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Genetic Alliance Celebrates Announcement of Genetic Tests Registry
Voluntary Registry First Step Toward Transparency and Collaboration in Genetic Testing

WASHINGTON DC – March 18, 2010 – [Genetic Alliance](http://www.geneticalliance.org) applauds the announcement today by Francis Collins, M.D., Ph.D., Director of the National Institutes of Health (NIH), of a voluntary registry for genetic tests offered by labs nationwide. The registry will be hosted at NIH, which will complete a broad consultation with prospective users and submitters before the registry is established.

Genetic Alliance, along with Genetics and Public Policy Center, Coalition for 21st Century Medicine and others, has called for a mandatory genetic testing registry for several years. “This is a wonderful step forward for genetic testing and the integration of genetics into medicine,” said Sharon Terry, president and chief executive officer of Genetic Alliance. “We are glad NIH plans to learn from the experiences and expertise of the individuals and institutions that will be using and registering information. We also look forward to the registry becoming mandatory so that we are all apprised of the quality and availability of genetic testing across the nation.”

A mandatory registry would enable a forward-looking oversight system that is flexible and nuanced. It would undergird a transformed system that is open, transparent, and coordinated with all stakeholders and agencies, and that balances safety, innovation, ethical and social issues, viability, and the risks and benefits of improved health. Dr. Collins’ announcement today is a major advance toward transparency, interagency collaboration and 21st century healthcare.

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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>.