

# Quality of Life

QUARTERLY

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VOLUME 19 ISSUE 3  
Newsletter for  
ISOQOL Members  
SUMMER 2013



## PRESIDENT'S MESSAGE

*Bryce B. Reeve, PhD*



of strategic planning performed by the Board during a two-day meeting held in May 2013. Below my signature, we present ISOQOL's Vision Statement, Mission Statement, Guiding Principles, and Goals. It is our hope that these statements will guide our organization to identify short- and long-term strategic initiatives, and that they will enhance ISOQOL's identity as a leader in the field for advancing the science of HRQOL measurement and research.

In addition to these statements, the ISOQOL Board also identified a set of Strategic Objectives for each of the three goals listed and specific tasks that ISOQOL will lead over the next 3 years that address these goals. Details on these objectives and tasks will be shared with you at our

Dear ISOQOL Members,  
On behalf of the ISOQOL Board of Directors, I would like to update you on the results

20<sup>th</sup> Annual ISOQOL Conference being held in Miami, Florida, USA, on October 9-12, 2013, and provided in future ISOQOL newsletters.

You, our members, informed the design of these strategic plans and the creation of the vision, mission, and goal statements. Prior to the Board's strategic planning meeting, ISOQOL members completed an on-line survey to express their feelings on ISOQOL's strengths, weaknesses, opportunities, and threats (i.e., the SWOT analysis). Responses from 138 ISOQOL members were summarized and used to guide the planning process. We thank you so much for your time and thoughtful comments.

You, our members, are central in ISOQOL successfully carrying out the tasks from the strategic planning effort. You all provide different expertise, perspectives, and experiences in shaping our scientific field. Your involvement is critical in developing and promoting standards, disseminating and implementing research findings, and teaching investiga-

*Continued on page 2.*



**The ISOQOL Newsletter is published four times a year by the International Society for Quality of Life Research.**

*Newsletter Editor*

**Ana Popielnicki, BA, USA**

Send articles with subject line addressed "Newsletter Submission" to:  
**info@isoqol.org**

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Jean Wenzel: [jwenzel@isoqol.org](mailto:jwenzel@isoqol.org)

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*President's Message, Continued from page 1.*

tors and clinicians how to carry out HRQOL research and to provide patient-centered care, respectively.

We hope you will participate. Much of the work will be carried out through our Special Interest Groups (SIGs). If you are not a member, please sign up to be a part of one or more SIGs including: Child Health, Ibero-America, New Investigators, Patient Engagement (new in 2013!), Psychometrics, QOL in Clinical Practice, Response Shift, Translation & Cultural Adaptation. There will also be additions of new Task Forces to focus on specific projects and all

ISOQOL members will be invited to participate.

The Board always welcomes your feedback and advice. Feel free to contact me or any of the Board members listed on this page: <http://www.isoqol.org/about-isoqol/isoqol-leadership>. It is an exciting time to work in this field and look forward to working with you to lead the way.

Sincerely,

Bryce



#### **VISION**

The best standards of health-related quality of life will be available to every human being.

#### **MISSION**

The mission of the International Society for Quality of Life Research (ISOQOL) is to advance the scientific study of health-related quality of life and patient-centered outcomes to identify effective interventions, enhance the quality of health care and promote the health of populations.

#### **GUIDING PRINCIPLES**

- Foster person and patient-centeredness
- Reflect the highest professional standards and scientific integrity
- Advance best practices through research, dissemination and implementation
- Be inclusive, collaborative and multi-disciplinary
- Be financially responsible

#### **GOALS**

- Develop and promote standards in the scientific study of health-related quality of life and person and patient-centered outcomes
- Enhance the understanding of the impact of illness and health interventions on patients and caregivers
- Provide and facilitate targeted educational activities

## FROM THE EDITOR'S DESK

By: Ana Popielnicki

Dear ISOQOL Family:

It is my pleasure to present to you the Summer 2013 issue of our *Quality of Life Quarterly*. I am confident that you will find, as usual, interesting news and announcements, as well as engaging articles and information on our society and our members.

In his President's Message, Dr. Reeve offers us a wealth of insight on the last Board Meeting, which focused on bringing all the input from your responses to ISOQOL's SWOT analysis into a thorough strategic planning session. This effort produced clear Vision and Mission Statements, as well as Guiding Principles, and Goals – these are shared by Dr. Reeve in his article.

Our featured article touches on an issue that is very pertinent to any of our members who are, or have been, involved in clinical trials: patient recruitment. McKesson presents a thought-provoking piece on how to tap on an abundant resource -- community pharmacists – and utilize this as a channel to educate, engage and recruit patients for prospective observational research.

This issue also brings you information on ISOQOL's committees and how you can get involved; the recipients of the Developing Country Scholarships (congratulations to all!), and the Student and New Investigator Awards finalists – we are asking for your

participation as a judge for the latter, during our 20th Annual International Conference this October.

Speaking of our Annual Conference, take a look at our highlighted Plenary Sessions. The distinguished panel of speakers will present engaging and innovative programs and initiatives – don't miss out! The Closing Plenary promises to be a wonderful celebration of 20 years of quality, learning and friendship. There is also important information about registration and the Closing Dinner (which you don't want to miss in beautiful Miami's Bayside!).

