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FOR IMMEDIATE RELEASE

Sisters Network® Inc. partners with FORCE and University of South Florida researchers to promote patient centered outcomes research

Research network partnership gives patients a voice

Tampa, FL (April 28, 2014) – Sisters Network® Inc., the only national African American breast cancer survivorship organization, announced today a partnership with Facing Our Risk of Cancer Empowered (FORCE), the leading advocacy organization for families affected by hereditary breast and ovarian cancer, and researchers at the University of South Florida to promote awareness and patient-centered research focused on inherited breast cancer in African American women.

Sisters Network will join the ABOUT Patient-Powered Research Network (PPRN), one of 29 networks participating in PCORnet, a new national research network formed by the Patient Centered Outcomes Research Institute (PCORI). PCORnet's goal is to improve patient outcomes by focusing on answering real-world medical questions that will help patients and their doctors make informed healthcare decisions. The ABOUT Network aims to enroll 10,000 people nationwide with a personal or family history of hereditary breast or ovarian cancer, and to collect information about their experiences to determine patterns and gaps in research, resources, and access to quality health services.

“Sisters Network serves an important group of stakeholders in patient-centered outcomes research. We know that there are disparities in access to genetic information and services, and representation in research for African American women with breast cancer,” said Sue Friedman, FORCE’s Executive Director. “The organization will play a central role in helping us identify unmet needs and in shaping the priorities for future comparative effectiveness research.”

The ABOUT Network will open its public portal for participation next month for anyone with a personal or family history that suggests inherited risk for breast or ovarian cancer (HBOC)—regardless of genetic counseling, testing, or a confirmed genetic mutation. Individuals who participate can securely contribute their data through a personal user account, and will receive regular updates on the growing number of network participants, hereditary cancer news, and research findings. Stakeholder and patient advocate partners in the network will play a vital role in study design, research questions, recruitment methods and analyses, and governance of this national network.

The ABOUT Network project is led by Principal Investigator Rebecca Sutphen, MD, Professor of Genetics, and a team of researchers at the USF Health Morsani College of Medicine; Dr. Sue Friedman

of FORCE, and Deb Duquette, CGC, Genomics Coordinator at the Michigan Department of Community Health (MDCH) Genomics and Genetic Disorders Section.

“Research shows that black women are less likely to get breast cancer than white women, but more likely to die from it. Black women are also diagnosed at a younger age, and their tumors tend to be more aggressive and harder to treat,” explains Karen E. Jackson, Sisters Network Founder/CEO. “We are committed to facilitating research that might help end these discrepancies. Our collaboration with ABOUT Network is a positive step in that direction.”

Funded by the Patient Centered Outcomes Research Institute (PCORI), ABOUT and the other PCORnet research networks form a secure, national data network that improves the speed, efficiency, and use of patient-centered comparative effectiveness research. By integrating information from the individual networks, PCORnet will provide a diverse, representative, current health information database which can support a range of research. 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.

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About Sisters Network® Inc.

Sisters Network® Inc., is the only national African American breast cancer survivorship organization. Presently, the organization has over 43 affiliate chapters nationwide. Sisters Network is recognized nationally as the leading voice in the African American women's fight against breast cancer. For more information, please visit www.sistersnetworkinc.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

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