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One Stop Shopping for All Diseases: Genetic Alliance Launches Disease InfoSearch

WASHINGTON, DC – March 19, 2013 – Disease InfoSearch (www.DiseaseInfoSearch.org), a one-stop shop for information and engagement on more than 13,000 conditions, launched today. Disease InfoSearch connects healthcare providers, researchers and the general public with support groups, relevant and timely peer-reviewed articles, open and appropriate IRB-approved clinical trials, and general disease information. Each condition page also features an interactive tool that enables individuals to contribute to biomedical research by securely sharing their health information.

For the past 26 years, Genetic Alliance has connected individuals to advocacy and support organizations. The release of this new online database marks a dramatic expansion in the information available for both common and rare diseases. Genetic Alliance takes a novel approach to the management of disease-specific information, calling on experts—disease advocacy organizations—to provide current, quality information on their respective conditions. This tailored information is supplemented with resources from quality federal databases, distilled through consumer-tested algorithms, and presented in an accessible interface. Disease InfoSearch can now be used by the public to answer questions after a family member’s diagnosis, find a clinical trial, and more; by healthcare providers to offer point-of-diagnosis referral to support groups; and by the research community to identify disease advocacy organizations with registries and biobanks, and to facilitate collaboration with other organizations doing similar work.

“Compiling these resources in a single location makes it significantly easier for healthcare providers, researchers and the public to find the information they need about thousands of conditions,” said Sharon Terry, President and CEO of Genetic Alliance. “Empowering individuals and families is a vital component of our vision – a world in which those affected by genetic conditions have everything they need to live fully – and this project brings us one step closer to achieving that vision,” she said.

For more information, please visit www.DiseaseInfoSearch.org and watch our video <http://youtu.be/BzUZxQWukVk>.

About Genetic Alliance Genetic Alliance improves health through the authentic engagement of individuals, families, and communities. Genetic

Alliance is the world's leading nonprofit health advocacy organization committed to transforming health through genetics and works to connect consumers to the smart services they need to make informed decisions about their health and healthcare. Genetic Alliance's network includes more than 1,000 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. To learn more about Genetic Alliance, visit <http://www.geneticalliance.org>.

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