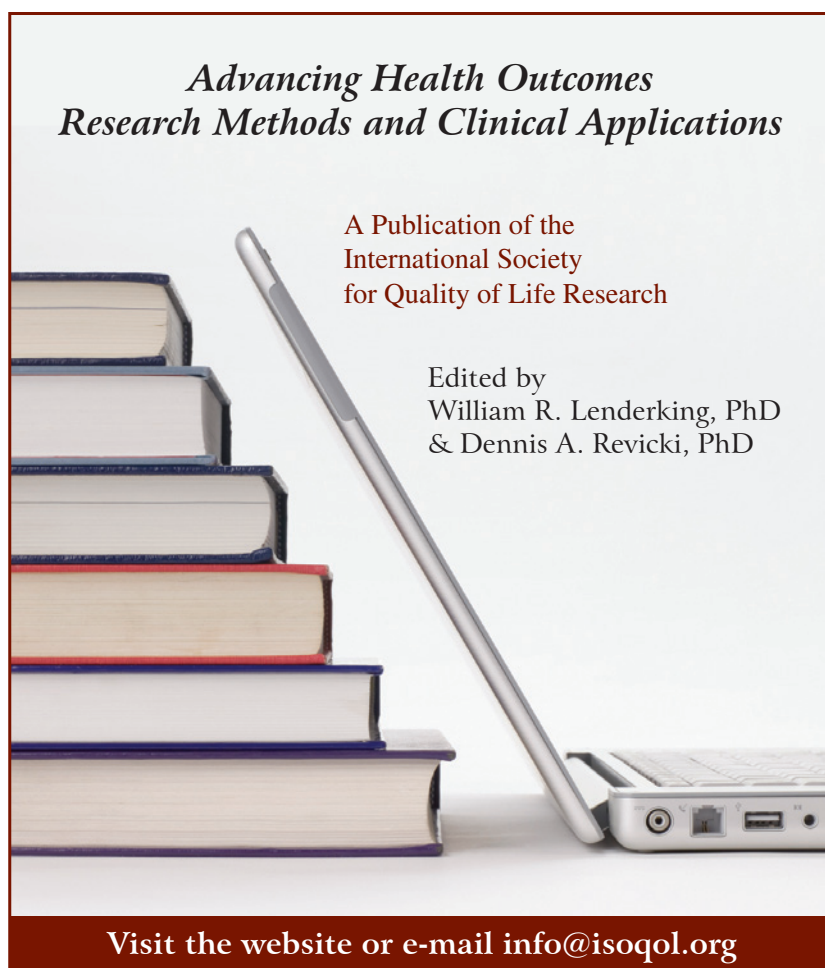
As usual, a Calendar of Events for the 3rd Quarter is included. Check it out to find many educational and networking opportunities in the July – September Calendar. We welcome any suggestions for the last quarter – please send us an email with your events for inclusion in future issues.

This will be our last issue before the Annual Conference – to stay informed, please visit our website or contact us directly with questions, comments, or submissions for the Fall issue – please send your queries/comments to your Communications Committee at [info@isoqol.org](mailto:info@isoqol.org) with "Newsletter" on your subject line.

Wishing you all a great summer, I hope to see you in Miami -- Enjoy!



Ana Popielnicki  
Editor



***Advancing Health Outcomes  
Research Methods and Clinical Applications***

A Publication of the  
International Society  
for Quality of Life Research

Edited by  
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& Dennis A. Revicki, PhD

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## BE A PART OF ISOQOL'S FUTURE

To help shape the future of ISOQOL, and network with other health-related quality of life researchers, join one of these committees today! ISOQOL committees will be meeting during the upcoming Annual Conference. Even if you are unable to attend the conference, please join the committee since projects will be worked on throughout the year. Send a message indicating the committee you are interested in joining to [info@isoqol.org](mailto:info@isoqol.org).

### **2014 ANNUAL CONFERENCE SCIENTIFIC PROGRAM COMMITTEE – CO-CHAIRS: JORDI ALONSO, MD PHD AND SUSAN BARTLETT, PHD**

The purpose of the Scientific Program Committee is to organize the annual conference of ISOQOL, consistent with the mission of ISOQOL, by promoting presentations on new developments in HRQOL research and providing state-of-the-art lectures and presentations addressing the spectrum of HRQOL research. Subcommittees are organized to manage plenary session development, abstract review, program evaluation, local activities/social events, and publicity.

### **COMMUNICATIONS COMMITTEE – CHAIR: DEBORAH MILLER, PHD**

The Communications Committee uses the newsletter (*Quality of Life Quarterly*), the website and other methods to inform membership about upcoming educational events, board activities and other information of interest to the membership.

### **EDUCATION COMMITTEE – CHAIR: JOAN BRANIN, PHD**

The Education Committee devises and implements plans to address educational needs of ISOQOL members and non members engaged in patient centered research. The following subcommittees have been formed to date by the Board of Directors: *Mentoring (including the Annual Conference Mentor/Mentee Reception); Annual Conference Workshops; Student/New Investigator Awards; Scholarships.*

### **INDUSTRY ADVISORY COMMITTEE – CHAIR: JOSEPHINE NORQUIST, MS**

The Industry Advisory Committee's goal is to increase participation of the pharmaceutical and device industry in ISOQOL activities through spearheading scientific and methodological initiatives such as leading workshops, organizing symposia, supporting fundraising, authoring papers and chairing meetings related to scientific and methodological topics of joint interest to industry and ISOQOL members.

