

Attention Congress: Our Genetic Nondiscrimination Laws Need Updating!

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The Genetic Information Nondiscrimination Act (GINA), enacted in 2008, protects what makes us who we are, our DNA. The law emerged in response to state-mandated screenings for sickle cell anemia, which disproportionately targeted Black Americans. Recognizing that this practice stigmatized the Black community, policymakers created GINA to protect against genetic discrimination in the realm of health insurance and employment. Under GINA, Americans can utilize genetic testing to learn about their health dispositions without fearing that the results will lead to higher health insurance premiums or lower job opportunities.

However, in the 16 years since GINA's enactment, science and technology have made significant advancements in the field of genetics. We now know that the environment around our genes, known as our epigenetics, can be used to infer our specific DNA sequence. The genetic nondiscrimination law, GINA, prohibits discrimination based on a person's specific DNA sequence—the particular order of A, C, T, and G nucleotides that make up their genetic code. However, there is ambiguity about whether our epigenetics are protected under GINA. Since epigenetic data can lead one to decipher a DNA sequence, access to it may allow insurance companies and employers to circumvent GINA's protections against genetic discrimination.

Courts have not ruled on whether GINA's protections against genetic discrimination apply to inferences about a person's genetics made through examining their epigenetics. Rather than wait for discriminatory incidents to occur and lawsuits to ensue, Congress should take proactive steps to close this potential loophole in the law. Congress has the power to clarify that GINA's intent is to prohibit discrimination based on any inferences regarding an individual's genetic information, even if derived indirectly through epigenetic data. Closing this loophole preemptively will help ensure robust protections against all forms of genetic discrimination.

Although a step in the right direction, simply amending GINA to address epigenetic discrimination will not fully solve the emerging privacy issues surrounding epigenetics. The growth of epigenetic knowledge will necessitate broad societal changes, beyond just healthcare insurance and employment. It will raise questions about how epigenetic data is obtained, stored, safeguarded, and shared, including with law enforcement. Currently, law enforcement access to genetic data is determined by state laws and the 4th Amendment, not GINA. Encryption methods for genetic data may also be insufficient for epigenetic data protection. Policymakers will need to grapple with these complex privacy concerns as epigenetic science advances. Comprehensive solutions are needed spanning technology, regulation, and public education around the ethical collection and use of sensitive epigenetic data. Updates to GINA alone cannot fully address the multidimensional privacy challenges ahead.

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