



International Society for Quality of Life Research

Volume 4 Issue 3

Newsletter for ISOQOL Members

Summer 1999

PRESIDENT'S MESSAGE

Dr. Sharon Wood-Dauphinee

It's summer and supposed to be a quiet time but, in fact, your Board of Directors and a few other members have never been busier. We have just moved the ISOQOL office from Seattle to Virginia - with all the transfer of files, databases, finances and signing authority. We are very pleased to be working with Degnon Associates Inc. and already believe that the decision to become involved with a professional management firm was the correct one. Dennis Revicki, our new Treasurer, is not only involved with the reorganization of financial policy, but he continues to interact with other members, ISPOR and the FDA regarding guidelines and policies for making quality of life claims by the pharmaceutical and medical device industries. Our President-Elect, Ivan Barofsky, is launching strategic planning and is particularly interested in ISOQOL policies. You will learn more at the Barcelona meeting.

Under the leadership of Rick Berzon, we are organizing two two-day workshops (to run concurrently), which will provide advanced information on psychometrics and analysis of quality of life data. Several ISOQOL members are donating their time, expertise and teaching skills to generate revenue for the Society. Diane Fairclough and David Osoba have prepared a revised structure for the annual election of Board Members and our new Journal Editor, Neil Aaronson, has assured us that 1999 publications of Quality of Life Research are imminent. Geri Padilla, who is in charge of communications for the Society has been instrumental in preparing this Newsletter and last but not least, Jordi Alonso and his Scientific Com-

mittee of the 6th Annual ISOQOL Conference, are engaged in putting together an exciting conference that will highlight the work of young investigators and bring everybody up to date about current research related to quality of life. Our new Board Members have volunteered for committee work so you will be hearing about their contributions in the near future. Keep checking our Website at www.isoqol.org to keep abreast of what is happening at ISOQOL. Enjoy the remainder of the summer and get ready for Barcelona.

WELCOME TO OUR NEW MANAGEMENT

The International Society for Quality of Life Research has engaged the services of a professional association management firm to work with the Board in the development of the Society. Degnon Associates of McLean, Virginia has been managing professional societies and medical associations for 20 years and has established a distinctive record of accomplishments among its clients. "We're absolutely delighted that George Degnon will be providing his skill and expertise in assisting the Society as we prepare for a dynamic role on behalf of our members in the twenty-first century," said Sharon Wood-Dauphinee, ISOQOL President.

A recent article in the McLean Times featuring the local business of the month reported, "Corporate America has experts who transform ailing companies into sweethearts for stockholders. Degnon is the counterpart in the not-for-profit community, revitalizing lagging associations into vibrant organizations. This small business provides a fully staffed operation to a variety of national and international associations

and professional societies. Contrary to a consulting firm, Degnon Associates not only collaborates with volunteer leaders in designing strategies to meet their needs, but it also manages on a daily basis a variety of programs and services to enhance these associations. Recently the company has entered the select fraternity of US book publishers producing its first book last year."

"As we grow, we'll be in a position to negotiate expanded services from our management company," said Rick Berzon, Chairman of the Task Force on the Future Management of ISOQOL, adding, "but initially we will be utilizing their services to help us better organize our infrastructure as we develop a plan of action for the Society's growth." Degnon Associates has been developing and nurturing national organizations through the application of sound management principles and a lot of old fashioned hard work. George Degnon, certified as an association executive (CAE) in 1979 and re-certified every 3 years since, is now assisted by a team of fourteen dedicated associates including his wife Marge, who manages the Ambulatory Pediatric Association (1,800 members), daughter Meg Gorham who manages the Academy for Eating Disorders (700 members), and daughter Laura Degnon who will be managing ISOQOL. The firm represents a variety of medical organizations and has managed conferences and meetings in major cities throughout the world.

Prior to establishing the company in 1979, George Degnon served 13 years with the American Academy of Pediatrics as a staff member, founding Director of its Washington Office and then

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Associate Executive Director. In 1979, the Association of State and Territorial Health Officials was the firm's first client and became its largest, growing from a \$50,000 annual budget to a \$3.5 million operation. The Association became a major force in public health policy under George's direction and in 1994 Degnon turned over the operation with 28 full time staff in order to devote more time and attention to developing smaller organizations which have the potential and desire to grow. He was awarded the Surgeon General's Medalion for his public health leadership.

