



International Society for Quality of Life Research

Volume 6 Issue 2

Newsletter for ISOQOL Members

July 2001

PRESIDENT'S MESSAGE

*Ivan Barofsky, PhD
Sandwich, Massachusetts (USA)*

In the year 2000, the World Health Organization (WHO) issued a report that has broad implications and should be of interest to the members of ISOQOL. The report, entitled "The World Health Report 2000: Health Systems Improving Performance," is based on a conceptual framework formulated by Christopher Murray and Julio Frank. What this report does is to provide a ranking of the performance of the health systems in 191 countries. The model on which it is based includes measurements of the responsiveness of the health system (e.g., the average length of time to wait for an appointment), the stewardship of the health system (e.g., how well the political process provides for appropriate health-related policies), and financial fairness (what proportion of the gross national product is dedicated to health care). The major outcome measure is in terms of disability adjusted life years.

This research should be of interest to ISOQOL members for several reasons. First, because it represents a continuation of a history that started with Sullivan's efforts (1971) to create an index that combined mortality and morbidity data. Second, because the authors systematically reject self-reported data. They do this because they seriously question the comparability of cross-cultural self-reported data. A third implication of this work is that while they are measuring loss of function, they have not included some of the positive consequences of the health care system. Fourth is the fact that the authors of this report aggregate these fairly diverse measures into a

single summary measure (as Sullivan did) so that an index is available to compare different countries. The actual method used for performing this aggregation is not obvious from the text provided.

More recently, the Pan American Health Organization (PAHO) has reviewed the applicability of the WHO Report model to countries in the Americas. At this meeting, which was held in May, 2001, it became obvious that the WHO Report was a "work in progress." I had the opportunity of attending this meeting and a summary of the meeting will be available on the list serve. A reasonable conclusion from the PAHO meeting was that while the WHO effort was commendable, it was in fact competing with a number of alternative approaches and second, that more had to be done about addressing the basic research questions which the report had to confront and resolve in ways that remain a concern of various investigators in the field.

The members of ISOQOL pride themselves as being, as a group, the most knowledgeable and experienced in the area of health-related quality of life and health status assessment. In the WHO Report we are faced with a number of fundamental questions. First, how is it that you can compare the self-reports from persons of diverse cultures? This is a highly significant question which clearly is not going to have a rapid answer and one of the concerns with the WHO Report is that it has proceeded to the point of attempting to influence policy when in fact the scientific foundation upon which the index was created may be considered limited.

What is also clear is that the investigators of this report have created

significant new research opportunities in that they have identified concepts such as stewardship, financial fairness, and responsiveness which offer opportunities for measurement. Finally, the most important research issue is the aggregation and creation of an index. How does one take the diverse measures from the WHO measure and combine them in a meaningful manner and what does this mean as a function of the 191 cultures? Is weighting of an index of this sort that may be characteristic for all 191 countries also applicable to individual countries which have different political systems?

(continued on page 2)

New ISOQOL Leadership Elected

Thanks for sending in your vote.
See story, page 2.

ISOQOL Conference November 7-10, 2001 Amsterdam, The Netherlands

*CALL FOR LATE-BREAKER
POSTER ABSTRACTS!!!*

See Details on Page 5

- July 30, 2001 ~ Early registration deadline

Link to more information and to register through the ISOQOL website at www.isoqol.org.



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ISOQOL 2001 ELECTIONS: PROCESS AND RESULTS

*Sharon Wood-Dauphinee, PhD
Past President
Montreal, Quebec (Canada)*

In line with ISOQOL's mission to foster a worldwide exchange of information associated with the study of quality of life relevant to health and health care, the Nominations Committee (Peter Fayers, UK; Donald Patrick, USA and Sharon Wood Dauphinee, Canada) presented a slate of highly qualified nominees from around the world.

The ballot, which was distributed to members, listed individuals from Australia, France, Germany, the Netherlands, the UK and the USA. Each nominee provided a biographical sketch highlighting his/her areas of professional interest and expertise as well as the reasons for wishing to be more closely involved in ISOQOL activities.

We are indeed fortunate as a Society to have so many experienced individuals who are members of the Society and who are prepared to devote time and energy to meeting the Society's goals.

The Nominations Committee wishes to extend its thanks to all those who participated in the election, and to congratulate the new members of the Board, Madeleine King of Australia and John Ware of the United States, as well as our incoming President Elect, Mirjam Sprangers of The Netherlands. Mirjam is currently a Member of the Board and Co-Chair of this year's Annual Meeting in Amsterdam. She will assume her new position this fall at the Annual Meeting. Madeleine and John will join the Board at this meeting for a three-year term, and participate among the leadership of ISOQOL. We look forward to their input.

The Nominations Committee would also like to thank all those members who took time to vote in this Election. It is very important to participate in selecting those who will work to further develop the Society.

Important 2001 Annual Meeting Dates:

- July 30, 2001 ~ Presenter Confirmation Due; Early Registration Deadline
- August 31, 2001 ~ Late-Breaker Call-for-abstracts deadline

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PRESIDENT'S MESSAGE

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Overall, the WHO Report is a wonderful challenge both from the measurement and conceptual perspectives for ISOQOL members. It also highlights one of the opportunities that ISOQOL members have which is involvement in population-based measures of health-related quality of life. This is an additional venue of activity that expands our work beyond disease-specific and treatment-development measurement opportunities. However, it is only one of several contexts for which health-related quality of life assessments can be of value and I would include institutional evaluation as well. Thus, the quality of life consequences that an institution can create (e.g., prisons, long-term care facilities, etc.) should also be measured and considered of interest to ISOQOL members.

