



# *International Society for Quality of Life Research*

Volume 9 Issue 2

Newsletter for ISOQOL Members

August 2004

## **PRESIDENT'S MESSAGE**

Albert W. Wu, MD, MPH  
Baltimore, MD, USA

In the dog days of summer, we are already looking forward to our next Annual Meeting, which will take place this year in Hong Kong from October 16-19. This will be ISOQOL's first meeting in Asia in eight years. Back in the day, we had referenced a "Three Continent" policy, but I think this formulation was too simplistic, reflecting an apparent problem with basic arithmetic, and a disturbingly North America/Euro-centric view of the world.

It must be acknowledged that in its first two decades, activity in the field of health-related quality of life was concentrated in Northern industrialized nations, and was conducted mostly in English. At present, we continue to hold major scientific meetings in Europe and North America, such as our well-received super-workshop "Stating the Art: Advancing Outcomes Research Methodology and Clinical Applications" held in Boston at the end of June.

However, this pattern is beginning to change, with meetings and other spontaneous expressions of interest by researchers in places including Brazil, Russia and Australia. In the past month, a meeting held in Taiwan on health-related quality of life drew a hundred scientists. At the XV International AIDS conference in Bangkok, which focused heavily on resource limited countries, there were over 300 presentations that included quality of life assessment. By encouraging these efforts and groups, ISOQOL is positioned to be a central part of the corrective.

Preparations for Hong Kong are in full swing, under the stewardship of Madeleine King, Kwok-fai Leung and Margaret Tay. Madeleine is certain to endorse the map shown below, developed by one of her countrymen who had been tormented as a child for coming from "bottom of the world". This formulation, the first modern South-up map, makes us aware that it is entirely arbitrary that we have North at the top of the map, and indeed makes us confront our own "direction-ism." It is fascinating to note the prominence of Aus-

tralia, how intriguing Indonesia appears, and that Hong Kong is placed smack dab in the middle of the globe.

At every possible occasion, I mention to colleagues that this year's ISOQOL meeting will be in Hong Kong (I encourage you to do the same). I have observed that the distribution of responses is very bimodal. While some have already ruled out the possibility of traveling what seems like such a long way, others evince great excitement about attending, and express expectations for a fascinating and invigorating experience.

I'm thoroughly in the second camp. It is an interesting coincidence that ISOQOL will have a President of Asian heritage to open our Annual Meeting in Hong Kong. Both of my parents are of Chinese descent. However, my father spoke Mandarin and my mother Cantonese, so growing up in New York they, and I, spoke mostly English. I only wish that I had paid more attention to the Chinese lessons that I attended when in the 7<sup>th</sup> grade.

This will not dampen my enthusiasm for an enriching and exciting meeting in Hong Kong. I hope to see you there!

### **IN THIS ISSUE . . .**

**ISOQOL is pleased to present the updated schedule for the 2004 Conference in Hong Kong. See page 6 for information.**

**ISOQOL is proud to welcome its new members on page 7. 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*  
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**Deadline for articles for our next issue is October 30, 2004**

Send articles and/or suggestions to:  
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### **ISOQOL Executive Office**

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## **FROM THE EDITOR**

Adam Smith, Ph.D., Associate Editor, Leeds, UK

As I sit in my office I can see the sun beating down, slowly melting the tarmac in the car park outside my window. It looks like summer has finally arrived in this part of the world! So, summer time, and the living is easy? Perhaps, but there again George Gershwin probably didn't have ISOQOL members in mind when he penned those words! Certainly not judging by all the activities and events in which ISOQOL members have been involved recently, and all the events planned over the next few months heading into autumn! To give you a flavour of what's going on in the "Quality of Life world" in this edition of the ISOQOL newsletter we have Albert Wu's presidential column - Mirjam Sprangers has provided a breakdown of the results of the leadership election - congratulations to those of you elected, and commiserations to those who weren't successful this time around - Dennis Revicki and Bill Lenderking have written a fascinating, as well comprehensive account of the 2004 ISOQOL Symposium in wintry Boston, and finally Bryce Reeve provides a very welcome overview of the NCI meeting which took place in Bethesda in June, which was themed around improving health outcomes using computerized-adaptive assessment, and where a number of ISOQOL members were keynote speakers. Many thanks are due to all our contributors - and along with that comes a gentle reminder to all members that all contributions to the Newsletter are very welcome (either through the ISOQOL Executive Office or directly to the editorial team). What with the Annual Conference in Hong Kong fast approaching this October, and the organization for the 2005 event in San Francisco already well underway, there seems to be little chance of the cotton getting too high! Finally it remains for the editorial team to wish you all a hopefully relaxing summer!!