"ISOQOL is an organization whose time has come and I envision it becoming a dynamic organization in the years ahead with the increasing attention our society is putting upon quality of life decision making," he said.

George, who in an earlier life had two distinctively different occupations, an Army Airborne Jumpmaster and also a high school Latin teacher, also devotes considerable time to community service whether working with DC youth in drug prevention programs, serving on community organization boards such as Children's Hospital, collaborating with daughter Chris in construction of a school building in rural Africa, advising members of Congress on both policy and campaign matters, or serving on corporate Boards of Directors. He truly enjoys the advent of each new day for the joy and challenges therein. "I'll never retire," he said, "I'm just having too much fun making the world a better place through the unique services we provide not-for-profit professional organizations."

"Our corporate mission is quite simple," said Degnon. "We enhance the associations we serve by providing quality services through good management practice and we provide our employees with the opportunity for professional development and career satisfaction. As long as our clients are happy and our dedicated employees are happy, we have the best of both worlds. We look forward to the opportunities and challenges

ahead with the Society, its dynamic leaders and its dedicated members." The contact information for ISOQOL's new Executive Office:

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1999 CONFERENCE IN BARCELONA, SPAIN

Prof. John E. Brazier ~ Chair, Scientific Committee and Dr. Jordi Alonso ~ Chair, Organising Committee, 6th Annual Conference of ISOQOL, 3-6 November, 1999, Barcelona, Spain.

We are rapidly approaching the celebration of the 6th Annual Conference of ISOQOL in Barcelona 3-6 November 1999. Year after year, the ISOQOL Conference is getting more attention from different audiences. This 6th Conference should be a great opportunity to facilitate the personal communication between researchers and professionals in the field.

An indication of the interest for the ISOQOL Conference is the high number of abstracts received. After checking for duplicates, we acknowledged receipt of a total of 482 abstracts. Of those, 150 (31%) have been accepted for Oral Presentation (in 25 Sessions) and 273 (57%) have been selected for Poster Presentation (in 2 Sessions). Only 59 abstracts (12%) were rejected. We would like to explain in some detail how these decisions were made.

Evaluation process:

Evaluators. - A total of 16 experts evaluated the abstracts. At least 3 individuals evaluated each abstract. Evaluators did not rate those abstracts with which they had a conflict of interest (e.g., being an author or from the same institution of the authors).

Dimensions evaluated. - Evaluators rated an Overall Judgement (1 'Poor' to 5 'Excellent'). This dimension was decided a priori to be the most important one for evaluating an abstract.

Additionally, the evaluators rated, on a 1 to 5 scale, the following four dimensions: Appropriateness, Originality, Scientific Quality, and Data Completion. Based on the four dimension scores, a weighted Composite Score was calculated for each abstract.

Ranking of abstracts. - Abstracts were ordered by median score in the 'Overall Judgement' dimension. Among those with the same median, abstracts were subsequently ranked based on the minimum score obtained in this category. For those abstracts still in an even situation, the average Composite Score was used to obtain a final unique rank.

Selection of abstracts:

The cut-off point for the median score in the Overall Judgement was set at 2 ('Marginal'). Abstracts with a median of 2 but with a mean Composite Score higher than 2.5 were also accepted. The first 150 abstracts that could be accommodated to the topic of one of the 25 sessions were accepted for oral presentation. The topics of the 25 sessions were defined by the Scientific Committee based on the topics of the 180 best ranked abstracts. For less than 1% of the abstracts, additional criteria were used. A maximum of 2 oral presentations by each presenter are allowed.

Acknowledgements:

These tasks would have been impossible without the generous support of the members of the Scientific Committee and an additional group of individuals: Rick Berzon, Montse Ferrer, Francis Guillemin, Patrick Marquis, Paola Mosconi, and Dennis Revicki. Their generosity and dedication has been decisive for a timely and accurate evaluation process.

We are convinced that the whole process has helped to improve the fairness of the decisions to be made. We hope that the procedures described here can be implemented (and improved) for future ISOQOL Conferences.

See you in Barcelona!

