

FOR IMMEDIATE RELEASE
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**Genetic Alliance Awarded Single Gene Resources
Network Cooperative Agreement**

Genetic Alliance and Partners to Increase Access to Scientifically Accurate Information

(Washington, DC October, 2005) – Genetic Alliance announced today that it has received a Centers for Disease Control (CDC) Cooperative Agreement Award in the amount of \$850,000 to develop the Single Gene Resource Network. Genetic Alliance received this grant in partnership with Parent Project Muscular Dystrophy; FRAXA Research Foundation; University of Maryland School of Medicine; National Coalition of Health Professional Education in Genetics, and Gene Tests/Gene Clinics. The CDC will play an instrumental role in the definition and development of evidence-based information about Duchene and Becker Muscular Dystrophy (DBMD) and Fragile X syndrome (FXS).

The grant will provide consumers and health professionals with increased access to accurate scientific information on etiology, diagnosis, treatment and management of individuals with DBMD and FXS. More than a million people are affected by these two conditions. Genetic Alliance and its partners have named this project the Access to Credible Genetics Resources Network (ATCG Resources Network). Sharon Terry, MA, President & CEO of Genetic Alliance will serve as the principal investigator.

“Genetic Alliance has a vision of a world where individuals affected by single gene disorders have all the resources they need to live fully,” said Sharon Terry. “Information is a huge part of this and we are excited to work with these partners to create and disseminate quality information for these two disorders.”

“We are thrilled to join the Genetic Alliance and others in establishing the ATCG Resources Network,” said Patricia Furlong, Founding President of Parent Project Muscular Dystrophy. “We provide support and assistance to our members, in part through accurate and accessible information about their genetic disorder. With Genetic Alliance’s leadership in increasing access to evidence-based health information, this program will encourage other members of the rare disease community to emulate the best practices we create for information production and dissemination.”