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**PCORnet CENA Project Launch
Spotlight on the National Gaucher Foundation and
Joubert Syndrome and Related Disorders Foundation**

WASHINGTON, DC (September 15, 2014) Community Engaged Network for All (CENA), a health data network initiative developed by Genetic Alliance, announced today that two of the nine disease advocacy organizations in the network launched research registries today.

The Joubert Syndrome & Related Disorders Foundation (JSRDF) launched the Joubert Syndrome Link to Information and Family Exchange (JS-LIFE) (jsrdf.org/JS-LIFE) and the National Gaucher Foundation (NGF) launched the Gaucher Network Registry (GNR) (gaucherdisease.org/gaucher-network-registry.php).

Each of these new registries is built on CENA's Platform for Engaging Everyone Responsibly™ (PEER), developed in conjunction with technology partner Private Access™. It allows each individual to determine his or her own level of personal data sharing, privacy and access preferences. As individuals enter health information into these registries, they will see in real-time a comparison of their responses with the grouped anonymous answers of other participants, thanks to technology by Traitwise™. PEER and each specific registry have Institutional Review Board approvals.

Matthew Smith, principal investigator for JS-LIFE said: "JS-LIFE is a truly transformative patient-centered registry for those with Joubert syndrome and related disorders. Those with rare conditions don't always have a strong voice in medical research and advocacy. If those with Joubert syndrome and other rare conditions cannot speak for themselves, then it is our duty at disease advocacy organizations like the Joubert Syndrome & Related Disorders Foundation to advocate boldly for them. CENA and JS-LIFE do just that, allowing the voices of those with Joubert syndrome and other related conditions to be heard: loud and clear. THEY control their own data, THEY are empowered, and THEY are given the voice that they deserve in rare disease advocacy and research. The ultimate goal of JS-LIFE is to improve the lives of those with Joubert Syndrome and related disorders by providing more appropriate means of information sharing and facilitating reciprocal medical research and care they greatly desire."

Each community or organization customizes PEER for their own use. Rhonda P. Buyers, CEO of NGF states, “It is important to us that PEER reflects our branding, uses guides from our community, and communicates our vision exactly. The National Gaucher Foundation’s Gaucher Network Registry is the first participant-powered Gaucher registry, providing those with Gaucher disease the opportunity to structure the record of their own individual disease experiences. It will empower individuals with Gaucher disease and their families with a means for using their health information to become proactive in improving the quality of their lives and instrumental in future research studies in the field.”

JSRDF and NGF are among the nine organizations involved in the CENA project, which range from a focus on common chronic conditions to genetic and rare disorders. Together they have identified outcomes they hope to achieve by supporting patient-centered, data-focused clinical research. CENA is funded by the Patient-Centered Outcomes Research Institute (PCORI) and is part of PCORnet: the National Patient-Centered Clinical Research Network. CENA 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. They are also working to integrate the common questions and data model of PCORnet to be research ready in 2015. CENA partners University of California, San Francisco and Davis are both engaged with these nine organizations in recruitment and design of research projects.

“The collaboration among these organizations is remarkable. This cross condition registry requires both general and condition specific elements and these organizations are doing a great job learning together about the rigors of registries and the benefits of being able to study comorbidities, quality of life, and burden of disease together”, explained Sharon Terry, principal investigator of CENA and CEO of Genetic Alliance.

The other seven condition advocacy organizations will all launch, or update, research registries in the next month. They are Alström Syndrome International, Association for X and Y Variations (AXYS, formerly KS&A), Dyskeratosis Congenita Outreach, Hepatitis Foundation International, Inflammatory Breast Cancer Research Foundation, MLD Foundation (metachromatic leukodystrophy), and PXE International (pseudoxanthoma elasticum).

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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 the Nine Condition-specific Partners

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.