### **MEMBERSHIP COMMITTEE – CHAIR: ANDREA PUSIC, MD MHS FRCSC**

The Membership Committee identifies, develops and implements strategies to retain existing ISOQOL members. This is achieved through measurement of members' needs and priorities, and working with other leaders and committees to develop and implement plans to address these needs. The committee also identifies, develops and implements strategies to attract new ISOQOL members. This is achieved through working with other leaders and committees to identify potential opportunities to identify and attract new members and to develop and implement strategies to engage potential new members. This includes outreach or educational activities.

Membership on the *Nominations Committee* and the *Past Presidents Advisory Council* is available only through appointment by the Board of Directors.





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PHARMA-07633-06-13

## CALENDAR OF EVENTS—JULY

- **July 15-17**  
**The 9th Annual Leadership Summit on Medicare**  
 Arlington, VA, USA  
<http://www.worldcongress.com/g4>
- **July 17-18**  
**6th Annual Congress on Access Programs for Investigational and Pre-Launch Drugs**  
 Philadelphia, PA, USA  
<http://www.cbinet.com/conference/pc13193?cid=ELMMPC13193HealthEconomics#.UaT08qwZGPZ>
- **July 17-18**  
**CBI's Orphan Drug Innovation Summit**  
 Philadelphia, PA, USA  
<http://www.cbinet.com/conference/pc13193?cid=ELMMPC13193HealthEconomics#.UaT08qwZGPZ>
- **July 17-18**  
**Clinical Data Standards and Analytics**  
 Philadelphia, PA, USA  
<http://www.cbinet.com/conference/pc13017?cid=ELMMPC13017HealthEconomics#.UaT1lKwZGPY>
- **Jul 17-19**  
**The SchARR systematic reviews course: Practical skills for undertaking reviews**  
 Sheffield, UK  
[http://www.sheffield.ac.uk/scharr/shortcourseunit/courses\\_new/systematic](http://www.sheffield.ac.uk/scharr/shortcourseunit/courses_new/systematic)
- **Jul 19-24**  
**2nd Annual IPSA-NUS Summer School for Social Science Research Methods**  
 Montreal, Quebec, Canada  
<http://www.ipsa.org/news/news/2nd-annual-ipsa-nus-summer-school-social-science-research-methods>
- **Jul 22-23**  
**Medical Affairs Leaders Forum Asia**  
 Singapore, Singapore  
[www.nextlevelpharma.com/events/view/medical\\_affairs\\_leaders\\_forum\\_asia](http://www.nextlevelpharma.com/events/view/medical_affairs_leaders_forum_asia)
- **Jul 23-24**  
**2nd Annual Asian Patient Access Leaders Forum**  
 Singapore, Singapore  
<http://patientaccessasia.nextlevelpharma.com/>
- **Jul 25-26**  
**3rd Annual Symposium on Medicare Advantage Member Accounting & Reconciliation**  
 Washington, D.C., USA  
<http://www.healthcare-conferences.com/conference.aspx?ccode=H171>
- **Jul 29-30**  
**Defined Contribution Healthcare & Private Exchanges Summit**  
 Carlsbad, CA, USA  
<http://www.healthcare-conferences.com/conference.aspx?ccode=H180>
- **Jul 29-30**  
**Technology & Operations on the Health Insurance Exchanges Summit**  
 Carlsbad, CA, USA  
<http://www.healthcare-conferences.com/conference.aspx?ccode=H173>
- **Jul 30-Aug 1**  
**Payer Strategies for Emerging Markets**  
 Philadelphia, PA, USA  
<http://payer-strategies.com/>



### Dr. Holger Muehlan and Prof. Dr. Silke Schmidt Recipients of Lilly Quality of Life Award

ISOQOL member Dr. Holger Muehlan and ISOQOL board member, Prof. Dr. Silke Schmidt from the Department of Health and Prevention at the Ernst Moritz Arndt University in Greifswald, Germany, received the Lilly Quality of Life Award due to their work on short-form development. The jury honored the award recipients' work as "outstanding research on the methods of quality of life research."

## CALENDAR OF EVENTS—AUGUST

- **Aug 1-2**  
**Long Term Care Management for Dual Eligibles**  
Las Vegas, NV, USA  
<http://www.healthcare-conferences.com/conference.aspx?ccode=H182>
- **Aug 5-7**  
**International Conference on Predictive, Preventive and Personalized Medicine & MolecularDiagnostics**  
Chicago, IL, USA  
<http://www.lifestylemedicine.org/events?eventId=638135&EventViewMode=EventDetails>
- **Aug 13-14**  
**Reimbursement and Access 2013**  
Philadelphia, PA, USA  
<http://www.cbinet.com/conference/pc13055#.UaT-CKwZGPY>
- **Aug 13-14**  
**Speed to Therapy**  
Philadelphia, PA, USA  
<http://www.cbinet.com/conference/pc13089?cid=ELMMPC13089HealthEconomics#.UaT-NKwZGPY>
- **Aug 20-21**  
**Cambridge Healthtech Institute's Fourth Annual Companion Diagnostics - Partnering with Pharma and Regulators**  
Washington, D.C., USA  
<http://www.nextgenerationdx.com/companion-diagnostics>
- **Aug 21-22**  
**Cambridge Healthtech Institute's Fourth Annual Companion Diagnostics - Advancing Technologies and Getting Reimbursed**  
Washington, D.C., USA  
<http://www.nextgenerationdx.com/companion-diagnostics>
- **Aug 25-28**  
**29th ICPE**  
Montreal, Canada  
<http://www.pharmacoepi.org/meetings/>
- **Aug 28-30**  
**The 4th SHIP conference 2013: Exploiting Existing Data for Health Research**  
University of St. Andrews, Scotland, UK  
<http://www.scot-ship.ac.uk/conference-2013>



Interested in Sharing  
Your ISOQOL **Experiences & Memories?**

**W**e are currently collecting photos and memories from the last twenty years of ISOQOL. Please send any photos or favorite memories to the ISOQOL Executive Office at [info@isoqol.org](mailto:info@isoqol.org) no later than October 1, 2013 to have them included in the 20<sup>th</sup> Anniversary Annual Conference celebration.