## **ISOQOL 2004 ELECTIONS PROCESS AND RESULTS**

Mirjam Sprangers, Ph.D., Amsterdam, The Netherlands, Immediate Past President and Chair Nominations Committee

The Nominations Committee's task is to select candidates for each year's leadership's election, thereby ensuring adequate representation according to a number of relevant background variables, e.g. discipline, geographical area, work setting, and gender. This year's Nominations Committee included David Osoba, Canada; Ivan Barofsky, USA; and Mirjam Sprangers, the Netherlands. The committee presented a slate of highly qualified nominees based, in part, on suggestions received from our membership.

All nominees have made a significant contribution to the quality of life field and some even to the Society. The Nominations Committee wishes to thank them for their willingness to devote their time and energy to the Society and to take part in the election.

We congratulate the new members of the board. Our incoming President-elect will be **Peter Fayers**, of the University of Aberdeen, UK and the University of Trondheim, Norway. The new at-large board members will be **Elaine McColl** of the University of Newcastle upon Tyne, UK and **Greame Hawthorne**, of the University of Melbourne, Australia. They will replace John Ware, USA and Madeleine King, Australia, whose terms on the board will end this fall. Peter and Elaine have already made significant contributions to the Society as Peter has been a board member from 2000 to 2003, and Elaine has been chair of the Membership Committee since 2003. Peter, Elaine, and Greame will assume their positions this fall at the Annual Meeting in Hong Kong.

The Nominations Committee also wishes to thank the members who took time to vote in this election. We would  
*Continued on page 5*

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## 2004 ISOQOL SYMPOSIUM

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William Lenderking, Ph.D., Groton, CT, USA and Dennis Revicki, Ph.D., Bethesda, MD

From 19 countries and five continents they came to Boston, brave souls (if we ever have an ISOQOL meeting in Boston in the winter, we might get some attendees from Antarctica and then we'll have had representation from all 7 continents—they'll feel right at home!). Actually, from our vantage point at the Park Plaza hotel right near the Boston Garden, the view was lovely and the weather was too. But the best thing about the ISOQOL Symposium was the symposium itself! The members of the Organizing Committee experimented with a new format which relied heavily on invited speakers—this was a draw for the meeting and it worked! This format gave junior investigators the opportunity to present along with leaders in the field, which was good for all.

After an initial opening plenary delivered by Marcia Testa and Robert Kaplan, the meeting split into two tracks, one more heavily methodological and statistical, and the other more clinically and theoretically oriented. Presentations by IRT specialists Ron Hambleton and Chih-Hung Chang were followed by sessions on statistical methodology delivered by Joe Hogan and Diane Fairclough. Competition for attendance at these sessions was fierce, as these sessions were held concurrently with a session on cognitive sciences, featuring presentations by Eve Wittenburg and Antonio Freitas, followed by presentations from James Pennebaker and Arthur Graesser on qualitative research approaches. In the latter session, we heard that suicide may be a career move for a poet (that had to be one of the best lines of the conference). I think many of us agreed with Peter Fayers when he said the most difficult thing about the meeting was choosing which session to sit in on. And there weren't too many conversations in the hallway, another indication that exciting things were happening in the meeting rooms.

