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For Immediate Release
March 24, 2015

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Platform for Engaging Everyone Responsibly Awardees Announced

Washington, DC (March 24, 2015) – Today Genetic Alliance announced the fifteen awardees for Phase I of its initiative to create a ‘white label’ of the Platform for Engaging Everyone Responsibly (PEER). PEER 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. The fifteen selected awardees will work with Genetic Alliance to develop and refine the ‘white label’ PEER while engaging their communities.

This initiative is made possible through a \$500,000 Robert Wood Johnson Foundation grant awarded to Genetic Alliance. Genetic Alliance and technology partner Private Access will collaborate with awardees to cost effectively expand participant-centric health research. Ultimately, the ‘white label’ will result in a simple online dashboard that will enable future groups to customize PEER for a specific use, and make it more user-friendly and culturally appropriate for their members.

“I am thrilled by the spectrum of organizations that will be helping us to develop the ‘white label’ PEER system,” said Sharon Terry, president and CEO of Genetic Alliance and co-creator of PEER. “The goal is to make the development of registries simple and easy. Organizations will just sign up online, create their own instance of the software and get to work. That is our plan for PEER.” Co-creator Robert Shelton, CEO of Private Access, said, “Each of these organizations will build a very sophisticated registry, brand it with their own look and feel, and invite their community to participate through guides specific to them. This is a wonderfully broad set of needs, sophistication, and technical capacity. These organizations will test the white label and refine it with us.”

“As we work to build deeper relationships between people, researchers and clinicians, it is crucial to ensure that we are providing them with appropriate and sensitive mechanisms and resources to share health data in the most secure and efficient ways,” said Paul Tarini, senior program officer at the Robert Wood Johnson Foundation. “It is great to see so many different organizations join development of the ‘white label’ PEER platform and bring us closer to a system that works for all patient populations.”

The awardees for Phase I are AliveAndKickn; American College of Nurse-Midwives; ARPKD/CHF Alliance; Asthma and Allergy Foundation of America; Beyond Batten Disease Foundation; Celiac Support Association; Centre for Health, Law and Emerging Technologies (HeLEX); Center for Jewish Genetics, a cooperative effort of the Jewish United Fund/Jewish Federation of Metropolitan Chicago and the Ann and Robert H. Lurie Children's Hospital of Chicago; The Fibrolamellar Registry; Gastroparesis Patient Association for Cures and Treatments; Medical Investigation of Neurodevelopmental Disorders (MIND) Institute and Center for Excellence in Developmental Disabilities at University of California, Davis; National Alopecia Areata Foundation; Spastic Paraplegia Foundation; Syndromes Without A Name USA; and Turner Syndrome Society of the United States. Another fifteen organizations will be awarded a PEER installation later in the year. Interested organizations should contact Genetic Alliance for further information.

For more information about this grant visit: www.geneticalliance.org/rwjfpeer.

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About PEER

The Platform for Engaging Everyone Responsibly (PEER) enables individuals to share health data on their own terms. Individuals set their own data sharing, privacy, and access preferences. With the help of guides from their community, they choose settings that strike a balance between their desire for solutions to their medical needs and their sensibility about privacy. This allows dynamic and granular contextual engagement. *For more information about PEER, visit www.geneticalliance.org/peer.*

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. *For more information, visit 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.*