



# International Society for Quality of Life Research

Volume 8 Issue 1

Newsletter for ISOQOL Members

Spring 2003

## PRESIDENT'S MESSAGE

*Mirjam Sprangers, PhD  
Amsterdam, The Netherlands*

Your board of directors, committee chairs, and the executive office have held a productive two-day board meeting in early April. The internal board training was focused on knowledge-based decision making. The key is to obtain good quality information to allow us to make the best decisions.

This insight was used in subsequent strategic planning discussions. Based on previous strategic plannings, we identified, discussed, prioritized, and planned the goals and tasks for the next three years. We agreed to take on a number of new tasks. Examples are first to identify and encourage the development of emerging areas in HRQL research, as a way to promote excellence in science. Second, to identify our stakeholders (i.e. consumers, providers, and sponsors of HRQL information or its methodology) and to assess their needs and interests. This information will enable us to promote the appropriate use of HRQL in research, practice, and policy. Third, to conduct a survey to understand the needs of our members and potential members to better attract and engage a diverse global membership.

We are aware that for a small society as ISOQOL the challenge is to ensure that such tasks will get implemented. We therefore tried to set realistic goals and timelines. Meanwhile the board and the executive office are working on improving the functioning of the committee structure and reporting system. We will also give the committee chairs and members more limited, more specific, and

clearer charges and provide them with adequate support.

Other major topics that were discussed during the board meeting were:

- Plans for future scientific conferences, symposia, and workshops. Importantly, the planning of our 10<sup>th</sup> meeting in Prague is well underway. The program committee co-chairs Donna Lamping and Jane Blazebly and their committee members have done an excellent job in devising an attractive and varied program. They succeeded in inviting outstanding plenary session speakers and first-rate chairs for invited symposia. A highlight will be the special 10<sup>th</sup> Anniversary Planning session (for more information see page 10 in this newsletter). The number of parallel oral sessions is expanded from 3 to 4 sessions since last year, allowing more oral presentations while keeping the challenge for choosing among concurrent sessions relatively limited (we had up to 6 parallel sessions in past years).

- A report on the Quality of Life Research journal including new ideas about how to make the journal more attractive to a wider audience (e.g. including substantive and clinical research reports) and ideas how to make the journal more profitable.

- The accountant's review report of 2001 and 2002. While ISOQOL is financially in good health, an important goal for the next year is to raise funds to support our goals and activities, and to establish a policy for securing reserve funds.

We reviewed many other interesting topics such as the new activities of the membership committee (chaired by Elaine McColl) to enhance retention and recruitment of members, the improvements to our website (headed by Jim

Donnelly), and the progress on projects on "oral history" (led by Ivan Barofsky) and "establishing standards for documenting terms and conditions of use for instruments" initiated by John Ware). You will hear about these activities in future issues of the newsletter and on our website. As you can see, the society is alive and vibrant, thanks to many members who donate their time, expertise, ideas, and skills.

This newsletter contains information on the 2003 candidates for election of president-elect and new board members. The slate of nominees is remarkably excellent and balanced according to region. Every vote is important. The elected candidates will represent you and will further the society on your behalf. Please, read the biosketches and cast your vote.

I wish you enjoyable and productive months until the next issue of the newsletter.

## IN THIS ISSUE . . .

**ISOQOL is pleased to announce the 2003 candidates for this year's leadership election.**

**See pages 4-7 and then cast your vote with the ballot enclosed by June 30, 2003.**

**ISOQOL is proud to welcome its 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.**



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*Newsletter Editors*  
**Ted Ganiats MD, USA**  
**L.K. Cindy Lam FRCGP, China**  
**Patrick Marquis MD, USA**  
**Ulrike Ravens-Sieberer, PhD, MPH, Germany**

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

Send articles to:  
 ravens-siebereru@rki.de

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ISOQOL is managed by Degnon Associates.

*Executive Director*

**George K. Degnon, CAE**

*Associate Executive Director*

**Laura Degnon**

*Association Manager*

**Bette Anne German**

**6728 Old McLean Village Drive**

**McLean, VA 22101-3906 USA**

**PH: 703-556-9222**

**FAX: 703-556-8729**

**info@isoqol.org**

**www.isoqol.org**

**EXPERT TECHNICAL WORKSHOP TO DEVELOP A RESEARCH AGENDA AND RESEARCH RESOURCES FOR HEALTH STATUS ASSESSMENT AND SUMMARY MEASURES OF HEALTH**

**Expert Technical Workshop, March 26-28, 2003**

*Linda Blankenbaker*

Representatives from several U.S. Department of Health and Human Services (DHHS) agencies formed an informal InterAgency Working Group on Summary Measures of Health (IAWG) in early 2000. The formation of the IAWG is a reflection of a shared interest in improving measurement of health and tracking the burden of illness in large-scale population studies as well as clinical trials and observational studies. It serves as a forum for sharing multi-agency perspectives on summary measures of health.