I did not hear much from others about the dine-around, but it was certainly a success from my perspective, as I dined with two special colleagues from the Czech Republic and witnessed a demonstration of simultaneous penmanship with both right and left hands (mirror image writing)! The second and last day of our meeting began with a plenary session that was very well-received, especially by those of us with industry affiliations. The speakers were David Osoba, Holger Schunneman (pinch hitting for Gordon Guyatt), and Robert Meyer of the FDA. Again, we split into two tracks and sessions on Statistical Analysis featuring Herbert Thijs and Dennis Fryback competing with sessions on theory with talks by Julia Fox-Rushby and Joe Sirgy, and where we even got to view theory from the perspective of "through the looking glass." Dennis Fryback provided insights in Bayesian analysis of health status data. After lunch, the final sessions were on daily process with spirited presentations by Howard Tennen and Alex Zautra, and one on the state-of-the-art of utilities, where we were privileged to hear from David Feeny, Reed Johnson, Rich Gelber, and Bernard Cole—finally a presentation on Q-TwiST from the developers of the method! Our closing plenary was intended to capture the essence of the meeting through summaries of the sessions, and featured a presentation by Peter Fayers on where the state-of-the-art is of our field, as represented in Boston.

The meeting was too short, but it was great to see old friends and make new ones. And to be reminded that for all we have learned and discovered, there is still so much more to learn. A heartfelt thanks from Dennis and I for all those who worked so hard to make this meeting a success. Some of the presenters have posted their slides on the ISOQOL website, and we are making plans to publish a number of the papers in a book. Stay tuned!

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## 2005 ISOQOL MEETING, HYATT REGENCY, EMBARCADERO CENTER, SAN FRANCISCO

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

The 12<sup>th</sup> Annual ISOQOL Meeting will be held in San Francisco from October 19-22, 2005 at the Hyatt Regency, Embarcadero. The meeting will open with workshops during the day on October 19<sup>th</sup> (Wednesday), and the opening reception will take place from 6-7pm. The official meeting will be kicked off by a welcoming address from President David Feeny on Thursday morning (October 20), followed by the opening plenary session.

An exciting mix of paper and poster sessions will be delivered during the next 3 days, culminating in the traditional ISOQOL Social dinner on Saturday evening (October 22). This meeting will feature a joint oral and poster session on Saturday afternoon (October 22) with members of the Society of Medical Decision Making (SMDM). In addition, a SMDM lead decision analysis course will be given as one of the ISOQOL workshops on Wednesday (October 19) and the ISOQOL workshop on dynamic assessment lead by John Ware will also be offered as one of the SMDM short courses on Friday afternoon (October 21).

Please mark your calendars now for the 2005 Annual ISOQOL Meeting. If you have any questions or suggestions, please contact Ron Hays, 2005 Meeting Chair, by email ([hays@rand.org](mailto:hays@rand.org)) or by phone (310-794-2294).

## UPDATE ON THE ISOQOL EDUCATION COMMITTEE

Claudette Varrichio, DNS, Bethesda, MD, USA

The Education committee of ISOQOL has been evolving and clarifying its role in the organization. In order to do this the committee undertook, under the leadership of Marcia Grant, a survey soliciting input from members who have educational materials available that they are willing to share with their colleagues. The purpose of this survey was to determine if there were easily accessible and useful educational materials that could be made available to ISOQOL members who want to design workshops, courses or symposia on the many aspects of QOL research.

Responses were solicited through notices in the ISOQOL Newsletter, notices on the web site and in some instances direct contact. There were 41 responses. 23 indicated that they had professional educational material that they would be willing to share with ISOQOL members by posting these on the ISOQOL web site. Many indicated that they would be interested in participating in a curriculum development project.

Given these preliminary, but encouraging, responses, the Committee chair proposed to the Board that we collect these educational materials, review them for accuracy and then, with permission and attribution, post them for informational purposes on the web site. The authors would be invited to periodically review and modify their work. The authors would be responsible for the content, not ISOQOL. This information would be a member benefit and members would be free to download the information, modify or adapt it for their local needs. With this last goal in mind we are attempting to have submissions from as many areas and language groups as possible. We are identifying members from different countries and regions of the world to help identify and collect submissions from these areas and in

local languages. Direct submission of materials to the Committee is encouraged.