## CALENDAR OF EVENTS—SEPTEMBER

- **Sept 4-7**  
**22nd European Workshop on Econometrics and Health Economics**  
 Rotterdam, The Netherlands  
<http://www.york.ac.uk/economics/postgrad/herc/ews/>
- **Sept 9-11**  
**18th Annual Medicaid Drug Rebate Program Summit**  
 Chicago, IL, USA  
<http://www.iirusa.com/medicaddrugrebates/home.xml>
- **Sept 10-12**  
**World Drug Safety Congress Europe**  
 London, UK  
<http://www.healthnetworkcommunications.com/conference/world-drug-safety-eu/index.stm>
- **Sept 11-12**  
**Clinical Phases and Real-World Data Congress, Phase II-III | IIIB-IV | Real World Studies**  
 Philadelphia, PA, USA  
<http://www.cbnet.com/conference/pc13075?cid=ELMMPC13075HealthEconomics#.UaUBjqwZGPY>
- **Sept 12-14**  
**ISPOR 4th Latin America Conference**  
 Buenos Aires, Argentina  
<http://www.ispor.org/Events/Main.aspx?eventId=41>
- **Sept 16-17**  
**4th Patient Adherence and Advocacy Summit**  
 Philadelphia, PA, USA  
<http://www.exlpharma.com/Adherence#.UaUB3qwZGPZ>
- **Sept 16-17**  
**5th Annual Pharmaceutical Reimbursement & Market Access Conference.**  
 Alexandria, VA, USA  
<http://www.q1productions.com/conferencepost/4th-annual-pharmaceutical-reimbursement-market-access-conference/>
- **Sept 16-17**  
**E-Patient Connections 2013**  
 Philadelphia, PA, USA  
<http://www.exlpharma.com/e-patient-connections#.UaUCEKwZGPZ>
- **Sept 17-20**  
**Big Data in Pharma 2013**  
 Boston, MA, USA  
<http://big-datapharma.com/>
- **Sept 18-19**  
**3rd Medical Communications and Information Summit**  
 San Francisco, CA, USA  
<http://www.cbnet.com/conference/pc13164#.UaUCt6wZGPY>
- **Sept 18-19**  
**Point of Care Marketing Summit**  
 Philadelphia, PA, USA  
<http://www.cbnet.com/conference/pc13068?cid=ELMMPC13068HealthEconomics#.UaUDrKwZGPY>
- **Sept 19-20**  
**4th Annual Forum on Strategic Distribution Planning for Specialty Products**  
 Philadelphia, PA, USA  
<http://www.cbnet.com/conference/pc13131?cid=ELMMPC13131HealthEconomics#.UaUD96wZGPY>
- **Sept 23-25**  
**Advanced Portfolio Management Masterclass for Pharma and Biotech Industry**  
 Copenhagen, Denmark  
<http://pharmappm.stamfordglobal.com/>
- **Sept 23-25**  
**Market Access: Overcoming the 4th Hurdle**  
 Brussels, Belgium  
[http://pharmexpand.com/market-access.htm?goback=.gde\\_1995770\\_member\\_183768241](http://pharmexpand.com/market-access.htm?goback=.gde_1995770_member_183768241)
- **Sept 23-25**  
**Medical Affairs Strategic Summit (MASS) West**  
 San Diego, CA, USA  
<http://west.exl-mass.com/>
- **Sept 24-25**  
**Health Economics for Non-Health-Economists**  
 Brussels, Belgium  
[http://www.celforpharma.com/pharma-management/training/pharma-health-economics-course.html?linkid=minimenu\\_dates#dates](http://www.celforpharma.com/pharma-management/training/pharma-health-economics-course.html?linkid=minimenu_dates#dates)
- **Sept 24-26**  
**Value Based Pricing**  
 London, UK  
<http://valuebased-pricing.com/>
- **Sept 26-27**  
**Principles of Pharma Market Access in Europe**  
 Brussels, Belgium  
<http://www.celforpharma.com/pharma-management/training/pharma-market-access-course.html>
- **Sept 30 - Oct 1**  
**Value Added Services in Pharma 2013**  
 London, UK  
<http://www.eyeforpharma.com/value-beyond-the-pill>

## DEVELOPING COUNTRY SCHOLARSHIPS

### CONGRATULATIONS TO THE 2013 DEVELOPING COUNTRY SCHOLARSHIP RECIPIENTS:

**Yu Changhe, MSc**, Student, Liaoning University of Traditional Chinese Medicine, China

**Divine Ewane Ediebah, MSc**, Research Fellow in Biostatistics, EORTC HQ, Belgium

**Yash Jalundhwala, MSc**, Doctoral Candidate and Research Assistant, University of Illinois at Chicago, United States

**Vasoontara Yiengprugsawan, PhD**, Postdoctoral Research Fellow, Thai Health Risk Transition Project: Thailand/Australia