The IAWG, with support from the Robert Wood Johnson Foundation, conducted an Expert Technical Workshop on March 26-28, 2003, to outline a research agenda for the continued development of the theory and practice of assessing health and to develop a set of requirements for research resources to support research on health status assessment (HSA), including summary measures of health (SMH). Co-Chairs of the Workshop were Edward J. Sondik, Ph.D. (Director, National Center for Health Statistics), and Donald L. Patrick, Ph.D. (Professor, University of Washington). Approximately 70 persons attended the invitational Workshop, about half from the extramural research community.

To initiate discussion of the research resources part of the agenda the members of the IAWG developed a "Starting Point Proposal" as a "strawman." The proposal called for a survey-derived data resource that would include

health status measures (and health preferences) as well as additional information such as demographics and health conditions. Goals of the proposed large-scale data resource were to promote and support research on measures of health and to monitor population health. Its potential uses were to facilitate comparison of multiple summary measures of health for a variety of applications, evaluation for heterogeneity in preference weighting across subgroups, and developing an item bank.

The Workshop featured five commissioned paper presentations, each with a respondent. Presenters included: Marthe Gold, M.D., "Health Status and Summary Measures of Population Health: Recommendations Past and Present;" discussant, Dean Jamison, Ph.D.; Dennis Fryback, Ph.D., "Understanding and Comparing Existing Summary Measures of Health and Health-related Quality of Life;" discussant, William Furlong; Colleen McHorney, Ph.D., "The Ten D's of Health Outcomes Measurement for the 21<sup>st</sup> Century;" discussant, Ron Hays, Ph.D.; John Brazier, Ph.D., "Current State of the Art in Preference-based Measures of Health and Future Promising Approaches;" discussant, Pennifer Erickson, Ph.D.; and Michael Wolfson, Ph.D., "On the Policy Implications of Summary Measures of Health Status;" discussant, Robert Kaplan, Ph.D.

These papers and the discussions about them served as foundation for break-out sessions which had as their ultimate goal the creation of recommendations for research and application to achieve development, acceptance, and use of summary measures (1) appropriate for surveillance and monitoring of population health and (2) appropriate for applications in clinical trials and observational studies.

The break-out groups identified activities to advance the field (including population health and clinical trials/observational studies). Questions posed included: What activities should be considered? What will be required for them to be successful? What are their rela-

tive values/advantages? What are their relative limitations/disadvantages?

The groups also considered how the Starting Point Proposal could be refined to support the activities identified above and answered the following questions: What are the research priorities in the different areas of measurement of health that could be addressed by a large scale data collection effort of health status and health preference instruments? What instruments and assessments should be included in such a data resource? What are the additional data needs of such a resource? Whom does the IAWG need to survey for this resource? What is the ideal vehicle for data collection for such a resource? What are the research priorities that can be addressed by a large-scale resource that would not be feasible in the absence of such a resource?

Once each group identified activities (in the first exercise), it attempted to fit them into matrices, according to whether the recommendations concerned development of measures, gaining acceptance, and putting measures to use. They were also tasked to array the recommendations in terms of whether their completion would be short-term (1-3 years), mid-term (4-7 years), and long-term (8-10 years).

On the last day of the Workshop, breakout session moderators presented the groups' specific recommendations for research, development, and evaluation activities pertaining to population monitoring and surveillance and clinical trials/observational studies. All participants were asked to cast a preliminary vote on their 10 priority recommendations for each category of recommendations. Overall the Workshop produced 69 recommendations for population monitoring and surveillance and 42 recommendations for clinical trials/observational studies. Participants had an opportunity to review the outcomes of first-round voting prior to adjournment of the Workshop.

Next steps include a second round of voting by mail to further refine the list

of priorities and preparation of proceedings. IAWG members will employ the outcomes of the Workshop in development of future research, development, and evaluation initiatives.

*Mrs. Blankenbaker is a Program Specialist in the Office of the Director, National Center for Health Statistics, and Executive Secretary of the Board of Scientific Counselors, NCHS, Center for Disease Control and Prevention in Hyattsville, MD.*

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## ANNOUNCING THE ISOQOL "OUTSTANDING ARTICLE OF THE YEAR" AWARD

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Beginning in 2003, ISOQOL will award the Article of the Year Award to recognize and honor the single best article dedicated to health-related quality of life (HRQL) research that was published in a peer-reviewed journal during the previous calendar year. This award recognizes the author(s) for significant intellectual contributions that promise to advance the state of the art in HRQL research methods or theory. The ISOQOL Article of the Year Award will be presented during the award ceremony at the annual meeting of the Society.

Each author of the winning article will receive a certificate and plaque recognizing the outstanding research. In addition, a cash prize of \$500 (US) and a 1-year paid membership in ISOQOL will be awarded (to be divided among all authors).

Any HRQL research article written by any author(s) that was published for the first time during the previous calendar year in a peer reviewed journal, will be eligible if nominated for this award by an active member of ISOQOL.

Any ISOQOL member may nominate an article by completing and submitting a nomination package. Self-nomination is permitted. If more than one person nominates a particular published article for

this award, a Lead Nominator will be assigned to assemble all nomination documents, submit the nomination package, and serve as the correspondent for all questions regarding the nomination. The deadline to submit a nomination is June 15, 2003.

