Congress of the United States

Washington, DC 20510

February 2, 2016

The Honorable Jenny R. Yang
Chair
U.S. Equal Employment Opportunity Commission
131 M Street, N.E.
Washington, DC 20507

Dear Chair Yang:

We write regarding the Equal Employment Opportunity Commission's (EEOC) proposed rule, *Amendments to Regulations Under the Genetic Information Nondiscrimination Act of 2008,* issued to ensure that wellness programs offered by employers comply with the Genetic Information Nondiscrimination Act of 2008 (GINA). As you know, GINA provides important protections against genetic discrimination that generally prohibit employers from requesting, requiring, or purchasing an employee's genetic or family health information in order to protect employee privacy and avoid the use of such data for discriminatory purposes. For the past fifty years, the EEOC has ensured that the protections afforded to workers under our nation's antidiscrimination laws exist not only on paper, but also in practice. The EEOC's guidance and regulations, combined with the important legal work to protect employee rights, help make our nation's workers and workplaces stronger. We also greatly appreciate that the EEOC extended the comment deadline for the proposed rule to allow all stakeholders additional time to weigh in on this important issue. To continue its important work protecting the rights of workers, we ask the EEOC to consider our concerns as the proposed regulation is finalized.

The Affordable Care Act (ACA) allows employers to offer financial incentives to participate in employer-provided wellness programs. As strong supporters of both the ACA and our nation's antidiscrimination laws, we are firmly dedicated to ensuring that these wellness programs are administered in an inclusive and responsible way and that workers' personal information is protected. While we appreciate the EEOC's effort to reconcile the ACA's allowance of financial incentives as part of wellness programs with the worker protections provided under GINA, we are concerned that this proposed rule allows employers to condition large financial incentives on a spouse providing sensitive medical information protected by GINA, meaning that an individual could be under significant financial pressure to provide this information to his or her spouse's employer.

As you know, GINA provides protections for genetic information beyond the individual providing such information. The statutory definition of protected genetic information covers the family medical history of the person providing the information, including information about the current health status of a spouse. For example, if the spouse of an employee participating in a wellness

program provides information about his or her current or past health status, that information is protected genetic information *of the employee* under GINA. Therefore, requesting the medical information of a spouse will specifically invoke GINA, as that information would constitute genetic information, and therefore be protected under GINA, as information of that employee.

The EEOC's 2010 GINA implementation regulations state that "the provision of genetic information by the individual is voluntary, meaning the covered entity neither requires the individual to provide genetic information nor penalizes those who choose not to provide it."[1] Additionally, those regulations make clear that an employer may request—but not require—an employee to provide his or her own genetic information as part of a wellness program. Specifically, those regulations clarify that "a covered entity…may offer financial inducements for completion of health risk assessments…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."[2]

The proposed regulation leaves these portions of the 2010 GINA regulations intact for most genetic information protected under GINA, but proposes new rules for when a wellness program asks an employee's spouse about his or her medical information. Much like the proposed rule that the EEOC released in April 2015 pertaining to the interaction between wellness programs and Title I of the Americans with Disabilities Act (ADA),[3] this proposed regulation seeks to redefine the requirement that wellness programs asking for information protected by the ADA or GINA protected information be "voluntary" by allowing a wellness programs to use a large financial inducement to solicit certain protected information. The provisions of the ACA that incentivize employer-provided wellness plans, which can include health risk assessments, should not be used to subvert GINA protections and should not be interpreted in a manner that would change the EEOC's historical definition of voluntary participation.

