



# International Society for Quality of Life Research

Volume 12 Issue 1

Newsletter for ISOQOL Members

August 2007

## PRESIDENT'S MESSAGE

*Madeleine King, PhD  
Sydney, Australia*

It's been a good year to be El Prez. Since my last message in February, I've traveled many miles in my capacity as ISOQOL's President. I've heard many excellent presentations about HRQOL in breathtaking locations, and while I'm a little worried about my carbon footprint, I feel privileged to have had these wonderful opportunities.

### Turkish Delight

In April, Peter Fayers and I had the pleasure of representing ISOQOL at the 2<sup>nd</sup> National Turkish Quality of Life Congress in Izmir. We were pleased to provide this small support to Erhan Eser in his efforts to promote HRQOL research in Turkey. Erhan is a long-time ISOQOL member and pivotal organizing force for HRQOL research in Turkey. As you will read in his article in this newsletter, the HRQOL activities in this region have been developing for some years. As Peter and I saw in Izmir, there is now a critical mass of clinicians and academics interested and involved in the investigation and use of HRQOL measures. Other international guests included Silke Schmidt of Germany, Ramona Lucas of Spain and Alain Leglege of France, and what delightful traveling companions they made. Erhan was a gracious and generous host – each evening was spent sampling the wonderful fresh fish, fruits and other delicacies of the region, and enjoying a range of local music. By the end of the conference, the international team was a cohesive social unit. We spent an unforgettable last day touring Ephesus (immaculate ruins of a complete Roman city), learning about the making of Turkish rugs and even purchasing one or two (I was glad I had

packed light on the forward trip). And then there was the Turkish bath – ah, but there's not enough space to do that story justice here. So on to the homeward leg, when I took time out for a quick look at old Istanbul city – an exotic skyline bristling with the minarets of so many magnificent mosques! An enriching and memorable trip all round.

### Buda and Pest

The mid-year conference on PROs in Clinical Practice in Budapest, Hungary was fantastic! Neil Aaronson and Claire Snyder put together a terrific collection of topics and speakers, there was a lot of coherence and flow in the program, and some very useful pointers towards useful directions for future research. As Ted Ganiats pointed out, the two cities, Buda and Pest, divided by the Danube River, provided a striking metaphor for the psychometrical and clinical camps represented in the topic of this conference. You can read more about the conference in an article by Neil and Claire in this newsletter.

### Busy, not Bored

June was a busy time, with the mid-year Board meeting back to back with the PRO's in Clinical Practice conference. Fundraising loomed large on the Board's agenda. Spike Milligan once said: Money can't buy you happiness but it does bring you a more pleasant form of misery. ISOQOL Board members are reminded of this at each Board meeting, when we review the society's financial report. As a rule, we are less miserable when the bottom line is in the black, more miserable when it is in the red. We verge on hysterical happiness when we make a tidy profit. I hasten to add that we are rarely morosely miserable, and from time to time we manage hysterical happiness. By careful financial management, we are slowly

building up a reserve of capital to make ISOQOL financially safe, secure and sustainable. This was a decision made some years ago at one of the Board's strategic planning sessions. Our job is to pursue ISOQOL's mission: to foster the worldwide exchange of information about health-related quality of life measurement. We do this largely through our conferences, special interest groups and educational outreach activities such as workshops. As you can imagine, money comes in handy from time to time. Obviously some of these activities make money, but they also consume funds in costs for set-up, room hire and so on. Scrutiny of ISOQOL's financial statements over the years reveals that it is our fundraising activities that keep us in the black and therefore make ISOQOL a sustainable enterprise.

### Making Money Schemes

And so it falls to Board members and chairs of conference organization committees and fundraising subcommittees to do fundraising. The June Board meeting saw some very constructive discussions about developing ISOQOL's capac-

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## ISOQOL 2007 IN TORONTO

*Nancy Mayo, PhD, Program Committee Chair and Dorcas Beaton, PhD, Program Committee Co-chair*

The plans for ISOQOL 2007 are well underway! We will be meeting in Toronto, Canada October 10-13, 2007.