For each nomination, a Nomination Package consisting of the following should be submitted to the ISOQOL Article of the Year Taskforce (Note: materials that are submitted with the nomination CANNOT be returned):

1. A complete copy of the published article must accompany the nomination.
2. A nomination letter should be provided that states why the article represents an outstanding contribution to the field of HRQL and describes how it advances HRQL research, clinical application or affects health policy.
3. Nomination will identify the author(s) and provide the full citation for the article.

The ISOQOL Board of Directors will appoint a Jury of ISOQOL members and a Jury Chair to serve as reviewers for this award. Jury members will be chosen based on their expertise in areas addressed in the articles submitted. If an article written by a member of the jury panel is nominated for the award, that Jury member will be removed from the Jury for the current year and the Board of Directors will appoint another ISOQOL member to serve on the Jury in his or her place.

After each member of the Jury reviews each article, the Jury will recommend the single article that promises to be the most significant advancement to HRQL research from all those nominated each year based on its scientific quality and societal relevance.

Should you have any questions regarding the Article of the Year award, please contact the ISOQOL Executive Office at [info@isoqol.org](mailto:info@isoqol.org) or call 703-556-9222.





# ISOQOL Election 2003

## Candidates for Nominations

April 2003

Special Election Insert

The ISOQOL Board is pleased to announce the 2003 candidates for this year's leadership election. Nominees for President are John Brazier, England and David Feeny, Canada. Those nominated for the four available Board of Directors positions are: Andrea Bezjak, Canada, Andrew Bottomley, Belgium, Dominique DuBois, Belgium, Dennis Gagnon, USA, Kwok-fai Leung, China, Mona Martin, USA and Laura Schwartzmann, Uruguay.

### FOR PRESIDENT

#### John Brazier

John Brazier is Professor of Health Economics and Director of the Sheffield Health Economics Group which is part of the multi-disciplinary School of Health and Related Research at the University of Sheffield. His main interests have been in the measurement and valuation of health for economic evaluation where he has published widely. He is perhaps best known for his work in developing a preference-based measure of health for the SF-36, but more recently has extended these methods to a number of condition specific measures. At the same time, he has been pursuing a more critical perspective on preference-based measurement, including a number of reviews for scientific journals and most recently he has been invited to prepare a review of the state of the art in preference-based measurement for a department of Health and Human Sciences Expert Technical Workshop on Summary Measures of Health.

He has always taken the view that quality of life research is a multi-disciplinary enterprise and he has devoted a large part of his research career to building a bridge between economic and psychometrics and more recently has been interested in the role of cognitive science and qualitative methods in the designing and testing of preference-based measures of health. He contributes more generally to the field through membership of Research Boards including the NHS HTA Commissioning Board and the MRC Advisory Board. He has had a direct involvement in policy making through his membership of the Appraisal Committee of the National Institute for Clinical Excellence of England and Wales.

John has been an active member of ISOQOL for many years, including the chairing and membership of Conference Scientific Committees. As an active member, he knows that the society exists primarily on the good will and hard work on its many members. He believes strongly in the continued importance of Quality of Life Research in health and that ISOQOL offers an important forum for developing and promoting the field. He would be very honoured to be its President and in this role would continue to champion the society and build on the excellent work of previous presidents.

#### David Feeny

David Feeny is a Professor at the University of Alberta and Fellow of the Institute of Health Economics. From 1976 to 1998 David was at McMaster University where he was a founding member of the Centre for Health Economics and Policy Analysis. David received his PhD in Economics from the University of Wisconsin-Madison in 1976. He has published extensively in health-related quality of life (HRQL), health economics, health-services research, health technology assessment, and on the determinants of health. David has developed several disease-specific measures and worked with generic profile measures. HRQL projects have included cancer, prenatal diagnosis, asthma, immune thrombocytopenic purpura, orthopedic surgery, stroke, cardiac rehabilitation, neonatal intensive care, COPD, arthritis, Alzheimer Disease, child health, primary care, cultural adaptation of measures, clinical trials, and population health.

Dr. Feeny, in collaboration with George Torrance, William Furlong, and others has developed widely-used direct preference measurement tools and two widely-used multi-attribute systems: Health Utilities Index (HUI) Mark 2 and Mark 3. HUI3 has been included in hundreds of clinical studies world-wide and in numerous population health surveys in Canada, the UK and the USA.

Currently David serves an Associate Editor of *Quality of Life Research (QLR)* and on the editorial boards of the *International Journal of Technology Assessment in Health Care*, *Pharmacoeconomics*, *Medical Decision Making*, and the *Canadian Medical Association Journal*. David has served on a Panel of the U.S. National Academy of Sciences, the Scientific Advisory Panel of the Canadian Coordinating Office for Health Technology Assessment, as well as on Scientific Program committees for ISOQOL, International Society of Technology Assessment in Health Care, and the International Association for the Study of Common Property (IASCP). David has experience in multi-disciplinary organizations and has served on the Board of Director of the Association for Asian Studies and as the President of the IASCP.

Dr. Feeny states "ISOQOL is the foremost forum for the exchange of knowledge on HRQL methods, drawing on diverse intellectual paradigms, disciplines, and areas of application. Major contributions include annual meetings and *QLR*. While preserving and enhancing those core activities, it will be important to increase membership and participation in ISOQOL by researchers from countries and disciplines not yet well represented."

