



International Society for Quality of Life Research

Volume 13 Issue 1

Newsletter for ISOQOL Members

August 2008

PRESIDENT'S MESSAGE

Donna Lamping, PhD
London, UK



15 Years Old and Eager to Leap

As ISOQOL celebrates its 15th year, it is much like any 15-year-old adolescent eager to leap into young adulthood. Motivated by a keen urge to spread one's wings, flex one's muscle, make one's mark on the world, this 15-year-old Society is at a crossroads in terms of its future growth and development, with many exciting possibilities ahead.

The key question being considered by the Board of Directors as the Society enters this new phase is how best to move from surviving to thriving. At the April Board meeting, our focus was on developing a strategic plan to guide the next stage in the Society's evolution. We considered proposals for several new initiatives, each fuelled by the commitment and enthusiasm of a dedicated group of "movers and shakers" who are helping to usher us into this next phase.

Among these were proposals from the Fundraising Committee (Chair: Rick Berzon) for further investment in our fundraising strategy, the Communications Committee (Chair: Jordana Schmier) for a re-design of the website, the Translation

and Cultural Adaptation SIG (Chair: Katrin Conway) for the development of a translation certification programme, the Industry Advisory Committee (Chair: Bill Lenderking) for a symposium on PROs and reimbursement at the annual meeting in Montevideo, and the Strategic Partnerships (Chair: Carol Moinpour) and Chapters/Cross Borders (Chair: Madeleine King) Working Groups for sponsorship of joint sessions with other sister Societies. Hats off, indeed, to the tireless volunteer efforts of these dedicated members in helping the Society to spread its wings!

The Society: What's New?

Our eagerness to thrive has resulted in a number of new initiatives for growth during the past year. In addition to the developments I reported in the December 2007 newsletter, recent Board-approved initiatives include:

- To advise the Board on specific matters related to strategic planning, we have established the *Advisory Council of Past Presidents* (ACPP Chair: David Feeny; Co-Chair: Sharon Wood-Dauphinee). The ACPP, which includes all 11 ISOQOL Past Presidents, has already provided invaluable contributions to Board deliberations about the future development and management of fundraising activities, and is currently prospecting further initiatives for the future growth and development of the Society.
- In considering new strategic directions, the Board identified two key areas of Society activity which would benefit substantially from further focus, review and development and has appointed two new committees to undertake this work:

- *Meetings Policy, Planning and Evaluation Committee* (Chair: Dorcas Beaton), to assume responsibility and provide oversight for all aspects of meeting policy, planning and evaluation, e.g. review of annual meeting policies (frequency, timing, location, type of venue), annual meeting evaluation, etc.

- *Ad Hoc Committee on Governance* (Chair: Cindy Gross), to produce a formal governance policy document outlining systems for controlling, monitoring and auditing Society activities.

- We are updating the Society's *Mission Statement* to reflect more clearly our efforts to reach out to the clinical community and bridge the gap with methodologists.
- To stimulate and foster scientific partnerships between the Society and members working in industry, the *Industry Advisory Committee* (Chair: Bill Lenderking) has planned a special symposium at the 2008 annual meeting on incorporating the views of patients and society into reimbursement decisions. See Bill's article for more details.

President, continued on page 3

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Newsletter Editor
Kathleen Wyrwich, PhD, USA

Send articles and/or suggestions to:
info@isoqol.org

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ISOQOL Executive Office
6728 Old McLean Village Drive
McLean, VA 22101-3906 USA
PH: 703-556-9222
FAX: 703-556-8729
info@isoqol.org
www.isoqol.org

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NEW OPPORTUNITY TO LEND A HAND ... AND AN EAR!

Rick Berzon, DrPH, USA

ISOQOL's Fundraising Committee was reinvigorated during the recent April mid-year Board Meeting. And we are looking to increase our committee's membership to help the Society reach its goals and meet its fiduciary obligations.

Current members Rick Berzon (ISOQOL Treasurer and Committee Chair), Bill Lenderking (Industry Advisory Committee Chair) and Juan Dapuetto (2008 Annual Meeting Co-Chair), with support from Sarah Shiffert (Degnon Associates), have already sent out our annual letters of solicitation from our master list of past and potential contributors.