Many thanks to the abstract reviewers, the scientific program committee and the workshop committee for all the work that went in to reviewing over 500 abstracts and many workshops. The reviews have been done and the conference is planned. Boy, does it look exciting! Dr. Claire Bombardier, a pioneer in quality of life research, will offer an opening keynote address under the theme of "From Measurement to Understanding" and will focus on ways quality of life researchers understand the numeric scores they achieve.

Other plenary sessions will include:

- a panel of experts who will follow up on the topics raised in the keynote address;
- *Ciaran O'Boyle, PhD*, of the Royal College of Surgeons in Ireland and *Allan Jette, PhD*, of Boston University's Sargent College of Health and Rehabilitation Sciences, who focus on models for measurement;
- *Kathleen Lohr, PhD*, of RTI International on methods for measurement.

There will be over 20 oral sessions — from innovative methods, to practice based applications through e-data collection and computer adaptive testing. And the meeting will wrap up with the banquet in true Canadian style — at the Hockey Hall of Fame — be ready for some participatory exhibits!

When you are not busy at the conference, you may have some time to explore the conference location — Toronto is a city built with and for the limitless imaginations of the people who come here to live and those who come to visit. It's a centre of rare openness, energy and style, an intimate metropolis showcasing world-

class dining, shopping, creativity, architecture and entertainment. Its skyline includes the CN Tower, a Modern Wonder of the World; beaches; parks and distinct neighbourhoods with inspiring surprises around every corner. Beyond the city limits are fabulous regional attractions such as Niagara Falls, a renowned wine region and many outdoor adventures. Toronto engages your imagination with an experience unlike any the world over.

Go to the ISOQOL website and visit the 2007 Conference page (<http://www.isoqol.org/2007Conf.htm>) for all the details. We look forward to seeing you in Toronto!



## MEMBER NEWS

The second edition of **Peter Fayers'** and David Machin's book on Quality of Life has now been published by John Wiley & Sons, and is available from bookshops or direct from the Publishers website (<http://eu.wiley.com/WileyCDA/WileyTitle/productCd-047002450X.html>). The first edition won first prize in the Basis of Medicine Category of the BMA Medical Book Competition 2001, and was "highly recommended" when reviewed in *Quality of Life Research*. The new edition is appreciably less expensive, despite being extensively expanded with new material. "**Quality of Life: The Assessment, Analysis and Interpretation of Patient-reported Outcomes, Second Edition Fayers & Machin**"



### Results from the recent ISOQOL Election

**Congratulations!**

**President Elect:**

**Neil Aaronson**

**Board of Directors:**

**Juan Dapueto**

**Montserrat Ferrer**



# 14th Annual ISOQOL Conference

## October 10 - 13, 2007

### Toronto, Ontario, Canada

Come join us as we explore the theme of this year's conference:  
*From Measurement to Understanding*

How do we understand quality of life research from the perspective of mainstream vs. non-mainstream populations? In health policy applications? When we use different theoretical frameworks for quality of life?

Speakers will include *Claire Bombardier, MD*, Head of the Division of Clinical Decision-making & Health Care, Toronto General Research Institute, who will discuss challenges and successes in using quality of life measures in clinical populations during the keynote address on Thursday, October 11.

A plenary panel of experts will follow up on the topics raised in the keynote address: *Jeff Reading, PhD*, Scientific Director of Canadian Institutes of Health Research: Institute of Aboriginal People's Health, will discuss understanding QoL from the perspective of mainstream and non-mainstream cultures and *Anita Hubley, PhD*, of the University of British Columbia will offer insight in the measurement and understanding of QoL from within an urban setting. They will be joined by additional panel members, to be confirmed.



