



# International Society for Quality of Life Research

Volume 6 Issue 3

Newsletter for ISOQOL Members

December 2001

## PRESIDENT'S MESSAGE

*David Osoba, MD  
West Vancouver, BC, Canada*

Hello! If you don't already know it, I am your new President until November of 2002. I'd like to tell you about what's happening in the Board of Directors of ISOQOL and about our plans for the future.

But first, let me say a few things about the meeting in Amsterdam. The meeting was highly successful by several measures. The Scientific Program Committee, led by Neil Aaronson and Mirjam Sprangers, selected over 400 abstracts for oral and poster presentation. This was more than ever before. We moved to a 2 ½-day meeting to be able to include all of them. I also heard several comments, from veteran members who have been at previous annual meetings, that the quality of the work being presented was the best ever! Registration was up with about 500 registrants. There were some new and innovative sessions, including an Assembly of Nations Panel Discussion on "Patients Rights Relative to Their Quality of Life," a satellite meeting on "Spiritual Aspects of Quality of Life" and a plenary session on "HRQL, Happiness and Social Indicators Research." We had a very high quality meeting and we intend to continue to provide an interesting and stimulating program.

I would also like to highlight the recipients of our awards this year. The first President's Award was given to Donald Patrick for his excellent contributions to quality-of-life research over many years and his many contributions to the Society. There were four awards for Young Investigators. You may find out more information about their topics on pg. 3.



*Past-President Ivan Barofsky awards Donald Patrick the first ISOQOL President's Award*

Now, back to the Board and to the future. Every year there are changes in the composition of the Board, with some members leaving and new ones taking their place. Thank you to Sharon Wood-Dauphinee (Canada), Geraldine Padilla (USA), and Shunichi Fukuhara (Japan) for their many years of service. Sharon was our President in 1999 and 2000. She presided over many changes during her term, including hiring Degnon Associates as our managers and consolidating our relationship with Kluwer as the publisher of *Quality of Life Research*. Geri has been a tremendous contributor in many ways, including assistance with organizing our meeting in Manila a few years ago. Shunichi has also contributed greatly in many ways, including contributing to this year's Annual Meeting through the resources of the Pan-Pacific Conference in Japan earlier this year. We shall miss the wise counsel that all of them gave to the organization, and hope they will continue their interest and participation for many years to come.

Welcome to Madeleine King (Australia) and John Ware (USA) as new members of the Board. We look forward to their contributions. Madeleine also is Chair of the Subcommittee on Conferences and Workshops of the Education Committee.

In previous years, many Board members chaired the standing committees of the Society. This dual responsibility meant that the workload inherent in being a committee chair left less than sufficient time to be fully engaged as a Board member. The main roles of Board members are to plan the future and to evaluate the progress of the Society. Board meetings should be devoted to these activities rather than "micromanaging" the affairs of the Society. Therefore, over the past year we have started to co-opt more and more regular Society members to chair our standing committees and

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## SEND IN YOUR 2002 WORKSHOP TOPIC SUGGESTIONS

The ISOQOL 2002 Workshop Planning Committee, led by Donald Patrick and Carol Moinpour, seeks workshop topics. Please send any ideas you have regarding new topics that have never been covered and you think would be of general interest to our members OR workshop topics that have been covered in the past and you think should continue, to the ISOQOL office ([info@isoqol.org](mailto:info@isoqol.org)).



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*Deadline for articles for our next issue is Feb. 15, 2002*

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**PRESIDENT'S MESSAGE**

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subcommittees. For example, the Public Policy and Practice Committee will be chaired by Frank Baker (USA). The new Editor of the Newsletter will be Ulrike Ravens-Sieberer (Germany) with associate editors from Europe, Asia and North America. We are actively seeking a Chair for the Education Committee. Some Committees will continue to be chaired by Board members, e.g., the Finance Committee, chaired by the Secretary-Treasurer, Dennis Revicki (USA) and the Nominations Committee, chaired by the Past-President, Ivan Barofsky (USA). Please visit the website at [www.isoqol.org](http://www.isoqol.org) for a complete listing of Committee and Subcommittee chairs.

What direction is the Society moving in? First, the most important function of the Society is to continue to provide education. By "education," I mean the presentations at the annual scientific meeting as well as the formal education in workshops. It is from the presentations at the scientific meeting that we learn what's new. So we will continue to focus on providing the highest possible quality of presentations. But this alone is not enough. As more and more of the world moves towards adopting quality of life endpoints (outcomes) in clinical research (and even in clinical practice) our Society needs to help emerging regional associations and networks in their efforts to organise and function.

Second, we need to maintain a strong journal, i.e., *Quality of Life Research*. To do this we need to publish our best work in the journal. We should submit our work there first and not only as a second or third choice.

Third, we need to pursue initiatives that will strengthen us. These include: an increase in the number of scholarships to help needy members attend the annual meeting (we have increased the total amount of scholarship money that will be available in 2002); an active campaign to increase our membership and to sustain it; a concerted effort to obtain more corporate sponsorship for our



*Donald Patrick accepts the first President's Award, the highest honor bestowed by the Society, for his many contributions to ISOQOL's success.*

activities; an expansion in the capabilities of our website; the development of an active voice in appropriate public policy. There are other initiatives as well that you will learn about during the course of the next year.

This Newsletter contains much information of interest to you. I encourage you to read it. I also encourage you to renew your membership and to actively help to recruit new members. Also, it is not too early to start thinking about the abstract you will submit to the next annual meeting in Orlando, from October 30 to November 2, 2002.

**THANK YOU FROM  
 ISOQOL'S FIRST  
 PRESIDENT'S AWARD  
 WINNER:**

Dear ISOQOL Members:

My heartfelt thanks to the leadership of ISOQOL, Ivan Barofsky, and all ISOQOL members for the high honor of receiving the first President's award from the Society. It was a great privilege to be involved in the founding of the Society and to watch it grow in numbers and quality over the years. The recognition made through this award is indeed cherished by me and my family.

*~Donald*

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## CONGRATULATIONS TO FIRST PRESIDENT'S AWARD WINNER, DONALD L. PATRICK, PHD, MSPH (USA)

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*ISOQOL presented its first-ever President's Award at this year's Annual Meeting in Amsterdam. New in 2001, the President's Award is given annually to someone who has advanced HRQL research and has made outstanding contributions to ISOQOL in one or more of the following areas: education of professionals, patients or lay individuals about HRQL's value; promotion or execution of HRQL or other scholarly activities; facilitating or furthering policy initiatives that have an impact on HRQL.*

*The award is selected and approved by the ISOQOL Executive Committee and is endorsed by the Board of Directors. Each recipient receives a commemorative plaque, a monetary honorarium and up to \$1000 in travel expenses to apply toward attendance at the Annual Conference of the year the award is received.*

*The following is an excerpt from Past President Ivan Barofsky's presentation of this most important award to this year's recipient, Donald L. Patrick PhD, MSPH:*

*This award is given to persons who have made outstanding contributions to the field of HRQL research, a public acknowledgment that the person has achieved a sufficiently high degree of accomplishment. What was true about Dr. Patrick, however, was that he was and has been successful since he graduated with his PhD. One of his children was born with a neurological defect that required physical accommodation. Dr. Patrick, as with so many of us who have had to cope with personal trauma, made this a sentinel event in his life as he became totally committed to improving the lot of the disabled. To his credit he remains so today. By so doing he told us about*

*his character, and this award is also to publicly acclaim character.*

Dr. Patrick is truly extraordinary prolific and clearly considered by the academic and pharmaceutical community **the person** to seek out when needing a knowledgeable consultant for doing HRQL research. He is the MAN. But Dr. Patrick does not and did not take a prescriptive approach to his work—applying some standard protocol to this or that disease or treatment evaluation. No, what marks his activities is his willingness to think differently about things, and this too is one of the defining characteristics that justifies this award.

