

November 25th, 2009

The Honorable Timothy F. Geithner  
Secretary of Treasury  
1500 Pennsylvania Avenue, NW  
Washington, D.C. 20220

The Honorable Kathleen Sebelius  
Secretary of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

The Honorable Hilda Solis  
Secretary of Labor  
200 Constitution Ave., NW  
Washington, DC 20210

Dear Secretaries Geithner, Sebelius and Solis

We wish to express our strong support for the Genetic Information Nondiscrimination Act (GINA) that was signed into law by President Bush in May 2008, and for the interim final rule implementing provisions of the law that will take effect on December 7<sup>th</sup>.

We are concerned, however, by calls for your agencies to delay when the regulations take effect, or to exempt employer-based wellness programs. Any delay in implementation would continue to allow employers to inquire about employees' private genetic information or their families' medical history, while penalizing employees who choose to keep that information private; any such exemption would create a loophole to significantly weaken the protections afforded to employees and the American people under GINA. We strongly oppose all proposals to weaken the rule or stop its prompt implementation.

When GINA becomes effective, the American people will for the first time enjoy broad protections against genetic discrimination by health insurance providers and employers. Insurance providers will not be able to use genetic information for underwriting purposes nor request patients to undergo genetic testing. Employers will not be able to discriminate against employees with respect to compensation, terms, conditions, or privileges because of genetic information. Genetic information will be protected medical information shared between individuals and their personal physicians and allied health professionals.

To minimize the potential for employer discrimination, GINA protects employee privacy by greatly limiting employer access to their genetic information. In general, employers may not request, require or purchase their employees' genetic information. They are also prohibited from asking employees about the medical conditions of their family members.

Reasonable exemptions are crafted in the law that enable employers to comply with all federal and state laws, to monitor the health of employees working under hazardous conditions, and to offer health or genetic services as part of a voluntary wellness program where each employee gives prior authorization. To protect the privacy of employees, GINA does not allow wellness or other programs that request or collect genetic information for underwriting purposes, which includes any changes to an individual's eligibility, benefits, or premiums.

Wellness programs are fully able to encourage healthy behaviors within the current legal framework: they need not collect and retain private genetic information to be effective. They do not need exemptions from important federal civil rights statutes like GINA, and individuals ought not to be subject to financial pressure by their health plans or employers to disclose their family's private medical information.

GINA was passed by Congress with very strong bipartisan support. It was passed by the Senate unanimously and in the House by a vote of 414-1 before being signed by President Bush, demonstrating overwhelming Congressional support for prohibiting genetic discrimination and ensuring that people's genetic information remains private. It is eighteen months since the legislation became law, and fourteen years since it was first introduced in Congress. We urge you to implement the law on December 7<sup>th</sup> without further delay.

Signed,

1-800-Therapist, LLC  
AARP  
Alliance for Aging Research  
Alpert Medical School at Brown University  
Alpha-1 Advocacy Alliance  
Alpha-1 Association  
Alpha-1 Foundation  
Alström Syndrome International  
Alzheimer's Foundation of America  
American Academy of Family Physicians  
American Academy of Pediatrics  
American Association for Cancer Research  
American Association for Respiratory Care  
American Association of People with Disabilities  
American Association on Health and Disability  
American Cancer Society Cancer Action Network  
American College of Medical Genetics  
American College of Physicians  
American Diabetes Association  
American Foundation for the Blind  
American Health Information Management Association

American Heart Association\*  
American Lung Association  
American Medical Association  
American Nurses Association  
American Public Health Association  
American Society for Human Genetics  
American Society for Pharmacology & Experimental Therapeutics  
American Society of Human Genetics  
American Stroke Association  
American Therapeutic Recreation Association  
Americans for Democratic Action  
Angioma Alliance  
ARPKD/CHF Alliance  
Association for Glycogen Storage Disease  
Association for Molecular Pathology  
Association of American Medical Colleges  
Association of Clinical Research Organizations (ACRO)  
Association of Gastrointestinal Motility Disorders, Inc. (AGMD)  
Association of University Centers on Disabilities  
Autism Society  
Batten Disease Support and Research Association  
BayBio  
Bazelon Center for Mental Health Law  
BCCNS Life Support Network  
Benign Essential Blepharospasm Research Foundation  
Breast Cancer Network of Strength  
Brooklyn Community-Based Sickle Cell Project, Brookdale Hospital Medical Center  
Burrill & Company  
Burton Blatt Institute  
BVVL International  
C3: Colorectal Cancer Coalition  
CADASIL Together We Have Hope  
Campaign for Mental Health Reform  
CARES Foundation, Inc  
Center for Independence of the Disabled of New York  
Center for Medical Consumers  
Centronuclear Myopathy Project, Myotubular Myopathy Resource Group  
Children's Sickle Cell Foundation, Inc.  
Children's Tumor Foundation  
Citizens for Quality Sickle Cell Care, Inc.  
Coalition for 21st Century Medicine  
Coalition for Genetic Fairness  
Coalition for Heritable Disorders of Connective Tissue  
College of American Pathologists  
Congenital Adrenal Hyperplasia Research Education & Support (CARES) Foundation, Inc.

