



# International Society for Quality of Life Research

Volume 8 Issue 2

Newsletter for ISOQOL Members

September 2003

## PRESIDENT'S MESSAGE

*Mirjam Sprangers, PhD  
Amsterdam, The Netherlands  
Albert Wu, MPH, MD, President-Elect  
Baltimore, MD, USA*

A chronic and deteriorating neck condition made Mirjam decide to take a break from work to enable recovery. Albert acted as president during her absence. After three months Mirjam called Albert and the following conversation evolved:

A: Hi Mirjam! How are you doing? I've missed you.

M: Hi Albert. It's so nice to hear your voice. I'm feeling much better than you. Physical therapy is a wonderful invention. I'm able to do more, and experiencing much less discomfort.

A: What a pain in the neck – if you'll forgive the pun. We should get you to complete the SIP every week so we can chart your progress.

M: In fact, I did complete a couple of questionnaires over time in the context of my exercise program. Interesting experience. I am sure it did not capture the response shifts I have undergone.

A: Yeah, researchers should complete patient-based questionnaires themselves. Such an enlightening experience.

M: Indeed. What's been happening with ISOQOL during the 3 months I've been on leave?

A: There have been a couple of decisions that can safely be described as of global importance.

After careful consideration and re-

consideration, we are very excited to announce that the ISOQOL 2004 meeting will indeed be held in Hong Kong. We paused to be sure that the SARS would blow over, and then did due diligence in trying to ascertain that this was a prudent decision. We were also aware of the potential injury caused by media-induced anxiety. However, we are now confident and excited about gathering in Hong Kong, one of the most cosmopolitan and energetic places on the planet. It will allow a venue for the many investigators now conducting quality of life research in China, Japan, Thailand, Taiwan, Singapore - all over East Asia.

M: Three continents!

A: Absolutely. We were also happy because this decision allows us to keep to our informal "Three Continents" philosophy, which directs us to meet in Europe, North America, and Asia in sequential years. This certainly assures that the "international" in ISOQOL is not just wishful thinking.

M: What about Australia?

A: We can't forget Australia - and New Zealand, especially since the 2004 meeting will be chaired by Madeleine King (Australia) along with Kwok-fai Leung (Hong Kong) and Margaret Tay (Hong Kong). They are now assembling their team.

M: Other events?

A: Well, the program for Prague (November 12-15) is set, and the entire enterprise is sailing ahead under the confident hands of chairs Donna Lamping and Jane Blazeby. It will be another exciting conference. I can attest to the fact that Prague is one of

the most attractive and romantic destinations in the world. And they are home to my three all time favorite cemeteries.

M: What a cheerful thought. Another happy news for us?

A: Let's see. Jane Scott, from her lofty new perch at the FDA, has managed to find time for two important activities. Five important articles have been entered and made it to the finals for our inaugural "ISOQOL Outstanding Article of the Year" award, which will be announced in Prague. And Jane will soon be conducting a "Stakeholder Survey" of the membership. All members will be asked to take a few minutes to respond to this brief but important effort. We are aiming to get a better fix on who we are representing, and what services our members would find most helpful and appealing.

*Continued on page 5*

## IN THIS ISSUE . . .

**Updated schedule for the 2003 ISOQOL Annual Conference in Prague.**

**Information about upcoming ISOQOL events including the 2004 June Meeting in Boston, MA, USA & Hong Kong, October, 2004.**

**ISOQOL is proud to welcome more new members for 2003 on page 8. Know someone who can benefit from being a member? Have them visit our website at [www.isoqol.org](http://www.isoqol.org) to download a membership application.**

The ISOQOL Newsletter is published three times a year by the International Society for Quality of Life Research with the cooperation of Degnon Associates.

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**Carola Bardage, PhD, Sweden**  
*Associate Editor*  
**Adam Smith, M.Phil,**  
*United Kingdom*

**Deadline for articles for our next issue is December 15, 2003**

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## EVERYONE INTO THE "POOLS": A COMMENT ON THE FUTURE OF ITEM BANKING

*John Ware, Jr., PhD, USA*

Approximately 10 years ago, we began searching for the "units" of measurement that quantify each of the functional health and well-being concepts underlying widely-used health-related quality of life measures. Our initial goals were to evaluate translations and adaptations of health-related quality of life (HR-QOL) measures. We began creating and evaluating "pools" of items using a multi-step empirical process that culminated in the application of item response theory (IRT) methods. From the successes documented in the fields of educational and psychological testing, we anticipated the following noteworthy advances: (1) improved scale scoring algorithms, (2) empirical evidence for evaluating the equivalence of translations and cultural adaptations, (3) algorithms for cross-calibrating items in widely-used "static" forms, and (4) the item parameters necessary to run the dynamic "engines" that power computerized adaptive testing (CAT) software.