The proposed regulation would permit employers to condition financial rewards or penalties worth up to 30 percent of the total annual cost of coverage of the health plan – which could mean $5,263 or more per year[4] – on an employee's spouse providing protected health information as a part of a wellness program. This is a departure from current regulations, which hold that no financial inducements can be offered in exchange for genetic information. It also problematically reinforces and goes beyond the EEOC's proposed regulations on wellness programs and the ADA, which would limit the total incentives offered to an employee to 30 percent of the total annual cost of *employee-only* coverage. By allowing incentives up to 30 percent of the more expensive *family* coverage cost, the proposed rule permits employers to condition an even higher amount of money on the participation of a spouse in a wellness program. We have significant concerns that the financial inducements allowed under both the ADA and GINA proposed rules are so substantial that they will have the effect of making the provision of protected information via wellness

[1] Regulations Under the Genetic Information Nondiscrimination Act of 2008, 29 C.F.R. § 1635.8 (2010)
[2] Id.
[3] Amendments to Regulations Under the Americans With Disabilities Act, 80 FR 21659 (proposed April, 20, 2015) (to be codified at 29 C.F.R. pt.1630)
[4] This is based on average annual family premiums in 2015 of $17,545. kff.org/report-section/ehbs-2015-section-one-cost-of-health-insurance/

programs compulsory in practice. A recent New York Times article agreed, calling these financial inducements "...an offer employees simply can no longer refuse."[5]

Although we are pleased that offering a financial inducement for an employee's personal genetic information is still prohibited and that the proposed regulation prohibits incentives for dependents to disclose additional health or genetic information, we encourage the EEOC to reconsider the implications for spouses under the proposed GINA regulation. In addition, as several of us have previously expressed, we continue to be concerned with the implications of the large financial inducements allowed under the earlier proposed ADA regulation to incentivize employees to provide their own personal health information.[6] In both instances, these proposed rules could lead to wellness programs that make the provision of protected information for an employee and his or her spouse coercive, rather than voluntary – which contradicts the intent of both of these important laws.

We encourage the EEOC to make needed changes to the proposed rule in order to guarantee that the equal opportunity and privacy of all employees is respected and we ask that, in developing the final rule, the EEOC address the following concerns:

1. Under both current GINA regulations and past EEOC guidance, a 'voluntary' wellness program has been defined as one that does not require participation or penalize employees who do not participate through financial disincentives or other means. The EEOCs' 2015 regulations on the ADA and GINA allow for financial incentives or penalties of up to 30 percent of the total cost of a health plan. EEOC has changed its definition of 'voluntary' in its 2015 proposed regulations and we ask that the final regulations reflect policy that is consistent with the EEOC's own previous definition of "voluntary."

2. The EEOC's 2010 regulations implementing GINA make clear that employees participating in a wellness program must be able to skip genetic information questions and remain eligible for the financial incentives and protected from any financial penalties associated with the wellness program.[7] The EEOC has departed from this approach in the 2015 proposed regulations and we ask that the final regulation reflect policy that is consistent with the approach used in its previous GINA regulations for all GINA-protected information.

It is our position that wellness programs can and should co-exist with robust civil rights protections. We believe that the EEOC can develop a sound policy that can accommodate financial incentives and protect the privacy of sensitive genetic information. We appreciate the EEOC's willingness to address this issue through thoughtful guidance that provides additional clarity to employers.

We look forward to continuing to work with you on this important issue.

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[5] Abelson, Reed. *Employee Wellness Programs Use Carrots and, Increasingly, Sticks.* The New York Times.
[6] Scott, Robert, Elizabeth Warren, Et al. Letter to Chair Yang, EEOC. 13 July 2015.
[7] Regulations Under the Genetic Information Nondiscrimination Act of 2008, 29 C.F.R. § 1635.8 (2010)

Sincerely,

ROBERT C. "BOBBY" SCOTT
Ranking Member
Committee on Education and the Workforce

ELIZABETH WARREN
U.S. Senator

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Ranking Member
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RICHARD BLUMENTHAL
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JANICE D. SCHAKOWSKY
Member of Congress

SHERROD BROWN
U.S. Senator

cc: The Honorable Constance A. Barker, Commissioner
The Honorable Chai R. Feldblum, Commissioner
The Honorable Victoria A. Lipnic, Commissioner
The Honorable Charlotte A. Burrows, Commissioner