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### **New Educational Resources on Law Against Genetic Discrimination Now Available**

WASHINGTON, DC – With genetic testing becoming increasingly pervasive in medical care and our daily lives, three of the most prominent organizations in genetics—the Genetics and Public Policy Center at Johns Hopkins University, the National Coalition for Health Professional Education in Genetics, and [Genetic Alliance](http://www.geneticalliance.org)—have teamed up to produce educational materials about the Genetic Information Nondiscrimination Act (GINA), a landmark federal law that protects individuals from the misuse of genetic information in health insurance and employment.

Enacted in 2008 after 13 years of debate in Congress, GINA limits health insurers from using a person’s genetic information to set eligibility requirements, or establish premium or contribution amounts. The law also prohibits employers from using genetic information in decisions about hiring, firing, job assignments or promotions.

“Almost every day, our center is asked for more detailed information about what GINA means,” said Joan Scott, director of the Genetics and Public Policy Center. “These targeted materials will go a long way towards answering the questions that still exist, paving the way for successful, long-term implementation of this important law.”

The user-friendly materials will help health-care providers and members of the public understand their rights and responsibilities under the law and provide essential information about its details. The documents are also clear about what GINA *doesn’t* cover.

The public-oriented materials—including an interactive website, “GINA & You” information sheet, and slide set for advocacy organizations—are available, at <http://www.GINAHelp.org>, in the Genetic Alliance Resource Repository, and on Genetic Alliance’s website, <http://www.geneticalliance.org>. The website also includes a history of GINA’s long struggle and passage.

“The public has waited a long time for these protections, and by providing this information as a resource we are helping individuals become informed consumers of genetic services,” said Sharon Terry, president and CEO of Genetic Alliance.

The materials for health-care providers include background documents, a discussion guide suggesting how and when to talk about GINA with patients, a teaching slide set, and case studies that describe how the law works in a variety of real-world, clinical settings. These materials are available on the website for the National Coalition for Health Professional Education in Genetics (NCHPEG), at <http://www.nchpeg.org>.

“We’ve heard many questions already from health-care providers about the specifics of GINA,”

said Joseph McInerney, NCHPEG's executive director. "Especially as genetic testing becomes more common and the value of family history more apparent, there's a real need for these materials to reassure providers and patients alike that GINA supports excellent clinical care."

The Genetics and Public Policy Center (GPPC), part of the Johns Hopkins Berman Institute of Bioethics, will have all of the materials on its website, at <http://www.dnapolicy.org>. The GPPC's site also includes FAQs and other fact sheets about GINA aimed at a general audience.

Development of the materials was supported by a grant from The Pew Charitable Trusts.

### **Additional information:**

Genetic Alliance: <http://www.geneticalliance.org>

Genetic Alliance is a national, nonprofit health advocacy organization based in Washington, DC committed to transforming health through genetics and promoting an environment of openness centered on the health of individuals, families, and communities. When GINA was signed into law, the Alliance chaired the Coalition for Genetic Fairness, a multi-stakeholder coalition of over 500 organizations committed to passing federal genetic nondiscrimination legislation.

National Coalition for Health Professional Education in Genetics: <http://www.nchpeg.org>

NCHPEG is a Maryland-based nonprofit organization whose mission is to promote genetics education for all health professionals. NCHPEG's membership represents a broad range of professional societies, advocacy groups, corporate entities, and government agencies dedicated to the integration of genetically based health care into mainstream practice.

Genetics and Public Policy Center: <http://www.dnapolicy.org>

The Genetics and Public Policy Center in the Berman Institute of Bioethics at Johns Hopkins University was created to help policymakers, the press, and the public understand and respond to the challenges and opportunities of genetic medicine and its potential to transform global public health.

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### ***About Genetic Alliance***

*Genetic Alliance transforms health through genetics, promoting 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 <http://www.geneticalliance.org>.*