



International Society for Quality of Life Research

Volume 7 Issue 2

Newsletter for ISOQOL Members

July 2002

PRESIDENT'S MESSAGE

*David Osoba, MD
West Vancouver, Canada*

Greetings! I must say that it's very pleasant around here at this time of year. The sun is shining, flowers are blooming, the birds are singing, and sometimes it's hard to think about the affairs of the Society. (With apologies to those for whom it is winter and the above conditions may not apply.)

But, the Society does not rest! The Board members and the Executive Office have been very busy. First, there was the Board meeting in early April at which an enormous amount of business was conducted. Some of the highlights were: further training of the Board members on their duties and how to be more effective members of the Board; a financial report indicating that we are doing well, but still need to be more active fund raisers; planning of future scientific meetings, symposia and workshops (to be announced in future issues of the Newsletter and on our website); improvements to our website, and communications; a better delineation of our policies for assisting regional meetings; a lively strategic planning meeting for the future of the Society; and other items to help make our Society more attractive and meaningful to members.

Then, the abstracts for ISOQOL IX in Orlando (October 30th to November 2nd) began to arrive by the hundreds. Carolyn Schwartz, Jeff Sloan (Co-Chairs), members of the Scientific Program Committee and other volunteers have been very busy reviewing the abstracts and rating them for selection for presentation. Plenary session speakers, discussants, debaters and others are being invited and symposia and work-

shops planned. This process will have been completed by the time you receive this Newsletter and the Scientific Program and registration materials should appear on the ISOQOL website shortly. I hope that you will be pleased with the program and that you will attend the meeting. It promises to be excellent!

At the same time, we have conducted elections for the positions of President-Elect, Treasurer and three Board members. The slate of candidates was remarkably excellent and I don't know how you were able to decide for whom to vote. Nevertheless, the election has been completed and the successful candidates are announced on page 2 of this Newsletter. Congratulations to them all!

It is with regret that I accepted the resignation of Carol Moinpour as Chair of the Membership Committee. Carol wished to devote her energies to other activities within the Society and I wish her great success! In the meantime, the Executive Committee has not yet appointed a new Membership Chair, but we are thinking about possible candidates. If you would like to volunteer to be on this, or any other committee, it would be very much appreciated. See the "Help Wanted" list of committees and tasks on page 9 of this newsletter to learn more.

ISOQOL members were well represented at the Mayo Clinic meeting on "Assessing Clinical Significance for Quality of Life Measures in Oncology Research: State-of-the-Science" in early April. Some of us were involved in the planning of this meeting (organized by Jeff Sloan and Marlene Frost) and all of us can feel proud of our participation in a very successful venture.

The Annual Scientific Meeting for 2003 (ISOQOL X) will be held in Prague from

November 12-15th. I am very pleased to announce that Jane Blazeby (Bristol) and Donna Lamping (London) will be the co-chairs of the Scientific Program Committee. Although there seems to be a lot of time between now and then, planning has already started and will pick up in pace over the next few months.

Finally, I would like to wish you all a pleasant and productive few months until the next edition of this Newsletter.

REQUEST FOR PROPOSALS OF SCIENTIFIC TOPICS FOR ISOQOL SYMPOSIUM IN 2004

*Diane Fairclough, DrPH
Denver, CO (USA)*

As part of a strategic plan to facilitate more frequent participation of all ISOQOL members in a scientific or educational meeting, the ISOQOL Board recommended that ISOQOL hold a symposium in North America during the spring of 2004. The North American location is proposed because the symposium will be held between two annual meetings, one in Europe (Prague, November 12-15, 2003) and one in the Asia/Pacific region (2004).

The Education Committee is currently soliciting proposals for **scientific topics** for this symposium. Topics may include methodological issues, specific diseases or special populations. Examples of the methodological topics might include "Modern Psychometric Methods in QOL Research" or "Use of QOL Assessment at the Individual Level in Clinical Practice." The proposed topic may also be population or

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Deadline for articles for our next issue is November 15, 2002

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ISOQOL 2002 ELECTIONS PROCESS AND RESULTS

*Ivan Barofsky, PhD, Past President and
Nominations Committee Chair
Sandwich, MA (USA)*

Each year's election offers members of ISOQOL the opportunity to select from amongst outstanding candidates, and this year was no exception. The Nominations Committee (Geraldine Padilla, Sharon Wood-Dauphinee, and myself) was able to select from an impressive list of potential candidates.

As explained to each nominee, being considered by the Nominations Committee is an acknowledgement that the candidate has made significant contributions to the Society and to the HRQL field. The selection of the nominees was designed to increase the geographical and disciplinary representation of the Board, and the election supported this intent.

Elected to the Board were Donna Lamping, (UK); Ingela Wiklund (Sweden) and Carolyn Schwartz (USA). Diane Fairclough (USA) was elected Treasurer-Secretary. Albert Wu (USA) was elected President-elect.

