

November 12th, 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,

Alpha-1 Association
Alpha-1 Foundation
AARP
American Association for Cancer Research
American Association of People with Disabilities
American Association on Health and Disability
American Cancer Society Cancer Action Network
American College of Medical Genetics
American Diabetes Association
American Foundation for the Blind
American Heart Association
American Lung Association
American Nurses Association
American Society for Human Genetics
American Stroke Association
American Therapeutic Recreation Association
Americans for Democratic Action
Association for Molecular Pathology
Association of American Medical Colleges
Autism Society
Bazelon Center for Mental Health Law
Breast Cancer Network of Strength
Brown University Medical School

Burton Blatt Institute
Campaign for Mental Health Reform
Center for Independence of the Disabled of New York
Center for Medical Consumers
Council for Responsible Genetics
Cystic Fibrosis Foundation
Disability Rights Education and Defense Fund
Easter Seals
Epilepsy Foundation
Families USA
Family Voices
Federation of American Societies for Experimental Biology
FORCE: Facing Our Risk of Cancer Empowered
Genetics and Public Policy Center
HealthFutures, LLC
Huntington's Disease Society of America
Japanese American Citizens League
Leadership Conference on Civil Rights
NAACP
National Association of Social Workers
National Council of Jewish Women
National Council of La Raza
National Disability Rights Network
National Foundation for Mental Health
National Health Law Program
National Partnership for Women & Families
National Patient Advocate Foundation
National Spinal Cord Injury Association
National Women's Law Center
National Workrights Institute
Navigenics, Inc.
New Yorkers for Accessible Health Coverage
Personalized Medicine Coalition
Platelet Disorder Support Association
Service Employees International Union
The Arc of the United States
The National Alliance for Caregiving
Tourette Syndrome Association
United Cerebral Palsy
United Jewish Communities: Jewish Federations of America
United Spinal Association