



April 23, 2024

To: Sen. Ginny Lyons, Chair, Senate Health and Welfare Committee
Members of the Senate Health and Welfare Committee

From: Tina Zuk, Government Relations Director, American Heart Association

Re: H.121 proposed change

We would appreciate your consideration of the following proposed change to H.121 requested by the American Heart Association (AHA).

The AHA supports consumer data privacy and the Vermont Legislature's desire to establish important consumer protections. AHA uses industry standard security protocols to protect our donors' and volunteers' information, and readily make our privacy policy available to the public. We do, however, have some concerns that the current version of H.121 will create unintended consequences in the form of significant compliance costs for non-profit organizations.

Every dollar that a public charity must devote to data privacy compliance is a dollar that we cannot use to further our missions. For AHA, this means less going toward funding cardiovascular research, setting clinical guidelines for cardiac and stroke care, and providing CPR training materials and courses that are used throughout the U.S.

Moreover, when a public charity like AHA does not commercialize that data (i.e., sell it), the costs are even more painful. Donors expect their funds to support the mission, not for handling consumer data questions and portability support requests, and they can easily read the privacy policies and charity watchdog ratings to see how their data is used.

With that in mind, we recommend connecting 501(c)3 nonprofit compliance with this legislation to the [Better Business Bureau Wise Giving Alliance Standards for Charity Accountability](#). By following these standards, we can demonstrate that we are following the spirit and intent of H.121, while removing the more burdensome process of demonstrating this compliance. There are 20 detailed standards that must be met by non-profits included in the BBB Standards for Charity Accountability which can be found in the link above.

We appreciate that there are already limited exemptions for nonprofit organizations in the bill. **We believe that it makes sense to add one more limited, tailored exemption for "501(c)(3) organizations that are registered with the state and comply with the Better Business Bureau Wise Giving Alliance Standards for Charity Accountability."**

Another option would be to include the following language that is in the current draft of Georgia’s data privacy legislation. This could be inserted as Section 2417(a)(20):

(20) A nonprofit organization that does not sell personal information and that has a process by which an individual's personal information will be removed upon request. For purposes of this paragraph, 'nonprofit organization' means a corporation qualified as a not for profit corporation by the Internal Revenue Service under Section 501(c)(3) of the Internal Revenue Code.

Currently, the Colorado Privacy Act is the only state data privacy law already in effect that does not exempt AHA. We have until 2025 to comply with the “signed, but not yet effective” data privacy provisions in Oregon, Delaware, and New Jersey that do not exempt nonprofit organizations. In the meantime, we are spending a lot of time and money on trying to configure our systems to distinguish between inconsistent state laws and manage to the requirements of each while continuing to remain engaged and accessible to volunteers, donors, survivors and others affected by heart disease and stroke, as well as their families and healthcare providers.

There are states where exemptions do exist. The following states have enacted consumer privacy laws that exempt non-profits: CA, CT, IN, IA, MN, NH, TN, TX, UT and VA.

Thank you for your consideration. We are very open to conversations on how to best work towards this exemption (or similar language) and stand ready to work with you to find the right solutions that meet the needs of both nonprofit organizations and the people of Vermont.

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