(Continued on page 5)

## FOR THE POSITION OF BOARD MEMBER

### Andrea Bezjak

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Dr. Bezjak graduated from McGill University Faculty of Medicine in 1985. She obtained her specialty degrees in Internal Medicine (1989) and Radiation Oncology (1991) and has been on staff as a Radiation Oncologist at the Princess Margaret Hospital, Toronto since that time. She is an Associate Professor in the Departments of Radiation Oncology and Clinical Epidemiology & Health Care Research Program, Department of Health Policy, Management and Evaluation, at the University of Toronto. Her clinical interests include lung cancer, palliative radiotherapy and supportive care.

Her interest in Quality of Life was developed during her MSc studies in Clinical Epidemiology at McMaster University in Hamilton, Ontario; her MSc thesis was on clinical usefulness of quality of life instruments in oncology. She has been a member of the Quality of Life Committee of the NCIC (National Cancer Institute of Canada) Clinical Trials group, and replaced David Osoba as that committee's chair in 1997 (but their close collaboration continues). Through her involvement in QOL assessment in NCIC CTG clinical trials, she has developed a better understanding of the methodological and practical challenges, as well as opportunities in QOL research in clinical trials in oncology. She has enjoyed the scholarly interactions and exchanges with colleagues at the EORTC Quality of Life Study Group, the HRQOL Intergroup Committee and particularly the ISOQOL members. She has fond memories of the 1995 Montreal meeting, her first (and her then 6 month old daughter's first too!). She has had an opportunity to present at the Vancouver, Amsterdam and Orlando meetings. Her involvement with ISOQOL activities has included participating in the abstract review process for all the most recent three meetings, and being on the organizing committee of the Orlando meeting.

"I am honoured to be considered for a position of board member of ISOQOL. If elected, I would endeavour to promote the multidisciplinary exchanges, with particular focus on the clinical relevance of quality of life research."

### Andrew Bottomley

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Dr. Bottomley's background includes studies as a psychologist in the United Kingdom (UK) where he obtained a PhD by examining the impact of group psychological interventions on cancer patient HRQOL. Andrew has worked in several areas of health care outcome assessment. During the early 1990s he worked in the UK National Health Service conducting outcome studies on the treatment of angina, mental health and neonatal intensive care. For more than a decade, Andrew has confined himself to understand the consequences of cancer and its treatment on patient HRQOL. Since 1998, he has been employed in the academic research setting of the European Organisation for Research and Treatment of Cancer (EORTC), Belgium, where he leads a specialized HRQOL Unit. This post involves working at an international level, developing HRQOL outcome approaches and instrument methodology most suited to the clinical trial arena. "One of the biggest challenges is collaborating with the EORTC Quality of Life Group in developing outcome measures that met the increasing demand for robust, culturally valid outcome measurements. Working at the EORTC has given me the unequivocal opportunity to learn and then deliberate with many of the most influential and idiosyncratic leaders in HRQOL field, including Peter Fayers, Neil Aaronson, and Mirjam Sprangers."

He serves on several editorial boards, including *Lancet Oncology*, *The Oncologist* and *Expert Review of Pharmacoeconomics and Outcomes Research*; has more than 80 publications on HRQOL, covering clinical trial design, instrument development and methodology; serves on several bodies, including the WHO International Agency for Research in Cancer (Ethical Committee); has worked to boost opportunities to implement HRQOL as an outcome in trials collaborating with several organizations such as the National Cancer Institute of Cancer; and he regularly lectures for the European School of Oncology in Italy.

Andrew is active in ISOQOL and joining the board would mean "the opportunity to improve the use of HRQOL outcomes in the medical research community and encourage participation of younger members, like myself, in ISOQOL activities to advance such robust approaches that are practical for everyday use."

### Dominique DuBois

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Dr. DuBois had been a medical doctor since 1975 and specializes in Pharmaceutical Medicine. Dominique is currently employed as Director, Global Health-Economics, with Johnson & Johnson Pharmaceutical Services, LLC c/o Janssen Pharmaceutica in Beerse, Belgium and is responsible, amongst others, for the development, validation, analysis, and interpretation of patient-reported outcomes. He also has a faculty appointment in the University of Brussels post-graduate master programme in pharmacology and pharmaceutical medicine (PHARMED). He has over 15 years experience in designing and conducting health-related quality of life studies in a broad range of therapeutic indications. Prior to his involvement in patient-outcomes research, he worked in clinical research for more than 10 years.

His primary research interest is in studying patient-reported outcomes assessment tools, their applicability as clinical trial endpoints, and the clinical importance of change scores. He has led the development and validation of several disease-specific measurement instruments for gastrointestinal disorders and is an active participant in the ongoing European Commission supported International Health-related Quality of Life Outcomes Database (IQOD) Program. Dominique is also actively involved in the PRO Harmonization Group, ERIQA, and other regulatory advice initiatives.

(Continued on page 6)

## For the Position of Board Member (continued)

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### **Dominique DuBois (con't)**

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He participated in the preparation of a Royal Decree (21.12.01) defining the role of the new Belgian commission for reimbursement of pharmaceuticals. The Decree officially recognizes that health-related quality of life is a key determinant of therapeutic value.