One of the key tasks of our committee members is to followup these letters with telephone calls directly to those individuals who have either made financial contributions to ISOQOL in the past; or who may be willing to make a contribution to our Society this year. Most of the contributors hail from private sector companies.

We count on our committee members to assist the Society in its efforts to effectively resource our activities whether

these take place at our annual meeting, or in the course of moving ISOQOL and its strategic activities forward. By making telephone contact with existing and potential contributors, we hope to continue our associations with existing businesses and to build new, long-term relationships with people who are interested in supporting ISOQOL's mission, goals and outreach efforts around the world.

We committee members with past experience in carrying out these activities provide coaching and a script to those who volunteer for this effort; and we are available to answer questions as to how best to negotiate your conversations with people you may not know personally.

In addition, suggestions regarding individuals at companies we may have missed or overlooked are always helpful; as are new ideas and approaches regarding fundraising for ISOQOL.

If you are able and willing—and not especially shy—to help us in our tasks in support of these efforts, we would greatly appreciate your help. Please contact either Sarah Shiffert (sarah@degnon.org) or Rick Berzon (rick.berzon@comcast.net) to volunteer.



NEW INVESTIGATORS SPECIAL INTEREST GROUP (SIG)

Are you a:

- full-time student
- post-doctoral researcher who received your doctorate within the past five years
- new investigator who has worked as an independent researcher in the QoL field for no more than five years

Please join the New Investigators SIG!

To find out more about what opportunities the New Investigators SIG can offer you, please contact:

Elsbeth Bloem: e.f.bloem@amc.uva.nl
Sandra Nolte: sandra.nolte@mh.org.au

Or check the link Special Interest Groups on ISOQOL's website: www.isoqol.org

President, from page 1

- The Education Committee (Chair: Carolyn Gotay) is revising our *Scholarships Policy* to broaden eligibility criteria in order to open up this opportunity to more of our early career members.
- To promote further growth and development of *Special Interest Groups (SIGs)*, and as a result of a recent survey of SIG Chairs by an Ad Hoc Task Force (Chair: Lena Ring; see article on page 5 for more details), we have implemented a new policy to provide additional resources for SIG activities and have organised a meeting of SIG Chairs at the 2008 annual meeting.
- To sustain our growth in membership, the *Membership Committee* (Chair: Joanne Greenhalgh) is carrying out an in-depth analysis of membership trends.

Kudos To....

It is with great personal pleasure that I announce that the recipient of the 2008 President's Award is Professor David Cella, for his prolific and influential contributions to research and education in health-related quality of life assessment over an extraordinary career. The Award will be presented at the Montevideo annual meeting, where you will hear more about Dave's impressive accomplishments and we look forward to his President's Award address.

Thanks to the impressive efforts of Ron Hays and the editorial team, the 2007 *Quality of Life Research* Impact Factor has risen to 2.466. No wonder the journal continues to expand its international scientific influence - each issue continues to stimulate and inspire.

Looking Before We Leap

The challenge when facing the leap into our next phase of development is to maintain a solid management and financial base to ensure that good ideas can be effectively implemented and sustained. The increased activity on many fronts

over recent months, for example, has led to a substantial increase in time and funding resources required to manage these initiatives. The Board is therefore taking a hard look at how best to meet our keen desire to thrive with current resources and, in particular, through planning for future growth.

In this regard, the Society has benefited substantially from the expertise of Capital Development Strategies, whose well-received report to the Board on fundraising offered a number of concrete and promising directions for us to pursue. A key objective over the coming months is to expand our fundraising activities by bringing in professional leadership and support services to provide strategic and operational expertise in this area. We are working closely with Degnon to consider various options for enhancing our management services, particularly with respect to fundraising activities.

Montevideo Here We Come!

Tango, parillada, beaches and gauchos here we come! It won't be long before we achieve another milestone in the Society's 15-year history with our first annual meeting in South America this October. Laura Schwartzman and Juan Dapuzo (Co-Chairs), with Sarah Shiffert's widely admired magic touch, have put together an excellent programme. We are particularly pleased that the President of Uruguay, Dr. Tabaré Vázquez, has agreed to give a plenary address. President Vázquez, an oncologist, received the World Health Organization Director General's Award in recognition of his leadership on tobacco control in Uruguay. Check the ISOQOL website for details about the scientific programme, as well as a plethora of helpful information to help you plan your visit and get the most out of this opportunity to explore a most amazing part of the world. I hope to see many of you in Montevideo!

