

VERMONT LEGAL AID, INC.
OFFICE OF THE HEALTH CARE ADVOCATE
264 NORTH WINOOSKI AVE.
BURLINGTON, VERMONT 05401
(800) 917-7787 (TOLL FREE HOTLINE)
(802) 863-7152 (FAX)

OFFICES:

BURLINGTON
RUTLAND
ST. JOHNSBURY

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SPRINGFIELD

To: Members of the House Committee on Commerce and Economic Development

Re: Support for S. 247

From: The Office of the Health Care Advocate

Date: April 19th, 2022

Dear Chair Marcotte and Members of the House Committee on Commerce and Economic Development:

For the record – my name is Sam Peisch, and I am a Health Policy Analyst at the Office of the Health Care Advocate (HCA). Thank you to the Committee for the opportunity to testify today. The HCA would like to express its support for the proposed bill as we believe it establishes important additional consumer protections for Vermonters related to genetic information.

As public awareness continues to grow regarding how genetic information is currently used and could be used in the future, so too have fears of how this data can be used in ways that negatively impact the public good. Fear of insufficient protection from discrimination adversely impacts the trust upon which appropriate prevention, diagnosis, treatment, and rights-based decision-making depends. This bill would take an important step to improve consumer trust in this vital area.

Genetic information – and its value in improving risk prediction, treatment, and overall decision-making – will grow in the future. Ensuring adequate protections for how this information is utilized will be critical to ensuring that trust is there not only in situations where treatment is advisable, but also in recruiting individuals to participate in the clinical research trials upon which medical advances rely heavily. For clinical trials to have translational value, the study population must be representative. Currently, clinical trials across disease types suffer from low representation from historically marginalized groups in large part due to fear discrimination. This bill aligns with Vermont's health equity commitments and goals.

With respect to the specific concern that the bill could potentially discriminate against people who could leverage *positive* information from a genetic test, I would say the benefits the bill's passage would provide with respect to consumer protection and health equity exceed the comparatively minimal projected costs to these individuals and the insurance entities involved in affected markets.

Thanks so much. Happy to take any questions.

Sincerely,

s\ Sam Peisch, Health Policy Analyst