

For Immediate Release

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GENETIC ALLIANCE ANNOUNCES REGISTRIES FOR ALL

WASHINGTON, DC – April 5, 2013 – Registries for All (Reg4ALL) was introduced today at the 3rd annual CanLiv Research Symposium. Genetic Alliance is proud to present this exciting new resource, which enables individuals to participate in clinical trials and registries on their own terms. By giving people the tools to safely participate, we can expedite research and create more treatments for the benefit of all.

Researchers working to discover treatments face a problem: despite living in a world in which corporations use massive amounts of information on public spending habits to predict buying trends, behavior, and recently, even pregnancy, there is little available data on the diseases with which people live. The dichotomy may be driven by a desire for privacy about health information, but a new tool called Registries for All is building a consumer-driven, cross-disease health registry platform in which individuals have complete control over who sees what. Using a gamified interface, individuals can see how they compare to others.

By allowing individuals to share the information they specify, with the researchers and research organizations they chose, from specific academic medical centers to advocacy groups, Registries for All unlocks a trove of data of immense public health value. It will build communities of patients ready for the right trial to come to them.

“Right now millions of people desperately need treatments for diseases from liver disease to diabetes, from heart disease to arthritis. The path to those treatments is clinical trials. Clinical trials are woefully under-enrolled – hundreds are shut down every year because only one or two people are signed up for them”, said Donna Cryer, patient advocate and Genetic Alliance advisor.

“Enter Reg4ALL, a system in which the right trial comes to the participant”, Robert Shelton, CEO and founder of Private Access, explained. “Private Access’ technology enables individuals to set their own sharing and data access preferences. This then provides the mechanism for the researcher to find the right group of individuals quickly and cost effectively.”

“By merging respect for their privacy wishes with access to relevant and actionable medical information, Reg4ALL is giving participants more control over their destinies,” explained Sharon Terry, CEO of Genetic Alliance, the 26-year old non-profit organization that owns Reg4ALL. “This collaboration has the potential to accelerate medical progress by putting patients’ needs front and center.”

Reg4ALL ultimately creates a living, dynamic registry, allowing individuals to log their experiences over time. This will accelerate translational science by creating well-characterized ready cohorts of individuals and communities that can participate in, and even initiate, clinical trials.

For more information, please visit www.reg4all.org.

About Genetic Alliance

Genetic Alliance empowers individuals, families, and communities to reclaim their health. Genetic Alliance's network includes more than 10,000 health organizations, including 1,200 disease advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. To learn more about Genetic Alliance, visit <http://www.geneticalliance.org>.

About Private Access

Private Access, Inc. is making it safer for sensitive personal information such as medical records to be accessible over the Internet. We accomplish this with technology that allows each person to grant private access to all or selected parts of their confidential personal information to doctors, family members, researchers and others based on their particular needs and interests. Our people, technology platform, and applications we build are dedicated to empowering individuals to improve the care they receive, accelerate the discovery of new treatments for diseases and chronic illnesses that affect them or others they care about, and reduce health care costs for their families and the nation. Founded in late 2006, Private Access is headquartered in Irvine, California. <http://www.privateaccess.com>