



Summary:

The ***Genetic Information Privacy Act*** clearly defines an individuals' right to privacy and control over what happens with some of their most private and sensitive information - genetic data and biological samples. Furthermore, it provides clear guardrails for obtaining informed, written consent before genetic information or samples are collected, stored, shared, or used.

The bill is nearly identical to a Montana law authored in 2023 by state Senator Daniel Zolnikov. Section 4.8 has been added from negotiated language intended to address medical research industry concerns. This amendment allows for genetic research using an individual's genetic information or material under clearly defined boundaries, but that consent must not be obtained at the same time the specimen is collected for its intended purpose. This fosters true, informed consent of the individual.

Section 1 – Short title

Section 2 – Definitions

Section 3 – Exceptions

Section 4 – Consumer testing: privacy notice and consent requirements

Section 5 – Disclosures and prohibitions

Section 6 – Enforcement

Reasons to support:

1. An individual's genetic information is perhaps their most private and sensitive information. Unlike other sensitive information, it is immutable and once compromised, the damage can never be undone. You can't just change your genetics to restore your privacy.
2. Without a strong state genetic privacy law, individuals have no way to prevent the use, storage, and sharing of their genetic information by the government, public institutions, researchers, for-profit corporations, and more.
3. This bill strikes an appropriate balance by protecting an individuals' right to be informed and in charge of what happens to their genetic material while also allowing for industry to advance research.
4. With the increased use of direct to consumer genetic testing such as Ancestry or 23andMe, individuals need clear rights protected in state law. An individual, and family members who share similar genetic profiles, should not lose control of their DNA and genetic data simply because they are curious about their ancestry.