



# International Society for Quality of Life Research

Volume 7 Issue 3

Newsletter for ISOQOL Members

December 2002

## PRESIDENT'S MESSAGE

*Mirjam Sprangers, PhD  
Amsterdam, The Netherlands*

The life cycle of organizations is likely to consist of three stages. It begins with a founding organization where the board does all the work, then it moves to a governing organization where the board governs, to end as an institutional organization. In the nine years of its existence, ISOQOL has moved from a founding professional society to a governing society. Thanks to the dedication of many board and committee members and the support of the management office, the society has made significant progress in the past years and moved to a more professional level.

This process was stimulated by the members who left the Board in November 2002, when their term ended. We are indebted to David Osoba, our former president. His leadership can be characterized as pragmatic, practical and highly task-oriented, with a clear eye for what is important and what is not. These characteristics made him a very efficient and effective leader. The preceding president, Ivan Barofsky, has contributed to the society by generating an impressively large number of good ideas. David has called him, for good reason, "our ideas man". The financial viability of ISOQOL is, to a large extent, to the credit of Dennis Revicki. His fundraising activities, in particular, were very successful. David Cella was our eloquent advocate for the use of HRQOL in research, practice, and policy. I am very pleased that they all continue to participate in various ISOQOL activities. I welcome the new board members Ingela Wiklund (Sweden), Donna Lamping (UK), and Carolyn Schwartz (US). Ingela will support Diane

Fairclough, our new treasurer, with fundraising.

The highlight of the ISOQOL activities is, no doubt, our annual conference. The Scientific Program Committee, led by Carolyn Schwartz and Jeff Sloan (US), have done a superb job in Orlando. They succeeded in creating the most optimal conditions for learning, exchanging ideas, and meeting old and new friends. These conditions included the high quality of the science presented, the varied format including new and innovative sessions, the relaxed time schedule, and the exotic, yet professional surroundings. Interestingly, each year I hear enthusiastic comments from participants, claiming that this year's meeting is even better than the preceding one. This progress will be the challenge for next year's committee and its chairs, Donna Lamping, Jane Blazeby, and Carolyn Schwartz.

I would also like to mention the recipients of our awards, handed over in Orlando. George Torrance received the second President's Award for his excellent contributions to utility- and quality-of-life research during the past decades. The recipients of the New Investigator Awards and their winning presentations are listed on page 4.

I would like to extend my gratitude to all other unnamed members of ISOQOL who served on committees or contributed to its welfare in other ways. The society's success is critically dependent on the input of its members. As president, I would like to continue the good work done by all these members. In addition, I would like to encourage wider international participation, solidify ISOQOL's structure in terms of its committees, and ensure that good ideas and initiatives will not get lost. I invite you

to provide feedback on our efforts. The ISOQOL Board and its management office will be responsive to your visions, suggestions, and comments.

I encourage you to renew your membership and to visit our website regularly at [www.isoqol.org](http://www.isoqol.org) to remain up-to-date about ISOQOL's activities. I also would like to encourage you to take part in any activity that is of interest to you. This will benefit both ISOQOL and you. I have learned a great deal by participating in ISOQOL. I have not only made new friends, but learned more of quality-of-life research and professional management. For example, the first lines of this column were taught by George Degnon, our Executive Director, who trains the Board members to increase their effectiveness. I also would like to remind you of the next annual meeting in Prague from November 12 to 15, 2003. It is time to start thinking about the abstracts you will submit. This Newsletter contains interesting information for you. I wish you enjoyable reading.

## IN APPRECIATION . . .

ISOQOL would like to thank  
**David Cella, PhD**  
for his three years of service as a  
Board Member;  
**Dennis Revicki, PhD**  
for his service as Secretary-  
Treasurer and  
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for his service as immediate Past-  
President.

Their hard work and dedication  
have helped to further the message  
of ISOQOL throughout the world.

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## METHODS AND MODELS IN HRQL RESEARCH: A STATE-OF-THE-ART RE- VIEW

9th Annual Conference of ISOQOL, The International Society for Quality of Life Research, Orlando, Florida, USA, 30 October - 2 November 2002

Rick Berzon, Jordi Alonso, Peter Fayers and Jane Scott

The 9<sup>th</sup> Annual Conference of the International Society for Quality of Life Research addressed state-of-the-art methods and theoretical models for measuring health-related quality of life (HRQL), and focused on opportunities for the use of these tools within practical settings and circumstances. The scientific program was chaired by Carolyn Schwartz (University of Massachusetts Medical School, Concord, MA, USA) and Jeff Sloan (Mayo Clinic, Rochester, MN, USA). A variety of topics were addressed at the conference; chief among them were: (1) end-of-life issues; (2) chronic illness; (3) the clinical significance and interpretation of research findings; (4) response shift; and (5) adherence to therapy.