As you would expect, an attempt by the investigators from the WHO to solve practical problems (e.g., measuring the performances of health care systems) strains and stresses the science upon which this measurement is based. We are currently going through this period relative to a number of issues, but in particular relative to the creation of summary measures or indexes. We have responded extremely well in the past to similar challenges and there is no a priori reason to believe we will not under the current circumstances.

A BRIEF REPORT OF THE ACTIVITIES OF THE PRO HARMONIZATION GROUP

Catherine Acquadro, MD
Lyon, France

Important Issues in Patient Reported Outcomes (PROs) Research

Starting year 2000, a harmonization project brought together members of ERIQA*, ISOQOL, ISPOR*, PhRMA HOC*, and the United States Food and Drug Administration (FDA) observers at the occasion of three meetings, to focus on issues related to Health-Related Quality of Life (HRQL) outcomes (first 2 meetings) and Patient-Reported Outcomes (PROs) (third meeting):

- March 31st, 2000 in Pentagon City, VA (see report at <http://www.mapi-research-inst.com/research/report.pdf>)
- September 14th, 2000, in Rockville, MD: one of the conclusions from the second meeting was to continue discussing issues related to outcomes research under the coordination of a Committee of representatives from each organization and the FDA.
- February 16th, 2001 meeting, in Rockville, MD: the purpose of the Program was to continue to clarify aspects and components of PROs evaluations, specifically to discuss the added value of this outcome, as it relates to patients, as well as to suggest use of this information within labeling and promotional claims. This meeting was organized in collaboration with Laurie Burke (FDA/Center For Drug Evaluation and Research (CDER)/Division of Drug Marketing, Advertising, and Communications (DDMAC), and in agreement with Dr Robert Temple, Director of Office of Medical Policy, and of Drug Evaluation I (FDA/CDER). Sixty persons attended (including 30 FDA representatives).

Four key issues were addressed. Each of them involved a group leader who

coordinated the development of the argument: Group 1: Conceptual and Definitional Issues; Group 2: The Value of Patient Reported Outcomes; Group 3: Methodological Considerations in Obtaining Patient Reported Outcomes in Clinical Trials; Group 4: Interest in and Demand for Patient Reported Outcomes.

Each issue raised generated a lot of discussion and interest. On a general perspective, the interest of including PROs (such as global impression, functional status, well-being, symptoms, HRQL, satisfaction with treatment) in clinical trials was recognized as adding value for decision-making, although further research in this area is needed. It was also stated that FDA guidance on PROs Issues is not to be planned in the short term. In conclusion, many participants saw the meeting as a turning point and an encouraging sign for the future of the field.

To follow up, FDA has continued the discussion internally (April 30th, 2001), and has clarified the issues needing solutions. It was agreed to move forward on these issues with representatives of ERIQA, ISOQOL, ISPOR and PhRMA HOC.

Following the FDA discussion, and at the occasion of the ISPOR meeting in May 2001, the creation of the PRO Harmonization Group has been made official. ERIQA, ISOQOL, PhRMA HOC and ISPOR will support the future activities of the group.**

Two Projects were suggested:

1. The production of a manuscript based on the February 16th meeting;
2. The organization of a 4th harmonization meeting in closer collaboration with the FDA (as FDA agents have been assigned to each new working group).

Four issues, meeting FDA's concerns, have been identified:

- Instrument development: what are the standards?

- Instrument selection: demonstrating hypothesis, relationships to measurement.

- Statistical issues: focus on handling missing data.

- Interpretation: interpreting changes that are not consistent between outcomes.

A working group will develop each, and present the outcomes to an audience composed of FDA agents, and members of the PRO Harmonization Group. Both projects have been launched and will meet completion by next fall. For more information, please contact: Dr. Catherine Acquadro, Mapi Research Institute, Lyon, France, cacquadro@mapi.fr.

*ERIQA: European Regulatory Issues on Quality of Life Assessment, *ISPOR: International Society for Pharmacoeconomics and Outcomes Research; *PhRMA HOC: Health Outcomes Committee of Pharmaceutical Research and Manufacturers of America.

** Contribution ISPOR to be confirmed.

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 or telephone 703-556-9222 (USA).

GUEST COLUMN: DEFINING ISOQOL'S ROLE IN THE HRQL ARENA

John E. Ware, Jr., PhD
Lincoln, Rhode Island (USA)

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.*

I feel very pleased and honored to have been elected to work with the members of ISOQOL as a member of our Board. When we meet in Amsterdam this fall, it will have been four years since I founded QualityMetric (QM), a for-profit health care information technology company. During those years, I've learned a lot about the relationship between business and science and I have had the opportunity to work with every segment of the health care industry.

Being in a very scientifically oriented corporation, QualityMetric, with a strong affiliation with the not-for-profit Health Assessment Lab (HAL), which I also direct, has made things a lot easier. In addition to making it possible to get things done, this diversity of perspectives has also helped me to better appreciate the importance and timeliness of both "public" and "private" solutions to the problems of health care research worldwide. When business and academic-based science both are handled well, the synergy is tremendous. I hope that I can help ISOQOL open its doors wider to our potential partners in the business community to the benefit of all.