An expansion of this project will be the soliciting of outlines, slides, lectures and other materials used in the course of workshops, symposia and other ISOQOL educational activities. These materials would be posted on the web so that persons in regions who have educational needs but have difficulties in attracting faculty to present at their regional meetings could prepare and present programs based on previous ISOQOL offerings. This is a relatively short term goal for the committee.

A longer term goal is a curriculum development project that will have the task of developing an outline of topics that should constitute an exhaustive compendium of knowledge needed to design, implement and interpret QOL research. We hope that this project may evolve into web based instructional sessions available in English, Spanish, French, German and other regional languages. This group may also commission the translation of classic QOL articles into Spanish or other languages.

We are considering clustering educational materials by topic, with versions in different languages when available. Where there are gaps in content, as identified by the curriculum project team, we will solicit the development of materials to fit this specific gap.

In order to reach our target of a reasonably complete compendium of materials, in as many languages as possible, we invite you to send us any materials you have developed for university courses, workshops, symposia or other activities that you are willing to share with ISOQOL members. The authors of all materials will be acknowledged. If you are interested in becoming a part of any of these projects, please contact the committee chair.

Claudette Varrichio, DNS  
6130 Roseland Dr.  
Rockville, MD 20852 USA  
Email: varriccc@mail.nih.gov

1. Do you have professional educational material that you would be willing to share with ISOQOL for the purposes of modification or adaptation for posting on an ISOQOL curriculum web site?
2. If yes, are they (check all that apply)  
University course materials  
Slide presentation  
Workshop materials  
Other (specify)
3. What is the target audience for your materials?  
University graduates  
University undergraduates  
QOL researchers  
Professionals  
Other (specify)
4. Would you be able/willing to share these materials with ISOQOL?
5. Do you have information about where in your area, country, language, this type of information may be available?
6. What kinds of materials would you find useful in planning educational activities for students or colleagues?  
University course materials  
Slide presentation  
Workshop materials  
Other (specify)
7. Would you be willing to participate in a curriculum development project of the ISOQOL Education Committee?
8. Are there names of anyone who is a member of ISOQOL that you would recommend we contact directly?
9. Are you a member of ISOQOL?

### BROCHURES AND SLIDES HELP YOU PROMOTE ISOQOL

Planning to attend a meeting or other large event for HRQL professionals? If so, contact the ISOQOL office for membership brochures about the Society to take with you. If you plan to speak at an HRQL-related meeting, you can also receive via e-mail a slide promoting ISOQOL to display during your presentation. Contact the ISOQOL office to learn more.

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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.*



Barbara S. Hawkins, PhD, Professor, Wilmer Clinical Trials and Biometry, Baltimore, MD, USA, received the 2004 Women's Leadership Award at the Johns Hopkins University School of Medicine (May 2004). Along with other living past presidents of the Society for Clinical Trials, she was honored at the 25th anniversary annual scientific meeting of the SCT in New Orleans in May 2004.



The American Nurses Foundation Distinguished Contribution to Nursing Science Award was presented to Joan Austin, Bloomington, IN, USA, on Sunday June 27, 2004 in Minneapolis, MN during the ANA Convention. It is presented biennially to recognize a registered nurse who has made significant contributions to nursing research.



Gail Low, MA, University of Victoria, School of Nursing, Vancouver BC, Canada, received a national grant to assist her in completing her final year of studies from the Social Science Health Research Council of Canada (SSHRC).



Ron Hays, PhD, Los Angeles, CA, USA and Peter Fayers, PhD, Aberdeen, UK has recently edited a new publication entitled *Assessing Quality of Life in Clinical Trials: Methods of Practice, Second Edition*. The book is a complete revision and update to

cover the increased breadth and importance of the field of quality of life measurement. It contains rigorous, broad comprehensive coverage of all aspects of QOL measurement, methods and practice.

This new publication is available to ISOQOL members at a discounted price of \$60.00US. You can download the order form from the ISOQOL website at [www.isoqol.org/resources](http://www.isoqol.org/resources).