Later this year, *Quality of Life Research* will publish results from nine peer-reviewed articles summarizing applications of IRT and CAT to widely-used measures of headache impact. The 20 authors of these articles concluded that (1) improvements in scoring based on IRT models have the potential to increase the responsiveness of clinical trials of treatment effectiveness; (2) questionnaire items from widely-used measures can be "pooled" and scored on a common metric or "ruler" on the basis of IRT calibrations, (3) the item parameters (slopes and thresholds) required for the programming of CAT software can be used successfully to administer questions dynamically. In contrast to traditional "static" surveys in which the same questions are asked

of everyone regardless of their answers, CAT will make it possible to individualize each health assessment so that only the most informative questions are asked at each persons particular level of health. Other practical advantages include the virtual elimination of "ceiling" and "floor" effects that plague many widely-used measures.

The advantage will be a timely solution to the challenges of more practical and more precise tools for assessing health status. Studies of headache impact demonstrate that reductions in respondent burden are possible while maintaining acceptable standards of validity and precision throughout the range that must be measured for purposes of patient screening and outcomes monitoring. It will be interesting to see whether these results are generalizable to other diseases and conditions and how fast IRT and CAT methods are adopted worldwide. Incidentally, we focused on headaches because they are common, their burden and variations in treatment outcomes are substantial, and the lack of practical self-assessment tools contributes to the under-diagnosis and treatment of headache disorders.

*John E. Ware, Jr., PhD, is CEO and Chief Science Officer, Quality Metric Inc., located in Lincoln, RI, USA. Dr. Ware co-founded QualityMetric in 1997, after serving for 12 years as Senior Scientist at The Health Institute, New England Medical Center (NEMC) in Boston, and Principal Investigator for the Medical Outcomes Study, where he created the SF-36® Health Survey and other tools widely used to monitor patients' outcomes. Before moving to NEMC, John spent 13 years as a Senior Scientist at the RAND Corporation. An internationally recognized expert in health-related quality of life assessment, John is a Research Professor in the Department of Medicine at Tufts University School of Medicine, an Adjunct Professor in the School of Public Health at Harvard University, and a member of the Institute of Medicine, National Academy of Sciences. Dr. Ware is also an At-Large Board member of ISOQOL.*

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## REPORT ON THE ISOQOL 2003 LEADERSHIP ELECTIONS

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*David Osoba, MD, Canada,  
Chair, Nominations Committee*

We are pleased to report the results of the 2003 election. Please join us in offering your congratulations to the successful candidates.

For President-Elect – **Dr. David Feeny**, from the Institute of Health Economics and University of Alberta, Edmonton, Canada.

For At-Large Board Membership – **Dr. Andrea Bezjak** from the Princess Margaret Hospital, Toronto, Canada; **Dr. Andrew Bottomley** from the EORTC Data Centre, Brussels, Belgium; **Mr. Kwok-fai Leung** from the Queen Elizabeth Hospital, Hong Kong, PRC and; **Dr. Laura Schwartzman** from the University of the Republic of Uruguay, Montevideo, Uruguay.

Unfortunately, Drs. John Brazier, Dominique DuBois, Dennis Gagnon and Ms. Mona Martin were not quite successful. We do hope that they will consider running again next year, since the ISOQOL Board is always looking for the best candidates to fill Board vacancies as they arise. The voting was very close, and it is unfortunate that not everyone can be elected. However, we do believe in giving the membership a choice of candidates rather than presenting just one slate.

We trust that the wishes of the membership have been fulfilled, but we do wish to point out that voter turnout was only about 25%. We urge you to vote next year to make sure that your wishes have been fully expressed.

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## ISOQOL JUNE 2004 MEETING, BOSTON, MA, USA

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*Bill Lenderking, PhD and Dennis Revicki, PhD, 2004 Symposium Co-Chairs*

ISOQOL is trying an experiment this year! In addition to our late fall annual meetings, held in Prague in 2003 and Hong Kong in 2004, we are holding a mid-summer meeting at the Park Plaza hotel in Boston, June 27-29, 2004. This meeting, entitled, “**Stating the Art: Advancing Outcomes Research Methodology and Clinical Applications**” is designed to allow participants to immerse themselves in the latest advances in the field of outcomes research as they pertain to patient-reported outcomes. We have organized the meeting into two tracks, methodology and clinical applications, so that attendees will be able to stay within a single track throughout the meeting or switch according to their preference. By locating the meeting in Boston, we have been able to take advantage of our proximity to leading universities and health researchers to invite some wonderful speakers and teachers. The meeting will start on Sunday with an excellent collection of 3-hour workshops. The meeting itself will run from Monday morning until Tuesday afternoon. Each session will include invited talks from leading researchers in the field, as well as submitted abstracts. Note that we are inviting abstracts around the specific topics being presented in each session, so be sure to indicate under what theme you would like your abstract to be considered when you submit. We will also have a lively poster session throughout the meeting. As always, your work will be considered by the Symposium Planning Committee—please don’t be intimidated by the revised format. Everyone’s work will be considered.

