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MEMORANDUM

TO: House Committee on Commerce and Economic Development
Senate Committee on Finance
FROM: Department of Financial Regulation
SUBJECT: Recommendation for Section 19 of Act No. 23 of 2025 (Genetic Privacy)
DATE: November 15, 2025

Section 19 of Act 23 of 2025, *An act relating to the regulation of insurance products and services*, requires that the Commissioner of Financial Regulation (DFR) provide a recommendation on whether a law should be enacted prohibiting or limiting an insurance company's access to a consumer's personalized genetic report that is not a part of the consumer's medical record. The recommendation was requested to address concerns relating to the prevention of unfair genetic discrimination and the safeguarding of an individual's genetic privacy in the context of insurance transactions. Section 19 of Act 23 of 2025 specifically requires that DFR consider, among other things, whether consumer consent should be obtained prior to disclosure of genetic information to an insurance company by a direct-to-consumer entity.

Based on discussions with legislators prior to the drafting of Section 19 of Act 23 of 2025, it is DFR's understanding that the concerns to be addressed by the requested recommendation were the result of issues that arose during bankruptcy proceedings involving 23andMe, a direct-to-consumer genetic testing organization. As a part of the bankruptcy proceedings, a U.S. Bankruptcy Court judge allowed 23and Me to sell consumer genetic testing data as a part of the bankruptcy process. This possible sale raised questions as to who might buy the data, how it might be used, what control consumers may have over the privacy of their genetic information, and whether consent to 23andMe's terms of use authorized the transfer and future use of the information. Concerns regarding the sale are heightened partially because, unlike genetic testing data held by health providers and insurers, data held by direct-to-consumer testing organizations is not protected under the Federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Currently, the use of genetic testing by insurers is governed primarily by 8 V.S.A. § 4724(22) and 18 V.S.A. §§ 9331 to 9334. These sections essentially prohibit an insurer, in connection with the offer, renewal or issuance of an insurance policy, from:

- imposing any requirement or agreement that a consumer undergo genetic testing; or
- using genetic testing results for a member of an individual's family unless they are in the individual's medical record.

In addition, 18 V.S.A. § 9332(e) protects disclosure of genetic testing results absent written authorization from the individual tested. Genetic testing is defined for purposes of both

statutes in 18 V.S.A. § 9331(7) as testing that is diagnostic or predictive of a particular heritable disease or disorder involving human genes, chromosomes, DNA, RNA or human genetically encoded proteins, with certain exceptions specific to insurance related to current conditions or conditions that have already manifested.

In considering whether Vermont law should be strengthened in this area, DFR spoke to representatives from Ancestry, a direct-to-consumer genetic testing organization; the American Council of Life Insurers (ACLI); and individual life insurers.

Discussions with Ancestry and a review of their website confirmed that consumer genetic information is generally not shared with third parties without additional consent from the consumer. Their policy with respect to sharing with insurers requires that the consumer share the results directly, rather than through Ancestry. Consumer DNA information is owned by the consumer, and consumers can request that data be removed from Ancestry systems at any time. Detailed information on data and privacy policies including extensive FAQs can be found on the company website. Similar to 23andMe, however, the policies also indicate that data could be shared because of an acquisition or transfer (such as bankruptcy) with the promises from the Privacy Statement continuing to apply to the new entity.

ACLI is a trade organization representing the interests of 275 life insurers offering a variety of products such as life, disability, and long-term care insurance, as well as retirement products such as annuities. Most of these products are subject to risk-based underwriting, including the review of medical records which may incorporate genetic testing results. ACLI and individual life insurers do not oppose consent requirements for the use of genetic testing results, since seeking consent to receive medical information from consumers is a routine part of their business model. There were concerns raised that statutory changes, unless carefully constructed, could result in the parties to an insurance transaction having unequal information affecting insurers' ability to properly underwrite risk. Specifically, if a consumer obtains genetic testing results not in their medical record indicating an existing health risk, but does not disclose those results to the insurer, the insurer's analysis of the risk would be incomplete and the underwriting inadequate. In that case, the insurer could ultimately be underpricing the risk for that consumer, while potentially raising costs for other consumers.

Based on the above, a potential consumer consent gap may exist with respect to direct-to-consumer genetic testing results. Consent obtained via terms of use and privacy statement disclosures may not protect consumers in the bankruptcy scenario unfolding for 23andMe. Since direct-to-consumer genetic testing organizations do not fall within DFR's jurisdiction under either Title 8 or Title 18, DFR recommends modifications to 8 V.S.A. § 4724(22) and 18 V.S.A. § 9332(e) to require insurers to obtain specific informed consumer consent prior to obtaining and using genetic testing results not contained in the consumer's medical files in connection with the offer, issuance or renewal of an insurance policy. This would prevent insurers from using genetic testing results obtained through scenarios such as the 23andMe bankruptcy data sale in the future.

To address insurer concerns regarding potential underwriting risk due to undisclosed genetic testing results, DFR recommends that the modifications be carefully constructed so as to not prevent insurers from asking if consumers have been subject to genetic testing which meets the definitions in 18 V.S.A. 9331. If insurers are permitted to ask, that would allow those results or the failure to disclose those results to be considered during the underwriting process.