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### **Genetic Alliance to Coordinate PCORI's Patient Powered Research Networks**

Washington, DC (April 20, 2015) – Genetic Alliance has been awarded a contract to lead the [PCORnet](#) Coordinating Center effort of leveraging the value of the Patient Powered Research Networks (PPRNs). The PPRNs are a unique aspect of PCORnet—an initiative funded by PCORI to harness the power of health information to conduct research faster, at lower cost, and with greater power and focus on patient needs and concerns.

The Patient-Centered Outcomes Research Institute (PCORI)—a nonprofit, nongovernmental organization authorized by Congress in 2010—embraced PPRNs as inherently focused on patients as central stakeholders, and as partners with healthcare providers and researchers. These coalitions and community-based groups form research networks and contribute to [Patient-Centered Outcomes Research](#) (PCOR), seeking answers to the questions and concerns most relevant to patients, caregivers, and clinicians. These networks are trust-based and together form an authentic and effective community.

PCORI's Program Director of CER Methods and Infrastructure, Rachael Fleurence, PhD, said, "I am thrilled that Genetic Alliance, under Sharon Terry's leadership, will coordinate the efforts of the Patient-Powered Research Networks. There is no question that this expertise will be invaluable to PCORnet in leveraging the full power of patient communities' involvement in research and their critical contribution to improving health outcomes."

Principal investigator of the PCORnet Coordinating Center Richard Platt, MD, MS, shared, "The PPRN are essential components of PCORnet. Sharon Terry's new role greatly enhances the Coordinating Center's ability to help them achieve their potential."

Engaging Genetic Alliance to coordinate the PPRNs emerged from a need to capitalize on their collective resources, explore the value inherent in the network, and to support the "network of networks"—PCORnet—by bringing the PPRNs to all research conversations, enhancing PPRNs collective activities and collaborations, and supporting global issues of the larger ecosystem. The PCORnet research network is innovative in its approach; this is the first national opportunity and challenge to rally multiple stakeholders in a systematic way to enable comparative effectiveness research with a participant-centric focus.

“This is a critical moment, and an amazing opportunity,” said Sharon Terry, president and CEO of Genetic Alliance and principal investigator of this effort. “The power of these collectives is in their immediate connection to individuals and communities. We are facile, flexible, and free to challenge the traditional logjams that slow research. Ultimately individuals, families, and communities are the catalyst for transformation of PCOR and the acceleration of appropriate services for all.”

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### **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 healthcare decisions. PCORI is committed to continuously seeking input from a broad range of stakeholders to guide its work. *For more information about PCORI, visit [www.pcori.org](http://www.pcori.org).*

### **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](http://www.geneticalliance.org).*