

NVIC Public Comment
Advisory Commission on Childhood Vaccines – June 4, 2015
Theresa Wrangham, NVIC Executive Director

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 vaccination practices. I appreciate the opportunity to comment today.

My comments today will again focus on the need for a higher degree of transparency in reporting the activities of the federal Vaccine Injury Compensation Program (VICP). To follow up on my initial comment this morning regarding the lack of current information on the Data & Statistics report I would clarify by saying that this lack of transparency was noted by investigative journalist Sharyl Attkisson in her article of May 31st titled *Government Wipes Recent Vaccine Injury Data from Website*.

NVIC has reviewed the information on the VICP website and it is clear that the information on the adjudications report has been changed since the February 2015 report which contained adjudicated information through 2015. The current adjudication information has been truncated to 2013, thus this information is not current. Not only is it not current, an additional note has been made to Ms. Attkisson's article that HRSA responded to her with the missing information but has made an internal decision to update the chart only when "all relevant data was available". The question today would be what changed between February's report and the current report that is no longer relevant and allows for a step backward in the truncating of data; data that is under law to be made available to the public?

This lack of transparency with the public is not new. NVIC is on the record as expressing concerns relating to the transparency of the data and statistics report as early as 2012. We requested that information be expanded in the to include what the alleged injuries are for each vaccine by vaccine be included on the website broken down by year and in total as well as the number of cases dismissed due to exceeding the statute of limitations to better inform the public on awards and activities of the VICP. Given the deficits in vaccine safety research noted by the Institute of Medicine for the most commonly reported vaccine adverse events, and provisions in the 1986 law, the public has a right to this information. Unfortunately in September of 2014 DICEP went on record during that ACCV meeting that they felt they have done enough to inform the public.

We again note that new information has been provided to the Data and Statistics report such as doses of vaccine distributed against the number of petitions for compensation. This information tells an incomplete story and minimizes vaccine injury and is not required to be included. This report does not include the number of vaccine reactions reported to VAERS for the same timeframe, or information regarding the fact that the majority of vaccine reactions go unreported. In addition, there is no mention of the likelihood that the lack of public awareness regarding the VICP impacts the number of claims submitted for compensation, though it was only a few years ago that the ACCV authorized an outreach project to raise public awareness.

The absence of this contextual information appears to undercut the seriousness of vaccine injury and death, which is the relevant focus of the VICP. While additions of information have been made to this report, there are also cutoffs in timeframes in the report contributes to the incompleteness of the report. Information the public has a right to by law is not provided, though it is relevant. Instead, by refusing to enhance the report and provide context, taxpayers are expected to traverse more than one website to get the raw information and piece it together...that is if they are aware of the VICP and have the luxury of time to do so. That is not the taxpayers' job; it is the job that taxpayers pay federal agencies involved in the VICP to perform. The current report is a travesty and affront to the individuals harmed by vaccines due to the selectiveness of information that is provided and deemed as "relevant". We encourage the ACCV to consider recommendations for reporting to reflect the information that the law states the public has a right to have and provide a higher degree of transparency in reporting of vaccine injuries.

We again support the need for the ACCV to meet face to face. All the other FACA reporting vaccine related committees meet face to face for all of their meetings; not half of their meetings. We support that all the ACCV meetings are as important as those of the ACIP and NVAC and should be face to face.

We appreciate the thoughtfulness of the SIRVA report. A universal certification program would lessen the potential for SIRVA injuries, which were noted to be on the rise. While this type of certification may not be in place for other similar medical procedures, there is a difference in terms of need. Currently there is no liability attached to vaccine providers when these errors occur and many are unaware of the VICP and may have to deal with an injury with no financial relief. We would encourage the ACCV to take into account the uniqueness of this circumstance and that there may be a need to place a higher priority on training vaccine providers given that vaccine injuries are treated differently from other injuries that result from medical procedures.

Relating to the VIS discussion, we believe it is important that distinctions on vaccine recommendations be made when using terms like “clearly necessary” when the vaccine has not been licensed for use in special populations like pregnant women. Without this language distinction, it is unclear to the vaccine recipient that the product they are considering may not have been licensed for use in their current circumstances, and is being recommended outside of how it was licensed and may confer additional risk to the consumer.

In closing, we appreciate the opportunity to provide public comment and thank commissioners that are leaving the commission for their efforts.