



March 22, 2023

Chair Becker-Finn
House of Representatives
Judiciary Finance and Civil Law Committee
100 Rev. Dr. Martin Luther King Jr. Blvd.
Saint Paul, MN 55155

RE: Future of Privacy Forum comments on HF 1520 - Genetic Information Privacy Act

Chair Becker-Finn and Members of the Committee,

The Future of Privacy Forum (FPF) welcomes this opportunity to submit testimony on HF 1520, the Genetic Information Privacy Act (“GIPA”).¹ FPF is a non-profit organization dedicated to advancing privacy leadership, scholarship, and principled data practices in support of emerging technologies in the United States and globally. FPF seeks to support balanced, informed public policy and equip regulators with the resources and tools needed to craft effective regulation.²

We appreciate the sponsors’ attention to the privacy of Minnesotans’ genetic information and write to provide additional information and resources concerning the Genetic Information Privacy Act. The Act would establish significant new protections for consumers of genetic services and is consistent with best practices informed by technical experts, scientists, civil society advocates, leading consumer genetic and personal genomic testing companies, and regulators. It is also consistent with privacy protections enacted by other states.

Genetic data is a highly sensitive category of personal information, based in part on its ability to reveal intimate information about health and heritage, both of the individual who provides the data as well as their familial connections. Furthermore, in the direct-to-consumer testing context, genetic information does not typically receive protections under the federal Health Insurance Portability and Accountability Act (HIPAA). And while the federal Genetic Information Nondiscrimination Act (GINA) prohibits certain types of discrimination based on genetic information, it does not provide comprehensive privacy protections for the collection of such data or the many ways that it can be used, sold, or shared (including for advertising or law enforcement purposes). Given these unique sensitivities and considerations, FPF supports the adoption of strong individual rights and protections governing the collection and processing of genetic data in the consumer testing context.

¹ HF 1520, The Genetic Information Privacy Act *available at* <https://www.revisor.mn.gov/bills/bill.php?b=House&f=HF1520&ssn=0&y=2023>.

² The opinions expressed herein do not necessarily reflect the views of FPF’s supporters or Advisory Board.

FPF's Best Practices for Consumer Genetic Testing Services

In July 2018, the Future of Privacy Forum released its *Privacy Best Practices for Consumer Genetic Testing Services* ("Best Practices").³ This industry-leading self-regulatory framework was the result of a multi-stakeholder process that engaged technical experts, leading consumer genetic and personal genomic testing companies, and civil society, with input from regulators including the Federal Trade Commission and the Department of Health and Human Services. The Best Practices include strong standards for the use and sharing of genetic information generated in the consumer context including transparency, strict consent requirements, consumer rights, limitations on use and onward transfer, and adherence to cybersecurity standards. Leading genetic testing companies adopted the Best Practices, making them enforceable by the Federal Trade Commission and state Attorneys General.

Adoption of Genetic Information Privacy Legislation

Principles for protecting the privacy of consumer genetic information first articulated in FPF's Best Practices have served as the foundation for new legal protections in the consumer genetic testing context. In October 2021, California Governor Newsom signed SB 41, the California Genetic Information Privacy Act into law, which shares many core substantive rights and protections for genetic information established in FPF's Best Practices.⁴ At the same time, the California GIPA expanded protections to govern the entire California consumer genetics testing industry (not just companies that voluntarily comply with FPF's Best Practices) and provided for robust Attorney General Enforcement. California's GIPA was supported by a wide array of stakeholders, including leading civil society & consumer privacy organizations such as Consumer Reports, the Electronic Frontier Foundation, and the ACLU of California.⁵

Since the adoption SB 41 in California, substantially aligned Genetic Information Privacy Acts have been adopted in Arizona (HB 2069); Utah (SB 277); Kentucky (HB 502); and Maryland (HB 866). This year, the Virginia legislature has passed its own Genetic Information Privacy Act (SB 1087) with unanimous, bipartisan votes at each stage of the legislative process and is currently awaiting the Governor's signature.⁶

³ Future of Privacy Forum, "Privacy Best Practices for Consumer Genetic Testing Services" (July 31, 2018), <https://fpf.org/wp-content/uploads/2018/07/Privacy-Best-Practices-for-Consumer-Genetic-Testing-Services-FINAL.pdf>.

⁴ John Verdi, "California's SB 980 Would Codify Strong Protections for Genetic Data," Future of Privacy Forum (Sept. 3, 2020), <https://fpf.org/blog/californias-sb-980-would-codify-strong-protections-for-genetic-data/>.

⁵ Consumer Reports et al., "Assembly Floor Alert, SB 41 (Umberg) - Support" (Sept. 2021), <https://advocacy.consumerreports.org/wp-content/uploads/2021/09/SB-41-Consumer-Privacy-Group-Support-9.1.21.pdf>.

⁶ Virginia SB 1087, "Genetic Data Privacy" available at <https://lis.virginia.gov/cgi-bin/legp604.exe?231+sum+SB1087>.

Strengths of HF 1520

Minnesota's Genetic Information Privacy Act proposal is substantially aligned with the principles of FPF's best practices guide and the Genetic Information Privacy Acts that have been adopted in six states. HF 1520 would establish strong, comprehensive protections for the collection, processing, use, and disposal of genetic information collected in a consumer context. Important elements of the draft legislation include:

- **Consumer Rights:** The Act would provide individual rights to access and delete genetic data and, crucially, to request and obtain the destruction of any biological sample provided to a genetic use company.
- **Data Use Limitations:** The Act would require that testing companies receive initial express consent for the collection, use, and disclosure of genetic data. The Act would further require separate express consent for further transfers or use of genetic data outside the context of providing a testing service.
- **Deidentified Data:** The Act provides a standard for "de-identified data," that is substantially aligned with the Federal Trade Commission's best practices⁷ that will ensure that consumers' personal information is protected while allowing for societally beneficial public health research.

Thank you again for the opportunity to provide input and your consideration of this important issue. The Future of Privacy Forum stands ready to provide further information about the privacy of genetic testing information if it may be of assistance to the committee.

Sincerely,

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⁷ Federal Trade Commission, "Protecting Consumer Privacy in an Era of Rapid Change" (March 2012) at 21, <https://www.ftc.gov/sites/default/files/documents/reports/federal-trade-commission-report-protecting-consumer-privacy-era-rapid-change-recommendations/120326privacyreport.pdf>.