Dear Senators,

We want to encourage you to support the Genetic Information Nondiscrimination Act (GINA) and all the procedural motions necessary to ensure this bill’s success.

The Coalition for Genetic Fairness was founded in 2000 to address the growing concern surrounding the misuse of genetic information in insurance and employment decisions. Over the past eight years, our members, including civil rights, patient and health care organizations, industry, and academia, have worked to pass comprehensive federal legislation outlawing genetic discrimination.

The current lack of federal legal protections against the misuse of genetic information has restricted individuals’ access to health information and clinical trials. Fear of the misuse of genetic information limits access to genetic tests. Refusal to utilize effective genetic tests hinders the ability of individuals to learn important medical information, which they could use to proactively manage their health. Fear of discrimination also causes a large number of people to opt out of clinical trials. This lack of participation in research has a negative impact on researchers, clinicians, and industry, slowing the research and development process for targeted drugs and treatments. In order to fully promote personalized medicine and the use of genetic information in healthcare, we must pass GINA.

We are encouraged by the Senate’s record on this legislation, having passed it unanimously in the 108th and 109th Congresses. In addition, the House of Representatives passed GINA by an astonishing 420-3 vote last year. This legislation has strong bipartisan support and the backing of hundreds of organizations including disease advocates, industry, academia, clinicians, researchers, and community groups.

Thank you for your leadership on this issue. We look forward to working with you to have GINA pass swiftly.

Sincerely,

Sharon F. Terry, MA
Chair, Coalition for Genetic Fairness

(LETTER SENT TO ALL SENATORS)
ORGANIZATIONAL CO-SIGNERS

AA CSA Foundation
ABQ Associates, Inc.
American Clinical Laboratory Association
American Heart Association
American Osteopathic Association
American Physiological Society
American Public Health Association
American Society for Pharmacology and Experimental Therapeutics
American Society of Human Genetics
Angioma Alliance
APS Foundation of America, Inc
ARPKD/CHF Alliance
Baxter Healthcare Corporation
BioBasix Solutions Inc.
Birt Hogg Dube Family Alliance
Coalition of Heritable Disorders of Connective Tissue
Expression Analysis, Inc.
Foundation Fighting Blindness
GeneDx
Genetic Alliance
Genetic Alliance BioBank
Genetics, Ethics & Policy Consulting, Inc.
Genzyme Corporation
Helicos BioSciences Corporation
IEEE-USA
Institute of Genomic Medicine
MAGIC Foundation
Medical College of Wisconsin
National Disease Clusters Alliance
National Workrights Institute
Navigenics
NBIA Disorders Association
PAGER
Personalized Medicine Coalition
Private Access
PXE International
Research America
Shire HGT
Smart Genetics, LLC
THE OLIVE BRANCH FUND: A Thisbe and Noah Scott Legacy
VHL Family Alliance
Y-ME National Breast Cancer Organization