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## PAID ADVERTISEMENT

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COMPENDIUM OF QUALITY OF LIFE INSTRUMENTS...2 August 2004 – Euromed Communications Ltd announce the publication of the 6th volume of the *Compendium of Quality of Life Instruments*. The 6th volume of the *Compendium* updates a number of instruments published in the first 5 volumes and also includes many new instruments and translations. The 6th volume of the *Compendium of Quality of Life Instruments* is available as a spirally-bound book with a CD-ROM at a price of \$315 from Euromed Communications (see details below). A limited number of the original 5 volumes of the *Compendium* can be obtained from Euromed Communications at a special discount price.

Contact: Joe Ridge, Euromed Communications Ltd, The Old Surgery, Liphook Road, Haslemere, Surrey GU27 1NL, UK. Phone +44 1428 656665 Fax +44 1428 656643, [info@euromed.uk.com](mailto:info@euromed.uk.com) or [www.euromed.uk.com](http://www.euromed.uk.com)

*Election, continued from page 2*

like to point out that the percentage of the voting membership has always been small, e.g. 25% last year, and has dropped to 20% this year. Since the selection of our leadership will have notable effects on the future of our Society, it is very important that all members express their wishes. Another concern is that it has been difficult to get members from industry to the board. As a consequence, members from academia are now overrepresented in the board. We are currently discussing how we can increase participation of the membership in the elections and improve the representativeness of the board according to work setting. We will keep you posted about possible changes in the election procedure.

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## UPCOMING MEETINGS

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Profs. Susan Embretson and Steve Reise (authors of "Item Response Theory for Psychologists") will present a workshop on Item Response Theory (IRT) on September 9-11, 2004, at the University of Chicago Gleacher Center in downtown Chicago. The workshop is being organized by Scientific Software International, Inc. (SSI).

This workshop offers an excellent opportunity to learn about the methodology of Item Response Theory (IRT) and see the latest features of our IRT (BILOG-MG, MULTILOG, PARSCALE, TESTFACT) products in action. For more information, contact SSI at 1-800-247-6113 or visit their website at [www.ssicentral.com](http://www.ssicentral.com) and go to the "workshops" page.

## QOL CONFERENCE IN HONG KONG, OCTOBER 16 - 19, 2004

The International Society for Quality of Life Research (ISOQOL) is holding its 11th Annual Scientific Meeting in Hong Kong, October 16-19, 2004. The conference theme, *Harmonizing International Health-Related Quality of Life (HRQOL) Research*, recognizes the kaleidoscope that HRQOL is today. With so many cultures and languages around the globe, so many ways of defining and conceptualizing HRQOL, with so many instruments and scales to measure HRQOL, and so many different uses and users of HRQOL measures, this theme provides a timely focus for what promises to be a fascinating and rewarding conference.

We have a stellar collection of international speakers, representing eastern and western perspectives. The keynote speaker, John Ware, PhD, has long provided leadership in harmonizing inter-

national HRQOL research, with his efforts in cross-cultural and cross-instrument calibration, and more recently in dynamic instruments bridging the gulf between individual patient management and population surveys. A special symposium will follow this by addressing the question "What do we need to do to harmonize international HRQOL research and how will we do it?". Speakers include China's leading proponent of HRQOL, Ji-qian Fang, leading Singapore clinician, Julian Thumboo, director of the WHO Centre for the Study of Quality of Life and deputy director of the ESRC Research Group on Wellbeing in Developing Countries, Suzanne Skevington, and Deputy Chief Science Officer at QualityMetric, Jakob Bjorner, who has been involved in the IQOLA project for many years now.

Item response gurus, David Andrich and Alan Tennant, will turn their considerable talents to the vexing issues of cross-cultural comparison of health status in a special plenary session. Andrich, originally from education, will

present findings from his recent collaboration in the WHOQOL endeavour, and he will also give an advanced level workshop on the Rasch Model.

