



Private Access and Genetic Alliance Announce Strategic Partnership to Accelerate Medical Research While Protecting Privacy

Through an innovative public/private partnership, Private Access will launch its suite of web-based privacy management and clinical trials recruitment tools with Genetic Alliance network participants.

Press Release

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Cambridge, MA - August 19, 2008 – Private Access, Inc, and Genetic Alliance, a 501(c)(3) organization, announced today that they have formed a novel public-private partnership designed to simultaneously protect patients’ privacy rights while creating a faster and more cost effective way for researchers to connect with patients in order to find causes and treatments for chronic illnesses and diseases. Leaders of both organizations believe that their combined efforts will help transform today’s medical research environment, saving time and money, producing better outcomes, and in a manner that respects each individual patient’s right to decide with whom they share their confidential health information.

The announcement was made today in conjunction with the prestigious Harvard Privacy Symposium and 16th Annual National HIPAA Summit. Private Access’ founder and CEO, Robert Shelton, speaking on a panel entitled “Privacy and Technology: Giving Patients Control Over Uses of Their Health Information,” previewed both the company’s planned technology and the strategic partnership struck with Genetic Alliance. In his comments, Shelton observed that, “this is a game-changing moment where the proponents of an extremely well-conceived technology focusing on privacy and controlling access rights to highly confidential health records and a patient population that has an uncommonly high need for these tools come together to solve a problem that has historically been a major impediment to health data exchange.”

Shelton, who also serves as chairman of a national non-profit disease advocacy organization that is a Genetic Alliance network participant, explained that the partnership between Private Access and Genetic Alliance will address the current problem that maintaining patient privacy and providing access to medical records are inherently at odds. “Getting a proper resolution to this complex issue accelerates the

translation of research into diagnostics and treatments,” said Sharon F. Terry, President and CEO of Genetic Alliance.

“Our vision for harmonizing privacy and access through a suite of web-based software applications is ideally suited to the needs of those who suffer from chronic illness and genetic diseases,” said Shelton. Explaining the unusual step of forming a partnership between a for-profit company and a not-for-profit, Terry added, “Genetic Alliance’s mission is to transform health through genetics and to do so in part through novel partnerships in advocacy. Robert has run one of the disease support organizations in our network and understands the needs and issues of these organizations. Private Access has the right technology, at the right time to serve individuals, families, providers, researchers and all healthcare stakeholders dealing with genetic conditions and chronic disease. By working together, I’m convinced we can create an essential environment of trust that empowers people to be the solution.”

“Our approach is to empower individuals to protect the privacy of their personal health information while simultaneously authorizing stakeholders to access to that information to find treatments to diseases quicker,” said Marc D. Kirshbaum, president of Private Access. Kirshbaum further commented, “Genetic Alliance has been very successful convening diverse stakeholders – including disease-specific advocacy organizations, universities, companies, government agencies, and policy organizations – to explore and create novel partnerships to overcome the historical barriers required to reduce medical research costs and speed the process of finding treatments. Earlier this year, we saw this in Genetic Alliance’s role in advocating for the Genetic Information Non-Discrimination Act (GINA) which was passed by the US Congress and signed into law by the President.”

Adds Kirshbaum, “Private Access is honored to be working with Genetic Alliance in this transformative initiative. Our privacy management, clinical trials recruitment and records sharing tools complement Genetic Alliance’s network to accelerate medical research.”

Private Access is building a technology platform that will give individuals a chance to be as explicit as they wish relative to who, when and under what circumstances others can access and use their personal medical information and to easily apply these explicit privacy rules to all conceivable uses of that information. In its first generation, the Private Access technology will be embodied in several user-centric applications that employ these individual directives to overcome the regulatory hurdles surrounding privacy in the recruitment of study subjects for medical research.

About Genetic Alliance

Genetic Alliance transforms health through genetics, using an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance brings together diverse stakeholders that create novel partnerships in advocacy; integrates

individual, family, and community perspectives to improve health systems; and revolutionizes access to information to enable translation of research into services and individualized decision making. For more information about Genetic Alliance, visit www.geneticalliance.org.

About Private Access

Private Access, Inc. develops web-based applications that solve the significant privacy hurdle that the medical community faces when attempting to recruit subjects for clinical trials and to share confidential records in pursuit of faster diagnoses and better treatments for diseases and chronic illnesses. The company's vision is to leverage its method for individuals to establish and manage their dynamic electronic consent and its suite of solutions to transform the healthcare industry – creating a unique environment of trust for consumers and accelerating research at a considerably lower cost. Founded in 2006, Private Access is headquartered in Aliso Viejo, California and holds several patents covering its proprietary technology. For more information, visit www.PrivateAccess.info.