The Big Easy

No, I'm not talking about what it's going to be like for my successor, our esteemed next President Neil Aaronson, but rather

the location of our 2009 annual meeting! After carefully reviewing several options in Europe, and mindful of the worrying effect of the strength of the euro on members' pocketbooks, the Board made the decision to have our 2009 annual meeting in North America rather than Europe. So, think jazz, Mardi Gras, the French Quarter, gumbo...yes, we're all very excited about heading to New Orleans in 2009!

Glances Backward and Forward

Reflecting over the past year, what has struck me most in my role as President is a keen awareness of how many folks among you are making a real difference to ISOQOL. The commitment that so many of you have shown to the Society over many years, as well as the continual flow of new blood contributions from many of our more recent members, is what makes our small but beautiful ISOQOL that special professional Society to which we all want to belong and remain actively involved. I'd like to say a huge thanks for your enthusiastic support and fresh ideas during the past year. I am particularly grateful to the efforts of the Executive Committee, the Board and Committee Chairs, and Degnon in helping steer the Society in this transition period from adolescence to young adulthood.

Looking ahead, I would like to express my sincere thanks to those of you who so graciously agreed to stand in the upcoming Board elections. You are the Society's lifeline into what promises to be an exciting future ahead. I look forward to my continuing and, as always, stimulating work on the Board's Executive Committee, and wish Neil Aaronson the very best as he prepares to take over the reigns of this eager adolescent.

Lastly, I would like to take this opportunity to thank Kathy Wyrwich for her superb work as Newsletter Editor. For the past 3 years, Kathy has done such a great job of keeping us all in the loop and waiting in anticipation for the next edition of the newsletter...



ISOQOL SPECIAL SYMPOSIUM ON PATIENT REPORTED OUTCOMES (PROS) AND REIMBURSEMENT DECISION MAKING

Bill Lenderking, PhD, USA

Economic evaluation based on a cost per quality adjusted life year is central to reimbursement decision making in many countries (Australia, Canada and UK) and emerging in many more. Recent years have seen many patient-reported outcomes (PROs) developed for measuring both health-related quality of life in clinical trials and for utility assessment for cost-effectiveness analysis. Will these two streams of research come together like the Uruguay and Parana rivers to form a broad river like the Rio de la Plata, or will they remain relatively separate, in some respects diminished by failing to fully take advantage of what the other has to give? In order to stimulate discussion and research into the intersection between PRO assessment and economic evaluation, the Industry Advisory Council

(IAC) of ISOQOL has put together a symposium to be held just before the ISOQOL Annual Meeting in Montevideo. During this exciting session featuring internationally recognized experts as well as speakers expert in the Latin American context, we will explore how these two streams of research can inform and support each other i.e., how a range of new PROs can be used to measure utilities, and how these relatively new methods might affect reimbursement decisions. We will explore both local Latin American issues and issues of relevance in Europe, North America, and elsewhere.

One key theme of the symposium is the issue of how well existing methods and measures are able to measure health-related quality of life accurately. We will

also explore the extent to which economic evaluation should be guided by what is important to patients compared with what is of importance to society.

All conference registrants are welcome to attend this symposium. We particularly hope that reimbursement authorities, health care decision makers, pharmaceutical company representatives, and those who develop evidence for the value of medicines will find something stimulating in the program and will choose to attend and stay for the duration of the ISOQOL conference! More details about this exciting program will follow via email to ISOQOL members, so be on the watch for these messages and plan to attend.



ISOQOL MEMBERSHIP BENEFITS

Know someone who might benefit from ISOQOL membership? Share these benefits with them and encourage them to join today!