I would like ISOQOL to consider taking a more active leadership role in defining

health and quality of life concepts internationally and in setting the standards that we apply in improving our measures of those important concepts. As those in the quality improvement (QI) field remind us often, to manage health care we must first measure it. Shouldn't we also "cast a much wider net" beyond health care? Can't we accomplish many of our objectives by working outside the health care system? To what extent is disability a reflection of the environment? What are the most mutable determinants of HRQL?

I am still an academic at heart and I teach regularly. Trying to figure out how to explain to others our science and its practical applications for health care is a big part of my discovery process. I highly recommend it. Within ISOQOL we have tremendous, and growing, expertise and experience in both the qualitative and quantitative methods of HRQL research. By sharing what we know more widely, we will advance more rapidly and be able to develop and implement our applications in practice much sooner. These are issues of dissemination, education and diffusion of technology. Should we expand and leverage ISOQOL's education and training programs even further with the goal of raising more funds to support ISOQOL's programs?

We also have the opportunity to help consumers take control of decision-making in health care. When they do, health care will never again be the same, for the better. For starters, ISOQOL can help make sure that the benefits of health care are well defined and soundly measured in terms of HRQL. Should we also be more proactive in supporting the consumer movement worldwide? Should we more aggressively take what we are learning to the forums where the problems of world health are being debated often with only the "filtered" voices of the public? What about other strategies? Is it enough to represent consumers in focus groups only in our research projects? Shouldn't we also give them a seat at our table when we meet annually and in between? Again,

empowering people and giving them more information are among the best things ISOQOL can do for people worldwide.

As I said in the last issue of this newsletter, ISOQOL is rich in the diversity of interests and the skills of its members. They have impressed me on many occasions with their sincerity and motivation and with the richness of their understanding of what quality means in life throughout the world. I imagine us, both young and old, sitting on one side of a very large table. On the other side I see those responsible for delivering health care services, including many who need to be reminded about the consumer-defined health benefit and the more general improvement in quality of consumer life that they should be trying to produce for the populations they serve. In between, I see the many advances in information technology and other potential solutions that are at our fingertips. It's a great time to be the society promoting the rigorous investigation of HRQL, with a strong commitment to taking what it learns to application and practice!

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

BROCHURES AND SLIDE HELP YOU PROMOTE ISOQOL

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

CALL FOR “LATE BREAKER” POSTER ABSTRACTS!!!”

*ISOQOL 2001, November 7-10
Amsterdam, The Netherlands
Submit By: August 31, 2001*

This year’s scientific program introduces an innovation aimed to assist the dissemination of late-breaking research findings. The main conference call produced a huge response of high quality abstracts from which the Scientific Committee has selected the best for podium presentations and poster sessions. However, there are inevitably circumstances where data analysis is completed after the deadline for abstract submission and it is with this in mind that a second call for abstracts is now being made. This second call is intended to cover quite specific cases where new, late-breaking research is involved.

The features of this second call are as follows :

- Abstracts will only be considered for poster presentation
- Accepted abstracts will **not** appear in the Conference edition of *Quality of Life Research* but will be printed for separate distribution at the meeting
- Authors will need to provide a brief letter to the Scientific Committee in support of their claim for late-breaker status.

For more information, visit the ISOQOL website at www.isoqol.org.

PAN PACIFIC CONFERENCE REPORT

*Shunichi Fukuhara, MD, MSc
Kyoto, Japan*

The first Pan-Pacific Conference of ISOQOL was held April 13-15 in Tokyo, and was chaired by Shunichi Fukuhara (ISOQOL Board Member) and Kiyoshi Kurokawa. The ISOQOL official liaison was Neil Aaronson.

More than 100 abstracts were submitted for presentation. They were

anonymously reviewed by international leaders in HRQL research, and the best 26 were printed in the official journal of ISOQOL, *Quality of Life Research*, copies of which were distributed to all attendees.

More than 400 people attended. The majority of the attendees came from Japan; simultaneous interpretation between English and Japanese was provided at many sessions. Other Asian participants came from Taiwan, Singapore, Hong Kong, China, the Philippines, Indonesia, and Australia. Participants also came from outside Asia: France, Canada, the USA, the UK, and the Russian Federation.

Day one: At the opening ceremony, addresses were given by a representative from Japan’s Ministry of Health, Welfare, and Labor, and by the conference organizers. There were six oral presentation sessions chaired by international leaders in HRQL research. These sessions were well attended and the audiences participated actively in the discussions. A panel discussion on HRQL as an end-point in clinical trials featured speakers from academia, the pharmaceutical industry, and regulatory agencies in Japan, the USA, and the European Union (EU), along with commentary by Lee Goldman, Chair of the Department of Medicine at University of California, San Francisco. Current issues regarding guidelines, policies, and methodology were discussed.

Day two: Excellent plenary lectures were delivered by John Ware and John Brazier. A special lecture was given by Lee Goldman on HRQL as one of the most important patient-based outcomes in contemporary outcomes research. The day also included Training Workshops on generic scales and disease-specific scales (SF-36, KDQOL), and on measures for COPD and cancer, Symposia (disabled persons, nursing, patient’s safety) and Satellite Symposia (incontinence, prostate cancer, inflammatory bowel disease, dementia, asthma).

