

Advisory Commission on Childhood Vaccines
NVIC Public Comment – Theresa Wrangham, Executive Director
December 5, 2013

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.

NVIC has commented in the past regarding the lack of awareness by the public of the ACCV and their activities, the VICP and awards made by the VICP. This lack of awareness contributes to the number of dismissals seen in the VICP for exceeding the statute of limitations, which is an ongoing area of concern expressed by the commission. While NVIC supports the Commission's recommendation to extend the statute of limitations, we cannot support extending it at the cost of the VICP becoming an exclusive remedy. We would encourage the commission to consider additional strategies to raise awareness to lower these types of dismissals such as media advisories and press releases on the activities and meetings of the Commission similar to what is done for the ACIP.

We note that the activities and meetings of the ACIP are recognized and followed by the public. This may be in part due to media advisories and press releases issued by federal agencies. We have found no similar media advisories and releases relating to the ACCV or VICP. Activities such as the expansion of the Vaccine Injury Table, ongoing discussion regarding research deficits acknowledged by the IOM and the need to close them, as well as the Commission's other recommendations to the Secretary are deserving of public awareness and attention. Media advisories and press releases similar to those issued on ACIP upcoming meetings and activities could assist in raising public awareness relating to ACCV and VICP. It would also humanize the vaccine injured and serve to remind all that vaccines are not without risk and that when vaccine injury or deaths occur is it just as tragic as when an individual is harmed or dies from an infectious disease that we vaccinate against.

With regard to the suggestion that the vaccine injury trust fund be used for closing acknowledged gaps in vaccine safety research, we respectfully remind the commission that it is not charged with solving funding issues associated with these research gaps. The trust was designed specifically to compensate the vaccine injured. We encourage the commission to recommend high quality research be funded outside the trust fund and conducted free from conflicts of interest. Additionally, we would request that such a recommendation include statements on the urgent need for such research due to the continued expansion of the recommended schedule. Funding of vaccine safety research should enjoy the same funding priority that is placed by our government on the development, licensure, promotion and distribution of vaccines. Funding of vaccine safety research should not come from funds that have been historically intended and earmarked for those who are injured or who die as a result of vaccine adverse events.

We take this opportunity to again state our support for face-to-face meetings of the ACCV for all regular meetings. The work of the ACCV is no less important than that of the NVAC and ACIP who continue to meet face to face for all their regularly scheduled meetings. To limit the meetings of the ACCV minimizes their role and those they represent...the vaccine injured. Similarly, the Chief Special Master should not have to choose between travel and personnel in order to process and award compensation to the vaccine injured and families of those who have died as a result of a vaccine adverse event. Care for the vaccine injured is often expensive and families need relief as soon as possible. This should be a funding priority to assure that the process of compensation is expedient and favorable to families and the injured. We would encourage discussion regarding finding a way to obtain an appropriation of funds well in advance of their need to solve these issues until such time as the illogical nature of how funding is accomplished in relation to the trust is resolved.

Where collaboration with the NVAC and ACIP has been discussed and receiving their meeting materials, we note that the ACCV is more timely in providing materials to the public than their NVAC and ACIP counterparts. Comments regarding the meeting books for these committees being large are correct, however, these books often contain materials that are not a part of meeting presentations made and the meeting book is not posted to their websites and have to be requested. NVIC just received this year's meeting books from the NVAC after waiting many months; they are not electronic, but hand copied, unlike the ACCV. We appreciate that the ACCV posts their meeting book electronically and are hopeful that other committees will follow that example, per Federal Advisory Committee Act requirements.

Our final comment would be a request that all correspondence from the Secretary in response to the Commission's past and present recommendations be posted to the website and that all ACCV recommendations to date be compiled into a spreadsheet or table type of format which notes how many times a recommendation has been repeated, and/or if it has been acted on and when. We would also like to request a timeline for parent organization participation on VIS revisions.

Thank you for the opportunity to provide public comment.