- * Online Membership Directory
- * Online access to *Quality of Life Research* Journal at no additional charge!
- * Reduced subscription rate for paper copy the *Quality of Life Research* Journal
- * Participation in a variety of Special Interest Groups
- * Reduced conference registration rates
- * Opportunity to present and hear cutting edge research presentations and posters
- * Opportunity to have special interest group meetings at the annual meeting
- * Access to the “Members Only” section of the ISOQOL website – an invaluable resource tool!
- * Participation in a variety of committees
- * Participation in the ISOQOL listservs - email communication with other QOL experts
- * Exposure to and participation with other professionals involved in quality of life research activities
- * Discount on annual subscriptions to the Quality of Life Instruments Database, offered by MAPI Research Institute
- * Complimentary receipt of newsletters
- * While supplies last: Quality Metric’s 9-CD set “Understanding Health Outcomes: An Accredited Educational Series on CD-ROM. Series One: Health Status: Concepts, Measures, and Applications”

ISOQOL, 6728 Old McLean Village Drive, McLean, VA 22101 USA 703-556-9222; fax: 703-556-8729; email: info@isoqol.org

2008 ISOQOL SIG SURVEY

Cynthia Gross (gross002@umn.edu)
Lena Ring (lena.ring@farmaci.uu.se)
Board SIG liaisons

Special interest groups or SIGs provide ISOQOL members with opportunities to meet investigators from around the world who share their interests. ISOQOL members have formed 14 SIGs which address a wide range of topics and populations. The ISOQOL Board recently conducted a survey of SIG Chairs and co-Chairs in order to learn more about SIG activities and determine how to best support SIGs and facilitate their role in achieving the mission of ISOQOL. Survey questions addressed SIG membership, objectives, current and planned activities, organizational structure and financial support. Eleven SIG chairs and co-chairs responded, representing 6 different SIGs i.e., Translation and Cultural Adaptation, QOL in Clinical Practice, Response Shift, New Investigators, HIV/AIDS and Statistical Analysis Methods.

Membership, Activities and Objectives

SIGs vary in size, from 4 to more than 60 members. Most SIGs reported that only 1/3 to 1/2 of their membership are actively engaged. Several SIGs hold regular email or conference calls during the year, and a few have formed working or coordinating groups, mounted collaborative writing projects or held workshops or conferences. Most SIGs have annual meetings in conjunction with the ISOQOL annual meeting. Some of the SIGs have well developed, specific objectives (i.e., the Translation and Cultural Adaptation and Response Shift SIGs) while others have a broad or general interest without very specific objectives. Overall, the SIG objectives correspond to their titles (e.g., the New Investigator SIG supports new investigators in sharing ideas and networking, seeks to liaise with experienced senior investigators). Several SIGs reported providing Web-based informational resources (e.g., reading list, seminal articles, guidelines, etc.) to their membership as an objective.

Support

The survey asked about SIG needs and the level of support the SIG currently receives from ISOQOL. SIGs currently perceive moral support from ISOQOL but seek more tangible support for things like an updated Web page, help organizing meetings and funding for teleconferences. SIGs want ISOQOL to provide more advertisement and coffee for SIG meetings, and facilitate correspondence among SIG members during the year. Additional Web, teleconference, e-communications, SIG newsletters and meeting support were viewed as ways ISOQOL could enhance the SIG chairs' abilities to revitalize and engage SIG membership. About half of the respondents would like direct financial support from ISOQOL for both ongoing communications and specific SIG initiatives. Some SIGs have obtained external support for their activities. Several respondents noted that SIGs contribute to ISOQOL when they organize workshops at the annual meeting.

Organization/Policy

Most of the SIG chairs wanted ISOQOL to approve SIG objectives and have policies for SIGs. Publication policies, conflict of interest and governance policies were cited. Governance policies included election rules and term limits for chairs. More than half the respondents (62%) asked for ISOQOL assistance with SIG elections and felt the ISOQOL board should approve new chair nominations. SIG chairs asked for policies specifying what support ISOQOL provides to SIGs and the majority (75%) would like these policies posted on the ISOQOL website. Some respondents did not believe that all SIG members needed to join ISOQOL (38%).

The survey highlighted numerous avenues for ISOQOL to improve communications between its Board and the SIGs and many opportunities for working with the SIG chairs to increase the enthusiasm, vitality and productivity of SIGs. To make the best use of ISOQOL resources, the Board will need to work with the SIGs to establish priorities.