“I look forward to share my medical and European experience and to strengthen the science-based partnering across the ISOQOL membership. ISOQOL provides a unique opportunity to work together for the patient. I am interested in serving on the ISOQOL Board because I want to help the Society promote the importance of the patient perspective on the impact of a health condition and its treatment on relevant aspects of life.”

### **Dennis Gagnon**

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Dr. Gagnon received his Master's degree in Philosophy and a second Master's degree in Economics, both from the University of California, Santa Barbara. Dennis has been continuously active in the area of Quality-of-Life (QoL) research for the past 14 years, having worked with MEDSTAT Systems, Inc. from 1987 to 1995 and with Johnson & Johnson from 1995 to the present. He is currently a Director in the Health Economics group, Johnson & Johnson Pharmaceutical Services, L.L.C. Dennis has published and presented in various areas, including QoL, Health Economics, and the Philosophy of Science. His work in QoL includes both applied and purely methodological pieces. Dennis' applied QoL work includes the development of questionnaires, the reporting of clinical trial treatment effects on QoL endpoints, and the interpretation of those results. Dennis' methodological work in QoL research includes the design of clinical trials in pharmaceutical development, the determination of the clinical significance of QoL results, the analysis of missing QoL data, cross-cultural validation of pooled multi-national trials, the philosophical distinction between patient-reported and clinical outcomes, and the purported normative aspect of utility theory. Dennis' current position with J&J includes being a member of the J&J Pharmaceutical Research & Development Protocol Review Committee, where he is responsible for the review and approval of all clinical trial protocols that include QoL endpoints. In a former life, during the early 1980's, Dennis was a political lobbyist representing the students of the University of California in Sacramento, California.

“My favorite motto is “Question Reality!” As an ISOQOL Board Member, I would apply my diverse background to seeing issues anew and from various perspectives. While maintaining absolute adherence to the principles of good scientific research, I also think it essential for ISOQOL to be socially responsible. Beyond facilitating research that has the potential to benefit all inhabitants of the globe, we are in a unique position to raise awareness of policies and actions that affect humanity's quality of life.”

### **Kwok-fai Leung**

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Dr. Leung is a practicing occupational therapist in Hong Kong. He is currently the Department Manger of the Department of Occupational Therapy of the Queen Elizabeth Hospital and the Cluster Manger of Occupational Therapy services in the Kowloon Central Hospital Cluster of the Hong Kong Hospital Authority. Kwok Fai graduated from the Occupational Therapy School of the Hong Kong Polytechnic in 1982. He obtained his master of philosophy degree in 1997 in the Department of Community Medicine of the Chinese University of Hong Kong. He got involved in the area of quality of life since 1994 when he represented the Hong Kong Hospital Authority to the WHOQOL group in the development of the Hong Kong version WHOQOL. He was the Project Manager of the multi-disciplinary project team in the HK Hospital Authority on development of the HK version WHOQOL. Kwok Fai has been member of the ISOQOL since 1995 and was one of the few delegates who attend the ISOQOL annual meeting from Asia throughout the years.

Kwok Fai is not a full time researcher. Rather, he is a full time clinician who has been trying to apply the theory of QOL and research findings of QOL in his clinical practices, especially in the area of rehabilitation of people with chronic illness and permanent impairment. He is an honorary research fellow in both the Baptist University of Hong Kong and Lingnan University of Hong Kong. He is co-supervisor of research projects on QOL of undergraduate and post-graduation studies. Kwok Fai is one of the key advocates of QOL in Hong Kong and Mainland China and has been heavily involved in the organization of many academic meetings / conferences on QOL.

“Many years ago, I was fortunate to be involved in this fascinating area of QOL service and research. I have chances to participate in the past ISOQOL activities and witnessed tremendous evolution of the Society. I have learned a lot and I think it is time for me to contribute. As a board member coming from China, I would try my best to promote the QOL services and researches to my fellow colleague in the health care and social sectors in Hong Kong as well as in the Mainland China. I would also try to attract more people from China and Hong Kong to be members of our Society”.

*(Continued on page 7)*

## For the Position of Board Member (continued)

### Mona Martin

Ms. Martin is a registered nurse, with a Masters Degree in Public Administration from the University of Kentucky. Coming from a public health and community development background, she began her research career at the University of Washington (Seattle) in 1986. After spending 9 years in the area of research methods and instrument development for health promotion programs, she became one of the founding partners, and Director of Health Research Associates (HRA) in 1995.

Through both her previous work at the University of Washington and currently as Director of HRA, Mona has participated in patient-based outcomes-research on an international basis, and has been a part of development teams for a variety of published measures, including the I-QOL, SFB, SAIL, MS-QOL, IBSQOL, OWL-QOL, US version of the WHOQOL, the N-QOL, the BPH-PIM, and the current effort to develop a WHOQOL version for older adults. She has directed several international studies, including the recent LIDO project (Longitudinal Investigation of Depression Outcomes), and now has more than 15 years experience in measurement development, validation, and cross-cultural adaptation.

