



# International Society for Quality of Life Research

Volume 10 Issue 3

Newsletter for ISOQOL Members

December 2005

## PRESIDENT'S MESSAGE

Peter Fayers, PhD  
Aberdeen, UK

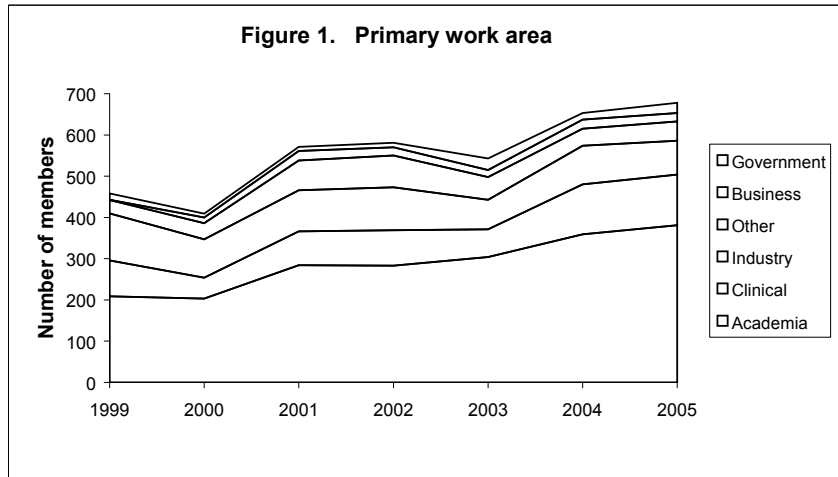
This year's annual conference has been a great success for ISOQOL – five hundred and ten attended the meeting in San Francisco, which is a record number for an ISOQOL meeting outside Europe (meetings in Europe consistently attract slightly larger numbers than those in North America). Also, I heard much positive comment about the way that ISOQOL meetings have evolved over recent years, becoming more interesting to a wider audience.

Each year's scientific program committee obviously tries to learn from the experience of the previous meetings, and to that end members from the previous year's committee also serve on the current one. But the scientific committees have a large degree of independence, and so the success of the meeting relies heavily on the efforts made by the conference committee chair and co-chairs and their supporting team. All credit, therefore, to Ron Hays, Anita Stewart, Leo Morales and the many others involved. This also includes, of course, the ISOQOL Secretariat Office of Laura and George Degnon, Sarah Shiffert, Daglyn Carr and their colleagues; they provide the indispensable continuity and professional expertise that complements the scientific input from our members.

The ISOQOL Executive Committee and Board pay great attention to these attendance figures, as the conference is the number one activity of ISOQOL – and probably some members regard it as the main reason for joining ISOQOL (but more about that, and the activities that we should support, in the next

newsletter). Also, the conferences are a major direct and indirect source of revenue to fund ISOQOL activities. Although there are many reasons why attendance figures can vary from year to year – including the geographical location of meetings and the resultant travel costs / time that this implies – it seems likely that the *quality* of the scientific meetings is a major factor, with increasing attendance figures implying greater satisfaction with recent meetings. Despite this, a recurring comment that I hear is “We ought to attract more clinical members,” or, “We have far too many measurement theoreticians, and too few clinician members.” Since I am the first statistician to be elected as president, and therefore assuredly not a clinician, this presents to me irresistible practical and research challenges. What do we know about our membership? Should we actively try to recruit more clinicians or other disciplines? How well do our conference programmes reflect the interests of our constituents? Well, although it is hardly a scientifically designed experiment, we do have some information from the responses that are made on the membership forms

and on the conference registrations. Figure 1 shows the total membership, listed by primary work area. The total membership has been growing, and as might be expected, academic members make up more than half the total (currently 59%, growing from 46% in 1999). I find it interesting that the second largest group is “clinical” and, as can be seen, recently this has grown appreciably; 19% of our members in each of the last two years. But of course this is “primary” area, and it might not be obvious how academic clinicians (or should I say clinical academics) would classify themselves. We also have



*President, continued on page 4*

### IN THIS ISSUE . . .

- ◆ A word from our President
- ◆ Kathy's Slant
- ◆ 2005 Conference Highlights
- ◆ “Advancing Health Outcomes Research Methods and Clinical Applications” order info



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Kathleen Wyrwich, PhD, USA

**Deadline for articles  
for our next issue is  
March 1, 2006**

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## LET'S TALK

Kathleen Wyrwich, PhD  
St. Louis, MO, USA

As a regular feature in each upcoming Newsletter, I have been encouraged to solicit views on substantive areas of our field. Therefore, in this issue, I am asking for your views to this question:

*Is "quality of life at the end of life" a different construct from the "quality of life" that we generally measure and study?*

I pose this question after attending a palliative care session at the 12th Annual Meeting where the audience size was one of the smallest of any concurrent session. Perhaps another competing session drew from those who might have an interest in end of life issues or the San Francisco sunshine was calling others outdoors at that time, but the dearth of session attendees beyond the five speakers and their research associates was noticeable. Moreover, I have had recent research experiences that suggest there are differing constructs associated with quality of life for individuals who know that they are at the end of life due to terminal illnesses. What do you think— are our current generic or disease-specific HRQoL measures relevant for these individuals beyond the measurement of physical pain? I look forward to reading and compiling member's responses in our next issue, so please send your ideas, comments, references, etc. to me via email at [wyrwichk@slu.edu](mailto:wyrwichk@slu.edu).

