Comments to the National Institutes of Health (NIH) in response to their request for information on data-sharing policy in relation to genome-wide association studies (GWAS)

November 30, 2006

November 5, 2006 Comments represent the opinion of Genetic Alliance and the undersigned organizations and individuals:

Introduction:
As a society, we often proclaim the promise of genomic science for health. Funding the Human Genome Project was an excellent start. As stakeholders with the most to gain in successful translation of genomic information to medical services, Genetic Alliance supports realizing the potential of this vast array of information as quickly as possible. Therefore, understanding the nuances of a balanced, but innovative, research enterprise is an important endeavor, and one in which we have an active role.

Genetic Alliance is a coalition of more than 600 genetic advocacy organizations nationwide representing more than 1000 genetic disorders, affecting more than 25 million Americans. Our mission is to increase the capacity of advocacy organizations to achieve their missions and leverage the voices of millions of individuals and families living with genetic conditions. We are committed to capacity building in all communities. The technical assistance we provide to advocacy organizations results in measurable growth: increased funding for research, access to services, and support for emerging technologies.

The following comments reflect the position of Genetic Alliance board of directors, not the members of Genetic Alliance, except those who have co-signed this document. We comment on the proposed Genome-Wide Association Studies (GWAS) data-sharing policy for (1) data sharing procedures, (2) data access principles, (3) intellectual property and (4) issues regarding the protection of research participants through all phases of GWAS. In general, the policy proposed by the National Institutes of Health (NIH) is consistent with our goals to increase quality and accelerate the outcomes of biomedical research, while maintaining safeguards for research participants.

Read the full text of the comments here.

Organizations

AboutFace USA
Acid Maltase Deficiency Association
Alpha-1 Advocacy Alliance
Alström Syndrome International
Angioma Alliance
ARPKD/CHF Alliance
BCCNS Life Support Network
Birt Hogg Dube Family Alliance
Cancer Information & Support Network
Caring Voice Coalition, Inc
CFC International
Claire Altman Heine Foundation, Inc.
Coalition of Heritable Disorders of Connective Tissue
Costello Syndrome Family Network
Cutis Laxa Internationale
Cystinosis Research Network
FOD Family Support Group
Genetic Alliance BioBank
HHT Foundation International
Hypertrophic Cardiomyopathy Association
In Need Of Diagnosis, Inc.
International Society of Nurses in Genetics
International Rett Syndrome Association
IsoDicentric 15 Exchange, Advocacy & Support
Jewish Genetic Disease Consortium
Marti Nelson Cancer Foundation
MHE Research Foundation
Moebius Syndrome Foundation
National Alopecia Areata Foundation
National Association of Social Workers
National Eczema Association
National Foundation for Ectodermal Dysplasias
National Hemophilia Foundation
National Organization of Vascular Anomalies
NBIA Disorders Association
Osteogenesis Imperfecta Foundation
Pachyonychia Congenita Project
Parent Project Muscular Dystrophy
PCD Foundation
Prader Willi Syndrome Association
Pull-thru Network, Inc.

PXE International
Stevens Johnson Syndrome Foundation
TMAU Foundation
Trisomy 18 Foundation, Inc.
VHL Family Alliance

Individuals

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