

February 11, 2015

Rep. Ann Pugh, Chair
Rep. Sandy Haas, Vice Chair
Rep. Francis "Topper" McFaun, Ranking Member
Rep. Steven Berry
Rep. Paul Dame
Rep. Larry Fiske, Clerk
Rep. Patsy French
Rep. Jill Krowinski
Rep. Patricia McCoy
Rep. Michael Mrowicki
Rep. Chip Troiano

Testimony ~ H98

Dear Honorable, Elected Lawmakers,

The Vermont Coalition for Vaccine Choice (VCVC) is a volunteer organization comprised of over 2000 Vermonters who are dedicated to preserving health choice and informed consent for parents and all Vermonters. We are active community members and a vital part of the Vermont economy: the young families that are the future of Vermont, as well as our grandparents, teachers, nurses, healthcare providers and others. We came together in 2012 to preserve the philosophical exemption to vaccination.

Thank you for hearing our testimony today on H98.

Our organization has concerns about the lack of privacy, and lack of consent in the immunization registry portion of this bill, but these concerns could also be applied in the other sections.

Specifically, on page 11, the requirement that registry information be kept confidential and privileged and shared only in summary, statistical, or other form in which particular individuals are not identified has been removed. This is troubling, because it appears that the last vestige of privacy protection in the current law would be removed, now allowing for confidential information to be passed on to other states, network providers, and even researchers, and children's individual names and private health data be passed on to school administrators. While page 12 does specify that a written agreement will be obtained which will keep any confidential information privileged, there are no penalties outlined for failure to perform this essential duty. What is the intent of such disclosure of children's names?

You should know that Vermont parents and adults consider their health information and that of their children to be private, protected information regardless of which procedures they choose to undertake or which diagnoses they receive. Patients enter a doctor's office with the assumption that their health information will be stored and kept private in that office. Most people assume that HIPAA (or in the case of school files, FERPA) laws exist in order to protect the privacy of patients regardless of the health practices they pursue or

which diseases they have. These registries, which call for mandatory participation with no permission necessary, prove that this is not the case.

It is our position that Vermonters have the right to protect their private medical information, and that the legislature should protect that right. Vermont children and adults should have the right to go to their doctor's office knowing their personally identifiable information is protected, not shared at the pleasure of a Department. So, what can we do?

We would like to ask that you consider amending this bill to require consent by patients, parents or guardians before health information such as this be entered into "the cloud." We all know that once something goes "out there," it is impossible to get it back, or to control where it goes next. Vermonters expect more, and to preserve trust and privacy any registry really should be require the permission of patients and parents.

We suggest the following language (underlined to be added) be considered as amendment:

(b) The Department may use the data to create a registry of immunizations. Except as provided by this subchapter, registry information shall remain confidential and privileged. Registry information regarding a particular adult shall be provided, upon written consent of said adult, to the adult, the adult's health, care provider, and the adult's health insurer. A minor child's record also may upon written parental consent be provided, upon request, to school nurses, ~~school administrators~~, and upon written parental consent, to licensed day care providers, to document compliance with Vermont immunization laws. Registry information regarding a particular child shall be provided, upon written consent to the child after the child reaches the age of majority and to the child's parent, guardian, health insurer, and health care provider. Registry information shall be kept confidential and privileged and may be shared only in summary, statistical, or other form in which particular individuals are not identified.

(c) The Department may exchange confidential registry information with the immunization registries of other states in order to obtain comprehensive immunization records for Vermont residents upon written consent of the resident. (d) The Department may provide confidential registry information to health care provider networks serving Vermont patients and, with the approval of the Commissioner, to researchers who present evidence of approval from an institutional review board in accordance with 45 C.F.R. § 164.512. upon written consent of the patient. (e) Prior to releasing confidential information pursuant to subsections (c) and (d) of this section, the Commissioner shall obtain written consent of the patient to do so, as well as obtaining from state registries, health care provider networks, and researchers a written agreement to keep any identifying information confidential and privileged. (f) Registry information may be shared for public health purposes in summary, statistical, or other form in which particular individuals are not identified.

This language would of course protect the privacy of Vermonters while balancing the public health needs. Thank you for your time.

Sincerely,

Jennifer R. Stella, President

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