

FOR IMMEDIATE RELEASE
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Genetic Alliance Awarded Two Newborn Screening Grants

(Washington, DC—May 24, 2007) Genetic Alliance announced today that it has received two cooperative agreements from the DHHS, Health Resources and Services Administration (HRSA) Genetic Services Branch of the Maternal and Child Health Bureau. Both grants are three-year special projects of regional and national significance. Sharon Terry, President and CEO of Genetic Alliance said, “We are thrilled to receive these grants. Our partners excel in advocacy, research and analysis, and these projects will make a tangible difference for families.”

The first grant is a qualitative assessment that focuses on the experience of families and professionals with respect to false positive screens and carrier identification. The results of this project will be used to develop models for improving newborn screening in the context of the medical home. Genetic Alliance will collaborate with the Save Babies Through Screening Foundation, Hunter’s Hope Foundation and the University of Maryland School of Medicine, as well as numerous parent and newborn screening advocacy organizations. Carol Greene, M.D., Professor of Pediatrics and Director, Pediatric Genetics Clinic, University of Maryland School of Medicine said, “We’re very much looking forward to working as team - health care providers and researchers with families - to better understand the effects of false positive newborn screening tests.”

The second grant is a quantitative measure of the public’s awareness of issues inherent in NBS and the changes of parental attitudes and responses with increased education about this form of screening. This project will promote family-centered care as an outcome of newborn screening by determining the information necessary for parents to make knowledgeable decisions as well as examining the public’s response to various newborn screening scenarios. Genetic Alliance will partner with the Genetics and Public Policy Center with involvement from the Save Babies Through Screening Foundation and Hunter’s Hope Foundation. “We are pleased to lend the Center’s expertise in assessing public attitudes and preferences to this important project,” says Kathy Hudson, director of the Center. “Figuring out what parents already know and believe about newborn screening is the first step toward improving education of new parents and improving health care for newborns and the quality of life for the entire family.”

Recent advances in technology have increased the number of conditions that can be screened for shortly after birth. In addition, changes in technology can reveal more information about the family. Though false positive results and identification of carriers have been part of NBS since PKU and sickle cell disease screenings were first introduced, the expansion of screening and the corresponding increase of positive results present new challenges for this public health system. Consumers will play a major role in advancing the number of disorders that can and will be considered for NBS.

These projects will put forward models based on consumer and medical home perspectives to minimize harm and maximize the benefits of the NBS system for all participants. “This is a

pivotal time in the world of newborn screening. It is very exciting to have the opportunity to work with such a wonderful team of people to address issues that are of the utmost importance,” said Jill Fisch of Save Babies Through Screening Foundation. Natasha Bonhomme, Program Coordinator at Genetic Alliance will oversee these two grants.

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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>.