Boston is well-known for its weather (the rest of the year), but summertime in Boston is a soft, gentle season, with hot days and warm nights, baseball in

the park, sailing on the river, sidewalk cafes, and lots of culture. The hotel is located right in downtown Boston, a short distance from the theater district, shopping, restaurants, live music, and so on. Beaches are a short distance away by car. The social committee promises to offer meeting participants several group activities on Monday evening. Travel to Boston is also easy by air. Logan Airport is very convenient to the meeting site, but bargain fares for domestic travelers can be obtained by flying into Providence, RI or Manchester, NH and taking a shuttle or renting a car (about one hour’s distance). On behalf of the ISOQOL 2004 Symposium Planning Committee, we look forward to greeting you in Boston next summer!

**Visit the ISOQOL website at [www.isoqol.org](http://www.isoqol.org) for more information including the Call for Abstracts in November, 2003. The deadline for abstract submission is January 10, 2004.**

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## APPOINTMENT OF NEWSLETTER EDITOR AND ASSOCIATE EDITOR

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Carola Bardage, PhD has been appointed Editor of the ISOQOL newsletter. With an MSc degree in Pharmacy, she received her PhD degree in Pharmacoepidemiology. She is currently a researcher and teacher at Uppsala University. Presently, as well as a postdoctoral researcher at the Department of Medical Epidemiology and Biostatistics at the Karolinska Institutet in Stockholm.

Adam Smith, M.Phil is a research psychologist working at the Cancer Research UK Clinical Unit, St. James’s University Hospital, England. His background is in experimental psychology, and he has worked as a research assistant on various projects before taking up his current position 8 years ago. His main areas of research and interest are methodological, and include exploring the use of Rasch models in quality of life research.

Welcome to the new Editor and Associate Editor!



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## HOW “I” IS THE “I” IN ISOQOL

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David Osoba, MD, Canada  
Past President, ISOQOL

“The International Society for Quality of Life” – that’s our title, so we all know that the “I” in ISOQOL stands for International. But how international are we – truly international? Many organizations call themselves “international”, but on closer inspection, it is evident they are comprised of a relatively few countries (out of all the countries in the world) and most of those are in Europe and North America. Are we the same? Are we mainly a European and North American organization?

Let’s look at the numbers. At the end of 2002, we had members from 44 countries, 24 of which are situated in Europe, but some of these (4) are in the Middle East. Perhaps it may surprise you to know that we have members from 11 Asian countries as well as from Australia and New Zealand! We also have members from 3 South American countries and from one African country. (Perhaps it’s not a surprise that we have none from Antarctica, as yet!)

So, the answer to my question is that we are decidedly not just European and North American. It’s true that the majority of our members hail from there, but over 10% of the membership is Asian. This is highly encouraging, particularly since Asian membership has grown three-fold in the past few years.

In it’s strategic planning, the Board of the Society has affirmed that part of our mission is to become truly and broadly international. We are gradually succeeding, but all too slowly, since we know from regional meetings held in Japan and Hong Kong recently that there is a great interest in QOL research in many parts of Asia. We could do more there and gain more members.

We should take the many messages that are part of ISOQOL’s activities to parts of the world that are showing a

rapidly increasing rise in interest in QOL research. Indeed, ISOQOL, with its unique combination of teaching and of basic and applied research, should be active all over the world. We are in the best position to provide a complete program, academically inspired and unvested of commercial interests.

We hope you will come to the 2004 Annual meeting in Hong Kong. It’s a way of making our presence known and of bringing our workshops and scientific findings to more researchers and clinicians in Asia, many of whom can’t find a way to pay for travel to a meeting in Europe or North America every year. On the other hand, we Europeans and North Americans *can* afford to travel outside of our continents from time to time.

The SARS outbreak in Hong Kong and China is now controlled. It’s strange to me, as a physician, to think how much fear has been generated by this disease. It’s new and it’s contagious – yes – but so is the flu. The flu kills tens of thousands of people every year and yet no one curtails their travel because of it. We are used to it. We live with it every winter. We rarely know of anyone who has died from it, so we are not afraid of it. SARS is far less dangerous. By October of 2004 it may well be a part of history. So, plan to come to Hong Kong. I’ll be there!

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### ISOQOL OUTSTANDING ARTICLE OF THE YEAR AWARD

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Jane Scott, PhD, USA  
Chair, Article of the Year Committee

The Board commissioned a task force to develop and assist in the administration of the OAYA award. Members of the OAYA taskforce included Jordi Alonso, David Cella, Peter Fayers, Jane Scott (chair) and Albert Wu. Together, the OAYA taskforce developed proposed guidelines for the award that were approved by the Board.

In this inaugural year, we received 5

nominations for the ISOQOL Outstanding Article of the Year Award. At this year’s annual meeting awards banquet in Prague, Czech Republic, ISOQOL will award the winners of the 2003 award. Congratulations to all the authors for their significant contribution to the science of health-related quality of life research. Below are the exceptional articles received as nominations that you won’t want to miss reading:

Bernstein D, Kleinman L, Barker CM, Revicki DA, Green J. Relationship of health-related quality of life to treatment adherence and sustained response in chronic hepatitis C patients. *Hepatology*. 2002 Mar;35(3):704-8.

Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. *Journal of Health Economics*. 2002 Mar; 21(2):271-92.

Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Health-Related Quality of Life Assessments and Patient-Physician Communication. *Journal of the American Medical Association*. 2002 Dec 18;288 (23):3027-34.

Domingo-Salvany A, Lamarca R, Ferrer M, Garcia-Aymerich J, Alonso J, Felez M, Khalaf A, Marrades RM, Monso E, Serra-Batlles J, Anto JM. Health-related quality of life and mortality in male patients with chronic obstructive pulmonary disease. *American Journal of Respiratory Critical Care Medicine*. 2002 Sep 1;166 (5):680-5.

Feeny D, Furlong W, Torrance GW, Goldsmith CH, Zhu Z, DePauw S, Denton M, Boyle M. Multiattribute and single-attribute utility functions for the health utilities index mark 3 system. *Medical Care*. 2002 Feb;40(2):113-28.

Thanks to former ISOQOL Presidents Donald Patrick, Robert Kaplan, Monica Bullinger, Sharon Wood-Dauphinee, Ivan Barofsky, and David Osoba, who served as the jury panel who reviewed the nominated articles.

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## NEW HORIZONS: ISOQOL 2004 ANNUAL CONFERENCE - HONG KONG

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*Madeleine King, PhD, 2004 Conference Committee Co-Chair*

The annual meeting is the highlight of ISOQOL's calendar: an opportunity for members to exchange news and views, to find out what the experts think, to get together with old friends and meet new ones. It is also a time for your own personal quality of life; a chance to broaden your horizons, to learn about other parts of our fascinating and diverse world. Over the years, we have met in 10 wonderful cities: Brussels 1994, Montreal 1995, Manila 1996, Vienna 1997, Baltimore 1998, Barcelona 1999, Vancouver 2000, Amsterdam 2001, Orlando 2002 and Prague 2003. With the exception of 1996, the annual meetings have alternated between Europe and North America. But with increasing interest and activity in HRQOL research across Asia, the time is right for ISOQOL to meet there again. So it is with great pleasure that ISOQOL and our conference co-organizers, the Hong Kong Hospital Authority, invite you to join us for ISOQOL's 11th annual scientific meeting in Hong Kong, 16-19 October 2004.

Hong Kong is one of Asia's business hubs, where centuries-old Chinese tradition blends with British colonial heritage and cutting-edge technology to create a fascinating, vibrant and cosmopolitan city with something for everyone. Our conference venue is the Jockey Club Building of the Hong Kong Academy of Medicine, an attractive, modern building with world-class state-of-the-art conference facilities. A selection of hotels is available nearby to suit every budget.

To foster the international network of QOL researchers, we will offer an innovative ambassador program. Local participants will be invited to be conference ambassadors. If you wish, an ambassador will be assigned to you

according to your research interests and specialty, well before you arrive in Hong Kong. Your ambassador will be able to link you to local QOL researchers and health organizations, and provide practical tourists tips on what to see and where to dine and shop in Hong Kong, as well as tourist options in Mainland China that may interest you. For those interested in the local health scene, we will offer tours of general hospitals and Chinese medicine facilities, both in Hong Kong and mainland China. And with mainland China just hours away, why not round off your conference experience with some of the world's most magnificent scenery.

Almost 50 ISOQOL members responded to our recent call for volunteers to help with preparations for the conference via the activities of the Scientific Committee. This is a wonderful response and a welcome indication of grass-roots support for Hong Kong 2004 - it augers well for the conference. I really appreciate the volunteers' enthusiasm and willingness to help. With their able assistance, and that of the Scientific Committee Co-chairs, Kwok-fai Leung and Margaret Tay, as well as ISOQOL's administrative partners, Degnon Associates, we are well on the way to a very successful meeting in Hong Kong 2004. If you'd like to get involved, its not too late. Feel free to email me at [madeleine.king@chere.uts.edu.au](mailto:madeleine.king@chere.uts.edu.au).

So please think about joining us in Hong Kong in October 2004. We look forward to making your trip safe, comfortable and very rewarding, both personally and professionally.

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## PRESIDENT'S MESSAGE

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*(Continued from page 1)*

M: Sounds good. How does the newsletter fare?

A: After what has actually been years of service, the team of Ulrike Ravens-Sieberer, Cindy Lam, Ted Ganiats and Patrick Marquis is stepping down. They deserve a long round of applause.

M: Bravo!

A: And a team headed by Carola Bardage and Adam Smith is stepping in. We look forward to an informative and entertaining product.

M: Great. What about our Journal?

A: Quality of Life Research continues under the admirable direction of Neil Aaronson. We have a new "Journal committee" which is headed by John Ware, that is charged with maximizing discussion back and forth with the ISOQOL board. The Journal is flourishing, and a decision was just taken to increase the number of issues from 8 to 10 per year. We will also be increasing the number of pages per issue. Together, this will assure that more articles come out quicker. We will also retain the popular Abstracts that will be distributed at the Annual Meeting as well a mailed to subscribers as usual.

M: What happened to the elections?

