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Testimony of the Department of Commerce and Consumer Affairs

**Before the
House Committee on Health, Human Services, and Homelessness**

Tuesday, March 15, 2022

9:00 a.m.

Via Videoconference

On the following measure:

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

Chair Yamane 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.

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, 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, 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.



House Committee on Health, Human Services, and Homelessness
Public Hearing

SB 2032 – Genetic Information Privacy

Representative Yamane and members of the Health, Human Services, and Homelessness Committee, thank you for the opportunity to submit testimony on SB 2032 – Genetic Information Privacy

Quest Diagnostics empowers people to take action to improve health outcomes. Derived from the world's largest database of clinical lab results, our diagnostic insights reveal new avenues to identify and treat disease, inspire healthy behaviors and improve health care management. Quest annually serves one in three adult Americans and half the physicians and hospitals in the United States, and our 45,000 employees understand that, in the right hands and with the right context, our diagnostic insights can inspire actions that transform lives.

As your healthcare industry partner, we write to express concerns with provisions in SB 2032, specifically its definition of "direct to consumer genetic testing companies". Quest Diagnostics is a strong advocate for transparency, but our diagnostics work puts us in a niche category where unfortunately this piece of legislation brings with it unintended consequences.

We respectfully request that the definition for "direct to consumer genetic testing companies" carve out covered entities under HIPAA. As a clinical lab company, Quest is a covered entity and subject to HIPAA whereas the direct-to-consumer genetic testing companies generally are not.

As the authors point out, only a few testing companies would be covered by HIPAA. In this scenario it seems appropriate that they carve those that are covered by HIPAA out of the applicability of the bill.

Thank you in advance for your consideration of our proposal.

Sincerely,

A handwritten signature in black ink that reads "David M. Reiner".

David Reiner
Executive Director, State Government Affairs, Quest Diagnostics

March 14, 2022

TO: Ryan I. Yamane, Chair
Adrian K. Tam, Vice Chair
Members of the House Committee on Health, Human Services and
Homelessness

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

RE: **SB 2032 SD2**- Relating to Genetic Information Privacy
Hearing Date: March 15, 2022
Time: 9:00 am

The Coalition for Genetic Data Protection (Coalition) is in support of the original bill and the SD2 with the exception of the penalty provision in Section 5 of the SD2 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-2

Submitted on: 3/12/2022 3:23:45 PM

Testimony for HHH on 3/15/2022 9:00:44 AM

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

Comments:

No gentic Crap in Hawaii. End this NOW!!!