## AND THE WINNERS ARE.....

Carolyn Gotay, PhD  
Honolulu, HI, USA

### 2005 New Investigator and Student Awards

The ISOQOL New Investigator and Student Awards recognize the best overall oral and poster presentations made by full-time students or post-doctoral individuals in the early stages of their career in QOL research. This year, the committee selected the top 16 abstracts based on abstract submission – 8 in the New Investigator category, and 8 in the Student category. During the Conference, committee members reviewed these papers and posters in order to select the best overall presentations. The best overall paper and poster awards were announced during the Conference Dinner on Saturday, October 22. Below are the names of the finalists, with the winner in each category bolded. Congratulations to all—You represent our field's future and we look forward to seeing your name in lights again very soon!

#### Student Paper Finalists

Kikuko Miyazaki, Japan  
**James Shaw, USA**  
Lilla Szeifert, Hungary  
HL Wee, Singapore

#### Student Poster Finalists

Rick Sawatzky, Canada  
**Paul Teixeira, USA**  
Shutimaporn Tripop, Thailand  
Gabrielle van der Velde, Canada

#### New Investigator Paper Finalists

Paul Crane, USA  
Winnie Mak, China  
**Amir Adel Rashidi, Canada**  
Patrick Sullivan, USA

#### New Investigator Poster Finalists

Fabio Efficace, Belgium  
**David Eton, USA**  
Pei Lua, Malaysia  
Miles Muraoka, USA

# Kathy's Slant

## Seeing the "I" in ISOQOL

During the 12<sup>th</sup> Annual Meeting, the *San Francisco Chronicle* ran a story on conventions titled "In an age of zippy communications, why are conventions such a big deal?" The accompanying graphic with the article used meeting name tags to display answers to the title's question, like sleep in, play hooky, eat, drink, and drink more! Although I can attest to the free flowing wine at the Closing Dinner and the scale of our Annual Meetings may be smaller than most conventions, the assembled ISOQOL members in San Francisco, like other ISOQOL Annual Meetings, reflected our coming together each year to learn and celebrate what we do across the globe.

I attended my first Annual Meeting in 1998. Organized by two ISOQOL pioneers, Rick Berzon and Dennis Revicki, we met in Baltimore, Maryland, and we enjoyed the wonderful redevelopment of this city's harbor area throughout our stay. New to the field, I planned to enroll in an introductory workshop in Item Response Theory, but inadvertently registered for the Response

Shift course (I got the "Response" part right!), and have benefited ever since from a deeper understanding of this difficult-to-measure phenomenon in QoL change over time.

Nearly 60% of the 1998 Annual Meeting attendees claimed North America as their home continent. Outreach by ISOQOL in varied forums and increased worldwide attention to the measurement and use of QoL as important outcomes have led to overall growth on our Society's membership and subtle shifts in our demographics.

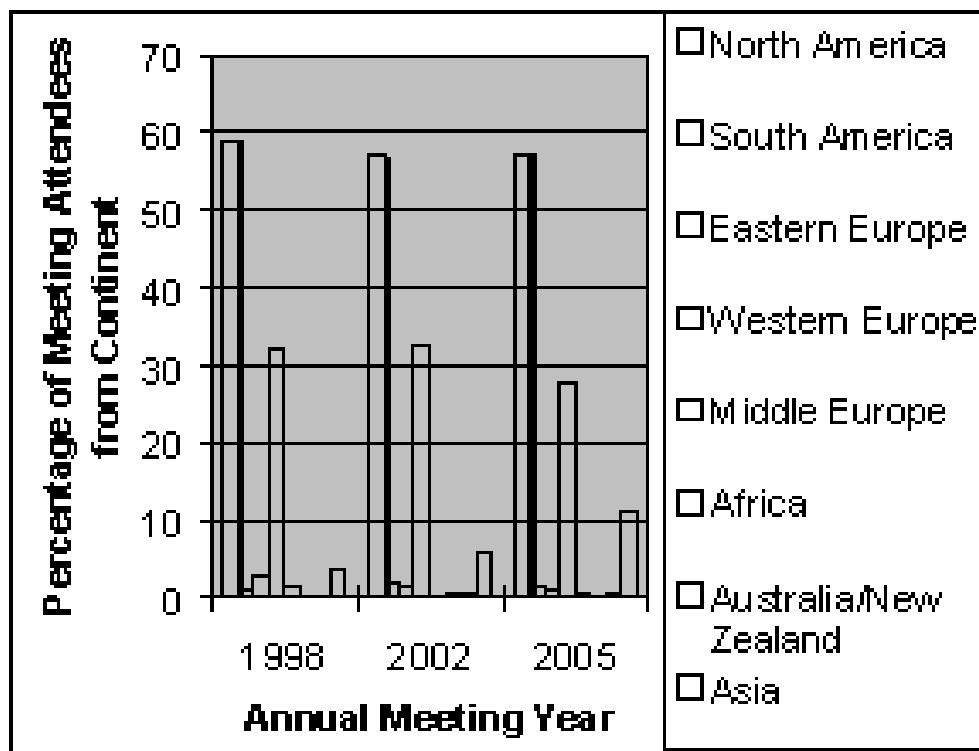
These shifts can be visually depicted by comparing the percentage of the Annual Meeting attendees from each home continent in 1998 to those at the Orlando, Fla. Meeting in 2002 and the most recent 2005 Meeting in San Francisco. A weak "control" variable in these three comparisons is their United States location, which facilitates ease in travel time and expenses for the largest portion of ISOQOL membership.

