

November 4th, 2009

Dear Senator,

As Congress considers health reform, we urge you not to take any action that would weaken the Genetic Information Nondiscrimination Act (GINA) that was signed into law by President Bush in 2008. We are concerned that some are calling for Congress to exempt employer-based wellness programs from the law. Such action would allow employers to inquire about employees' private genetic information or their families' medical history, while penalizing employees who do not wish to participate. This would create a loophole to significantly weaken the protections afforded to employees and the American people under GINA, and we strongly oppose this or any similar proposal to exempt employer-based wellness programs from GINA in health care reform legislation.

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.

The statute provisions will become effective in the coming months, and we urge you not to take any action to weaken the existing law.

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 Civil Liberties Union  
American College of Medical Genetics  
American Diabetes Association  
American Foundation for the Blind  
American Nurses Association  
American Society for Human Genetics  
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  
Family Voices  
Federation of American Societies for Experimental Biology  
FORCE: Facing Our Risk of Cancer Empowered  
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  
United Cerebral Palsy  
United Jewish Communities: Jewish Federations of America  
United Spinal Association