



4301 Connecticut Ave NW
Suite 404
Washington DC 20008-2304
Telephone: 202.966.5557
Fax: 202.966.8553

For Immediate Release
July 27, 2015

Contact: [Tanya Murza](#)
202-966-5557 ext. 205

CENA Approved for \$1.2 Million in Second Phase of Development of PCORnet, a New National Clinical Research Network

Washington, DC (July 27, 2015) – A collaborative, cross-disciplinary, team led by Genetic Alliance has been approved for a three-year \$1.2 million funding award by the Patient-Centered Outcomes Research Institute (PCORI) as part of the second phase of PCORnet, the National Patient-Centered Clinical Research Network.

This funding award continues PCORI's support for the Community-Engaged Network for All (CENA), participation in PCORnet's, a large-scale collaborative research initiative designed to deeply engage individuals, families and communities to seek the answers relevant to them. PCORnet is a community of patients, their families and caregivers, researchers, scientists, clinicians, health system leaders, and other committed individuals and organizations dedicated to the common purpose of accelerating patient-centered outcomes research (PCOR).

PCORI provided \$1 million to CENA during the first phase of PCORnet's development, which began in the spring of 2014.

As one of 34 health networks comprising this national clinical research resource in Phase II, CENA is unique among the Patient Powered Research Networks: 1) it is itself a network of eleven organizations; 2) it empowers people to set (and change) their own health data sharing, privacy, and access preferences; and 3) it has refined a scalable system for prioritizing and conducting research with these communities.

The new funding award will support CENA's continuing efforts to give people the tools they need to be part of PCOR. A key team member, Private Access, co-developed the [Platform for Engaging Everyone Responsibly \(PEER\)](#) together with Genetic Alliance. PEER helps the eleven disease advocacy organizations engage their own communities while also letting individuals share health information on their own terms with researchers, organizations, and data analysis platforms of their choosing. Participants decide when, how much, and with whom to share. The University of California, San Francisco has also partnered in the project and has added a platform called [Mosaic](#), an online system that creatively manages crowdsourcing research questions from multi-stakeholder communities to design, implement, and disseminate relevant research studies. Also contributing to the effort, the

University of California, Davis offers relevant and innovative expertise in informatics and data standards. Finally, CENA currently includes eleven disease advocacy organizations (see below in About CENA).

“We are delighted to continue participating in PCORnet,” said Sharon Terry, principal investigator. “Biomedical research, particularly PCOR, has got to be driven by the people, for the people. CENA allows all comers, regardless of condition or interest, to work together toward that goal.”

“We're pleased that CENA has been approved for this funding support to continue our productive mutual efforts to build what we intend to be a premier national resource for conducting high-quality, patient-centered clinical research,” said PCORI Executive Director Joe Selby, MD, MPH. “I greatly appreciate the contributions of all the PCORnet partners during Phase I, which readied PCORnet for a robust start on an exciting second phase of expansion and the launch of several research studies.”

The funding award to CENA has been approved by PCORI's Board, pending completion of a business and programmatic review by PCORI staff and negotiation of a formal award contract.

###

About CENA

CENA strives to empower people to accelerate the solutions they need for their lives and the lives of their loved ones. Currently, the eleven organizations that participate in CENA are [Alström Syndrome International](#), [AXYS](#), [Celiac Disease Foundation](#), [Dyskeratosis Congenita Outreach](#), [Hepatitis Foundation International](#), [Inflammatory Breast Cancer Research Foundation](#), [Joubert Syndrome and Related Disorders Foundation](#), [LymeDisease.org](#), [MLD Foundation](#), [National Gaucher Foundation](#), [PXE International](#). They engage their communities, survey members based on the concerns of individuals affected by those conditions, and conduct patient-centered outcomes research.

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 <http://www.geneticalliance.org>.*

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 <http://www.privateaccess.com>.*

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 <http://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 <http://www.ucdmc.ucdavis.edu>.*

About PCORI

PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund research that will provide patients, their caregivers and clinicians with the evidence-based information they need to make better-informed healthcare decisions. PCORI is committed to continuously seeking input from a broad range of stakeholders to guide its work. *More information is available at <http://www.pcori.org>.*