

January 28, 2016

Submitted electronically to www.regulations.gov

Bernadette Wilson
Acting Executive Officer
U.S. Equal Employment Opportunity Commission
131 M Street NE
Washington DC 20507

**Re: Comments on Proposed Rule, Genetic Information
Nondiscrimination Act, RIN 3046-AB02**

Dear Ms. Wilson:

Thank you for the opportunity to comment on the Equal Employment Opportunity Commission's (EEOC) proposed rule concerning the intersection of the Genetic Information Nondiscrimination Act and workplace wellness programs. The Disability Rights Education and Defense Fund (DREDF) is a leading national law and policy center that advances the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development.

DREDF opposes the proposed rule as a clear erosion of GINA's protections against disclosure of disability-related information by employees and their family members. The Commission's proposed rule disregards the plain language and stated purpose of GINA, recorded in Congressional history and statements, and the regulations already that the EEOC has already promulgated under GINA. Ultimately, a weakened GINA rule, in concert with the expanding promulgation of untested employer wellness programs, will easily and inevitably lead to adverse employment decisions based on fears about the cost of insuring an employer and his or her dependents.

As a member of the Consortium of Citizens with Disabilities (CCD), we fully support CCD's comments on the proposed rule. Our additional comments below reflect some of the chief inconsistencies that we see between the goals and achievements of the Affordable Care Act (ACA) with respect to people with disabilities, and the increasingly diminishing protections that the EEOC is affording to employees and their families in the face of workplace wellness programs that have questionable value for those same employees and families.¹

¹ See e.g., S. Mattke, K. Kapinos, et al., *Workplace Wellness Programs: Services Offered, Participation, and Incentives*, at xiv (Rand, for DOL, 2014), available at <https://www.dol.gov/ebsa/pdf/WellnessStudyFinal.pdf> (as in 2013 study, we still find no significant cost savings or reduction in health care utilization associated with participation in lifestyle management programs); J. Horowitz, B. Kelly, et al., *Wellness Incentives in the Workplace: Cost Savings Through Cost Shifting to Unhealthy Workers*, 32 HEALTH AFFAIRS 468 (2013) available at <http://content.healthaffairs.org/content/32/3/468.long> (wellness programs appear to achieve cost savings through discriminatory cost shifting rather than general health improvement, with the most vulnerable employees in socioeconomic and health risk factors seemingly bearing the greatest costs); A. Lewis, V. Khanna, et al., *Employers Should Disband Employee Weight Control Programs*, 21 AM. J. MANAG. CARE, at e91-e94 (2015), available at <http://www.ajmc.com/journals/issue/2015/2015-vol21->

The ACA's enactment achieved such significant reforms as a prohibition on refusal to provide health insurance because of an applicant's pre-existing condition, and essential health benefit categories that recognized the need for coverage of habilitation services and devices. The creation of health insurance marketplaces and incentives for states to engage in Medicaid expansion similarly helped to meet the needs of many individuals and families with disabilities that need reliable, high-quality health coverage, but who do not have the option of employment coverage. People with disabilities and other minorities also have the reassurance of Section 1557 of the ACA, which prohibits discrimination on the basis of disabilities and other civil rights grounds in all health programs and activities that receive federal financial assistance, including federal and state marketplaces.

On the one hand, the ACA has helped to create a new more level playing field for people with disabilities, where they can find and maintain essential healthcare services while pursuing such vital life goals as higher education, advanced training, and gathering valuable work experience. With these tools, students and people with disabilities have greater opportunities to qualify for the kinds of jobs that offer comprehensive health benefits as an employee benefit. On the other hand, the ACA's wellness program provisions appear to have inspired a wholesale loosening of civil rights protections afforded to those employers with disabilities who *do* have access to employment coverage.