Friday's plenary will focus on models for measurement with *Ciaran O'Boyle, PhD*, of the Royal College of Surgeons in Ireland and *Allan Jette, PhD*, of Boston University's Sargent College of Health and Rehabilitation Sciences, who will discuss how models or theory can inform and enhance our quality of life measurement and understanding. Dr. O'Boyle will speak to theoretical aspects of quality of life and models for individuals, and Dr. Jette will address the links between models of disability and function such as the WHO's ICF model and quality of life.

The final plenary on Saturday will focus on methods for measurement, and will feature *Kathleen Lohr, PhD*, of RTI International, who will address the PROMIS initiative item banking across several instruments to allow comparison and communication across different instruments, disease groups and populations, along with a speaker to be confirmed on e-health initiatives and how they impact the patient-clinician interaction.

In addition, there is a full schedule of **workshops** planned for Wednesday, October 10. We would love to see you in Toronto in October 2007. Please put the **October 10 - 13** dates on your calendar and tell your colleagues about the meeting! Information is available at the ISOQOL website [www.isoqol.org](http://www.isoqol.org).



## ISOQOL TACKLES THE TOPIC OF PROS IN CLINICAL PRACTICE

*Neil Aaronson, PhD and Claire Snyder, PhD, Conference Co-Chairs*

On June 24-26, 2007, ISOQOL hosted a special conference focused on using patient-reported outcomes (PROs) in clinical practice. Held in picturesque Budapest, Hungary, the conference provided an opportunity to delve into this topic of increasing interest in the PRO field. Over 130 researchers and clinicians from around the globe discussed and debated a variety of issues related to using PROs in clinical practice: the theoretical underpinnings behind their use, the different ways they can be used, the appropriate content of PROs for clinical practice applications, logistical issues, how to train health care providers in their use, and methods for evaluating the impact of PROs on clinical practice.



*View of Budapest from conference site*

With presentations from a distinguished panel of 16 speakers and 6 discussants serving as the foundation, the conference provided ample opportunities for group discussion during the plenary sessions and end-of-day integrating panel sessions. Through the active participation from speakers and attendees alike, we tackled a variety of issues. One question that engendered much debate was “To score or not to score?” Some questioned whether PROs could be useful without numerical scores while others warned that we should not fall victim to numerical reification. Another topic of debate was the extent to which PROs must affect

practice in order to demonstrate their value. That PROs have consistently demonstrated the ability to improve patient-clinician communication is for some sufficient evidence of their value. However, others hold that the value-added of PROs must be demonstrated in terms of their impact on patient management and health outcomes.

There was broad agreement that PROs can only provide one part of the picture. Brad Zebrack, PhD, MSW, MPH, a researcher and cancer survivor, pointed out that what patients report on questionnaires is not the complete story. As he said, “There is not one truth. There are many truths.” Thus, clinicians will never simply be able to look at questionnaire results and know what is going on with the patient. Gary Donaldson, PhD, building on that theme, indicated that PROs cannot provide “the truth, the whole truth” but suggested that, by using the right methods, they can provide “nothing but the truth.”

A good deal of the conference was devoted to discussing patient, clinician, and system issues critical to the success of applying PROs in clinical practice. Molla Donaldson, DrPH, MS, warned that simply urging clinicians to use PROs would not achieve large-scale adoption and that the systems in which clinicians work must be considered. Jane Blazeby, MD, a surgeon and quality of life researcher, did not dispute that point but suggested that clinicians are the key to having PROs used in clinical practice. Many speakers reminded us that patients play an important role in this process and require education on the role of PROs, as well.

The plenary sessions were complemented by nearly 100 proffered posters related to using PROs in clinical practice. Congratulations to Ethan Basch, MD, and Adam Smith, PhD, who shared the “Best Poster” award. Their two posters were selected from among 13 nominated. We want to thank Heather-Jane Au, MD, Jane Blazeby, MD, and Mogens Groenvold, MD, PhD, for serving as judges.

