISOQOL and hope that you will take advantage of the opportunities available to you, as a member. If you have any questions about ISOQOL, the benefits of membership, or opportunities for involvement in the Society, please do not hesitate to contact us at [info@isoqol.org](mailto:info@isoqol.org) or by phone at +1 (414) 918-9797.

## HOW TO GET INVOLVED:

- **Serving on a Committee, Task Force, or Panel:** Each year, ISOQOL asks our members to help in various roles. ISOQOL has a number of committees, task forces, and panels that seek volunteers each year. Renew your membership so you don't miss our calls for volunteers, many of which will go out at the beginning of 2017.
- **Joining a Special Interest Group (SIG):** Being involved in an ISOQOL SIG is one of the best ways to make new connections within the society, your specific area of research, and geographically. SIGs are specialized sub-groups of ISOQOL members, organized around similar interests, methodologies, populations, and geographic locations. Once you've joined a SIG, you may have many more opportunities to get involved. We encourage members to serve in SIG leadership positions as co-chairs or secretaries. We also hope that members get involved in the SIG's Annual Conference sessions and activities and collaborate through our specialized SIG online project management program Teamwork.
- **Reviewing Annual Meeting Submissions:** Being part of an international research society means that you have a direct connection to a wide range of expert researchers, clinicians, and patient research partners. Each year, ISOQOL takes advantage of the collective expertise of our members and enlists numerous volunteers to review abstract, symposium, and workshop submissions for the Annual Conference. When you renew this year, be sure to indicate your willingness to serve as a reviewer.

### WELCOME TO OUR NEWEST ISOQOL MEMBERS

Line Andersen

David A. Andrae, PhD

Dwana M. Bush, M.D.

Zoe Clancy, PharmD, MS

Jonathan Comins

Sheena Dempsey, BSc

Carolyn E. Eberle, MPH

Nicola Germain, BA/MA

Melanie Hawkins, BA, BHSc, MPH

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