WASHINGTON – September 26, 2008 – Genetic Alliance President and CEO, Sharon Terry, today issued the following remarks in response to the resignation of Elias Zerhouni, M.D., director of the National Institutes of Health (NIH):

“Since joining NIH in 2002, Dr. Elias Zerhouni has promoted interdisciplinary collaboration and supported the accelerated translation of biomedical research into tests and treatments. His openness to partnerships led to the Roadmap for Medical Research, which connects the resources of all 27 NIH Institutes and Centers to fund innovative research historically considered risky and/or big science. This collaboration is leading to a sustainable infusion of genomics in the overall framework of NIH.

Dr. Zerhouni has been always accessible to those who suffer from genetic conditions and agreed with the need for individuals to have their genetic information protected from discrimination by their employer or insurer. He supported the passage of the Genetic Information Nondiscrimination Act, legislation the genetics community worked toward for 13 years.

Earlier this month, Dr. Zerhouni rallied for more open health systems; defending the public’s right to view the results of taxpayer-funded research as provided by the NIH Public Access Policy during a legislative hearing on H.R. 6845, the “Fair Copyright in Research Works Act”. The NIH policy is essential to translating biomedical research into clinical results. Individuals, families and healthcare providers now have open access to publicly funded research, and this achievement will be a hallmark of Dr. Zerhouni’s tenure.

The genetics community thanks Dr. Zerhouni for his commitment to health advocacy and novel partnerships. We wish him well as he undertakes his next endeavor and explores his own ‘open space’. In this networked age, leadership comes from all directions, and we are certain we will not be losing his leadership, only seeing it renewed in new ways. We look forward to working with Dr. Zerhouni’s successor as NIH continues to foster transparency, robust partnerships, and continued investment in the health of America.”

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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.