The meeting was preceded by a half-day of workshops. Topics included

oncologists’ use of PRO data in patient encounters, interpreting PRO scores for individual patients, and an introductory course on PRO assessment. Many thanks to Galina Velikova, MD, PhD, Jeff Sloan, PhD, and Ron Hays, PhD, for presenting these stimulating and informative workshops.

A welcome reception was held Sunday night to kick-off the meeting. Attendees enjoyed delicious food, seeing old friends and colleagues, meeting new ones, and a breathtaking view of the Danube River and the city. On Monday night, attendees had the opportunity to take a break from the discussion and debate (or continue it!) during a traditional Hungarian meal at a restaurant on the Pest side of the city.

At the meeting’s close, attendees left with a clearer picture of the current state of the art of research on and application of PROs in clinical practice, and of the challenges and opportunities still to be faced. Current, on-going studies are addressing a number of important issues related to both the process and outcome of PRO assessment in clinical practice, and future research is needed to address the many conceptual, attitudinal, methodological and practical issues still remaining. We look forward to following the progress of this field as the ideas from the meeting get translated into action.

We would like to thank the members of the conference planning committee: Michael Brundage, MD, MSc; David Osoba, MD; Galina Velikova, MD, PhD; Albert Wu, MD, MPH; Susan Yount, PhD; and Sarah Shiffert who provided managerial support. They all spent countless hours working to ensure the conference’s success. We also want to thank our sponsors, whose financial support was critical. Most of all, we want to thank everyone who attended the meeting for their active participation. We look forward to continuing the dialogue at the annual meeting in Toronto.



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**PATIENT REPORTED OUTCOMES IN CLINICAL PRACTICE**  
**JUNE 24-26, 2007**  
**BUDAPEST, HUNGARY**

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*Pictures courtesy of Dr. Albert Wu*



*Bernhard Holzner, Neil Aaronson,  
Andrea Bezjak, Matthias Rose*



*Ron Hays, David Feeny, Peter Fayers and  
Maria Santana during the Opening Reception*



*Kathy Lohr, Claire Snyder, Brad Zebrack*



*Mogens Groenvold presents an award to  
Ethan Basch, co-recipient with Adam  
Smith (not pictured) of Best Poster Award*



*Roxanne Jensen displays her poster during  
a Meet the Author Poster Session*

## FELLOWSHIPS AVAILABLE ON HEALTH AND DISABILITY IN THE MURINET PROJECT

*(pre- and postdoctoral level, 6-12 months duration, over the next 4 years in European Universities and Institutions)*

MURINET “Multidisciplinary Research Network on Health and Disability in Europe” is a 48 months project funded by the European Commission (EC) in the 6th framework program (Contract number: MRTN-CT-2006-035794), which started in 2007.

The Co-ordinator of the project is Dr. Matilde Leonardi at the Istituto Nazionale Neurologico “Carlo Besta” [INNCB] established in Italy. Project Partners are:

- World Health Organisation [WHO] established in Switzerland;
- Università Cattolica del Sacro Cuore [UCSC] established in Italy
- Jönköping University [HJ], established in Sweden
- Paedagogische Hochschule Zurich [PHZH], established in Switzerland
- Universitätsklinikum Hamburg-Eppendorf [UKE], established in Germany
- Universidad Autonoma de Madrid [UAM], established in Spain
- Ludwig-Maximilians Universitaet Muenchen [LMU-MUENCHEN], established in Germany
- Institute for Rehabilitation [IRRS], established in the Republic of Slovenia
- Stichting Wetenschappelijk Onderzoek Revalidatievraagstukken, iRv -Institute for rehabilitation research [SWOR-iRv], established in The Netherlands
- Consiglio Nazionale sulla Disabilità [CND], established in Italy
- Stichting Katholieke Universiteit [RUNMC], established in The Netherlands
- CF consulting Finanziamenti Unione Europea s.r.l. [CFc] established in Italy

### Project Overview

The proposed MURINET joint collaborative research project shares the following objectives:

1. To operationalise ICF (International Classification of Functioning) for research and practical implementation by applying the ICF model in different settings (clinical and rehabilitative environments, child health, psychology and educational field, and ethics and human rights), with the ultimate aim of improving health and disability research and policy across Europe;
2. Reorienting health disability-related clinical practice and policy by exploring the validity of the various continua of functioning and disability, grounded in the ICF model;
3. To explore the practical consequences of the ICF-inspired intervention strategy in which all interventions are designed to increased participation, by means of environmental facilitation or increased functioning.