Special thank you to the 2013 Scholarship Committee:

Chair, Gloria Juarez, PhD RN MSN, United States

Joan Branin, PhD, United States

Doris Mwesigire, MD, Uganda

Kathy Wyrwich, PhD, United States

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## COMMUNITY PHARMACISTS: A NEW CHANNEL TO EDUCATE, ENGAGE AND RECRUIT PATIENTS FOR PROSPECTIVE OBSERVATIONAL RESEARCH

Steve Hoffman, Chief Pharmacy Officer, McKesson Patient Relationship Solutions

Since the Patient Protection and Affordable Care Act became law in 2010, considerable attention has focused on prospective observational research. Pharmaceutical manufacturers, policymakers, insurers, regulators, physicians and patients are all seeking information to better understand “what works” in the real-world where diseases are treated and products are used outside of the clinical setting.

In addition to providing information based on real-world practices, prospective observational research is being used to design more pragmatic clinical trials, inform clinical practice, and, perhaps most importantly, serve as a cornerstone of comparative effectiveness research. According to the International Society for Pharmacoeconomics and Outcomes Research (ISPOR), “Prospective observational studies will undoubtedly be conducted with increased frequency to assess the comparative effectiveness of different treatments, including as a tool for ‘coverage with evidence development,’ ‘risk-sharing contracting,’ or as a key element in a ‘learning healthcare system.’”

This trend, however, also intensifies one of the thorniest and most intractable problems prevalent in all types of clinical research – patient recruitment. Although timely patient recruitment is widely acknowledged to be an important aspect of successful clinical trials, delays hamper almost 85% of all Phase II – IV clinical trials.

Given these circumstances, it’s no surprise that the clinical research industry is looking for new ideas. An innovative strategy especially suitable for observational studies

involves leveraging pharmacies as a channel for education, engagement and clinical research recruitment.

### PATIENTS TRUST PHARMACISTS

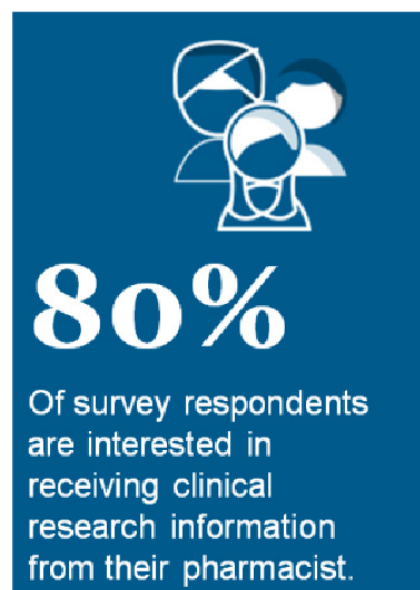
In many ways, pharmacists are the ideal conduit for patient recruitment. First and foremost, they are highly trusted by patients. In Gallup’s most recent Honesty and Ethics survey covering 21 professions, pharmacists ranked second only to nurses and ahead of physicians — the ninth consecutive year they ranked in the top three.

Pharmacists also are the most accessible healthcare providers in the country: Americans visit pharmacies at more than five times the annual rate at which they visit their primary and specialty care physicians combined. These interactions help pharmacists learn things about their patients that are invaluable in determining whether they would be appropriate candidates for an observational study.

The general public is open to the idea of receiving information about clinical research from pharmacists. In fact, market research conducted by the Center for Information and Study on Clinical Research Participation (CISCRP) found that nearly 80% of respondents would like their pharmacists to tell them about clinical research.

### A PATIENT-CENTRIC SOLUTION THAT COMBINES TARGETING WITH REACH

Pharmacy-based recruitment programs can combine precision targeting (for example, by geographic areas or therapies) with the ability



#### Results

Through the McKesson StudyLink Program, 221 patients were referred into the study, of which 161 patients were enrolled — a **73% referral-to-enrollment rate**.



Continued on page 12.



to recruit from an immense pool of potential candidates. There are more than 62,000 pharmacies in the U.S., of which 33% (more than 20,000) are independent community pharmacies.

On average, these independents fill 64,000 prescriptions a year and can be accessed through specialized pharmacy networks. Their customer databases are brimming with rich, privacy-protected data to target patients with specific diagnoses and co-morbidities, enabling studies to quickly and easily filter candidates based on protocol inclusion and exclusion criteria.

Community pharmacists generally have strong relationships with patients, which make them well-suited to identify potential participants. For example, the McKesson StudyLink program is designed to leverage the insights of independent community pharmacists whose patient programs McKesson contractually supports. StudyLink provides access to a large pool of real-world patients who might not otherwise hear about opportunities to participate in surveys, registries or other prospective observational studies.

After doing the first cut of eligibility screening based on geographic proximity (when applicable) and prescription claims data, McKesson sends a list of potential candidates to pharmacists to remove those whom they consider inappropriate. Often, the reasons for exclusion cannot be inferred using prescription history, and require knowledge that only the pharmacist would have. For example, one candidate may recently have become pregnant; another might be on a medication for a different indication than what the records seem to show; others may have mobility, language or personality barriers that would make them a poor fit for certain research opportunities.