Mona is a long-standing member of the International Society for Quality of Life Research (ISOQOL) and has been active on the Awards Committee and assisted with mentorship activities and local conference logistics. She has collaborated on and provided numerous workshops and seminars (including Asia), and has co-authored a wide variety of outcomes research publications. I strongly believe in the value of ISOQOL as an effective forum for allowing this collaboration and for promoting continuing advancement and application of QOL research. I am honored to be nominated for a Board position, and would be delighted to have the opportunity to roll up my sleeves and see where I can be of help in moving our organization into a challenging and exciting future.”

### Laura Schwartzmann

Dr. Schwartzmann is a medical doctor (1974) specializing in Psychiatry (1979) with a post-doctoral degree in Outcome Evaluation (1983). Laura is currently Associate Professor and Head of the Research Program of the Department of Medical Psychology at the School of Medicine of the University of the Republic of Uruguay. Simultaneously devoted to both the clinic and research Laura has a long-standing experience in psychosocial research, and she was awarded by the Uruguay National Academy of Medicine (1996) for her work on psychosocial factors affecting child development in underserved families in Urban Uruguay.

The main area of expertise of Laura is Liaison-Psychiatry and her team introduced Health-Related Quality of Life (HRQL) research in Uruguay, with pioneering work initiated in 1994. Their research has focused on cultural adaptation, validation and application of questionnaires for clinical practice in adults and children. Laura was appointed Research Consultant for Outcome Evaluation (1999) by the Uruguay National Regulatory Body, the institution deciding the national level on the allowance of resources for high cost and high complexity medical interventions.

Laura joined ISOQOL in 1999 and ever since she has actively participated in all the Annual Conferences, and she currently serves in the Membership Committee. In 2001, Laura and her team organized the Latin American Meeting on HRQL in Montevideo, with local and international sponsorship. Subsequently, Laura was actively involved in several HRQL meetings in Brazil and Chile. These initiatives are stimulating the involvement of a number of Latin American HRQL researchers who view ISOQOL as the natural framework for learning and communicating their research.

“Joining the Board of Directors of ISOQOL is an opportunity to further contribute to the Society in promoting the active incorporation of Latin American (LA) researchers. Also, I want to see ISOQOL promoting initiatives targeted to the effective utilisation of HRQL measures in clinical practice and population-based studies, as well as to raise attention on specific approaches of HRQL measures in the LA realities.”

**Please find enclosed a ballot for this year’s nominees. Please take a moment to vote for your fellow members and return to ballot to the ISOQOL Executive Office by June 30, 2003.**

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## ISOQOL WELCOMES NEW MEMBERS FOR 2003

