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***Genetic Alliance Receives Robert Wood Johnson Foundation Grant
to Create 'White Label' Version of Platform for Engaging Everyone Responsibly***

WASHINGTON, DC (December 22, 2014) Genetic Alliance today announced a \$500,000 grant award from the Robert Wood Johnson Foundation (RWJF). The award will be used over the next year to create and evaluate the effectiveness of a 'white label' version of the Platform for Engaging Everyone Responsibly (PEER) that enables individuals to share health information with researchers and each other on their own terms to advance an understanding of health and disease, and to accelerate the development of cohorts for clinical trials.

Using PEER, individuals are able to set data sharing, privacy, and access preferences, and manage their information in a dynamic and granular system. The 'white label' version of PEER will include a simple dashboard and standard operating procedure to facilitate easy customization of the system by disease advocacy and community organizations wishing to offer it to their members.

"We are thrilled to receive this grant from RWJF," said Sharon Terry, president and CEO of Genetic Alliance. "This is our twelfth year working on cross-disease registries in a cooperative nonprofit model. This year, we've worked with a number of disease advocacy organizations in our project within the National Patient-Centered Clinical Research Network (PCORnet) to expand our registry platform. We have found that the whole process would really benefit from production of a 'white label' version to permit disease and community organizations to build registries with dynamic consent quickly and efficiently. I am especially excited that this is an opportunity for organizations and communities to work together for the greater good, and not just for their own need."

Choosing community guides, configuring preference choices, and determining which common data elements and validated instruments to use, are just some of the critical elements in which disease advocacy organizations engage. "This grant will enable us to make these essential aspects simpler and more cost effective for anyone interested in creating a registry, conducting a survey, or wishing to embark on other forms of participant-centric research. This project will essentially create a 'kit', simplifying registry creation," Terry added.

Terry has devoted much of the 20 years since her children were diagnosed with pseudoxanthoma elasticum (PXE) to creating efficient, collaborative, scalable systems to accelerate research on genetic conditions. Since 2008, Genetic Alliance has worked with technology partner Private Access to develop improved ways for individuals to grant faster, easier, and less costly access to otherwise confidential information in order to improve care or accelerate research. Simultaneously, the two organizations work to assure that the concerns many individuals feel regarding the privacy of their sensitive health information are reflected in who can access it and how the information can be used. Private Access and Genetic Alliance collaborated in developing the PEER system in 2011, and since then have launched nearly 20 registries for a variety of conditions. All PEER installations use PrivacyLayer® and related innovations from Private Access to enable participants to manage their information through granular privacy settings and dynamic consent tools.

“With each successive launch, we have been able to streamline the process for interested groups to configure a condition-specific registry and to get underway more quickly and begin producing tangible benefits,” stated Robert Shelton, CEO of Private Access. “The RWJF grant provides an incredible opportunity to take this work to the next level and to give individuals and communities the tools they need to be true participants in research, and to accelerate the discovery of interventions.” Shelton has a child who was pre-natally diagnosed with a chromosomal variation that affects approximately 1 in 650 children, and which led to his serving for seven years as chairman of the nation’s largest disease advocacy organization for that condition prior to forming Private Access. His work with Terry has been a natural outgrowth of the experience the two share in leading condition-specific support organizations and seeking ways to create better systems for disease advocacy organizations and the individuals they serve.

“Giving people the mechanisms to share their health data in ways that are meaningful and comfortable to them is critical to developing a new relationship between people and researchers and clinicians, a relationship better able to develop new knowledge and insights that can improve health,” said Paul Tarini, senior program officer at the Robert Wood Johnson Foundation. “The deeper engagement has tremendous potential to bring us closer to a Culture of Health where all people can live healthier lives.”

The RWJF grant will also provide resources to analyze PEER, offering pre- and post- tests to assess the experience of participants as they make granular and dynamic decisions about data sharing, privacy and access. Genetic Alliance’s Ethics Team will provide their expertise in designing and executing the study of a series of questions, such as: “Does dynamic and granular consent lead to greater and/or more diverse participation in clinical trials? Do researchers have greater or lesser access to data if individuals have more control? Do individuals understand the options in sharing, privacy and data access in the PEER system? Does engagement through advocacy organizations and condition-specific communities unduly coerce potential participants?” Members of the Ethics Team include: Nicholas Anderson, Director of Informatics Research, UC Davis Health System; Greg Biggers, Chairman, Genomera; Kieran O’Doherty, Associate Professor, Applied Social Psychology, University of Guelph; Kelly Edwards, Professor, Department of Bioethics and Humanities, University of Washington School of Medicine; Leila Jamal, Research Assistant, Baylor

College of Medicine, Center for Medical Ethics and Health Policy; Jane Kaye, Director, Centre for Law, Health and Emerging Technologies, University of Oxford; Dean Suhr, President & Board Chair, MLD Foundation; David Winickoff, Associate Professor of Bioethics and Society, University of California, Berkeley.

Approximately 30 organizations will participate in this research. Genetic Alliance will select these groups through a Request for Proposals (RFP) to be issued in January. Interested organizations should contact Erika Lutins (elutins@geneticalliance.org) to receive the RFP when it is issued.

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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 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 the Robert Wood Johnson Foundation

For more than 40 years the Robert Wood Johnson Foundation has worked to improve health and health care. We are striving to build a national Culture of Health that will enable all to live longer, healthier lives now and for generations to come. For more information, visit www.rwjf.org. Follow the Foundation on Twitter at www.rwjf.org/twitter or on Facebook at www.rwjf.org/facebook.