## COMPONENTS OF A SUCCESSFUL PROGRAM

Although it is still too soon for pharmacy-based recruitment programs to have established best practices, much can be learned from the pharmaceutical industry's experiences in partnering with pharmacists on compliance and behavioral intervention programs. For example, it's critically important for any program to avoid disrupting the pharmacy dispensing workflow. Other success factors are likely to include:

- A contractual relationship with a sufficiently large network of interested pharmacists to meet volume criteria in different geographic areas.
- Legally compliant access to prescription claims and demographic data with the clinical infrastructure and information technology to systematically identify targeted candidates.
- Active involvement from pharmacists in vetting and validating pre-qualified candidates based on personal knowledge of their patients.
- Patient outreach and proactive follow-up to inform and educate patients about the clinical research opportunity and to confirm eligibility and interest.
- An operational infrastructure for training and compensating pharmacists that also ensures compliance with federal and state privacy laws and regulations.
- Ongoing communications with participating pharmacists (e.g., updates on the status of which candidates were enrolled in the study) to keep them informed and engaged.

## CONCLUSION

The explosive growth of clinical research has created a rapidly growing demand for more and more patients, especially among diverse, difficult-to-reach populations. Although big data is all the buzz, it's equally important to truly engage patients in the drug development process outside of a controlled environment. Why? Because observational, real-world studies that demonstrate differentiated product value and satisfy regulators and payers have become the new normal.

Instead of casting bigger and costlier nets to meet these demands, the industry should consider exploring alternative, more targeted and trusted channels. As a complement to more traditional tactics, pharmacy-based patient recruitment programs can be part of the solution. By involving community pharmacists in the recruitment process, sponsors and research organizations can "personalize" patients' initial experiences in the drug development process. Recruiting through the pharmacy allows patients to learn about a clinical research opportunity right in their own neighborhood – at their local pharmacy.

Though still in the early stages of development, pharmacy-based patient recruitment programs show promise as a strategy to meet study recruitment goals. While it's important to be realistic about goals and expectations, results suggest that pharmacy-based recruitment strategies for observational could see high rates of success.

*Continued on page 13.*



## REFERENCES

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## 20<sup>TH</sup> ANNUAL CONFERENCE REGISTRATION

Registration is available for the 20<sup>th</sup> Annual Conference through **September 16**. Register before **August 12** in order to receive the early registration discount.

Visit the Registration page of the website for more information. (<http://www.isoqol.org/2013conference/registration>)

Registration fees include access to all scientific content from Thursday through Saturday. This includes all plenary sessions, symposia, plus concurrent oral and poster sessions. Registered attendees will also have access to the exhibit area, plus the Welcome Reception and several additional events throughout the conference. A listing of Highlighted Events (<http://www.isoqol.org/2013conference/preliminary-schedule/highlighted-events>) can be found on the website.

A limited number of tickets are available for the Closing Dinner on Saturday evening, and can be purchased through online registration. The Closing Dinner will be held at a casual seafood restaurant, Bubba Gump Shrimp Co, located in the Bayside Marketplace. Outdoor seating is available to enjoy the Miami weather. After dinner, a live Latin band will perform, and space will be available for dancing.

The restaurant is just a ten minute walk from the InterContinental Miami Hotel, but you can order a Monkey Shuttle (<http://themonkeyshuttle.com/>) in advance if you want to save your energy for salsa dancing.



October 9-12, 2013 **MIAMI, FLORIDA, USA**



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## DON'T MISS OUR EXCITING PLENARY SESSIONS!

The ISOQOL Plenary sessions are a highlight of each Annual Conference. This tradition of excellence continues in Miami. Scientific Program co-chairs, David Eton, PhD and Simon Pickard, PhD, have assembled four stimulating plenary session that coincide with the 2013 Annual Conference theme, *"Energizing the Science of Quality of Life Research: Where have we been and where can we go?"*

### WELCOME PLENARY, NEW HORIZONS IN QUALITY OF LIFE RESEARCH

Thursday, October 10, 9:00 am – 10:30 am

Plenary co-chairs, Katherine Bevans, PhD and Simon Pickard, PhD, have created a plenary session exploring emerging concepts and methodological issues in quality of life research.



**Christopher B. Forrest, MD PhD** of the Children's Hospital of Philadelphia and University of Pennsylvania will begin the session with a discussion on life course challenges in quality of life research. Life course science integrates across several disciplines including areas of epidemiology, psychology, sociology, biology, and origins of chronic disease. An emerging meta-theory is tying these frameworks together. This presentation will summarize the emerging science of life course health, identify challenges to quality of life research presented by these new models, and conclude with the research frontier in this field. Dr. Forrest's discussion will have a significant focus on children, but will address challenges inherent to all populations.



**Carolyn E. Schwartz, ScD** of DeltaQuest Foundation, Inc and Tufts University School of Medicine will present on cognitive reserve. The concept of cognitive reserve is increasingly relevant in research on neurological disorders and aging populations. Comprised of both pre-morbid childhood enrichment activities (passive reserve) and current leisure and educational stimulation (active reserve), it has prognostic significance in predicting better disease trajectories in people with Alzheimer's disease and multiple sclerosis (MS), as well as in the elderly. Dr. Schwartz will introduce this construct to ISOQOL and also discuss implications of cognitive reserve for quality of life research and theory, clinical trials research, and clinical practice.