One of Donald Patrick's major contributions was actually reflected in his dissertation topic. Who says dissertations aren't important. His dissertation was entitled; "Measuring social preferences for function levels of Health Status." Dr. Patrick in 1972 was telling us that measuring preferences or values was what made a functional assessment a quality of life assessment. Thus, nearly, 30 years ago he started the task of teaching us that a quality of life assessment is a value or preference statement and what is of interest is that it still remains an idea that has not been fully integrated into our measurement activities. Now a second major achievement was the book he wrote with Penny Erickson. The book was important for the field because it brought all the elements of the field together and demonstrated how this work could be relevant to policy formation. It again asserts that HRQL is a value statement.

Dr. Patrick is of course interested in public health and was trained as a medical sociologist. In fact I was interested to learn from his vitae that he is a "certified" medical sociologist. Now I can understand that he is certified, I can think of a variety of reasons why he should be certified, including being a person of extraordinary accomplishment. Consistent with this is the number of committees and editorships he is involved with. His public service activities have been outstanding.

At this point I think I have said enough; it is time to give him his award and I understand he is taking us all out to dinner.

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## ISOQOL ANNOUNCES AWARD WINNERS FOR SCHOLARSHIPS AND YOUNG INVESTIGATOR AWARDS

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

### **Best Oral Presentation Winner:**

Hester Loonen ~  
Amsterdam, The Netherlands  
COPING STYLES PREDICT QUALITY OF LIFE IN ADOLESCENTS WITH INFLAMMATORY BOWEL DISEASE

### **Top Poster Presentations Winners:**

Michael Vitale ~  
New York, New York (USA)  
ASSESSMENT OF HEALTH STATUS IN PATIENTS WITH CEREBRAL PALSY: WHAT IS THE ROLE OF QUALITY OF LIFE MEASURES?

Adam Smith ~  
Leeds, West Yorkshire, England  
THE PSYCHOMETRICS OF THE HOSPITAL ANXIETY & DEPRESSION SCALE: FACTOR AND ITEM-RESPONSE BASED ANALYSES

Luis Prieto ~ Barcelona, Spain  
COULD LINEAR REGRESSION BE REPLACED BY ITEM RESPONSE THEORY ANALYSIS WHEN ADDRESSING CRITERION-REFERENCE INTERPRETATION OF TEST SCORES? A DISCUSSION EXAMPLE

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## EDITOR'S COLUMN

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*Mirjam Sprangers, PhD  
Newsletter Editor and President-Elect  
The Netherlands*

This will be the last issue of the ISOQOL Newsletter that will be produced under my direction as Editor. I would like to thank all those members who have contributed to the Newsletter during the past two years and who have made it informative and a pleasure to read. A special thanks is extended to the ISOQOL management, who have eminently helped by acquiring and collecting articles, and with desk-top publishing, printing, and mailing the Newsletter.

While I enjoyed the work of editor, I faced one difficulty. It was not easy to involve other ISOQOL members in the preparation of the Newsletter, despite the presence of people who have voiced their willingness to take part. Clearly, this is undesirable. To stimulate wider participation of ISOQOL members in the preparation of the Newsletter, the ISOQOL Board of Directors decided to appoint one editor and three associate editors each representing a geographical part of the world.

We are very happy that Ulrike Ravens-Sieberer (Germany) has agreed to take on the editorship. We are equally happy that Patrick Marquis (USA) will be the associate editor for Europe, Ted Ganiats (USA) for North America, and that Cindy Lam (Hong Kong) will represent Asia. This team of dedicated members will move the Newsletter to a new level of representation and the next phase of accomplishment, starting in 2002. They continue to be professionally supported by the ISOQOL management. I wish the new editorial team great success and enjoyment.

**If you have a colleague  
that would be interested in  
joining the Society, please  
have him/her contact the Executive  
Office at [info@isoqol.org](mailto:info@isoqol.org)**

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## MEMBERSHIP COMMITTEE REPORT

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*Carol Moinpour, PhD  
Membership Committee Chair, USA*

As I become Membership Chair, on behalf of ISOQOL, I would like to thank Jane Scott for serving as Chair of the Membership Committee; the Society certainly appreciates her efforts to increase ISOQOL membership.

### **Current Membership Status**

As of October 2001, ISOQOL had 571 members; this represents a 35% increase from the number of members in October 2000. Our membership comes primarily from academia (284) and the pharmaceutical industry (100). We would like to attract more members from clinical (currently 82) and government (currently 10) professions. The three main areas of training for current members are medicine (137), psychology (77), and statistics (72). ISOQOL lost members from epidemiology, sociology, and psychology from 1999 to 2001. The vast majority of our memberships are regular (498) as opposed to, for example, student, corporate, or institutional memberships. Countries with more than 20 members as of October 2001 are: United States (253), United Kingdom (47), Canada (45), Japan (37), Germany (24), Sweden (24), and France (22).

A survey was sent in July 2001 to 261 individuals who have been past ISOQOL members, but were currently not members, to identify reasons for not renewing. The primary reasons were forgetting to do so (and eight renewed as a result of the survey), were retired, or were no longer engaged in quality of life research (11). Reminders will be sent to current members who don't renew in 2002.

### **2001-2002 Strategies**

The Membership Committee now has 12 members: Robin Cohen, Carol Ferrans, Ron Hays, Anadi Law, Deborah Miller, Carol Moinpour, Claudia Moy, Koichi Nishimura, Amy Perwien, Francisco Luis Pimentel, Ingela Wiklund, and Kathleen Wyrwich. Four of the committee mem-

bers were able to meet briefly while attending the meeting in Amsterdam. We welcome the assistance of any ISOQOL member and encourage you to join the committee or pass along any ideas you may have for increasing our membership.

For the coming year, each committee member will be identifying at least one professional organization with which he/she is associated in order to communicate the value of ISOQOL membership. This communication will likely take place through permission to: include an ISOQOL link on that organization's website; include a description of ISOQOL with upcoming ISOQOL workshops and meetings in the organization's newsletter; distribute brochures at the organization's meetings. Nursing and palliative care organizations are of interest in this effort as well as clinical trials (e.g., Society for Clinical Trials), epidemiology, and health services research associations.

Again, please contact Carol Moinpour ([carolm@swog.fhcrc.org](mailto:carolm@swog.fhcrc.org)) with the names of any organizations that share a similar mission to that of ISOQOL and thus might be open to informing its membership about ISOQOL.

