



International Society for Quality of Life Research

Volume 5 Issue 2

Newsletter for ISOQOL Members

July 2000

PRESIDENT'S MESSAGE

Dr. Sharon Wood-Dauphinee

In academia, summertime, with only graduate students around, is the best period for concentrated thinking and planning. Along with several other ISOQOL Board Members, I have been busy reflecting on the internal workings of the Society and prioritizing what needs to be done to insure that both the day to day activities and the policies and plans are of benefit to ISOQOL and its members.

ISOQOL is very privileged to have a Board comprised of bright, and dedicated individuals, who represent three continents as well as diverse professional and clinical backgrounds, and working environments. Each member makes unique contributions and collectively they interact, contributing both opinions and information on subjects of interest. Each member views the Board position as a responsibility as well as an honour associated with receiving recognition from one's colleagues.

While occasionally there is a conference call for the Executive Committee, the costs are prohibitive to using this mode of communication with our geographically disbursed Board Members, not to mention the fact that the idea of 15 vocal ISOQOL Board Members on one conference line is daunting! In consequence, email is our usual method of interacting. Let me assure you that all Board members have strong opinions on most topics related to ISOQOL, and have the writing skills to state them most eloquently. It makes for a lively debate and one that can be accomplished within a fairly short time at no cost to the Society.

Several issues are currently in various

stages of discussion and debate. One has to do with other organizations who would wish some type of sponsorship from ISOQOL for their own activities. While in principle we like to be helpful, we feel that there should be some benefit for ISOQOL in addition to advancing the general field of quality of life research. We are thus trying to formulate a proposal as to ISOQOL's role when asked to "sponsor" an event.

On a related topic, members around the world are wanting to hold local quality of life meetings and conferences and we need guidelines as to how the core organization will work together with regional groups in terms of roles, responsibilities, and benefits. In line with this subject, some members of the Board are wondering if ISOQOL is mature enough to have national or even regional chapters and how they would interact with the International Society. During our recent Strategic Planning Exercise, one of the strengths of the Society was that it is international. It was acknowledged, however, that most members live in North America and Europe. We are thinking about approaches to increasing membership from other continents to make us truly global, and also how to facilitate broad geographic representation on the Board and among the Officers. Finally, a matter of particular interest of the Board is how to conduct the voting process so that it can be done in a timely fashion and achieve a large proportion of membership votes. By voting process, I refer not only to the annual vote for Board Members and Officers, but also for voting on policy issues. This last type of voting will become more common in the near future. The issues being discussed within the Board will hopefully result in a number of policy proposals which will be circulated among the membership for wider

discussion and debate. Prior to adoption, they will need to be "voted on" by the members. One of the reasons for providing you with information about the internal deliberations of the Board is to encourage those of you with interest in these kinds of activities to consider running for Board membership in some future election. If you don't feel you are ready for the Board, think seriously about volunteering for committee work to learn more about ISOQOL activities. Please do not hesitate to contact me directly, if you have further questions on this subject. I would be pleased to discuss them with you. Email: swoodd@po-box.mcgill.ca

ISOQOL Conference October 29-31, 2000 Vancouver, Canada

~ Sunday: Workshops, Posters & Opening Reception
~ Monday & Tuesday: Invited Speakers, Papers & Posters
More Information on Page 3

- August 18, 2000 ~ Early registration deadline

Scholarship Applications are available. Please contact the ISOQOL office for information or visit the website.

ISOQOL Executive Office
6728 Old McLean Village Drive,
McLean, VA 22101-3906 USA
Phone: 703-556-9222;
Fax: 703-556-8729;
Email: info@isoqol.org;
WEB PAGE: www.isoqol.org

GUEST COLUMN-

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 new column, quality of life researchers are invited to give their personal view on how the field could further mature. Carolyn Schwartz, Associate Professor at the University of Massachusetts Medical School and member of the ISOQOL Newsletter Committee, is the first to take up this challenge. While this is an invitational column, readers with strong views, either supporting or contradicting the opinions voiced by the columnist, are encouraged to react.*

New Directions in Quality of Life Research

Dr. Carolyn Schwartz

The field of quality of life (QOL) research has a unique niche in medical research. A relatively young field, it has grown substantially in the past two decades to become increasingly broad in scope. Clinical research studies are rarely designed without some QOL measure as a secondary or primary outcome. Further, applications of QOL research to health services research have been recognized as new methods are created that link cost-effectiveness analysis with QOL outcomes. In the wake of such success, it is worthwhile to contemplate how the science of our field can proceed to a higher level of development so that we can expand the depth, utility, and recognized implications of the field. In this column, I would like to highlight two promising areas for development so that our field can continue to mature.