Congratulations to them all.

THIRD ANNUAL METHODS WORKSHOPS SUCCESSFUL

*Kathleen Wyrwich, PhD
St. Louis, MO (USA)*

Munich, Germany—a city well known for its long-standing tradition and commitment to quality—was the perfect site for ISOQOL's Third Annual Methods Workshops, held June 10-11.

Although busy summer schedules kept some interested researchers from attending, those who gathered had fun and informative opportunities to learn more

about methodologies related to: Constructing and Using HRQL Measures, Neglected Aspects of Questionnaire Development, Cross Cultural Issues, Adaptive and Dynamic Health Assessments, Item Response Theory, Missing Data, and Clinically Significant and Important Change Assessments.

The Workshop's Faculty: Paul Kind, Hanne Thorsen, Thomas Kohlmann, Stephen McKenna, Francis Guillemin, Jakob Bjorner, Desmond Curran, and Kathleen Wyrwich were most grateful for the planning and assistance from the ISOQOL staff, who kept every event running as smoothly and reliably as the Glockenspiel in Marienplatz! Moreover, those attending this mid-year occasion for learning more methodologies for the advancement of their own, as well as their institutions' HRQL research agendas, found the quality to rival that of the BMW factory tour and to be as gratifying as the Sunday evening visit to the Munich Summer Festival.

EARLY CAREER INVESTIGATORS' AWARDS

Each year at the Annual Meeting, ISOQOL presents prestigious awards honoring individuals in various categories. ISOQOL is committed to promoting excellence in quality of life research; therefore, new in 2002, the **Early Career Investigators' Awards** will be presented during the conference closing dinner.

These awards, which replace the "Young Investigator Awards" of previous years, recognize the best overall oral and poster presentations made by full-time students or post-doctoral individuals in the early stages of their careers in QOL research, having either received their doctorate within the last five years or having worked as an independent researcher in the field for five years or less. During the abstract submission process, authors were asked if they wanted to apply for an early investigator award. The top rated abstracts will have their papers/posters viewed by a committee at the Annual Meeting and winners will be announced during the closing dinner.

PRO HARMONIZATION GROUP MEETING

*Dennis Revicki PhD
Bethesda, MD (USA)*

ISOQOL continues to participate in the PRO Harmonization Group related activities along with International Society for Pharmacoeconomics and Outcomes Research, the PhRMA Health Outcomes Committee, and the European Regulatory Issues on Quality of Life Assessment (ERIQA) group. On March 1 of this year the PRO Harmonization Group held a meeting at the Food and Drug Administration (FDA) to discuss methodological issues associated with the assessment of health-related quality of life and other patient based assessments. ISOQOL representatives included Rick Berzon, Ivan Barofsky, Donald Patrick, Dennis Revicki, and Albert Wu. Presentations were made on the following topics and health outcomes research related questions:

1. What are the scientific standards associated with PRO instrument development?
2. What are the issues associated with PRO instrument selection, including rationale and hypotheses and relationship with clinical endpoints?
3. What is the state of the science in handling missing data in PRO statistical analyses?
4. How are PRO results to be interpreted when there are inconsistencies between PRO and clinical outcomes?

Work is under way on two manuscripts that are intended to summarize the content and discussion in the two meetings at the FDA. The first paper, titled "Incorporating the Patient's Perspective into Drug Development and Communication," summarizes the meeting held on Feb. 16, 2001 and is nearly ready for submission for publication. The second manuscript is currently under development and we hope to have a completed draft by this fall. These papers do not include any guidelines for industry or regulatory agencies, but do summarize areas of consensus and directions for future research on health outcomes assessment.

Additional information about the PRO Harmonization Group, including copies of all presentations made at the two FDA meetings, can be found on the website, www.PRO-Harmonization-Group.com.

CURRENT STATUS OF EUROHIS PROJECT

*A. Nosikov, MD
Medical Officer, Health-related Evidence WHO Regional Office for Europe
Denmark*

The EUROHIS project aims to promote the use of common instruments in health interview surveys in Europe. The project, which is coordinated by WHO/EURO, began in 1988 and has already resulted in the publication of recommended instruments for 11 indicators (Health Interview Surveys: Towards International Harmonization of Methods and Instruments, edited by de Bruin A et al. WHO Regional Publications, European Series No. 58, 1996). The current phase of the project focuses on the development of common instruments for a further eight indicators, i.e. chronic physical conditions, mental health, alcohol consumption, physical activity, use of curative medical services, use of medicines, use of preventive health care, and QOL.