**Kirsi Tirri, PhD MTh**, from the Department of Teacher Education at the University of Helsinki, Finland, will speak on the cognitive construct of multiple intelligences, the existence of multiple independent abilities to solve problems and create products. Her talk will include discussion of the development of the Multiple Intelligences Profiling Questionnaire (MIPQ). The MIPQ aims to assist learners in understanding how they best learn and teachers in understanding their student's strengths. Dr. Tirri will also discuss how her research could inform and enhance health related quality of life research.

Visit the *New Horizons in Quality of Life Research* plenary page for speaker bios. (link to: <http://www.isoqol.org/2013conference/plenary-sessions/plenary-sessions>)

### CUTTING EDGE RESEARCH IN QUALITY OF LIFE PLENARY

Thursday, October 10, 11:15 am - 12:45 pm

This plenary will showcase three of the most highly-rated abstracts from open submission. Visit the Cutting Edge Research in Quality of Life plenary page for the speaker announcement. (link to: <http://www.isoqol.org/2013conference/plenary-sessions/cutting-edge-research-plenary>)

This session will be chaired by ISOQOL President, Bryce Reeve, PhD and President-elect, Galina Velikova, MD, and will demonstrate some of the remarkable research being conducted by ISOQOL members.

*Continued on page 16.*

## ACCENTUATE THE POSITIVE – THE SUNNY SIDE OF QUALITY OF LIFE RESEARCH

Friday, October 11, 9:00 am – 10:30 am

Plenary co-chairs, David Eton, PhD and John Salsman, PhD, take inspiration from the Miami sunshine for Friday's plenary session on Positive Psychology. Traditionally, health researchers studying quality of life issues have focused more on negative aspects of well-being such as symptoms, functional impairment, disability, and psycho-social morbidity. Yet as more and more people today are living with chronic illness, a better understanding of how individuals positively adjust, thrive, and grow from their illness experience is becoming increasingly important. This plenary session is designed to encourage greater dialogue on the positive aspects of well-being and quality of life.



**Mihaly Csikszentmihalyi, PhD**, the C.S. and D.J. Davidson Professor of Psychology and Management and Director of Quality of Life Research Center at Claremont Graduate University, is best known for his work on the concept of “flow” which he describes as being fully focused on the situation or task at hand “for its own sake.” In addition to introducing the concept and history of flow and the methods used to study it, Dr. Csikszentmihalyi will describe the potential for integrating the study of flow into quality of life research with chronically ill patients. Dr. Csikszentmihalyi will also introduce intervention strategies to enhance “flow experiences”.



**Crystal L. Park, PhD**, Professor of Psychology and Director of Health Psychology Graduate Certificate Program at the University of Connecticut, has an extensive record of research in the area of post-traumatic growth and psychological adjustment after cancer, including investigation of the religious and non-religious pathways to growth and meaning making in cancer survivors. She also has experience in measure development and currently has an NCCAM-funded R01 to develop a questionnaire to measure the key dimensions of an effective yoga intervention.

Visit the *Accentuate the Positive: The Sunny Side of Quality of Life Research* plenary page for speaker bios. Link to: <http://www.isoqol.org/2013conference/plenary-sessions/accentuate-the-positive-the-sunny-side-of-quality-of-life-plenary>

## CLOSING PLENARY, TWENTY YEARS OF ISOQOL – A CELEBRATION

Saturday, October 12, 3:30 pm – 5:00 pm

2013 marks the 20<sup>th</sup> anniversary of the ISOQOL Annual Conference. ISOQOL will celebrate this in the final plenary session by bringing together past presidents of ISOQOL on one stage to reflect on past achievements, rejoice in camaraderie, and provide insight into the future of the Society. Plan on attending this stimulating and fun Q&A, with live microphones provided for audience engagement.

This is your celebration and we want to hear from you. Send your favorite photos and memories to the ISOQOL Executive Office, at [info@isoqol.org](mailto:info@isoqol.org).





## MEET US IN MIAMI

On behalf of ISOQOL, we invite you to participate as a sponsor/exhibitor at this year's Annual Conference.

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## ISOQOL 20<sup>TH</sup> ANNUAL CONFERENCE



October 9-12, 2013 MIAMI, FLORIDA, USA

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### Access the Archive

#### *Lessons Learned from PROs in FDA and EMA Label Claims (May 2013)*

This webinar includes presentations from industry sponsors that have interacted with the FDA or EMA to support labeling of their products. The webinar includes a review of PRO measures and determination of how to move them forward and/or revise them as appropriate to support labeling claim. Specifically, the webinar addresses how to conduct a gap analysis and how to adapt or modify existing measures to assess and/or confirm the validity of the measure. FDA and EMA considerations of PRO measures are addressed through the use of case studies.

#### Featured Presenters:

Kathy Beusterien, MPH, Senior Director, Oxford Outcomes  
Thomas Hare, Vice President, Development Operations, Incyte  
William Lenderking, PhD, Senior Research Leader, United BioSource  
Linda Abetz-Webb, EU Practice Lead, PRO Adelphi Values

Participants of this webinar will obtain key information on interactions with regulatory agencies when seeking product labeling specific to patient reported outcomes from sponsors who have successfully gone through the process with new or existing measures.



