Senator/Representative

RE: Proposed bill to amend enrolled HB213

Dear \_\_\_\_\_\_\_\_\_\_\_\_\_

**Thank you for your consideration to sponsor or co-sponsor a proposed bill next legislative session that will fix the serious ethical and procedural problems with enrolled HB213.**

**What is the difference between the “Opt-Out” amendment added to HB213 during last legislative session and our proposed bill for 2020 legislative session that makes the tracking registry a true and proper “Opt-In” registry system?**

**The short answer is that while enrolled HB213 includes an opt-out provision that allows an individual to refuse to have himself/herself included or** the parent to refuse to have his or her child included in the *vaccination registry* (and existing data removed from *the registry*), the Department of Health remains the keeper of the individual’s medical **data.**

**According to enrolled HB213, the opt-out of vaccination registry forms will be filed with the DOH. The DOH keeps the medical and exemption data in their own DOH database system for population data tracking purposes and for sharing with industry partners and other agencies. The tracking and data sharing by the DOH are already happening. As is currently the case with religious exemption in the Florida SHOTS system, the opt-out status will be noted. Existing data with the DOH does not go away as is presumed to be the case with the “opt-out” registry. The parent or individual who opts out is misled and thinks that their medical data is not in ANY database tracking system, however the data is STILL filed and tracked at the DOH.**

**Any medical database tracking registry must be a TRUE OPT-IN SYSTEM for both health care providers/doctors and patients/individuals in order to provide for true informed consent to track medical information. The proposed bill to make the tracking registry a true OPT-IN database system will allow ONLY the health care provider to release vaccine information to the DOH if the individual has willingly given Opt-In informed consent. This protection is critical, especially considering the many existing abuses of using registry data.**

**There are several serious ethical and procedural problems with the current existing database system and the new enrolled HB213:**

* Currently patients' confidential health records are being data mined by the health department without informed consent to do so. HB213 law allows the upload of patient data from existing automated systems. This data is then shared with other agencies and industry partners.
* DOH currently uses birth records from the Office of Vital Statistics without parental consent to start a registry file. Parents should be asked for their informed consent to having their newborn child put in this registry.
* The Florida Shot Registry is being used as an enforcement tool to target families not fully vaccinating. Clinic staff identifies those who are due for or have missed vaccinations and targets them for compliance with calls, letters and HOME VISITS. The health department records religious exemptions into the registry even if a family has opted out of tracking in the Florida SHOTS system. Like the current system already does, the HB213 tracking registry is designed to include the capability to track and target specific geographic areas and groups for missed opportunities and for the uptake of new vaccines.
* The DOH allows this data to be used to enforce compliance and discriminate. For example, using religious exemption data to produce a map of where in Florida and in what schools’ children with religious exemptions live. These maps are released and promoted by the media to fuel the removal of the religious exemption provision.
* The HB213 opt-out mandatory registry makes informed consent for the tracking of private medical information obsolete because data is still tracked by the DOH. That is why it must be an opt-in system.
* The immunization database is already being used to track adult health data as well as children. Tracking every person, including all adults, is the end goal for the Healthy People public health policy program. The mandatory tracking bills being introduced in all states are the trickle-down means for achieving this goal. What was promised to be a childhood-only vaccination registry includes adults as well.
* The enrolled HB213 makes it mandatory for health care providers to report vaccination information and other private medical data to the registry. There is no opt-out provision for doctors. They have no informed consent choice.
* Mandatory reporting makes health care practitioners agents of the State. This negates the doctor/patient relationship, the medical privacy of information between doctor/patient, and the practitioner's autonomy and expertise in providing for a patient's individual health care needs.
* Health care provider performance & compliance in vaccinating all citizens is already being tracked by the department and insurance companies.
* Health care providers who treat children not fully vaccinated will be under more pressure to deny care to these individuals. They are financially rewarded for vaccinating more people and they are penalized if their patient database is not fully vaccinated.
* HMO’s are already trading records back and forth with the Florida Shots Registry to determine vaccination coverage levels and for monitoring the performance of individual doctors on fully vaccinating their patients.
* Health care providers should be required to obtain OPT-IN informed consent to tracking and the release of records. This protection is critical considering the many existing abuses of registry data.

These are very important reasons why the database MUST BE a true informed consent OPT-IN system. The proposed bill corrects the many ethical violations that exist with the current system and the enrolled opt-out law.

A legislator’s first job is to make sure that every piece of legislation that comes up for a vote protects our rights and constitutional freedoms … not take them away. Privacy of personal medical data (not sharing the data) and informed consent (opting-in to the system) should be clearly written into laws and policies to safeguard these rights.

Legislation that gives more power to a government agency while taking away the rights of citizens serves only the state and leads to the abuse of power. When the two social policies of protecting the public health and protecting the individual’s rights collide, greater protection must be afforded to the individual. These rights must be clearly written into the laws.

We greatly appreciate your commitment to protecting the rights of individual freedoms. Please consider sponsoring this proposed bill and working with other legislators to support this action. We also appreciate your NO VOTE on the pre-filed SB64, a dangerous bill that removes the religious exemption provision and restricts medical exemptions.

Sincerely,