Quality of life (QOL) at the end of life is a topic that does not ordinarily receive the attention it deserves. During the first plenary session, Tom Hack (Canada) presented the results of a qualitative study through which the construct "dignity" was operationalized and assessed. His approach to qualitative research, using innovative methodology undertaken with cancer patients receiving palliative care, was engaging and practical. At the same session, remarks provided by Carol Tishelman (Sweden) that focused on how to add precision to qualitative research were well received by the audience. The end of life issue received further attention at the conference during a special symposium chaired by Carolyn Schwartz (USA). In the symposium, research was presented that ranged from new tools developed

specifically for a seriously ill and/or dying population; to measuring the treatment preferences for those receiving end-of-life care.

The end of life period and the issues raised by it are relevant for exploration by HRQL research because the field has a natural relationship with chronic illness, regardless of whether the illness is in remission or is progressing. As is always the case at ISOQOL annual conferences, chronic illnesses of all sizes and shapes were fodder for HRQL presentations. Topics that received special attention at one such session, chaired by Jane Scott (USA), included examination of models to accurately reflect the multidimensional nature of HRQL assessment, using data from patients with AIDS; the psychological impact of cancer and treatment for it, and how this relates to post-traumatic stress disorders; the relationship between HRQL findings in patients with multiple sclerosis and other chronic neurologic illnesses; HRQL findings in cancer survivor patients; and the interrelationships between pain, mental and physical health, and HRQL in people living with HIV infection.

Three oral sessions were devoted to cancer. The papers presented and the issues discussed within one of these sessions included the use of QOL as a primary endpoint within a lung cancer study. The paper, offered by Andrea Bezjak (Canada), was innovative because the successful use of HRQL as a primary endpoint was conducted within an international clinical study. Other noteworthy topics presented within this session, chaired by Galina Velikova (UK), included insights into the timing of QOL assessments to better account for treatment efficacy and more accurately determine drug toxicity; the role of dedicated nursing staff in caring for seriously ill esophageal cancer patients, regardless of treatment regimen; validation of the FACT-G in Uruguay, employing both psychometric and IRT methodology; and assessing QOL in newly diagnosed cancer patients awaiting surgery.

A session on one of many other areas of chronic illness, neurology, was chaired by Rick Berzon (USA). It contained papers that ranged from the QOL in partners of patients with glioma; to a discussion of sample size issues in the context of psychometric studies; to separate talks on outcomes evaluations in stroke and migraine headaches. Perhaps the most exotic paper of that session was the one entitled, "Stress induced immunosuppression and self-rated health in an indigenous Siberian population." In it the author, Mark Sorensen (US), investigated the association between a biomarker of psychosocial stress (antibodies to the Epstein-Barr virus) and self-rated health, using a Russian version of the SF-12. The findings indicated that psychosocial stress is associated with poor self-reported physical health status.

Clinical significance was a subject on the minds of nearly everyone who attended this conference, especially following this year's successful Mayo Clinic symposium on the same topic. The ISOQOL conference included a number of papers that addressed it. Along these lines, a special symposium, chaired by Carolyn Gotay (USA), reviewed major findings from the Cancer Outcomes Measurement Working Group (COMWAG). This group, which includes 35 HRQL researchers, was created as a consequence of the National Cancer Institute's Quality of Care Initiative. The purpose of COMWAG is to assess the state of the science of outcomes measurement in cancer. It is believed that use of HRQL and interpretation of the findings contribute to treatment decision-making because the data provide information that go beyond traditional biomedical outcomes. Among other feats, COMWAG analyzed clinical study reports of interventions in cancer patients that included HRQL (and biomedical) assessments to better understand their added value in the decision-making process. Their findings will appear in a book, *Outcomes Assessment in Cancer*, next year. The symposium (and the overall effort) was

lead by Joseph Lipscomb (USA) of the NCI.

Response shift is a construct that attempts to explain discrepancies in HRQL assessment, particularly when divergence is found between expected and observed QOL outcomes over time. The topic was addressed through two separate forums. The first consisted of an oral session, chaired by Elaine McColl (UK). In that session, papers included models and clinical research study data, and presentations were intended to more clearly define and further expand the concept's underlying principles.