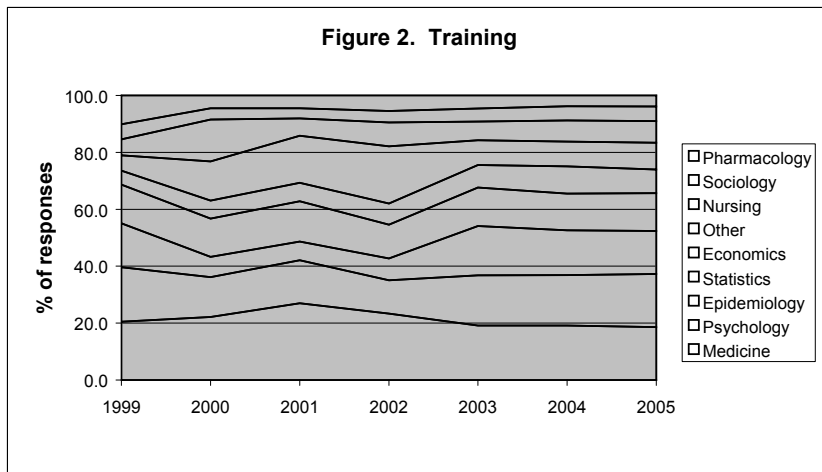
Although the percentage of delegates from North America and Western Europe have remained about the same, there is a visible increase in participation for other continents, namely Asia,

Australia and Africa. These shifts are also seen in our membership, and reflect the emerging growth of our field worldwide.

Who should we thank? Without a doubt, the organizational leadership of Degnon Assoc. has kept our ship afloat and running full steam ahead. But the list of "thank yous" needs to also be extended to all of ISOQOL's past and present membership. *You* are the ambassadors of our field of research and practice. *You* are the connectors who individually convince others that ventures into QoL assessments will enhance their understandings and intervention, and that the ISOQOL community is the place to share in this endeavor.

I am very excited about the new opportunity to edit the Society's newsletter and to share my points of view in this column. I eagerly welcome your comments and ideas on topics of interest, as well as your contributions of articles, graphics, and photos to share with others in ISOQOL. Please send these to me at [wyrwichk@slu.edu](mailto:wyrwichk@slu.edu).





data on “training” information, in which members could tick several boxes.

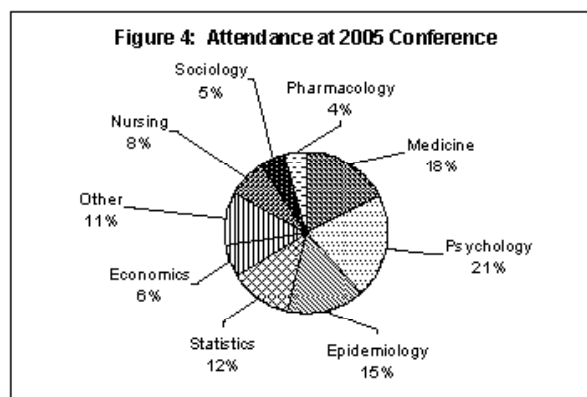
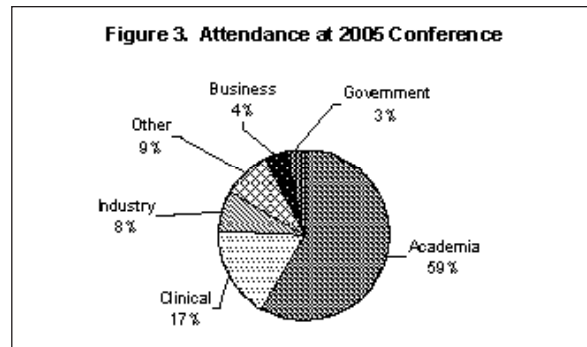
Figure 2 shows that medicine and psychology stand out as the two largest areas, currently at 19% each, followed by epidemiology (15%), and statistics (13%). Medicine *was* represented appreciably more highly in 2002, at 27%. Personally, I find these figures pleasantly reassuring. I was surprised to see how stable the membership has been over the years. It would be interesting to know what others feel – are we becoming “unbalanced”? Should we be trying to recruit more people from particular backgrounds?

One group that I feel we ought to pay more attention to is patients themselves! Is it not curious that we place so much emphasis on “asking the patients”, patient-completed questionnaires, patient experiences, patient satisfaction, and so on, and yet we do not involve patient advocacy groups in our meetings? Other organisations, such as the Cochrane Collaboration, have long felt the need to ensure that the patient perspective is represented, both inside and outside their conferences. Why have we failed to do this? Sometimes we debate how best to increase and improve the use of HRQL assessments in clinical trials or for routine patient management. If patients regard our tools as making useful contributions, they will surely demand that they should be properly assessed with reputable instruments. Figures 3 and 4 show the equivalent information in terms of attendance at San Francisco.

So, to the crux of the matter: how well do our programs match the interests of our members? Jordana Schmier, who chairs our communication committee, teasingly suggested to me that ISOQOL should be renamed with the delightful acronym MALAPROPS - Measurement And Linguistic Adaptation of Person-Reported Outcomes Professional Society. Indeed, among the opinions that I heard concerning the content of the program, two contrasting views stood

out. Several people commented about the amount of psychometric instrument validation, while others opined that although in the past this might have been the case, now there is a much better balance with greater emphasis on applications and the value of using HRQL assessments. Again, it would be great to hear your views – how can we improve the balance of topics? Or is it the consensus view that, on balance and considering the diversity of our membership, the meetings are fine?

I know that Andrew Bottomley and Henning Flechtner, Francisco Luis Pimentel and Pedro Ferreira, the chairs for Lisbon 2006, are already wrestling with issues like this, and no doubt they would appreciate constructive suggestions!