The objectives of full participation by persons with disabilities in all areas of life, full inclusion in society, and access to health and other resources that facilitates participation are the underlying rationale of the research done by this network. ICF provides the theoretical foundation for this research by emphasizing the need to look at the complete lived experience of disability, but also by providing a common language that links together clinical and rehabilitative services, population data collection, and other health-related services, such as education and employment.

### Overall Objectives

This Multidisciplinary Research Network on Health and Disability in Europe (MURINET) aims to link up institutions (see above) cooperating for 10 years in national and international projects related to the International Classification of Functioning, Disability and Health (ICF) development and to health and disability research and management. The synergy from these linkages will be used to design and implement a joint structured re-

search and training programme in the field of health and disability management.

MURINET will create a European pool of experts in health and disability research and management, able to integrate several skills, within the framework of the ICF model. MURINET links different operational sectors and build up a multidisciplinary and intersectorial approach to health and disability research and management, joining involved stakeholders, from policy makers to clinical professionals, from education to rehabilitation. The ICF model, which is MURINET’s framework, embodies the principles of full participation, mainstreaming disability and the universality of disability. It has been developed in close partnership with persons with disability (PwD).

### Overall Approach and Methodology

MURINET collaborative project activities are anchored in research, using ICF in the areas of health and rehabilitation, but will also span clinical and policy research, across the continuum of time, and will be grounded in a fully developed disability epidemiology.

A main feature of MURINET is that it provides Marie Curie fellowships for a period of 6 - 12 months for junior predoctoral applicants (up to 4 years after master level) and senior fellowships (4 - 10 years, postdoctoral) from European and non-European countries. These fellowships located at the partners institution and are open to all applicants except nationals from the respective country in which the fellowship is provided (e.g. German residents can not apply for MURINET fellowships in Germany).

### Skills and individual training provided in MURINET fellowships

Activities are divided into individually guided study, complementary courses and free participation to relevant events on the topic, under the guidance of a scientist in charge. Whenever possible, full credit transfer is guaranteed by the European Credit Transfer System (ECTS). Fellows will attend courses aimed to develop complementary skills needed to perform and manage research in the field,



organised in the frame of the host's usual activities. Participants will undergo an immersion programme, in which language courses will be organised. ICF model application in operational environments requires to acquire basic IT skills to be able to manage complex databases: a devoted course will address database management, data mining techniques and statistics tools to analyze wide databases. Further courses will be: Built environment ICF and disability, ICF and IT assistive devices development and independent living skills and web accessibility rules. Main training areas are intended to supply all researchers with wide knowledge on the ICF model and its intersectorial applications.

They are:

**A. Clinical and rehabilitative applications (neurology, rheumatology and internal medicine, orthopaedics, rehabilitation, psychiatry, psychology, technological applications)**

This training area includes:

1. Empirical applications of ICF use in clinical practice;
2. Crosswalks to ICF of assessment tools and terminologies in different fields;
3. Development and validation of devoted ICF-based assessment tools;
4. Measurement of quality of care using ICF;
5. Scientific appraisals of ICF in classifying functional status;
6. Content comparison of existing health status measures based on the ICF;
7. Applications of ICF in health programs;
8. ICF core sets training;
9. Environmental factor perspective on ICF.

