



March 7, 2017

The Honorable Virginia Foxx
Chairwoman
U.S. House Committee on Education
and the Workforce
2176 Rayburn House Office Building
Washington, DC 20515

The Honorable Robert C. Scott
Ranking Member
U.S. House Committee on Education
and the Workforce
2176 Rayburn House Office Building
Washington, DC 20515

CC: Members of the U.S. Committee on Education and the Workforce

Dear Chairwoman Foxx and Ranking Member Scott,

The American Society of Human Genetics (ASHG) wishes to communicate its opposition to H.R.1313, the Preserving Employee Wellness Programs Act. If enacted, this legislation would undermine fundamentally the privacy provisions of the Genetic Information Nondiscrimination Act (GINA) and the Americans with Disabilities Act (ADA). It would allow employers to ask employees invasive questions about their and their families' health, as well as genetic tests they and their families have undergone. It would further allow employers to impose stiff financial penalties on employees who choose to keep such information private, thus empowering employers to coerce their employees into providing their health and genetic information.

ASHG, founded in 1948, is the world's largest genetics professional society, with nearly 8,000 members representing all areas of research and application in human genetics. The Society's membership comprises diverse professionals in genetics, molecular biology, medicine, biochemistry, and other areas of experimental science, as well as computational science, statistics, and epidemiology. For thirteen years, ASHG was a leading voice for the passage of GINA, and the Society supports the robust implementation of the law. All Americans should be free to participate in genetic research or benefit from genetics-based clinical advances without fear of genetic discrimination.

When Congress passed GINA in 2008, strong privacy provisions established that employers and issuers of health insurance could not request, require or purchase genetic information with respect to employees and enrollees. These privacy provisions have been key for reassuring Americans that they can volunteer as genetic research participants or undergo genetic testing without concern that they would be vulnerable to genetic discrimination by their employer or issuer of health insurance.

GINA includes a number of common sense exceptions to the general prohibition against requesting or requiring genetic information. One is that an employer may ask an employee to undergo genetic testing if it is part of health or genetic services offered by the employer, such as might be included in a wellness program. However, the law stipulates that only the employee and the licensed health care professional or board certified genetic counselor involved in providing such services can receive individually identifiable information concerning the results of such services. Further, to prevent potential coercion by employers, the law states that employee participation must be entirely voluntary. Similar workplace privacy protections in the ADA establish that submitting to medical examinations as part of wellness programs must also be voluntary.



In 2016, the Equal Employment Opportunity Commission issued regulations addressing how wellness programs may seek employee health and genetic information while maintaining compliance with GINA and the ADA. These rules already allow employers to ask employees questions about their health and the health of their spouses, and to require that employees who choose to keep their and their spouses' health information private pay significantly higher health insurance premiums. For plans that cover both the employee and the spouse, the employee can be required to pay a penalty of up to 60 percent of the cost of self-only coverage. According to the Kaiser Family Foundation, the average cost of an employee-sponsored self-only plan is \$6,435 per year; the new rules allow an employer offering such a plan to impose an annual \$3,861 penalty for an employee and his or her spouse.

If enacted into law, however, H.R.1313 would effectively repeal the fundamental genetic and health privacy protections in GINA and the ADA. It would allow workplace wellness programs to ask employees questions about genetic tests taken by themselves or their families, and to make inquiries about the medical history of employees, their spouses, their children, and other family members. GINA's requirement that employees' genetic information collected as part of a wellness plan only be shared with health care professionals would no longer apply. It would further permit workplace wellness programs to penalize much more severely employees who wish to keep their genetic and health information private, allowing penalties of up to 30 percent of the total cost of an employee's health insurance.

According to a Kaiser Family Foundation report, the average annual premium for employer-sponsored family health coverage in 2016 was \$18,142. Thirty percent of this amount is \$5443. Thus, for such a plan, a wellness plan could charge employees an extra \$5443 in health care premiums annually if they do not share their genetic and health information and thereby fail to meet the requirements of participation in the wellness program. Moreover, the Public Health Service Act permits the Administration to increase the maximum size of the penalty to 50 percent of the total cost of health care coverage. In such a circumstance, for this same average family plan, the maximum allowable penalty would be \$9071. Penalties of this magnitude would compel Americans to choose between retaining the privacy of their health and genetic information and accessing affordable health insurance.

ASHG urges the committee not to move forward with consideration of H.R.1313. The Society instead encourages the committee to pursue measures that encourage workplace wellness programs and foster employee health without undermining Americans' civil rights.

Sincerely,

Nancy J. Cox, PhD
President