SIG Chair Meeting

At its recent meeting, the ISOQOL Board

of Directors decided to hold a meeting of SIG Chairs at the upcoming ISOQOL Annual Conference, to be held in Montevideo, Uruguay from October 22-25. The goal with this meeting is for the SIG Chairs and the ISOQOL Board (through the SIG liaison persons) to jointly discuss a plan for the SIGs, including for example expectations from the SIGs and requirements from the Board. When the Conference program is finalized we will be in touch to provide additional details on this meeting, but please plan on joining us in October in Montevideo. We welcome you to contact us if you have ideas about this meeting or want to discuss SIG related matters.

We are looking forward to meet you in Montevideo.



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Quality of life studies form an essential part of the evaluation of any treatment. Written by two authors who are well respected within this field, *Quality of Life: The Assessment, Analysis and Interpretation of Patient-reported Outcomes, Second Edition* lays down guidelines on assessing, analysing and interpreting quality of life data. The new edition of this standard book has been completely revised, updated and expanded to reflect many methodological developments emerged since the publication of the first edition.

This book will be of interest for everyone involved in quality of life research, and it is applicable to medical and non-medical, statistical and non-statistical readers. It is of particular relevance for clinical and biomedical researchers within both the pharmaceutical industry and practitioners in the fields of cancer and other chronic diseases.

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15th Annual ISOQOL Conference

Research and Action: Toward Good Quality of Life and Equity in Health

October 22 - 25, 2008
Montevideo, Uruguay

Visit www.ISOQOL.org for the latest information.



Preliminary Schedule

Wednesday, October 22

8:30 am – 12:00 pm; 1:00 – 4:30 pm
 Half-day workshops

1:00 – 5:00 pm
 Special Symposium: Incorporating the Views of Patients and Society in Reimbursement Decisions
(separate registration required)

5:30 – 7:00 pm
 Welcome Reception

7:00 – 9:00 pm
 Special Evening at Teatro Solis

Thursday, October 23

8:30 – 10:30 am
 Plenary I: Welcome Session *

10:30 – 11:15 am
 Poster Session: Meet the Authors

11:15 am – 12:00 pm
 Lecture: Health, Quality of Life, and Stigma *

12:15 – 1:00 pm
 4 Concurrent Sessions (papers & symposia)

1:00 – 2:00 pm
 Lunch/SIG meetings

2:00 – 3:30 pm
 4 Concurrent Sessions (papers & symposia)

3:30 – 4:15 pm
 Poster Session: Meet the Authors

4:15 – 5:45 pm
 Plenary II: Population Surveys *

5:45 – 6:45 pm
 SIGs/Satellite Meetings

7:00 – 8:00 pm
 Mentor/Mentee Reception

Friday, October 24

8:30 – 10:00 am
 Plenary III: Quality of Life: What are We Measuring? *

10:00 – 10:45 am
 Poster Session: Meet the Authors

10:45 – 11:30 am
 Lecture: Happiness: A Theoretical Perspective *

11:45 am – 12:45 pm
 4 Concurrent Sessions (papers)

12:45 – 2:15 pm
 Business Meeting and Luncheon

2:15 – 3:15 pm
 4 Concurrent Sessions (papers & symposia)

3:15 – 4:00 pm
 Poster Session: Meet the Authors

4:00 – 5:30 pm
 Plenary IV: QoL in Kids *

5:30 – 6:30 pm
 SIGs/Satellite Meetings

Saturday, October 25

8:30 – 10:00 am
 Plenary V: QoL in Mental Health: Burden of Disease *

10:00 – 10:30 am
 President's Message and President's Award Lecture *

10:30 – 11:15 am
 Poster Session: Meet the Authors

11:15 am – 12:45 pm
 Plenary VI: What Can Clinicians Expect from Health-Related QoL *

12:45 – 1:45 pm
 Special Session: Cancer and QoL*/Lunch/SIG meetings

1:45 – 3:15 pm
 4 Concurrent Sessions (papers & symposia)

3:15 – 4:00 pm
 Poster Session: Meet the Authors

4:00 – 5:30 pm
 4 Concurrent Sessions (papers & symposia)

8:00 pm
 Closing Dinner

* *simultaneously translated*