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Genetic Alliance team among PCORI funding recipients to establish the National Patient Centered Clinical Research Network

WASHINGTON, DC (December 18, 2013) A team led by Genetic Alliance has been approved for a funding award by 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. **Community-Engaged Network for All** (CENA) is one of 29 networks approved to form this new national resource that aims to boost the efficiency of health research.

Under the CENA proposal, Genetic Alliance, University of California San Francisco, University of California Davis Health System, and Private Access will collaborate with ten disease advocacy organizations that were competitively selected earlier this year from nearly 100 Genetic Alliance partners that had applied to take part in the pilot. CENA will employ Genetic Alliance's award-winning Platform for Engaging Everyone Responsibly (PEER) to launch and/or upgrade online registries for each of the ten conditions; and through each, to help engage additional participants in participant-centric biomedical research. Genetic Alliance will provide technical assistance for engaging communities to safely share their information online, as well as community building and collaboration among condition communities, and with other PCORI projects. Dixie Baker, a renowned privacy and security technology expert and senior partner at Martin, Blanck and Associates, will be an advisor on the project.

"We are pleased that CENA 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 CENA demonstrated it has the expertise, resources, and commitment to engaging patients and other stakeholders to be an excellent fit in PCORnet."

The initiative will use and improve upon participant-led governance models that Genetic Alliance has pioneered for more than a decade, bringing leaders and affected individuals from each condition community together to oversee CENA. Explained Genetic Alliance CEO and Principal Investigator Sharon Terry: "We are thrilled. Collaboratively building a participant-centric clinical research network has long been part of Genetic Alliance's vision. Using PEER, these advocacy organizations and academic partners will collaborate in ways that will align incentives, empower data sharing, and revolutionize clinical research."

The group plans to test the prospect of recruiting patients from academic medical centers into participant-led models. The ten patient support organizations participating in CENA are Alström Syndrome International, Dyskeratosis Congenita Outreach, Inflammatory Breast Cancer Research Foundation, Hepatitis Foundation International, Joubert Syndrome Foundation, KS&A, MLD Foundation, National Gaucher Foundation, National Psoriasis Foundation, and PXE International. The conditions range from rare to common, and cover a broad demographic spectrum. Additionally, through collaboration with another UCSF proposal selected by the PCORI Board (Health eHeart), the initiative will assess the utility of CENA to recruit for a co-morbidity (cardiovascular disease) that affects patients in each of the ten groups.

In addition, CENA will pilot new methods of facilitating collaboration among researchers and participants by supporting a broadly accessible online environment where communities and researchers have equal voice in the development of research hypotheses. The condition-specific communities will be supported and grown through inter-community collaboration and sharing best practices. Through the development partnership with Private Access, PEER will allow for extremely cost-effective data capture from participants using technology that enables individualized and dynamic privacy permissions management.

PEER employs a Traitwise gamified survey interface to present questions in a way that provides immediate feedback to maximize participant engagement, and that provides flexibility for continual fine-tuning or addition of questions, including changes based on input from condition-specific communities and academic research partners. PEER's novel approach of empowering each participant to determine with whom and for what purpose his or her information may be shared, and its potential to radically accelerate participant engagement and the collection of participant-reported outcomes has been recognized through earning top honors in the Sanofi Collaborate | Activate and Ashoka Changemaker Challenges, as well as being designated by Forbes as one of six business models that are transforming health systems around the world. This initiative will utilize Syapse for Registries, which enables the management of large-scale phenotypic, "omics," and other relevant patient data, all linked through a flexible platform that can be quickly configured to meet complex needs.

Co-PIs Mini Kahlon at UC San Francisco, and Nick Anderson at UC Davis, will lead the academic partnership, and will invite researchers and their patients into CENA. In addition to testing whether patients at their institutions can be successfully engaged using PEER and other participant-led initiatives, CENA plans to employ a UC San Francisco developed tool called Open Proposals to help support dynamic and meaningful communications among individual participants, leaders of the disease advocacy organizations, and UC San Francisco and UC Davis researchers interested in those conditions.

Commenting on the announcement, Dr. Kahlon, Executive Director of the Clinical and Translational Science Institute at UC San Francisco, stated: "We couldn't be more

delighted! We are firmly committed to facilitating cross-institutional collaboration to share clinical data for research purposes. By involving both UC San Francisco and UC Davis, this initiative ties directly into that objective, and is consistent with the Chancellor's theme regarding the importance for discovering new ways in which to engage patients in accelerating research."

Adds Sharon Terry: "Particularly for genetic and chronic conditions, academic medical centers and specialized treatment centers hold great promise as focused points of engagement for recruitment into participant-led networks." Reflecting on the potential of the initiative, Ms. Terry, who founded and heads a disease advocacy organization for a genetic condition that affects her two children, adds: "CENA will help to identify best practices for engaging participants in advancing research, and we're all eager to extend these practices to the more than 1000 other condition-specific organizations in Genetic Alliance's network."

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

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About Genetic Alliance
Genetic Alliance engages individuals, families and communities to transform health. Founded in 1986, it is the world's largest nonprofit health advocacy organization network. Genetic Alliance's network includes more than 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. For more information about Genetic Alliance, visit *www.geneticalliance.org*.

About UC San Francisco (UCSF)
UCSF is a leading university dedicated to promoting health worldwide through advanced biomedical research, graduate-level education in the life sciences and health professions, and excellence in patient care. It includes top-ranked graduate schools of dentistry, medicine, nursing and pharmacy, a graduate division with nationally renowned programs in basic biomedical, translational and population sciences, as well as a preeminent biomedical research enterprise and two top-ranked hospitals, UCSF Medical Center and UCSF Benioff Children's Hospital. More information is available at *www.ucsf.edu*.

About UC Davis Health System
UC Davis Health System improves lives by providing excellent patient care, conducting groundbreaking research, fostering innovative, interprofessional education and creating dynamic, productive community partnerships. It encompasses one of the country's best medical schools, a 619-bed acute-care teaching hospital, a 1,000-member physician practice group and the Betty Irene Moore School of Nursing. Together, they make UC Davis a hub of innovation that is transforming health for all. For information, visit *www.healthsystem.ucdavis.edu*.

About Private Access
Private Access is striving to make it safe for sensitive personal information such as medical records and genomic data to be accessible over the Internet. Through PrivacyLayer®, the firm 's core services platform, Private Access empowers individuals to set granular privacy preferences and use dynamic consent tools to address a number of critical privacy concerns and related hurdles that have traditionally impeded privacy-protective sharing of this valuable information. In 2009, Forbes named Private Access as #12 on its list of America's Most Promising Companies. More information is available at *www.privateaccess.com*.

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*.