To: The Senate Health and Welfare Committee Re: S.197 An act relating to prohibiting discrimination based on genetic information Date: 3/11/20



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James Duff Lyall Executive Director

Falko Schilling Advocacy Director Thank you for the opportunity to testify today on S.197 an act relating to prohibiting discrimination based on genetic information. The ACLU of Vermont supports this legislation and the efforts to ensure people do not face discrimination based on their decision to learn more about their personal genetics.

Individuals may want to learn more about their genetic profile for a number of important reasons, and they should not fear repercussions based on that decision. Genetic information may identify an individual's predisposition to develop certain diseases, allowing for early diagnosis and treatment and ensuring that people can make informed decisions and retain maximum control over their health. Although genetic research can lead to important medical discoveries and treatments for disease, many people wish to keep their genetic information private.

The reason for their concern is that genetic material holds personal information about an individual's traits, disease profile, and family medical history. Tissue samples taken during a medical examination contain information not only about the patient but also about his or her blood relatives. People rightfully want to keep this information private because they fear it could be misused to deny individuals healthcare, employment, and necessary insurance. Fear of such discrimination could have a chilling effect, causing individuals to refuse potentially life-saving testing due to fear of how the results will be used by employers, insurers, or the government.

Discrimination based on a person's genetic information, just like that based on race or disability, should not be tolerated. Genetic information, like other kinds of sensitive private information, needs robust protections and safeguards. For these reasons we support S.197 and would be happy to answer your questions.

Sincerely, Falko Schilling Advocacy Director ACLU of Vermont