The clinical and rehabilitative part of the project will take care of the organization and administration of courses. The theoretical and practical sessions will tune the ICF tools to the clinical and rehabilitative environment. The fellows interested to develop a background in clinical and rehabilitative applications, will complete their training by individual research in the topics at the selected host site. Lectures and seminars will focus on developmental theory, data collection methods, fam-

ily and care givers' involvement in intervention, and measuring the process and outcome of intervention looking at early intervention, habilitation and rehabilitation. ICF-DIN basic and advanced course will be integrated with teaching sessions on: the model of functioning disability and health in clinic and rehabilitation, the use of the ICF, the ICF checklist, the WHO DAS II, and the ICF Core Sets, ICF-based case management in clinical and rehabilitation settings, and team work using a common language of functioning and disability will be implemented in the different clinical centres involved in the project.

**B. Child health, psychological and educational applications**

This training area will cover:

1. Empirical applications of ICF use in childhood disabilities;
2. Crosswalks to ICF of assessment tools and terminologies in different fields;
3. Development and validation of devoted ICF-based assessment tools;
4. Measurement of quality of childhood intervention and habilitation using ICF;
5. Scientific appraisals of ICF in classifying activity status;
6. Applications of ICF in the natural contexts of children with disability, e.g. home, preschool and school;
7. Evaluation of the feasibility of the ICF model in education systems.

The child health psychological and educational area will take care of the organization and administration of course B. The theoretical sessions will tune the ICF tools to the child health psychological and educational environment. The ESRs, interested to develop a background in child health psychological and pedagogical applications, will complete their training by individual research at the selected host sites. The training in this area will also have round tables with external experts to establish the feasibility of using the ICF model to collect and merge information relevant for children and youth with disabilities both in clinical and educational settings. Key issues to be developed are the differences in body functions and structures, participation and health on the basis of age or non-typical

development. The validity of the ICF model will be tested through cross-walks between ICF codes and disability categories and assessment information on activity limitations and participation restrictions used in clinical and educational settings and between the ICF model and available clinical, administrative and educational data. A basis will be the field-trials of ICF-CY and assignment of ICF-codes to items from extant rating instruments and other types of information. Another important issue is the use of ICF-CY in measuring stability and change (sensitivity to change) in functioning following interventions.

**C. Health and Disability research management and policy**

There are two streams of training that will be provided:

- C1. Evaluation of administrative applications and ICF policy application

This training area will cover:

1. Data collection based on the ICF;
2. Assessments of ICF uses in administrative records;
3. Use of ICF in payment and reimbursement systems;
4. National and international comparisons of ICF implementation and policy application. This training area is intended for all researchers involved in health and policy management or disability status monitoring. The theoretical sessions will be followed by practical sessions to implement the learnt techniques and methodologies.

- C2. Harmonization and comparison of international ICF applications

This includes:

1. Harmonization of survey questions with ICF terms, including data dictionaries;
2. National and international comparisons of ICF implementation;
3. Assessment of disability in population surveys;
4. Assessment of disability in clinical populations;
5. Burden of disease studies;

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**Murinet Project, continued on page 8**

## TURKISH SOCIETY OF HRQOL (SAYKAD) ORGANIZED THE 2ND NATIONAL CONGRESS

Ethan Eser, MD  
Manisa, Turkey

SAYKAD was founded in 2002 in Izmir - the third biggest city of Turkey- by a group of medical doctors working in the area of public health, psychiatry and medical oncology. The founders of SAYKAD also belong to the core study group of WHOQOL Project Turkish team. The main target of SAYKAD has been to introduce and disseminate knowledge about HRQOL to diverse health disciplines and health care professionals in Turkey. To achieve this aim, the society has participated in and organized a number of scientific meetings and workshops and has provided methodological support to professionals in Turkey who work on HRQOL in clinical practice.

The organizational structure of SAYKAD has led to the establishment of a number of working groups such as Allergy, Dermatology, Urology, Pneumatology, Rheumatology, Cardiology, Public Health and Occupational Health and Endocrinology. These working groups are in close collaboration with the relevant medical specialty societies in Turkey, ensuring that these societies include HRQOL in their regular scientific meetings in the shape of HRQOL plenary sessions and workshops.