ISOQOL METHODS WORKSHOPS WILL BE HELD IN JANUARY 2000

Dr. Rick Berzon

Members and guests are invited to attend the first ISOQOL-sponsored series of seminars in state-of-the-art research methods. These intermediate and advanced workshops are intended to provide a hands-on training experience for persons interested in developing HRQL instruments, evaluating their measurement characteristics, and analyzing data from their use within longitudinal studies. The purpose of the workshops is to help those in the research community, private industry, managed care companies, payers, statisticians, and policymakers better understand HRQL measurement and interpretation of self-report data.

The seminars are divided into two tracks. Track I includes workshops that focus on analysis of HRQL data. The following topics are addressed in this track: analysis of longitudinal studies with missing HRQL data; methods for multidimensional and repeated measures; and imputation of non-randomly missing HRQL data within longitudinal studies. Track II includes workshops that address HRQL instrument development and psychometric evaluation; conducting cognitive interviews and focus groups; testing reliability, validity and responsiveness of multiple-item rating scales; and identifying (clinically) meaningful change and important differences in HRQL assessments between groups.

The workshops will be held on 10-11 January 2000 at the Ritz-Carlton Hotel in Tysons Corner, Virginia. Within the next month, you will receive a flyer in the mail which will detail registration and other logistical information.

2001 AND 2002 MEETINGS

Dr. Sharon Wood-Dauphinee

The Board of Directors of ISOQOL is once again soliciting bids to hold the Annual Conferences in 2001 and 2002. As you are probably aware, the policy of ISOQOL is to hold its conferences in various countries around the world to reflect the fact that we are truly international. To date, we have held conferences in Belgium, Canada, The Philippines, Austria, and the United States. The 6th Annual Conference will be held in Barcelona, Spain this coming fall and one year later we will all meet in Japan. If we follow our aim of alternating between Europe, America and another continent, the 2001 Conference should probably be held in America and the 2002 in Europe. This policy, however, is not rigid and we would certainly be prepared to entertain other suggestions.

Organizing a conference is now not nearly as daunting a task as it has been in the past. Currently we have a management firm based in Virginia who will help with all the hotel organizations, registration, processing abstracts, social events etc. Our member organizers and hosts would primarily have to deal with the scientific component of the conference. That means the Host Committee would be involved in soliciting abstracts, selecting those for presentation and organizing the scientific sessions. Clearly you would work hand in hand with both the ISOQOL Board of Directors and our management firm. Between the expertise on the Board of Directors and that of our management firm, you would receive lots of help. Organizing a conference is an exciting experience and would provide you an opportunity to increase tourism in your area and to show off your particular part of the world. Moreover, it is fun to work closely with colleagues interested in quality of life.

If you are interested in hosting either of these conferences, please contact President Elect Ivan Barofsky Tel: (410) 550-0162; Fax: (410) 558-9346; ibarofsk@welchlink.welch.jhu.edu OR

President Sharon Wood-Dauphinee
Tel: (514) 398-4501; Fax: (514) 398-6360; swd@physocc.lan.mcgill.ca

We are anxious to hear from you and hope that several individuals will respond. Hosting an ISOQOL Conference is truly a memorable experience.

A TRIBUTE TO DARIAN SHAW AND THE SEATTLE ADMINISTRATIVE OFFICE

Dr. Marcia Grant

In July, 1999 the Seattle Administrative Office of ISOQOL closed. Operational since 1995, this office hummed daily with phone, mail, faxes and e-mails from around the world. I have worked closely with Darian since 1996 when I became Treasurer. Darian carried out a variety of administrative responsibilities for our organization. She created the database for processing membership fees and maintained those files. She also created the database for journal subscriptions, processed orders, and recently transferred the journal business to our new journal publisher Kluwer. She created our stationery and our voting sheets. She assembled and disseminated four newsletters per year after nudging us to get our reports submitted. She maintained monthly financial records, set up conference calls, produced meeting agendas, and transcribed minutes for the Board members and other committees. She assisted with arrangements for annual meetings.

Carrying out these responsibilities in the setting of an international organization includes the challenges of language differences, foreign exchange rates, and time differences. Darian solved many problems in a way that was sensitive to the needs of our membership.

The move to a new management office occurs at a time when our Organization is examining new potentials for growth. Our thanks to Darian for working with us during our formative years, for supporting and encouraging our volunteer board, and providing kind and professional service to our members. We shall miss you. Good luck!

