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Testimony of the Department of Commerce and Consumer Affairs

**Before the
Senate Committee on Health
Monday, January 31, 2022
1:00 p.m.
Via Videoconference**

**On the following measure:
S.B. 2032, RELATING TO GENETIC INFORMATION PRIVACY**

Chair Keohokalole and Members of the Committee:

My name is Stephen Levins, and I am the Executive Director of the Department of Commerce and Consumer Affairs' (Department) Office of Consumer Protection. The Department supports this bill and offers amendments.

The purposes of this bill are to: (1) Require direct-to-consumer genetic testing companies to adhere to certain requirements pertaining to its collection, use, and disclosure of genetic data; (2) establish fines for violations; (3) allow the Director of the Office of Consumer Protection, by and through the Attorney General, to bring civil action against violators on behalf of the State or consumers for injunctions, collection of civil penalties, and recover damages; and (4) all the State to recover the costs of suit and reasonable attorneys' fees.

Current Hawaii law fails to provide adequate guidelines for what can be done with genetic data collected by companies outside of the protective ambit of state and federal health privacy laws. S.B. 2032 fills this gap by creating the Hawaii Genetic Information Privacy Act.

SB 2032 safeguards the privacy, confidentiality, security, and integrity of a consumer's genetic data by requiring direct-to-consumer genetic testing companies ("DTC") to provide clear disclosures and more consumer control. It also requires these companies to obtain express consent for the collection, use, and disclosure of the consumer's genetic data, including separate and express consent for specified actions.

The sudden rise of DNA testing, through self-administered testing kits sold by companies has made headlines. However, as people line up to find out more about their family history or their "genetic ethnicity," serious concerns about the privacy of the information have arisen. At the federal level, the Genetic Information Nondiscrimination Act of 2008 ("GINA") addresses discrimination based on genetic information. (42 U.S.C. § 2000ff et seq.) However, the law does not holistically protect against widespread collection, dissemination, and use of such information.

S.B. 2032 is meritorious because it requires DTC companies to obtain a consumer's express consent to the collection, use, and disclosure of the consumer's genetic data. It accomplishes this by including a robust definition for "express consent" that ensures meaningful consumer control. In view of the fact that this Bill extends important privacy protections to Hawaii consumers the Department is in support.

The Department has a few concerns, however, with the penalty and enforcement provisions of the Bill and would suggest the following amendment to address them.

Delete sections -5 and -6 (page 11, line 19 to page 12, line 18) and create a new Section -5 with the following language:

"§ -5 Violation, penalties. (a) Any person who violates any provision of this chapter shall be deemed to have engaged in an unfair or deceptive act or practice in the conduct of any trade or commerce with the meaning of section 480-2. (b) The penalties provided in this section shall be cumulative to the remedies or penalties available under all other laws of this State."

Including the above referenced amendment would automatically allow both the State of Hawaii Office of Consumer Protection and the Hawaii State Attorney General to enforce the Act's provisions and would be consistent with other consumer protection statutes currently in place in the Hawaii Revised Statutes.

Thank you for the opportunity to testify on this bill.