Day three: The Pan-Pacific Forum on issues in HRQL research was a highlight of the conference. It was chaired by Chitr Sitthi-amorn, Dean of the College of Public Health at Chulalongkorn University, Thailand, and by Cindy Lam from the University of Hong Kong. Speakers from Thailand, Hong Kong, Korea, and Singapore gave presentations on current issues in HRQL research unique to the Pan-Pacific region; the invited commentator was Ron Hays of University of California, Los Angeles (UCLA). Active discussion including the speakers and the commentator, and the audience followed the formal presentations.

Seven researchers from developing countries in Asia who presented their work at the conference each received an “Asia Travel Award” (a cash award of 50,000 yen). The young investigator awards were given to Shinji Matsumura (Japan) and Yi-Ping Lin (Taiwan) and the award for the best poster was given to Andera Shreiner (Japan).

THE ISOQOL LIST SERVE: A VALUABLE NEW MEMBER BENEFIT!

The ISOQOL e-mail list serve is officially available for networking by members. Perhaps you have received a few e-mail messages sent to all ISOQOL members, or are interested in sending a message that you would like all members to receive. Messages may include subjects such as interest in project collaboration, requests for HRQL-related information or research results, job opportunities, or other appropriate announcements. If interested, ISOQOL members may send e-mails to be posted on the list serve to info@isoqol.org.

FINANCIAL STATUS OF ISOQOL: DOING WELL AND GETTING BETTER

*Dennis Revicki, PhD
Secretary/Treasurer
Bethesda, Maryland (USA)*

ISOQOL is successful as an organization both in terms of scientific quality and financial resources. Over the last three years the financial viability of ISOQOL has steadily improved to a level where we have sufficient funds to support the society and in time support new initiatives. This improvement in financial resources is directly attributable to the success of the Baltimore, Barcelona and Vancouver annual meetings and the success of several training workshops sponsored by ISOQOL. We have also conducted successful fundraising with the pharmaceutical industry and other health outcomes organizations. In addition, we have successfully negotiated an agreement with Kluwer for the society to receive revenues from subscriptions to *Quality of Life Research*. Thanks to everyone who helped make the annual meetings and workshops a success and to those organizations providing needed monetary support.

Although the financial security of ISOQOL is much more secure, we still have the need for support beyond that provided by individual memberships and journal revenue. We are continuing our efforts at fundraising from industry and other sources. We have also initiated institutional memberships in ISOQOL. Institutional memberships are possible for universities, health outcome research organizations, and healthcare organizations. Check out the ISOQOL website for information about institutional memberships and related benefits. I am happy to announce that we already have two institutional members, Abbott Laboratories (Research Institution) and AstraZeneca (Corporate).

Since ISOQOL is now registered as a non-profit organization in the United

States, we are exploring applying for grants from USA federal agencies and foundations for the support of different initiatives and meetings. I will be coordinating these activities over the next year and welcome volunteers from the ISOQOL membership to assist in identifying foundations and other sources of funding support and to prepare grant applications.

Interested members can contact me through the ISOQOL office or by email at revicki@medtap.com. We have a financially viable organization because of the efforts of a number of ISOQOL members and this financial viability will help ISOQOL continue the scientific and health policy activities that we are involved with now and in the future.

I HAVE SEEN THE FUTURE OF ISOQOL, AND IT IS ELECTRONIC!

*Albert Wu, MD, MPH
Chair, Electronic Communications Task Force
Bethesda, Maryland (USA)*

The ISOQOL website (www.isoqol.org) is of central and growing importance to the Society's success in serving its members and the community at large. Since its start a little over two years ago, under the wise stewardship of Diane Fairclough the ISOQOL Website has grown in size and functionality.

To date, usage of the site has been highest around our scientific meeting. This spring the electronic abstract submission process went exceptionally smoothly, making us wonder how we ever could have done it any other way. On-line registration is also up and running for our upcoming Annual Meeting in Amsterdam.

Members Only. As a service to our members, and as an incentive to others to join the Society, we have begun to offer a "members only" section of the website. At the moment, its sole offering is access to the current membership list, but long-term plans call for additional useful resource items to assist members, including the goals of the Electronic

Communications Task Force outlined later in this article.

Reaching the 'members only' section on the website is easy for members. The username is simply the first letter of the first name, followed immediately by the entire last name, with no spaces between. The password is the member's id number, sent in a letter to all members early last Fall, 2000, included in all new-member welcome letters, and also maintained on the database in the ISOQOL Central Office. If you have forgotten your member id number, you can contact the Central Office via e-mail at info@isoqol.org with a request for this number.

List serve. I have now taken up the responsibility for the website, as well as the latest addition to our electronic family, the list serve. Perhaps many members might recognize the effect of this service on the Society — because information in the "Member News" section of the newsletter is solicited via this electronic means. For those of you who question our spelling or are otherwise unfamiliar with the concept, the list serve is an electronic mailing list that allows messages to be posted to all who subscribe. Have a burning question? Post a query to the list, and get responses from fellow members. Have an announcement? Post it on the list for rapid dissemination to a relevant audience. Have a topic for discussion? Post it to the list and see what others think. Right now, the list is sent to all current members. If you want to post a message, or want to unsubscribe, send an e-mail request to info@isoqol.org.

