ACMG
American College of Medical Genetics and Genomics
Translating Genes into Health®

June 19, 2015

Ms. Bernadette B. Wilson, Acting Executive Officer
Executive Secretariat
U.S. Equal Employment Opportunity Commission
131 M St., NE
Washington, DC 20507

RE: RIN 3046-AB01, Amendments to Regulations under the Americans with Disabilities Act

Dear Ms. Wilson;

The American College of Medical Genetics and Genomics (ACMG) appreciates the opportunity to submit these comments on the proposed regulations changing the EEOC's treatment of wellness programs under the Americans with Disabilities Act (ADA).

ACMG is the only nationally recognized medical organization dedicated to improving health through the practice of medical genetics and genomics. ACMG has over 1800 members, nearly 80% of which are board certified clinical and laboratory geneticists and genetic counselors. The College's mission includes the following major goals: 1) to define and promote excellence in the practice of medical genetics and genomics and to facilitate the integration of new research discoveries into medical practice; 2) to provide medical genetics and genomics education to fellow professionals, other healthcare providers, and the public; 3) to improve access to medical genetics and genomics services and to promote their integration into all of medicine; and *4) to serve as advocates for providers of medical genetics and genomics services and their patients.*

The medical genetics community worked for over a decade to assure that employees' genetic information, including personal and family health history information and genetic test results would neither be required, sought, nor used to discriminate in the workplace. Under the Genetic Information Nondiscrimination Act (GINA), employers are banned from requiring or penalizing employees for refusing to provide information about their family medical history or other private genetic information, especially as it relates to disease predispositions. The EEOC has already taken a firm stance against allowing penalties or "rewards" to coerce employees into providing medical information to their employers involuntarily. The EEOC needs to maintain that approach here.

The Americans with Disabilities Act (ADA) makes it unlawful disability discrimination for an employer to ask their employees medical questions or to require them to take medical exams unless they are necessary to perform the job. This is an important protection: once an employer has information about an employee's disability, there is a greater likelihood that the employer will discriminate based on that disability — or in the case of genetic risk information — a potential disability.

Contrary to the plain language of the statute and the EEOC's established guidance, the Commission now proposes to allow employers to charge employees who decline to turn over their medical information to their employer a penalty of up to 30% of the total cost of employee-only coverage, and it eliminates any option to "opt-out." These penalties can be in the form of higher employee premiums, higher deductibles, higher copays, or other health expenses. And they can be very expensive. The average cost of an employee-only PPO plan in 2014 was $$6,217, with the employee paying $1,134 of that.[1] A 30% penalty of $1,865 would more than double what that employee is contributing toward health insurance.

There is no conceivable definition of "voluntary" that could encompass such significant financial penalties for failure to "volunteer." No employee would "voluntarily" pay hundreds or thousands of dollars more for their health coverage if they had a real choice. These penalties will be financially coercive, especially for workers who feel they cannot afford the penalty for refusing to participate.

The EEOC should withdraw its proposal allowing employers to fine workers for refusing to turn over their medical information. In the event that the Commission decides to permit penalties on involuntary inquiries and exams, however, the proposed regulations don't contain nearly enough protections for employees. For instance, the EEOC proposes to require any medical information collected through wellness programs to be "aggregated" to hide individual workers' identities and protect their privacy. But, the EEOC proposals allow significant exceptions that swallow the rule. The EEOC should ban employers from gaining access to individually identifiable medical information in **all** cases, and if the employer's program is structured to enable it to have access to that individual information, it shouldn't be allowed to use inquiries, exams or genetic tests as part of its wellness program. The EEOC should also permit employees to avoid being penalized for nonparticipation by getting a medical certification to the effect they are already receiving care for any condition asked about or tested by the wellness program.

All workers have a stake in the ADA's protections from being coerced into revealing private medical and genetic information to their employer that has nothing to do with their ability to do the job.

The ACMG cannot support the EEOC's proposed amendment and asks the Commission to look to the protections set forth in GINA as a model that is fair, non-coercive, and places the right to privacy of private genetic and medical information on the individual to whom it belongs.

Sincerely,

Michael S. Watson, MS, PhD, FACMG
Executive Director

[1] Kaiser Family Foundation, *2014 Employer Health Benefits Survey*, Exhibit B (Sept. 10, 2014) at http://kff.org/report-section/ehbs-2014-summary-of-findings/

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The **Equal Employment Opportunity Commission** (EEOC) Proposed Rule: **Regulations under the Americans with Disabilities Act; Amendments**

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ACMG

Mailing Address 2:

Email Address:
mwatson@acmg.net

Phone Number:

7220 Wisconsin Avenue; Suite 300

City:
Bethesda

ZIP/Postal Code:
20814

301-718-9603

Fax Number:
301-718-9604

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