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TESTIMONY IN OPPOSITION TO 19-H 5541, RELATING TO ADULT IMMUNIZATION REGISTRY

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The ACLU of Rhode Island opposes this Department of Health bill, which would require that all adult immunization medical information be included in a DOH database unless the person opts out. We believe that, when it comes to important medical information, it should be up to the patient to opt in, rather than imposing the burden on them to opt out. The reasons for insisting on such a position in this instance are numerous:

1. Perhaps the major reason DOH would like an opt-out provision is why we believe an opt-in is more appropriate. With an opt-out system, not only will few patients exercise their right to opt out, but they will likely not even know that the information is being added to a database like this. Patient autonomy should be respected by requiring them to opt in to a database like this. That is the essence of informed consent.

2. The database will contain much more information than the person's immunization status. The bill provides that the information collected for the registry will "only include data elements nationally endorsed" by the CDC, but those data elements take *nine pages* to list on the CDC's website.

As the committee knows, a similar immunization database for children already exists as part of the Department's Kidsnet program – and a similar, somewhat alarming, collection of information takes place there. The information contained in the Kidsnet database takes at least five pages to list. Of course, Kidsnet covers much more medical ground than immunization, but even in a limited capacity, an adult's immunization information will, like Kidsnet, clearly be paired with a great deal of "demographic" and "identification" information so that it can be used for various data-matching and data sharing purposes. Patients should be made aware of this through an opt-in process.

3. Once the patient's immunization information is in the database, DOH will be able to share the information with "data partners" for a variety of unpublicized uses. Again, this is something patients should be made aware of up front, along with an opportunity for them to know who those partners are and the purposes for which the information is being used.

4. Once this information is in the database, adults may find themselves facing adverse consequences as a result. For example, the Department has been issuing regulations over the past few years increasing the number of people who are must get immunized as a condition of employment or licensing. It is reasonable to assume that list will be expanded over the years, and that this database will at some point be used for data-matching purposes in those situations. And just as parents now can be barred from volunteering at their school due to past criminal records, we can see this database eventually being used to bar non-vaccinated parents from volunteering at their children's schools. Whether that is a good idea or not, it should not happen circuitously through passage of a supposedly innocuous piece of legislation like this – but it easily could.

5. Finally, we must regretfully reiterate concerns we have made in the past about the Department's general lack of concern about patient confidentiality when more general public health interests are put in the balance. We agree that both patient privacy and public health are critical interests, and coming up with the right balance can sometimes be difficult. Too often in the recent past, however, the Department has shown that it does not consider patient confidentiality a priority in its mission.

Two years ago, the DOH supported legislation sponsored on behalf of the Attorney General to give law enforcement access to the Department's prescription drug monitoring database without a warrant. DOH did so only a few years after it got a bill passed to vastly expand the prescription information in that database by agreeing that police would *not* be able to gain access to the information without a warrant. The agency's support of Kristen's Law last year further highlighted its bias toward supporting other public interests at the expense of individual rights. Proposed DOH regulations in recent years to expand third party access to two other large agency databases with confidential patient information – the health information exchange and the all-payer claims database – further lend credence to our concerns about creating bigger and more intrusive health databases.

For all these reasons, we urge rejection of this legislation.