

National Vaccine Advisory Commission Meeting – February 14, 2020

NVIC Public Comment

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My name is Theresa Wrangham and I am the Executive Director for the National Vaccine Information Center. Our organization has long embraced informed consent to vaccination and worked with Congress to draft and pass the National Childhood Vaccine Injury Act of 1986. Since that time, vaccine informing required under federal law has been watered down. VAERs, created by the Act has not been strengthened and physician committee reports from the National Academies of Science that inform the VICP have continued to grade the science as inadequate and prevents causality statements to be made, with the result being that over 95% of injury compensation is for off table claims. This and creates a heavy burden for the vaccine injured to be compensated. The VICP continues to suffer from the public's lack of awareness of the program.

Referring to parents as anti-vaccine is counterproductive. Many parents only opt out of a one or a few vaccines, and are not saying abolish them, but to respect the right to informed consent – including the right to refuse vaccination. Today, the parents concerned about the car seat that recently failed to protect against side impacts are not being referred to as anti-car seat. Demeaning parents with vaccine concerns, many of which are legitimate, will not inspire trust or change minds.

What is often considered an incentive, like higher insurance premiums or taxes, could also be viewed as sanctions and punitive measures that discriminate against a minority that choose not to use one or all vaccines. Trust is also in limited supply for doctors and perhaps that is in part due to the many reports NVIC receives from families across the US who are being refused well-care for asking questions about vaccination or exercising their right to refuse under the informed consent ethic.

The NVAC could assist in building trust by not encouraging state mandates that do not incorporate flexible exemptions upholding informed consent rights. NVAC could also recommend independent research that would close vaccine safety research deficits noted by the Institute of Medicine reports and to be more inclusive of the hesitant and vaccine injured community in their recommendation processes.

Public health would also be able to build trust by talking about vaccine failures when they occur, rather than only vaccine success and abuse of rule-making to force vaccination or being tracked in registries – registries should be opt-in as there are privacy concerns held by many parents. Clear communications about disease in context to the U.S. vs Africa – for example measles deaths. As the gentleman from Oxford noted, there are lots of scary stories – and public health also promulgates scary stories to get people to vaccinate – this is also dishonest. For example, systematic reviews by the Cochrane Collaboration have noted little merit to influenza vaccines as a public health measure or for healthcare workers, but that they may be an option at an individual level. They also note that much of the evidence base is funded by industry and of lower quality than independent research that is not being published. Yet the public is told this vaccine should be used by all.

Similarly, as noted today, HPV as infecting many people and it resolves within two years in over 90% of people with no complication, and according to the CDC there is excellent screening for cervical cancers and they are highly treatable...yet the recommendation is for everyone to use this vaccine. NVIC supports resolving vaccine access issues so that those seeking to vaccinate can, however, where there is risk, there must be choice. Freedom of speech includes being able to dissent.

Vaccine injuries and deaths are also real, just as are deaths and injuries from disease. Both sets of stories require empathy. Where were the vaccine injury stories today, and the honor, compassion and empathy for their stories? Where was that dialogue and inclusion? Why are those who are injured by vaccines told they are less than or that they are imagining their story - \$4 billion worth of stories that are under reflected by the VICP because the public remains largely unaware of this program. There should be no bullying or judgement of stories from either side of this spectrum of injury from vaccines or diseases. However, why has the schedule expanded faster than our understanding of the mechanisms of vaccine injury, as demonstrated by IOM reports? Are safety deficits going to be addressed and informed consent upheld, or will we be a society that sets this important ethic aside in favor of coercion and compliance?

We appreciate the opportunity to provide comment today on behalf of our supporters who range from being fully vaccinated to unvaccinated, the vaccine injured to the safety concerned and who uphold the primacy of the informed consent ethic for any medical treatment or procedure, inclusive of vaccination.