University of South Florida and cancer advocacy organization FORCE receive PCORI award to boost new national clinical research network

Tampa, FL (Jan. 23, 2014) – A team led by the University of South Florida (USF Health) Morsani College of Medicine and the leading national hereditary breast and ovarian cancer advocacy organization, FORCE (Facing Our Risk of Cancer Empowered), has received a funding award from the Patient-Centered Outcomes Research Institute (PCORI) to develop and expand a health data network that will be part of PCORnet: the National Patient-Centered National Clinical Research Network.

The ABOUT Network (American BRCA Outcomes and Utilization of Testing Patient-Powered Research Network) is one of 29 that were recently approved for a total of $93.5 million from PCORI to form this new national resource that aims to boost the efficiency of health research.

PCORI envisions PCORnet to be a secure, national data network that improves the speed, efficiency, and use of patient-centered comparative effectiveness research (CER). By integrating data available in the 29 individual networks, PCORnet aims to provide access to a large amount of diverse, nationally representative health information that can support a range of study designs. It will reduce the time and effort needed to launch new studies and focus research on questions and outcomes especially useful to patients and those who care for them.

Moreover, PCORnet will join networks operated by both patient communities and health systems and will require patients' and other stakeholders' involvement in all aspects of the collection and use of the data. By enabling researchers and patients, clinicians, and other end-users of study results to interact directly and jointly determine research priorities, such as the selection of specific studies to support, PCORnet will advance the shift in clinical research from investigator-driven to patient-centered studies.

During the next 18 months, the USF Health and FORCE-led ABOUT Network team will use the PCORI funds to expand and improve its systems, work to standardize its data, and be part of the process to develop policies governing data sharing and security and protection of patient privacy. It also will refine its network’s capacity to engage and recruit patients and other stakeholders interested in participating in research.

The team is led by principal investigator Rebecca Sutphen, M.D., professor of genetics at the USF Health Morsani College of Medicine. The team also includes patient advocates focused on advancing hereditary cancer research led by Dr. Sue Friedman, founder and executive director of FORCE. The Michigan Department of Community Health (MDCH) Genomics and Genetic Disorders Section is also partnering in the network.
“Our USF and FORCE teams bring highly complementary expertise in research and advocacy to this effort and we anticipate that together we will play an important role in shaping the future of hereditary cancer research to improve health for the high-risk community,” said USF’s Dr. Sutphen. “We’re honored to be selected as an inaugural member of the PCORnet National Clinical Research Network.”

“FORCE’s involvement in this collaboration will advance our mission to improve the lives of people and families affected by hereditary breast and ovarian cancer,” said FORCE’s Dr. Friedman. “Our participation in PCORnet will provide members of our community with unprecedented input to establish goals, identify unmet needs, and shape the priorities for comparative effective research.”

“We are pleased that the ABOUT Network will be part of this exciting initiative to build the data structures needed to significantly enhance the speed and efficiency of patient-centered comparative effectiveness research,” said PCORI Executive Director Joe Selby. “The process to select the awardees was very competitive and the ABOUT Network demonstrated it has the expertise, resources, and commitment to engaging patients and other stakeholders to be an excellent fit in PCORNet.”

The ABOUT Network was selected through a review process in which patients, caregivers, and other stakeholders joined scientists to evaluate the proposals. Applications were assessed for the capacity of their networks to collect comprehensive clinical data, how well they will engage patients and other stakeholders, and their ability to maintain data security and patient privacy, among other criteria.

All awards are approved pending completion of a business and programmatic review by PCORI staff and issuance of a formal award contract.

PCORI has awarded a total of $464.4 million since it began funding CER in 2012. For more information about PCORI funding, visit http://pcori.org/funding-opportunities.

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About PCORI
The Patient-Centered Outcomes Research Institute (PCORI) is an independent, non-profit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers and clinicians with the evidence-based information needed to make better-informed health care decisions. PCORI is committed to continuously seeking input from a broad range of stakeholders to guide its work. More information is available at www.pcori.org.

About USF Health
USF Health’s mission is to envision and implement the future of health. It is the partnership of the USF Health Morsani College of Medicine, the College of Nursing, the College of Public Health, the College of Pharmacy, the School of Biomedical Sciences and the School of Physical Therapy and Rehabilitation Sciences; and the USF Physician’s Group. The University of South Florida is a Top 50 research university in total research expenditures among both public and private institutions nationwide, according to the National Science Foundation. For more information, visit www.health.usf.edu

About FORCE
No one should have to face hereditary breast and ovarian cancer alone. For more than 15 years, FORCE has been the voice of the hereditary breast and ovarian cancer community. FORCE provides support,
education and programs to help those facing hereditary breast and ovarian cancer know their healthcare options and make informed decisions. The organization is the de facto leader in guiding critical research and policy issues that impact the hereditary breast cancer and ovarian cancer community. For more information about FORCE and hereditary breast and ovarian cancer, please visit www.facingourrisk.org