

June 29, 2010

Jacqueline A. Berrien
Chair
U.S. Equal Employment Opportunity Commission
131 M Street, NE
Washington, DC 20507

Dear Chair Berrien,

We wish to express our continued support for the Genetic Information Nondiscrimination Act (GINA) that was signed into law by President Bush in May 2008. We recognize that the Commission will play a critical role in ensuring the effectiveness and strong enforcement of the new law. In that regard, we urge you to ensure that the final regulations include strong provisions that prohibit employers from coercing employees into revealing their private genetic information.

To protect Americans from genetic discrimination, GINA not only prohibits discrimination itself but it also greatly restricts access by employers and issuers of insurance to genetic information to minimize the potential for discrimination. A few exceptions allow employers or insurers to request genetic information under very limited circumstances. However, the law is very clear: employers or insurers may only request genetic information when responding to such a request is entirely voluntary and not coerced.

This important principle is evident throughout GINA. For example, Title I permits health insurers involved in conducting legitimate medical research to request, but not require, that enrollees undergo genetic testing as part of the research, but only if the insurer informs the enrollee that participation is voluntary and “will have no effect on enrollment status or premium or contribution amounts.”

As you know, Title II also permits employers to request genetic information when the employer offers health or genetic services, including such services provided as part of a voluntary wellness program. The employee must provide “...prior, knowing, voluntary, and written authorization.” Any individually identifiable genetic information collected as part of that service cannot be made available to the employer, but only to “...the licensed health care professional or board certified genetic counselor involved in providing such services.” This is a narrow exception, carefully crafted to ensure that employers can only obtain or request genetic information when the employee voluntarily chooses to provide it. Under this exception, employees, for example, may enjoy the undoubted benefits of a clinic provided by their employer that includes voluntary health screening services, while remaining confident that they are protected from potential genetic discrimination.

We anticipate that one of the issues that will be addressed in the forthcoming GINA Title II regulations will be how GINA’s prohibition on coercion by employers interacts with employers’ offering wellness programs that require the worker to divulge genetic information as part of a health risk assessment (HRA). We are aware that during the rule-making process there have been calls for the Commission to create an additional exemption allowing employers to ask employees’ for their private genetic information through a HRA or similar program, where participants are rewarded with cash, gifts or adjustments to their health care premiums. Any

such exemption would create an environment where employers can coerce employees into divulging their genetic information by withholding rewards from, and therefore penalizing, employees who choose not to complete the HRA in order to not reveal their genetic information. This completely undermines one of GINA's most important tenets, that individuals have the right to keep their genetic information private without penalty. The provision of genetic information must be truly voluntary.

In issuing regulations for GINA Title II, we urge you to maintain consistency with the interim final rule (74 FR 51664) for GINA Title I issued by the Department of Health and Human Services (HHS), the Department of Labor (DOL) and the Department of the Treasury. HHS and DOL have explained (1, 2) that, under this interim final rule, plans and issuers of health insurance may continue to offer participatory rewards to individuals to encourage them to participate in wellness programs and complete an HRA that includes questions on family history, so long as they notify individuals that *answering the questions concerning family history is optional*, and that the reward will be received whether the section is completed or not. Enrollees can benefit from the wellness programs without penalties being levied on individuals who wish to keep their genetic information private. We believe this is a reasonable approach and urge you to mirror these protections in the Title II final rule.

As stated by the sponsors of GINA and other Congressional leaders with key roles in its enactment, "...employee wellness plans can be successful without the collection of family history or other genetic information." (3) Indeed, effective wellness programs providing comprehensive and prevention programs, such as for tobacco cessation, nutrition education or stress management, can truly be a win-win proposition for employers and employees, and we applaud the employers who are providing such services. Such programs, including ones that utilize HRAs, can continue to be effective under GINA.

To the extent that the Commission intends to use the GINA regulations as a platform to endorse penalties or rewards for participation in wellness programs in general, or the use of penalties or rewards for workers who meet the goals of certain wellness programs, we urge the Commission to consider the following factors. First, there is no reason in the context of the GINA regulations to reach the question of incentives or penalties for wellness programs other than in the context of questions on genetic information in HRAs. Second, any incentives or penalties offered by employers as part of wellness programs must be awarded or determined in a manner that does not violate the laws that the Commission enforces, and the Commission must make that fact clear to the businesses it regulates.

Congress intended to protect individuals from financial pressure to disclose their family's private medical information. If the EEOC regulations were to allow employers to penalize employees who do not divulge genetic information, it would greatly undermine the protections Congress deliberately included in GINA and create an untenable inconsistency with the regulations implementing Title I.

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. We urge you to issue a strong rule that reflects the statute and the intent of Congress.

Signed,

AARP
American Academy of Pediatrics
American Association for Cancer Research
American Association of People with Disabilities
American Association of University Women (AAUW)
American Civil Liberties Union (ACLU)
American Diabetes Association
*American Heart Association/American Stroke Association
American Lung Association
American Music Therapy Association
Americans for Democratic Action, Inc.
Association for Molecular Pathology
Association of University Centers on Disabilities
Bazelon Center for Mental Health Law
Breast Cancer Network of Strength
Center for Democracy & Technology
Center for Self-Determination
Community HIV/AIDS Mobilization Project (CHAMP)
Consumers Union
Council for Responsible Genetics
Epilepsy Foundation
Families USA
Family Voices
FORCE: Facing Our Risk of Cancer Empowered
Genetics and Public Policy Center
Huntington's Disease Society of America
Little People of America
National Association of County Behavioral Health and
Developmental Disability Directors (NACBHDD)
National Association of Social Workers
National Coalition for Mental Health Recovery
National Disability Rights Network
National Organization for Rare Disorders (NORD)
National Organization of Nurses with Disabilities
National Partnership for Women & Families
National Patient Advocate Foundation
National Workrights Institute (NWI)
Not Dead Yet
Paul Steven Miller
Service Employees International Union (SEIU)
Sudden Cardiac Arrest Association
TASH
The Arc of the United States
United Cerebral Palsy

*Please respond via Derek Scholes at the American Heart Association at 202-785-7927 or derek.scholes@heart.org.

References

1. Letter dated December 1st, 2009 from Secretary Sebelius to American Heart Association
2. Letter dated January 20th, 2010 from Secretary Solis to American Heart Association
3. Letter dated December 2nd, 2009 from Chairwoman Slaughter, Chairman Waxman, Chairman Miller, Chairman Rangel, Chairman Pallone, Chairman Stark, Chairman Emeritus Dingell, Chairwoman DeLauro and Congresswoman Biggert to Secretaries Sebelius, Solis and Geithner

CC: Commissioner Constance S. Barker; Commissioner Chai Feldblum; Commissioner Stuart J. Ishimaru; Commissioner Victoria A. Lipnic; General Counsel P. David Lopez