

Oregon Legislature

SB 703 Public Hearing

Public Personal Testimony of:

Jeff Gaus, Oregon Citizen

Founder, Oregon Blockchain Venture Studio (OBVS)

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Chairman Prozanski, members of the Committee, thank you for the opportunity to share my views with you today.

I am Jeff Gaus; I'm an Oregonian, a seasoned technology executive, and the Founder of the Oregon Blockchain Venture Studio (OBVS). For the majority of my career, I've provided technology solutions to the Healthcare and Life Sciences industries. I have a strong background in the issues this Bill addresses and the technology and processes that will be required to implement the provisions of this Bill.

First, I commend this committee on bringing this Bill to the Legislature on behalf of the Citizens of Oregon.

One need only follow the media to gain an appreciation of the magnitude of the issues at hand: how many more non-responsive answers in legislative committee hearings, apologies, or mea-culpas from technology executives are we willing to endure before we take steps to prevent the mishandling of our personal data, especially our health data?

Second, I cannot think of any data that is more personal or more confidential than health data. It captures the essence of who I am; it captures the essence of each and every one of us.

In 1996, the United States Congress adopted the Healthcare Insurance Portability and Accountability Act (HIPAA), this legislation, besides many other provisions, established privacy guidelines for how individual patients' data is to be protected. It is really good legislation; it is landmark legislation; however, the privacy requirements do not go far enough and are not effective enough. Data breaches are common; and as the tech publication TechCrunch reported last week data brokers and data aggregators – some of whom you heard from today – have developed algorithms and methods that enable companies to re-identify specific individuals using

anonymized data. And, they obtain this data, buying it from pharmacies, healthcare providers, insurance companies, etc., without the consent of the individual patient. Clearly, this conflicts with the spirit and intent of HIPAA.

And, just three weeks ago, Family Tree DNA admitted to selling the genetic data of two million of its customers to the FBI, without its customers' knowledge or permission. I cannot think of a more egregious civil rights violation. I hope someone can explain why this does not violate the intention and spirit of the protections afforded us under the 4th Amendment.

The FBI has this data because it was acquired through a commercial transaction, which only occurred because there was no law specifically **DISALLOWING** the transaction. This needs to stop; you have the power to stop it.

My position is very clear: Nobody has commercial rights to my health data – anonymized or not – without my specific, expressed permission.

Third, this past Fall, Portland Business Journal Publisher Craig Wessel interviewed the CEOs of Oregon's largest healthcare providers, including: OHSU, Providence Oregon, and Legacy. These CEOs unequivocally stated their belief that patients **OWN** their data. Think about what they said.

Implicit in their statements and, implicit in the spirit and intent of HIPAA, is the concept of patient data ownership; implicit in "ownership" is the concept of property. Ownership cannot exist without property rights. What SB 703 does is state, in **EXPLICIT** terms, that personal health data is personal property, and this personal property is governed by the property rights we enjoy as citizens of the State of Oregon.

Finally, you heard today how "insignificant" is the value of these data sets. Let me put this "insignificance" in perspective: For example, as reported on Bloomberg, leading data broker IQVIA's 2018 revenues were \$10 billion dollars. That is anything but insignificant.

Because of my background as a healthcare and life sciences technology executive, I understand the positions you've heard today; however, this is not a technology issue; this is not a business model issue; this is not a "value of the data" issue – this **IS** a Civil Rights issue. This is about doing what is right for the citizens of Oregon.

Our National and State constitutions define and protect our civil rights, including our property rights. Throughout our history, we've passed landmark legislation recognizing and protecting our civil rights. Examples include:

- In 1990, The Americans with Disabilities Act (ADA), banned discrimination against individuals with disabilities in all aspects of public life (without which I would have been prevented from being heard today);
- In 1996, The Health Insurance Portability and Accountability Act (HIPAA), established standards to ensure the privacy of individuals' healthcare data.

Both of these bills had detractors and faced stiff opposition; opponents plead: "...upsets the status quo...", "...too expensive...", "...too complicated...", "...undue burden...", etc. In spite of this opposition forward-thinking legislators prevailed, passed the laws, and forever impacted our society.

You have before you, in SB 703, a Bill comparable in importance and stature. I urge this Committee, and the entire Oregon Legislature, to continue Oregon's legacy of progressive policy leadership by passing this Bill on behalf of all of our fellow citizens. You will again establish precedent for the entire Nation.

Again, thank you for your time and for the opportunity to be heard.