

**Rich Neumeister testimony to Senate Commerce
and Consumer Protection Committee
Thursday, February 16**

Good afternoon, Chair Klein and Committee members,

I will be commenting on SF 1138, legislation that will regulate the direct/consumer genetic testing companies which run the gamut of 23andMe to Minnesota Monitoring in this state.

The bill is being pushed by the industry strongly by the Coalition for Genetic Privacy, which is an industry created group consisting of two organizations per their website, Ancestry and 23andMe.

I applaud the industry for taking the initiative to make a movement to enact a regulation scheme from a self regulated one. But I have one huge concern, it's the industry that's proposing the legislation.

Over the decades in my unpaid work at the Minnesota Legislature I have run across such consumer bills. Typically, an industry such as banking, insurance, or whoever foresees issues with use of personal data. The action they've pushed I've been there to make the bill better for Minnesota residents with policy makers.

Senate File 1138 needs improvement on several fronts. I'm guided by: how individuals can enforce their rights and

address violations, fair information principles implementation in law for the Minnesota consumer to have maximum clarity on decisions with their most fundamental private information one can possess (their DNA), and the need for accuracy and meaning with definitions of the bill.

General enforcement of the bill is with the Department of Commerce. In the Senate Judiciary Committee there was discussion of a private right of action similar to other Minnesota statutes. There was an oral amendment done to place a possibility of right to private action. Discussion occurred in committee on the common law privacy tort recognized in Minnesota as an option. For an individual to use this remedy one would have to meet a high standard and burden.

I suggest a narrow right of private action for misuse and wrongful disclosure. Minnesota Statute 144.298, subdivision 2 and 72A.503 can serve as a model.

Fair information principles I use as a guide when I review privacy legislation. These precepts deal with consent, that individuals have meaningful understanding of how information is being being used, they know who it is being shared with, no secrecy with the use of your data, i.e.

These are several suggestions (using SF 1138, as introduced) to help maximize these principles in law and to the consumer:

On page 3, line 8, after practices, add "of genetic data and"

(This new language below would begin on page 3, line 9)

New "(iii) information that clearly describes how to file a complaint alleging a violation of this section, pursuant to 45.027"

On page 3, lines 14 through 17, (SF 1138 as introduced) should be separate, so it would read like this,

"separate express consent for each transfer or disclosure of the consumer's genetic data or biological sample to any person, including the name of that person, other than the company's vendors and service providers."

"separate express consent for each use of genetic data or the biological sample beyond the primary purpose of the genetic testing product or service and inherent contextual uses;"

On page 4, line 9, after, after life insurance, add "disability insurance"

In regards to definitions and terms used in the bill, there needs to be clarity. I do have questions and concerns about several of them. For example:

What does "reidentify" mean? In what situations will

reidentification happen?

"Direct-to-consumer genetic testing company", Who does it apply to? In what situations?

One thought I leave you with as I've been doing research on this topic: Should there not be rules from the Commerce Department guiding this burgeoning industry? I think so. The Commerce and Consumer Protection Committee may wish to entertain this notion.