NVIC Public Written Comment Advisory Commission on Childhood Vaccines – Mar. 8, 2019 Theresa Wrangham, NVIC Executive Director

Good afternoon. My name is Theresa Wrangham and I am the Executive Director for the National Vaccine Information Center. Our mission is to prevent vaccine injury and death through public education and to defend the informed consent ethic in U.S. vaccine policies and laws.

Since the last meeting of the ACCV Congress has held hearings on exemptions and measles. For both of those hearings NVIC contacted these committees to request an understanding of the premise of those meetings and opportunities for NVIC as an organization of standing relating to the federal law and in the representation of vaccine safety and informed consent concerns to participate.

Sadly, we were told we could not submit questions or statements to the committee, and that if submitted they would not be a part of the record. Additionally, we were not allowed to participate in either hearing, though NVIC has historically for almost four decades represented consumer concerns in this regard, as we did when we worked with Congress to pass the National Childhood Vaccine Injury Act of 1986.

As a result, these hearings were very one-sided in their representation of concerns relating to current vaccine policy and law, with no representation relating to existing, significant vaccine safety research deficits and little information on the VICP and vaccine injuries. As a result, we will go on record here, where vaccine injuries are to some extent represented.

As this Commission well knows, those at risk for vaccine injury and death are rarely identified in advance of the administration of a vaccine. In addition, due to vaccine safety research deficits, the characterization of the mechanisms of injury are not well understood or recognized. As demonstrated by VICP awards, vaccine injuries can be life-long and extremely debilitating and none of that information was presented at these hearings and we hope that this Commission will explore this lack of representation.

It is critical that there be balanced information and representation in such hearings, as there are risks to vaccination which were given short shrift due to the absence of this balance. Vaccine injuries and deaths are real and the significant, acknowledged vaccine safety research deficits that prevent the identification of those at most risk for vaccine injury and death should have been a part of the conversation, as well as the human right to informed consent. This lack of balance serves only to demonize, discriminate and treat those injured by vaccines as acceptable collateral damage in the forwarding of an unrealistic one-size-fits-all policy, regardless of who is harmed.

Such policy and law would discriminate against a minority that is often invisible until harmed and prevent the exercise of the basic human right of autonomy in medical risk-taking procedures. Societally it disadvantages this minority and creates educational and possible employment barriers, as already seen in California, and it deprives individuals of the exercise of religion and conscience, while unnecessarily pitting families against each other.

It is our hope that this Commission, like NVIC, has many questions about this lack of representation and its impact to trust in government and ongoing vaccine hesitancy. To be critical of vaccine law and policy doesn't necessarily equate to being anti-vaccine and this criticism is part of a healthy government and the discharge constitutional rights.

NVIC in closing appreciates the efforts of the process working group in creating the VICP questionnaire and hopes that a retroactive look at such a questionnaire to award recipients is also considered as recommended in previous federally commissioned reports to examine award adequacy. Such an effort would better inform awards going forward.

Thank you for the opportunity to provide public comment today.