### **ISOQOL SPEAKERS BUREAU: JOIN TODAY**

Are you interested in delivering a talk or lecture at a future ISOQOL event? We are seeking experienced teachers and researchers to assist in future HRQL workshops and symposia. By adding your name to ISOQOL's Speaker's Bureau roster, you have a direct link to program organizers who review the roster and select speakers from this distinguished list!

This speaker's list is for the sole use of ISOQOL-sponsored activities. It is not sold or released to any outside organizations. If you are interested in adding your name to the roster, please contact the ISOQOL Executive office at [info@isoqol.org](mailto:info@isoqol.org) or telephone 703-556-9222 (USA).

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## ISOQOL EDUCATION COMMITTEE UPDATE APRIL-NOVEMBER, 2001

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*Rick Berzon, DrPH, Past Chair  
Education Committee, USA*

The Education Committee has had a very busy six months. Over this period of time, the Committee was structured such that three subcommittees were identified and staffed. These included (1) Conferences & Workshops; (2) Policy Guidelines; and (3) Scholarship & Training. Each subcommittee had a separate charge and subcommittee chair, and each was tasked according to the goals and objectives identified by the Education Committee Chair in consultation with the full Board.

The Conferences & Workshops Subcommittee was chaired by Jim Shaw; and members included Madeline King, Ulrike Ravens-Sieberer, and Kathleen Wyrwich. Their charge was to identify potential sites and venues for annual meetings, workshops, and regional gatherings to be held over the next five years. Sites were to include all the major world continents. A full report was drafted and discussed at the ISOQOL Board Meeting in Amsterdam; methods, outcomes, and recommendations are detailed in the report. While it is not within the scope of this article to review all outcomes, a few deserve mention: (1) it was recommended that the 2003 Annual Meeting take place in Prague, Czech Republic; (2) it was recommended that a push be made to hold some type of ISOQOL meeting in those parts of the world that here-to-fore have not held such meetings (e.g., Hong Kong, China; Sydney, Australia; and/or Porto Alegre, Brazil); (3) it was recommended that ISOQOL meetings cycle through Asia, South America, and Australia/New Zealand, as well as through Europe and North America.

The Policy Guidelines Subcommittee was chaired by Claudette Varricchio; and members included Ted Ganiats,

Elaine McColl, and Deborah Miller. Their charge was to review versions of two policy papers previously drafted by the ISOQOL Board, and to offer suggestions and recommendations on unresolved issues contained within these policy papers. The policies included *Guidelines for endorsement of HRQL workshops and symposia*; and *Guidelines for providing assistance to local affiliates in conducting workshops and symposia*. The subcommittee was also asked to consider drafting additional policy papers. The Chair of the Subcommittee discussed its recommendations with the ISOQOL Board in Amsterdam.

The Scholarship & Training Subcommittee was chaired by Diane Fairclough; and members included Judith Barr. Their charge was to identify and discuss mechanisms through which ISOQOL could offer scholarships, training programs, and financial support to investigators and researchers who are interested in HRQL. The Chair of the Subcommittee discussed its recommendations with the ISOQOL Board in Amsterdam. With respect to 2001 scholarship applications, two types of awards were offered: the Young Investigator Scholarship and the Developing Country Scholarship. A total of approximately US \$13,000 in scholarship awards was given out this year to 6 individuals from separate countries around the world. In addition, a new initiative was piloted in Amsterdam: a program to meet an established investigator for purposes of mentoring. This program is to be evaluated to determine whether it will again be offered next year in Orlando, Florida. Copies of all reports can be obtained from the ISOQOL management office ([info@isoqol.org](mailto:info@isoqol.org)).

All Subcommittee Chairs and their members are to be commended for their hard work.

Thank you all!

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## DEVELOPMENT OF THE ISOQOL WEBSITE: AN INVALUABLE RE- SOURCE

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*Albert Wu, MD, MPH  
Chair, Internet/Website  
Subcommittee, USA*

Our goals for the year 2001 were to develop and promote the ISOQOL listserv, and the Society's website. We have had some success with the former, but need to do more with regard to the latter. Progress has been due to the efforts of a group of approximately 15 participating committee members. For the website, our aim has been to establish it as The place that people go when they are interested in issues related to health-related quality of life. In the last year, the website was used most heavily for online abstract submission and meeting information. We would like folks to begin visiting for other reasons. Therefore, we have begun to add services.

To start, we have established links to other highly relevant sites, such as organizations (e.g., the Medical Outcomes Trust (<http://www.outcomes-trust.org>), other societies (e.g., the Society for Medical Decision Making (<http://www.smdm.org/>), and texts (e.g., The Research Methods Knowledge Base (<http://trochim.human.cornell.edu/kb/measure.htm>)). Some of these sites are already linked back to ours. To check it out, go to [www.isoqol.org](http://www.isoqol.org) and click the button in the left margin entitled "other sites." Let us know what additional sites we should add!

We are now developing a bank of articles and resources relevant to quality of life research, such as lectures, an annotated bibliography of important articles, a glossary of terms, and guidelines for the conduct of HRQL research. To start things off, we would like to assemble a collection of essential, important and best-loved articles from the HRQL literature. What is your favorite paper? One that you couldn't do with-

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## GUEST COLUMN: NEW DIRECTIONS IN HRQL RESEARCH

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### A European Perspective on Cancer Clinical Trials Involving Quality of Life

Andrew Bottomley, PhD  
Head, QOL Unit of the EORTC Data Center, Belgium

**Editor's Note:** *With its roots firmly based in psychosocial, psychometric, and statistical research, the field of quality of life has expanded during the past decades. In this column, quality of life researchers are invited to give their personal views on how the field would further mature. While this is an invitational column, readers with strong views, either supporting or contradicting the opinions voiced by the columnist, are encouraged to react.*

When I was approached by the newsletter editor to contribute to this column, I was honored. However, I declined. I simply had no time to put together 500 words. Six months later I was again diplomatically approached, carefully, gently persuaded and I finally stole some time to jot down personal views on where we may progress in years to come. The reality is that within the largest non-profit cancer clinical trials organization in Europe, it is difficult to spare the time. For the past four years, I have been involved in coordinating, designing, integrating, and monitoring Quality of Life (QOL) in over 100 phase 2 and 3 cancer clinical trials. QOL is integrated into approaching 70% of these trials. I envy my friends in the U.S.A and Canada who we frequently work with, groups such as the National Cancer Institute (NCI), South West Oncology Group (SWOG), Eastern Cooperative Oncology Group (ECOG), and National Cancer Institute Canada (NCI-C). I imagine that their life must be far simpler, designing cancer clinical trials where you do not have to deal with dozens of regulatory bodies, where you do not require dozens of translations of questionnaires, where

systems for collecting data from QOL studies can be standardized more simply than across Europe. Perhaps I am looking at my American friends' situation with somewhat rose colored glasses, but it is clear to me that we face a host of challenges when we undertake large cancer clinical trials across Europe.