A: Congratulations are in order to David Feeny, who is our new President Elect to-be (as of November). I'll be very happy to pass the reins to him in November 2004. We also have new board members, including Kwok-fai Leung from Hong Kong, Laura Schwartzmann from Uruguay, Andrea Bezbek from Canada, and Andrew Bottomley from Belgium. But congratulations and thanks are really in order to all of the candidates who stood up, many of whom are likely the new usual suspects for future elections.

M: I am very pleased to hear all this. Albert, I'm so grateful to you. You, Laura Degnon, Diane Fairclough, and David Osoba, are to be commended for your hard work during the summer. I am very glad that you continued to make consensus decisions and involved the entire board whenever needed. Many thanks and kudos to the entire team. I look forward to seeing you and our other colleagues in beautiful Prague this November.

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## UPDATE ON THE 2003 ISOQOL ANNUAL CONFERENCE

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*Joanne Greenhalgh, MPH and  
Elaine McColl, MSc*

There is every indication that this year's 10<sup>th</sup> anniversary ISOQOL conference to be held in Prague 12<sup>th</sup>-15<sup>th</sup> November will be a very special occasion. For a start, it is being held in one of the most beautiful and fascinating cities in Europe. Secondly, this year's conference saw a record number of 615 abstracts submitted, a clear sign that quality of life research is continuing to grow at a very healthy rate. The Scientific Committee, chaired by Donna Lamping and Jane Blazeby, have been working hard to bring you a programme that will have something for everyone, and will ensure that ISOQOL celebrates its 10<sup>th</sup> Anniversary in style.

This year's plenary speakers are internationally renowned in a diverse range of fields and will address a variety of topical issues. On Thursday, Nov. 13<sup>th</sup>, Paul Cleary will discuss the use of patient reports to assess the consequences of health care and Chris Murray will consider methods to measure health across nations. On Friday, Nov. 14<sup>th</sup>, John Wasson will explore the contribution of HRQOL measures to office practice and Ellen Idler will examine the relationship between self-ratings of health and mortality. On Saturday, Nov. 15<sup>th</sup>, there is a special plenary session to celebrate ISOQOL's 10<sup>th</sup> anniversary that will address some of the current challenges faced by HRQOL research. Ivan Barofsky will reflect on how we can bridge the gap between quantitative and qualitative research, Monika Bullinger will provide a critical review of cross national quality of life research, David Osoba will discuss the use of HRQoL in clinical practice and John Ware will consider how new technology may change the face of HRQoL measurement.

Other highlights to this year's conference are the invited symposia

that reflect the debates that are currently informing quality of life research. These include the measurement of patient satisfaction, the role of culture in quality of life assessment, assessing the clinical significance of changes in HRQoL, the use of quality of life in resource allocation, an example driven approach to the use of HRQoL measures in clinical practice and the contributions of Jim Bush to HRQOL through the oral history project. Given the large number of high quality abstracts received this year, the oral and poster sessions are sure to be a source of inspiration and lively debate. The oral sessions have a more methodological focus this year, while at the same time addressing the measurement of HRQoL in specific conditions, populations and settings.

There will also be plenty of opportunities for networking and catching up with friends and colleagues. Another mentor-mentee breakfast will be held, following its success last year. This provides a valuable opportunity for early career researchers to meet with more experienced researchers in their field to discuss career related issues. If you are interested in being either a mentor or a mentee, be sure to indicate this on your registration form. There will also be a business lunch on Friday, Nov. 14<sup>th</sup> where attendance is open to everyone, whether you are an ISOQOL member or not. This provides an opportunity to learn more about what ISOQOL can offer you as well as brainstorm new initiatives that will better serve you. It will also give you the chance to become more involved in ISOQOL activities including task forces, committees and leadership positions. You can sign up on your registration form.

We hope that you will be able to join us in Prague to make the 10<sup>th</sup> anniversary ISOQOL conference the success that it promises to be.

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## IMPORTANT INFORMATION ABOUT TRAVEL TO THE CZECH REPUBLIC

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Situated in the heart of Europe, Prague is easy to reach by air or rail or car. Prague International Airport is served by dozens of international carriers from most major cities. Trains run daily between Prague and most major European cities such as Paris, Amsterdam, Munich and Vienna, to mention a few. Once you arrive in Prague, the City Transport system makes getting around easy.

**Entry Visas** - One very important piece of information you will need to explore before leaving for Prague is the Czech Republic's rule and regulations about "Entry Visas." Most countries are NOT required to obtain Entry Visas, however, to be sure of your own countries status, please visit this very helpful website at <http://www.czech.cz/index.php?section=1&menu=141>. It contains very helpful information about entry into the Czech Republic. **For example, citizens of the United States do not need to obtain an entry Visa, however, citizens of Canada and Australia are required to obtain a visa.** We highly recommend you take this seriously, especially since visas cannot be obtained at Prague's airport and may take weeks to obtain through the Czech Embassy in your country.

The unit of the Czech money is Ceska Koruna, or Crown, abbreviated KCZ or CZK (for Koruna Ceska). While the Czech currency is floating and could increase or decrease at any time, it rarely falls below the rate of 30 KCZ to one US dollar.

