

NVIC Public Comment
Advisory Commission on Childhood Vaccines – September 3, 2015
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My name is Theresa Wrangham and I am the Executive Director for the National Vaccine Information Center, the mission of which is to prevent vaccine injury and death through public education and to defend the informed consent ethic in vaccine policies and laws. I appreciate the opportunity to comment today.

I would like to express both my personal and professional thanks to members of the Commission who today humanized what it means to be a victim of vaccine injury and the very real challenges facing those who are injured and/or who die as a result of vaccine adverse events. Your stories are stories we have heard since our inception in 1982. NVIC's co-founders worked with Congress to pass the law that created the VICP. Part of the intent of this law was to acknowledge that vaccine injuries were real and deserving of compensation, the need for ongoing vaccine safety research to prevent future injuries and deaths and to provide injury compensation in a no-fault environment. The law also provided that those receiving vaccines also receive information on both the risks and benefits of vaccines and information on the disease the vaccine was designed to prevent.

The law has changed over the years and its interpretation in general, and the VICP program more specifically, has become increasingly adversarial for petitioners. Today, vaccine injury victims who vaccinated in good faith and those who delay or decline one or more vaccines are treated as traitors to public health for even suggesting that a vaccine is responsible for a health condition. They are demonized in the media and minimized by government and public health officials.

NVIC receives consistent complaints from parents, like the one you just heard, and adults who are literally crying on the phone as they tell us their vaccine injury stories. Stories of horrible financial and emotional burdens associated with even finding a doctor who will treat their concerns with respect and consider the possibility that a vaccine is responsible for the health condition of concern; stories of parent fears that child protective services will be called if they do not continue to vaccinate their already injured child; shock that through no fault of their own that they found out about the VICP too late and are not eligible for compensation; anger because parents cannot get a medical exemption for their injured child, which has been increasingly narrowed in definition; parent fears that their child will be excluded from daycare and school. That fear is now a reality in California. We hear stories of anger because non-medical exemptions are under aggressive attack and human, parental and informed consent rights are being eroded. These families have become cruelly aware that vaccines, like all pharmaceutical products, carry with them the risk for injury and death – many were never told that vaccines are not risk free.

However, vaccines are not exempt from the informed consent and precautionary principles. This attack on non-medical exemptions is being encouraged by the federal government and the National Vaccine Advisory Committee and tramples upon basic human and informed consent rights to voluntarily accept, delay or decline one or more vaccines without sanction. This trampling of rights and the wholesale promotion of mass vaccination, while not giving equal effort to prevent vaccine injuries and deaths due to fears of lower uptake creates the very challenges Commissioners and NVIC voice today. It is the vaccine injured who are paying the price in this politically charged, high-stakes game of compliance with a one-size-fits-all vaccine schedule for the greater good at the expense of human and informed consent rights.

Vaccine risks are not being equally shared and the loss of non-medical exemptions will in essence make the vaccine injured acceptable collateral damage. This sacrifice of human life and the demonization of those injured and who vaccinated in good faith is morally and ethically bankrupt of the values that created our country. Because people do not all respond to vaccines the same way, and that there will be those who are injured and who will die as a result of vaccination, we encourage the ACCV to issue recommendations that support non-medical exemptions and the informed consent and precautionary principles and the human right of every human being to make voluntary medical risk-taking decisions without sanction and free from governmental coercion and interference.

We note that characterizing the occurrence of vaccine injury as rare is 1) no comfort to those for whom the risk of injury is 100% and 2) is likely to be inaccurate given significant gaps in vaccine safety research noted by the Institute of Medicine and the fact that vaccine injuries are acknowledged as grossly underreported. Not only are parents continually challenged to find doctors to investigate vaccine injury and to find appropriate medical treatment for their loved ones, they are challenged in finding VAERS and the VICP, all against the backdrop of a government that lacks the political will to fund quality research to close vaccine safety research gaps. As a result, if the injured can find the VICP within with specified statutory timeframe, they are likely have trouble finding medical experts for an off-the table claim, which represent the majority of claims today, and their claim will be dismissed.

These challenges put into question the need for a statute of limitations. Would any amount of time correct this vicious cycle? Shouldn't vaccine injury cases be judged on the merits of the case? Why are petitioners suffering the consequences of inadequate science and gaps in science that may prevent them from obtaining compensation?

The minimizing and lack of interest in vaccine injury by government and public health officials is likely to result in many families being left uncompensated, and becoming victims to be bullied and demonized publicly as bad citizens.

NVIC supports increasing the statute of limitations, however, it can't be at the expense of pursuing civil action. The intent of the law was twofold – provide a mechanism for compensation, while preserving the ability of petitioners to pursue civil suits. Though the Supreme Court's flawed ruling in *Bruesewitz v. Wyeth* has essentially closed the door on liability lawsuits, it does not follow that the ACCV should trade the ethical intent and spirit of the law to achieve an extension of the statute of limitations.

Outreach activities to inform healthcare providers of the VICP, while well intended, miss the mark. Efforts are needed to raise awareness in the general populace, as noted by the Banyan report commissioned by the ACCV. Where the VIS is concerned, we receive many complaints that they are not being given out, or that they are given out after vaccination and/or that there was no discussion of the VIS making awareness of the VICP and VAERS challenging.

Soon there will be no lack of flu vaccine commercials and ad campaigns to get a flu shot. Where are those same campaigns for informing on vaccine risks, vaccine safety deficits, vaccine reaction reporting, and vaccine injury compensation? Citizens have a right to know about these programs and the known and unknown risks posed by vaccines. Outreach efforts should include commercials and ad campaigns in mainstream publications about vaccine injury and these government programs and actually doing some Direct to Consumer marketing, similar to what vaccine-makers use for marketing vaccines. These outreach efforts should include stories that would humanize vaccine injury and create a less hostile environment that would empower parents and healthcare professionals explore the possibility vaccine injury and pursue timely investigation of those injuries. We encourage the ACCV to recommend aggressive outreach efforts be directed to the general population.

We would also encourage the ACCV to actively pursue a line of reasoning from the Secretary on why previous recommendations are not pursued. Increasing the statute of limitations has been previously recommended by the ACCV numerous times and outside receiving an acknowledgement of receipt of the ACCV's recommendations, there has been no response from the Secretary posted on the website that informs on why this recommendation, like so many others, is not pursued by HHS.

We again support the need for the ACCV to meet face-to-face and ask that face-to-face meetings be posted well in advance of meetings to enable the public to physically attend meetings.

In closing, we appreciate the opportunity to provide public comment and welcome the new commissioners.