Much of the science of our field has been borrowed from other fields. The psychometric methods we use to validate new QOL measures are borrowed from personality assessment, which creates tools to measure dispositional characteristics of the individual. Although these methods have certainly provided a useful starting point for the development of our field, the assumptions of such methods may not apply to a dy-

amic construct such as QOL appraisal. It is time we considered seriously the impact of applying methods used to measure static constructs to those intended for dynamic constructs. It may be worthwhile to consider borrowing methods from other fields that habitually measure dynamic constructs, such as physics, as we seek new models and methods for evaluating the reliability and validity of QOL assessment.

A second domain that invites development is the evolution of theoretical models that can help to guide a next generation of QOL research. I would like to see fewer articles that describe and compare various illness groups in terms of their observed scores on a QOL measure. In their stead, I would like to see a growing number of articles that address the complex factors that influence QOL which are currently below the surface of standard measurement and analytic approaches.

One construct I am particularly interested in is response shift phenomena. This construct refers to the idea that when people undergo changes in health state, they may change their internal standards, their values, or their conceptualization of a target construct about which we might be asking them to self-report, such as health, QOL, or fatigue. Recent research on response shift has documented its role in the disparity between clinical and self-report, its implications in cost-effectiveness analysis, and its possible impact on outcomes or evaluation research. Response shift theory has evolved to become increasingly testable, with an eye toward evaluating its import to key applications of QOL assessment, such as adaptation to stress, cross-cultural differences, and disparities among observers.

The construct of response shift elicits a range of reactions from QOL researchers. Some find it threatening, because it could undermine everything they have done to date. Others find it trivial, for example because they focus on functional status alone and rely on recent advances in Item Response Theory to select the best items for their measure

and to minimize any "bias" not related to strict functional status assessment. To a growing group of QOL researchers, however, response shift represents a challenging opportunity to link their work to a fundamental exploration of the process of adaptation. I believe that it provides a valuable bridge to related fields such as health psychology, medical sociology, cost-effectiveness analysis, and psychoneuroimmunology, especially with regard to understanding what patients can do to have an impact on the course of their disease and their well-being.

In closing I would like to note that this is an exciting time for QOL researchers. Given the sophisticated technology that is available, we are in an unprecedented position to develop our science with tools that can greatly facilitate collecting (e.g., handheld PC's, voice activated computers) and analyzing (e.g., statistical software, qualitative analysis software) increasingly complex data. Such data allow us to develop the depth of our inquiry to enhance its relevance and implications for clinical research.

References related to this column can be obtained upon request by emailing the author at: carolyn.schwartz@umassmed.edu.

Carolyn Schwartz, Sc.D.
University of Massachusetts
Medical School
Department of Family Medicine and
Community Health
55 Lake Avenue North
Worcester, MA 01655
Fax: 508-856-1212

**If you would like to
share your reaction to
this column,
please contact the
Newsletter Editor at
m.a.sprangers@amc.uva.nl**

7th ANNUAL ISOQOL
RESEARCH ANNUAL
CONFERENCE ~
October 29-31, 2000
Vancouver, Canada

Dr. David Osoba

By now you should have received at least one announcement of the Seventh Annual Scientific Conference and Business Meeting (to give it its full and flowery name) and so this announcement should not be a surprise to you. However, you may not be fully aware of the “goodies” that have been planned for you by your hard-working Scientific Program Committee, headed by Diane Fairclough and assisted by Carol Moinpour and me.

The opening plenary session presents two of the best speakers we could envisage along with two equally distinguished discussants. They will be addressing two hot topics that will interest everyone. Dr. George Torrance will speak about “Utility measurement of health-related quality of life; past, present and future” and the discussant will be Dr. Les Lenert. The second plenary speaker will be Dr. Ron Hays, asking the question “When does a profile beat a single number, or are two always better than one?” The discussant, Dr. Robert Kaplan may not agree with everything that Ron has to say.