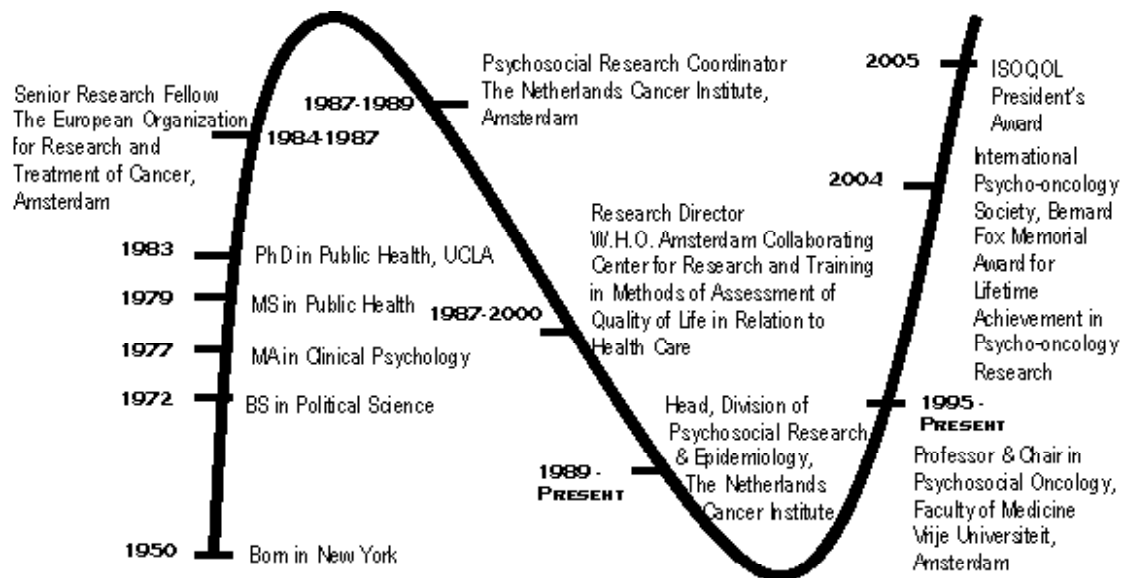
## OUTLINING NEIL

At the Closing Ceremony of 12<sup>th</sup> Annual Meeting, outgoing President David Feeny presented ISOQOL's President Award to Neil K. Aaronson. Many ISOQOL members may know Neil first and foremost as the Editor-in-Chief of the Society's journal, *Quality of Life Research*, from 1999 to 2005. Under Neil's leadership, this journal has made an important turn-around in management and ever-increasing respect for

our research field.

However, Neil's accomplishments extend far beyond this publication fete. As this timeline shows, Neil's ability to study and communicate to others the need and purpose of focused measurement of health-related quality of life has extended world-wide, and indeed, laid groundwork for research and practice in the field that allows others to continue to build bridges for better understand-

ings of quality of life. We continue to learn from Neil's on-going efforts as he actively persists in his stalwart achievements and passionate avocation for the mission of ISOQOL, that is, *the scientific study of Quality of Life relevant to health and healthcare, promoting the rigorous investigation of health-related quality of life measurement from conceptualization to application and practice*. Congratulations, Neil!



## ADVERTISEMENT

### Research Scientists, Center for Health Outcomes Research

The MEDTAP Institute at UBC is a private health research firm providing health outcomes and health economic research and consultancy services to the pharmaceutical and device industry, and health service and government clients globally. MEDTAP scientists perform challenging work in a stimulating, collegial environment where everyone is dedicated to conducting the highest quality research in the industry.

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## REFLECTING BACK

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David Feeny, PhD  
Edmonton, Alberta Canada

### **ISOQOL. Live Culture. Nurture with Care.**

Kathleen Wyrwich has asked me to write a brief article reflecting on our Society during the past year. It is my pleasure to comply.

**A Highly Collegial Culture.** The membership of ISOQOL is diverse with respect to disciplinary training, areas of clinical focus, stage of career, and a host of other factors. Yet we seem to communicate among ourselves quite effectively. Two of the graduate students with whom I am working and a research associate attended the 12<sup>th</sup> Annual Meeting in San Francisco. Intellectually and socially they had a great time. They found the sessions and hallway conversations exciting and stimulating. They report that they learned a great deal. (Of course, this could just be a comment on the learning opportunities I provided for them in the past!) Their posters were visited by both senior and junior people in the field who showed genuine interest in their work. By design and serendipity ISOQOL has developed a very healthy culture. The family recipe for our sourdough culture calls for regular feedings of milk, flour, and sugar, stirred gently. We could speculate on what the ingredients are for nurturing ISOQOL's culture. I recommend that we be careful to continue to nurture our respectful multi- and interdisciplinary culture; it is one of our most valuable assets (priceless, as they say in the credit card commercials).

**Collegial and Consensual Decision Making.** Having served on the Editorial Board for *Quality of Life Research*, the ISOQOL Executive Committee, and the ISOQOL Board, I can report that the respectful culture of ISOQOL is also quite evident in its governance. ISOQOL frequently goes beyond "two heads are better than one" in its deliberations and decisions. Again, this is a valuable but fragile asset which we need to nurture.

**Major Accomplishments and Initiatives.** As you know, the ISOQOL Board, with the bulk of the work being done by a special committee, successfully recruited a "replacement" for Neil Aaronson as Editor-in-Chief of *Quality of Life Research*. Both process and outcome were superb. ISOQOL's vital signs look great. ISOQOL also devised a plan for the formation of Chapters. The Special Interest Groups initiative is gaining momentum. Indeed the Quality of Life in Clinical Practice SIG is organising an ISOQOL Symposium for 2007 (probably June and in Europe) to examine evidence on the effects, or lack thereof, of using health-related quality of life measures in routine clinical care settings, one of the most important hot topics in the field today. We are getting better at fund raising, both from industry and from peer-reviewed granting agencies. Our fiscal house is in order.