The second forum on response shift was an expert panel. It was moderated by Peter Fayers (UK) and was designed to be controversial, with a range of enthusiastic and sceptical panellists. Dr. Fayers introduced the session by expressing contrasting reactions to the construct. On the one hand, he believes that response shift is an elegant, theoretical model that encapsulates numerous unusual and disparate phenomena; on the other hand, he is not convinced that it is useful for clinicians who seek evaluation of interventions. The panellists—who included Drs. Mirjam Sprangers (Netherlands), Carolyn Schwartz (USA), Bruce Rapkin (USA), Patrick Devlieger (Belgium) and Jane Blazeby (UK)—discussed the construct's relevance, complexity and usefulness for clinicians. Dr. Bruce Rapkin presented a testable extension of the Sprangers-Schwartz model that included appraisal processes; he postulated that response shift is quantified by discrepancies between expected and observed HRQL outcomes within the change-over-time context. Perhaps the most outspoken remark on the panel was offered by the final speaker, Dr. Jane Blazeby, a surgeon. She commented: "Why bother studying response shift at all?" believing that it is an essential part of every clinical intervention and no different than other patient outcomes which routinely receive attention by clinicians. Needless to say, the issue was not resolved, and the usefulness of response shift as a theoretical

construct to encapsulate disparate phenomena in HRQL measurement will remain a topic for further research that is likely to be presented at next year's annual ISOQOL conference.

Patient adherence to therapy, a research topic addressed within the final plenary session, has been reported in the literature to be associated with better HRQL. The speakers who offered papers on the topic are well-known academics; the therapeutic areas discussed included asthma (Cynthia Rand, USA) and rheumatoid arthritis (Jackie Dunbar-Jacob, USA). Dr. Rand presented data that associated low baseline maternal mental health scores and decreased mother and child adherence to asthma therapy. She also noted this relationship affects use of health care resources, a finding with potential enormous economic ramifications for every health care system in the world. Dr. Dunbar-Jacob's presentation suggested that use of disease-specific HRQL instruments are more likely to demonstrate a causal relationship between patient behaviors (that include adherence as well as HRQL outcomes) and management of the illness.

Drs. Daniel Kahneman (USA) and Carol Ryff (USA) spoke at a plenary session devoted to theoretical models. Dr. Kahneman, a Princeton University professor, was recently awarded the Nobel Prize in economic science. He delivered his remarks by video-link, explaining that because a person's QOL varies markedly from moment to moment, there are serious weaknesses in asking people to rate it. His team measured the quality of the daily lives of numerous individuals—in one case, the sample size exceeded 1000 persons—to reconstruct the previous day's successive episodes and associated emotions. In one study, observing the social support provided by friends, Kahneman explained, "People are happier with friends than they are with their families." The Nobel laureate suggested that his approach to QOL assessment is valid and useful, and reveals unexpected findings.

As the poster and oral research  
(Continued on page 4)

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## METHODS AND MODELS IN HRQL RESEARCH:

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(Continued from page 3)

presented at the conference indicated, there is much interest in the development of more robust and precise instruments based on item banks and other state-of-the-art methodology. Computer-Adapted Testing, for example, has allowed researchers to develop instruments that require only a few items. However—due to the fact that each person's response is dynamically matched to the best estimate of his/her level of health—these types of approaches result in shorter administration time, producing a final score that is practically identical in value and reliability to longer instruments, which must be completed in their entirety to be effectively scored and interpreted. A debate regarding the pros and cons of Computer Adaptive Testing was moderated by David Osoba (Canada) during the conference.

In the course of the meeting, a number of events were scheduled that offered opportunities for the attendees to discuss their research with colleagues. One such effort included a mentor/mentee breakfast, at which early career investigators were paired with more experienced scientists to discuss their work. This successful forum for interchange is likely to become a regular event at future ISOQOL annual meetings.

The awards ceremony and closing dinner was, as always, a highlight of the conference. The winners of this year's awards for best podium presentations were Mirjam Locadia, who is based at the Academic Medical Center in Amsterdam, The Netherlands and Sara Ahmed, MSc, from McGill University, Epidemiology and Biostatistics Montreal, Canada.

Mirjam's paper is entitled, "A comparison of three health state valuation methods for temporary health states in patients treated with oral anticoagulants." Sara's paper is entitled,

"Using Structural Equation Modeling to Assess Response Shift in Health Related Quality of Life (HRQL) Post-Stroke."

The winner of this year's award for best poster presentation is Stacie Hudgens, a research statistician at the Center for Outcomes Research Evaluation (CORE) at Northwestern University in Evanston, Illinois, USA. Her poster is entitled, "Cross-cultural validation of the Functional Assessment of Cancer Therapy instrument for patients receiving biologic response modifiers (FACT-BRM)."

In conclusion, the 9<sup>th</sup> Annual Conference of the International Society for Quality of Life Research served as a forum for the discussion and dissemination of worldwide, state-of-the-art activity within the HRQL field. This conference in Orlando, Florida, USA, attracted over 400 registrants. The next conference will be held in Prague, Czech Republic in November 2003. All those who undertake research in the field—and those who contemplate it—are welcome; watch the website ([www.isoqol.org](http://www.isoqol.org)) for further details!