At the closing of the scientific portion of the meeting, Dr. Ian Tannock will challenge us with “Health-related quality of life: where are we and where should we be going?”. Just in case there is any room left for discussion, a panel consisting of Drs. Ann Cull, Sally Shumaker, Rick Berzon and David Cella will give us their own views. Between them, these five speakers are bound to be both comprehensive and thought provoking.

In the Invited Masters Series, three “masters in the art and science of health-related quality of life” and three additional masters will discuss important issues that need to be aired and resolved. Dr. Dennis Revicki’s topic is “The added value of health-related quality-

of life evidence; is safety and efficacy enough?” The discussant will be Dr. Robert Meyer of the FDA. Dr. Jeff Sloan has chosen to speak about “Methods for Assessing Clinical Significance in Quality-of-Life Measurement”. The importance of this subject is clear and Dr. Mirjam Sprangers will add to the subject. It may be surprising that anyone may have the thought expressed in Dr. Peter Fayers’ talk on “Overuse and abuse of psychometrics – is there a role for clinimetrics?”. It’s hard to think of “overuse and abuse” as being something that could happen in our fields of study. Dr. John Ware will add his views. It is perhaps not so surprising that many of our invited speakers (four out of five) have given us titles in which they ask questions. Let’s hope that they also provide us with some answers!

A special panel has been convened in the place of a fourth Masters Lecture. The panel consists of Dr. Ronald D. Burr, Ms. Jeanne Landgraf, Dr. Ulrike Ravens-Sieberer, who will tell us what they know and what needs to be done about the “Evaluation of HRQL in special populations: Children”.

In between the opening and closing plenary sessions you will be able to present your own work in oral and poster sessions. The abstract deadline has long passed and by now the reviewers have made their best judgements about which abstracts will be presented. We hope there will not be too many disappointments, and we will do our best to present to work of the highest scientific standard and importance. One of the Society’s goals is to ever increase the scientific quality of the work presented at the Annual Conference and the abstract review team has been instructed to keep this in mind. We expect this process to result in a number of excellent oral and poster presentations. Some of the poster sessions will have discussants as well. In the past, many poster presenters have been pleasantly surprised by the number of people that have come by to view and discuss their posters. In fact, they have said that they prefer poster presentation to oral presentation. The opportunity for mean-

ingful discussion is much greater after a poster presentation than after an oral presentation. We look forward to excellent sessions!

Finally, there will be a full day of Workshops on October 29th, along with an afternoon poster session, and on the morning of the 30th there will be sessions devoted to “Meet the Developer” of various instruments used in HRQL research.

I have used the word “surprise” in two or three ways. It’s a word that can be “overused and abused” and I fear I may be doing that when I say that dinner for all of us at the Vancouver Art Gallery and the other social activities will be a wonderful surprise. For those who have not been to Vancouver before, the city is unabashedly beautiful in one of the most scenic settings imaginable. (Does it sound as if I’m from Vancouver? No, I don’t work for the Chamber of Commerce, but I do like living here.) We hope that Mother Nature will be kind and that we will have sunshine while everyone is here. The autumn weather is very changeable and you should come appropriately dressed. That’s one surprise we don’t want you to have. Expect temperatures to be anywhere from 10-20C (50-70F) in the daytime and about 5-10C (40-50F) at night.

Please go to our website to get more information about more topics, registration, etc. The address is www.isoqol.org.

And Bon Voyage!



**Register
on-line!
Visit our
website at
www.isoqol.org**

BOARD ELECTION BALLOT 2000

Dr. Monika Bullinger, Past President

The ISOQOL election was prepared by the election committee (consisting of Monika Bullinger as past president, Diane Fairclough and David Osoba) prior to the 1999 Barcelona meeting and was initiated at the ISOQOL meeting. The opening for candidate nomination was published in the newsletter proceeding that meeting, so the nominations were possible during the business meeting in Barcelona as well as within a period of two months thereafter. Opening for board positions included the president elect position as well as five board positions due to previous board members expiration of terms. Through written notification or ad hoc nomination, a slate of 15 candidates was nominated and invited by a letter from the past president to provide their bio-sketches for publication in the ISOQOL newsletter of spring 2000. Twelve bio-sketches arrived, were included in that newsletter and thus formed the basis for the election. The election process was, as in previous years, conducted by a fax or mail in that each member together with the ISOQOL newsletter received a numbered election sheet on which to identify preference for one of the two nominated president elect position and five of the ten nominated board positions.

