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Genetic Alliance Applauds Major Step in Mitochondrial Disease Research

WASHINGTON, D.C., August 26, 2014 – Genetic Alliance saluted the striking results of acquiring responses to over 40,000 survey questions concerning mitochondrial disease through the new Mitochondrial Disease Community Registry (MDCR), all in less than one week. Sponsored by the United Mitochondrial Disease Foundation (UMDF), the new registry employs Genetic Alliance’s Platform for Engaging Everyone Responsibly (PEER), and is being populated by patients, caregivers and family members who are committed to gathering information about mitochondrial disease to accelerate the development of diagnostic tools, treatments and cures.

UMDF Science and Alliance Officer, Philip Yeske, Ph.D., leads the effort on behalf of UMDF. MDCR enables the collection of patient health data in a novel manner. Each participant makes informed decisions about data sharing, privacy, and access. Guides from the community provide templates for these decisions that help the individual understand the process. As Dr. Yeske states, “ This information will be used to develop treatments, identify new symptoms leading to better diagnosis, and provide information to researchers that seek to study mitochondrial disease. Our goal is to identify and characterize every person affected by mitochondrial disease, no matter where they are located, living or deceased. One critically different aspect of this system is the ability of the participant to determine who can view their data or make contact with them to gauge research study or clinical trial interest”.

The UMDF is committed to the long-term financial sponsorship of the MDCR and will serve as guardian of the information and coordinator of the project. In an effort to unify the community and build as quickly as possible the most robust registry, the UMDF has invited other mitochondrial disease related organizations to ask their members to participate. Because individuals make decision about how their data are used, the registry allows multiple uses, and cross symptom research. “This is important toward understanding a diverse set of related neurological and metabolic conditions, such as Alzheimer’s, Parkinson’s, ALS, autism and diabetes,” emphasized Dr. Yeske.

PEER was developed through a long standing partnership between Genetic Alliance, a health advocacy organization, and Private Access, a privacy company. Both are committed to accelerating research through access to health information that remains in the control of the participants. “People have a wide range of sensibilities about privacy with regard to their health information”, said Robert Shelton, founder and CEO of Private Access, “and we enable granular and dynamic privacy settings. I am very excited to see nearly 40,000 survey questions answered by almost 400 unique participants in the first week that can now be employed by support groups and researchers in precisely the manner each individual wishes.” PEER is in development for a wide range of organizations and uses, including a PCORI funded project and Patient Powered Drug Development projects associated with the FDA mandate to engage a number of

communities. Genetic Alliance president and CEO, Sharon Terry, stated, “I am so excited to see the MDCR launch. It is time that the people whose lives are affected by disease have a big role in discovering interventions for those conditions. Individuals affected by mitochondrial disease have a tremendous opportunity to ‘tell their story’ by sharing their data. Let this be the start of a movement!” Both Shelton and Terry are motivated because they both have children affected by genetic conditions.

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ABOUT THE UMDF

Founded in 1996, the United Mitochondrial Disease Foundation (UMDF) works to promote research and education for the diagnosis, treatment and cure of mitochondrial diseases and to provide support for affected individuals and families. Since its inception, the UMDF has funded nearly \$13 million in research, making it the leading non-governmental contributor of grants focused solely on mitochondrial disease. The UMDF, based in Pittsburgh, PA, is a national organization, represented around the world by thousands of members. For more information about mitochondrial disease or the UMDF, visit www.umdff.org

ABOUT GENETIC ALLIANCE:

Founded in 1986, Genetic Alliance engages individuals, families, and communities to transform health. Through multiple programs that have launched many products, Genetic Alliance provides tools to improve the research to services continuum. Platform Engaging Everyone Responsibly was launched in 2014 as a major effort to give individuals a powerful way to contribute to translational and participant-centered outcomes research. For more information about Genetic Alliance, visit geneticalliance.org. For more information about PEER, visit <http://geneticalliance.org/programs/biotrust/peer>.

ABOUT PRIVATE ACCESS:

Private Access, Inc. is dedicaed to making it safe for sensitive personal information such as medical records to be accessible over the Internet. The company’s technology allows individuals to grant “*private access*” to all or selected parts of their confidential personal information to advocacy groups, researchers and others based on each participant’s particular needs and interests. Founded in late 2006 upon issuance of its core patent, Private Access is headquartered in Irvine, California. For more information, visit <http://www.privateaccess.com>.