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Testimony of the Department of Commerce and Consumer Affairs

**Before the
Senate Committee on Commerce and Consumer Protection
And
Senate Committee on Judiciary
Tuesday, March 1, 2022
10:00 a.m.
Via Videoconference**

**On the following measure:
S.B. 2032, S.D. 1, RELATING TO GENETIC INFORMATION PRIVACY**

Chair Baker, Chair Rhoads, and Members of the Committees:

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; and (2) Provide that any violation of the Act is deemed to be an unfair or deceptive trade practice in violation of section 480-2, Hawaii Revised Statutes..

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, S.D. 1, fills this gap by creating the Hawaii Genetic Information Privacy Act.

SB 2032, S.D.1, 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, S.D. 1, 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.

Thank you for the opportunity to testify on this bill.

February 28, 2022

TO: Rosalyn H. Baker, Chair
Stanley Chang, Vice Chair
Members of the Senate Committee on Commerce and Consumer
Protection

Karl Rhoads, Chair
Jarrett Keohokalole, Vice Chair
Members of the Senate Committee on Judiciary

FROM: The Coalition for Genetic Data Protection
(William Goo)

RE: **SB 2032 SD1**- Relating to Genetic Information Privacy
Hearing Date: March 1, 2022
Time: 10:00 am

The Coalition for Genetic Data Protection (Coalition) is in support of the original bill and the SD1 with the exception of the penalty provision in Section 5 of the SD1 to the extent that it creates a private right of action. Under both versions, enforcement would be by the office of consumer protection and the attorney general which is sufficient and effective to address privacy issues that may arise. This bill also provides for strong protections by requiring separate express and informed consent by the consumer with respect to the use of genetic data. The creation of a private right of action does not increase privacy protections and may incentivize unfounded lawsuits.

The Coalition therefore supports the passage of this bill in its original form.

Thank you for considering this testimony.

SB-2032-SD-1

Submitted on: 2/25/2022 3:47:59 PM

Testimony for CPN on 3/1/2022 10:00:00 AM

Submitted By	Organization	Testifier Position	Remote Testimony Requested
Gerard Silva	Individual	Oppose	No

Comments:

Opposed to all Genetic Experiments Period!!