In addition a question regarding the acceptance of a new incorporation of the society in the US was added.

Elections came back to the ISOQOL administrative office and were counted to identify the number of votes for each candidate. The ISOQOL board was notified about these counts in May 2000 together with a written notification of the candidates elected to a board position for the 2000 ISOQOL board as well as those not elected this time. According to the election procedure, the next ISOQOL president elected is David Osoba, Canada, board positions go to Jordi Alonso, Spain, Diane Fairclough, US, Peter Fayers, UK, Rick

Berzon, US and Marianne Amir, Israel. The votes were very close so that the society sincerely hopes that the candidates not elected to the board this year will be willing to be nominated for the next election round. The majority of voters supported an incorporation of the society in the US (of 163 ballots collected 128 were positive, 16 were negative and for the rest there was no response). The election committee wants to congratulate the new president elect and the new members to the board who will be introduced to the membership in the next upcoming ISOQOL conference in Vancouver.

SUMMARY OF THE STRATEGIC PLANNING RETREAT

Dr. Ivan Barofsky, President-Elect

On April 28 and 29, nine members of the Board of Directors of ISOQOL--plus the current president, president-elect, and three committee chairpersons--participated in the preparation of a strategic planning document. This meeting was facilitated by Carolyn Pizzuto of CDA Management Consulting, Inc. The participants generated a vision statement, but also engaged in an analysis that reviewed the strengths, weaknesses, opportunities, and threats to the organization. In addition, the attendees generated a mission statement and specified organizational goals and objectives. A variety of action plans was also proposed and responsible persons identified to implement these objectives. The strategic planning document, in its drafted form, is to be reviewed at the board meeting in October, 2000 and a final decision made concerning its contents.

The document included the formulation of a vision statement. The participants shared their concept of the organization vision. It was agreed that the organization must focus on health-related quality of life. It also was agreed that the research implementation on health-related quality of life must be put into practice globally. Therefore, after a healthy exchange of ideas and challenges, the

participants adopted the following vision for the organization.

ISOQOL VISION:

Health-Related Quality of Life (HRQOL) is the ultimate outcome of health care.

MISSION OF ISOQOL:

Upon reviewing the currently published mission statement, the participants agree as follows:

The scientific study of quality of life relevant to health and health care is the mission of the International Society for Quality of Life Research (ISOQOL). The society promotes the rigorous investigation of health-related quality of life measurements from conceptualization to application and practice. ISOQOL fosters the worldwide exchange of information through:

- *Scientific publications*
- *International conferences*
- *Educational outreach*
- *Collaborative support for HRQOL initiatives*

The revised mission statement serves to emphasize three identifying elements of the society that distinguish it from other organizations. They are:

1. *Scientific study and methodology*
2. *Health-related focus*
3. *International in scope*

ORGANIZATIONAL GOALS:

The participants adopted the following goals for the five year plan:

Promote excellence in science of health-related quality of life (HRQOL).

- *Advocate for the use of HRQOL research in practice and policy.*
- *Provide and facilitate targeted educational activities.*
- *Attract and engage in a diverse global membership.*
- *Develop financial resources to achieve objectives of the society.*

Specific goals were identified for each of these objectives and an action plan was stipulated which is in the process

of being acted on by the attendees.

ISOQOL would like to thank the following companies for their generous contributions. Without their support, this important strategic planning retreat would not have been possible.

