



For Immediate Release

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Contact: Tanya Murza
tmurza@geneticalliance.org

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**Genetic Alliance's PEER Registry Recognized
at White House Precision Medicine Initiative Event**

Washington, DC (July 8, 2015) – The award-winning [Platform for Engaging Everyone Responsibly registry \(PEER\)](#), developed by Genetic Alliance and Private Access, was showcased along with four other precision medicine tools at today's White House Champions for Change Celebration. The event honored nine precision medicine leaders and highlighted advances in the field.

The White House invited five innovative projects to describe their commitment to precision medicine. As one of the five, Genetic Alliance president and CEO, Sharon Terry, announced that the registry has newly added the capability for individuals to directly upload data from their Electronic Health Record (EHR) systems into PEER. She added that the group plans to begin deploying this in both existing and slated PEER Community releases over the next few weeks. Speaking about the new functionality, Terry said: "We have a long history of commitment to the vision of precision medicine and to providing people a way to be engaged in research safely and securely. The ability to upload clinical data directly into PEER Community portals adds a critical feature that will advance this work."

PEER differs from traditional registry systems in that it lets participants dynamically control: a) how much information they wish to share, b) with whom they elect to share it, and c) for what purpose. These tools have set PEER apart by putting granular and dynamic information control in the hands of patients, participants, and their authorized representatives. In her remarks, Ms. Terry explained that these controls extend to all clinical information entered, including EHR data. "It is fundamental to the PEER vision that each participant be able to decide who can access their information, and for what purpose," she stated. "We believe this is foundational to engagement and trust."

Cerner Corp. and the National Association for Trusted Exchange (NATE) assisted in adding PEER's new clinical data acceptance capabilities—PEER can now accept coded, clinical, Direct-compliant data. Consistent with Meaningful Use, participants can securely send this

information directly to PEER from their patient (PHR) portals, or can instruct their providers to transmit this information on their behalf. PEER's systems will automatically route data into each individual's record, where it will be governed by the individual's personal privacy preferences.

PEER will be interoperable with other programs announced at the Champions for Change event, including the Data Independence movement (getmyhealthdata.org) and Sage Bionetworks' project with Apple Research Kit. For more information about PEER visit <http://peerplatform.org>.

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About Genetic Alliance

Genetic Alliance engages individuals, families, and communities to transform health. Founded in 1986, it is one of the world's largest nonprofit health advocacy organization networks. 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. Genetic Alliance values openness and transparency as a mechanism for transformation and challenges the status quo in health systems and research. PEER is funded through PCORI/PCORnet and Robert Wood Johnson Foundation. *For more information about Genetic Alliance, visit 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. *For more information, visit www.privateaccess.com.*