SAYKAD has also begun work on a national HRQOL bibliography. In addition to this, for the sake of harmonizing the terminology used in the country, a new working team has started to work on creating a HRQOL Terms Dictionary for Turkish language. Due to the lack of drug industry relationships, SAYKAD has no financial support except membership dues and potential international project contributions. A new emerging target of SAYKAD is to establish a national ISOQOL chapter of Turkey. The negotiations between SAYKAD and ISOQOL on this issue have reached a very promising point.

SAYKAD has organized two national scientific meetings in Izmir, first on 8-10 April 2004 and the recent one on 5-7 April 2007. A noticeable scientific development has been apparent in the 2007 meeting compared to the previous one. In addition to the plenary sessions there were 17 parallel symposia on various medical specialties in the scientific program. About 350 medical professionals and a few from different disciplines such as health economics participated in the congress. One hundred and fifty eight papers were presented in the congress, 97 of which were presented in the thematic poster sessions. There were also 6 workshops, 3 of which were given by invited international experts of HRQOL. The presentations (in plenary sessions and workshops) of these experts brought the international view of HRQOL to the audience. ISOQOL supported the congress by giving financial travel support to president (Dr. Madeleine King) and past-president (Professor Peter Fayers) of ISOQOL. ISOQOL was also introduced to the Turkish HRQOL community by means of its president and the promotional material that was disseminated to the participants. The SAYKAD executive committee greatly appreciates ISOQOL's valuable support for the 2<sup>nd</sup> SAYKAD congress. A more detailed information can be obtained at the website of SAYKAD: [www.saykad.org](http://www.saykad.org)



*ISOQOL delegates with Turkish hosts at Izmir meeting.*

The highlights of future projects of SAYKAD are:

- A 3<sup>rd</sup> National HRQOL congress in 2009.
- Establishment of National Bibliography and Compendium of HRQOL studies and instruments validated for Turkish.

- Collaborative instrument validation projects with diverse societies of clinical disciplines.
- Ongoing statistical and methodological country education workshops
- And participating international multicenter HRQOL projects such as DISQOL (a EU FP 6 project)



### Murinet Project, from page 7

6. Sectorial cost-benefit analysis using disability measures as outcome variables.

Researchers will learn two major aspects of disability research: First, how disability statistics are generated, what data are available, what data collection strategies are used and how these data can be compared. They will be trained on how disability should be measured, quantified and explained. Second, they will learn about aspects of conceptualizing and classifying disability and aspects of models of disability. They will learn about national applications of the ICF and its multi-sectorial use. They will also explore relationships between different members of WHO's family of international classifications. WHO and its collaborating centres maintain an up to date database on ICF related activities that will be available to the fellows.

All partners will provide training to their hosted researchers, being all involved at each national level in the implementation of health and disability policies.

### **Applications**

To obtain further information please consult the MURINET homepage <http://www.headnetgroup.it/murinet.asp>. For specific questions and application materials please contact Monika Bullinger ([bullinger@uke.uni-hamburg.de](mailto:bullinger@uke.uni-hamburg.de))





## CHAPTERS UPDATE

*John Brazier, Sheffield, UK, Madeleine King, Sydney, Australia, and Cynthia Gross, Minneapolis, Minnesota, USA*

We recently saw a new chapter in the development of ISOQOL (pardon the pun), with the establishment of the first Chapters of ISOQOL. Following the call in the last Newsletter, we had 11 expressions of interest. We were very impressed by this response and the high quality of the applications. These were reviewed by Madeleine King, Cynthia Gross and John Brazier (Board Chapter Liaison) and letters were sent out to all applicants with suggestions for the main applications.