For those wishing to learn more about cross-cultural adaptation and translation, there will be a choice of three workshops, giving attendees the opportunity to learn from the extensive experience of Cindy Lam, Mona Martin, Beng Li Tin, Sonya Eremenco, Ben Arnold, Charles Cleeland, Andrei Novik, Xin Wang and Tatyana Ionova.

We will also hear about the integration of western and traditional Chinese medicine (TCM) from Ka-Kit Hui, Director of the UCLA Center for East-West Medicine, while Ron Hays (also UCLA) and Lai Shilong (of the Chinese Medicine Research and Service Center) address HRQOL in TCM. This promises to be a unique and fascinating symposium.

Other interesting and varied topics with equally interesting and varied speak-

*Continued on page 8*

<p><b>Saturday, October 16</b></p> <p>8:30am Registration Opens</p> <p>9:30am- Workshops 1 - 7 12:30pm</p> <p>12:30pm- Lunch on your own 1:30pm</p> <p>1:30pm- Workshops 8 - 14 4:30pm</p> <p>5:00pm- Welcome Reception 6:00pm</p>	<p>12:30pm- 2:00pm Lunch / Meet the Author: Poster Session I</p>	<p>11:30am- 1:00pm Invited Symposium III Use &amp; Value of HRQOL Invited Symposium IV Stress, Depression &amp; HRQOL</p>	<p>10:30am- 11:00am Morning Tea</p>
	<p>2:00pm- 3:30pm Oral Session I Utility 2 - Methodologies Cross-cultural Methodologies Cancer Elderly</p>	<p>1:00pm- 2:30pm Business Meeting Lunch and Networking Session</p>	<p>11:00am- 12:30pm Invited Symposium V Individualized Measurement of PROs Invited Symposium VI ICF</p>
	<p>3:30pm - 4:00pm Afternoon Tea</p>	<p>2:30pm- 4:00pm Oral Session III Utility I - Specific Populations Responsiveness QOL as a Predictor of Outcome Chronic Conditions II Cross-cultural Issues in Scale Development</p>	<p>12:30pm- 2:00pm Lunch on your own / Meet the Author: Poster Session IV</p>
	<p>4:00pm - 5:30pm <b>Oral Session II</b> Applications of Item Response Theory Translation/Cross-Cultural Validation Alternative Views Chronic Conditions 1</p>	<p>4:00pm- the 5:00pm Afternoon Tea / Meet III</p>	<p>2:00pm- 3:30pm Oral Session IV CAT and Computerized Data Entry Asian HRQOL Measures Proxies Breast Cancer Mental Health</p>
	<p>5:30pm - 6:30pm Mentor/Mentee Session</p>	<p>5:00pm- 6:30pm Special Interest Group Meetings / 2005 Conference Program Committee Meeting</p>	<p>3:30pm- 4:00pm Afternoon Tea</p>
<p><b>Sunday, October 17</b></p> <p>8:30am- Registration</p> <p>9:00am - Opening Ceremony and Keynote Address 10:30am John Ware</p> <p>10:30am- Morning Tea 11:00 am</p> <p>11:00am- Invited Symposium I Conceptualization of HRQOL 12:15 am Invited Symposium II Integration of Western &amp; TCM</p>	<p><b>Monday, October 18</b></p> <p>8:30am - Registration</p> <p>9:00am- Plenary I Harmonising International HRQOL Research 10:30am Ji Qian Fang Suzy Skevington Jakob Bjorner Julian Thumboo</p> <p>10:30am- Morning Tea / Meet the Author: Poster Session II 11:30am</p>	<p><b>Tuesday, October 19</b></p> <p>8:30am - Registration</p> <p>9:00am- Plenary Session II IRT &amp; Cross-Cultural Equivalence 10:30am David Andrich Alan Tennant</p>	<p>4:00pm- 5:30pm Oral Session V Longitudinal/Missing Data Scale Development - Methodological Issues Using PRO's in Clinical Practice Children Response Shift</p> <p>7:00pm- 9:30pm Cocktail Reception &amp; Social Dinner/Awards and Closing Ceremony</p>

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## ISOQOL WELCOMES NEW MEMBERS

