



Testimony on [SF 1138 \(Klein\)](#) – Consent for Direct to Consumer Genetic Testing

*Testifier: Natasha Chernyavsky, legislative and policy specialist
MN Senate Commerce Committee, Thursday February 16, 2023*

Thank you, Mister Chair, and members of the committee.

My name is Natasha Chernyavsky, I am the legislative and policy specialist of Citizens' Council for Health Freedom. CCHF has long supported genetic privacy and, although we appreciate the sentiment and goals of SF 1138, as we've expressed to Senator Klein, we are concerned that the bill does not truly protect privacy and individual rights and gives a false sense of security to consumers.

We're pleased to see the amendment for revocation of consent for use and sharing of genetic data. However, we are deeply concerned by **line 2.25 which states that "genetic data does not include deidentified data."** "Genetic data" is written 20 times in this bill, often referring to the protections that will be guaranteed to consumers. However, because deidentified data is not defined as genetic data, there are no protections in this bill for deidentified genetic data – which could become a very large subset of consumer DNA.

Furthermore, there is a lack of clarity regarding the standards of deidentification. Even though it's still the person's blood or the person's spit, it will no longer be deemed genetic data, and those specimens and any related data will be exempt from any protective provisions of this bill. In addition, as noted by 23&Me, if the un-pooled individual data is breached, **a person could potentially be identified by their deidentified DNA** if a public database is used.

Also, with reference to the federal Common Rule for federally-funded research, **it appears the bill would transfer authority to federal officials to determine the definition, revocation, and notice for consent data sharing.** Essentially MN would cede authority to federal regulators, to regulations which can be changed by unelected officials under every administration, rather than determining these provisions by state law. Importantly, this includes the provisions in the federal rule for waiving consent requirements as permitted under Part 46 of Title 45.

This bill appears to be less about privacy and more about providing companies with the right to use genetic data as they wish without consent. Deidentified or not, it's still genetic data, it's still DNA, but under this bill it won't be identified or protected as such. To truly protect consumers, line 2.25 should be deleted. Consumers have the right to protect their DNA, regardless of whether it is deidentified or not.

Also, thank you for the amendment regarding 13.386, we do support it, however given that Chapter 13 protects the right to sue the government, does 13.386 truly give individuals the right to sue private entities?

Finally, if this committee intends to pass this bill, we have three suggestions to strengthen consumer protections – in addition to our request to delete line 2.25.

First, in 16-point font, the consent forms referenced in Subdivision 2 could say, "Under Minnesota state law, genetic data that is de-identified is no longer considered "genetic data" and is not protected by the 2023 state law on genetic testing companies. Do not provide consent if you want to limit the use and sharing of your DNA."
Second, require informed written consent specific to deidentification of the specimen. The consumer would be informed that they lose all rights to where it goes and what happens to it once it's deidentified, and they'd have a choice in whether it is deidentified. **Third**, on line 4.4 give consumers access to an accounting of disclosures so they know how often and with whom it was shared.

Thank you for your time and attention to these concerns.