

FACTS MA

FOSTERING ADVOCACY AND
COLLABORATION THROUGH SCIENCE

HR1313

Weakens genetic
privacy protection

SPONSOR

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COMMITTEES

House Education and
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Ways and Means

HR1313 proposes to allow collection of genetic information about employees through wellness programs.

- Bypasses the protections of the Genetic Information Nondiscrimination Act (GINA) and thus the Health Insurance Portability and Accountability Act (HIPAA).
- Employee wellness programs are nominally voluntary, but current rules allow incentives of up to a 50% discount of health insurance premiums, allowing powerful coercion for participation.

What are the implications of passing HR1313?

HR1313 would allow employers to collect genetic information on employees and their families and share it with, or sell it to, other companies.

What is the significance of genetic information?

- May reveal predisposition to traits or diseases
 - Could be used to make hiring, firing, and health insurance decisions.
- Reveals ancestry, non-paternity, fertility, and other sensitive information.
- Provides genetic information about one's relatives.
- Cannot be made private again once it is public.

What are some broader implications of passing HR1313?

Genetic information is the essential core of modern precision medicine and the large (and growing) genetic testing industry. These enterprises are founded on the principle that one's genetic information is private and secure, as codified in GINA and HIPAA.

HR1313 will bypass those principles, exposing employees' genetic information to commercial entities, opening them to discrimination and potentially eroding trust in genetics-based medicine.

Research in human genetics depends on a foundation of anti-discrimination principles established by GINA.

Weakening those provisions risks stifling innovation in:

- *private-sector*
- *direct-to-consumer genetic testing*
- *publicly-funded, precision medicine initiatives*

Sources

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