Website Features. We would like to see the website be "The Place" where people go when they are interested in issues related to HRQL. Thus, we would like to develop other useful and attractive features. One example would be an expanded members list, perhaps a list of "experts" who could be queried about specific issues; another would be a repository for important documents. Still another would be as the jumping off point to other related sites.

(continued on page 9)

REPORT ON THE 1st INTERNATIONAL SYMPOSIUM ON HRQL AND PHARMACOECONOMICS, APRIL, 2001 IN ARGENTINA

*D. Rex Billington, PhD
Auckland, New Zealand*

Don't cry for HRQL in Argentina

The truth is, its really thriving

All through the seven years

Of its existence

It's made an impact

Don't keep your distance.

(apologies to Rice and Lloyd-Weber)

A symposium on health-related quality of life (HRQL) was held April 5th and 6th 2001, in Buenos Aires, Argentina, hosted by the Fundacion Fundonar, an oncology foundation based in La Plata, Argentina, that has been instrumental in the promotion of quality of life assessment and research since the early 1990s. A primary objective of the Foundation and for the symposium is/ was to promote the education and training of health care professionals and associated disciplines in the evaluation of quality of life and to integrate this knowledge into different disciplines of clinical care and public health planning.

The Executive Director of the Foundation, Dr. Silvia Bonicatto, and her team have been conducting high quality HRQL research for several years. Their work has expanded beyond the original applications to improving cancer care into other areas of health concern, including heart disease, mental health, and health service applications. The Foundation has collaborated with other countries and international partners in the development, adaptation and translation of a variety of HRQL instruments.

This symposium was the first of its kind to bring experts to Argentina to discuss international developments in QOL assessment, probably the first conference in Latin America. There were 386 national participants consisting of physicians, psychologists, sociologists,

health service administrators, epidemiologists, health care auxiliaries, social workers, pharmacists and representatives from the pharmaceutical industry. International participants came from Canada, Japan, Uruguay, USA, Chile, New Zealand, Puerto Rico, Brazil, and Austria. Speakers included the ISOQOL experts Rick Berzon, Monika Bullinger, David Osoba, Donald Patrick and Dennis Revicki, as well as Mary Amanda Dew, Elizabeth Hahn, Oscar Lopez (formerly of Argentina), and Rex Billington, formerly of the World Health Organization (WHO) and one of the keynote speakers.

The program addressed basic concepts in HRQL measurement, general methods in the design and adaptation of instruments and applications of HRQL to different aspects of clinical care. The presentations were made in English with excellent instant translation into Spanish in a local dialect. A panel discussion was the final item on the agenda. It was conducted in Spanish and chaired by Dr. Bonicatto. And, what a useful exercise the panel discussion turned out to be. It provided an opportunity for senior health officials and decision makers in Argentina to say what they thought about the place of HRQL in health assessment and as a goal of medicine. Representatives came from the drug licensing authority, the pharmaceutical industry, the presidency of the Argentina Medical Association, the medical director of a health maintenance organization (HMO) and a WHO health planner/consultant involved in healthcare system (HS) reform in Argentina. They gave a variety of viewpoints about the place of HRQL in medicine. All recognized HRQL as a major outcome of health care. Several spoke of the barriers to realizing this goal including intransigence and ignorance at all levels of the health service that needed to be overcome. Of particular interest was the importance attached to HRQL criteria by the national drug regulatory authority for the approval of medicines in Argentina. They stressed the need for valid high quality HRQL instruments to compliment the accepted measures of toxicity and economics.

This requirement has of course been voiced by drug regulators in other countries.

A new national association of researchers interested in HRQL research in Argentina will be formed as an outcome of the meeting. The symposium confirmed not only a national interest in HRQL assessment and studies but that Argentina is a leader in HRQL studies in Latin America.

The organizers are to be both complimented and thanked for arranging such a full, yet varied and relevant symposium. I hope it will be emulated by other countries of Latin America in the near future with or without the tango entertainment.

November 7-10, 2001

Annual Meeting

Early Registration

July 30, 2001

www.isoqol.org

JOIN AN ISOQOL COMMITTEE TODAY!

Interested in Participating more actively in ISOQOL? Opportunities to make change happen within the Society abound.

Visit the ISOQOL website, www.isoqol.org, click on the "ISOQOL Committees" button, and click on committee chairs' names to contact them via e-mail and express your interest today!

ISOQOL WELCOMES
NEW MEMBERS SINCE
February 15, 2001

Puree Anantachoti

University of Minnesota
Minneapolis MN USA

Ceser Armoza PhD

Holistic Center & Presbyterian Columbia Hospital, Great Neck NY USA

Waldo Belloso MD

Hospital Italiano de Buenos Aires
Buenos Aires Argentina

Ahmad Fadzil Bin Abdullah MBBS

International Islamic University Malaysia Kuantan, Pahang Malaysia

Annabel Bowden BSC

London School of Hygiene and Tropical Medicine, London UK

Ezequiel Consiglio PhD

Universidad de Buenos Aires
Buenos Aires Argentina

Ann Cull PhD

Imperial Cancer Research Fund
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Michael Curran

Curran Partners, Inc., Stamford CT USA

Juan Jose Dapuelto MD

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Mayo Clinic and Foundation
Rochester MN USA

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Mount Sinai School of Medicine
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Nakako Fujiwara MD

