



**FOR IMMEDIATE RELEASE**

Contact: Eva Maciejewski/Research!America  
703-739-2577, ext. 44  
Tamara Parr/GYMR Public Relations  
202-745-5114

**GENETIC ALLIANCE HONORED WITH  
RESEARCH!AMERICA ADVOCACY AWARD**

*Paul G. Rogers Distinguished Organization Advocacy Award*

**WASHINGTON** – March 20, 2009 – Genetic Alliance will receive Research!America’s 2009 Paul G. Rogers Distinguished Organization Advocacy Award. The award recognizes Genetic Alliance’s exemplary advocacy on behalf of people with genetic diseases, particularly its leadership role in advocacy for the Genetic Information Nondiscrimination Act of 2008 (GINA).

Genetic Alliance will be honored March 24, 2009, at the 13th Annual Research!America Advocacy Awards event at the Andrew W. Mellon Auditorium in Washington, DC. Sharon Terry, president and CEO of Genetic Alliance, will accept the award.

Formed in 1986 as an alliance of genetic support groups, Genetic Alliance has become the world’s leading advocacy organization committed to transforming health through genetics. With a network of more than 10,000 organizations, Genetic Alliance brings together parent and family groups, community organizations, professional societies, corporations and government agencies to create novel partnerships. The organization also actively engages in improving access to information for individuals, families and communities, while supporting the translation of research into services.

In addition to her role with Genetic Alliance, Sharon Terry is a co-founder of the Genetic Alliance BioBank and PXE International. Following the diagnosis of her two children with the genetic condition pseudoxanthoma elasticum (PXE) in 1994, Terry entered the world of advocacy and genetics. She serves on the board of directors of both the Coalition for 21st Century Medicine and the National Coalition for Health Professional Education in Genetics. She is also a liaison to the Health Resources and Services Administration’s Secretary’s Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children and liaison to the National Advisory Council for Human Genome Research. She chairs the Coalition for Genetic Fairness and is a member of the Institute of Medicine Roundtable on Translating Genomic-Based Research for Health. In these positions, she champions the engagement of informed consumers to transform health systems. Her passionate leadership and commitment to the health of individuals are central to her work to achieve comprehensive, effective healthcare.

Hogan & Hartson LLP is the benefactor of Research!America’s award to exemplary organizations. The award was named in 2007 for the former Congressman and renowned advocate for health, The Honorable Paul G. Rogers. Rogers was Research!America’s chair emeritus until his death in October 2008.

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Other 2009 Research!America Advocacy Award winners are House Speaker Nancy Pelosi; Senator Arlen Specter; former Surgeon General C. Everett Koop, MD, ScD; Stowers Institute founders James E. Stowers Jr. and Virginia G. Stowers; Nobel Laureate David Baltimore, PhD; and ABC News anchor Bob Woodruff.

Research!America is the nation's largest not-for-profit public education and advocacy alliance working to make research to improve health a higher national priority. The 2009 Advocacy Awards represent Research!America's 13th year of recognizing the accomplishments of leading advocates for medical and health research. For more information, visit [www.researchamerica.org/advocacy\\_awards](http://www.researchamerica.org/advocacy_awards).

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