**Ask Not What ISOQOL Can Do for You but What You Can Do for ISOQOL (and the Field).** Tell your colleagues how wonderful our meetings and activities are. Get them to join ISOQOL. ISOQOL is fortunate to have an efficient and highly collegial Secretariat. Nonetheless, we mainly rely on volunteers who already typically have more than one full-time job. More of you need to become involved. It is time for some of the "old hands" to step aside, not because their performance is lagging but because in the long run we need to broaden our base of active volunteers who produce the public goods associated with ISOQOL.

As Immediate Past President one of my duties is to participate in the selection of the paper published in 2005 (in any journal) that will receive ISOQOL's Outstanding Article of the Year Award. When you read an article this year that so impresses you (positively) that you give it to your students, put it on the reading list for your course(s), or make copies to distribute to colleagues because you think that the article is really important, share that judgement with ISOQOL. Send a brief explanation (see the Awards section on the web site for more detail) of why the paper is impor-

tant and a copy of the paper (PDFs are even better) to the ISOQOL Secretariat (info@isoqol.org) so that we include it in the pool of nominated papers! This is just one small example of how you can become more involved.

There were many personal highlights over the year. One was being able to recognise Neil Aaronson by awarding him the President's Award (and subsequently to drink from the ISOQOL cup). See you in Lisbon, October 11-14, 2006.

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## MENTOR-MENTEE SESSION IN SAN FRANCISCO A SUCCESS

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Claire Snyder, PhD  
Baltimore, MD, USA

The 2005 Mentor-Mentee session during the San Francisco Annual Meeting was another huge success. Over 30 mentees met with mentors during an evening reception. Mentees had the opportunity to seek advice on topics ranging from research issues to career counseling. One mentor-mentee pair found that they were born in the same town in Austria. Another pair decided to continue its discussion over dinner the following evening. These are just some examples of the connections that are made through this ISOQOL initiative. For both mentors and mentees alike, participation in the program provides a fun and rewarding venue for exchanging ideas.

If you are interested in participating in this program during the 2006 meeting in Lisbon, Portugal, please check [www.isoqol.org](http://www.isoqol.org) for information.

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## lenty of owerful olicy and ractice

### lenary Sessions at 2005 Annual Meeting

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*Rick Berzon, DrPH, Washington, DC, USA and Kathy Wyrwich, PhD, St. Louis, MO, USA*

In the many cultures that ISOQOL embraces, the event of a twelfth birthday has significance in a young person's life as a symbol of adolescent growth. Therefore, it was quite fitting that the organizing team for ISOQOL's 12<sup>th</sup> Annual Meeting invited wonderfully articulate speakers to this year's plenary sessions to discuss the impact of our work on both health policy and practice.

At the opening session on Thursday, October 20, Robert Brook, Vice President and Director of RAND Health and Professor of Medicine and Health Services at the Center for Health Sciences at the University of California-Los Angeles, gave us all a historical perspective of health status and quality of life measurement. At the same time, he also challenged us to identify ways to increase the use of these tools within clinical research and everyday patient care. Later in the day, policy-related issues surfaced during the symposium on Stakeholders. During that symposium, Steve Clouser, the Chief of the Outcomes Research Branch at the National Cancer Institute, in an understatement, observed that key policy players within the United States healthcare system do not routinely use HRQL assessment to guide health policy. Dr. Clouser—as did Dr. Brook—noted that the meaningfulness of these assessments is problematic; and he suggested that we who conduct QOL research have yet to make a convincing case as to why policymakers should care about its measurement.

Public policy is dependent upon in-

formation; and good public policy is a function of appropriate data collection and straight forward, easily interpreted and understood findings. The tools that we develop and the outcomes that result from their use must be accessible and comprehensible across unique audiences and settings in the developed and the developing world. Whether the topic is AIDS in Nigeria or the added value of a new pharmaceutical agent for the treatment of epilepsy, the measures that we invent to offer information to inform public policy must provide clear-cut, uncomplicated results. One of our many challenges, therefore, is to make these complex outcomes simple, so that our findings can be understood by non-social science and medical experts, patients, and policy-makers.

On the morning of Friday, October 21, three experts, brought together within the Plenary Session, offered examples of their work to provide insights into the public policy process at a macro or higher level. Galina Velikova, a physician in the Cancer Medical Research Unit of St. James Hospital in Leeds, UK, began with a focus on HRQL within clinical trial research, and how these findings can be implemented. Michael Wolfson of Statistics Canada then moved to issues surrounding HRQL measurement and Canada's efforts to develop public policy around its appropriate use. Paul Kind, Director of the Centre for Health Economics at the University of York, UK, concluded with a presentation that addressed the extent to which we have been successful in convincing the policy community that HRQL assessment has value.

Saturday morning's plenary turned to the micro-level of incorporating HRQL measures into clinical practice

to improve the quality of patient care. David Osoba outlined the need for such efforts, and Michael Barry, MD and Director of the Health Services Research Program at Massachusetts General Hospital gave the clinician's perspective on the benefits and barriers. Then David Cella, Director of the Center for Outcomes Research at Evanston (Illinois) Northwestern Health Care, chronicled how his Center has initiated, revised, and ultimately won over both clinicians and patients to the benefits of regular HRQL monitoring of cancer patients.

These powerful plenary presentations gave all attendees an opportunity to reflect on how our work in HRQL measurement has evolved and how much is still needed so that both healthcare policy and practice are improved by patient-reported outcomes. This seems appropriate for a Society entering the exciting teenage years and advancing toward adulthood and future maturity. Many thanks to the 12<sup>th</sup> Annual Meeting's Organizing Team, led by Ron Hays, for these great perspectives on where we have been and where we need to go!