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## CONGRATULATIONS TO THE 2002 PRESIDENT'S AWARD WINNER, GEORGE TORRANCE, PHD (CANADA)

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This year's President's Award was presented at the 2002 ISOQOL Annual Conference to **Dr. George Torrance**. Dr. Torrance is well known to most of you. He is currently Vice President, Scientific Affairs for Innovus Research, Inc. He is Professor Emeritus at McMaster University and affiliated with the Centre for Health Economics and Policy Analysis and the Centre for Evaluation of Medicines. Dr. Torrance's many publications on economic evaluation of health care include both contributions to the methods, some of which he has pioneered, and applications in various clinical areas. Methodological contributions include the use of utility theory, to mea-

sure individuals' preference for health outcomes. Dr. Torrance and his colleagues developed the Health Utilities Index, a general utility-based measure of health-related quality of life for use in program evaluation and in the measurement of population health. The President's Award presentation took place at the Closing Ceremony, on Saturday, November 2.

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## ISOQOL'S 2002 AWARD WINNERS FOR NEW INVESTIGATORS

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*ISOQOL is committed to promoting excellence in quality of life research; therefore, again this year, the New Investigators' Awards were presented during the conference closing dinner. These awards recognized the best overall oral and poster presentations made by individuals under age 35.*

### Best Oral Presentation

#### Winners:

Mirjam Locadia ~ Amsterdam, The Netherlands

"A Comparison of Three Health State Valuation Methods for Temporary Health States in Patients Treated with Oral Anticoagulants"

Sara Ahmed, MSc ~ Montreal, Canada

"Using Structural Equation Modeling to Assess Response Shift in Health Related Quality of Life (HRQL) Post-Stroke."

### Top Poster Presentation

#### Winner:

Stacie Hudgens ~ Evanston, IL, USA

"Cross-Cultural Validation of the Functional Assessment of Cancer Therapy Instrument for Patients Receiving Biological Response Modifiers (FACT-BRM)"

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## REVIEWS OF THE 2002 ANNUAL MEETING

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*Articles from ISOQOL members who share their reflections of the 9th Annual Conference in Orlando, Florida*

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### Observations from Two Attendees

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*Michael B. Nichol and Denise Globe*

Three days into the excellent Orlando meeting, we were struck with the observation that, similar to many other professional organizations, ISOQOL was in the midst of an identity crisis. Fortunately, ISOQOL possesses the critical elements necessary to survive this crisis and evolve positively. Most importantly, in our view, ISOQOL is on the precipice, prepared to evolve as a leader in a number of key areas of health services research. In a sense, ISOQOL could develop a brand identity that distinguishes itself from its many sister organizations, while building a broad demand for an enduring product. This can incorporate the expertise from investigators from a wide cross-section of disciplines that constitute the organization's membership.

In order to accomplish the branding process, the organization needs to identify the consumer. It seemed that there were three research streams at the meeting: clinically based, population-based, and multidisciplinary. While much of the clinical research presented at the meeting was well executed and interesting, all too often the implied purpose was to produce results generalizable to an entire population, whether that was a population suffering from a particular disease or a national or other geographic group. Evidence of this was in the theoretical models that demanded multi-directional solutions (which way is cause and effect in this relationship?) and sophisticated analytic techniques (such as latent variable, MIMIC and other methods). Another, but much smaller group of investigators, was focused on the use of QOL for policy-setting purposes. This group tended to gravitate to utility as-

essment methods and applications.

But in each of these areas, we watched investigators grappling with making sense of insignificant results. We couldn't help but wonder if these results had focused on cohorts within their population maybe they would have more successfully explained both the phenomena under investigation and the direction of causality. If these investigations tried to determine specific categories of individuals that could be treated differently, perhaps tailored interventions would show dramatic success. The irony is that ISOQOL members appreciate and endorse the heterogeneity of the human experience better than many health services researchers, and may be reluctant to draw conclusions about 'categories' of people. But if ISOQOL focused on cohorts, its brand might be most helpful to clinicians.

The upcoming seminar linking QOL and clinical practice is a strong step in the right direction. But we think the organization would maximize success if it were to re-focus on two key areas of particular interest to clinicians: Who are these people that need help? And how can I best help them (what works for them)? In so doing, the organization may well attract more clinicians, as well as other disciplines with constructs and models relevant to the problems of HRQOL assessment and application.

