

**Advocacy letter from 29 undersigned organizations regarding
Genetic Information Nondiscrimination Act**

October 30th, 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 enquire 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 employment provisions of the statute take effect in November. We urge you not to take any action to weaken the existing law.

Signed,

Alpha-1 Association
Alpha-1 Foundation
American Association for Cancer Research
American Association of People with Disabilities
American Cancer Society Cancer Action Network
American Civil Liberties Union
American College of Medical Genetics
American Diabetes Association
American Heart Association
American Society for Human Genetics
American Stroke Association
Americans for Democratic Action
Association for Molecular Pathology
Association of American Medical Colleges
Breast Cancer Network of Strength
Brown University Medical School
Campaign for Mental Health Reform
Council for Responsible Genetics
Cystic Fibrosis Foundation
Federation of American Societies for Experimental Biology
HealthFutures, LLC
Huntington's Disease Society of America
Leadership Conference on Civil Rights
National Council of Jewish Women
National Partnership for Women & Families
National Workrights Institute
Navigenics, Inc.
Personalized Medicine Coalition
Platelet Disorder Support Association