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## MEMBER NEWS

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Sonja Boehmer, PhD, former doctoral student at the Health Psychology Department, Freie Universitaet Berlin, Berlin, Germany, has been awarded a Feodor Lynen Fellowship by the Alexander von Humboldt Foundation. She was invited for a 12-month postdoc stay by Dr. Aleksandra Luszczynska to the Department of Psychology, University of Sussex, Falmer, Brighton, Great Britain.

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## REPORT FROM THE CHAIR OF THE 2005 SCIENTIFIC PROGRAM COMMITTEE

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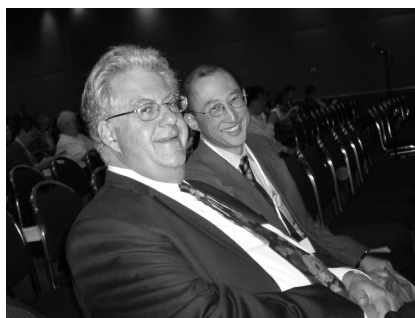
Ron D. Hays, PhD  
Los Angeles, CA, USA

I have attended and enjoyed all twelve ISOQOL annual meetings: Brussels, Montreal, Manila, Vienna, Baltimore, Barcelona, Vancouver, Amsterdam, Orlando, Prague, Hong Kong, and now San Francisco. This year's meeting at the San Francisco Hyatt Regency Embarcadero was also a success, with over 500 participants and a variety of presentations under the "Building Bridges to Enhance Quality of Life" theme.

The meeting began with workshops on Wednesday (October 19). I attended an excellent workshop on the basics of decision analysis conducted by Gillian Sanders and Douglas Owens (Society for Medical Decision Making representatives). As there were only three other attendees, it was pretty much a private tutorial.

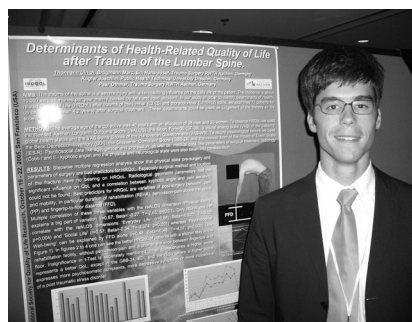
The opening reception that night was well attended and several people stayed around past the scheduled closing time to catch up with colleagues and friends.

Thursday we woke up to hear Bob Brook begin his plenary on "measuring health" by conducting a poll of the number of people in the audience who thought they were going to die in the future. Not everyone raised a hand but some of them were still asleep.



Invited Plenary Speaker Bob Brook and ISOQOL past president Albert Wu

Neil Aaronson, this year's recipient of the ISOQOL President's Award, gave an excellent lunch session on the peer review process during the meeting. During the conference we also heard from our stakeholders (chaired by Carolyn Schwartz), about policy applications of QOL research (chaired by Rick Berzon), and about QOL assessment in clinical practice (chaired by Claire Snyder). In addition, we had a joint paper session with the Society for Medical Decision Making that included two ISOQOL presentations (I-C. Huang, A. Raczek) and a closing message from David Feeny (ISOQOL past-president).



Ulrich Thormann of Aachen, Germany and a Student Member of ISOQOL shares his research with meeting attendees.

and awards at the Atrium restaurant. El Tren, a 4-piece Cuban jazz ensemble featuring piano, flute, bass, and percussion, provided entertainment.

I want to thank Anita Stewart and Leo Morales for co-chairing this year's meeting and the program committee for all their outstanding work. Thanks are also due to the individuals who organized the workshops (Carol Moinpour), new investigator awards (Carolyn Gotay), Scholarships (Cindy Gross), and mentor-mentee program (Claire Snyder). As always, Degnon Associates (especially Sarah Shiffert and Laura Degnon) did a wonderful job in managing every detail of the meeting. Anyone who reviewed abstracts for the meeting or attended it is also greatly appreciated.

I hope to see all (most) of you next year in Lisbon.

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## ARTICLE OF THE YEAR AWARD

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The ISOQOL "Outstanding Article of the Year Award" is given annually to recognize and honor the single best article dedicated to health-related quality of life research that was published in a peer-reviewed journal during the previous calendar year (2004). This award recognizes the authors for significant intellectual contributions that promise to advance the state of the art in health-related quality of life research methods or theory.

This year, eight high-quality papers were submitted for this award. These papers covered a wide range of important topics and each paper represented a significant intellectual contribution to the field of health-related quality of life.

The nominated articles were:

1. Alonso J, Ferrer M, Gandek B, Ware J, Aaronson N, Mosconi p, Rasmussen N, Bullinger M, Fukuhara S, Kaasa S, Leple' A; IQOLA Project Group. Health-related quality of life associated with chronic conditions in eight countries: Results from the International Quality of Life Assessment (IQOLA) Project. *Quality of Life Research* 13: 283-298, 2004.
2. Arnold R, Ranchor AV, Sanderman R, Kempen GIJM, Ormel J, Suurmeijer TPMB. The relative contribution of domains of quality of life to overall quality of life for different chronic diseases. *Quality of Life Research* 13: 883-896, 2004.
3. Devlin NJ, Hansen P, Selai C. Understanding health state valuations: a qualitative analysis of respondents' comments. *Qual Life Res.* 2004 Sep;13(7):1265-77
4. Kuppermann M, Varner RE, Summitt RL Jr, Learman LA, Ireland C, Vittinghoff E, Stewart AL, Lin F, Richter HE, Showstack J, Hulley SB, Washington AE; Ms Research Group. Effect of hysterectomy vs



medical treatment on health-related quality of life and sexual functioning: the medicine or surgery (Ms) randomized trial. *JAMA*. 2004 Mar 24;291(12):1447-55

5. Rapkin BD and Schwartz CE. Toward a theoretical model of quality-of-life appraisal: Implications of findings from studies of response shift. *Health and Quality of Life Outcomes* 2004; 2:14.
6. Schwartz CE and Rapkin BD. Reconsidering the psychometrics of quality of life assessment in light of response shift and appraisal. *Health and Quality of Life Outcomes* 2004; 2:16.
7. Van Osch SMC, Wakker PP, Van den Hout W, Stiggelbout AM. Correcting biases in standard gamble and time trade-off utilities. *Med Decis Making* 2004;24:511-517.
8. Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, Selby PJ. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *J Clin Oncol*. 2004 Feb 15;22(4):714-24.