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### Views of Students

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*Rolanda Baars PhD-student, Leiden University Medical Center, The Netherlands and Symone Detmar PhD, TNO Prevention and Health, The Netherlands*

The 2002 annual meeting of the ISOQOL took place on October 30-November 3 in Orlando, Florida. We found the scientific program to be comprehensive and to offer a wide overview of the field of quality of life studies. The three major themes in the conference were: theoretical issues, (concept of quality of life and determinants), methodological aspects (qualitative research, IRT) and clinical

work (quality of life in clinical trials and clinical practice), which is in line with the former conference of ISOQOL in Amsterdam. Most issues that were "new" then, were now elaborated: IRT and computer-adaptive testing; QL in terminal illness and more emphasis on the interpretation of QL. A large difference with last years' conference however, was the environment. Beautiful weather, holiday resorts and highways instead of cold, rain and a derelict old city center.

On the first day, we especially enjoyed the lecture by Tom Hack about enhancing the dignity of palliative cancer patients; a sensitive and inspiring talk in what issues could be important in assessing QL and in the usefulness of qualitative methods to quality of life research.

The following day was highlighted by the plenary session with a "tele-talk" from Daniel Kahneman.

First of all, the talk was understandable and, even more important, it was an excellent presentation about an innovative method to collect QL data; the Experience Sampling Method. This means that participants parse a day into episodes, then complete a detailed report of the setting, the activities and the feelings associated with each episode. The results showed that this is a valid method to receive very detailed information about QL during different episodes of the day.

Interesting for researchers in the field of pediatrics, as we are with our own Kidscreen and Disabkids projects was a special symposium on Friday afternoon by Anne Riley and Christopher Forrest regarding pediatrics. They took us by the hand and guided us through their developmental steps and mishaps of the CHIP-CE development. In addition, two oral sessions were held about pediatric aspects in QL research. Both were interesting sessions, including results and new developments in pediatric research. It is encouraging that pediatric aspects are increasingly represented in the ISOQOL meeting.

*(Continued on page 6)*

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## Student Views

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*(Continued from page 5)*

While we concentrate on therapy adherence on the Saturday morning we saw the conference adherence decreasing, probably due to an inclining temperature and the world famous theme parks.

However, well visited in the afternoon was the item reduction panel. Here the important but seldomly described process of item reduction was presented to us and the presenters gave us hope in telling us that in the near future reduction guidelines would be constructed.

There were some new aspects in the organization of the conference; the number of oral sessions was reduced, which led to more audience and less rumor during the talks. Round-table lunches were held to facilitate the opportunity for discussions with people interested in the same topics. This goal was reached in the lunch in which we participated. However, from other sessions we heard that the number of participant was too large, to have real discussions. The last change was an increase in poster discussion sessions. However, we would favor more round-table lunches, poster sessions during lunches, or “different perspective” debates instead of cited poster discussions at the very end of the afternoon (as these had to compete with the urge to go out into the warmth of the Florida sun).

At the end there were still discussion topics left for at the poolside. It was noted by several that presentations often reflected on small aspects of QoL research and that there was still little on the overall impact of practical health practice or clinical significance. Nevertheless, most agreed that this conference was a high quality meeting, in which an interesting and stimulating program was offered.

Thanks to the organization!

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## Other Views

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*Kwok Fai LEUNG, Hong Kong, China*

The 2002 ISOQOL annual conference was the seventh ISOQOL conference that I have attended since 1997 in Montreal. Throughout these years, I have seen many changes in ISOQOL and her annual meetings.

My past impression of ISOQOL conferences was that it was a meeting for methodologists interested in developing and validating of QOL scales, designing RCT on QOL, and debating the relative merit of various types of measures and methods of psychometric testing, handling of missing data, clinical significance determination and statistical modeling, etc.

I witnessed an obvious change in the 2002 conference. This year was the first time I have seen a lot of emphasis on qualitative research and the cognitive aspects of QOL, with presentations from nursing and medical professionals who are experienced in qualitative research. The presentations brought about a new horizon to QOL research methodologies and a great potential in combining qualitative and quantitative methods in QOL research.

There seemed to be an increasing interest in the cognitive process underlying an individual’s response to a QOL question. The discussion started with the issues on response shift, which I first heard of in the Vienna meeting in 1998. This year the discussion extended into an arena that sought to the understanding of the adaptation process and the underlying psychological or cognitive processes of patients. This emphasis blurs the line between HRQOL and the more global concept of QOL. It also makes the control of confounding variables more difficult in QOL research. As an occupational therapist helping people to reconstruct a meaningful and happy life, these discussions were both interesting to me and helpful in my work. I hope ISOQOL will continue to explore these cognitive issues in the future meetings. We will have to learn from a wide range of disciplines to gain a deeper understanding of the underlying pro-

cesses of QOL appraisal and therapeutic intervention. However, will the inclusion of a wider range of academic disciplines affect the uniqueness of ISOQOL? This is an issue that ISOQOL members and Board should discuss further.