Organizations in 30 European WHO Member States are involved, and the work is co-sponsored by the BIOMED2 program of the EC. Stage A of the project was completed in March 2001. It included the following steps: concept exploration and working definitions of relevant indicators, survey and review of instruments currently used in Europe, development of draft instruments, Pilot testing in 18 countries, an International meeting to review the instruments, and production of revised draft instruments. Stage B of EUROHIS, which is currently being implemented, consists of coordinated field-testing of the revised draft instruments. This includes the use of a common methodology for translation, sampling, interview administration, data coding and analysis. Computer-assisted telephone interviews (CATI) are being used in France, Germany, Greece, Israel and the UK, while face-to-face inter-

views are being conducted in Albania, Azerbaijan, Croatia, Czech Republic, Kyrgyzstan, Latvia, Lithuania, Moldova, Romania, Russia, Slovakia, The former Yugoslav Republic of Macedonia, and Ukraine.

So far, participants have encountered various difficulties in field-testing the draft EUROHIS instruments. Some questions are considered too long or too complicated, and the instructions to the interviewers are not always clear. Translation of concepts from English to the local language is sometimes difficult, although the translation protocol used (forward translation followed by back translation into English, and subsequent revisions as necessary) appears to resolve most of these difficulties. Regarding the routine use of these instruments in national health interview surveys, there is a potential conflict with currently used questions, as national data may no longer be longitudinally comparable if new questions are used. However, it is agreed that there is a need for common instruments to be adopted in order to increase the comparability of health interview survey data collected in different countries. A book with the experiences and conclusions of the EUROHIS project is expected to be published in 2002.

Principal Investigators for the eight indicators of the Health Interview Surveys (EUROHIS) project:

V. Egidi PhD and V. Buratta, PhD, ISTAT, Rome, Italy

H. Meltzer, PhD, Office for National Statistics, London, UK

J. Simpura, PhD, STAKES, Helsinki, Finland (moved to Statistics Finland)

P. Oja, PhD, UKK Institute, Tampere, Finland

A. de Bruin, MSc, Central Bureau of Statistics, Heerlen, Netherlands

T. Klaukka, PhD, The Social Insurance Institution (KELA), Helsinki, Finland

M. de Kleijn-de Vrankrijker, PhD, TNO Prevention and Health, Leiden, Netherlands

M. Power, DPhil, University of Edinburgh, Edinburgh, Scotland.

GUEST COLUMN: A SYSTEM MODEL OF QOL FOR REHABILITA- TION AND PSYCHOSO- CIAL CARE

*Kwok-fai Leung
Hong Kong SAR, China*

This paper tries to incorporate theories and concepts of QOL into a System Model for guiding interventions in rehabilitation and psychosocial services. Since rehabilitation and psychosocial care concern beyond the individual's health and disease, a broader concept of "overall QOL," referring to a global, lasting state of being, which comprises perceived life satisfaction, presence of positive affect, and absence of unpleasant affect, is adopted in this paper. It is used synonymously with the concept of "subjective well-being" and "happiness." Health related quality of life (HRQL) is regarded as a narrower scope of the overall QOL that is affected by ill health and treatment.

Determinants of QOL

One key strategy of QOL intervention in rehabilitation is to introduce desirable determinants and remove undesirable determinants of QOL from the individual. In the past 30 years, many determinants to QOL have been identified¹. These determinants behave differently in terms of their effects on QOL. For some factors, the lack of which will lead to poor QOL, but abundance of them may not necessarily lead to very high QOL. Obvious examples are health and material affluence. Poor health and poverty lead to low QOL; however, when health and income have reached a certain level, very good health and very high income may not add much happiness to people. These factors can be called negative determinants.

Some determinants behave in an opposite manner. For example, coping skills, social skills, intimate relationship, family and social support network, social, leisure, sports, art, and cultural activities can promote high QOL. The lack of

them may not cause significant deterioration in the perception of QOL. These factors can be called positive determinants. These facts lead us to the understanding that ill-being and well-being are two related but distriacted dimensions rather than two ends of a continuum². Therefore, our key strategy for the promotion of QOL can be rephrased as "to introduce as many positive determinants for well-being as possible and to remove negative determinants leading to ill-being." Many of the above mentioned factors are subject to changes and improvement, which rehabilitation should target. At the societal level, modernity, material affluence, safety, freedom and equality are associated with higher levels of happiness in nations. Cultural climate and social climate are associated with QOL of the people as well^{2,3}.

Among these determinants, no single one can account for a major portion of the total variance of the overall QOL when the effects of other determinants are controlled for one. The effect of all of these external determinants may be indirect and variable for different individuals⁴, subject to the person's internal processing in the formation of QOL perception⁵. This subjective process can be changed by carefully designed rehabilitation and psychosocial interventions.