However, with such challenges there also exist new opportunities for exploration of solutions and developing better methods for integrating QOL into clinical trials. For example, is it sensible for us to continue to pool QOL data from large international cancer clinical trials from across many different countries without knowing just how much culture can lead to variation of scores? You will see such practices reported in many publications, including the European Organization for Research and Treatment of Cancer (EORTC) papers, yet is it not possible that such cultural variation could mask results and influence our conclusions? The exploration into such effects are now ongoing in the EORTC, but much work needs to be done on this topic, requiring large data sets and sophisticated analysis methods.

Years ago many of us perhaps have spent time encouraging clinicians to include QOL in their clinical trials – I know I have. Now I spend a lot of my time persuading clinicians to do the opposite; not to include QOL in their trials! We must be focused in the cancer clinical trials we do in the future. I believe we must start producing more persuasive studies, where the results have a genuine impact and it is likely that a trial lacking a hypothesis is perhaps one that will struggle to have such an impact. We now reject all ideas for clinical trials in the EORTC unless we have clear answerable questions, that we expect to produce valuable and meaningful results. A tough policy, but nevertheless an important one.

One of the present day and future challenges we face are ways to improve the way we collect data and avoid missing data. This is something that has plagued QOL cancer clinical trials for years. De-

spite different techniques and approaches that are used to improve this problem, when we take a close look at the published cancer literature it demonstrates that in many international cancer clinical trials QOL compliance is still a fundamental problem. It becomes even more problematic the more advanced the cancer disease. Yet many of us who have worked directly with cancer patients know that we can collect this information, and frequently cancer patients are more than happy to provide it, even those with advanced disease. It is a shame therefore that sometimes, at the scale of large international clinical trials, where results can influence clinical practice that it still represents a problem. Hence, we can frequently see good robust clinical studies with QOL as secondary endpoints producing poor quality data simply because we fail to collect this to adequate standards. We must do better. In the EORTC, a host of approaches have been adopted to try and improve compliance. Some with more success than others. Training doctors and nurses, educating data managers, and teaching health care workers has made some progress. It is clear that this is not enough. One effective solution applied in some clinical trial groups in the USA and also in the EORTC is to include a financial incentive to return completed questionnaires. Money may be the route to all evil, but it certainly can lead to better compliance! However, the collection of questionnaires is resource intensive, and this helps address this problem where limited resources are an issue.

Where do I see QOL research progressing in the future? I see a need to really demonstrate we can produce usable results. Results that can regularly and consistently impact on treatment. Results that are meaningful to users, be it future patients, regulatory bodies, clinicians and researchers alike. We have demonstrated in a number of studies that QOL can be invaluable, but we have quite some way to go. We must develop our methods further, we must continue to educate those we work with and ex-

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## FIVE PERSPECTIVES: REVIEWS OF THE 2001 ANNUAL MEETING

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*Editor's Note: The next five articles are from ISOQOL members who share their reflections of the 8th Annual Conference in Amsterdam, The Netherlands*

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### A Board Member's Perspective

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*Marianne Amir, PhD  
Ben-Gurion Univ. of the Negev, Israel*

It would not be surprising that a member of the board has a biased and positive view of a scientific society meeting, in this case the ISOQOL meeting, but I would like to claim that in this case it is strictly objective! I found the scientific program to be comprehensive and to offer a wide overview of the field of quality of life studies. Conferences give us an opportunity to get new ideas, but also organize our old thoughts on which our daily research and clinical practice is built. Often a lecture at a conference will present things we feel we know, but from a new angle that we have not thought about before.

The conference had four themes: HRQL in daily clinical practice, HRQL and mental health, psychosocial modeling of HRQL outcomes and HRQL, happiness and social indicators research, each presented in plenary lectures by leading scientists in the field. I especially found the first plenary lecture by Michael Baum ("The humane practice of evidence based medicine") a sensitive and excellent insight into the issues surrounding treatment of breast cancer and quality of life. His presentation was clear and his overview was excellent, but the part that excited me most was his approach stating that while we should gather and apply scientific knowledge, we must not forget that treatment decisions cannot be based on statistical evidence alone.

As a clinical psychologist I found Hans Ormel's talk about the impact of depres-

sion on HRQL exceptionally informative. He presented data from the World Health Organization's study of psychological problems in general health care showing the enormous personal cost of these disorders in terms of quality of life. He presented data showing that mental disorders which are co-morbid with physical disorders seem to worsen the prognosis of the physical disorders.

Another highlight of the conference was the last plenary session where Alex Michalos and Ruut Veenhoven presented a long awaited bridge between two related areas of research, namely happiness (positive psychology) and HRQL. Alex Michalos very sharply illuminated some pitfalls in our research as when we measure the same concepts as dependent and independent variables. I learned that in some populations self-esteem and other psychological variables are more important than health in determining our overall quality of life. Also, the model he presented, the Multiple Discrepancies Theory, provides a theoretical framework in which we can organize our findings and promote our scientific endeavor. Ruut Veenhoven made a strong and convincing point for the usefulness of integration between HRQL and happiness research in order to get a fuller picture of the person and the consequences of illness.

The oral presentations were for the most part challenging and provided an insight into the field. And last, but not least, all the above occurred against the backdrop of one of the most fascinating and beautiful cities in Europe.

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### Impressions from a Veteran

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*Alex C. Michalos, PhD, FRSC  
University of Northern British Columbia  
Canada*

My impressions of the last ISOQOL meeting were similar to my impressions of the first I ever attended. The speakers at plenary sessions displayed commands of their subjects that were comprehensive, deep, subtle and admirable.

The variety of issues and especially of diseases investigated by those making oral or poster presentations should have provided something of interest for everyone throughout the conference period. I have been working in quality-of-life studies since the late 1960s, and still found many more topics about which I knew nothing than topics about which I thought wheels were being re-invented. Reflecting on the range of issues examined by social indicators researchers since the early period in the International Sociological Association and to some extent in the Public Choice Society, and in the past half dozen years in the International Society for Quality of Life Studies, it is safe to say that ISOQOL researchers are exploring rich fields of uncharted territory which will yield valuable knowledge for future researchers and practitioners.

Thanks again to everyone on the organizing committee for giving us a splendid conference in Amsterdam.

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### A Student Speaks

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*Sally Stapley, MS  
University of Newcastle upon Tyne, UK*

Amsterdam, November 2001 was my first attendance at the ISOQOL Annual Meeting. As a student new to both my PhD and to quality of life research, I arrived expecting to learn a lot from the conference—and I did!

I was struck initially by the volume and diversity of research being presented. From 'Methodological Issues in HRQL Measures' to 'HRQL and Mental Health' there was much to capture my attention. I wrote pages of notes; 'The Phantom Scribbler' at the back of the room, determined not to miss anything.

By the end of the four days, I felt that I had much greater insight into current, key debates. I had also found the workshops extremely useful and, as a new researcher, wished I could have attended more of them. However, critically

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## A Student Speaks

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*Continued from page 7*

for me, I now had the context in which to posit my own research question of response shift. This question is obviously a complex and important one, which will challenge both me and more experienced others for many years to come. Now though I am much more aware of which piece of the HRQL jigsaw I am trying to fit.