It was nice to have a meeting in a luxurious resort with many attractions around but it was hard to decide between the scientific programme and the theme parks. This might be why there were not many people in the sessions on the last day.

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## THANK YOU...

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...to the following organizations who in various ways contributed to the 2002 Annual Meeting in Orlando:

Abbott Laboratories  
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In addition, thank you to the following exhibitors at this meeting:

MAPI  
MEDTAP, International, Inc.

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As always, our Institutional Members are appreciated:

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AstraZeneca (Sweden)  
CORE (USA)  
MEDTAP International (USA)  
Quality Metric, Inc. (USA)

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## DEBATE SYNOPSIS

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*Report from Orlando*

*Albert Wu, MPH, MD*

The Halloween afternoon debate examined the proposition: Resolved: computer adaptive testing (CAT) should become the standard method of health status assessment in clinical trials. Albert Wu moderated.

Bryce Reeve from the National Cancer Institute, is known for his preternatural ability to explain CAT in such a way that people believe they understand what he is talking about. He led off with an explanation of CAT, followed by a persuasive series of arguments. First, CAT can provide an accurate estimate of the patient's score using a minimal number of questions, thus increasing efficiency and decreasing respondent burden. Second, CAT automates a whole series of operations including question administration, data recording, scoring, and recording. Third, CAT all but eliminates floor and ceiling effects. Finally, it is versatile, available on multiple delivery platforms.

In a virtuoso performance Ron Hays and David Cella substituted on very short notice for Colleen McHorney, who was trapped in an Indiana airport. They presented the best kind of critique - comments from investigators actively pursuing work in this area. Through some feat of legerdemain, Ron Hays produced an illustrated power-point presentation that emphasized the following points: First, is the field sufficiently advanced? There is still internal debate within the IRT community about the best models and methods for assessing dimensions of health. In addition, there are problems with the unidimensionality of many of the scales we might want to measure. Second, there is little known about "order effects" - when questions are presented in a different order than how they appear in their parent questionnaires, this may affect the answers given by respondents. Third, creation of item banks is laborious and expensive. There is controversy about whether these banks should be propri-

etary, a public utility, or both. Fourth, there are potential problems with how well the underlying IRT models fit individual persons. Taken together, these unresolved technical issues raise a red flag.

David Cella, after a heartening plea to his sponsors from the National Cancer Institute (who were sitting in the audience) mustered honest reservations about the feasibility of CAT in clinical trials research. He argued against short-term application, because: 1) Measurement science has not developed to the point where there are available programs to conduct CAT beyond developmental research settings. Item banks for CAT are not readily visible or available. 2) CAT is the "highest form" of IRT, and there are other contributions of IRT that are ready for prime time, such as contributing to the development of short form questionnaires. In reality, trials do not need the precision gained by CAT...good short forms are more than adequate. 3) Most of the arguments offered by Dr. Reeve in his support of CAT (Computer ADAPTIVE testing) were actually in support of Computer BASED testing. Computer BASED testing is a great idea, as it reduces error and labor, and offers immediate feedback. But this is much less complicated than computerized ADAPTIVE testing, which requires algorithm-based, patient-specific assessment. 4) One of the main reasons CAT is so popular in education is the protection against cheating, and this is not an issue in health status assessment 5) In clinical trial research and evaluation, there is an advantage to having all patients answer the same clinical questions, especially since we are not sure we can define constructs so tightly that questions indeed can be used interchangeably, as is required with CAT.

Nancy Santanello provided a reality test from the perspective of industry, who are likely to be important consumers of CAT technology. Although it is certain that the use of CAT is likely to increase in the future, there are important unanswered questions. First, CAT requires large populations with wide distributions of responses to set up the

underlying metric for each measure of health status. Are these likely to be available, especially for people with specific diseases or conditions? There is a lack of disease specific CAT measures - future development would be needed. Second, item banks will be required before CAT can be a reality. How will this be accomplished, and who pays for this work? Third, CAT will require technology to be applied (web, portable devices, laptops) to allow collection of CAT measures. Will companies be willing to commit to expensive technologies to assess what for them may be secondary or tertiary endpoints? Fourth, what is the usefulness of CAT methods to collect daily symptoms on a diary record or on a periodic questionnaire rather than a health status measure? Fourth, a technical question, does CAT metric methodology meet CRF (Case Report Form) part 11 compliance? Fifth, how do you compare treatment groups when patients within each group do not answer the same questions? And how do you interpret the scores? What is a clinically relevant change, and how is this to be established? Sixth, will the FDA accept results from CAT measures for labeling and promotion?

