



4301 Connecticut Avenue NW - Suite 404
Washington DC 20008-2304
Telephone: 202.966.5557 x205
Fax: 202.966.8553

Contact: Tanya Murza
tmurza@geneticalliance.org or
<mailto:media@hepatitisfoundation.org>

FOR IMMEDIATE RELEASE

Hepatitis Foundation International Patient Registry Network (HepPRN) Launched Today

WASHINGTON, DC (October 21, 2014) Community Engaged Network for All (CENA), a Patient Centered Outcomes Research Institute (PCORI) funded project, announced that the Hepatitis Patient Registry Network (HepPRN) launched today. This registry is a project of the Hepatitis Foundation International (HFI).

The Hepatitis Foundation International (HFI) is a 501 (c) 3 non-profit organization established in 1994 with world headquarters located in Silver Spring, MD. Since its inception, HFI has worked on eradicating chronic hepatitis by promoting and advocating for health and wellness. HFI has been on the forefront promoting preventative action to help modify unhealthy liver-damaging behaviors before they start. HFI implements its mission through its touchstones to educate, prevent, serve, support and reach well over 5 million patients and health care professionals annually, through its public and private partnerships.

HFI's Hepatitis Patient Registry Network (HepPRN) collects self-reported data on the determinants of a patient's health along the hepatitis health care continuum. This patient-centric registry is focused on what it's like to live and/or provide care for those with hepatitis. HepPRN also serves to engage more individuals in patient-centered research and trials.

HepPRN joins a growing number of other registries using the Platform for Engaging Everyone Responsibly™ (PEER). "The HepPRN will greatly add to preliminary HFI data collected during the past 15 years and will allow the Foundation to gain more insight on the demographic profile and provide answers to pressing research needs for the population it serves. HFI is using this platform because PEER provides participants with complete control over what they wish to share and don't want to share," explained Ivonne Perlaza Fuller, NRRP, MPA, Chief Executive Officer of HFI.

Each individual determines his or her own personal data sharing, privacy and access preferences. Private Access™ designed this contextual granular preference setting system technology. In addition, as individuals enter health information they receive real time feedback that allows them to see how they compare to others, thanks to gamification

technology by Traitwise™. HepPRN received institutional review board approval from the Genetic Alliance IRB. The platform itself has IRB approval from Western IRB.

“With the launch of this registry, there’s now a way to share information with privacy controls, which gives me a lot of hope for more effective research in the future”, said Karen C. Wirth, MBA, Chair of the HFI Board of Directors. “Each year we reach more than 5 million patients, families and community based organizations. We add this registry as a research resource to the suite of tools we use to educate, prevent, serve and support our constituents in their quest for optimal health outcomes.” HFI invites all individuals affected by hepatitis to join the registry at http://www.hepatitisfoundation.org/RESEARCH/Patient_Registry.html.

Like CENA on Facebook: [facebook.com/cenaproject](https://www.facebook.com/cenaproject)
Follow on Twitter: @CENAPROJECT

###

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.