Nagoya City University School of Nursing, Nagoya Japan

Yoko Goto PhD

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Gordon Guyatt MD, FRCP

McMaster University Health Sciences Centre Hamilton ON Canada

Magdalena Halim Atmajay

Catholic University Jakarta
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Institute of Life Sciences, Taipei Taiwan

David Latini PhD, UCSF

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Silapakorn University Nakorn
Pathom Thailand

Kurt Lucas

Schering Canada Inc.
Pointe Claire PQ Canada

Isabelle Mear

Mapi Research Institute, Lyon France

Michael Molla PhD

National Center for Health Statistics
Bethesda MD USA

Masako Morikawa PhD

Toyko University of Pharmacy and Life Science, Tokyo Japan

Geoff Norman PhD

McMaster University, Hamilton ON
Canada

Nutjaree Pratheepawanit PharmD, PhD

Khon Kwen University
Khon Kaen Thailand

Mike Robling

Llanedeyrn Health Centre Maelfa
Cardiff UK

Oswaldo Rodrigues

Dos Santos Leccia, Barcarena Portugal

Bae Sang-Cheol MD, PhD, MDM

Hanyang University, Seoul Korea

Fu-Jin Shih RN, DNSc

National Taiwan University
Tapei Taiwan

Hashimoto Shiori PhD

Tokyo Women's Hospital University
Shihjuka, Tokyo Japan

Javier Soto MD

Pharmacia Spain SA, Madrid Spain

Toshiko Tada PhD, RN, PhD

The University of Tokushima
Tokushima Japan

Tomoko Takayama MSc

University of Tokyo, Bunkyo-ku Japan

Gunnel Ragnarson Tennvall PhD

The Swedish Institute for Health Economics (IHE), Lund Sweden

Melvin Toh MBBS

Pharmacia Corporation, Singapore

Lijiljana Trajanovic

Clinic for Mental Health Protection
Serbia Yugoslavia

D. S. Tulsy PhD

Kessler Medical Rehabilitation Research & Ed. Corp. West Orange NJ USA

Jung-Der Wang MD, ScD

Institute of Occupational and Industrial Hygiene
Taipei Taiwan

Yoshiyuki Wantanabe MD, PhD

Kyoto Pref. University of Medicine
Kyoto Japan

Ellick Wong PhD

Pharmacia Corporation, Singapore

ADVERTISEMENTS
POSITIONS AVAILABLE

The American Cancer Society's National Home Office in Atlanta, GA (USA) announces a position as *Director, Quality of Life Science* for an individual with expertise and 3-5 years exp. in science-based QOL issues. Doctoral degree, demonstrated publication record, and good management, interpersonal, and oral and written comm. skills. To learn more, please contact Thomas J. Glynn, PhD at 202-661-5737 or tglynn1@cancer.org.

Global Health Economics Manager (The Netherlands): for Global team at corp. hq, NV Organon, European-research based pharm. co., part of AKZO-Nobel. Proven record in health econ./outcomes research; pharmacist, medic or life scientist with exp. in drug developm. or mktg./sales; business acumen; pricing exp. plus. Annoesjka Novak: a.novak@organon.oss.akzonobel.nl.

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.

As of July 1, **Carola Bardage PhD** (Sweden) will now be located at the Department of Medical Epidemiology, Karolinska Institute, Box 281, S-171 77 Stockholm, Sweden; E-mail: Carola.Bardage@mep.ki.se

Silvia Bonicatto, MD (Argentina) informs that on May 30th the Sociedad Argentina de Farmacoeconomía y Evaluación de Resultados en Salud (SAFERS) was created. This translates in English to the Argentine Society of Pharmacoeconomics and Health Outcomes. President is Silvia Bonicatto, MD; Vice President is Hector Darbon, MD. E-mail for the Society is: safers@netverk.com.ar.

Marie-Pierre Emery MSc (France) announces the new Mapi Research Institute website: www.mapi-research-inst.com, to provide and disseminate information on health outcomes and HRQL issues, including events, publications, and last minute news. For more information or to contribute, contact Marie Pierre Emery at mpemery@mapi.fr.

Roger W. Evans PhD (USA) has recently embarked on a private consulting practice in Rochester, MN. His consulting activities continue to focus on all aspects of organ transplantation, technology assessment, coverage and reimbursement policy, and the uninsured. He is also involved in the development of clinical and health services research programs, as well as centers of excellence for health care services.

Cynthia Gross PhD (USA) will be taking a sabbatical from the University of Minnesota this coming year to be a visiting professor with the Dept. of Nursing at the Karolinska Institute in Stockholm (Sweden) and to work with

HRQL researchers at Uppsala University. Her hosts will be Regina Wredling and Lena Ring.

Taketoshi Matsumoto MD (Japan) is now in a new position at Musasigaoka Hospital in Kumamoto 7-15-1 Kusunoki Kumamoto-shi, Kumamoto-ken 862-8003, JAPAN; telephone: 81-96-339-1161 fax 81-96-339-4717; e-mail: tsmatsum@nifty.com.

Geraldine Padilla, PhD (USA) announces that she will be leaving the American Cancer Society, California Division July 31, 2001, for a new position as Professor and Associate Dean for Research at the University of California San Francisco School of Nursing in October 2001.

