

April 21, 2015

Dear Members of Congress:

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 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 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 are carefully crafted to ensure that employers can only obtain or request protected genetic and medical information when the employee *voluntarily* provides it. Under this rule, 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 employees' medical and genetic 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 you to preserve the nondiscrimination protections afforded to all Americans by GINA and the ADA and oppose the Preserving Employee Wellness Programs Act.**

Signed,

5p- Society

ACCSES

Activate Networks

Alstrom Syndrome International

American Academy of Family Physicians

American Academy of Pediatrics

American Association for Cancer Research

American Association for Respiratory Care

American Association on Health and Disability

American Diabetes Association

American Foundation for the Blind

American Heart Association

American Public Health Association

American Society of Human Genetics

American Stroke Association

Angioma Alliance

Association for Molecular Pathology

Association of American Medical Colleges

Association of University Centers on Disabilities

Autistic Self Advocacy Network

AXYS: Association for X and Y Chromosome Variations

Batten Disease Support and Research Association

Bazelon Center for Mental Health Law

Brain Injury Association of America

Bridge the Gap - SYNGAP Education and Research Foundation

CADASIL Together We Have Hope

Center for Independence of the Disabled of New York

CFC International

Children's Sickle Cell Foundation
Clinical Bioethics, Georgetown University Medical Center
Coalition of Baltimore HIV Providers
Coalition of Heritable Disorders of Connective Tissue
Congenital Adrenal hyperplasia Research, Education & Support (CARES)
Foundation
Congenital Hyperinsulinism International (CHI)
Cooley's Anemia Foundation
Council for Bile Acid Deficiency Diseases
Council for Responsible Genetics
Cranberry Fog
Dempster Family Foundation
Disability Rights Education and Defense Fund
Dyason Inc.
Epilepsy Foundation
Fabry Support & Information Group
Families USA
Family Voices of California
Family Voices of New Jersey
FORCE: Facing Our Risk of Cancer Empowered
Foundation for Prader-Willi Research
Friedreich's Ataxia Research Alliance
GBS/CIDP Foundation International
Geneforum
Genetic Alliance
Global Healthy Living Foundation
Hadassah, The Women's Zionist Organization of America
Hannah's Hope Fund
Hepatitis Foundation International
Hermansky-Pudlak Syndrome Network
HHT Foundation International
Huntington's Disease Society of American
Inflammatory Breast Cancer Research Foundation
International Myeloma Foundation
International Pemphigus and Pemphigoid Foundation (IPPF)
International WAGR Syndrome Association
Jewish Federations of North America
Johns Hopkins AIDS Education and Training Center
Lakeshore Foundation
Living Beyond Breast Cancer
Marfan Foundation

M-CM Network
MLD Foundation
Myotonic Dystrophy Foundation
National Alliance on Mental Illness
National Alopecia Areata Foundation
National Ataxia Foundation
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Hemophilia Foundation
National PKU Alliance
National Society of Genetic Counselors
National Tay-Sachs and Allied Diseases Association
National Urea Cycle Disorders Foundation
National Women's Law Center
NBIA Disorders Association
New England Regional Genetics Group
New Yorkers for Accessible Health Coverage
Organic Acidemia Association
Ovarian Cancer National Alliance
Oxalosis and Hyperosuria Foundation
Pachyonychia Congenita Project
Paralyzed Veterans of America
Parent Project Muscular Dystrophy (PPMD)
Personalized Medicine Coalition
Phelan-McDermid Syndrome Foundation
Phoenix Fox Foundation
Potocki-Lupski Syndrome Outreach Foundation
Prevent Cancer Foundation
Project DOCC
PTEN World
Pulmonary Hypertension Association
PXE International
Rare Disease Perspectives LLC
RASopathies Network USA
Sarcoma Foundation of America
Scleroderma Foundation
Society of General Internal Medicine
St. John Providence Health
Statewide Parent Advocacy Network
Stickler Involved People

Sudden Arrhythmic Death Syndromes (SADS) Foundation

Susan G. Komen

SWAN USA

The Life Raft Group

The Sturge-Weber Foundation

The Transverse Myelitis Association

Translational Genomics Research Institute (TGEN)

Tuberous Sclerosis Alliance

United Leukodystrophy Foundation

Vibrant Gene

Wilson Disease Association