

March 20, 2015

The Honorable John Kline
Chairman
Committee on Education and Workforce
House of Representatives

The Honorable Robert "Bobby" Scott
Ranking Member
Committee on Education and Workforce
House of Representatives

The Honorable Tim Walberg
Chairman
Subcommittee on Workforce Protections
Committee on Education and Workforce
House of Representatives

The Honorable Frederica S. Wilson
Ranking Member
Subcommittee on Workforce Protections
Committee on Education and Workforce
House of Representatives

Dear Chairman Kline, Ranking Member Scott, Chairman Walberg, Ranking Member Wilson and Members of the House of Representatives Committee on Education and Workforce:

We wish to express our strong support for the Genetic Information Nondiscrimination Act (GINA) that was signed into law by President George W. Bush in 2008 and the Americans with Disabilities Act (ADA) signed into law by President George H.W. Bush in 1990. We are concerned, however, by recently introduced legislation that seeks to exempt employer-based wellness programs from GINA and the ADA. **We strongly oppose any policy that would allow employers to inquire about employees' private genetic information or medical information that is unrelated to their ability to do their jobs, and penalize employees who choose to keep that information private.**

GINA ensures that all Americans are free from genetic discrimination by health insurance providers and employers. Insurance providers cannot use genetic information for underwriting purposes nor request patients to undergo genetic testing. Employers cannot discriminate against employees with respect to compensation, terms, conditions, or privileges because of genetic information. Furthermore, 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. 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. However, importantly, an exception to this general prohibition allows an employer to offer health or genetic services as part of a wellness program where an employee's participation is *voluntary*.

The ADA protects Americans from workplace discrimination on the basis of disability. Among other things, 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 the ADA are carefully crafted to ensure that employers can only obtain or request protected genetic and medical information when the employee *voluntarily* provides it. Under these rules, employees, for example, may 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.

We oppose provisions within the Preserving Employee Wellness Programs Act (S. 620/H.R. 1189) that would repeal GINA and ADA requirements that wellness program requests for genetic and medical information be voluntary, opening the door to employers coercing employees into revealing their private health and genetic information. 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. They do not need exemptions from important federal civil rights statutes like GINA and the ADA, and 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 unanimously approved by the House of Representatives. **We, the undersigned, strongly urge Members of the Committee on Education and Workforce to preserve the nondiscrimination protections afforded to all Americans by GINA and the ADA and not pass the Preserving Employee Wellness Programs Act.**

Signed,

Sp- Society

Alstrom Syndrome International

American Association on Health and Disability

American Diabetes Association

American Foundation for the Blind

American Heart Association

American Society of Human Genetics

Angioma Alliance

Association of Molecular Pathology

Association of University Centers on Disabilities

Autistic Self Advocacy Network

AXYS

Bazelon Center for Mental Health Law

Brain Injury Association of America

CFC International

Coalition of Heritable Disorders of Connective Tissue

Congenital Adrenal hyperplasia Research, Education & Support (CARES) Foundation

Council for Responsible Genetics

Dempster Family Foundation

Disability Rights Education and Defense Fund

Epilepsy Foundation

Fabry Support & Information Group

Families USA

Family Voices of NJ
FORCE: Facing Our Risk of Cancer Empowered
Foundation for Prader-Willi Research
Friedreich's Ataxia Research Alliance
Genetic Alliance
Global Healthy Living Foundation
HHT Foundation International
Inflammatory Breast Cancer Research Foundation
International Myeloma Foundation
International Pemphigus and Pemphigoid Foundation (IPPF)
International WAGR Syndrome Association
Lakeshore Foundation
M-CM Network
MLD Foundation
National Council on Independent Living
National Disability Rights Network
National Hemophilia Foundation
National Urea Cycle Disorders Foundation
NBIA Disorders Association
Ovarian Cancer National Alliance
Paralyzed Veterans of America
Parent Project Muscular Dystrophy (PPMD)
PXE International
Statewide Parent Advocacy Network
Sticker Involved People
Sudden Arrhythmic Death Syndromes (SADS) Foundation
Susan G. Komen
The Life Raft Group
Tuberous Sclerosis Alliance
United Leukodystrophy Foundation