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Genetic Alliance and PCORnet to Participate in Precision Medicine Summit with President Obama

PCORnet Pledge Announced at Precision Medicine Initiative Summit

Washington, DC (February 25, 2016) - Genetic Alliance is participating in the Precision Medicine Initiative Summit with President Obama today. Amidst several other 'health data flow' announcements, Sharon Terry, CEO, announced that the Patient Powered Research Networks (PPRN) of the National Patient-Centered Clinical Research Network (PCORnet) will prioritize patient access to electronic health record (EHR) data in order to let it flow into research studies. As a leading voice in the National Patient-Centered Clinical Research Network (PCORnet)—a network changing the culture of medical research by involving participants, their families, and communities in all phases of research—Genetic Alliance, represented today by Sharon Terry, CEO, is thrilled to be involved in this commitment to help people more readily obtain their health information for advancing research.

PCORnet engages its community of stakeholders in research to enable faster, more informative, clinical research that transforms clinical practice, improves health outcomes, and helps people make better care decisions. A "network of networks," PCORnet is comprised of 20 Patient Powered Research Networks (PPRNs), serving more than 100 conditions, and 13 Clinical Data Research Networks (CDRNs), representing the health systems that serve millions of patients. One of these PPRNs is run by Genetic Alliance, the Community Engaged Network for All (CENA). CENA is quite novel in that it is a collaborative effort of 10 disease advocacy organizations; the University of California, San Francisco; the University of California, Davis; and Private Access. Using technology and services from Private Access, CENA utilizes the Platform for Engaging Everyone Responsibly (PEER) to enable individuals to share their health information according to their personal data access and privacy preferences.

"CENA has implemented the capability to receive EHR data transmitted using the Direct secure-email protocol within PEER, and their participants are giving CENA's Direct address to their providers with the request that their EHR data be sent to CENA. We have been following the work of the Argonaut Project and are eager to implement apps that will enable our participants to request the PCORnet clinical data elements through a FHIR-based API," said Dixie Baker of

Martin Blanck & Associates. Dr. Baker surveyed the 20 PPRNs and wrote a report detailing their capacity and needs. All 20 networks are modeling novel engagement strategies that include collecting data from participants within their networks, and extracting and integrating high quality, clinical data from participants' electronic health records (EHRs). Five PPRNs are currently obtaining EHR data directly from healthcare providers after implementing technology capable of receiving structured data that all certified EHR technology is required to produce.

To create a more robust network, the PPRNs pledge to help participants access their EHR data and to make it available for research. This will greatly enhance the quality, sensitivity, and power of the available research data. The PPRNs will enable participants to retrieve their own EHR data through existing patient portals, giving them an immediate option to make these data available for research, while building toward data retrieval using apps to query OAuth 2.0 based APIs, and ultimately retrieval of FHIR resources. The first PPRN deployments are already in use.

"I am delighted to see these data flow! The goal for the PPRNs is to empower people to ask for their health data from healthcare providers and receive it in the easiest and most useful way," said Sharon Terry, CENA PPRN PI, co-PI of the PCORnet Coordinating Center, and a member of the Precision Medicine Initiative Cohort Program Advisory Panel.

"This EHR data, combined with information from self-reported data and other sources, will be critical in understanding health outcomes for millions of Americans," Terry added.

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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 PCORnet

PCORnet, the National Patient-Centered Clinical Research Network, is an innovative initiative of the Patient-Centered Outcomes Research Institute (PCORI). The goal of PCORnet is to improve the nation's capacity to conduct comparative clinical effectiveness research efficiently by creating a large, highly representative network for conducting clinical outcomes research that directly involves patients in the development and execution of the research. *More information is available at www.pcornet.org.*