Currently, FDA wants to look at questions that make up measures. CAT gives a score for each health state - is a score sufficient for label and promotion? Questions between patients will most certainly differ at each time point and questions within patients may differ at each time point - implications for labeling and promotion? In summary, although CAT is a promising new technology, still needed are time to do work necessary to establish the methods, money to pay for that work, application in different populations to establish validity and interpretation, and guidance on how to analyze the results.

The debate adjourned without a clear resolution, and without Ron Hays donning the fright mask that he had brought, just in case, in his back pack.

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## CATHERINE POUGET'S AWARD 2002

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In remembrance of our friend and colleague Catherine Pouget, Mapi Research Institute has set up a prize to be awarded annually for research contributing to the improvement of the quality of life for the terminally ill.

For the year 2002 seven applications were submitted to Mapi Research Institute. These applications were evaluated according to the following criteria:

- Significance (this refers to the likelihood of improving the quality of life and / or the health care of the terminally ill),
- Methodological rigour,
- Originality,
- and likelihood to be completed.

For each criterion, a 4-point scale has been used: low (1), moderate (2), good (3), high (4). The criteria have not been weighed, i.e. each of them are given the same importance; although it could be argued that significance and methodological rigour could be weighed higher. The review committee included Catherine Acquadro, MD, Scientific Director of Mapi Research Institute, and Mapi Research Institute Scientific Advisors, namely, CRB Joyce, PhD, Donald L. Patrick, PhD, MSPH, John E. Ware, Jr., PhD, Albert W. Wu, MD, MPH.

We are happy to announce that the 2002 Catherine Pouget Prize has been awarded to Mrs Colleen J. Nordstrom, PhD candidate, Department of General Practice, University of Melbourne, Victoria, Australia for her project entitled: *The Influence of Spirituality on QOL and Pain in the Terminally Ill: An Exploratory Study of the Patient Perspective to Develop an Empirical Model.*

The purpose of this study is to determine how dying patients understand and define the term spirituality, in order to develop a model that offers both clinical and conceptual explanatory capacities. The significance of this research

lies in the clinical contribution that may result in improved quality of life, and potentially decreased pain, by identifying aspects of spirituality that can be employed as therapeutic interventions.

A summary of the study results will be published in a future issue of the Quality of Life Newsletter.

We would also like to warmly thank the other candidates for submitting their research projects and for their will to contribute to the improvement of quality of life for the terminally ill.

The Application form for the 2003 Catherine Pouget Award is available on the Mapi Research Institute website at <http://www.mapi-research-inst.com/other.asp> and [http://www.mapi-research-inst.com/pdf/art/Catherine\\_Pouget\\_Research\\_Award-Application.pdf](http://www.mapi-research-inst.com/pdf/art/Catherine_Pouget_Research_Award-Application.pdf). We are looking forward to receiving your research proposal.

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## ELECTRONIC COMMUNICATION IN 2003

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James P. Donnelly, PhD

The Electronic Communication Committee would like to thank Dr. Albert Wu, Laura Degnon, and Bette Anne German for their very positive leadership and many contributions in building the society's communication and information network. Our goals for the coming year very much reflect the progress to date and will involve further development of the web site and listserv capabilities. We'll try to take an evaluative perspective, making improvements based on informal and formal feedback throughout the year. Behind the scenes, our friends at Degnon Associates have already been upgrading hardware and software to better serve the society.

One of the first improvements you will notice is that we will have two society mailing lists. One list will primarily involve one-way communication from the society to members. This listserv can be thought of as an "announcements only" list to keep the membership posted on important events. The second list will

be a discussion list to facilitate two-way communication related to quality of life research. When you receive your renewal notice, you will have an option of choosing one or both listservs. Other enhancements will include list archives and simpler subscription procedures. Longer-term goals include adding listservs for specific interest groups within the society as they develop.

The web site will also continue to evolve in the coming year. We have established reciprocity with most of the sites linked on our page. In addition to adding new sites (suggestions welcome!), we will attempt to organize them by category. The information value of the site should increase as we continue to add bibliographic resources and a Frequently Asked Questions section. In addition, a survey of site visitor needs will be conducted. We will report on the results in the newsletter and begin to respond with refinements to content and structure of our site. The committee will also study the "best practices" in web site structure and function and will attempt to emulate them.

We will also continue to monitor statistical indicators of web site activity. In the first ten months of 2002, the site received approximately 170,000 hits based on nearly 30,000 visits. About 78% of the site visitors made only a single visit (i.e., most of the visits were generated by unique IP addresses). There were about 100 visitors per day, and the average length of a session was about seven minutes. The statistical summaries also indicate that site visitors have most frequently accessed information related to the annual conference, the newsletter, links, and society organization (membership, leadership, and committees). We might think of this data as a kind of baseline, and hope improvements to the web site and continued growth in the society will be reflected in the site activity report for 2003.

