

November 30th, 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 7th.

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 7th without further delay.

Signed,

1-800-Therapist, LLC
AARP
Affiliated American CSA Foundation
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 Academy of Physician Assistants
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 Sickle Cell Anemia Association
American Society for Clinical Pathology
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
Celiac Sprue Association
Center for Emerging Technologies
Center for Independence of the Disabled of New York
Center for Medical Consumers
Centronuclear Myopathy Project, Myotubular Myopathy Resource Group
Children's Alopecia Project
Children's Rare Disease Network
Children's Sickle Cell Foundation, Inc.
Children's Tumor Foundation

Citizens for Quality Sickle Cell Care, Inc.
Claire Altman Heine Foundation, 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
Diabetes Action Research and Education Foundation
Diamond Health Consulting
Disability Rights Education and Defense Fund
Dysautonomia Foundation, Inc.
Dystonia Medical Research Foundation
Dystrophic Epidermolysis Bullosa Research Association of America
Easter Seals
Ehlers Danlos National Foundation
Ehlers-Danlos Syndrome Network C.A.R.E.S. Foundation
Epilepsy Foundation
Exact Sciences Corporation
Expression Analysis, Inc.
Fabry Support & Information Group
FACES: The National Craniofacial Association
Facing Our Risk
Families USA
Family Voices
Federation of American Societies for Experimental Biology
Fight ALD
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
Friends of Cancer Research
Gene Logic, An Ocimum BioSolutions Company
GeneDx
Geneforum
Generation Health, Inc.

Genetic Alliance
Genetic Disease Foundation
Genetic Task Force of Illinois
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
Hereditary Disease Foundation
Hermansky-Pudlak Syndrome Network Inc.
HHT Foundation International
Hide & Seek Foundation for Lysosomal Disease Research
Huntington's Disease Society of America
Hypertrophic Cardiomyopathy Association - HCMA
Indiana Network of Genetic Counselors
Innolyst, Inc.
Institute for Cultural Partnerships
International 22q11 Deletion Syndrome Foundation
International Society of Nurses in Genetics (ISONG)
International WAGR Syndrome Association
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
Lymphangiomas & 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
Medical Genetics Services, PC
MLD Foundation
Muscular Dystrophy Association
Myotonic Dystrophy Foundation
NAACP

Narcolepsy Network
National Alliance for Caregiving
National Alliance for Thrombosis and Thrombophilia
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 MSP Society
National Organization for Rare Disorders (NORD)
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.
NBIA Disorders Association
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
OpenHelix LLC
Osteogenesis Imperfecta Foundation
Oxalosis and Hyperoxaluria 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.
Project DOCC - Delivery of Chronic Care
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 of America, Inc.-Eastern NC Chapter
Sickle Cell Disease Association/PDVC
Sickle Cell Foundation of Georgia, Inc.
Sickle Cell/Thalassemia Patients Network
SistaMoon Foundation for Devic's Disease
Smith-Lemli-Opitz/RSH Foundation
Society of General Internal Medicine
Spastic Paraplegia Foundation, Inc
ST/Dystonia, Inc.
Statewide Parent Advocacy Network (SPAN)
Sudden Arrhythmia Death Syndromes (SADS) Foundation
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
Turner Syndrome Society of the US
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
VHL Family Alliance
XDx

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