At the conference my more immediate challenge was simply finding out who to talk to. As a new PhD student I am ashamed to admit that I do not know who many of you are yet! At times I felt that I could have done with a “Who’s Who” directory of HRQL researchers. However I did engage in several opportunistic discussions, and have to say that some people were more willing to talk to me than others; as soon as I said that I was a student, quite a few lost interest. Having said that, I did meet some ISOQOL members who were keen to offer me advice and direction, not only at the conference but also via subsequent emails; I am grateful to them for their mentorship.

ISOQOL’s 8th Annual Conference proved to be a fertile learning ground for me. This massive meeting of minds and perspectives has, I hope, generated ideas of my own. No doubt along with others I would like to thank the organizers for their hard work in creating such a strong and comprehensive program. Next time I would very much like to attend the mentoring meetings for students, which had been set up for Amsterdam, but of which I had been unaware. Also, not least because of the special student rates, I shall and have encouraged other postgraduate students to attend future conferences and to join the Society. I look forward to Orlando, 2002.

**Oct. 30 - Nov. 2, 2002  
Orlando, Florida USA  
Annual Meeting  
Abstracts Due  
April 24, 2002**

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## Progress of the Field

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*Mogens Groenvold, MD, PhD  
Bispebjerg Hospital, University of  
Copenhagen, Denmark*

I attended the inaugural ISOQOL 1994 conference in Brussels, the second in Montreal in 1995, the 6<sup>th</sup> in Barcelona, 1999, and now the 8<sup>th</sup> in Amsterdam. The quality of presentations has increased, and the discussions are getting more sophisticated. Grey hair was not an uncommon thing in Amsterdam – in these relatively few years there seems to have been a remarkable increase in the number of senior researchers working in the area.

For me Barcelona was the conference where item response theory (IRT) changed from being something taught by few dedicated statisticians and psychometricians to something enthusiastically adopted as fashionable: the recognition of a paradigm shift.

Coming to Amsterdam I wondered what would be the big news of the year. It may not be so surprising, but I did not identify a single, major change. Rather, a number of fields tended to be gradually maturing. Many presentations discussed ‘interpretation/clinical significance’ seen from different angles, and preliminary reports from Jeff Sloan’s work bringing specialists together were presented. Their reports will start coming in Mayo Clinic Proceedings shortly. Maybe the ‘big news’ will be coming at the Mayo Clinic conference on clinical significance next year?

Presentations based on IRT were common and tended to be more varied, now also addressing problems and limitations. A lunch meeting chaired by Frank Baker addressed the issue whether we can measure suffering in palliative care and terminal illness. The concept of suffering was discussed: is it quality of life with opposite sign? Is it the usual discussion of a too broad concept that needs to be broken down in easier definable dimensions to be meaningful? There was agreement to return to these

unresolved questions at a later conference.

It was an excellent idea to arrange a series of ‘differing perspectives’ sessions where two experts discussed important topics. Next time, I would favour more time for such sessions rather than poster discussion sessions.

Finally, I appreciated the opportunity to spend three hours on a single topic: I enjoyed the excellent pedagogics at the workshop organized by Ware, Bjorner and Kosinsky on the methodology of computerized adaptive testing.

All in all it was an exciting and well-organized conference.

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## Clash of Paradigms

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*Geoff Norman, PhD  
McMaster University, Canada*

While I have been playing around in the Health Related Quality of Life game for a few years now, it is only in the past 12 months that I “joined the club,” beginning with an invitational conference held by Jeff Sloan at Mayo last spring. At that meeting, I met many of the “key players” in ISOQOL – Ivan Barofsky, Neil Aronson, David Osoba, Mirjam Sprangers and others. And it was at that meeting that I decided to take the leap, and join. Attendance at the Amsterdam meeting was a natural sequel, both because of the friendships and intellectual stimulation that developed at Mayo, and because I have had a long love affair with the Netherlands and never turn down an opportunity to return.

I arrived as somewhat of a skeptic. I have spent considerable time thinking about psychometric issues related to HRQL, and have been concerned that many studies are not sufficiently rigorous. Well, the skeptic has been won over. I did something at ISOQOL I haven’t done at conferences for years: I attended some sessions. There was tremendous intellectual stimulation to be found at many sessions, and my mind was left spinning for three days.

*Continued on page 9*



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## Paradigms

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*Continued from page 8*

There was also a wonderful ambience. The community welcomed me and I was astonished by the degree of camaraderie and sharing that occurred during the conference. They weren't all strangers; I rediscovered some old friends, like Donna Lamping and Sharon Wood-Dauphinee and made many new ones.

Returning to the academic dimension, it would not be fair to isolate a single study for praise, as there were many deserving studies. Instead, I'll opt for some more global impressions. It seems to me that there is somewhat of a clash of paradigms in ISOQOL. At the one extreme, folks recognized that patients may redefine their goals during the course of time, and their responses may or may not shift according to changing standards. The word "response shift" was uttered frequently, as a kind of reassuring mantra when evidence arose that patient standards had changed, (the study by Sara Ahmed and Sharon Wood-Dauphinee was a superb example). And some researchers went further in this direction and encouraged such changes. Thompson and Cella had patients identify their own goals and rate their success in achieving these goals. Then at follow-up they were able to first redefine goals then rate success on these redefined goals. While this may be a very informative strategy for caregivers, it makes the use of such a tool for research very problematic. The computer doesn't know where the 4.5 / 7 came from, and it seems illogical to average my attainment of my goals and your attainment of your goals.

At the other extreme, the folks pursuing utility assessment act as if their numbers are perfectly robust with respect to such changing criteria. But there is no reason to presume that this is the case; for example, several studies have shown that utility assessments can be biased by framing effects. There is no reason to presume that a multidimensional index like the HUI3 would be any less vulnerable to such systematic ef-

fects than a classical time tradeoff or standard gamble. A study by Bernier, Berthelot, Erickson, and Barofsky showed systematic differences between a global scale and the HUI3 for various diseases; one explanation is that the HUI3, whose utilities were derived from healthy people, is systematically biased downwards. The "disease-specific quality of life" folks appear to have their cake and eat it too. Measures like the Asthma Quality of Life Questionnaire permit some individual goal setting, then go ahead and average them in with the standard questions. But since these measures are used extensively in randomized trials, it is safe to assume that they ascribe to the view that their numbers have some external validity.

All this would be of little account if the primary goal was to monitor and assess progress of individual patients. But this is only one goal. To assess treatment effects, there must be some defensible basis for averaging individual observations, and the introduction of individual goals weakens the rationale, and must inevitably reduce reliability and interpretability of the results.

Some might just say that I have simply rediscovered the "idiographic -nomothetic" axis of qualitative research. But the roots of the debate are deeper than this. It is not simply an issue of observations for the individual versus generalizations to the group, although this is part of it. The debate is also reminiscent of Cronbach's "two disciplines" (1957), where correlational psychologists revel in individual differences, and experimental psychologists try their best to eliminate the same differences. Or even deeper, it could be framed as a tension between positivist views of science, which presume that theories are a reflection of some external reality, and constructivist views, which in their radical form, presume that all theories are mental constructions, and the external world is unobtainable.

