UCSF Center for Translational & Policy Research on Personalized Medicine

NEWSLETTER
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# A Letter from Center Director Kathryn A. Phillips, PhD

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It's been a busy summer for TRANSPERS!

We invite you to read about our recent activities, particularly our work on health policy and reimbursement. We welcome any input or questions.

Kathryn

Kathryn Phillips, PhD
TRANSPERS Center Director

# TRANSPERS Center Director an Invited Speaker at NIH Common Fund Conference

TRANSPERS Director Kathryn Phillips was an invited speaker on July 19th, 2012 at the National Institutes of Health's Common Fund Conference on: "Economics of Personalized Health Care and Prevention." The purpose of the meeting was to identify gaps in research knowledge and clarify the science of the economics of personalized medicine. Invited experts also included long-time TRANSPERS collaborator Dr. Elena Elkin. Attendees included representatives from the NIH, CDC, various universities, and other government institutions.

Dr. Phillips presented viewpoints on personalized medicine and the work of the TRANSPERS Center at UCSF in her presentation *Economic Perspectives on Personalized Health Care and Prevention: An Overview.* Dr. Phillips identified key gaps in current research and proposed approaches for future research strategies in the economics of personalized medicine.

A key recommendation from Dr. Phillips' presentation was the need for systematic reviews of the value of personalized medicine technologies and identification of gaps in what is known about their value – and TRANSPERS has now addressed this need. We found in our recent study that many personalized medicine tests have not been evaluated – even those already in widespread use or part of FDA drug labels – and thus where more evidence is needed (manuscript under review).

An Executive Summary can be accessed online.

# TRANSPERS Welcomes CIGNA and New Representatives from Humana and Regence BlueShield to the Reimbursement Advisory Council; Developing an IOM Roundtable on Innovation

TRANSPERS continues to work on coverage, reimbursement, and policy decisions by health payers through meetings and studies with its Evidence and Reimbursement Advisory Council, which has met since 2007. Jacob Asher, MD, representing Cigna, is the latest addition to the Council. We are also pleased to welcome two new representatives to the Council: Bryan Loy, MD of Humana and Robert (Bob) Herr, MD of Regence BlueShield. The Council now includes all of the seven largest health plans in the US. The next meeting is scheduled for November and will include discussions on evidence and coverage factors for emerging diagnostics and whole genome sequencing, and our work developing a Roundtable with the Institute of Medicine on facilitating innovation for emerging technologies in an evolving health care environment. For more information, contact Julia Trosman PhD at TrosmanJ@pharmacy.ucsf.edu

## TRANSPERS Founder Dr. Phillips joins the Editorial Board at Health Affairs

We are pleased to announce that Dr. Phillips has been invited to join the Editorial Board at *Health Affairs*, The Washington Post has stated that "For more than 20 years, *Health Affairs* has been a **must-read** for anyone with a serious interest in medicine, health care, and health care policy." — *Washington Post*

Her first three-year appointment will begin on November 15, 2012. Congratulations, Dr. Phillips!

## TRANSPERS colleague Deborah Marshall continues excellent leadership as President of ISPOR

Deborah Marshall, Ph.D., is serving as President of the International Society of Pharmacoeconomics and Outcomes Research (ISPOR) for 2012-2013. Dr. Marshall is Associate Professor at the University of Calgary, Director of Health Technology Assessment (HTA) at the Alberta Bone and Joint Health Institute, and Associate Professor at McMaster University.

ISPOR promotes health economics and outcomes research and helps facilitate translation of this research into useful information for healthcare decision-makers. The organization's goal is to improve health by making health care more efficient, effective, and fair. ISPOR has grown dramatically in recent years with over 6500 members in over 100 countries around the world.

Dr. Marshall recently led a seminar focusing on TRANSPERS research at the ISPOR 17th Annual International Meeting entitled: "Assessing the Value of Personalized Medicine in Practice: Utilization, Economics & Preferences." This presentation highlighted the 'value' of personalized medicine in translational research. Work also underway during Dr. Marshall's tenure as President includes helping develop and lead a new set of research guidelines published by the ISPOR-Society for Medical Decision Making (SMDM) Modeling Good Research Practices Task Force in *Medical Decision Making* (Med Decis Making. 2012 Sep;32(5):667-743). This comprehensive, seven-part report contains updated recommendations for best practices in conceptualizing models. Please see http://www.smdm.org/ispor_smdm.shtml for links to the report.