The System Model of QOL

In order to design services specifically for the promotion of QOL, we need to understand in greater depth the possible mechanisms related to the formation of the QOL perception in an individual. The Gap Model of QOL⁶ proposes that the perception of QOL is a result of the appraisal of the gaps between personal aspiration and the reality. There is an aspiration-fulfillment gap, which relates more to the level of fulfillment of basic or higher level human needs, and an aspiration-achievement gap, which relates more to the level of achievement of the individual in various life domains. The appraisal, especially of the fulfillment and achievement in different life domains, is predominantly cognitive in nature⁵. The bigger the gap, the poorer quality of life will be.

The appraisal process, however, is mediated by one or more prominent comparative frames, which are the past, present and possible future status of the individual, the peer groups, and societal and cultural norms. Although the exact mechanism of these mediating mechanisms is not yet fully understood, it is believed that a person will generate a mental picture of his/her aspirations or expectations and a mental picture of the reality before appraisal or comparison can take place. The mental picture of one's aspiration is the standard against which the reality is compared. Information generated from past experiences, peer and social norms will come into action when the standards are generated. The standards formed may not be the same at different times if different information is drawn to form the standards.

The reality of the person can be understood as the result of the interaction between the person and his/her external environment. The environment inherits certain demands and expectations on the person and the person acts on the environment within the limitation of his/her life abilities. The environment also provides various kinds of life events, usually in a fairly random manner, so that different people interact with the environment fairly differently⁴. Some people attribute such random events to luck of the individual. Formation of the mental picture of the reality requires the selection and assembly of certain information about the processes and results of the human-environment interaction. As in forming the mental picture of the standards, different information may be drawn to form the mental picture of the reality.

The human-environment interaction will generate positive and/or negative feelings toward different aspects of the overall life of the individual. These feelings will mediate one's appraisal of the quality of life domains⁴. These feelings are important in determining how one appreciates the overall quality of life. It is believed that the appraisal of life as a whole is more affective in nature be-

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System Model

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cause it is too complex and too difficult to form the mental pictures of the standards and the reality with respect to the overall life⁵.

The appraisal process does not end when the perception of quality of life is established. A perceived low QOL may energize changes toward achieving a higher QOL through a feedback loop. One may try to improve his/her own life abilities and to change the external environment to facilitate a more rewarding and gratifying human-environment interaction.

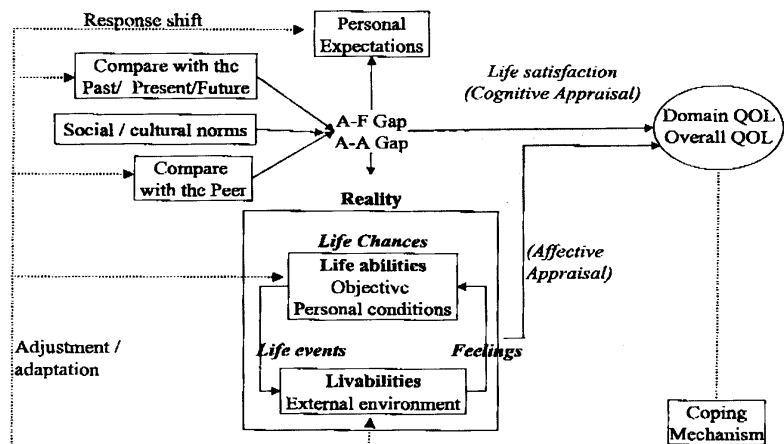
One may also shift the comparative frames and the mental picture of the standards or the reality so as to perceive a higher level of QOL. This process can be regarded as a kind of adjustment or adaptation process. The above-mentioned mechanisms and the adjustment process form an open system by which human perception of QOL can be understood and at which specific services can target. (See Figure 1.)

Designing of Services for the Promotion of QOL

All the potential points of intervention to improve QOL are shown in the boxes in the System Model in Figure 1. The traditional QOL interventions concentrate on the reduction of symptoms and side effects of treatment, and the promotion of functional capacity of patients. These interventions focus on a relatively small part of the total "life abilities" of the person⁷. Promotion of other life abilities and the establishment of balanced life styles, which comprise of social, work and leisure activities, are also important. Besides, altering the immediate physical and social environment and providing favorable life events are helpful. On the other hand, finding alternative comparative frames and standards for QOL appraisal, facilitating adjustment and adaptation, are also effective strategies for promoting QOL.

At the personal level, these require a multidisciplinary health and social care team to provide the necessary services.

Figure 1. The System Model of QOL



At the societal level, it is the responsibility of the government, policy makers and social advocates to adopt a wider perspective of the System Model to establish appropriate policies and service systems to promote QOL for citizens.

As a conclusion, the System Model provides a tentative conceptual framework for us to understand the nature of QOL and to design QOL interventions in rehabilitation and psychosocial services. However, further study is needed to test the model empirically.