While there is no indication that this polarization endangers the community, it seems to me that there is a danger that the lack of a critical perspective on these

issues may ultimately damage the external credibility of the Society. I think that this is time for frank and open discussion of these issues. Thanks for the memories...

### References

Cronbach, L.J. (1957) The two disciplines of scientific psychology. *American Psychologist*, 12: 671-684.

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## THANK YOU...

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...to the following organizations who in various ways contributed to the 2001 Annual Meeting in Amsterdam:

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American Home Products  
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In addition, thank you to the following exhibitors at this meeting:

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Assist Technologies  
Galen Research  
MAPI  
MEDTAP, International, Inc.

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As always, our Institutional Members are appreciated:

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Abbott Laboratories (USA)  
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Quality Metric, Inc. (USA)

**SCENES FROM THE ISOQOL ANNUAL MEETING  
AMSTERDAM, THE NETHERLANDS  
NOVEMBER 7-10, 2001**



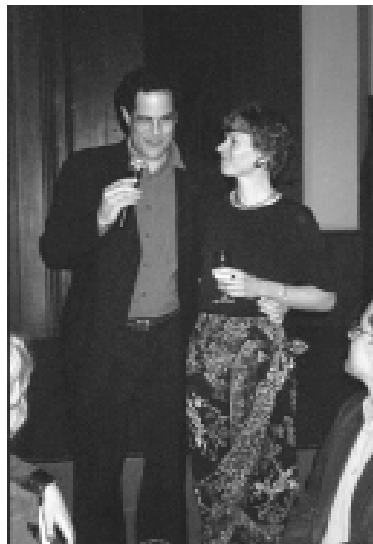
*ISOQOL Board members, Committee Chairs and staff meet to discuss the final plan for the week's events: (standing, l-r: Frank Baker, Peter Faylers, Rick Berzon, Albert Wu, Mirjam Sprangers, Neil Aaronson, Diane Fairclough, Carol Moinpour, Ivan Barofsky, Madeleine King, David Osoba, Dennis Revicki; seated, l-r: Bette Anne German, Sarah-Jane Ziaya, Laura Degnon, George Degnon, Marianne Amir)*



*William Lenderking and Jane Scott meet at the ISOQOL Annual Meeting, a great opportunity to meet with colleagues to further personal education and contribute to HRQL advancement*



*David Cella and Rick Berzon deep in conversation about HRQL*



*Laura Degnon, ISOQOL Associate Executive Director, welcomes young investigator scholar Louis Prieto to the 2002 Annual Meeting*



*Singing Sailors entertain guests with songs of the sea at the Annual Meeting dinner*

*Annual Meeting Chairs Neil Aaronson and Mirjam Sprangers welcome attendees to the Annual Meeting dinner*



*Thanks to photographers: Marianne Amir, Adrienne Baker and Albert Wu*

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## HRQL RESEARCH: PSYCHOMETRIC-BASED HEALTH STATUS VERSUS UTILITY-BASED MEASURES

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*Dennis Revicki, PhD, MEDTAP International, USA and Agota Szende PhD, MEDTAP International, The Netherlands*

A pre-ISOQOL conference satellite symposium on HRQL was organized by scientists from MEDTAP's European and US offices. The session was developed to contrast the advantages and disadvantages of psychometric-based and utility-based HRQL outcomes in evaluating health care interventions. Dr. Agota Szende was the chairperson, Drs. Alan Williams (York University), David Feeny (University of Alberta), Ingela Wiklund (AstraZeneca), and David Cella (Northwestern University) made presentations, and Dennis Revicki served as discussant.

Alan Williams discussed the importance of HRQL outcome measurement in a universal health care system in which the allocation of resources aims to maximize population health and reduce inequalities in society. Health state utilities derived from the general population are needed to calculate quality-adjusted life years (QALYs) resulting from health care interventions. In the calculation of QALYs, "Q" should reflect lay concepts of health and should reflect the trade-offs the community is willing to make both between different aspects of HRQL and between quality and duration of life. David Feeny emphasized that an important feature of utility-based measures is that they measure not simply HRQL but the value of health. He summarised the advantages of the utility-based approach for applications in clinical studies, individual-level clinical decision-making, decision analysis, in monitoring the health of populations, and in resource allocation decisions.

Ingela Wiklund, in contrast, provided examples from clinical studies that demonstrated that disease-specific HRQL

measures were more responsive to changes in clinical status compared with direct utility assessments. HRQL research in the pharmaceutical industry has focused on the patient's perspective rather than societal perspective and concentrates on demonstrating value in terms of health status outcomes. David Cella argued that the main threat from the psychometric approach is that trivial differences in health status might be exaggerated by turning the lens on specific sub-domains of HRQL and increasing magnification. In contrast, the main threat from the utility-based approach is that the lens is not focused enough to see important differences. Due to weaknesses of both approaches, researchers are left with the strategy of using both methods wisely and hoping that they agree or at least not contradict each other in clinical studies.

Dennis Revicki concluded that psychometric-based and utility-based HRQL measures currently serve very different objectives, and utility-based and psychometric-based outcome data provide complementary but not interchangeable information on health outcomes. For more information, contact Dennis Revicki, [Revicki@medtap.com](mailto:Revicki@medtap.com) or Agota Szende, [Szende@medtap.nl](mailto:Szende@medtap.nl).

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## Website

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*Continued from page 5*

out? The one that you would want with you if you were stranded on a desert island? Please send in yours.

Our aim for the listserve is to provide an open channel for members and others to discuss issues related to HRQL, to get questions answered, and to feel more personally connected with colleagues. Our listserve (an emailing list that potentially includes all ISOQOL members willing to provide email addresses, as well as others interested in HRQL who signed on) is up and in working order but is tragically underutilized. Have a question? Got issues? Looking for an expert? To send a message, all you need to do is send an email message to: [isoqol@isoqol.org](mailto:isoqol@isoqol.org) and it will be broadcast to the list.

Are there other services we should offer to our membership? Additional thoughts? Please contact the ISOQOL management office ([info@isoqol.org](mailto:info@isoqol.org)) or myself ([awu@jhsph.edu](mailto:awu@jhsph.edu)) with suggestions.

## CALENDAR OF EVENTS

- **Clinical Significance for Quality of Life Measures in Oncology Research**  
April 5-6, 2002, Mayo Clinic Cancer Center, Rochester, MN (USA)  
Visit [www.mayo.edu/cme/QOLmeeting](http://www.mayo.edu/cme/QOLmeeting) for more information
- **International Network on Health Expectancy (REVES) Annual Meeting**  
April 24-26, 2002, Hammamet, Tunisia. Further details displayed on the REVES website, [www.prw.le.ac.uk/reves](http://www.prw.le.ac.uk/reves).
- **Special Session on Outcomes Research/Health Service Research in Internal Medicine**  
May 28 from 2:00-4:00 pm, during the 26th International Congress of Internal Medicine (ICIM), May 26-30, 2002, Kyoto, Japan. E-mail deadline is Jan. 20, 2002 (posted abstracts deadline passed). For submission guidelines, visit the website at [www.icim2002.org](http://www.icim2002.org); e-mail: [isim26@mx6.nisiq.net](mailto:isim26@mx6.nisiq.net).
- **Quality of Life Research in Medicine Conference**  
Oct. 3-5, 2002, St. Petersburg, Russia, abstracts due May 30, 2002. For more, contact Tatyana Ionova, e-mail: [tion@atlant.ru](mailto:tion@atlant.ru).
- **\*ISOQOL 9th Annual Conference**  
Oct. 29-Nov. 3, 2002, Orlando Florida, USA, abstracts due April 24, 2002

\*Sponsored by ISOQOL

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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.*

**Jane Blazeby MD** of the Bristol University Bristol Royal Infirmary, UK has a new e-mail address: [j.m.blazeby@bristol.ac.uk](mailto:j.m.blazeby@bristol.ac.uk).