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**Sara Ahmed MSc**

McGill University  
Montreal, PQ Canada

**Stephen Arcona PhD**

Novartis Pharmaceuticals Corp.  
East Hanover, NJ, USA

**Mohsen Asadi-Lari MD**

Nottingham, UK

**Carrie Balone MS**

SUNY at Buffalo  
Eden, NY, USA

**Robert Baran PharmD**

Roche Laboratories, Inc.  
Nutley, NJ, USA

**Dorothy Barnard MD, FRCPC**

IWK Health Centre  
Halifax, NS, Canada

**Susan Bauer-Wu RN, DNSc**

Dana-Farber Cancer Institute  
Boston, MA, USA

**Jurg Bernhard PhD, PD**

Swiss Institute for Applied Cancer  
Research  
Bern, Switzerland

**Anat Blaustein MA**

Maccabim, Israel

**Andrew Bottomley PhD**

EORTC Data Center  
Brussels, Belgium

**Catherine Bradley BSc**

Hospital for Sick Children  
Toronto, ON, Canada

**John Connelly**

MAPI Research Institute  
Rochester, NY, USA

**Janice Cormier MD, MPH**

MD Anderson Cancer Center  
Houston, TX, USA

**Tunya Davidson**

MD Anderson Cancer Center  
Houston, TX, USA

**Martina Deibl**

Institute of Biostatistics &  
Documentation  
Innsbruck, Austria

**Lisete Del Bianco**

Pontificia Universidade Catolica  
Sao Paulo, Brasil

**Emily Beth Devine**

University of Washington  
Seattle, WA, USA

**Deborah Dobrez PhD**

CORE  
Evanston, IL, USA

**Linda Emanuel MD, PhD**

Northwestern Univ School of  
Medicine  
Chicago, IL, USA

**Patricia Ganz MD**

UCLA, Div of Cancer Prevention  
Los Angeles, CA, USA

**Joanne Greenhalgh MPH**

University of Salford  
Salford, UK

**Francis Guillemin MD, PhD**

School of Public Health  
Nancy, France

**Clarice Hayes PhD**

Eli Lilly  
Indianapolis, IN, USA

**Yoo Hee Jung PhD**

Asan Medical Center  
Seoul, Korea

**Stefan Hofer PhD**

University of Innsbruck  
Innsbruck, Austria

**Sang-Bum Hong**

Pochan CHA University  
Sungham, South Korea

**Jo Hsieh PhD**

Protech Pharmservices Corp.  
Taipei, Taiwan

**Arieke Janse MD**

Wilhelmina Children's Hospital  
Utrecht, The Netherlands

**Allyson Jones PhD**

University of Alberta  
Edmonton, AB, Canada

**Ian Kudel MA**

Johns Hopkins School of Medicine  
Catonsville, MD, USA

**L.M. Lamers**

Institute of Medical Technology  
Assessment  
Rotterdam, The Netherlands

**Je-Hyun Lee**

Pochon CHA University  
Sungham, South Korea

**Pei Lin Lua Bpharm**

Welsh School of Pharmacy  
Cardiff, UK

**Modise Mogotsi**

Umea, Sweden

**Lucie Motlova MD**

UC Berkeley  
Berkeley, CA, USA

**Maureen Neary PhD, MS**

Hoffman-LaRoche Inc.  
Morristown, NJ, USA

**Hemraj Pal MD**

India Inst. of Medical Sciences  
New Delhi, India

**James Perrin**

Harvard Medical School  
Boston, MA, USA

**Berta Romera**

Municipal Institute in Med. Research  
Barcelona, Spain

**Vera Lucia Santos PhD**

University of Sao Paulo  
Sao Paulo, Brazil

**Jeong-Cheol Seo**

Dept of Accupuncture and  
Moxibustion  
Gumi, South Korea

**Carol Tishelman PhD**

Stockholm Nursing Home & Hospital  
Foundation  
Stockholm, Sweden

**Julie Trudel MSc**

University of Montreal  
Montreal, PQ, Canada

**Milen Vrabevski MD**

Comac Medical Ltd.  
Sofia, Bulgaria

**Kathi Weis DrPH**

Pfizer Inc.  
New York, NY, USA

**John Wilson MD**

Outcome Technologies  
London, UK

**Eve Wittenberg MPP**

Massachusetts General Hospital  
Boston, MA, USA

**Wenchen Ken Wu PhD**

St. John's University  
Edison, NJ, USA



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## MEMBER NEWS

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**Editor's Note:** *This column about ISOQOL members will appear as often as there is news worthy of note. Members are encouraged to submit information about new positions, awards, assignments, and memberships of themselves and/or their colleagues.*

*Please keep announcements brief, ie, one or two short paragraphs maximum length. Given space limitations, the editor reserves the right to abbreviate contributions exceeding the recommended length.*

**Mirjam Sprangers, PhD** (the Netherlands) has been appointed Foreign Adjunct Professor at the Karolinska Institute in Stockholm (Sweden).

**Michael A. Hagan, DrPH** (USA) has been appointed Director of Biometrics & Outcomes of the Spine Center at New York Neurological Institute of Columbia University. In his new capacity, Dr. Hagan is responsible government as well as industry sponsored research into the treatment of spinal conditions. All research projects have HRQoL measures in addition to clinical endpoints and some have economic components. Prior to joining the Spine Center, Dr. Hagan worked as a manager at Ortho Biotech supporting HRQoL drug research through statistical analyses.

**Geraldine V. Padilla, PhD** (USA) announces that the University of California San Francisco School of Nursing has a new Center grant from the National Institutes of Health, National Institute for Nursing Research. The Center is called the "Nursing Research Center on HIV/AIDS Health Disparities." The goal of the Center is to enhance the knowledge base for nursing care in order to improve the quality of lives of people living with and affected by HIV disease and to enhance minority nurse investigators working in HIV/AIDS research. The UCSF School of Nursing is in partnership with the University of Puerto Rico School of Nursing in this effort. From UCSF, Dr. William Holzemer is the Principal Investigator, Dr. Padilla is a Co-investigator and Director of the Research & Mentorship

Core, and Dr. Carmen Portillo is a co-investigator and Director of the Pilot Core. The centers counterparts at the University of Puerto Rico are Drs. Marta Rivero, Jose Rodriguez and Evelyn Crouch respectively.

**Marcie Parker, PhD, CFLE** (USA) is an active member of the Boards of the American Hospice Foundation, the Minnesota Council on Family Relations, and Chair-Elect of the International Stress Management Association. Her papers, "Anthrax and Bioterrorism Calls to Counselors and Nurses" and "Job Stress Calls to Counselors", were accepted for presentation at a recent conference. Her papers, "Legal and Financial Call Trends of a One-Year Period" and "Helping Managers Manage Workplace Crises: the results of the Optum Management Consultation Evaluation Survey", have appeared in Acta Academia 2003. Parker's paper, "Components of a Great Pharmaceutical/Non-Pharmaceutical Support Program for those with Alzheimer's Disease", has been accepted for presentation at the 11th National Alzheimer's Disease Education Conference in July in Chicago.

**Jane Scott, PhD** (USA) (formerly Scott-Lennox) moved to Silver Spring, Maryland in February 2003 to take a newly created position as a Social Science Analyst with the US FDA in the Center for Drug Evaluation and Research's (CDER) Study Endpoints and Label Development team. In her new position, Jane provides technical support and training to CDER's 15 reviewing groups on psychometrics and methods for the development, validation, and application of question-based assessments for medical product evaluation research.

**Brad Zebrack, PhD** (USA) was recently awarded an American Cancer Society Quality of Life Research Award by the Association of Oncology Social Workers at their recent annual assembly in Salt Lake City.

