

NVIC Public Comment
ACCV – March 7, 2013
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 reduce 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 is entering its fourth decade of public service and we remain the largest and oldest consumer led non-profit organization representing the vaccine injured, those who have died as a result of vaccine adverse events, those with vaccine safety concerns and those concerned with protecting informed consent in vaccination.

I address my comments today on transparency and public participation within workgroups established under the ACCV. I appreciate all comments made by presenters and committee members on thoughtful transparency. I would also offer as background to my comments that NVIC led efforts to assure that those injured by vaccines receive compensation and we actively worked with Congress to pass the law that created the VICP. NVIC's founders, the parents of the vaccine-injured children, understood that vaccine injuries were real and required attention and compensation and brought public attention to the matter.

Additionally, NVIC members and staff have served on the NVAC, ACCV and FDA VRBPAC as committee members and voting members of workgroups. NVIC has also been invited to numerous public engagements sponsored by federal agencies. In short, we have a long-standing reputation for our expertise in representing the continued increase in vaccine safety concerns, injuries and deaths, as well as an understanding of the depth of vaccine safety research deficits.

With the most recent IOM reports finding little in the way of research to comprehensively assess the safety of the ACIP recommended schedule and whether or not the most commonly reported vaccine adverse events are indeed caused by vaccines, public safety concerns are likely to continue to rise.

NVIC supports public involvement in transparency efforts and information dissemination efforts, as it is the public asking for answers. NVIC routinely receives reports from parents and adults considering vaccination regarding injuries and compensation. Much of the public is unaware of the ACCV or the VICP and their work. Those that are, have questions regarding the information that is available.

Today committee members questioned whether the public can be voting members of ACCV workgroups. I believe the answer is yes, as NVIC has participated in workgroups within NVAC and was a voting member. We also appreciate Mr. Krause's mention of parent organization involvement in vaccine information and we are unaware of an invitation to participate in updating of the VISs and I am happy to participate and my email is tkw.nvic@gmail.com.

Concerns regarding how information that Mr. Krause gave as examples of transparency during today's meeting could be misinterpreted by the public could be part of the charge to any workgroup formed by the ACCV. It has been my experience that many agencies that strive to be more transparent with the public have been able to articulate limitations on the data they provide to the public. There already exists on the Data and Statistics webpage statements of limitations on the autism awards made out of the VICP. I would think any workgroup formed would also consider the need for similar statements that may need to be considered while examining how information provided to the public could be improved to provide a higher degree of transparency. In short, NVIC supports transparency and the public's right to information regarding vaccine risks, as well as vaccine injuries and deaths settled by the fund.

As the ACCV makes decisions regarding vaccine information and its dissemination, the public's participation would seem to be necessary outside of representation already present within the committee. From our perspective, it simply makes sense to involve organizations with standing and who represent concerns that are relevant to this committee's charge into the process.

While NVIC is encouraged by discussions regarding increasing the statute of limitations for claims to the VICP, we would caution that the public remains largely unaware of the VICP and recommendations to the Secretary in this regard should include that background information as well.

In closing, I would also request that notes on the Process Workgroup and Maternal Immunization Workgroup forwarded to the committee this afternoon, also be posted to the ACCV's website.

Thank you for the opportunity to provide comment today.