UCSF Center for Translational & Policy Research on Personalized Medicine

NEWSLETTER **Summer 2019**

A Letter from Center Director Kathryn A. Phillips, PhD

Dear Colleagues,

In this issue we are pleased to report on a new focus of TRANSPERS - "Big Data" and "Precision Health" and TRANSPERS contributions to work on consumer genomics and global health economics. Additionally, we highlight a number of high-profile contributions to the field by TRANSPERS collaborators Deborah Marshall and Lew Sandy, and congratulate Deborah on her recent awards.

Please circulate our announcements of position openings for faculty and post-doctoral fellowships.

As always, we welcome your thoughts, comments, and ideas for collaboration.

Best,

Kathryn Phillips, PhD
TRANSPERS Founding Director

In This Issue

TRANSPERS Stays on Cutting Edge by Moving into "Big Data"

and "Precision Health"

We are rapidly entering an era where "Big Data" - the aggregation and analysis of data across diverse sources using artificial intelligence and other approaches - is increasingly important in health care. Simultaneously, there is a new focus on "Precision Health", which focuses not only on using genomic information for treatment decisions but also on using a wide range of data for disease prevention and detection across the lifespan.

TRANSPERS is venturing into new exploration of the economic and payment implications of the increased intersection of "Big Data" and "Precision Health", through a new grant awarded by the National Human Genome Research Institute. Kathryn Phillips will lead this effort, which includes collaborations with the UCSF Program in Prenatal and Pediatric Genomic Sequencing (P3EGS), UCSF Baker Computational Health Sciences Institute (BCSHI), and the Stanford Precision Health and Integrated Diagnostics Center (PHIND), on Bringing Economics to Big Data and Precision Health.

The Global Economics and Evaluation of Clinical Genomics Sequencing Working Group (GEECS) held their annual meeting in Basel

GEECS held their annual meeting in Basel in conjunction with the International Health Economics Association Congress. The Working Group, chaired by Kathryn Phillips, is made up of an esteemed group of health economists and policy researchers from major institutions across the globe who have been at the forefront of the incorporation of genomics into clinical care. For more on the Working Group, please see the summary of their work.

Kathryn Phillips participates in Aspen Institute San Francisco Discussion on Consumer Genomics

Kathryn Phillips, in conversation with Sue Siegel (GE's Chief Innovation Officer and CEO of GE Ventures), spoke on 3/26 at an Aspen Institute San Francisco Discussion on the topic: Should You Get Genetic Testing? Should Everyone Get Genetic Testing? She enjoyed the lively conversation and the range of participants, from experts in the field to those who were now to the topic.

TRANSPERS Collaborator Deborah Marshall Publishes First Study of Personal Utility of Exome Sequencing for Parents of Children with Rare Diseases

Exome Sequencing (ES) identifies rare disease-causing genetic variants quickly, often expediting the diagnostic process. Though undoubtedly valuable in many cases, the question remains whether it should be supported and reimbursed by a publicly-funded healthcare system. In this study published in Genetics in Medicine, TRANSPERS collaborator Deborah Marshall examines how the parents and families of children with rare genetic diseases value such tests. This is the first study quantifying the personal utility of exome sequencing for parents of children with rare diseases.

The authors found that parents highly valued exome sequencing. They were willing to pay CAD$6590 (US$4943), wait 5.2 years to obtain results, and accept a 3.1% reduction in the chance of diagnosis for ES compared with operative procedures. The authors conclude that timely access to ES could reduce the diagnostic odyssey and associated costs.

TRANSPERS congratulates Collaborator Deborah Marshall on her speaking engagement in Australia and several awards

Long time TRANSPERS collaborator, Deborah Marshall (University of Calgary), recently traveled to Brisbane, Australia for an invited speaking engagement on patient preferences on decisionmaking at Asia Pacific League of Associations for Rheumatology. Deborah has also been recently honored with an award for her excellence in health technology assessment and a Peak Scholar award for her work in patient preferences.

TRANSPERS Payer Advisory Council Member, Lew Sandy, published on Building Trust Between Physicians, Hospitals, and Payers in a recent JAMA **article**

Kathryn Quoted in Wall Street Journal and CNBC Articles

Kathryn was interviewed by the WSJ on the tax implications of DTC genomic testing and by CNBC on personalized medicine costs.

The WSJ article addressed the recent determination by the IRS that the 23andMe DTC test meets the standard for individuals to use their Tax-Free Health Savings Accounts. She was quoted on the regulation of 23andMe tests which are "regulated differently from clinical genetic tests," and "If you get a result and see a physician, they need to redo the test in a clinical lab," she said. "In that way, it is not health testing in the normal sense."

In the CNBC article, Kathryn was interviewed on the cost and insurance coverage for genetic tests. She noted that "The reason insurers have been slow to cover genetic tests is not the label "preventative care," but instead the uncertainty of whether or not genome sequencing can currently lead to actionable clinical results. Insurers are very interested in using genetic testing for prevention, but we need to ... demonstrate that the information will be used and that it's a good trade-off between the benefits and the costs."

TRANSPERS seeks faculty and post-doctoral fellows

Please see position announcements at:

Faculty Position

TRANSPERS Postdoc

Joint TRANSPERS/World Economic Forum Postdoc