Genetic Alliance Hires Sharon Terry as President and Chief Executive Officer

Non-profit organization veteran brings extensive expertise in genetic disease innovation and lay advocacy capacity-building

Washington, DC – February 26, 2004 – The Genetic Alliance today announced the appointment of Sharon Terry to the new role of President and Chief Executive Officer.

Terry, who will join the staff effective immediately, brings a decade of experience in genetic disease lay advocacy, including serving on the board of the Genetic Alliance for the last five years – two as president – and founding PXE International. She will work closely with her staff and the 12-member board of directors to fulfill the primary mission of the Genetic Alliance: to build capacity in lay advocacy organizations so they may improve the lives of individuals and families living with genetic conditions.

The creation of this new position signals a higher level of excellence, expectation and execution for the Genetic Alliance, according to the board of directors’ chairwoman, Jannine Cody. While Terry will still sit on the board, she will have much greater accountability for personal and organizational performance metrics than previous leaders.

“We have complete confidence that Sharon will lead the Genetic Alliance to new heights of visibility and influence within the research-medical community and in government where policy is increasingly critical to genetic diseases,” said Cody. “To be effective and fiscally viable, we must overhaul the Alliance into a corporately-structured nonprofit that enables success for all our stakeholders, especially with access to services for underserved communities.”

Terry said she decided to accept this position because of the Alliance’s commitment to create a new model of excellence within the organization and throughout the lay advocacy community. “This change is indicative of a new ‘corporate’ paradigm being embraced by many non-profit organizations,” said Terry. “We plan to accelerate and stabilize our ability to help lay advocacy groups make the life and death differences they need to make.”

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Terry has served as the president of the Genetic Alliance for the last two years and is the founding executive director of PXE International, a lay advocacy group for the genetic condition pseudoxanthoma elasticum (PXE), a condition with which both of her children have been diagnosed. She is an advisor to the National Institutes of Health's National Human Genome Research Institute and the Johns Hopkins University Genetics and Public Policy Center, a board member of the Biotechnology Institute, and serves on many of the major governmental advisory committees on medical research. Terry has co-authored numerous scientific papers including two about the discovery of the PXE gene (of which she is a co-inventor) published in *Nature Genetics*. Most recently, she founded the Genetic Alliance BioBank, a cooperative biological samples and data repository.

**About the Genetic Alliance**

The Genetic Alliance is the world's largest coalition of genetic advocacy organizations, including more than 600 advocacy groups, community groups, health professionals, researchers, hospitals and clinics. Founded in 1986, it is a 501(c)(3) organization which provides technical resources and support to lay advocacy organizations and serves as a collective voice in matters of policy, research, education and advocacy. For more information, please visit [http://www.geneticalliance.org](http://www.geneticalliance.org) or call 202-966-5557.

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