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**Jonathan Agnew**

S. San Francisco, CA, USA

**Barbara Andersen, PhD**

Columbus, OH, USA

**Gillian Barnett, MSc**

Brentford, United Kingdom

**Libby Black, PharmD**

Research Triangle Park, NC, USA

**Daria Boccher-Lattimore, DrPH**

New York, NY, USA

**Anita Chawla**

S. San Francisco, CA, USA

**Ali K. Chouair, MD**

Salt Lake City, UT, USA

**Darren Clayson, BSc, MSc**

Oxford, United Kingdom

**Bethan Davies, BSc, MRES**

Derbyshire, United Kingdom

**Hongyan Du, MSc**

Evanston, IL, USA

**Amy Durtschi**

Powell, OH, USA

**Majorie Marcoux Faiia, PhD**

Danville, NH, USA

**Xie Feng, MSc**

Singapore, Singapore

**Ancilla Fernandes, PhD**

Lincolnshire, IL, USA

**Shona Fielding, BSc, MSc**

Aberdeen, United Kingdom

**Yuki Fujiki**

Saitama, Japan

**Olatz Garin**

Barcelona, Spain

**Jacqueline Gough, Mmath**

Indianapolis, IN, USA

**Winfried Graninger, MD**

Graz, Austria

**Marion Haas, PhD**

Broadway, Australia

**Alex Hakuzimana**

Rwanda

**Jane Hall, PhD**

Broadway, Australia

**Shinobu Iwase, MS**

Nagasaki, Japan

**Shrividya Iyer, PhD**

Lincolnshire, IL, USA

**Gretchen Jacobson, MS**

Baltimore, MD, USA

**Tripti Kamath**

S. San Francisco, CA, USA

**Patsy Kenny, MPH**

Broadway, Australia

**Pattarin Kittiboonyakun, MSc**

Bath, United Kingdom

**Marianne Laouri**

S. San Francisco, CA, USA

**Wee Hwee Lin, BSc**

Singapore, Singapore

**Gail Low, MA**

Vancouver, BC, Canada

**George MacKinnon, PhD**

Abbott Park, IL, USA

**Linda Marc, MPH, MS**

Boston, MA, USA

**Faith Martin, MA**

Bath, United Kingdom

**Marie Martin, PhD**

Lincoln, RI, USA

**Christine McDonough, MS**

Lebanon, NH, USA

**Antonieta Medina Lara, Mphil**

Liverpool, United Kingdom

**Stacie Metz, MPH**

St. Louis, MO, USA

**Eugene Anthony Meyer, PsyD**

Boston, MA, USA

**David W. Miller, PhD**

Research Triangle Park, NC, USA

**Constance Milton, RN, PhD**

Bourbonnais, IL, USA

**Angie Morrow, MB, BAO, BCh, MRCPI, FRAGP**

Sydney, Australia

**Yuen Yee Jenny Ng, MSc**

Hong Kong, China

**Jan Nilsson, MSc**

Stockholm, Sweden

**Merrickay Oleen-Burkey, PhD**

Kansas City, MO, U SA

**Holly Posner, MD, MS**

Ridgefield Park, NJ, USA

**Rukmini Rajagopalan, DrPH**

Lincolnshire, IL, USA

**Stephen Raymond, PhD**

Charlestown, MA

**Naomi Reay, MA, BSc**

W. Yorkshire, United Kingdom

**Maria-Jose Santana**

Edmonton, AB, Canada

**Neil Scott, MA, MSc**

Aberdeen, United Kingdom

**William Shaw, PhD**

Hopkinton, MA, USA

**Mohammad Taghi Sheykhi, PhD**

Tehran, Iran

**Martha Shumway, PhD**

San Francisco, CA, U SA

**Hyojeong Song, PhD**

Cheju, South Korea

**Susan Stewart**

Cambridge, MA, USA

**Carren J. Stika, PhD**

Rancho Santa, Fe CA, USA

**Jayant Talwalkar, MD, MPH**

Rochester, MN, USA

**Maria Watson, PhD**

Research Triangle Park, NC, U SA

**Eric Qiong Wu, PhD**

Boston, MA, USA

**Yaping Xu, MPH**

Lincolnshire, IL, USA

**Jacqueline Yap, MBBS, FANCZA, FHKCA**

Tai Po, Hong Kong

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# International Society for Quality of Life Research

