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FOR IMMEDIATE RELEASE

Community Engaged Network for All Announces the Addition of Two More Patient-Powered Research Networks in PCORnet

WASHINGTON, DC (November 19, 2014) Community Engaged Network for All (CENA), a Patient Centered Outcomes Research Institute (PCORI) funded project announced the launch of registries for dyskeratosis congenita (DC) and related telomere biology disorders, and pseudoxanthoma elasticum (PXE) today. These registries join three others that have launched as part of this project.

DC Outreach, Inc. launches the first international Dyskeratosis Congenita and Telomere Biology Disorder Registry (www.dcoutreach.org/solve-the-puzzle). PXE International launches the PXE Health Engagement and Lifestyle Program (PXE HELP) (pxe.org). These registries are built on CENA's Platform for Engaging Everyone Responsibly (PEER), developed in conjunction with technology partner Private Access. PEER allows each individual to determine his or her own level of personal data sharing, privacy and access preferences.

As individuals enter health information into the registry, they see real-time comparisons of their responses with the grouped anonymous answers of other participants.

Rachel Godfrey, principal investigator for the DC Outreach Registry, said: "This is a truly transformative patient-centered registry for those with Dyskeratosis Congenita and Telomere Biology Disorders. Those with rare conditions don't always have a strong voice in medical research and advocacy. The ultimate goal of the DC Outreach Registry is to improve the lives of those with Dyskeratosis Congenita and Telomere Biology Disorders by providing more appropriate means of information sharing and facilitating reciprocal medical research and care they greatly desire."

PXE International's mission is to tame pseudoxanthoma elasticum (PXE), a metabolic condition that causes vision loss and cardiovascular disease. PXE HELP will empower individuals affected by PXE to share their health and lifestyle information to generate a full picture of the condition and its ramifications. Several important discoveries this year point to potential treatments, and the survey will provide the foundation for clinical trials. In addition, most people with PXE suffer from early macular degeneration and the registry

will provide an opportunity to compare current treatments. “We’ve had a registry for almost 20 years, in fact we were the first lay run registry in the world. But we are really excited by this because individuals will have the tools they need to share their health information across conditions and institutions in a way that has never happened before! This truly puts the participant at the center,” declares Sharon Terry, CEO of PXE International and Genetic Alliance, and principal investigator of CENA.

CENA is funded by the Patient Centered Outcomes Research Institute (PCORI) and is part of PCORnet: the National Patient Centered Clinical Research Network. CENA is a project of Genetic Alliance, and also includes the University of California, San Francisco, and the University of California, Davis along with technology partner Private Access. CENA's partner organizations have built surveys using common data elements and validated instruments where possible, and are especially interested in the cross condition commonalities. For more information about CENA, visit www.geneticalliance.org/cena.

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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.

The Nine Condition-specific Partners of PCORnet

Alström Syndrome International <https://www.alstrom.org/>
Association for X and Y Variations (AXYS, formerly KS&A) <http://www.genetic.org/>
Dyskeratosis Congenita Outreach <http://www.dcoutreach.com/>
Inflammatory Breast Cancer Research Foundation <http://www.ibcresearch.org/>
Hepatitis Foundation International <http://www.hepfi.org/>
Joubert Syndrome and Related Disorders Foundation <http://www.jsrdf.org/>
MLD Foundation <http://www.mldfoundation.org/>
National Gaucher Foundation <http://www.gaucherdisease.org/>
PXE International <http://www.pxe.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 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 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 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.