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CALENDAR OF EVENTS

Quality of Life Research in Medicine Conference
Oct. 3-5, 2002, St. Petersburg, Russia

ISOQOL 2002 Annual Meeting
October 30-November 2, 2002,
Orlando, Florida, USA
Early Registration Deadline: July 24, 2002

International Society for Quality-of-Life Studies (ISQOLS) Conference on Community Quality of Life
December, 2002, Williamsburg, Virginia, USA

International Society for Quality-of-Life Studies (ISQOLS) Annual Conference
July, 2003, Frankfurt, Germany

International Network on Health Expectancy (REVES) Annual Meeting
May 5-7, 2003, Guadalajara, Mexico

ISOQOL 2003 Annual Meeting
November 12-15, 2003,
Prague, Czech Republic

MEMBER NEWS

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.

Catherine Acquadro, MD (France), Scientific Director of Mapi Research Institute, was presented a Distinguished Service Award during the Second Plenary Session of the ISPOR Seventh Annual International Meeting, held May 19-22 in Arlington, VA (USA), for her contribution and her commitment in serving the science of pharmacoeconomics and outcomes research, especially through the PRO Harmonization Group Project (www.PRO-harmonization-group.com).

Erhan Eser, MD (Turkey), of Celal Bayar University, and colleagues, working together as a QOL group on WHOQOL projects and other cultural validation projects since 1996, have formed as of April the Turkish Health Related Quality of Life Society ("Saglikla Ilgili Yasam Kalitesi Arastirmalari Dernegi," or SAYKAD, in Turkish).

SAYKAD is planning to organize an Eastern Medditeranean Quality of Life Regional Meeting in Izmir in Sept. 2003.

Founders of the society are: Huray Fidaner MD. Prof. of Psychiatry; Caner Fidaner MD. Assoc. Prof. of Public Health; Erhan Eser MD. Assoc. Prof. of Public Health; Sultan Yalcin Eser MD: PhD on Public Health; Serap Ozturkcan MD. Prof. of Dermatology; Omer Aydemir MD. Prof. of Psychiatry; Tumer Pala MD. PhD on Public Health; Pinar Dundar MD. Assist. Prof of Public Health; Dilek Dalli Assist. Prof. of Nursing Surgery.

Ping Ping Li, MD (China) has just been inducted as a member of the Chinese Anti-Cancer Association, Palliative Treatment Committee earlier this year.

Nancy Kline Leidy, PhD, FN (USA), Director of the Center for Health Outcomes Research, MEDTAP International, Inc., received the ISPOR Distinguished Service Award for Quality of Life Special Interest Group Chair, ISPOR Seventh Annual International Meeting, 2002.

Lena Ring (formerly Lundberg), PhD (Sweden), of the Disciplinary domain of Medicine and Pharmacy at Uppsala University, will become a post-doctoral research fellow in Dublin, Ireland on Sept. 1. The position is based at the Health Services Research Centre at the Royal College of Surgeons with Professor McGee and Professor O'Boyle, and funded by an EU Marie Curie Development Host Fellowship. The topic is theoretical development of the concept of QOL.

John E. Ware, PhD (USA), CEO and Chief Science Officer of QualityMetric Inc., was named the first annual recipient of ISPOR's (International Society for Pharmacoeconomics and Outcomes Research) Outcomes Research Lifetime Achievement Award at the Society's annual conference, held in Washington, D.C. on May 20. According to ISPOR President Eva Lydick, "The award was established to acknowledge an individual who has made a major contribution to the improvement of health outcomes for patients or other populations. After a long process that involved nominations, selection of a panel of finalists and a ranking by a committee of 35 outcomes researchers, Dr. Ware was selected as the first recipient of this reward."

DEADLINE APPROACHING FOR NOMINATIONS FOR THE ISOQOL PRESIDENT'S AWARD

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

Please submit your nomination package consisting of: 1. A letter from the nominator specifying the contributions of the nominee(s); 2. The curriculum vitae of the nominee(s), and 3. An external support letter. The deadline for the nominations is **July 31, 2002**.

Please send your nomination package to: Dr. David Osoba, President ISOQOL Executive Office, 6728 Old McLean Village Drive, McLean, VA, 22101, OR Fax to ISOQOL Executive Office at (703) 556-8729.

The award will be selected by the ISOQOL Executive Committee and approved by the Board of Directors. The award will consist of a plaque, a \$1000 honorarium and up to \$1000 in travel expenses if the recipient plans to attend this year's Annual Conference in Orlando, Oct. 30 - Nov. 2.

If you have any questions regarding the President's Award, please contact the ISOQOL Executive office at info@isoqol.org.

If you have a colleague that would be interested in joining the Society, please have him/her contact ISOQOL at info@isoqol.org

CLASSIFIED ADVERTISEMENTS

Outcomes Research Scientist: The National Cancer Institute anticipates an opening for a social, behavioral, or clinical scientist in the Outcomes Research Branch (ORB) of the Division of Cancer Control and Population Sciences. ORB is expanding its national research program to foster the development and application of valid, reliable, and feasible endpoint measures in a variety of important areas of application, including clinical trials and a range of observational studies. ORB is seeking an individual with expertise in the development, evaluation, or application of patient-centered outcome measures, with a focus on health-related quality of life.