**Prof. Monika Bullinger, Dr. Silke Schmidt and Corinna Petersen** of the University Hospital of Hamburg Eppendorf in Hamburg, Germany announce new project news: the process of cross-cultural item development—The DISABKIDS approach. Within the Fifth Framework of Research funded within the program “Quality of Life and Management of Living Resources,” the European Union (EU) has granted a European project on the development of a modular instrument to assess health-related quality of life in children with chronic conditions.

In the project, called DISABKIDS, children with asthma, diabetes, cerebral palsy, epilepsy, rheumatoid arthritis, cystic fibrosis as well as skin disease are involved in the process of cross-cultural instrument development and testing. In the first phase of the project, the children as well as their parents are involved in so-called focus groups in which they are interviewed with the aim to obtain statements of quality of life which they feel relevant for their situation. In addition to this bottom-up strategy, domains and dimensions of quality of life are identified from the literature, including available instruments, resulting in a top-down consensus on

HRQL areas to be assessed in the future questionnaire. For more, please view the websites: [www.disabkids.de](http://www.disabkids.de) and its sister project, [www.kidscreen.de](http://www.kidscreen.de).

**Mapi Research Institute** is pleased to announce the launch of the new Quality of Life Instruments Database (QOLID), a comprehensive and unique source of information on QOL instruments available on the internet. QOLID provides (1) an overview of existing QOL instruments, (2) a description of over 300 instruments including copies of over 220 original questionnaires, 100 translations and 50 user-manuals and (3) facilitated access to the instruments and their developers. We invite you to visit QOLID at [www.QOLID.org](http://www.QOLID.org). For more information, contact **Marie-Pierre Emery** at [mpemery@mapi.fr](mailto:mpemery@mapi.fr).

**Patrick Marquis MD** has moved from France, to Boston, MA (USA). Please note that Dr. Marquis' new contact information is as follows: Patrick Marquis MD, Managing Director, MAPI Values USA, 15 Court Square, Suite 620, Boston, MA 02108 USA; phone: 617/720-0001, fax: 617/720-0004; e-mail: [patrickmarquis@mapivaluesusa.com](mailto:patrickmarquis@mapivaluesusa.com).

**Benjamin Movsas MD** has just been appointed this year as Vice-Chairman of the Radiation Oncology Department at Fox Chase Cancer Center in Philadelphia, PA. He has also been the Chair of the Quality of Life Committee of RTOG (Radiation Therapy Oncology Group) since 2000.

**Geraldine Padilla PhD** is now Professor and Associate Dean of the University of California San Francisco School of Nursing, N339, Box 0604, 2 Koret Way, San Francisco, CA 94143 USA; phone: 415/476-1763, fax: 415/476-9707; e-mail: [geraldine\\_padilla@nursing.ucsf.edu](mailto:geraldine_padilla@nursing.ucsf.edu).

**Marcie Parker PhD, CFLE** is Senior Qualitative Researcher with Optum, a health information firm in Golden Valley, Minnesota. She has been appointed to the Editorial Board of two new journals, *Alzheimer's Disease Quarterly* and *Alzheimer's Caregivers Activity Quarterly*.

**Toshiko Tada, RN, PhD** is in a new position as Professor of Nursing, School of Health Sciences at the University of Tokushima, Tokushima, Japan.

**Mapi Research Institute's Boston based Foundation** announces the **creation of a Directory of Databases (DDB)** which, in collaboration with developers and users of questionnaires, will identify, locate and describe existing databases created from the collection and centralization of patient-reported outcome (PRO) data from national and international studies. The aim of the DDB project is to help researchers and companies involved in the evaluation of PROs to interpret results from different studies using the same or different PROs. For more information on this project, contact **Vilayvanh Vetsmany** at [vvetsmany@mapi.fr](mailto:vvetsmany@mapi.fr).

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## PAID ADVERTISEMENTS

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Faculty Position in Health Services Research, Evanston, IL: hospital-based health outcomes research center with strong academic ties seeks candidates for a newly-created faculty position in applied health services research. Area of research specialization is open, but preference given to those experienced/interested in underserved populations, health disparities, or health services research in clinical trials. MD or PhD, demonstrated ability to obtain extramural research funding required. Responsibilities include maintaining program of extramurally funded research, mentoring junior-level colleagues, and providing consultation on health outcomes research to internal or external clinicians/investigators. To apply, please submit a letter of interest, curriculum vita, and three letters of recommendation to: Amy Peterman, PhD, Search Committee Chair, Center on Outcomes, Research and Education, **Evanston Northwestern Healthcare**, 1001 University Pl., Suite 100, Evanston, IL 60201; To learn more, e-mail: [apeterman@northwestern.edu](mailto:apeterman@northwestern.edu).

*Continued on page 13*

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## IN MEMORY CATHERINE POUGET

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There still seems to be a long way to go before a patient's quality of life receives the attention it deserves from the medical staff. After a long and courageous battle against cancer our friend and colleague Catherine Pouget died on 3 July at the age of 31.



Catherine was one of the first to join our Institute in 1995. She had a real passion for the science of language and managed countless translations of questionnaires and played a vital part in structuring our linguistic validation department which now numbers over 30 people. Besides her project work, Catherine's efforts were devoted to internal staff training and lectures on translation issues at the University of Lyon. She was also in charge of building up and consolidating Mapi Research Institute's worldwide network of consultants. The enthusiasm she brought to all of her encounters will be remembered by many friends of the Institute and readers of the Quality of Life Newsletter. As one of the founding members of the Institute she will be greatly missed not only for her contribution to our activity, but also as a friend with whom we shared so many things.

During the year of her illness Catherine suffered greatly, not only from the effects of her disease and treatment, but perhaps most of all from the lack of understanding and compassion she experienced in the attitude of medical staff. In her remembrance, Mapi Research Institute will set up a prize which will bear Catherine's name, to be awarded annually for research contributing to the improvement of the quality of life for the terminally ill. Although this will not decrease our sadness, it will provide a step towards the realization of the ultimate aim which we should always bear in

mind - the improvement of the quality of life of the patient.