## TRANSPERS Enjoys Visiting Scholar from Memorial Sloan Kettering Cancer Center

On August 1, long time TRANSPERS collaborator and Cancer Outcomes researcher Elena Elkin, Ph.D. delivered a presentation at UCSF entitled "Cancer Decision Screening Aids." Dr. Elkin spent the month of August with the TRANSPERS Center before returning to Memorial Sloan Kettering Cancer Center in New York.

## TRANSPERS Center Welcomes New Program Manager

We welcomed Claire Richardson as the new TRANSPERS Center Program Manager this October. Claire has a background in Public Health programs and research, and dual Master's degrees in Medical Anthropology and Public Health.

## New TRANSPERS Research on BRCA

**Beattie MS, Wang G, Phillips KA.** *Differences in US healthcare coverage policies in BRCA testing and potential implications. Personalized Medicine. 2012;9(1):5-8.*

Beattie et al. discuss variations in coverage by health plans for BRCA testing for over 70 million people. These variations, particularly between private and public plans, have important policy implications and the potential to increase disparties in underserved families with high risk of hereditary breast and ovarian cancer (HBOC). The authors suggest several ways to bridge the gaps between clinical utility and healthcare policy, using BRCA testing as an example. {Read More}

**To learn more about TRANSPERS Center collaborators and our research, please visit our website at http://transpers.ucsf.edu or email us: TRANSPERSinfo@ucsf.edu**

## Important TRANSPERS Center Research on Lynch Syndrome in *JAMA*, *Cancer*, and other journals

**TRANSPERS research is working toward answering questions about the value of colorectal screening, particularly as it relates to Lynch Syndrome, an inherited condition that increases the risk of colorectal and other cancers. Four recent publications examined this important issue:**

1) ***Ladabaum U, Ford J.*** *Lynch Syndrome in Patients with Colorectal Cancer: Finding the Needle in the Haystack. JAMA. Oct 2012; 308(15): 1581-1583.*

The authors of this editorial discuss current research supporting screening colorectal cancer (CRC) patients for Lynch syndrome. The authors advocate for up-front germline testing of at the time of CRC diagnosis, claiming that the potential for individualized preventive medicine provides rationale for screening. {Abstract}

2) ***Kuppermann M, Wang G, Wong S, Blanco A, Conrad P, Nakagawa S, Terdiman J, Ladabaum U.*** *Preferences for Outcomes Associated with Decisions to Undergo or Forego Genetic Testing for Lynch Syndrome. Cancer. Jul11 2012 .*

Kuppermann et al. highlighted the lack of data on patient preferences for outcomes of testing decisions for Lynch Syndrome cost-effectiveness analyses. Preferences related to the outcomes of testing were found to vary substantially. The utilities data collected in this study will be useful for future cost-effectiveness analyses. {Abstract}

***3) Walsh J, Arora M, Hosenfeld C, Ladabaum U, Kuppermann M, Knight SJ****. Preferences for genetic testing to identify hereditary colorectal cancer: perspectives of high-risk patients, community members, and clinicians. J Cancer Educ. Mar 2012;27(1):112-119.*

Using the example of genetic testing (GT) for hereditary Lynch Syndrome, the authors assessed key characteristics of GT valued by patients, consumers, and health professionals. Through focus groups, Walsh et al. discovered different priorities held by patients, community members, and health care providers. {Abstract}

4) ***Wang G, Kuppermann M, Kim B, Phillips KA, Ladabaum U.*** *Influence of patient preferences on the cost-effectiveness of screening for lynch syndrome. Am J Manag Care. May 2012;18(5):e179-185.*

Wang et al. examined how changes in quality of life related to medical services for Lynch Syndrome affects cost-effectiveness of screening for Lynch Syndrome among newly-diagnosed colorectal cancer patients and their relatives. Using an adapted a state-transition Markov model of screening for Lynch syndrome, the authors concluded that screening in this population is likely to yield increases in life-expectancy that decrease short-term decreases in QoL. {Abstract}