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RE: Proposed rulemaking 10-242 (communicable and noncommunicable diseases)

To Whom It May Concern:

The PA Department of Health is making a shocking attempt to expand its scope and scale to further infringe on the rights of parents to oversee their children's health care, curtail freedom and liberty of PA citizens and to increase tracking and surveillance of citizens all under the guise of "ensuring overall public health and safety". Addressed here are three main concerns:

1. **The proposal to create a birth defects registry is intrusive, mandatory, puts personal health information of children at risk while initiating potential long-term health surveillance of vulnerable citizens.**

   The Department proposes to create a birth defects registry and to require health care practitioners and health care facilities to report cases of certain birth defects and congenital anomalies through this registry within 180 work days of diagnosis.

The proposal references CDC Birth Defects Tracking[1] which states the birth defects must be identified by the child's sixth birthday. The CDC discusses 'surveillance' of patients to track health issues and lifespan whether they are attending specialty clinics or not and without patient or parent consent. It is the PA Department of Health's responsibility to explain and provide for the protection of patient's personal health information. It is unclear how the Department proposes to track and surveil to better understand life expectancy if the information provided is anonymous and vulnerable to hacking as we have seen in other similar instances. In the last few years alone, data breaches and ransomware resulted in over 193 million stolen medical records, impacting many US residents.[2]

The Department also proposes to require reporting for "fetuses that are not born alive but have completed 19 weeks of gestation. In the absence of a gestational age estimate, a congenital anomaly in a fetus that is not born alive shall be reported if the fetus had a weight of at least 500 grams. The Department proposes such reporting to account for congenital anomalies which developed during pregnancy and may have attributed to the infant's death. The Department proposes to add language indicating that the reporting requirements in this section apply to each infant or fetus born, expelled or extracted and to clarify that reporting of birth defects and congenital anomalies is required of all infants or fetuses, regardless of whether the infant or fetus is born alive."

The PA Department of Health notes that funding from the CDC may be available to fund the institution of the Birth Defects Registry at least in part. It is likely that the reliance on CDC funds will require initial and future alignment with expansion of scope and ever more invasive testing as technologies further develop, providing deeper insights into personal health, without a doubt.

While the CDC and PA Department of Health cite noble goals for the prevention and treatment of birth defects, the wealth of information available from current and future testing methods, data analysis and the synthesis of data from multiple sources without an individual's knowledge make it a big concern for the

1 https://www.cdc.gov/birth-defects/tracking/index.html
2 https://techcrunch.com/2026/07/20/hackers-stole-significant-amount-of-data-from-tech-firm-relied-on-by-thousands-of-us-hospitals-and-pharmacies/

impact to the individual arising from data breaches, leaking of personal information and abuse of data by nefarious entities now and in the future. In addition, it is unclear how the data may be used in the future to inform or counsel expectant mothers about how to proceed with their pregnancy or what the parents may or may not have done to contribute to the birth defect.

What might insurance companies do with this information should they gain access to the data? It's not hard to imagine how discriminatory pricing for health care premiums and deductibles may use this data in the future should it become available.

How might the CDC use this information in identifying "clusters"? While the CDC claims identifying clusters and potential environmental causes of birth defects are goals, most investigations end without a cause being found and this can lead to unnecessary public panic. The CDC, through its own Guidelines for Investigating Clusters of Health Events, states that "investigators will rarely be able to demonstrate an excess of cases or establish a direct etiologic link to an environmental exposure. This, along with other public health sources, confirms that finding an environmental cause in a localized cluster is uncommon."[3]

There are several active federal lawsuits challenging the collection, storage and usage of biological and genetic data of this sort because it is a violation of rights. Examples:

- In NJ, on behalf of parents who discovered the state routinely holds onto leftover baby blood spots for up to 23 years without explicit parental consent. In this case, blood is shared with law enforcement and mentions that in Texas the state was "turning over blood to the Pentagon to create a national (and someday international) registry.-- https://ij.org/wp-content/uploads/2023/11/Lovaglio-Complaint.pdf
- In MI, on behalf of parents who sued for violation of civil rights to medical privacy by storing children's genetic profiles with no explicit consent. The plaintiffs "contend that Michigan's scheme entails coercive, non-consensual taking and keeping of baby blood for the state's profit, in violation of the Fourth and Fourteenth Amendments." -- https://www.opn.ca6.uscourts.gov/opinions.pdf/25a0168p-06.pdf

3 https://www.cdc.gov/mmwr/preview/mmwrhtml/00001797.htm

2. **The proposal allowing for isolation and quarantine measures to prevent and control the spread of disease is a massive overreach and tramples on PA citizens' constitutional rights.**

"This proposed amendment aligns Pennsylvania's disease control measure provisions with those of its neighboring states, such as New York, New Jersey and West Virginia. See 10 NYCRR § 2.13[4] (allowing for disease control measures to be enacted "whenever appropriate"); N.J.A.C. 8:57-1.11 (isolation and quarantine measures may be used as "medically and epidemiologically necessary to prevent or control the spread of the disease"); W. Va. Code R. § 64-7-21 (allowing for isolation and quarantine measures to prevent and control the spread of disease)."

