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Testimony of the Department of Commerce and Consumer Affairs

**Before the
House Committee on Consumer Protection and Commerce**

Tuesday, March 22, 2022

2:00 p.m.

Via Videoconference

On the following measure:

S.B. 2032, S.D. 2, H.D. 1, RELATING TO GENETIC INFORMATION PRIVACY

Chair Johanson 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) Establish the Hawaii Genetic Information Privacy Act; (2) Require direct-to-consumer genetic testing companies to adhere to certain requirements pertaining to its collection, use, and disclosure of genetic data; and (3) 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. 2, fills this gap by creating the Hawaii Genetic Information Privacy Act.

SB 2032, S.D.2, H.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. 2, H.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.

March 21, 2022

TO: Aaron Ling Johanson, Chair
Lisa Kitagawa, Vice Chair
Members of the House Committee on Consumer Protection & Commerce

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

RE: **SB 2032 SD2 HD1** - Relating to Genetic Information Privacy
Hearing Date: March 22, 2022
Time: 2:00 pm

The Coalition for Genetic Data Protection (Coalition) is in support of the original bill and the HD1 with the exception of the penalty provision in Section 5 of the HD1 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 best and most effective way to address privacy issues that may arise. All versions of this bill provide strong protections for a consumer by requiring separate express and informed consent with respect to the use of genetic data. Also, the original version of the bill already includes sufficient enforcement provisions somewhat similar to that provided in Chapter 480 consisting of the imposition of a civil penalty of up to \$2,500, injunctive relief and damages including attorney's fees and costs. The creation of a private right of action only incentivizes unfounded lawsuits and does not increase privacy protections. Of the handful of states which have enacted privacy protection laws, only one (Illinois) includes a private right of action. Lawsuits by consumers in that state have either been dismissed or were unsuccessful. Finally, the HD1 excludes entities covered by HIPAA under which there is no private right of action.

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

Thank you for considering this testimony.

SB-2032-HD-1

Submitted on: 3/19/2022 1:54:49 PM

Testimony for CPC on 3/22/2022 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Gerard Silva	Individual	Oppose	Written Testimony Only

Comments:

This should be Illegal and any one pushing this should be locked Up!!



LATE

**SB2032, SD2 HD1
RELATING TO GENETIC INFORMATION PRIVACY**

Ke Kōmike Hale o ka Hoʻomalū Mea Kemu a me ka ʻOihana Kālepa
House Committee on Consumer Protection & Commerce

Malaki 22, 2022

2:00 p.m.

Hālāwai Kelekaʻaʻike / Lumi 329

The Office of Hawaiian Affairs (OHA) **SUPPORTS** SB2032, SD2 HD1, which protects the privacy and confidentiality of genetic data of consumers who use the products or services of direct-to-consumer genetic testing companies by requiring these companies to adhere to certain requirements pertaining to the collection, use, and disclosure of genetic data.

Genetic information is culturally and spiritually significant, so the Office of Hawaiian Affairs urges the Committee to PASS SB2032, SD2 HD1. Mahalo piha for the opportunity to testify on this measure.