

FOR IMMEDIATE  
RELEASE  
September 5, 2006

Contact: Sharon Terry  
202-966-5557 x201  
<mailto:sterry@geneticalliance.org>

## **Genetic Alliance Establishes the National Consumer Center for Genetics Resources and Services**

(Washington, DC-September 5, 2007) Genetic Alliance announced today the opening of the National Consumer Center for Genetics Resources and Services (NCCGRS). It is funded by a cooperative agreement from the Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA) Genetic Services Branch of the Maternal and Child Health Bureau. The major purpose of this 5-year, \$500,000/year special project is to mitigate the substantial information and resource deficit for consumers of genetic services. Sharon Terry, President and CEO of Genetic Alliance, and Director of the Center, declared: "Genetic Alliance has tracked the difficulties in obtaining credible information and quality services. We've built substantial systems to alleviate the burden caused by these issues. The establishment of the Center will allow the community to accelerate the development of solutions and resources."

The Center will offer the open access resources developed by Genetic Alliance: Disease InfoSearch, Resource Repository, Understanding Genetics, the Interactive Guide, Strategies for Success, the customizable Family Health History Guide, and the two new resources - WikiGenetics ([wikigenetics.org](http://wikigenetics.org)) and WikiAdvocacy ([wikiadvocacy.org](http://wikiadvocacy.org)) - to meet the needs of consumers and stakeholders.

WikiGenetics and WikiAdvocacy - user-friendly, user-generated online tools that provide new resources for consumers - embody the ideals of the NCCGRS: to hold open the space for the network, the community as it defines itself, to share resources that will increase access to resources, improve services, and promote the consumer voice. WikiGenetics ([wikigenetics.org](http://wikigenetics.org)) is a "by the public, for the public" encyclopedia on human genetics that provides credible and up-to-date information that anyone, including people with no scientific background, can understand. Similarly, WikiAdvocacy ([wikiadvocacy.org](http://wikiadvocacy.org)) is a communal resource for aiding advocacy. It offers a real-time, interactive, online community where advocates contribute to the education and support of their fellows by sharing their own wisdom and experiences. All members of the genetics community are free and encouraged to contribute to both WikiGenetics and WikiAdvocacy. The strength of the resources can only grow through the contributions and collaboration of countless volunteers.

In addition to these tools, the NCCGRS reaches out to stakeholders across the country to determine the most pressing issues facing consumers of genetic testing, newborn screening, and other services. In collaboration with disease-specific advocacy organizations and family groups, the NCCGRS develops and makes accessible informational materials and educational programs for consumers. Further, the NCCGRS aims to bring the voices of consumers and their concerns to the attention of policymakers

and government agencies through reports, white papers, and articles on these issues. The Center focuses on ensuring the consumer voice is heard, and on improving services for all who need them. Every person will need genetics resources and services some day. The Center works proactively to focus the future of the field on the issues that matter most to the consumer and make sure these services are accessible, affordable, and of high quality.

The diagnosis of a genetic disorder is a life-altering event and the difficulty of accessing information adds to the stress of coping with a new diagnosis or managing a chronic genetic condition. Individuals and families must be part of the deliberations and decision-making with regard to genetic services. Genetic tests offer a gateway to personalized medicine, disease management, and comprehensive care in the genomic era. The ultimate goal is improved health. The National Consumer Center for Genetics Resources and Services seeks to convening space within which transformational thinking and action occurs, to support practices resulting in transformation and promote the collaboration required to revolutionize networks and systems to serve the public's needs.

The NCCGRS is directed by Sharon Terry. The Associate Director is Heather Ferguson, MS, CGC, and the Assistant Director is Amelia Chappelle, MS, MA. Topic specific expertise is provided by James O'Leary (Family History) and Natasha Bonhomme (Newborn Screening). In addition, Vaughn Edelson will be key in developing and maintaining the Center.

###

For more information, contact [Heather Ferguson](#), 202.966.5557 x212