



January 28, 2016

Bernadette Wilson
Acting Executive Officer
U.S. Equal Employment Opportunity Commission
131 M Street NE
Washington D.C. 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 related to the Genetic Information Nondiscrimination Act (GINA). We have serious concerns with several aspects of the proposal, which would authorize workplace wellness programs to impose large penalties on employees' covered spouses who decline to disclose disability-related information.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of more than 2.8 million Americans with epilepsy and seizures. We foster the well-being of children and adults affected by seizures through research programs, educational activities, advocacy and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime, and people living with epilepsy must have meaningful and timely access to physician-directed care and specialists, to avoid breakthrough seizures and related complications and costs.

We believe the EEOC's proposed rule would significantly diminish protections for workers' spouses to keep their disability-related information out of the hands of employers. The proposed rule is inconsistent with the plain language and the purpose of GINA, as well as with the GINA regulations already promulgated by the EEOC, and would erode important protections against adverse employment decisions based on fears about the cost of a spouse's insurance.

The proposed rule would remove "spouse" from GINA's statutory protections for family members' health information and permit significant financial penalties on families that choose to keep health information private. The proposed change does not reflect Congressional intent behind GINA and would enable workplace wellness programs to make it too costly for employees and their spouses to abstain from providing disability-related information to employers.

GINA's definition of "family member" includes spouses, and Congress intended to protect the health information of employees' spouses and adopted children, regardless of whether it would reveal information about employees' genetic makeup, and this included protecting employees from discrimination based on fears about these family members' health care costs.



The proposed rule is inconsistent with the statutory requirement that inquiries be voluntary and with the EEOC's own definition of voluntary in its GINA regulations, which state that a wellness program inquiry is voluntary if the covered entity neither requires the individual to provide genetic information nor penalizes those who choose not to provide it. The EEOC's existing GINA regulations further clarify that an employer "may not offer a financial inducement for individuals to provide genetic information" in a wellness program, and that any inducement for completing a health risk assessment must be offered regardless of whether an employee chooses to answer the questions about genetic information. The proposed rule would consider inquiries about a spouse's medical information to be voluntary when the "choice" not to answer carries significant financial penalties.

The Affordable Care Act (ACA) and the Health Insurance Portability and Accountability Act (HIPAA) address wellness program penalties that constitute insurance discrimination. While it may not be insurance discrimination to impose penalties for employees' failure to provide their spouses' medical information, it is employment discrimination under GINA, which defines employment discrimination to include requesting employees' genetic information, including their spouses' health information, as part of a wellness program if the inquiries are not voluntary. The wellness provisions in the ACA do not repeal by implication GINA's protections of spouses' health information. The EEOC should not allow penalties on employees for declining to provide spouses' health information to a workplace wellness program by preserving GINA's protection of spouses' health information and should treat spouses' health information the same as other genetic information, as required by the statute.

We urge the EEOC to require that, to be "reasonably designed," a wellness or other program offering health or genetic services must offer services beyond simply telling employees' spouses to follow up on potential health risks. Otherwise the program would exist solely to obtain individuals' medical information without offering them any help in addressing health or wellness issues are considered reasonably designed.

We also urge the EEOC to require that, to be "reasonably designed," a program must have a solid evidence base demonstrating that the program—including any penalties or rewards that it imposes—results in significant improvement in employees' health and significant reductions in health care costs. Wellness programs that subject employees and their spouses to financial penalties should demonstrate improved health outcomes and not just serve as health data mining. Additionally, we urge the EEOC to state that to be "reasonably designed," a wellness program cannot be used for insurance underwriting purposes.

Authorization to knowingly and voluntarily disclose genetic information should in fact be voluntary. Therefore the EEOC should require that an employee's indication that his or her participation is not voluntary would enable the employee to receive the reward, or avoid the penalty, without his or her spouse disclosing medical information. Otherwise, the written confirmation would not serve any purpose because signing a form does not eliminate the coercion exerted by imposing huge financial penalties for failure to disclose information. Additionally, the authorization requirement should apply to all wellness programs inducing the disclosure of spouses' health information.

We urge the EEOC to require that employers that offer inducements for spouses to disclose health information provide similar inducements to spouses who provide a certification from a medical professional



stating that the spouse is under the care of a physician and that any medical risks identified by that physician are under active treatment. Permitting individuals to avoid penalties by showing that their spouses are already receiving care for any condition asked about by a health risk assessment is an important protection that the EEOC should include in the final rule should it exempt spousal health information from GINA's protections.

The EEOC should consult electronic data experts to ensure the confidentiality of genetic information stored in electronic records and should require specific protocols to maximize the safety of electronically stored genetic information. Even with good electronic data storage practices, the EEOC is placing the confidentiality of individuals' health information at serious risk.

The EEOC should restrict genetic information collected by workplace wellness programs to the minimum necessary to directly support specific wellness activities and interventions. This is necessary to protect the confidentiality of individuals' genetic information. Additionally, the EEOC must implement safeguards to ensure that information about spouses' current health status is protected from disclosure to protect against employment discrimination based on concerns about spouses' health care costs. The final rule should require employers to grant waivers of inducements for the provision of spouses' health information where necessary to ensure equal opportunity in the wellness program.

The Epilepsy Foundation has serious concerns with the proposed rule and urges EEOC to ensure that wellness programs are designed to promote health and do not shift costs to employees with health impairments or stigmatized conditions. Please do not hesitate to contact Angela Ostrom, Chief Operating Office & Vice President Public Policy, at 301-918-3766 or aostrom@efa.org with any questions or concerns.

Sincerely,

A handwritten signature in black ink that reads "Philip M. Gattone".

Philip M. Gattone, M. Ed.
President & CEO
Epilepsy Foundation