Candidates should hold a PhD, MD, or equivalent training and experience; background in cancer outcomes research is highly desirable but not required. Excellent communication, interpersonal, and quantitative skills are essential. Salary range is anticipated to be \$65,000-\$100,000 (GS-13 or 14), though for a very highly qualified senior investigator, salary may be set beyond this range. Location is Rockville, Maryland, near the NIH campus and D.C. Excellent benefits. For further information, contact Dr. Joseph Lipscomb at LIPSCOMJ@NIH.GOV. All applicants will receive consideration without regard to race, color, gender, national origin, age, religion, disability, or sexual orientation. NCI/NIH is an equal opportunity employer.

Associate Professor, Symptom Research: The University of Texas M. D. Anderson Cancer Center, Division of Anesthesiology and Critical Care, is inviting applications for an Associate Professor in the Department of Symptom Research. The selected candidate will be responsible for the development, support and performance of cancer-related symptom control research. Will develop independent thematic program (i.e., cancer-related symptom burden, fatigue, pain, multiple symptom assessment) for research funding and performance.

Qualifications: M.D. or Ph.D. with six years' post-doctoral experience in oncology and/or symptom control and management. Supervision of large-scale symptom control studies, descriptive and/or intervention-based. Presentation of data at a national and international level. Evidence of success in obtaining funding for symptom control research. Significant record of publications to support associate professor appointment.

Interested candidates are invited to contact: Charles S. Cleeland, Ph.D., McCullough Professor of Cancer Research, The University of Texas M. D. Anderson Cancer Center, 1515 Holcombe Blvd., Box 221, Houston, TX 77030. Phone: (713) 745-3470. E-mail: ccleeland@mdanderson.org. The University of Texas M. D. Anderson Cancer Center values diversity in its broadest sense. Diversity works at M. D. Anderson. EEO/AA, Smoke-free environment.

Scales & Quality of Life Specialist-Analyst: The Pharma Sector of UCB is conducting worldwide activities in research, development, manufacturing and marketing of ethical drugs in the fields of the central nervous system and immuno-allergy.

The outcomes Research Unit is dedicated to measuring the clinical, economic and humanistic (quality of life, productivity) outcomes of the implemented projects. In order to expand the "Clinical Epidemiology & Outcomes Research" Unit, in Braine L'Alleud, 15 km away from Brussels, we would like to hear from applicants for the following position: *Scales & Quality of Life Specialist-Analyst (m/f, Ref 000986)*.

Function:

- Developing and writing research proposals
- Implementing Health Related Quality of Life instruments or other instruments in clinical trials
- Collecting, analyzing and interpreting data in order to contribute to the new drug development plans and/or indications

- Integrating the results with the clinical, psychosocial and ethical dimension
- Being the expert in the domain and ensure the analyses related to the patient reported outcomes/quality of life scales in the R&D projects.

Profile:

- Psychosocial or medical sciences university degree, you have expertise in methodology, scales and instruments, medical statistics and computer science
- You have gained experience in the academic field or in pharmaceutical industry in the socio-medical field, methodology, and or measurement scales
- This position requires good communication and cooperation skills in order to establish effective interaction with project leaders, medical/clinical staff and data management
- Spoken French is certainly an asset for local contacts although the international working language is English.

If you are interested in this position, please send your application with complete c.v. to UCB Pharma, attn. Mrs. C. Thiry, Selection and Recruitment Manager, Chemin du Foriest, B-1420 Braine-l'Alleud, Belgium. It will be treated in utmost confidence. Please mention ref. 000986. More information about UCB: www.ucb-group.com or www.ucb.be.



**ISOQOL
Annual Meeting
Oct. 30 - Nov. 2, 2002
Orlando, Florida USA
Early Registration
Deadline
July 24, 2002**

ISOQOL 2004 Symposium

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disease specific: "Assessment of QOL in Cognitively Impaired Individuals," "QOL Assessment in Cancer: Where Are We Now and Where Are We Going?," or "QOL in HIV: State of the Art of Measurement and Interpretation." Several related topics may also be proposed.

We are asking that you propose a symposium format that would be appropriate for the single topic focus, with a brief rationale for that format. This should include number of days (approximately 2 days), format of presentations (e.g. plenary sessions, panel discussions, contributed oral/poster) and how these will be distributed over the available time. Contributed oral/poster sessions should constitute a minimum of 25% of the available time. A potential list of invited speakers would be helpful, if applicable.