Bernard Jambon, Katrin Conway, Isabelle Mear, Christelle Giroudet for all the Mapi Research Institute Team

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### Announcing the Catherine Pouget Research Award

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#### Description

The Catherine Pouget award is intended to encourage young investigators to study the impact of quality of care on, or to improve the quality of life of the terminally ill. Applicants may include students, degree candidates, fellows, or faculty members early in their research. The selection committee will consider a wide range of research projects whose results are likely to contribute to the quality of life and /or the health care of the terminally ill. Appropriate research projects would include studies of the impact of interventions on the quality of life of the terminally ill and studies of measures and determinants of quality of life and patients and/or families perspectives about the quality of care and or life experiences. The maximum amount that will be funded will be \$10,000 for work to be completed over a 1 to 2 year period.

#### Evaluation Criteria

Selection criteria used by the committee to evaluate proposals include originality, significance, methodological rigor, and likelihood of being completed. Significance refers to the likelihood of improving the quality of life and / or the health care of the terminally ill. The review committee includes Mapi Research Institute Scientific Advisory Committee and in-house members of staff.. One grant will be funded every year.

**Application Due Date:** 28 February 2002. Announcements of funding will be made in the Quality of Life Newsletter (QQLNL) of September 2002.

Visit the ISOQOL website and click on the "awards" button for further details.

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### Paid Advertisements

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*Continued from page 12*

Dr. John Ware and his colleagues at **QualityMetric Inc. (QM)** in Lincoln, RI and Health Assessment Lab (HAL) in Boston, MA announce new employment opportunities working with leading health outcomes researchers in both academic and health care industry settings. Positions range from entry-level **outcomes research analysts** with a Masters degree (statistics, behavioral or social sciences, public health) or the equivalent, to **outcomes research scientists** with a PhD or equivalent formal training and demonstrated experience in psychometrics, health outcomes research, epidemiology or other health-related field. Applications for one **Senior Research Scientist** position are also invited.

Expanded teams at HAL and QM, led by Dr. Ware, are supported by both industry and government agencies to develop, standardize, and apply more practical and more precise patient-reported outcomes measures for use by adults and children in population health surveys, clinical trials, other outcomes research, and clinical practice settings worldwide. These teams are producing traditional "static" and dynamic measures of both generic and disease-specific outcomes using item response theory (IRT) and computerized adaptive testing (CAT) software. Multiple data-collection technologies (Internet, handheld computers, interactive telephone interviews with voice recognition) are being evaluated in collaboration with various technology partners. Interested in joining one of these Ware-led teams? Please send a cover letter summarizing your professional objectives and relevant experience along with a current resume to: Shelley Moulton, Manager of Human Resources, QualityMetric Incorporated, 640 George Washington Hwy, Lincoln, RI 02865, USA or e-mail [hr@qualitymetric.com](mailto:hr@qualitymetric.com).

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## ISOQOL WELCOMES NEW MEMBERS SINCE JUNE 26, 2001:

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**Carol Albright, MS**

Albright Consulting, St. Paul, MN, USA

**Erika Ammerman, BSc**

Oxford Outcomes  
Headington, Oxford, UK

**Rolanda Baars, MD**

Leiden University Medical Center  
Leiden, The Netherlands

**Julie Bernier, MSc**

Statistics Canada, Ottawa, ON, Canada

**Jean-Marie Berthelot, BSc**

Statistics Canada, Ottawa, ON, Canada

**Jakob Bjorner, MD, PhD**

National Institute of Occupational  
Health, Copenhagen, Denmark

**John Chaplin, PhD, MSc, BA**

University of Lind, Lund, Sweden

**Maria Coccossis, PhD**

University of Athens, Melissia, Greece

**Helen Doll, DSc, MSc**

Oxford Outcomes,  
Headington, Oxford, UK

**Dory Durr, MD, MSc, FRCSC**

Outremont, PQ, Canada

**Lars Eriksson, MSc**

Karolinska Institute, Stockholm, Sweden

**Carol Ferrans, PhD, RN, FAAN**

University of Illinois at Chicago  
Chicago, IL, USA

**Stephan Gohmann, PhD**

College of Business & Public Adminis-  
tration, Louisville, KY, USA

**Angela Gosch, Dr. Phil**

Robert Koch Institute, Berlin, Germany

**Susan Grandy, PhD, MBA**

DuPont Pharmaceutical Company  
Wilmington, DE, USA

**Wolfgang Greiner, PhD**

University of Hanover  
Hanover, Germany

**Michael Herdman**

Catalan Agency for Health Technology  
Assessment and Research  
Barcelona, Spain

**Mark Johnston, PhD**

KMRREC, West Orange, NJ, USA

**Sehyun Kim, PhD**

Pochon Cha Medical University  
Sungham, Gyonggi, South Korea

**Sue Ellen Kline, MS, PhD**

ConvaTec, A Bristol-Myers Squibb  
Company, Skillman, NJ, USA

**David Lewis, PhD**

St. Joseph's Healthcare  
Hamilton, Hamilton, ON, Canada

**Michelle Melia-Gordon, BA, BSc, MA**

Carleton University  
Ottawa, ON, Canada

**Anna Morris, MSc**

University of Southampton,  
Southampton, UK

**Bala Nadesan, RPh, MBA, PhD**

Texas Tech University, HSC, School of  
Pharmacy, Amarillo, TX, USA

**Siri Naess**

Norwegian Social Research  
Oslo, Norway

**Monica Nortvedt, PhD**

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Bristol, Monmouthshire, UK

**Luis Rajmil**

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Barcelona, Spain

**Trond Riise, PhD**

University of Bergen, Bergen, Norway

**Adam Smith, Mphil**

ICRF Clinical Cancer Centre, Leeds, UK

**Chris Speed, BSc, CHSR**

University of Newcastle  
Newcastle upon Tyne, UK

**Patrick Sullivan, PhD**

University of Colorado Health Science  
Center, Denver, CO, USA

**Jian Sun, PhD**

Institute of Health Economics  
Edmonton, AB, Canada

**Costellia Talley, MSN**

University of Tennessee - Memphis;  
VAMC Cordova, TN, USA

**Lijiljana Trajanovic**

Clinic for Mental Health Protection  
Nis, Serbia, Yugoslavia

**Ursula von Rueden, Dipl. Psych**

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**Samuel Wiebe, MD, MSc**

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**Nina Wojciechowska**

Atlantic Veterinary College  
Charlottetown, PEI, Canada

**Toshiko Yoshida, RN, PHN, PhD**

Miyagi University School of Nursing  
Miyagi, Japan

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### Guest Column

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*continued from page 6*

plain our approaches in simple terms, in language they can understand. We need to improve the way we design and particularly report our QOL studies. As many of you will know, few international cancer clinical trials include QOL as a primary endpoint, and I believe we have some way to go before we are able to regularly include this routinely as such an endpoint.

In my view, to help QOL become more accepted we must design, collect and report the results of cancer clinical trials QOL data at the same standards as we do other clinical data. This is not always the case. Once we achieve this, then I believe QOL will become a more accepted endpoint in all our cancer clinical trials.

**To share your reaction to  
this column, please contact  
the Newsletter Editor at  
[m.a.sprangers@amc.uva.nl](mailto:m.a.sprangers@amc.uva.nl)**