- Warner-Lambert/Parke Davis
- Aventis Pharmaceuticals
- Astra Zeneca
- Ortho Biotech
- Genetech

SUMMARY OF SYMPOSIUM & WORKSHOPS ON QUALITY OF LIFE IN HEALTH & DISEASE

Bangalore, India

Dr. Santosh K. Chaturvedi

The Symposium & Workshop on Quality of life in health & disease were held on December 13 & 14, 1999, at the Seminar Room, Library block, NIMHANS (National Institute of Mental Health & Neurosciences), Bangalore, India. There were 77 participants who attended the Symposium, of whom 45 attended the Workshop. The Workshop was conducted by Dr. Santosh K. Chaturvedi and Dr. Prabha S. Chandra from the Department of Psychiatry, NIMHANS. Participants came from Malaysia, Canada and England, as well as locally. The participants represented several different disciplines. There were researchers, physicians, psychiatrists, psychologists, neurologists, counselors, administrators, speech therapists, social workers, and volunteers. The overall objective of the Symposium was to have a current update on the concept of quality of life. The objective of the Workshop was to familiarize participants with the common QOL scales, and apply QOL measures in their researches.

The Symposium was inaugurated by the Director-Vice Chancellor Dr. M. Gourie-Devi, who pointed out the importance of QOL in health and disease and also emphasized the cross cultural differences in QOL from the West. Since QOL was dependent on expectations and achievement, these differences were due

to differing expectations, she pointed out. Dr. N. Janakiramiah, In-Charge Head of Department of Psychiatry also mentioned the difficulty in quantifying the qualitative subjective perception of quality of life.

The first presentation was on the general concepts on quality of life by Dr. Chaturvedi. Different definitions and concepts were presented, and also the lack of consensus on QOL was pointed out. Paucity of research on QOL in the Indian setting was mentioned, but it was mentioned that some studies indicated the importance of psychological, spiritual and religious aspects by Indians. Therefore, this talk was followed by spiritual aspects of quality of life by Dr. Sanjeev Vasudevan from Pain & Palliative Care Society, Calicut. The importance of spiritual aspects in QOL was acknowledged by all. Some participants wanted to know how spiritual methods can be used for intervention to improve QOL.

Dr. Shivarama Nair, a neurologist, discussed the QOL measurement and improvement in patients with chronic neurological disorders. The use of physiotherapeutic methods to minimize disability was described. QOL in medical disorders like diabetes mellitus and hypertension were discussed by noted endocrinologist, Dr. S.S. Srikanta. He suggested ways by which patients with chronic medical disorders could maintain reasonably good QOL, despite following dietary and life style restrictions. QOL of advanced cancer and HIV-AIDS were discussed by Dr. Chaturvedi and Dr. K.S. Sateesh. The importance of QOL issues in cancer is well known, and a lot of research has been focused on this aspect, as was pointed out. The improvement in QOL by improving communication skills, detection of emotional problems, selective surgical procedures, and indigenous low cost rehabilitative measures were also discussed.

Dr. T. Hegde, a neurosurgeon, presented issues related to QOL of neurosurgical conditions including brain tumors, and post head injury conditions. Currently, QOL in brain tumor patients,

is being assessed prospectively in the institute. Unexpected complications or consequences of surgery affected the QOL of the patient as well as the surgeon, he mentioned.

QOL issues in children were discussed by Dr. Shoba Srinath, a child psychiatrist. These issues are somehow ignored in clinical and research practice. However, the newer developments in understanding QOL were highlighted. Measurements and Instruments were introduced and discussed by Dr. Prabha Chandra, a psychiatrist. The limitations of currently available scales were discussed. Also difficulties in adaptation to suit Indian setting was found to be complex. Later, Dr. Les Shter, a visiting orthopedic surgeon from UK made a brief presentation on QOL issues in rheumatology and orthopedics.

Lastly, QOL issues pertaining to renal disease, dialysis and transplantation, was presented by Dr. Anupam Kishore. QOL was better among patients receiving renal transplantation as compared to those on dialysis or conservative treatment. Dr. Kirthana gave a brief presentation on issues considered important for quality of life of alcoholics. They mentioned different themes as important for their quality of life, including peace of mind and peaceful co-existence at job and home.

