

**Letter to the Chairs of the Senate and House Appropriations Subcommittees
on Labor-HHS**

May 21, 2007

The Honorable Tom Harkin
Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related
Agencies
United States Senate
The Capitol, S-131
Washington, DC 20510

The Honorable Dave Obey
Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related
Agencies
United States House of Representatives
2358 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Harkin and Chairman Obey,

Thank you for your leadership on health policy. In considering the very important task of allocating funds for FY 2008, Genetic Alliance strongly urges the Subcommittee to increase appropriations for the following four Department of Health and Human Services agencies:

- * The National Institutes of Health (NIH);
- * The Centers for Disease Control and Prevention (CDC);
- * The Federal Drug Administration (FDA); and
- * The Health Resources and Services Administration (HRSA)

As an organization that includes more than 600 advocacy, research, and healthcare organizations that represent the interests of millions of individuals living with genetic conditions, we have a clear understanding of how the various branches of government can be effective in advancing human health. Though most of our member organizations are disease-specific patient support organizations, we are philosophically opposed to earmarking funds for specific diseases. Instead, we urge

you to allocate funding in ways that best promote biomedical research, population surveillance, and public health studies, and the translation of these findings into improved health services for all.

Genetic Alliance recommends that the Subcommittee increase funding for the National Institutes of Health.

The United States government made a strong statement for the value of genomic medicine when it decided to fund the Human Genome Project. What resulted from that project was the sequencing of the human genome, a scientific achievement that has already resulted in incredible advances in our fundamental understanding of health and disease. However, without additional funding, the NIH, specifically the National Human Genome Research Institute (NHGRI) and the Office of Rare Diseases (ORD), cannot possibly capitalize on or sustain that original investment. Genetic Alliance supports a 6.7% funding increase for the National Institutes of Health, particularly for the National Human Genome Research Institute and the Office of Rare Diseases.

Genetic Alliance recommends that the Subcommittee increase funding for the Centers for Disease Control and Prevention.

The ability to identify and link genes, genotypes, and disease is critical to improving health here in the United States and around the world. However, without substantial surveillance and extensive epidemiological information, the exciting advances made by NIH scientists cannot be fully appreciated. This translation of fundamental science into improved public health is the ultimate goal of all of our national biomedical research pursuits. Genetic Alliance recommends increased funding for the Centers for Disease Control, particularly for the Office of Genomics and Disease Prevention (OGDP).

Genetic Alliance recommends that the Subcommittee increase funding for the Food and Drug Administration.

Safety, efficacy, and security of drugs, biological products, and medical devices are necessary to ensure the good health of our nation. In order to continue advancement of public health, the FDA must be funded to accelerate innovations that make medicines more effective, safer, and more affordable. These advancements are especially important to chronic disease populations who rely on medications to sustain life. Genetic Alliance recommends increased funding for the Food and Drug Administration, particularly for the Office of Orphan Products Development (OOPD).

Genetic Alliance recommends that the Subcommittee increase fund for the Health Resources and Services Administration.

As a nation, we have recently begun to understand just how important scientific and medical research is to the health of our citizens. However, too often we have fallen

short when it comes to providing funds for the translation of what is truly incredible science into clinical applications and improved health services. Genetic Alliance has witnessed the effective and dedicated work done by HRSA - particularly by the Maternal and Child Health Bureau, Genetic Services Branch (MCHB/GSB) - to serve the public as advances in medical genetics continue to be made. Genetic Alliance recommends increased funding for the Health Resources Services Administration, particularly for MCHB/GSB.

As you allocate funds to the numerous divisions of the United States government, many difficult decisions must be made. We hope that you will consider our recommendations to provide the NIH, CDC, FDA, and HRSA with the funds they need to help improve the state of human health around the world.

Best,

Sharon F. Terry, MA
President and CEO