Lastly, we welcome anyone who would like to join in the committee and look forward to receiving suggestions from all members. You may write to me at [jpd1@buffalo.edu](mailto:jpd1@buffalo.edu). Thank you in advance for your help!



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## RESUSCITATING THE ISOQOL LISTSERV

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Albert Wu, MPH, MD

Members with a good memory and a steady connection to their email may know that for several years, ISOQOL has maintained an electronic mailing list, or "listserv." The purpose of the list was to create a virtual forum for information, discussion or and advice. Initially, all ISOQOL members with an email address were enrolled, with the invitation to opt out if so desired. Despite this, it must be admitted that members have had an on-again, mostly off-again relationship with the listserv. The service was neglected, with long periods of time elapsing between individual postings, which emerged seemly a random from members with a concern that aligned momentarily with a recollection of the email address to send to.

In the interim, email evolved from novelty, to necessity, to nuisance, coincident with increasing torrents of intended messages spam. In October, an attempt was made to resuscitate the listserv, and a reminder message was sent to everyone on the list. A couple of members posted queries, including an interesting (to some) thread concerning individualized QOL assessment. Others were less charmed and submitted urgent requests to be disenrolled. These messages were posted to everyone on the list, further fueling concern. Added to this was an inexplicable and alarming barrage of error messages from inactive accounts that assaulted the email boxes of random individuals. At this point the list was temporarily shut down for a cooling off period of reflection and improvement.

We will be starting up again by the new year. So, once again: Have a question? Looking for a collaborator? Need a curbside consult, expert advice or help in finding an instrument or article? Want feedback on a new idea? Send a message to the ISOQOL electronic mailing list, and plug into a international network of virtual colleagues.

If you are interested in participating, please be sure to indicate your listserv preferences on your ISOQOL Member-

ship Renewal form, or contact [info@isoqol.org](mailto:info@isoqol.org).

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## CALL FOR WORKSHOP PROPOSALS: ISOQOL 2003

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We are soliciting proposals for workshops that can be offered at the ISOQOL 2003 meeting in Prague. The proposal application (along with general requirements for delivery of a workshop) is located on ISOQOL's website: [www.isoqol.org](http://www.isoqol.org). All applications will be peer reviewed by Society members.

The purpose of the workshops at annual meetings is to provide educational opportunities for ISOQOL members and to raise funds for the Society. These workshops generally have two major foci: measurement and analysis and interpretation. However, we are also interested in going beyond the basic information provided in previous workshops. Therefore, we are appealing to the membership to propose workshop topics considered important in the conduct of your quality of life research, as well as topics of interest to you.

If you are interested in offering a workshop, please complete the workshop proposal application on ISOQOL's website. If you would just like to suggest a topic, please email Carol Moinpour ([carolm@crab.org](mailto:carolm@crab.org)).

Individuals presenting workshops are not compensated for doing so because income generated by the workshops is used to support Society activities including scholarships to attend the annual meeting. We believe that workshop presenters benefit in at least three ways: you are helping to improve the conduct of research in our field; you are helping ISOQOL provide a service to its membership; and, as a presenter, you are obtaining recognition for your own knowledge about and contributions to the field of quality of life research.

So please either contribute your ideas for workshop topics or apply to provide a workshop. ISOQOL benefits from your involvement in its educational mission.

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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.*

**Alex C. Michalos, PhD, F.R.S.C.**, University of Northern British Columbia, was given the Vincentian Ethics Scholar Award for 2002, awarded by the Vincentian Universities of the United States for valuable contributions to fostering business ethics research.

**Nancy Kline Leidy, PhD**, Global Scientific Director of MEDTAP International was awarded the 2002 Distinguished Alumni Award from Michigan State University. The selection is made from candidates who have distinguished themselves by obtaining the highest level of professional accomplishments and who possess the highest standards of integrity and character to positively reflect and enhance the prestige of Michigan State University.

Dr. Leidy has more than 25 years of experience in clinical and health outcomes research. She has served on the faculties of Michigan State University and the University of Arizona and the research staff of the International Council of Nurses in Geneva, Switzerland. Immediately prior to joining MEDTAP, Dr. Leidy was an intramural scientist at the National Institutes of Health (NIH) where she studied performance variation and structure in people with chronic obstructive pulmonary disease. She currently serves as an Adjunct Faculty Member at Johns Hopkins University.

# *ISOQOL 2003*



**November 12 - 15, 2003**

The Hilton Prague

Prague, Czech Republic

**Abstract Submission Deadline:**

**April 30, 2003**

To submit an abstract and for more meeting information, visit our website at [www.isoqol.org](http://www.isoqol.org)