INTERNATIONAL INITIATIVE APPLAUDS THE SUPREME COURT DECISION ELIMINATING GENE PATENTS AND ANNOUNCES THE LAUNCH OF A PUBLIC DATABASE FOR HEREDITARY GENE MUTATIONS

A patient and physician directed initiative to build a comprehensive, open reference database to help in diagnosing BRCA1 and BRCA2 mutations

San Francisco, California – June 13, 2013 – A consortium of policy makers, advocacy organizations, individuals, academic centers and industry today announced the formation of a first-of-its kind initiative, ***Free the Data!,*** to fill the public information gap caused by the lack of available genetic information for the BRCA1 and BRCA2 genes and plans to expand to provide other types of genetic information in open, searchable databases, including the National Center for Biotechnology Information's database, ClinVar. The primary founders of this project include Genetic Alliance, University of California San Francisco (UCSF), InVitae Corporation and patient advocates.

Women with certain variations in the BRCA 1 and BRCA2 genes can have significant increases in their lifetime risk for breast and ovarian cancer. Faced with these odds, women who are diagnosed with a BRCA mutation often have to make difficult decisions. ***Free the Data!*** empowers women to impact health outcomes for themselves and others by sharing their genetic information to further the medical community's understanding of how gene variations impact disease and advance translational research. The accessibility of genetic testing is expected to rapidly expand over the coming decade, in part due to the recent Supreme Court ruling that naturally occurring DNA is not patentable and the rapidly decreasing cost of DNA sequencing. However, to date there has not been a coordinated effort to allow patients and physicians to share their genetic results in a way that would allow better interpretation of genetic information for all patients.

Joanna Rudnick, patient advocate and filmmaker said: "Over a decade ago, I learned I had a BRCA mutation and wrestled with my incredibly high odds of getting both breast and ovarian cancer. It took making a documentary film to start talking about it and remove the stigma. I've gone full circle with surveillance, a breast cancer diagnosis, and within the last month, a bilateral mastectomy with reconstruction and prophylactic oophorectomy. We need better choices for our daughters. With this landmark Supreme Court decision, we have an opportunity to pull together and take back our data – as patients, we have the power to change the way our information is shared. I am dedicated to help others free the data and pledge to share my information to help improve patient care and advance the treatment of these diseases that have affected my family for generations." Rudnick's Emmy-nominated ***In the Family*** documentary, produced by Kartemquin Films, aired on PBS' POV series in 2008 and was broadcast in several countries around the world. ***In the Family*** is currently streaming free on PBS' website to coincide with the decision by the Supreme Court at http://www.pbs.org/pov/inthefamily/full.php#.Ubn31WS9Kc0.

"Despite national attention on the patentability of human genes and its effect on patient care, a ruling against gene patentability doesn't immediately provide broad

access to BRCA 1 and 2 mutations or place them in a public database that will allow for better diagnosis and care," said Sharon F. Terry, M.A., president and CEO of the Genetic Alliance. "This effort enables individuals to contribute their information publicly, albeit with appropriate privacy and security protections through a customized portal that can be used by all patients and their clinicians in order to improve care."

"We are entering a new era in genomic medicine not unlike the emergence of the internet two decades ago" said Randy Scott from InVitae, a clinical laboratory focused on comprehensive genetic testing, "The value of genetic information is far greater when shared and the more we share genetic information the greater value we can deliver to patients. We are excited to be a part of the "Free the Data! movement."

***Free the Data!* How it Works**

This initiative invites individuals to share their genetic variation on their own terms and with appropriate privacy settings, in a public database so that their families, friends, and clinicians can better understand what the mutation means. Working together to build this resource means working towards a better understanding of disease, higher quality patient care, and improved human health.

"There is much known about the human genome but little understanding on how variations in genes can lead to disease. We want to create an easy way for patients and physicians to share information with each other, providing the research community with a robust source of data and enabling the rapid improvement of knowledge of clinically relevant genetic mutations which will ultimately accelerate the race for more effective treatments and a cure," said Robert. A. Nussbaum, M.D., chief of Medical Genetics at UCSF.

Individuals who have received genetic testing and who are interested in participating are invited to:

a. Go to the *Free The Data!* Project web site at www.free-the-data.org

b. Follow the instructions to upload your test results, set your privacy and sharing settings, and answer a brief questionnaire.

Individuals may also send a scan or PDF of the test report form with the personal identifying information blocked to Genetic Alliance at freethedata@geneticalliance.org or facsimile to 202.966.8553.

We encourage patients, advocacy groups, research organizations, physicians, policy groups, professional societies and industry to join this cause. For more information, please visit free-the-data.org or contact: 202.966.5557 x201.