

Privacy perils: Impact of legislation that would strip genetic secrecy protections in US

A Republican-sponsored bill that passed its first hurdle in Congress threatens to take away genetic privacy protections put in place with the [Genetic Information Nondiscrimination Act \(GINA\)](#) of 2008. [H.R.1313](#), the “Preserving Employee Wellness Programs Act,” might instead be called the “telling on relatives” ruling. It would also allow companies to compel employees to take genetic tests or pay a fine.

According to GINA, employers can’t use genetic information to hire, fire, or promote an employee, or require genetic testing, and health insurers can’t require genetic tests nor use results to deny coverage. The law clearly defines genetic tests – DNA, RNA, chromosomes, proteins, metabolites – and genetic information –genetic test results and family history of a genetic condition.

GINA refers to a case, [Norman-Bloodsaw v. Lawrence Berkeley Lab](#) from 1998, that allowed clerical and administrative workers to sue their employer for requiring testing for “highly private and sensitive medical genetic information such as syphilis, sickle cell trait, and pregnancy” without their consent or knowledge during a general employee health exam. I’m not sure how syphilis and pregnancy got lumped in with sickle cell trait (a carrier), but requiring any such test is considered an illegal search under the Fourth Amendment. The sickle cell request also violates Title VII of the Civil Rights Act by singling out employees of African ancestry.

On March 8, the bill passed its first “mark-up session,” and will either head for the next markup with the Ways and Means Committee or become part of a package of health-care-related bills that goes to the House floor soon, according to Derek Scholes, the American Society of Human Genetics’ (ASHG) director of science policy, who attended the session.

Nancy J. Cox, ASHG president, in a letter to the U.S. House Committee on Education and the Workforce, provides a frightening overview:

“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.”

[GINA](#) Single-gene diseases are unlike other health conditions or clinical findings, such as infections or high serum cholesterol readings, because a diagnosis in one person reveals risks to relatives in accordance with Mendel’s laws. A 24-year-old school bus driver in perfect health, for example, whose parent receives a diagnosis of Huntington’s disease, could under the new bill face queries from an employer or health insurer about the 50% risk.

All is not well(ness)

The bill is built around an exception in GINA concerning genetic testing that is part of health or genetic services the employer offers, such as part of a wellness program. However, GINA stipulates that only the person and the health care provider or board certified genetic counselor can view the results. GINA also spells out that genetic testing as part of a wellness program must be entirely voluntary.

A May 16, 2016, ruling from the [Equal Employment Opportunity Commission](#) laid the groundwork for penalizing employees who refuse to answer questions about their or their spouses' health. This could amount to thousands of dollars a year, according to a report from the [Kaiser Family Foundation](#). H.R.1313 would make that even worse.

"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," Cox wrote. And the Public Health Service Act permits an increase to 50%. "Penalties of this magnitude would compel Americans to choose between retaining the privacy of their health and genetic information and accessing affordable health insurance."

Is charging for the right to enjoy the genetic privacy that was once mandated by law a mechanism to underwrite the new health care plan?

Repercussions

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," Cox wrote.

"*Other family members*" harkens back to GINA, bastardizing its protections, for the 2008 law casts a wide net for relatives, down to the "fourth degree."

gina

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ATCG's with a silhouette of people.

While first-degree relatives are a person's children, siblings, and parents, and second-degree are grandparents, grandchildren, uncles, aunts, nephews, nieces, and half-siblings, third-degree relatives extend to great-grandparents, great grandchildren, great uncles/aunts, and first cousins, and, ridiculously, fourth-degree relatives to great-great-grandparents, great-great-grandchildren, and first cousins once-removed. I remember my disappointment when I realized that the notifications of new fifth cousins pouring into my email after taking an ancestry test were pretty meaningless, since we each have more than 4,000 of them.

Also worrisome is that the new mandate reeks of genetic determinism, the idea that genotype dictates phenotype.

Genetic information alone does not a diagnosis make. That's why a clinical diagnosis considers symptoms and results of other types of tests. And while the example of the young bus driver with a family history of HD lies at an extreme because people who inherit the mutation nearly always develop the disease, that situation of 'complete penetrance' is unusual. Most inherited diseases are incompletely penetrant — some people with a disease-associated genotype may never develop the condition due to protections from other genes (see Why do healthy people have harmful mutations?). Another repercussion of H.R.1313 is that it might frighten people away from participating in clinical trials.

I also fear misunderstanding on the part of people charged with analyzing anyone's genetic fitness, so to speak, on the basis of a list of mutations or other gene variants. Remember the sickle cell screen of the early 1970s? That was a [disaster](#) because many parents thought that a finding of children having "sickle cell trait" meant that they had or would develop the disease. I was even told off-the-record that at least one parental suicide resulted from the well-meant but widespread misinformation.

Will wellness coaches serve as the go-betweens for employees and employers, and if so, how much genetics do they know? Would a wellness coach know that the Huntington's disease that is in the family of

the active and healthy 24-year-old takes many years to develop, even after the first symptoms appear? I didn't see any hard science requirements in [this job description](#) or a few others. (I'm thinking of the Pilates instructors who have told me that I am lengthening my spine, but that's probably not the same thing.)

The letter from ASHG urges the committee not to support H.R.1313, and to encourage workplace wellness programs without sacrificing employees' civil rights. "All Americans should be free to participate in genetic research or benefit from genetics-based clinical advances without fear of genetic discrimination," Cox concluded.

As we gear up to encourage folks to participate in the [Precision Medicine Initiative](#) by contributing their personal genome information, the [direct to consumer genetic testing industry](#) is not only alive and well but growing, and loading our genome sequences onto our [smartphones](#) is no longer science fiction, H.R.1313 seems to be coming at a most inopportune time. Let's hope the "1313" is bad luck for its passage!

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Ricki Lewis is a long-time science writer with a PhD in genetics. She writes the [DNA Science blog](#) at PLOS and contributes regularly to [Rare Disease Report](#) and Medscape Medical News. Ricki is the author of the textbook *Human Genetics: Concepts and Applications* (McGraw-Hill, 12th edition out late summer); *The Forever Fix: Gene Therapy and the Boy Who Saved It* (St. Martin's Press, 2013) and the just-published second edition of [Human Genetics: The Basics](#) (Routledge Press, 2017). She teaches Genethics online for the Alden March Bioethics Institute at Albany Medical College and is a genetic counselor at CareNet Medical Group in Schenectady, NY. You can find her at her website or on Twitter at [@rickilewis](#)