Marcie Parker PhD, CFLE (USA), Senior Qualitative Researcher with Optum in Minnesota, announces that she will present a series of papers: "The Impact of Alzheimer's Disease on the Workplace: Quality of Life and Costs," [with Sean McNattin], at The 10th National Alzheimer's Disease Education Conference in July in Chicago, IL (USA); "A Workplace Model That Has Demonstrated Success in Assisting Employees with Domestic Abuse Issues," in Sept. at The Nursing Network on Violence Against Women International Conference in Madison WI (USA); "Caring for Chronically Ill Children: The Case of Tuberculous Sclerosis Complex," in The National Council on Family Relations Report [June 2001]; and "Job Stress Calls in Call Centers of a large healthcare firm: who calls and why and what is the outcome of these calls," [with Sean McNattin] in the next International Stress Management Association newsletter.

In April, **Luis Prieto PhD** (Spain) joined Eli Lilly and Company at the Spanish affiliate in Madrid, Spain as Health Outcomes Scientist, Clinical Research Department.

June 19, **Kjell Reichenberg MD** (Sweden) successfully defended a thesis for the doctorate of public health at the Nordic School of Public Health in Göteborg, Sweden, entitled "Children with Asthma and their Families: Coping,

Adjustment and Quality of Life." It can be read at the web-site www.allergi.org.

George Sillup PhD (USA) announces that since January 1999, Daemion House has used the SF-36 instrument to determine the progress made by its clients. This self-administered quality of life assessment enables clients to report opinions about their physical and emotional well-being. Daemion House uses these "quantifiable" clients' assessments as a guide to the goals and treatment plans for further therapy.

Follow-up to Daemion House's presentation of results at the 2000 ISOQOL Meeting, Daemion House has used the SF-36 with 250 clients to date. The SF-36 results continue to help therapists determine whether a client is improving with therapy. Furthermore, the SF-36 results are especially helpful to therapists when they need to convince clients to speak to their doctors about the possible use of prescription drugs to treat depression and anxiety. For additional information, please contact his colleague, Mary Buggy, via telephone (610-647-1431) or e-mail (DaemionHouse@aol.com).

ELECTRONIC

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The Electronic Communications Task Force has been convened. So far, Task Force members have outlined a number of goals for 2001, including: 1) increasing use of the list serve, 2) developing a bank of articles and resources for the website, including links to other sites, and 3) developing policies for what ISOQOL should be posting, to whom we should be linking, and what services should be provided to members only. If you are indeed interested in working on these issues, or in offering suggestions for the direction and development of electronic communications to ISOQOL members, please send me a message to let me know: awu@jhsph.edu. Once you have all identified yourselves, our next step will be to generate a list of essential articles and resources, and useful sites with whom we should develop reciprocal links. See you on-line!

8th ISOQOL Annual Meeting

November 7-10, 2001, Amsterdam, The Netherlands.

Co-Chairs: Neil Aaronson, PhD and Mirjam Sprangers, PhD

Register before July 30 on the ISOQOL website and save! www.isoqol.org



Confirmed Speakers:

Breakfast Meetings: Current Issues in QOL Measurement: Differing Perspectives (two concurrent sessions each day)

I. Thursday morning

A. David Feeny (Canada) and Paul Kind (UK), Different Utility Approaches such as the HUI versus EQ-5D

B. John Ware (USA) and Gordon Guyatt (USA), Issues around the Use of Generic versus Disease-specific HRQL Questionnaires

II. Friday morning

A. Geoff Norman (Canada) and David Osoba (Canada), Approaches to Determine Distribution versus Anchor-based Clinical Meaningfulness

B. Diane Fairclough (USA) and Koos Zwinderman (NL), Approaches to Dealing with Missing Data in Longitudinal HRQL Investigations

Plenary and Special Multi-Speaker Sessions:

I. Plenary Sessions

A. HRQL in Daily Clinical Practice: **Michael Baum (UK) and John Ware (USA)**, Chair: **Neil Aaronson (NL)**

B. HRQL and Mental Health: **Hans Ormel (NL) and George Awad (USA)**, Chair: **William Lenderking (USA)**

C. Psychosocial Modeling of HRQL Outcomes: **Susan Folkman (USA) and Hannah McGee (Ireland)**, Chair: **Carolyn Schwartz (USA)**

D. HRQL, Happiness and Social Indicators Research: **Ruut Veenhoven (NL) and Alex Michalos (USA)**, Chair: **Mirjam Sprangers (NL)**

II. Special Multi-Speaker Sessions

A. Clinical Significance of HRQL Outcomes, Chair: **Jeff Sloan (USA)**

Presenters: Gordon Guyatt: Methods Used to Date for Clinical Significance, **Monika Bullinger:** Group versus Individual Clinical Significance Differences, **Jeff Sloan:** Single Item versus Summated Scale Scores, **Marlene Frost:** Patient versus Clinician versus Population Perspective of Clinical Significance, **Mirjam Sprangers:** Assessing Changes over Time, **Tara Symonds:** Practical Considerations for Specific Audiences