The city's main foreign-exchange banks are: American Express, Ceska Obchodni Banka, Komerčni Banka, Thomas Cook, and Zivnostenska Banka. Banks charge 2-3% commission for cash exchange; they are generally open Mon-Fri. 8 a.m. – 5 p.m. At any other time or on weekends you can use some Bureau de change offices in the center of Prague.

## Wednesday, November 12

8:00 am - Registration Opens  
(Lounge Forum)

9:00 am - **Workshops**  
12:00 pm 1, 2, 3, 4, 5, 6

1:00 - **Workshops**  
4:00 pm 7,8,9,10,11,12,13

6:00 pm Welcome Reception

## Thursday, November 13

7:30 - Mentor/Mentee Breakfast  
8:30 am

8:00 am Posters on Display:  
12:45 pm Poster Session I

8:45 - Presidential Welcome  
9:00 am

9:00 - **Plenary I**  
10:15 am

10:15 - Break / Meet the Authors:  
11:15 pm Poster Session I

11:15 am - **Oral Sessions/  
Symposium**  
12:45 pm  
Psychometrics  
Family & Caregivers II  
(Children)  
Missing Data  
Utility: Comparison of  
Methods  
Interpretation

**Symposium I**  
Oral History Project: The  
Contributions of Jim Bush  
to Quality of Life  
Research

12:45 Posters on Display:  
6:30 pm Poster Session II

12:45 - Lunch on you own **-or-**  
2:00 pm Lunch Session  
"Translating the Science of  
QOL Assessment into  
Clinical Practice: An  
Example-Driven Approach  
for Practicing Clinicians  
and Clinical Researchers

2:00 - **Oral Sessions**  
3:30 pm  
Qualitative  
Cardiovascular Disease  
Scale Development II  
Utility: Comparison of  
Methods  
Interpretation

3:30 - Break  
4:00 pm

4:00 - **Invited Symposia**  
5:30 pm  
A. Patient Satisfaction  
B. The Role of Culture in  
Quality of Life Assess-  
ment

5:30 - Posters Session II / Meet  
6:30 pm the Authors

## Friday, November 14

8:00 am Posters on Display:  
12:45 pm Poster Session III

9:00 - Plenary II  
10:15 am

10:15 - Break / Meet the Authors:  
11:15 am Poster Session III

11:15 am - **Oral Sessions/  
Symposium**  
12:45 pm  
Scale development/  
validation  
Oncology 2  
Measuring Change

**Symposium II**  
Evidence Regarding  
Children's Ability to Self-  
Report on Their Health

**Symposium III**  
Quality of Life in Special  
Populations

12:45 Posters on Display:  
6:30 pm Poster Session IV

12:45 - Business Meeting Lunch  
2:15 pm and Networking Session

2:15 - **Oral Sessions/  
Symposium**  
3:45 pm  
IRT  
Public Health & QOL  
Misc. Methods II  
Proxies

**Symposium IV**  
The Value of HRQOL  
Assessments in Routine  
Oncology Clinical  
Practice: Issues and  
Evidence

3:45 - Break  
4:15 pm

4:15 - **Oral Sessions**  
5:45 pm  
Methodology  
Mode of Administration  
Chronic Illness  
Responsiveness  
Cultural adaptation/  
translation  
Theoretical / Conceptual

5:45 - Poster Session IV / Meet  
6:45 pm the Authors

## Saturday, November 15

8: am Posters on Display:  
12:45 pm Poster Session V

9:00 - Plenary III  
10:15 am

10:15 - Break / Meet the  
11:15 am Authors: Poster  
Session V

11:15 am - **Oral Sessions/  
Symposium**  
12:45 pm  
Oncology 1  
Misc. Methodology  
Treatment Satisfaction  
Family & Caregivers I

**Symposium V**  
Challenges in the  
Translation  
Methodology:c  
Comparing Ap-  
proaches and a  
Discussion of Good  
Practice

12:45 Posters on Display:  
6:30 pm Poster Session VI

12:45 - Lunch on your own  
1:45 pm

1:45 - **Oral Sessions**  
3:15 pm  
Predictors of QOL  
Response Shift  
Clinical trials/practice  
Psychosocial  
intervention  
Methodology III

3:15 - Break / Meet the  
4:15 pm Authors: Poster  
Session VI

4:15 - **Invited Symposia**  
5:45 pm  
"Clinical Significance  
of Changes in HRQL  
Scores"

"The Use of Quality  
of Life Valuations in  
Resource Allocation in  
Health Care: A  
Critical Debate"

8:00 pm Social Dinner/  
Awards and Closing  
Ceremony at  
Municipal House

**PLEASE NOTE:  
WORKSHOPS AND  
\*THURSDAY'S LUNCH (\*if  
you want lunch  
provided) REQUIRE  
ADDITIONAL FEES AND  
REGISTRATION IS  
REQUIRED.**



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## ISOQOL WELCOMES NEW MEMBERS