At the Conference Awards Dinner on Saturday, October 22, Former Past President Albert Wu announced that the last listed article, Velikova et al., was named the recipient of the 2004 Outstanding Article of the Year Award. Congratulations to those authors and **all nominated articles** representing the growing contributions that promise to advance the state of the art in health-related quality of life research.

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## QUALITY OF LIFE RESEARCH JOURNAL

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Ron D. Hays, PhD, Editor-in-Chief,  
*Quality of Life Research*  
Los Angeles, CA, USA

In July Neil Aaronson retired after six years of outstanding service as Editor-in-Chief of the *Quality of Life Research* journal. The current associate editors are Diane Fairclough, David Feeny, Jeanne Landgraf, Kathy Lohr, Elaine McColl, Carol Moinpour, Michael Ritsner, Carolyn Schwartz, and Albert Wu. The tenure for three (Feeny, Landgraf, Lohr) will be ending in the near future. Two new associate editors (John Brazier, Graeme Hawthorne) are beginning their terms in 2006. Additional appointments will be made as needed. We are also looking to appoint a new book review editor to replace Peter Fayers, who is retiring at the end of this year.

At the time of the 2005 ISOQOL Conference, the journal had published 9 issues of this year's volume (14) with the last issue being conference abstracts. The flow of manuscript submissions is very healthy with 343 submitted in 2004 and 316 by the end of September of this year. Average time between submission and initial decision was 2 months in 2004 and 1.5 months in 2005 so far. Time between acceptance and publication averaged about 10.5 months in 2005. The acceptance rate was 40% for 2004 and is about 35% for 2005.

The latest impact factor (2004) compiled by Journal Citation Reports was 1.820. The 2004 impact factor represents the average number of times articles published in the two prior years (2002, 2003) were cited in 2004. There were 66 and 95 articles published in 2002 and 2003, respectively, in *Quality of Life Research*. A total of 293 citations in 2004 were made to the 161 articles published in 2002 and 2003. Remember when you write articles to cite articles published in *Quality of Life Research* if it is appropriate.

In the latest revisions to author instructions, we have set a limit of 3,500 words for regular articles and 1,500 words for brief communications (not including abstracts, references, tables, figures, appendices). We are also requiring a structured abstract. In addition, we want to remind those submitting papers that authorship requires substantial contribution to the work. That is, all authors should have been involved in study conception and design, or analysis and interpretation of data, and drafting the article or revising it critically for important intellectual content.

One of my main goals as Editor-in-Chief is to facilitate timely processing of submitted manuscripts. If you do not hear back from us about your manuscript within 3 months of submitting it, please send me an email (drhays@ucla.edu) so I can check into its status and get back to you with further information.

I want to thank all of you who have reviewed for us in the past and will do so in the future. Good reviews are critical to the success of the journal and we appreciate the time and efforts you make in helping the editors reach decisions and your colleagues to improve their work. In November of 2005 we started a process of rating each review we receive so that we can identify the reviewers perceived to be most helpful to the journal. We will send a letter of acknowledgement to the top reviewers each year.

We encourage each of you to submit your best work to *Quality of Life Research* and to review manuscripts whenever possible.

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## 13<sup>TH</sup> ISOQOL ANNUAL CONFERENCE 2006 IN LISBON, PORTUGAL

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### *HRQOL Research: Making an Impact in the Real World*

The Chair and Co-chairs Andrew Bottomley, Henning Flechtner, Francisco Luis Pimentel and Pedro Lopes Ferreira cordially invite you to attend the 13<sup>th</sup> ISOQOL Annual Conference in Lisbon, Portugal, October 11-14, 2006.

The Conference will be a packed HRQOL program, with international speakers, bringing you the latest clinical news and research findings. The theme will be broad, but focused: *HRQOL Research: Making an Impact in the Real World*.

#### **The Conference**

The aims of the Conference are to encourage ISOQOL members to look at how HRQOL research has and can be used in practice to improve patient well-being.

The chairs are preparing a program to interest everyone, covering the whole spectrum of relevant HRQOL topics, including sessions for patient advocacy groups to examine and report on the value and use of HRQOL data.

We hope to bring together regulators of HRQOL, such as the EMEA to inform us on our progress to date and the challenges facing us.

In addition, special sessions will include discussion on the latest in scientific advances in classical and modern psychometric approaches. As well as the usual pre-conference workshops, a pre-conference meeting for local participants will be held in both Portuguese and English.

Again, scholarships will be available to help develop and foster young HRQOL researchers and those who reside in developing countries. We plan to invite abstract submissions in late February 2006.

#### **The City**

After a full day at the conference, the

historic city of Lisbon awaits you. Since its conquest from the Moors in 1147, Lisbon has become a legendary city with over 20 centuries of history. Situated under radiant skies, on the south-western coast of Portugal lies Lisbon, the *white city*, so called because of its unique luminosity. The city is distinct with its typical tile-covered façades and narrow Medieval streets, where one can hear the fado being played and sung at night.



The city is also the stage for many popular festivities, is a place for expansive shopping, exciting night-life and interesting museums. Touring the coast offers rich and impressively diverse scenery and social custom. It is hardly surprising that Lisbon has an international reputation as a highly popular conference venue.