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## FROM OUR PARTNERS AT THE SOCIETY OF BEHAVIORAL MEDICINE

Dear ISOQOL Members,

We enthusiastically invite you to attend the 35th Annual Meeting & Scientific Sessions of the Society of Behavioral Medicine (SBM) to be held in Philadelphia, Pennsylvania from April 23–26, 2014. The meeting will convene at the Philadelphia Marriott Downtown, providing close access to attractions that embody the rich and vibrant history of the spectacular and unique community of Philadelphia.

The 2014 Annual Meeting Program will feature the theme, “Behavior Matters: The Impact and Reach of Behavioral Medicine.” Philadelphia is a perfect place for SBM to celebrate its 35th Annual Meeting and to showcase the significant impact of behavioral medicine on health and health care across diverse settings, populations, and cultures.

Invited speakers will highlight areas that represent the broad range of interests within our diverse membership and describe important opportunities to expand the impact and reach of behavioral medicine. Featured presentations will address thematic areas including obesity, cancer, cardiovascular health, behavioral economics, health policy, dissemination and implementation, and mentoring/career development.

**The deadline to submit an abstract is September 12, 2013.** Visit the 2014 Annual Meeting website, <http://www.sbm.org/meetings/2014>, to read the full call for abstracts and submission details, and receive additional information about program updates, registration information, as well as things to see and do in Philadelphia.

Sincerely,



Elliot J. Coups, PhD  
Program Chair



Lila J. Finney Rutten, PhD, MPH  
Program Co-Chair

## CONGRATULATIONS TO THE 2013 STUDENT AND NEW INVESTIGATOR PRESENTATION AWARD FINALISTS

### STUDENT ORAL PRESENTATION FINALISTS

**Jo Brett, United Kingdom,** *Patient reported experience of fracture of the proximal femur in patients over 65 years*  
Oral Session 205 – Quality of Care Experience

**Sophie Cleanthous, MSc, BSc, United Kingdom,** *Development and validation of a new patient reported instrument of uncertainty in systemic lupus erythematosus (SLE) and rheumatoid arthritis (RA)*  
Oral Session 104 – Patient Reported Outcomes Measure Development and Evaluation

**Kim Nicolaije, The Netherlands,** *The Impact of an Automatically Generated Survivorship Care Plan on Patient Reported Outcomes: Results of a Pragmatic Cluster Randomized Controlled Trial (ROGY Care) among Endometrial Cancer Patients*  
Oral Session 204 – Personalized Medicine

### NEW INVESTIGATOR ORAL PRESENTATION FINALISTS

**Zeeshan Butt, PhD, United States,** *Psychometric Properties of a Brief, Clinically-Relevant Measure of Pain in Patients with Hepatocellular Carcinoma*  
Oral Session 207 – Patient Reported Outcomes Measure Development and Evaluation

**Bellinda King-Kallimanis, PhD, Ireland,** *Investigating measurement invariance and extreme response style in longitudinal quality of life data*  
Oral Session 203 – Statistical Methods

**Ester Villalonga, PhD, United States,** *Health-related quality of life of children with immigrant backgrounds: towards a new pattern in Europe?*  
Oral Session 201 – Quality of Life in Children

### STUDENT POSTER PRESENTATION FINALISTS

**Amin Abdul-Galeel Amro, RN, MSN, Norway,** *Symptom clusters predict mortality among dialysis patients in Norway*  
Poster Session 1

**Aaron C. Roberts, United States,** *Behind the Scenes: A Review of Instruments Used in Electronic Patient-Reported Outcomes Systems*  
Poster Session 1

**Neuza Silva, Portugal,** *Quality of Life and Psychological Adjustment of Children and Adolescents with Chronic Health Conditions*  
Poster Session 2

### NEW INVESTIGATOR POSTER PRESENTATION FINALISTS

**Eva-Maria Gamper, Austria,** *Development and calibration of an item bank for the EORTC role functioning computer adaptive test (EORTC RF-CAT)*  
Poster Session 1

**Kelly Kenzik, PhD, United States,** *Refining symptom measurement tool for long-term survivors of hematopoietic stem cell transplant*  
Poster Session 2

**Jiseon Kim, United States,** *Validation of CESD-20 and PHQ-9 Crosswalks to PROMIS Depression in Multiple Sclerosis*  
Poster Session 1

Finalists' presentations will be evaluated by the Student and New Investigator Presentation Award Judges led by Subcommittee Chair, Roxanne Jensen, PhD. Winners will be determined at the Annual Conference and announced at the ISOQOL Business Meeting and Awards Presentation on Saturday, October 12.

### CALL FOR VOLUNTEERS – STUDENT AND NEW INVESTIGATOR PRESENTATION AWARD JUDGES

The Annual Conference is right around the corner and we are in need of judges for the Student and New Investigator Awards. Serving as a judge for these awards not only allows you to help reward up and coming investigators for their hard work and research, but also offers an opportunity for involvement in the Society with a limited time commitment. The duties of a Student and New Investigator Judge can easily fit into your conference schedule. Judges will be assigned a variety of presentations to observe and evaluate. Once you have reviewed your assigned presentations, simply complete a brief evaluation form and return it to the Registration Desk.

Please consider serving as a judge for the Student and New Investigator Awards. If you are interested, please contact the Student and New Investigator Award Subcommittee Chair, Roxanne Jensen, PhD from Georgetown University at [rj222@georgetown.edu](mailto:rj222@georgetown.edu) or Heather Vitale from the Executive Office at [hvitale@isoqol.org](mailto:hvitale@isoqol.org).