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**Richard Adams PhD**

New York Academy of Medicine  
New York NY, USA

**Louise Allen PhD**

Pfizer, Ltd.  
Bucks, UK

**Maru Barrera PhD**

Hospital for Sick Children  
Toronto, ON, Canada

**Silvina Berra MPH**

Barcelona, Spain

**Kevin M. Biglan MD**

Johns Hopkins University  
Baltimore, MD, USA

**Catharine Bradley MSc**

Hospital for Sick Children  
Toronto, ON, Canada

**Joan Branin PhD**

University of LaVerne  
LaVerne, CA, USA

**Melanie Calvert PhD**

Univ. of Birmingham  
Birmingham, UK

**Bettina Caporale**

State University  
Montevideo, Uruguay

**Marianne Carlsson PhD**

Uppsala University  
Uppsala, Sweden

**Mary Cooley PhD, RN**

Dana-Farber Cancer Institute  
Boston, MA, USA

**Madeline Cruice**

City Univeristy  
London, UK

**Gillian Currie PhD**

University of Calgary  
Calgary, AB, Canada

**Martina Deibl MSc**

Institute of Biostatistics & Doc.  
Innsbruck, Austria

**Lisete Del Bianco**

Pontificia Universidade Catolica  
Sao Paulo, Brasil

**Vlatka Duric BSc**

University of Sydney  
Camperdown, NSW, Australia

**Todd C. Edwards PhD**

University of Washington  
Seattle, WA, USA

**Astrid Engbersen**

Novartis Pharma BV  
Amhem, The Netherlands

**Simon Ferrazzi MSc**

Janssen-Ortho Inc.  
Toronto, ON, Canada

**Dennis Fryback PhD**

University of Wisconsin  
Madison, WI, USA

**Sergey Golubev PhD**

Saitama Cancer Center  
Saitama, Japan

**Jacek Kopec MD**

Arthritis Research Centre of Canada  
Vancouver, BC, Canada

**Agnes Zsofia Kovacs**

Semmelweis Univ.  
Budapest, Hungary

**Marline Kovacs**

Foundation for Informed Medical  
Decision Making  
Boston, MA, USA

**Daniel Kuessner**

University of Ragneburg  
Hannover, Germany

**Hsien-Wen Kuo**

China Medical Univ.  
Taichung, Taiwan

**Stephanie Land**

NSABP and University of Pittsburgh  
Pittsburgh, PA, USA

**Chia-Ing Li**

Taichung, Taiwan

**Tsai-Chung Li**

China Medical Univ.  
Taichung, Taiwan

**Chulaporn Limwaltanon**

Khon Kaen University  
Khon Kaen, Taiwan

**Daniel Longo ScD**

Univ of MO - Columbia  
Columbia, MO, USA

**Sheri Maddigan MScPharm**

Univ of Alberta  
Edmonton, AB, Canada

**Colleen Maxwell PhD**

University of Calgary  
Calgary, AB, Canada

**Joanna Mazur PhD**

National Res. Inst. of Mother & Child  
Warsaw, Poland

**Jennifer Morone**

Dana-Farber Cancer Institute  
Boston, MA, USA

**Mariko Naito**

Kyoto University  
Kyoto, Japan

**Alberto Jose Ogata MD**

Associacao Brasileira de Qualidade  
Sao Paulo, Brazil

**Kavita Patel MBA**

Hoffman LaRoche, Inc.  
Nutley, NJ, USA

**Ellen Perrin**

Tufts New England Medical Center  
Boston, MA, USA

**James Perrin MD**

Mass General Hosp for Children  
Boston, MA, USA

**Morten Petersen MScI**

Bispedjerg Hospital  
Copenhagen, Denmark

**Alexandra Quittner PhD**

University of Florida  
Gainesville, FL, USA

**Bryce Reeve PhD**

National Cancer Institute  
Bethesda, MD, USA

**Afsane Riazi PhD**

Inst. of Neurology Queen Square  
London, UK

**Joe Ridge**

Haslemere, UK

**Nancy Roberts PhD**

Mayo Clinic Scottsdale  
Scottsdale, AZ, USA

**Doris Rubio**

University of Pittsburgh  
Pittsburgh, PA, USA

**Bernice Ruo MD**

University of California  
San Francisco, CA, USA

**Jisoo Ryu**

Research Institute of Oriental Medicine  
Seongnam City, South Korea

**Tonya Schuster**

Univ of CA - Irvine  
Irvine, CA, USA

**Kate Senior**

University of Wollongong  
Wollongong, NSW, Australia

**Ana Flavia Barros de Silva Lima MS**

Universidade Federal do Rio grande  
Porto Alegre, Brazil

**Meredith Smith PhD**

Purdue Pharma, LP  
Stamford, CT, USA

**Barotfi Szabolcs MSc**

Quintiles  
Budapest, Hungary

**Charles Taft PhD**

Goteborg University  
Goteborg, Sweden

**Margaret Tay**

Hospital Authority  
Kowloon, Hong Kong

(Continued on page 9)



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## NEW MEMBERS

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(Con't from page 8)

