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TESTIMONY IN OPPOSITION TO 18-S 2530, 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 impose 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, 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 likely contain much more information than the person's immunization status. (The statutory section being amended specifically talks about "requiring the reporting of immunization status *and any other relevant information* that the director determines appropriate…") An immunization database for children already exists as part of the Department's Kidsnet program. All the information contained in the Kidsnet database takes five pages to list. Of course, Kidsnet covers a lot more medical ground than immunization, but even in a limited capacity, we assume an adult's immunization information will 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 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, and sadly, we have no reason to believe these fears are beyond the pale. In the recent past, the DOH has shown that it does not consider patient confidentiality a priority in its mission. Last year, Committee members will recall, 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. In the past year alone, the Department has proposed regulations 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. There is simply no reason to trust the Department to put the confidentiality interests of patients first once this information is included in a DOH database.

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