**11<sup>th</sup> Annual Conference**

**October 16 - 19, 2004**

**The Hong Kong Academy of Medicine**

**Co-organized by the Hospital Authority of Hong Kong**

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

## THE NATIONAL CANCER INSTITUTE'S CONFERENCE ON IMPROVING HEALTH OUTCOMES MEASUREMENT

Bryce Reeve, Ph.D., Bethesda, MD, USA

On June 24 and 25, 2004, the National Cancer Institute (NCI) and the Drug Information Association (DIA) co-sponsored the conference, "Advances in Health Outcomes Measurement: Exploring the Current State and the Future of Item Response Theory, Item Banks, and Computer-Adaptive Testing." This conference focused on well-developed, innovative methods for improving patient-reported outcomes assessment based on the applications of item response theory (IRT) modeling. Leaders in the field discussed: 1) the science of health outcomes measurement: facts, fiction, and the future; 2) the strength of IRT modeling for evaluating questionnaire properties and developing short forms; 3) the importance of assessing measurement equivalence for instruments administered in different languages or cultures; 4) the methods to link or equate instruments on a common metric; 5) the issues and challenges one faces to develop item banks; and 6) how clinical research and practice will benefit with the availability of computer adaptive testing (CAT). A special feature of the conference included presentations from two research teams demonstrating these IRT applications on a HRQOL data set and a behavioral science dataset.

Recognizing the value of CAT, members of both public and private industry took the opportunity to identify the key challenges for integrating these techniques in health outcomes measurement and the role each should play to foster the development and management of these tools. Suggestions to facilitate use of CAT-based measurement in the healthcare industry included more demonstrations of the value of these tools for different applications in clinical research, trials, and practice and willingness among developers to make the developmental process transparent to the research community and to make the final products available in the public domain.

The meeting was well attended by representatives from academia, industry, and government, who together identified key research areas for the future, including the role of multi-dimensional IRT modeling in HRQOL assessment, integration of CAT-based HRQOL measures in doctor-patient decision making, the challenge to make IRT software more user-friendly, and the need for standard setting when reporting IRT results. Most of the conference's presentations and background papers can be viewed on NCI's website: <http://outcomes.cancer.gov/conference/irt/>.

*Meeting, continued from page 6*

ers include: the use and value of HRQOL assessment in different countries and health care systems, with Donald Patrick, Jan Sansoni, and Olivier Chassany; individualizing the measurement of patient reported outcomes with Ciaran O'Boyle, Mark Haggard and Holger Schunemann; and stress, depression and HRQOL, with Mick Power, Laura Schwartzmann, Zorianna Hyworon and Mona Martin.

The recently released International Classification of Functioning (ICF) will get a good airing, with a symposium and a workshop lead by Gerold Stucki with guest speakers Alarcos Cieza, Leonard Li, and Nancy Mayo.

In addition to those mentioned previously, there are a range of workshops, at both introductory and advanced levels, given by established luminaries such as George Torrance, David Feeny, John Ware, David Osoba, Diane Fairclough, Sharon Wood-Dauphinee, Benny Zee, Jordan Louviere and Jane Hall, and rising stars such as Jakob Bjorner, Kathleen Wywrich, Wayne Weng and Rosalie Viney. As always, there will be a stimulating program of submitted papers and posters, advancing our understanding, challenging our beliefs, and broadening our horizons.

For the latest program details, check the provisional program at [www.isoqol.org](http://www.isoqol.org). Online registration is also available there, along with detailed information and a short video about Hong Kong. See you there!

### Plan now for 2005!

12<sup>th</sup> Annual ISOQOL Conference

October 19-22

San Francisco, CA USA  
Hyatt Regency, Embarcadero