Cooley's Anemia Foundation  
COPD-ALERT, National Patient Support and Advocacy Organization  
Council for Responsible Genetics  
Cranberry Fog  
Crohn's and Colitis Foundation of America  
CryerHealth  
Cystic Fibrosis Foundation  
Cystinosis Foundation  
Diamond Health Consulting  
Disability Rights Education and Defense Fund  
Dystonia Medical Research Foundation  
Dystrophic Epidermolysis Bullosa Research Association of America  
Easter Seals  
Epilepsy Foundation  
Exact Sciences Corporation  
Expression Analysis, Inc.  
FACES: The National Craniofacial Association  
Facing Our Risk  
Families USA  
Family Voices  
Federation of American Societies for Experimental Biology  
First Candle/SIDS Alliance  
FOD Family Support Group  
FORCE: Facing Our Risk of Cancer Empowered  
Foundation Fighting Blindness  
Foundation for Ichthyosis & Related Skin Types, Inc.  
Foundation for Prader-Willi Research  
FRAXA Research Foundation  
Gene Logic, An Ocimum BioSolutions Company  
GeneDx  
Geneforum  
Generation Health, Inc.  
Genetic Alliance  
Genetic Disease Foundation  
Genetics and Public Policy Center  
Global Sickle Cell Alliance, Inc  
Gluten Intolerance Group of North America (GIG)  
Hadassah  
Hannah's Hope Fund  
HealthFutures, LLC  
Helicos BioSciences Corporation  
Hemophilia Federation of America  
Hepatitis Foundation International  
Hereditary Disease Circle  
Hermansky-Pudlak Syndrome Network Inc.  
HHT Foundation International

Hide & Seek Foundation for Lysosomal Disease Research  
Huntington's Disease Society of America  
Indiana Network of Genetic Counselors  
Innolyst, Inc.  
International 22q11 Deletion Syndrome Foundation  
International Society Of Nurses in Genetics  
Japanese American Citizens League  
Joubert Syndrome & Related Disorders Foundation  
Kleiner Perkins Caufield & Byers  
Klinefelter Syndrome & Associates (KS&A)  
Klippel-Trenaunay Support Group  
Leadership Conference on Civil Rights  
Living Beyond Breast Cancer  
Living with Trisomy 13 – Patau Syndrome  
Lung Cancer Circle of Hope  
LYMF Foundation  
Lymphangiomatosis & Gorham's Disease Alliance  
Lymphatic Research Foundation  
Malignant Hyperthermia Registry of the Malignant Hyperthermia Association of the United States, University of Pittsburgh Medical Center  
March of Dimes Foundation  
MDV—Mohr, Davidow Ventures  
MLD Foundation  
Muscular Dystrophy Association  
Myotonic Dystrophy Foundation  
NAACP  
Narcolepsy Network  
National Alliance for Caregiving  
National Association for Anorexia Nervosa and Associated Disorders (ANAD)  
National Association of Social Workers  
National Ataxia Foundation  
National Council of Jewish Women  
National Council of La Raza  
National Disability Rights Network  
National Eczema Association  
National Fabry Disease Foundation (NFDF)  
National Foundation for Ectodermal Dysplasias  
National Foundation for Mental Health  
National Fragile X Foundation  
National Gaucher Foundation  
National Health Council  
National Health Law Program  
National Hemophilia Foundation  
National Marfan Foundation  
National Organization of Vascular Anomalies  
National Partnership for Women & Families

National Patient Advocate Foundation  
National PKU Alliance  
National Society of Genetic Counselors  
National Spasmodic Dysphonia Association  
National Spinal Cord Injury Association  
National Tay-Sachs & Allied Diseases Association, Inc. (NTSAD)  
National Women's Law Center  
National Workrights Institute  
Navigenics, Inc.  
NERGG, Inc (New England Regional Genetics Group)  
NeuroMark, Inc.  
New Yorkers for Accessible Health Coverage  
NOMID Alliance  
Northeast Velo Cardio Facial Syndrome Support Network  
Northern Nevada Genetic Counseling  
Olive Branch Fund  
Osteogenesis Imperfecta Foundation  
Pachyonychia Congenita Project  
Parkinson's Action Network  
Pediatric Adolescent Gastroesophageal Reflux Association  
Personalized Medicine Coalition  
Personalized Medicine Partners, LLC  
Physician-Parent Caregivers  
PKD Foundation  
Platelet Disorder Support Association  
Prader-Willi Syndrome Association of Pennsylvania  
PreventionGenetics  
Progeria Research Foundation, Inc.  
PTC Therapeutics  
Pull-thru Network  
PXE International  
Rare Chromosome Disorder Support Group  
RedPath  
Research Advocacy Network  
Research!America  
SADS Foundation  
Scleroderma Foundation  
Service Employees International Union  
Shwachman Diamond Syndrome Foundation  
Sickle Cell Disease Association of America  
Sickle Cell Disease Association/PDVC  
Sickle Cell Foundation of Georgia, Inc.  
Sickle Cell/Thalassemia Patients Network  
SistaMoon Foundation for Devis's Disease  
Smith-Lemli-Opitz/RSH Foundation  
Society of General Internal Medicine

ST/Dystonia, Inc.  
Statewide Parent Advocacy Network (SPAN)  
Sudden Cardiac Arrest Association  
The Arc of the United States  
The National Alliance for Caregiving  
TMJ Association  
Tourette Syndrome Association  
Trimethylaminuria Foundation  
Tuberous Sclerosis Alliance  
UCLA Society & Genetics Undergraduate Organization  
United Cerebral Palsy  
United Jewish Communities: Jewish Federations of America  
United Mitochondrial Disease Foundation  
United Ostomy Associations of America  
United Spinal Association  
Vascular Disease Foundation  
XDx

\* Please respond via Derek Scholes (202-785-7927; [derek.scholes@heart.org](mailto:derek.scholes@heart.org)) at The American Heart Association.