The Workshop QOL was held on 14th December 1999. It began with seeking the issues related to QOL which the participants wanted addressed. This was followed by a description of common scales like the EQ-5D, WHOQOL, and FACT and the participants were encouraged to use these scales on themselves and score them. Two Scales on Spiritual QOL [FACIT-Sp and Beliefs & Systems Inventory] were also self administered and discussed. The Workshop was interactive with simultaneous discussion. It provided the participants an opportunity to familiarize themselves with some common measurement instruments. Certain cultural differences in assessment and interpretation of QOL came up for discussion. It was noted that there were no exact phrases in dif-

ferent Indian languages to describe the phrase quality of life, which was a major handicap in the translations and adaptations of QOL instruments for Indian settings.

In the end, three proposed studies on QOL in alcoholism, HIV, and caregivers of children with cerebral palsy were discussed. The Workshop ended with written feedback from the participants. Most participants reported their ignorance about QOL measures, though its importance in clinical practice and research was acknowledged by most. They wanted more time for the Workshop, and more such programs in future. The Workshop covered most common but difficult and practical aspects of QOL assessment. The participants were satisfied, and claimed to have learned from the lectures during the symposium and discussions during the workshop. Some were still unclear about the concept and measurement issues. The program was sponsored by NIMHANS and also by the Medical Education & Research Trust, Karnataka.

We need
volunteers
for the
Education
Committee.
Contact the
ISOQOL
office to get
involved!
Info@isoqol.org

NEWS OF MEMBERS

Editor's Note: This is a new column about ISOQOL members. It 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.

- **Robert Kaplan** has been named Editor-in-Chief of the Annals of Behavioral Medicine. He hopes to see more quality of life studies submitted to the journal.

- **Bryan Weber**, PhD candidate at Case Western Reserve University, who received the Year 2000 MNRS Dissertation Award, recently received the Bolton School Award. The award was given by the Midwest Nursing Research Society. Bryan also recently received a New Investigator Research Grant from the Oncology Nursing Foundation and the Rhone-Poulenc Rorer, Pharmaceuticals, Inc.

- **Peter Fayers**' and **David Machin**'s book on QOL has now been published by John Wiley & Sons and is in the bookshops. Quality of Life: Assessment, Analysis and Interpretation. Fayers PM, Machin D. John Wiley & Sons, Chichester (2000) ISBN: 0-471-96861-7 (hardback, 400 pages. £60) As implied by the title, it covers all aspects from development of new QOL instruments, validation of instruments, their use in clinical trials, analysis of the data, and presentation and interpretation of results.

- **Cindy Gross** has been promoted to Professor in the College of Pharmacy at the University of Minnesota.

- **Jim Shaw** was selected as the winner of the Best Overall Student Contribution at the ISPOR 2000 Annual Meeting for "Methods for comparing areas under receiver operating characteristic curves: application in screening for depression".

- Since October of 1999, **Geraldine Padilla** has been working for the American Cancer Society California Division as Vice President for Cancer

Control. Her responsibilities include administration of the day-to-day operation of the Cancer Control Department; evaluation of the department's programs including those programs that address Quality of Life; and planning, coordination and implementation of the Colorectal Cancer Initiative.

- Twenty five of the world's foremost experts on quality of life research will convene at Mayo in a state of the science think tank consensus meeting October 6-7, 2000. The goal of the meeting is to produce six manuscripts summarizing the research and presenting guidelines for assessing clinical significance of quality of life measures in oncology. The list of attendees includes QOL research pioneers **John Ware**, **David Cella**, **Neil Aaronson**, **David Osoba**, **Gordon Guyatt**, and **Donald Patrick**. Attendance for this meeting is closed, however, in 2001 Mayo will host a follow-up open registration meeting to disseminate the results of this year's meeting. Plans for the manuscripts produced include for them to be published as a series of papers in a leading journal and as a separate monograph. Primary funding for this meeting has been provided by a generous unrestricted grant from Pfizer, an R13 meeting grant from NCI.

CALENDAR OF EVENTS

- The Society for Medical Decision Making (SMDM) will hold its 22nd annual meeting in Cincinnati, Ohio from 24-27 September 2000.

- 7th Annual Conference of the International Society for Quality of Life Research ~ October 29-31, 2000 Vancouver, Canada Early registration deadline is August 18, 2000

- Pan-Pacific Conference ~ April 13-15, 2001 Tokyo, Japan

NEWS FROM UKRAINE

Dr. Svitlana Pkhidenko

The concept of Quality of Life (QoL) is a new one in Ukrainian medical practice and there is a strong need and interest among the clinicians to implement the standardized QoL instruments.