Note that we are not asking for volunteers to be responsible for the logistical aspects of the meeting; the ISOQOL Executive Office (Degnon Associates) will be responsible for the non-scientific aspects of the meeting. You should, however, suggest realistic sources for requesting supplemental funding for the meeting to help defray expenses. Thus, the proposal is limited to the topic, meeting format, potential supplemental funding sources and 3-5 ISOQOL members who would be interested in forming the core of a scientific program committee.

If ISOQOL members have topics that they wish to suggest, they are requested to submit a brief proposal by **September 1, 2002**. These will be reviewed by the Education Committee and recommendations will be made to the Board, who will select the topic at the October 29th Board meeting.

The brief proposal should include the following:

1. Brief description of the symposium topic/content (50-200 words).
2. Targeted audience and expected attendance.

3. Recommended region of North America for conference (optional).

4. Hypothetical symposium format and rationale. This should include number of days, format of presentations (e.g. plenary sessions, panel discussions, contributed oral/poster) and how these will be distributed over the available time, and a potential list of invited speakers, if applicable.

5. Suggested funding sources for the conference, including Foundations, Government, and/or Private Sector.

6. ISOQOL members who would be willing to serve as Scientific Program Chairs or members of Advisory Committees. (*please note*: these individuals should be aware of and in agreement with this potential involvement.)

ISOQOL WELCOMES NEW MEMBERS SINCE MARCH 19, 2002

Francesca Baiardi
Clicon S.r.l, Ravenna, Italy

Yvonne Brandberg
Karolinska Institute, Stockholm, Sweden

Jeanet Bruil PhD
TNO Prevention and Health
Leiden, The Netherlands

Birgitta Dietz MD
Abbott GmbH & Co. KG
Ludwigshafen, Germany

David Eton PhD
Evanston Northwestern Healthcare
Evanston IL, USA

Christopher Forrest PhD
Johns Hopkins University
Baltimore, MD USA

Page Ginette PhD
Dunham, PQ Canada

Ariella Haber MBA
Amgen, Studio City, CA USA

Jeremy Hobart PhD, MD
National Hospital for Neurology & Neurosurgery, London, England UK

Kenneth Johnson PharmD
NeoPharm, Lake Forest, IL USA

Yong S. Paul Kim PhD
Aventis Pharmaceuticals Inc.
Bridgewater, NJ USA

Jonathan Kowalski PharmD, MS
Allergan, Irvine, CA USA

Beng Li Ting
HRAsia, Singapore

Michael T. Moser Dpsych
University of Freiburg
Freiburg, Germany

Lumu Nkoy MD
IHC, Salt Lake City, UT USA

Marlene Reimer PhD
Faculty of Nursing, Univ. of Calgary
Calgary, AB Canada

Robert Rush MSc
Western General Hospital
Edinburgh, Scotland

Jens-Ulrich Siebmann Dipl Psy
Christian-Albrechts Univers. Kiel
Kiel, Schleswig-Holstien, Germany

Anusha Sinha MPH
Quintiles Late Phase
San Francisco, CA USA

Soren Skovlund
Novonordisk, Sorgenfri, Denmark

Martin Taphoorn PhD
University Medical Center
Utrecht, The Netherlands

Ashutosh Tewari MD
Henry Ford Hospital
Detroit, MI USA

Charoen Treesak PharmD
University of Minnesota
Minneapolis, MN USA

Bart Van Den Eynden
University of Antwerp, Belgium
Mortsel, Belgium

Maybelle Vidamo MD
Paranaque City, Phillipines

Amanda Welton
Medical Research Council
London, UK

HELP WANTED FOR ISOQOL COMMITTEES AND SUBCOMMITTEES

ISOQOL needs your input! Please take a moment to review the following selection of opportunities for you to contribute to the Society, through participating in one of the committees or subcommittees below. Then contact the chairs directly via e-mail at the addresses provided.

The Early Career Investigators (ECI) Subcommittee for the 2002 Annual ISOQOL Meeting

This Subcommittee, preparing for the meeting in October in Orlando, Florida, needs your help with the following:

1. Arranging beneficial ECI-Mentor matches before the Meeting,
2. Planning the ECI Events at the Meeting, and
3. Judging the top EIC presentations in Orlando.

Please contact Kathy Wyrwich at wyrwichk@slu.edu if you would like to join Marcel Dijkers, Diane Fairclough, Cindy Gross, Mona Martin, Elaine McColl, Deborah Miller and Kathy with these fun and important tasks! By the way, ECI takes the place of the former Young Investigators Subcommittee. An Early Career Investigator is described as “a full-time student or post-doctoral trainee or a person in the early stages of their career in QOL research, having either received their doctorate within the last five years or been working as an independent researcher in the field five years or less.”

