

June 19, 2015

The Honorable Jenny R. Yang, Chair
The Honorable Constance S. Barker, Commissioner
The Honorable Chai R. Feldblum, Commissioner
The Honorable Victoria A. Lipnic, Commissioner
The Honorable Charlotte A. Burrows, Commissioner
Equal Employment Opportunity Commission
131 M St. NE
Washington, DC 20507

*RE: Equal Employment Opportunity Commission Proposed Rule "Amendments to Regulations Under the Americans with Disabilities Act
(Regulatory Information Number: 3046-AB01)*

To the Commissioners of the Equal Employment Opportunity Commission:

We the undersigned 68 organizations representing patients, health care providers, disability rights activists and researchers appreciate the opportunity to comment on the Proposed Rule regarding the Americans with Disabilities Act (ADA) and employer-sponsored wellness programs. We are gravely concerned that the proposed rule would erode long-standing and important protections afforded to employees under the ADA and would pave the way for weakening the Genetic Information Nondiscrimination Act (GINA). **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. Therefore, we urge the Commission to withdraw this rule and maintain strong civil rights protections for all Americans.**

The ADA was signed into law in 1990 by President George H.W. Bush after receiving wide bipartisan support in Congress. The law is intended to protect all Americans from workplace discrimination on the basis of disability. Importantly, the law clearly states that 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 an employee health program.

In this context, voluntary means exactly that; an employee would be free from coercion, financial or otherwise, and would only provide their medical information if they chose to do so. Indeed, it has been the EEOC's position for the last 15 years that "a wellness program is 'voluntary' as long as an employer neither requires participation nor penalizes employees who do not participate."¹

¹ 42 U.S.C. § 12112(d); 29 C.F.R. §§1630.13, 1630.14; EEOC Enforcement Guidance on Disability-Related Inquiries and Medical Examinations of Employees Under the ADA ("Enforcement Guidance"), Question and Answer 22, available at <http://www.eeoc.gov/policy/docs/guidance-inquiries.html>.

However, this proposed rule seeks to redefine “voluntary” medical inquiries or exams that are part of wellness programs as ones where employees may be offered incentives or penalties of up to 30 percent of the total cost of employee health insurance coverage if they decline to answer or be examined. To put this in real terms, the average cost of a health plan in 2014 was approximately \$6000 for a single worker². This would allow employers to penalize employees who refuse to participate in wellness programs upwards of \$1800 for an average individual; for some people with higher cost health insurance, the penalties could even exceed \$3000. Financial incentives of this magnitude are hardly *voluntary* and instead will allow employers to coerce employees into disclosing medical information they would otherwise want to keep private. Employees will have no choice but to disclose their private health information if they want access to affordable health insurance. It is unclear why EEOC previously defined this type of practice as coercive, yet now seeks to make it the definition of “voluntary.”

Redefining voluntary in this way forces individuals to turn over sensitive disability and health related information to their employers, making it harder to prevent employment discrimination against a group that already has the lowest employment rates of any group tracked by the Bureau of Labor Statistics; it also sets a dangerous precedent. The EEOC has already interpreted the term “voluntary” in the parallel context of wellness program questions seeking genetic information differently from its interpretation in the Proposed Rule—and in a way that reflects Congress’s intent to ensure that such inquiries are not conducted in a coercive manner. It is unclear how the EEOC can square these two radically different interpretations of “voluntary” wellness program inquiries in these two similar statutes. We are concerned this dissonance could lead the EEOC to abandon its correct interpretation of voluntary under GINA and apply this new definition of voluntary to employer requests for genetic information, rolling back strong protections explicitly laid out in the GINA regulations. The GINA regulations state unequivocally that employers:

“...may not offer a financial inducement for individuals to provide genetic information, but may offer financial inducements for completion of health risk assessments that include questions about family medical history or other genetic information, provided the covered entity makes clear, in language reasonably likely to be understood by those completing the health risk assessment, that the inducement will be made available whether or not the participant answers questions regarding genetic information.”³

We strongly urge the Commission to retain the definition of voluntary as laid out in the GINA regulation and apply the same standard to the ADA regulations and employer requests for medical information.

Wellness programs are fully able to encourage healthy behaviors within this 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 pressure from their health plans or employers to disclose their or their families’ genetic and medical information. **Therefore, we, the undersigned, strongly urge you to preserve the nondiscrimination protections afforded to all Americans by the ADA and GINA and withdraw this deeply flawed Proposed Rule.**

Signed,

² Kaiser Family Foundation. 2014 Employer Health Benefits Survey. Available at: kff.org/report-section/ehbs-2014-section-one-cost-of-health-insurance/

³ 29 C.F.R. § 1635.8(b)(2)(ii)

5p- Society – Cri du Chat Syndrome Support Group
Academy for Eating Disorders
Alstrom Syndrome International
American Academy of Pediatrics
American Association for Respiratory Care (AARC)
American Multiple Endocrine Neoplasia Support
Angioma Alliance
Association for Molecular Pathology
Autistic Self Advocacy Network
AXYS
Bridge the Gap - SYNGAP Education and Research Foundation
CARES Foundation
Center for Independence of the Disabled
Council for Bile Acid Deficiency Diseases
Council for Responsible Genetics
Cure HHT
CureCADASIL/CADASIL Association Inc.
Fabry Support & Information Group
Family Voices Indiana
Family Voices of New Jersey
Family Voices of Ohio
Fight Colorectal Cancer
FORCE: Facing our Risk of Cancer Empowered
Foundation for Ichthyosis and Related Skin Types
Genetic Alliance
Global Healthy Living Foundation
Hadassah, The Women's Zionist Organization of America, Inc.
Hepatitis Foundation International
Inflammatory Breast Cancer Research Foundation
Institute for Science and Human Values
International Fibrodysplasia Ossificans
International Myeloma Foundation
International WAGR Syndrome Association
Klippel Trenaunay Support Group
M-CM Network
MLD Foundation
Myotonic Dystrophy Foundation
National Employment Lawyers Association
National Hemophilia Foundation
National Society of Genetic Counselors
New England Regional Genetics Group (NERGG)
New Yorkers for Accessible Health Coverage
Organic Acidemia Association

Ovarian Cancer National Alliance
Oxalosis & Hyperoxaluria Foundation
Powerful Patient Inc
Progressiva Association (IFOPA)
Project DOCC
PXE International
RASopathies Network USA
Society of General Internal Medicine
Statewide Parent Advocacy Network of New Jersey
Sudden Arrhythmia Death Syndrome (SADS)
Susan G. Komen
Team Sanfilippo Foundation
The Arc of Aurora
The Arc of Pikes Peak Region
The Dempster Family Foundation
The Jewish Federations of North America
The Megan Foundation
The Transverse Myelitis Association
Trisomy 18 Foundation
Tuberous Sclerosis Alliance
United Leukodystrophy Foundation
Usher 1F Collaborative
Utah Family Voices
Vermont Family Network
Wilson Disease Association