

[Date, 2017]

Dear Representative:

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 you to oppose the Preserving Employee Wellness Programs Act, and to preserve the nondiscrimination protections afforded to all Americans by GINA and the ADA.**

Signed,

AARP

Academy for Eating Disorders

ACRIA

AFL-CIO

AIDS Alabama

AliveAndKickn

Alpha-1 Foundation

Alstrom Syndrome International

American Academy of Pediatrics

American Association for Cancer Research

American Association for the Study of Liver Diseases

American Association of Diabetes Educators

American Association on Health and Disability

American Cancer Society Cancer Action Network

American College of Medical Genetics and Genomics

American Diabetes Association

American Federation of State, County and Municipal Employees

American Society for Investigative Pathology

American Society for Metabolic and Bariatric Surgery

American Society for Bone and Mineral Research

American Society of Clinical Oncology

American Society of Human Genetics

Angioma Alliance
Association for Molecular Pathology
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Binge Eating Disorder Association (BEDA)
BingeBehavior.com
Black Lives Matter Austin
Bladder Cancer Advocacy Network
Bridge The Gap - SYNGAP Education and Research Foundation
Bright Pink
Cancer Genomics Consortium
Center for Democracy & Technology
Center for Genetics and Society
CFC International
CMTC OVM
Cockayne Syndrome Network, Share & Care
College of American Pathologists
Congenital Adrenal hyperplasia Research, Education & Support Foundation (DBA: CARES Foundation, Inc.)
Cooley's Anemia Foundation
COPD Foundation
Coriell Institute for Medical Research
Cure HHT
CUTIS LAXA INTERNATIONALE
Disability Rights Education and Defense Fund
Dyskeratosis Congenita Outreach, Inc
Dystonia Medical Research Foundation
Eating Disorders Coalition
Epilepsy Foundation
Fabry Support & Information Group
Familial Hypercholesterolemia Foundation
Families USA
Fibrous Dysplasia Foundation
First Unitarian Society of Westchester, Hastings on Hudson NY
FOD Family Support Group
FORCE: Facing Our Risk of Cancer Empowered
Foundation Fighting Blindness
Friedreich's Ataxia Research Alliance – FARA
GeneDx
Genetic Alliance
Genetic Support Foundation

Genetics Society of America
GeneYes
Global Genes - Allies in Rare Disease
Global Healthy Living Foundation
Hadassah, The Women's Zionist Organization, of America, Inc.
Hannah's Hope Fund
HealthHIV
Hemophilia Federation of America
Hepatitis Foundation International
HeritX
Hermansky-Pudlak Syndrome Network
Human Rights Campaign
Huntington's Disease Society of America
Hypertrophic Cardiomyopathy Association
Idaho Cytogenetics Diagnostic Laboratory
International Center for Technology Assessment-Human Genetics Project
International Pemphigus and Pemphigoid Foundation
Islamic Civic Engagement Project
JDRF
Jeffrey Modell Foundation
K-T Support Group
Kids With Heart National Association for Children's Heart Disorders, Inc
Lakeshore Foundation
Lambda Legal
Little Miss Hannah Foundation
Living Beyond Breast Cancer
M-CM Network
March of Dimes
MLD Foundation
NARAL Pro-Choice Washington
National Ataxia Foundation
National Black Justice Coalition
National Council on Independent Living
National Eating Disorders Association
National Employment Lawyers Association
National Hemophilia Foundation
National Ovarian Cancer Coalition
National Partnership for Women & Families
National PKU Alliance Inc.
National Physicians Alliance
National Spasmodic Dysphonia Association

National Urea Cycle Disorders Foundation
National Women's Law Center
National Workrights Institute
NBIA Disorders Association
Neurofibromatosis Michigan
Noah's Hope
Obesity Action Coalition
Obesity Medicine Association
Obesity Society
Organic Acidemia Association
PCD Foundation
Pediatric Adolescent Gastroesophageal Reflux Association
Positive Women's Network-USA
Powerful Patient Inc.
Preeclampsia Foundation
PreventionGenetics
PRISMS, Inc. (Parents and Researchers Interested in Smith-Magenis Syndrome)
Professional & Technical Employees, Local 17
Project Inform
PROS Foundation
PTEN Hamartoma Tumor Syndrome Foundation
Puget Sound Advocates for Retirement Action (PSARA)
PXE International
Rare and Undiagnosed Network (RUN)
Rare Genomics Institute
RASopathies Network USA
Society of General Internal Medicine
Sudden Arrhythmia Death Syndromes Foundation
Susan G. Komen
The Association for Frontotemporal Degeneration
The National Coalition for LGBT Health
The Oxalosis & Hyperoxaluria Foundation
The Transverse Myelitis Association
Tigerlily Foundation
Turner Syndrome Society of the U.S.
UCHAPS: Urban Coalition for HIV /AIDS Prevention Services
UNITE HERE
United Leukodystrophy Foundation
United Steelworkers
Usher 1F Collaborative
Usher Syndrome Coalition

Washington Community Action Network

Washington Healthcare Access Alliance