

For Immediate Release
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Genetic Alliance Releases
“Understanding Genetics: A Guide for Patients and Health Professionals”

Genetic Alliance and the District of Columbia Department of Health Announce the Publication of a Comprehensive Genetics Education Manual for Patients and Community Health Providers in Metro Washington, DC

(Washington, DC, May 25, 2006) –Genetic Alliance announced today that it has published “Understanding Genetics: A Guide for Patients and Health Professionals” in collaboration with the District of Columbia Department of Health (DC DOH). This comprehensive manual provides a wealth of genetic education materials for patients and health professionals for Washington area community-based healthcare clinics. It is designed to help patients and health professionals understand the place of genetics in health care. The straightforward and intuitive guide covers basic genetic concepts, complemented with in-depth information about diagnosing genetic conditions, newborn screening, family-history collection, genetic counseling and genetic testing. A section on local information focuses on patient care, patient and provider education, and genetic services in the Washington, DC area. The 120-page manual is published in print and electronic formats and is being distributed by the DC DOH Washington area healthcare clinics.

“This Guide is another critical step forward in achieving higher genetic literacy rates for both patients and their providers by bridging a gap in access to basic genetics information,” said Sharon Terry, MA, President & CEO of Genetic Alliance who served as Executive Editor for the guide.

“Genetic Alliance has a vision of a world where individuals affected by genetic disorders have all the resources they need to live fully,” Terry said. “Information is a huge part of this and we were excited to work with the Department of Health to create and disseminate quality information for patients and health professionals in Washington, DC.”

Over the past few decades, advances in genetics and genomics have revolutionized the way we think about health. While genetics has traditionally been associated with pregnancy, birth defects, and newborn screening, every disease is influenced to a greater or lesser degree by an individual’s genetic make-up. Therefore, it is important to consider the impact of genetics for any condition diagnosed throughout a patient’s lifetime and in any community throughout the world.

“We are pleased to announce the availability of this guide because of its tremendous value in its ability to translate genetic information, which at first may appear complex, to

both the general public and healthcare providers,” said Dr. Gregg A. Pane, MD, Director, DC Department of Health.

“This guide is exceptional because it was written for community-based healthcare centers in the Washington, DC metro area, but at the same time, the guide presents basic genetics information that can be accessed by providers at all levels, working with patients from any community.” said Sharon Terry.

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Genetic Alliance increases the capacity of advocacy organizations to achieve their missions and leverages the voices of millions of individuals and families living with genetic conditions. We build communication and mentoring networks, design and sponsor rigorous training courses, and provide infrastructure that strengthens and empowers our 600 member organizations. The technical assistance we provide to advocacy organizations results in measurable growth: increased funding for research, access to services and support for emerging technologies. For more information: <http://www.geneticalliance.org>.

The mission of the District of Columbia Department of Health is to promote healthy lives, prevent illness, provide equal access to quality healthcare services, and protect the safety of all in the Nation’s Capital. Call 202-671-5000 for more information or print copies of, “Understanding Genetics: A Guide for Patients and Health Providers.”