

March 7, 2017

The Honorable Virginia Foxx
Chairwoman
U.S. House Committee on Education
and the Workforce
2176 Rayburn House Office Building
Washington, DC 20515

The Honorable Robert C. Scott
Ranking Member
U.S. House Committee on Education
and the Workforce
2176 Rayburn House Office Building
Washington, DC 20515

CC: Members of the U.S. Committee on Education and the Workforce

Dear Chairwoman Foxx and Ranking Member Scott:

As strong supporters of the Genetic Information Nondiscrimination Act (GINA) and the Americans with Disabilities Act (ADA), the undersigned national organizations oppose H.R.1313, the Preserving Employee Wellness Programs Act. This legislation seeks to exempt employer-based wellness programs from GINA and the ADA. **We strongly oppose any legislation that would allow employers to inquire about employees' private genetic information or medical information unrelated to their ability to do their jobs, and to impose draconian penalties on employees who choose to keep that information private.**

GINA ensures that all Americans are free from genetic discrimination by issuers of health insurance and employers. Importantly, GINA not only prohibits discrimination itself but also greatly restricts access by employers and payers to the genetic information of employees and enrollees. In general, employers may not request, require or purchase their employees' genetic information, nor inquire about their families' medical conditions. An exception to this general prohibition allows an employer to ask employees to provide their genetic information or undergo genetic testing as part of a health or genetic service, such as part of a wellness program. However, this exception states that an employee's participation in such a wellness program must be *voluntary*.

Similarly, the ADA protects all Americans from workplace discrimination on the basis of disability. Employers are prohibited from subjecting employees to medical inquiries and examinations that are not job-related and consistent with business necessity, unless those inquiries are *voluntary* and asked as part of a wellness program.

These provisions of GINA and ADA protecting privacy in the workplace were carefully crafted to ensure that employers can only obtain or request protected genetic and medical information when the employee *voluntarily* provides it. Employees may, for example, enjoy the benefits of an innovative wellness program such as a clinic provided by their employer that includes voluntary health screening services, while remaining confident that they are protected from potential discrimination.

The Equal Employment Opportunity Commission has already promulgated rules implementing this requirement in the ADA and GINA that employee health and genetic information sought by wellness programs be provided voluntarily. These rules already take into account employers' desire to use penalties to incentivize employees to provide this information, allowing penalties that may amount to thousands of dollars for employees who choose to keep this information private. If enacted, H.R.1313 would overturn the employee protections in these rules, and would allow penalties that are far more severe.

With respect to employees' genetic information, the change would be particularly dramatic. Other than with respect to the medical history of employees' spouses, the current regulation does not allow the imposition of any penalties for employees who choose not to disclose genetic information. However, H.R.1313 would allow penalties up to a maximum averaging many thousands of dollars per year if employees decline to disclose information from genetic tests that they, their spouses, their children or their other family members have had, or if they do not reveal their families' medical histories. Allowing penalties of this magnitude would clearly allow employers to coerce employees into revealing their private genetic information.

Workplace wellness programs are fully able to encourage healthy behaviors within the current legal framework: they need not collect and retain private genetic and medical information to be effective. Individuals ought not to be subject to steep financial pressures by their health plans or employers to disclose their or their families' genetic and medical information.

GINA was passed by Congress with very strong bipartisan support. It was passed by the Senate unanimously and in the House of Representatives by a vote of 414-1, demonstrating overwhelming Congressional support for prohibiting genetic discrimination and ensuring genetic privacy for employees. Likewise, the ADA passed the Senate by a vote of 76-8 and was passed by unanimous consent by the House of Representatives. **We, the undersigned, strongly urge the Committee on Education and the Workforce not to advance the Preserving Employee Wellness Programs Act, but instead to preserve the nondiscrimination protections afforded to all Americans by GINA and the ADA.**

Signed,

AARP

Academy for Eating Disorders

AliveAndKickn

Alpha-1 Foundation

American Academy of Pediatrics

American Association for the Study of Liver Diseases

American Association on Health and Disability

American Cancer Society Cancer Action Network

American College of Medical Genetics and Genomics

American Diabetes Association

American Society for Metabolic and Bariatric Surgery

American Society of Human Genetics

Angioma Alliance
Association for Molecular Pathology
Autistic Self Advocacy Network
Bazelon Center
Binge Eating Disorder Association (BEDA)
BingeBehavior.com
Bridge The Gap - SYNGAP Education and Research Foundation
Bright Pink
Center for Democracy & Technology
CFC International
Cockayne Syndrome Network, Share & Care
Congenital Adrenal hyperplasia Research, Education & Support Foundation (CARES Foundation)
Cooley's Anemia Foundation
COPD Foundation
Cure HHT
Disability Rights Education and Defense Fund
Epilepsy Foundation
Fabry Support & Information Group
Families USA
FORCE: Facing Our Risk of Cancer Empowered
Genetic Alliance
Genetics Society of America
Global Genes - Allies in Rare Disease
Global Healthy Living Foundation
Hannah's Hope Fund
Huntington's Disease Society of America
International Pemphigus and Pemphigoid Foundation
Jeffrey Modell Foundation
K-T Support Group
Kids With Heart National Association for Children's Heart Disorders, Inc
Lakeshore Foundation
Living Beyond Breast Cancer
M-CM Network
March of Dimes
MLD Foundation
National Council on Independent Living
National Eating Disorders Association
National Ovarian Cancer Coalition
National Partnership for Women & Families
National PKU Alliance Inc.
National Urea Cycle Disorders Foundation
National Women's Law Center

NBIA Disorders Association
Obesity Action Coalition
Obesity Medicine Association
Powerful Patient Inc.
PXE International
Rare and Undiagnosed Network (RUN)
RASopathies Network USA
Society of General Internal Medicine
Sudden Arrhythmia Death Syndromes Foundation
Susan G. Komen
The Obesity Society
The Transverse Myelitis Association
United Leukodystrophy Foundation
Usher 1F Collaborative
Usher Syndrome Coalition