In 1997, Dniepropetrovsk Association for the Quality of Human Life (DAQHL) was founded. The main objective of our organization was to establish a Group of QoL researchers, especially in such areas of health status of population as the correlation between QoL of population and environmental conditions. Dniepropetrovsk Association for the Quality of Human Life (DAQHL) is a non-profit, voluntary, non-government organization operating in the field of health-related Quality of Life research.

The main objectives of the Dniepropetrovsk Association of the Quality of Human Life are as follows:

- Translation of the existing QoL instruments into the Ukrainian language, cultural adaptation, localization and validation of the existing QoL instruments.
- Elaboration of the national versions of the methods of QoL assessment.
- Scientific study Health Related Quality of life and QoL of the different social groups.
- Informational exchange, creation of the regional information bank of QoL.
- Establishment, development and support of international science and business contacts with the scientists who expressed interest in research of the quality of life in society and medical practice.

Since the moment of creation of our organization our association has collaborated with the International Society for the Quality of Life Research. Our association took part at the 4th Annual Conference of the International Society for the Quality of Life Research (November

5-8, 1997, Vienna, Austria).

DAQHL has translated the instrument of the World Health Organization - WHOQOL - 100 into Ukrainian in order to provide QoL research performance in Ukraine in accordance and compliance with the international standards. In 1999 our research team carried out the investigation of QoL in schizophrenia patients with WHOQOL-100.

At present we are taking part in the World Health Organization project for assessment of the Quality of Life in people living with HIV/AIDS. We have completed translation and back-translation of the WHOQOL-HIV module (instrument of the WHO for the assessment of the Quality of Life in the people living with HIV/AIDS), recruiting a sample of 300 individuals living with HIV/AIDS (100 symptomatic, 100 asymptomatic, and 100 AIDS-converted) in order to test the WHOQOL-HIV module. We are planning to hold a national meeting to review the results of this project in July 2000.

We are also at the planning stage of a joint project together with physicians from St. Petersburg (Russia) to study the correlation between the insight in the mentally ill and the quality of their life, as well as opportunities for their rehabilitation. We are going to establish a Ukrainian national QoL Center based on the grounds of our association.

For further information, please contact:

Svitlana Pkhidenko, MD, PhD
Head of Dniepropetrovsk Association
for the Quality of Human Life
4, Vysotsky St., Apt. 268
Dniepropetrovsk 49080 UKRAINE
Telephone: +38 (0562) 32 60 71
Email: svphid@pgasa.dp.ua

**If you have a colleague
that would be interested in
joining the Society, please
have them contact the Executive
Office at info@isoqol.org**

POSITION AVAILABLE

Research Faculty Position: The University of Massachusetts Medical School Department of Family Medicine & Community Health is recruiting an experienced social sciences or health services researcher at the Assistant/ Associate Professor level to join a growing research division focused on psychosocial factors in health, quality of life research in primary care, and community-based health services research on underserved populations. Individual will play an important role in collaborating with Departmental leadership to develop and establish a practice-based research network. Ideal candidate will have demonstrated success in obtaining extramural funding and track record of peer-reviewed publications. Candidate will be expected to conduct a program of independently-funded research and collaborate with other faculty. Start-up funding available. Contact: Carolyn Schwartz, Sc.D., carolyn.schwartz@umassmed.edu for full description.

ISOQOL Executive Office
ISOQOL is managed by Degnon Associates.

George K. Degnon, CAE,
Executive Director
Laura Degnon, Associate Director
Linda Kozlowski, Executive Assistant
Sarah-Jane Ziaya, Association Manager
6728 Old McLean Village Drive
McLean, VA 22101-3906 USA
PH: 703-556-9222
FAX: 703-556-8729
info@isoqol.org
Web Page: www.isoqol.org

**The ISOQOL Newsletter is published
three times a year by the
International Society for
Quality of Life Research with the
cooperation of Degnon Associates.**

Mirjam A.G. Sprangers, Ph.D.,
Newsletter Editor
Amsterdam, The Netherlands
m.a.sprangers@amc.uva.nl