The meeting was held April 9-12, 2003 at the Wyndham Hotel in Salt Lake City, Utah. The Association of Oncology Social Workers is a professional organization comprised of approximately

1,000 oncology social workers in the US, Canada and abroad. Last year, the American Cancer Society began sponsoring a "Quality of Life Research Award" for AOSW, to recognize a member conducting research in the area of quality of life and cancer. The recognition came with a \$1,000 award and certificate.

## Advertisement



### **Outcomes Research Scientist**

**(Multiple openings—Title TBD commensurate with experience)  
Pfizer, New York, NY**

**Job Description:** The candidate will play a key role in developing product strategy for the marketing-medical teams by leading others to collectively maximize business impact of marketing, medical, and OR programs; interacts and works with the economic models, designs, clinical trials with OR components; coordinates the implementation of phase III and IV OR; develops and implements goodwill programs to support product marketing; initiates and leads key cross-divisional task forces to help improve processes; influences OR policies and methodological advances outside the company; serves as a resource for product price defense issues.

**Requirements:** Ideal candidate should have an advanced degree (Masters or Doctorate) in health services research, public health, epidemiology, economics, social psychology, medicine, or pharmacy with training in the conduct of outcomes research to evaluate health care interventions. The candidate should have 2+ years industry experience including conducting socioeconomic evaluations of health care interventions. The candidate should have a broad working knowledge of all key disciplines and have demonstrated success in at least 2 or 3 of the following areas: contributing to multi-disciplinary teams, outcomes research, clinical research, product marketing and pricing and reimbursement. The candidate should have process and project management skills and ability to design and manage contracted research projects.

**For additional information or to submit a resume:**

Website: [www.pfizer.com](http://www.pfizer.com)

E-mail: [stlc@pfizer.com](mailto:stlc@pfizer.com)



# International Society for Quality of Life Research

**10<sup>th</sup> Annual Conference**  
**November 12 - 15, 2003**  
**Hilton Prague, Prague, Czech Republic**

## Preliminary Schedule

### PLENARY TOPICS INCLUDE:

*“Using Patient Reports To Assess The Process And Consequences Of Health Care”*,

- Paul D Cleary, PhD (USA)

*“Measuring Health Across Nations: Experience Using Anchoring Vignettes”*

- Chris Murray, MD, DPhil (Switzerland)

*“Office Practice Today: As Good As It Gets? Tomorrow: As Good As It Can Be?”*

- John H Wasson, MD (USA)

*“In Sickness But Not In Health? Self-Ratings, Identity, and Mortality”*

- Ellen L Idler, PhD (USA)

*“Special 10<sup>th</sup> Anniversary Plenary Session”*, **Chair:** Sharon Wood-Dauphinee, PhD, PT (Canada), **Speakers:** Ivan Barofsky, PhD (USA), Monika Bullinger, PhD (Germany), Robert M Kaplan, PhD (USA), David Osoba, MD (Canada), John E Ware, Jr., PhD (USA)

### INVITED SYMPOSIA:

*“Patient Satisfaction”*

Ron D Hays, PhD (USA), Paul Cleary (USA), Michael Murray (Canada), Chris Murray

*“The Use of Quality of Life Valuation in Resource Allocation in Health Care: A Critical Debate”*

John Brazier, PhD (UK), Jack Dowie (London), David Feeny, PhD (Canada), Jan Olsen (Univ of Tromso)

*“The Role of Culture in Quality of Life Assessment”*

Carolyn Gotay, PhD (USA), Monika Bullinger, PhD (Germany), Lea Baider, Cindy Lam, FRCGP (China), Michael Herdman (Spain)

*“Clinical Significance of Changes in HRQL Scores”*

Kathleen Wyrwich, PhD (USA), TBD

### PROGRAM TO INCLUDE:

*Debate / Panel Discussions*

*Symposia*

*Workshops*

*Poster Sessions*

*Paper Sessions*

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

Special social events will take place throughout the meeting. Bring your family and friends to this exciting meeting.

**SEE YOU IN PRAGUE!!**

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### PRESIDENT’S AWARD *(July 31, 2003 - Deadline for Nominations for the ISOQOL President’s Award)*

The goal of this award is to recognize outstanding contributions (by an individual or group) to the advancement of the quality of life field in one or more of the following areas: “education of professionals, patients or lay individuals about the value of quality of life assessment as related to health”; “promotion or execution of quality of life research or other scholarly activities”; and “facilitating or furthering policy initiatives that impact upon health-related quality of life.”

Please submit your nomination package consisting of 1) a letter from the nominator specifying the nominee’s contributions, 2) the curriculum vitae of the nominee, and 3) an external support letter. The deadline for nominations is **July 31, 2003**. Please send your nomination package to:

Dr. Mirjam Sprangers, President, ISOQOL Executive Office, 6728 Old McLean Village Drive, McLean, VA 22101, USA or Fax to ISOQOL Executive Office at 703-556-8729.

*The award will be selected by the ISOQOL Executive Committee and approved by the Board of Directors. The award will consist of a plaque, a \$1000 honorarium and up to \$1000 in travel expenses if the recipient plans to attend this year’s Annual Conference in Prague, November 12-15.*