

FOR IMMEDIATE RELEASE  
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### **Genetic Alliance and Partners to Engage Communities in Family Health History Collection**

(Washington, DC–May 22, 2006) Genetic Alliance announced today that it has received a cooperative agreement from the Genetic Services Branch of the Maternal and Child Health Bureau, HRSA, DHHS in the amount of \$600,000 annually. Community Centered Family Health History is a three year project, during which Genetic Alliance will collaborate with the Institute for Cultural Partnerships, Seattle Indian Health Board's Urban Indian Health Institute, Intermountain Healthcare, National Council of La Raza, Appalachian Office of Justice and Peace, Iona College Social Work Department, American Folklife Center at the Library of Congress, and American Society of Human Genetics, as well as numerous disease advocacy and community organizations.

The project, Community Centered Family Health History, focuses on family health history, folklore, genetics, and accessibility and sets a new bar for what it means to tailor health-related materials and resources to a community. "The American Indian and Alaska Native community has been using stories for countless generations to pass on history, culture and tradition." explains Maile Taulii, Associate Director of the Urban Indian Health Institute. "We are delighted to participate in a project that will support those traditions and help address the burden of disease in communities we serve."

In addition, the project demonstrates that, not only will a community-based model be effective for geographic, ethnic, or cultural groups, but it can also be applied effectively to those who share significant characteristics in common, such as a shared health condition, occupation, or life event. "Genetic Alliance advocacy organizations empower their respective member communities to take charge of their health and their future," said Sharon Terry, President & CEO of Genetic Alliance. "Family health history is an opportunity for families and communities to take proactive steps to improve their health and to do so within the context of their lives and culture."

The partners will further develop and evaluate the Healthy Choices through Family Health History Awareness Tool. Evaluation of family health history represents a first step in identifying genetic contributors to health and can serve as an important basis for improving health care and encouraging a healthy lifestyle. Though multiple family health history tools abound, neither the premise that they will make a difference in health outcomes, nor the analysis of their usefulness along a medical-non-medical continuum, has been validated in a systematic, evidence-based study as measured by changed behavior leading to better personal health. This project will address these issues and result in a customizable template of the Tool – information, health stories, pictures, and descriptions of conditions will be available for diverse communities. The tool will be implemented on a national scale through interested national and community-based organizations.

“Hispanics experience numerous conditions – diabetes, heart disease, obesity, and certain cancers, to name a few – that may have a genetic link. It is critical that Latinos become informed about their family health history so they can make healthier choices for their families. Thus, we are happy to partner with the Genetic Alliance in the evaluation of this tool,” said Liany Arroyo, Director of the Institute for Hispanic Health of National Council of La Raza (NCLR).

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Genetic Alliance increases the capacity of advocacy organizations to achieve their missions and leverages the voices of millions of individuals and families living with genetic conditions. We build communication and mentoring networks, design and sponsor rigorous training courses, and provide infrastructure that strengthens and empowers our 600 member organizations. The technical assistance we provide to advocacy organizations results in measurable growth: increased funding for research, access to services and support for emerging technologies. For more information: <http://www.geneticalliance.org>.

To read about Genetic Alliance's other Family Health History Projects, visit [http://www.geneticalliance.org/ws\\_display.asp?filter=fhh](http://www.geneticalliance.org/ws_display.asp?filter=fhh)