B. HRQL in Ethnic Minority Cancer Populations, Chair: **Claudette Varricchio (USA)**

Presenters: Carolyn Gotay: QoL Assessment in Cancer Patients of Asian, Pacific Islander and European Ancestry, **Carol Ferrans:** QoL Index for Black and Hispanic Patients, **Frank Baker:** Measuring the QoL of Culturally Diverse Cancer Survivors, **Carol Moinpour:** Using Structural Equation Modeling to Test Measurement Equivalence of English and Spanish Questionnaires, **David Cella:** An Item Response Theory (IRT) Based Approach to Evaluating QoL Measurement Equivalence Across Languages, Cultures and Literacy Levels

C. HRQL and the Cognitive Sciences, Chair: **Ivan Barofsky (USA)**

Presenters: Keith Meadows: Applying Cognitive Aspects of Survey Methods (CASM) to Health-Related Quality of Life Assessment: The Hull Meeting, **Jennifer Madans:** The History and Use of the Single, Self-Assessed Health Status Item in Health Surveys and Clinical Applications, **Debbie Collins:** Cognitive Interviewing: Methods and Analysis of Data, **Ivan Barofsky:** The Cognitive Interviewing/Self-Assessed Health Status Protocol: Draft Protocol

D. Summary Measures of Population Health: Design and Applications, Chair: **David Feeny (Canada)**

Presenters: David Feeny: Designing Preference-Based Summary Measures of Population Health, **Jean-Marie Berthelot:** Using Summary Measures of Population Health to Make Comparisons Across Time and Space: Results from Population Health Surveys in Canada, **Colin D. Mathers, Chris J. L. Murray, Ajay Tandon, and Josh Salomon:** New Methods for Improving the Cross-Population Comparability of Health Status Data for Summary Measures of Population Health. **Discussant: Donald L. Patrick**



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MAILING LIST OPTIONS: LETTER ENCLOSED WITH THIS ISSUE

The Board of Directors has agreed to lease the ISOQOL mailing list to outside sources. Please take a moment to review the notice included in this issue, and return the completed form to the ISOQOL executive office if you wish for your name to be removed from this list.

PRESIDENT'S AWARD: NEW IN 2001

New in 2001, The President's Award will be 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 will be selected by the ISOQOL Executive Committee and approved by the Board of Directors. It will consist of a plaque, a \$1000 honorarium and up to \$1000 in travel expenses if they plan to attend this year's Annual Conference in Amsterdam in November. All nominations for this award were submitted by the deadline June 30 and the recipient will be announced at the Annual Conference. If you have any questions regarding the President's Award, or would like information about how to nominate individuals to receive this award in future years, 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 the Executive Office at info@isoqol.org

ISOQOL 2001 ~ 8th ANNUAL MEETING UPDATE~ Amsterdam, The Netherlands; November 7-10, 2001

*Neil Aaronson, PhD and Mirjam Sprangers, PhD
Co-Chairs, 8th Annual Conference
Amsterdam, The Netherlands*

By now, acceptance letters have been mailed to all applicants whose abstracts have been chosen for presentation at the 2001 ISOQOL Annual Conference in Amsterdam. One-hundred twenty-five abstracts have been allocated for oral presentation, 75 for poster discussion

and close to 300 for poster display. The 2001 program committee members express that they were delighted to receive such a large number of high-quality abstracts. All participation in this program is greatly appreciated.



Several members of the 2001 Annual Conference Committee meet in Amsterdam: left to right: Paul Kind, Mirjam Sprangers, Neil Aaronson, Diane Fairclough (not pictured: Marianne Sullivan, Laura Degnon)

CALENDAR OF EVENTS

- **Palliative Medicine and HRQL International Conference**
September 28-29, 2001, St. Petersburg Russia
Registration Deadline: August 1, 2001
- **Latin American Conference in HRQL: Methods and Politics**
August 18-19, 2001, Montevideo, Uruguay
Sponsored by Pan American Health Organization (PAHO), WHO, and ISOQOL
- ***ISOQOL 8th Annual Conference**
Nov. 7-10, 2001, Amsterdam The Netherlands
Early Registration Deadline: July 30, 2001
Late-Breaker Abstract Deadline: August 31, 2001
- **Fourth Conference of the International Society for Quality-of-Life Studies "How to Measure Quality of Life in Diverse Populations"**
Nov. 29-Dec. 1, 2001, Wyndham Hotel, Washington, DC (USA)
Registration Deadline: Sept. 1, 2001
- **Clinical Significance for Quality of Life Measures in Oncology Research**
April 5-6, 2002, Mayo Clinic Cancer Center, Rochester, MN (USA)
- ***ISOQOL 9th Annual Conference**
Oct. 29-Nov. 3, 2002, Orlando Florida, USA *Sponsored by ISOQOL

In 1885, Vincent Van Gogh was meeting a friend at the Central Station in Amsterdam. Since the train was delayed, he went for a walk and sat on a bench in front of the station and painted the Domed Koepelkerk, the Lutheran Church in downtown Amsterdam.

The Koepelkerk owes its name and fame to its beautiful copper dome – a point of orientation for every citizen of Amsterdam. Built in 1671, it still retains all its history and charm.



The International Society for Quality of Life Research

cordially invites you to attend

Dinner at the Koepelkerk

Amsterdam, The Netherlands

Friday, November 9, 2001

starting at 7:00 pm

Please come and share this unique experience with old and new friends

in a truly exquisite setting.

Ticket prices:

Register before July 30, 2001 (\$75) to save!

\$85 after July 30, 2001

\$95 on site

Reserve your place when you register for the Annual Conference, online at www.isoqol.org