Modification of GINA's protections is in no way *required* by the ACA. The proposed rule asserts that its creation of an exception to GINA's protection of an employer's family member's information is to meet "the goal of the wellness program provisions of the Health Insurance Portability and Accountability Act ("HIPAA"), as amended by the Affordable Care Act, of promoting participation in employer-sponsored wellness programs." But surely the ACA's goal cannot be increasing participation in wellness programs for the mere sake of increasing enrollment, but must be *the actual provision of health and wellness benefits to employers who have employment health coverage*. This latter goal could best be achieved by *strengthening employment civil rights protections of health and genetic information*, so that wellness program participants are increasingly assured that universally designed and accessible wellness programs will both meet a variety of health maintenance needs and goals, while simultaneously maintaining absolute confidentiality of any health information that is truly voluntarily provided to third-party wellness entities for desired wellness services.²

n2/Employers-Should-Disband-Employee-Weight-Control-Programs (dearth of published evidence that large-scale corporate attempts to control employee body weight through financial incentives and penalties generate long-term weight loss or savings from long-term weight loss). See also S. Begley, 'Workplace wellness' fails bottom line, waistlines – RAND," Reuters (May 24, 2013), at <http://www.reuters.com/article/us-wellness-idUSBRE94N0XX20130524> (noting studies), and *Premium-based Financial Incentives Did Not Motivate Obese Employees to Lose Weight, Penn Study Finds* (Penn Medicine News Release, Jan. 5, 2016), available at http://www.uphs.upenn.edu/news/News_Releases/2016/01/patel/.

² DREDF agrees with the statement of the National Society of Genetic Counselors (NSGC) and the American Board of Genetic Counseling (ABGC) that "It is unclear if molecular genetic data can ever be stored in a way that guarantees that re-identification is impossible. For this reason, and taking into consideration the commonality of data breaches, employers should not store such data."

Instead, the proposed rule's approach of making exceptions in existing civil rights protections places employers, their spouses *and* their children at great risk of having their personal health and genetic information subject to involuntary disclosure, while placing employers under few concrete obligations to ongoing monitoring of their wellness programs for quality, physical and programmatic accessibility, non-discriminatory impact, and mid-and long-term effectiveness. The porous nature of health information gathered for wellness programs has been evident in recent decisions in which courts have approved an employer's use of wellness program information for insurance underwriting purposes (see CCD comments). If an employer's spouse draws on employment benefits for in-vitro fertilization (IVF) procedures as a covered benefit, for example, is the genetic counselling and testing that is usually part of that procedure considered health or genetic information? Has it been "voluntarily" disclosed amidst the myriad waivers and information forms that the couple signs when they undergo IVF treatment?

Even if the genetic results of IVF treatment are kept from the employer, as they should be, that employer can require the spouse to respond to wellness program requests or be penalized 30% of family premiums. What if the wellness programs offers the "benefit" of genetic counselling for the purposes of family planning? In this age of increasingly full genomic mapping of inheritable genetic conditions and probabilities, it is specious to argue that GINA continues to protect children from health and genetic inquiries when a child's parent is subject to highly significant financial penalties for failing to disclose information required in a wellness program.

Additionally, we are witnessing an unprecedented degree of corporate mergers and acquisitions in the field of healthcare. It is entirely plausible that the child of parents whose genetic information is known by a wellness program entity, because the couple could not afford to enforce their civil rights by paying 30% of family premiums, could then seek employment or be retained by a corporate employer that uses that same wellness program entity, or possibly a corporate entity that has acquired the parents' wellness program. The point is simple. Once confidential health and genetic information is acquired and stored in electronic form by wellness entities, it becomes a corporate asset over which individual consumers have virtually no control. Virtually every adult with a credit card in the U.S. has experienced the limits of their control over the privacy of financial and consumer information when faced with a deluge of targeted virtual and mailed offers. The health and genetic information disclosed to wellness entities is not currently subject to significantly greater electronic safeguards or corporate confidentiality requirements, yet breaches and corporate information sharing has the potential to influence employment and benefit decisions far beyond the mere inconvenience of getting junk mail.

For the above reasons, DREDF opposes the modification of GINA made in the proposed rule. Thank you again for the opportunity to comment. Please feel free to contact us if you have any questions concerning the above.

Sincerely,

A handwritten signature in dark ink, appearing to read "Silvia Yee", with a stylized flourish at the end.

Silvia Yee
Senior Staff Attorney