**Ute Thyen**

Universitaetsklinikum Schleswig-Holstein  
Luebeck, Germany

**Marieke Tollenaar MS**

University of Amsterdam  
Amsterdam, The Netherlands

**Teresa Topolski**

University of Washington  
Seattle, WA, USA

**Elyse Trudeau**

MAPI Values  
Lyon, France

**Wan-Sik**

Uhm Hospital for Rheumatic Disease  
Seoul, Korea

**Jennifer Walker BSc**

University of Calgary  
Calgary, AB, Canada

**Young Ho Yun MD**

National Cancer Center  
Goyang, Korea

**Lisa Zetes-Zanatta**

Queens Cancer Research Institute  
Kingston, ON, Canada

ISOQOL would like to welcome all of these new members. If you know of a colleague that could benefit from membership in ISOQOL, please contact the ISOQOL Executive Office at [info@isoqol.org](mailto:info@isoqol.org).

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## MEMBERSHIP MATTERS!!

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*Elaine McColl, MSc, ISOQOL  
Membership Committee Chair*

As with any society, ISOQOL's greatest asset is its membership. Without the members, there would be no society. The Board and Membership Committee of ISOQOL are delighted that you have chosen to renew your subscription – if you had not, you would not be reading this newsletter! As we said in our letter of welcome to all those renewing their subscription, we are keen to share your ideas for how we can make the society as relevant and responsive as possible to the needs of researchers and practitioners in the field of quality of life. We want to ensure that we continue to meet your needs and provide you with good value for your

membership fee. Please let me, as chair of the Membership Committee, know what you think of the society and what you would like to receive from your membership – my e-mail address is [e.mccoll@newcastle.ac.uk](mailto:e.mccoll@newcastle.ac.uk) and I look forward to hearing from you. Current membership stands at 566. The vast majority of our members are 'regular' members, but student membership is steadily growing and we continue to attract members from non-industrialised nations, who – like students and the retired – can take advantages of a significantly reduced membership fee. Our members come from a wide variety of disciplinary backgrounds, including medicine, statistics, psychology, economics and nursing. In terms of primary work area, academia dominates (58%) but significant numbers of members also work in clinical settings and in industry. Members are drawn from 39 countries across five continents (we have no members from Africa), though the vast majority are based in North America or Europe.

A priority for the coming years is to widen our geographical base and to attract more members from South America, Asia, Australia and Africa. Quality of life researchers and practitioners in many of these countries are entitled to the concessionary membership rates for non-industrialised nations – so spread the word, and encourage your international colleagues to join us! To this end, the membership committee has produced a 'Please Join' letter, to alert those with an interest in quality of life research to the existence of ISOQOL and to the benefits of membership. This letter can be made available to any ISOQOL member who can then tailor it to suit particular circumstances (e.g. emphasising reduced rate membership for students or those from non-industrialised countries) before sending it to targeted colleagues. If you would like to help our membership drive by sending this letter of invitation to colleagues, please contact the ISOQOL office at [info@isoqol.org](mailto:info@isoqol.org). As a committee, we are planning to send

copies to folk we know to have an interest in quality of life research, including non-members presenting at this year's annual scientific meeting in Prague, and authors of papers in *Quality of Life Research*. We hope that this personalised, targeted approach will encourage many new members to sign up. Just think – if each one of us signed up just one colleague, we could double our membership!

While we have a strong and loyal core of folk who renew their subscription year on year, analysis of the membership figures for the last few years also shows that a significant number of people let their membership lapse after a year or so. For example, 153 of those who were members in 2001 did not renew their membership in 2002, almost exactly off-setting the 170 new members for 2002. Of course, some of those who do not renew their subscriptions may no longer be working in the field of health services research. But we suspect that is not the only reason for non-renewal, since some of these individuals attended the annual scientific meeting in the same year. So, we're also targeting those who don't renew with a special 'Don't Leave' letter, reminding them of the benefits of membership. With the letter, we enclose a short questionnaire asking why they have not renewed. We hope that analysis of these data will help us to identify why people perceive that ISOQOL is 'not for them' and to address these barriers to continued membership. If you know someone who has decided to leave ISOQOL, please encourage them to let us know why – once again, e-mail me at [e.mccoll@newcastle.ac.uk](mailto:e.mccoll@newcastle.ac.uk).

We hope that all of these initiatives will lead to a growing and vibrant society and I look forward to a successful year for ISOQOL.

*For more information about the benefits of membership in ISOQOL, please visit our website at [www.isoqol.org](http://www.isoqol.org).*

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**2004 ISOQOL Symposium  
“Future of HRQL Measurement:  
Methods and Applications”**

June 27-29, 2004  
Boston, MA

**~Call for Abstracts - November, 2003~**



**ISOQOL 11th Annual Conference  
Hong Kong ~ October 16-19, 2004**

Join us in this exciting, colorful  
and truly international city as we  
extend ISOQOL’s activities to  
Hong Kong.

**~Call for Abstracts - February, 2004~**

For more information on all these events, visit our website at [www.isoqol.org](http://www.isoqol.org).