There were 4 full applications made by June 7, 2007, and these were discussed at the late June 2007 ISOQOL Midyear Board meeting. We are pleased to announce that two were approved (Chinese and Ibero-American), and another two were deferred following some further details being provided (Singapore and Russia). We expect some of the other initial expressions of interest to be developed into full proposals in due course.

This has been a great start. It was clear from the applications that there is tremendous enthusiasm for this idea. It offers the opportunity for improving access to ISOQOL meetings for members around the world and fosters meetings that focus more on local issues and concerns. In the end our society will gain from being larger, more representative and fostering more quality of life research around the world.

We strongly encourage further applications at any time. The website ([www.isoqol.org](http://www.isoqol.org)) contains the current Guidelines for Chapters on National and International Chapters of ISOQOL. We do, however, ask that you send us an expression of interest initially, so that we can help you in the process.



### President, from page 1

ity to raise funds, led by the indefatigable Rick Berzon, who has championed ISOQOL's fund-raising efforts for many years. In recent years, Mona Martin has taken on the important and challenging role of chairing our Fundraising Committee. With Rick and Mona's leadership, and the full support of the Board, we are now heading into a new fundraising era. We'll be looking for new ways to broaden, deepen and strengthen our fundraising strategy, capacity and capabilities. We need some enthusiastic volunteers, so if you're intrigued by this news, please contact Rick or Mona - I'm sure they will welcome you into our new fundraising initiative.

### Group-wise Voting

Another item on every mid-year agenda is the leadership election slate. In ratifying this year's slate, the Board discussed the composition of the Board. The upshot was that we agreed, beginning this year, to implement a grouping system to ensure a richer representation of ISOQOL's membership on the Board. Which explains why, in the voting this year, you saw a group representing Latin America. Next year, we will allocate a group to non-academics - a segment typically under-represented on the Board. A strategic approach to these groupings over successive years will ensure the inclusion of key segments of ISOQOL's membership in Board discussions and decisions. While the purpose of grouping the election slate is not only about geographic representation, it will be important as we extend our geographical range.

### Who's Blooming Global?

Which leads me to the regional chapters update I promised in my last message. In Budapest, the Board reviewed our first ever round of applications for regional chapters. It was clear from the applications that there is tremendous enthusiasm for this idea, as Board Chapters liaison, John Brazier, writes in this newsletter. It turns out ISOQOL is budding and will soon be blooming in several exotic locations around the global - to find out where, read John's article.

### 2008 - and the winner is ...

While we're on the theme of ISOQOL's global expansion ... Its official! ... The 2008 annual conference will be held in Montevideo, Uruguay, ably hosted by Laura Schwartzmann. I hear Montevideo is a beautiful place, and I am sure you are looking forward to seeing Latin America just as much as I am.

### Next Stop Toronto!

Can our annual meeting really be just weeks away!?! Toronto 2007 is looking good, as you will see in the article by co-chairs Dorcas Beaton and Nancy Mayo. I hope to see you there.

### Seriously, Thanks

Its been a great year - I've enjoyed it all, even the late nights hunched over the laptop. The only lingering worry is the massive carbon debt I've accumulated. But hang that - bring on Toronto! I'm ready for another slice of that deliciously ISOQOL-flavoured quality of life!



***ISOQOL members can join a  
Special Interest Group at no  
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**ISOQOL 14th Annual Conference**  
**October 10 - 13, 2007**  
**Health Related QOL Research: From Measurement to Understanding**  
**Toronto, Ontario, Canada**

*Visit [www.ISOQOL.org](http://www.ISOQOL.org) for the latest information.*

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**Slides from the ISOQOL Conference on**  
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- \* Online access to *Quality of Life Research* Journal at no additional charge!
- \* Reduced subscription rate for paper copy the *Quality of Life Research* Journal
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- \* Opportunity to present and hear cutting edge research presentations and posters
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- \* Access to the "Members Only" section of the ISOQOL website – an invaluable resource tool!
- \* Participation in a variety of committees
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