Interestingly, New York's 10 NYCRR § 2.13 (Isolation and Quarantine Procedures) was deemed void of active enforcement per a lawsuit filed against NY in 2022.[5]

In that suit, Senator George Borrello said on behalf of the plaintiffs, "the expansive emergency powers that were given to the Executive Branch during the pandemic set a dangerous precedent that was ripe for abuse. That is what occurred here. Reluctant to relinquish the unrivaled authority that accompanied New York's 'state of emergency', the governor sought to improperly use the agency rulemaking process as another conduit for unilateral control. If we allowed that to occur unchallenged, it would be inviting further violations of the constitutional separation of powers."[5]

Assemblyman Michael Lawler, also a plaintiff in the suit against NY stated, "We're talking about a proposal that would've empowered the state to take you, your child, your grandparent, or other members of your family from your home and into quarantine centers with little due process, for as long as the government felt necessary. One would think such a frightening policy would come from a book or a movie, but it was proposed by our state Health Department and cannot be allowed to stand."[5]

While an appellate court dismissed the case on a technicality, Supreme Court Judge Ronald Ploetz had stated serious deep concerns with the law's

4 https://govt.westlaw.com/nycrr/Document/I3783ab18c22411dd80c2c6f42ff0193c?viewType=FullText&originationContext=documenttoc&transitionType=CategoryPageItem&contextData=(sc.Default)

5 https://www.assembly.state.ny.us/mem/Chris-Tague/story/102797

constitutionality. [6]

This proposal is frightening to the extent that residents of PA may avoid seeking medical help for fear of being investigated, involuntarily put under isolation with a 'placard' on their door or even transported to a facility chosen by PA Health Department authorities with no freedom to leave when they choose. This is de facto incarceration without a crime. The dangers of such an obvious violation of freedoms in the United States should be reason enough to reject this proposal entirely.

It appears that the PA Department of Health has assigned itself the roles of judge, jury and jailor for health challenges that individuals are suffering only to add to their suffering. Didn't we learn anything from COVID-19?!

3. **The proposal includes entering a school to have unfettered and unsupervised access to minors (without the notification, involvement or respect for parents) for 'contact tracing' and the determination and treatment of diseases.**

"The Department proposes to require a school to provide the Department or local health authority with reasonable and timely access to a person for the purpose of contact tracing or partner services, including access when classes are in session or at any other time the person is present at school, on school premises or attending a school function."

"The Department proposes to require a person, including an employee or official of a school, to permit the Department or local health authority to meet and speak with a student or other person, in private, and to prohibit the person from interfering with the student or other person's ability to exercise their right to give consent under 35 P.S. § 10103. Pursuant to 35 P.S. § 10103, "any minor may give effective consent for medical and health services to determine the presence of or to treat . . . venereal disease and other diseases reportable under the act April 23, 1956 (P.L. 1510), known as the 'Disease Prevention and Control Law of 1955,' and the consent of no other person shall be necessary."

"Parents have rights under the HIPAA privacy rule to access their minor children's health information. The Office for Civil Rights (OCR) reiterates that parents are considered personal representatives for their minor children when

6 https://www.votervoice.net/AUTISMACTION/Campaigns/109552/Respond

they hold legal authority for healthcare decisions. OCR is also initiating compliance reviews of large healthcare organizations to determine whether parents are receiving timely access to records. HRSA's new requirement extends across medical, dental, behavioral health, counselling, and preventive services at HRSA-supported centers, including services related to sensitive topics, and reinforces that parental consent rules remain in effect unless state or federal law provides an exception."[7]

"Matt Bowman, senior counsel at Alliance Defending Freedom and former HHS deputy general counsel, said the current enforcement push is overdue, noting that "schools need to realize they are subject to federal laws that protect parental rights and access when they start engaging in the practice of medicine."[7]

This proposed regulation presumes that involvement of parents in the diagnosis, testing and treatment of certain conditions would be detrimental to the health of the child and the public at large. Or perhaps the PA Department of Health finds communication with parents too much effort. The proposed regulation does not clarify its position on usurping parents' rights. If the Department determines parents uncooperative and can prove that there is a legitimate health concern for the child or others there are other legal avenues to pursue. Parents have a right to rear their children and oversee their medical treatment without the State interfering with that right in secret with their minor children.

I implore the IRCC members George Bedwick, John Mizner, John Soroko, Murray Ufberg and Dennis Watson to put the constitutional rights, dignity and safety of Pennsylvania citizens and their children over the dystopian desires of government employees who are not considering the frightening consequences of such regulations in the PA Department of Health.

Respectfully Submitted,

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7 https://www.paubox.com/blog/hhs-announces-new-actions-to-reinforce-parental-rights-in-pediatric-care