UPDATE ON BOOK
“Quality of Life Assessment in Clinical Trials”

Dr. Ron Hays

Quality of Life Assessment in Clinical Trials, edited by Maurice J. Staquet, Ron D. Hays, and Peter M. Fayers, was published by Oxford University Press (1998; ISBN 0 19 262785 6). The book begins with an introductory chapter written by Richard A. Berzon and ends with a chapter on Guidelines for reporting results of quality of life assessments in clinical trials written by Maurice J. Staquet and others. Sixteen other chapters are included covering the following topics: 1) Guidelines for measuring health-related quality of life; 2) Sample size and power; 3) Cross-cultural issues; 4) Profile versus utility-based measures; 5) Decision theory and utilities; 6) Applications of quality-adjusted life-years; 7) Summarizing health-related quality of life; 8) Questionnaire scaling; 9) Reliability and validity of measurement; 10) Item response theory models; 11) Factor analysis; 12) Analysis of longitudinal studies; 13) Analysis of incomplete quality of life data; 14) Using the Q-TWiST method for treatment comparisons; 15) Clinical interpretation of health-related quality of life data; and 16) Summarizing quality of life data using graphical methods. Contributions are included from many of the leading experts in the Quality of Life Research field.

Sales thus far have been outstanding with approximately 500 copies sold. All royalties from the book go to The International Society for Quality of Life Research. Books may be purchased through Amazon.com for \$42.50.

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PROPOSAL FOR CHANGES IN THE TIMING OF THE TERMS OF OFFICE FOR ISOQOL BOARD MEMBERS

Drs. Diane Fairclough & David Osobo

Under the current timing of elections and the terms of office for board members, two problems exist: 1) Elections are completed in the late spring or early summer and newly elected board members are notified 4-6 months after their term of office officially begins (January 1). 2) In practice, new board members only become functioning members after their first board meeting at the November annual ISOQOL meeting. This is 10-11 months after their term officially starts. As a result, board members are only able to contribute to the society for two years; further, in the first year they are basically learning what roles they can play. That leaves only one year to really implement programs and/or projects. The following proposals will be made, discussed and voted on by the membership at the General Business Meeting of ISOQOL in Barcelona, Spain on 05 November 1999.

Proposal:

1) Terms of offices will start during the first ISOQOL annual meeting occurring after the completion of the elections. The terms of office will extend three years from that time and terminate at the time of the ISOQOL annual meeting.

2) During the primary board meeting, which occurs the day before the ISOQOL annual meeting, new members of the board are invited to participate in all discussions, join committees, etc. but will not be voting members. During the follow-up meeting of the board (if it occurs), which will occur at the end of the ISOQOL annual meeting (sometime after the general business meeting), new members of the board will be voting members and the retiring members will not be voting members.

3) Transition: If the change in the term of offices is approved by both the board and the membership at the 1999 annual meeting, the following adjustments are proposed for the transition.

Proposal for transition in terms of office for ISOQOL board members: Rick Berzon, Diane Fairclough, Paul Kind, Laurie Ramiro were elected Spring 1997. Their modified terms would be Nov 1997 - Nov 2000. Shunichi Fukuhara, Geri Padilla were elected Spring 1998. Their modified terms would be Nov 1998 - Nov 2001. David Cella, David Osoba, Mirjam Sprangers, Albert Wu were elected Spring 1999. Their modified terms would be Nov 1999 - Nov 2002.

The following box below illustrates a possible schedule for nomination and elections. The schedule may be modified to some extent by the timing of newsletters (to avoid the cost of additional mailings).

Timing	Tasks
Summer Newsletter Sept/Oct	Publish request for nominations Nominations/Election committee reviews nominations; checks nominees for willingness to run; solicits additional candidates if necessary
Oct/Nov	Election committee finalizes list of nominees (will be prepared to presents list at Board meeting)
Dec/Jan	Biographical sketches are provided by nominees for inclusion in balloting materials
Winter (Newsletter) Late May	Ballots are mailed with newsletter Deadline for return of ballots (should be at least 6-8 weeks after mailing)
July July/Aug	Ballots are counted Newly elected members are notified (allows time to arrange to attend ISOQOL meeting in fall)
Summer Newsletter	Election results are published
Oct/Nov ISOQOL Meeting: Board Meeting: Pre Meeting	Newly elected members attend as observers; volunteer for committees
Board Meeting: Post Meeting	Term of newly elected members begins; term of members leaving the board expires.