Conferences and Workshops Subcommittee of the Education Committee

Interested in the world and the future? ISOQOL takes a long-term, strategic approach to planning its conferences, symposia and workshops, around the world and into the future. **Want to learn about interesting places and meeting interesting people?** Tasks include identifying and researching potential host cities and venues, and networking with local people who do or use QOL research. **We need people from around the globe**, including the Asia/Pacific region, the Middle East, Africa, South

and North America, Western and Eastern Europe; in short, a place near you! Contact Madeleine King at madeleine.king@chere.uts.edu.au.

Policies/Guidelines Development Subcommittee of the Education Committee

ISOQOL needs members to serve on the Policies / Guidelines Development subcommittee of the Education Committee. Tasks include:

1. The writing of policies/ guidelines for access to ISOQOL services at the request of the ISOQOL Board of Directors.
2. Evaluation of the application of these guidelines to specific requests for ISOQOL support. The work of this subcommittee is done primarily by e-mail. Reports of activities are generated for the ISOQOL Board twice a year. Contact Claudette Varricchio at cv9h@nih.gov.

Scholarships and Training Subcommittee of the Education Committee

ISOQOL members from **Asia/Pacific region** to serve on advisory/planning committee for regional Methods Workshops to be held in the Asia/Pacific region during the Winter/Spring 2003. Tasks include identification of topics of regional interest, evaluation of alternative formats, and suggestions of locations. Contact Diane Fairclough at dianefairclough@earthlink.net.

ISOQOL members to serve on a planning committee for collection and **dissemination of educational materials** (lectures, workshop materials, etc.) that would increase the visibility of HRQOL in medical education. Tasks would include plans for identifying materials and proposals for dissemination (e.g. free on the ISOQOL Web site, income generating publications, etc.). Contact Diane Fairclough at dianefairclough@earthlink.net.

Become a Part of the Finance/Fundraising Committee

We are requesting members for participation in the finance/fundraising committee. This committee, under the leadership of the Treasurer, is involved with

identifying and securing funds for ISOQOL-related activities. This involves direct fundraising, preparation of grant applications for foundations and government agencies, and further development and recruitment of institutional memberships. If interested, contact Dennis Revicki at Revicki@medtap.com.

Good Practices Committee Seeks Committee Members

Wanted: Quality of Life Researchers interested in furthering the goals of ISOQOL's newly-formed Good Practices Committee. What are these goals? The Committee has a two-fold aim—

1. To study and understand how HRQL instruments and their documentation can be accessed, as well as the terms of usage for the HRQL instrument, and
2. To eventually recommend policies for “Good Practices” in our field.

If you would be interested in joining Jordi Alonso, Ivan Barofsky, David Cella, Geoff Norman, John Ware, and Kathy Wyrwich in pursuing these goals, or just want to find out our more about the Committee's efforts, please e-mail Kathy at wyrwichk@slu.edu.

Membership Committee Thought for the Day

Recruit one new member for ISOQOL before the November 2002 meeting in Orlando. Please think about your colleagues who are currently not members but who share an interest in the use of quality of life outcomes in research. Do you think you could convince any of these individuals to become an ISOQOL member? It never hurts to ask. Direct colleagues to the ISOQOL website (www.isoqol.org). If you are attending another professional meeting that shares an interest in quality of life outcomes, please take along some brochures advertising ISOQOL. Contact the ISOQOL headquarters for an electronic file of the brochure (info@isoqol.org). All of these efforts will help us increase our membership. And by the way, if you would like to be a member of the ISOQOL Membership Committee, please contact the ISOQOL office (info@isoqol.org). We'd be most pleased to have your help.



International Society for Quality of Life Research

9TH Annual Conference
October 30 – November 2, 2002
Caribe Royale Resort Suites and Villas,
Orlando, FL, USA

Plenary Topics Include:

What are the Primary Alternative Theoretical Models of QOL?

Scheduled to present: Daniel Kahneman, PhD (USA) and
Carol Ryff, PhD (USA)

*The Contribution of Qualitative Methods and Cognitive Science
to QOL Research*

Scheduled to present: Carol Tishelman, PhD (Sweden) and
Tom Hack, PhD (USA)

*Is There a Relationship Between Findings of Patient Quality of Life and
Adherence / Compliance within Clinical Research Studies?*

Scheduled to present: Jackie Dunbar-Jacob, DNS (USA) and
Cynthia Rand, PhD (USA)

ISOQOL is committed to promoting excellence in quality of life research, by
developing a peer-reviewed program of state-of-the-art presentations and
by offering the following programs:

Early Career Investigator Awards ~ Scholarship Program ~ Mentoring Program

Program to include:

**Debate/Panel Discussions ♦ Symposia ♦ Roundtable Lunches ♦
Poster Sessions ♦ Paper Presentations ♦ Workshops**



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

**For more information, visit our website
at www.isoqol.org**

See you in Orlando!!

**International Society for Quality of Life Research
6728 Old McLean Village Drive
McLean, VA 22101
703-556-9222 ~ Fax: 703-556-8729
info@isoqol.org ~ www.isoqol.org**