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**STATE OF HAWAII
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DEPARTMENT OF COMMERCE AND CONSUMER AFFAIRS**

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Testimony of the Department of Commerce and Consumer Affairs

**Before the
House Committee on Judiciary and Hawaiian Affairs**

Wednesday, March 30, 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 Nakashima 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, 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.

LATE



OFFICE OF HAWAIIAN AFFAIRS

‘Ōlelo Hō‘ike ‘Aha Kau Kānāwai

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

Ke Kōmike Hale o ka Ho‘okolokolo a me ke Kuleana Hawai‘i
House Committee on Judiciary & Hawaiian Affairs

Malaki 30, 2022

2:00 p.m.

Hālāwai Keleka‘a‘ike / Lumi 325

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.

March 29, 2022

TO: Mark M. Nakashima, Chair
Scot Z. Matayoshi, Vice Chair
Members of the House Committee on Judiciary & Hawaiian Affairs

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

RE: **SB 2032 SD2 HD1** - Relating to Genetic Information Privacy
Hearing Date: March 30, 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.



March 29, 2022

The Honorable Mark Nakashima
Chair, House Judiciary Committee
Hawaii State Capitol
415 South Beretania St.
Honolulu, HI 96813

RE: Senate Bill 2032 (Genetic Information Privacy) – OPPOSE UNLESS AMENDED

Dear Chair Nakashima –

The Advanced Medical Technology Association (AdvaMed), the national association of medical technology providers, shares this letter to respectfully express our current opposition to [SB 2032](#), a bill establishing a unique state structure regulating the privacy of genetic information. Robust protection of consumer and patient data – including genetic information – is critical to the long-term health and wellness for populations throughout the country and around the globe. AdvaMed supports consistent and meaningful protections that continue to enable ethical and effective use of genetic information and urges the adoption of amendments that accomplish this in Hawaii by aligning SB 2032 with policies adopted in other states.

The consumer genetic testing industry has spent over a decade earning the trust of users through ensuring transparency, upholding high standards for the protection of data, and empowering users through control over their data. Companies who are part of the Coalition for Genetic Protection adhere to the standards and policies identified in the *Privacy Best Practices for Consumer Genetic Testing Companies* that were published in July 2018 by the Future of Privacy Forum. Abiding by best practices like these reflects the industry's understanding and responsibility in protecting the personal information of consumers and enabling them to take a more proactive role in their health.

Restore Uniformity to the Enforcement Mechanism in SB 2032

As introduced, SB 2032 allowed for the Attorney General and the Office of Consumer Protection to enforce the policy provisions of the bill. This mirrors the enforcement protocol in the other states that have passed a similar model bill (Arizona, California, and Utah; with Kentucky and Maryland pending.) Additionally, every state that has passed a general consumer privacy act so far (California, Colorado, Utah, and Virginia) has opted to not include a private right of action, recognizing the complexity of privacy law and the potential for costly frivolous litigation.

Only one state has passed restrictions on the sharing of genetic data with a private right of action: Illinois. To date, industry has been the target of several suits brought through that private right of action, but none have successfully prevailed on the grounds of statutory violation. Moreover, several have been dismissed after being filed.



AdvaMed

Advanced Medical Technology Association

Conclusion

AdvaMed urges the adoption of amendments aligning SB2032 with policies adopted in other states by reinstating the enforcement mechanism present within the introduced version of the bill.

Given the significant research opportunities presented by this information, uniform and reasonable privacy regulations help to ensure the responsible and ethical handling of the genetic data of each and every consumer.

Sincerely,

Bobby Patrick
Vice President, State Government and Regional Affairs
Advanced Medical Technology Association (AdvaMed)

COALITION FOR GENETIC DATA PROTECTION

March 29, 2022

The Honorable Mark Nakashima
Chair, House Judiciary Committee
Hawaii State Capitol
415 South Beretania St.
Honolulu, HI 96813

RE: Senate Bill 2032 (Genetic Information Privacy) – OPPOSE UNLESS AMENDED

Dear Chair Nakashima –

On behalf of the Coalition for Genetic Data Protection, a national coalition of the leading consumer genetic testing companies including 23andMe and Ancestry – we are writing to voice concerns with Senate Bill 2032 and urge amendments to bring the bill in line with other states that have passed this model genetic information privacy act.

The consumer genetic testing industry understands the importance of protecting personal information to continue enabling consumers to take a proactive role in their health and wellness and to gain a greater understanding of their ancestral origins in unprecedented ways. We have spent more than a decade earning customers' trust by maintaining high standards for data protection, acting transparently, and providing users control over their data. Trust is the essential foundation of our continued success.

To continue building on our strong foundation of proactive data protection, the leading consumer genetic testing companies – led by Ancestry and 23andMe – formed the Coalition for Genetic Data Protection in early 2019. Coalition members adhere to the standards and policies set forth in the *Privacy Best Practices for Consumer Genetic Testing Companies*¹. These *Best Practices* were developed out of the collaboration of consumer genetic and personal genomic testing companies, including current Coalition members, and published by the Future of Privacy Forum in July 2018. The Coalition recognizes the significant opportunities genetic testing and research present, and we support and advocate for reasonable and uniform privacy regulation that will ensure the responsible and ethical handling of every consumer's genetic data.

SB 2032 Does Not Need a Private Right of Action

As introduced, SB 2032 allowed for the Attorney General and the Office of Consumer Protection to enforce the policy provisions of the bill. This mirrors the enforcement protocol in the other states that have passed a similar model bill (Arizona, California, and Utah; with Kentucky and Maryland pending.) Additionally, every state that has passed a general consumer privacy act so far (California, Colorado, Utah, and Virginia) has opted to not include a broad private right of action, recognizing the complexity of privacy law and the potential for costly frivolous litigation.

¹ <https://fpf.org/wp-content/uploads/2018/07/Privacy-Best-Practices-for-Consumer-Genetic-Testing-Services-FINAL.pdf>



Unfortunately, in the bill's first committee, the Hawaii Office of Consumer Protection requested an amendment to, "allow both the State of Hawaii Office of Consumer Protection and the Hawaii State Attorney General to enforce the Act's provisions." However, the Office of Consumer Protection already had enforcement authority in the original version of the bill and the amendment offered provided an overly broad private right of action in addition to Agency and AG enforcement.

Only one state has passed restrictions on the sharing of genetic data with a private right of action: Illinois. To date, Ancestry and its parent company have been subject to several suits brought through that private right of action, but none have successfully prevailed on the grounds that Ancestry violated the statute. Moreover, several have been dismissed after being filed. Even when our companies prevail against frivolous lawsuits, we must expend considerable resources.

Conclusion

The consumer genetic testing industry has relatively few providers and our companies are under constant scrutiny in the media. As such, a dispersed enforcement mechanism like a private right of action does not increase privacy protections for consumers. Rather, it incentivizes unfounded lawsuits brought against the very companies that took the lead in implementing privacy protective policies for genetic data.

We look forward to working in partnership with the State of Hawaii to ensure consumers are protected and have control over their data. Toward that end, we are requesting amendments to remove the adversarial private right of action and instead provide consumers with clear, informed consent requirements that allow for a transparent and healthy working relationship with a regulator.

Sincerely,

A handwritten signature in black ink, appearing to read "Eric Heath".

Eric Heath
Chief Privacy Officer
Ancestry

A handwritten signature in black ink, appearing to read "Jacquie Cooke Haggarty".

Jacquie Cooke Haggarty
VP, Deputy General Counsel & Privacy Officer
23andMe