Finally, the Conference organisers have a social program to be envied, with a Farewell Gala Dinner you will never forget. So make sure you put these important dates – **October 11-14, 2006** – in your diary and go collect your data. Exchanging research and ideas – successes and failures – is the basis of any conference.

Looking forward to seeing you improve your QOL at the ISOQOL Conference October 2006 in **Lisbon, Portugal**.

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## ISOQOL WELCOMES NEW MEMBERS

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**Richard Barron, MS**, Trabuco Canyon, CA, USA

**Tomm Bernklev**, Sandefjord, Norway  
**Lee Bowman, PhD**, Indianapolis, IN, USA

**Katherine Byers**, Gainesville, FL, USA  
**Huang-Mann Cheng, MS**, Taichung, Taiwan, ROC

**Wei-Chu Chie, PhD**, Taipei, Taiwan, Taiwan

**Charles Christiansen, PhD**, Galveston, TX, USA

**Charles Cleeland, PhD**, Houston, TX, USA

**Josh Epstein, BS, BA**, Santa Monica, CA, USA

**Herbert Fliege, PhD**, Berlin, Germany  
**William Furlong, MSc**, Dundas, ON, Canada

**Richard Gershon, PhD**, Evanston, IL, USA

**William C. Gerth**, Whitehouse Station, NJ, USA

**Elizabeth Gibbons**, England, United Kingdom

**Norissa Honea**, Chandler, AZ, USA

**Monika Klinkhammer-Schalke, MD**, Regensburg, Bavaria, Germany

**Christel Le Petit, BSc**, Ottawa, ON, Canada

**Tiffany Miller, BA**, San Francisco, CA, USA

**Samir Mody, PharmD, MBA**, Chapel Hill, NC, USA

**Michelle Naughton, PhD**, Winston-Salem, NC, USA

**Louis A. Penner**, Detroit, MI,

**Herb Pierrie, BBA, BS, MSN**, San Francisco, CA, USA

**Ana Maria Pinto**, Lisboa, Portugal  
**Andrea Pusic**, New York, NY, USA

**Kathryn Richardson, BSc, MSc**, Vancouver, BC, Canada

**Kathleen Rosa, PhD**, Wilmington, NC, USA

**Risa Rosenberg, MA**, West Hollywood, CA, USA

**Bodo Schniewind**, Kiel, Germany  
**Tetine Sentell, PhD**, San Francisco, CA, USA

**Andrew H. Soll, MD**, Pacific Palisades, CA, USA

**Anita Stewart, PhD**, San Francisco, CA, USA

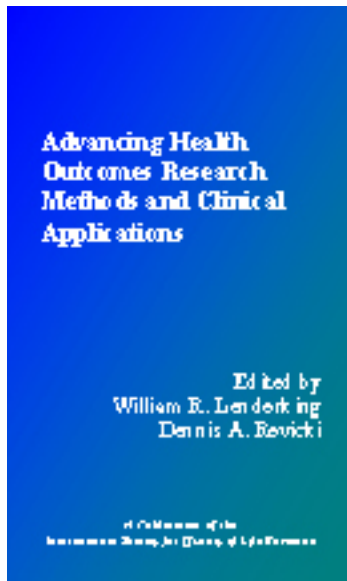
**Virginia Sun**, Duarte, CA, USA

**Eszter Vamos, MD**, Budapest, Hungary  
**J.P. Wietze van der Veen, MD, PhD**,

Amsterdam, The Netherlands

**John Wei, MD**, Ann Arbor, MI, USA

**Ning Wu, PhD**, Cambridge, MA, USA



**A new book from the  
International Society for Quality of Life Research**

**Advancing Health Outcomes Research  
Methods and Clinical Applications**

Edited by William R. Lenderking & Dennis A. Revicki

ISOQOL is pleased to offer a volume of invited papers from the recent Symposium “Stating the Art: Advancing Outcomes Research Methodology and Clinical Applications,” which captures the heterogeneity, science, and creativity of our field.

The papers are not direct transcripts the talks presented, but rather chapters inspired by the presentations delivered at the Symposium. In organizing this symposium, we sought to create a program that illuminated the state of the art of health outcomes research from the perspectives of statistical methodology, clinical applications, and theory. Rather than attempting to cover the entire breadth of the field, our aim was to invite leading investigators and thinkers in their field of specialization. The end result is this volume, which is available at the price of \$80 for ISOQOL members and \$95 for non-members. Bulk discounts are available for orders of 100 copies or more (for details, please visit [www.isoqol.org](http://www.isoqol.org), or call the ISOQOL Executive Office at 703-556-9222, or email [info@isoqol.org](mailto:info@isoqol.org)).

Please send me \_\_\_\_\_ copies of *Advancing Health Outcomes Research Methods and Clinical Applications* at **\$80** member price/ **\$95** non-member price (please circle).

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Mark your Calendar. . .

## ISOQOL 13th Annual Conference October 11 - 14, 2006 Lisbon, Portugal



The 10th-century Castle of Guimarães, a national symbol, is known as the "Cradle of Portugal"

***ISOQOL invites you to journey  
with us to Portugal, one of the  
oldest nations in Europe***

Abstract submissions will begin  
February 2006.

Visit [www.ISOQOL.org](http://www.ISOQOL.org) for the  
latest information.

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### ISOQOL MEMBERSHIP BENEFITS

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

- \* Online Membership Directory
- \* Participation in a variety of Special Interest Groups
- \* Reduced subscription rate for the *Quality of Life Research Journal*
- \* Reduced conference registration rates
- \* Annual meetings of the International Society for Quality of Life
- \* 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 listserv - 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 published 3-times/year
- \* 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"

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