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National Vaccine Information Center
Advocacy Panel Statement
Vaccine Safety Working Group Stakeholder Meeting
National Vaccine Advisory Committee
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Washington, D.C.

Thank you for the opportunity to make a short statement today on behalf of the non-profit National Vaccine Information Center. We have submitted a longer referenced statement outlining our position on the Vaccine Safety Working Group's comprehensive draft recommendations, which clearly represents many hours of reflection and deliberation by members of the Committee.

NVIC serves as an information resource and voice for hundreds of thousands of educated health care consumers and health professionals concerned about improving vaccine safety and protecting informed consent rights. Having participated with parents of DPT vaccine injured children in the creation of historic vaccine safety provisions included in the National Childhood Vaccine Injury Act of 1986, NVIC has the longest public record of advocating for the institution of safety reforms in the vaccination system.

During the past quarter century, NVIC has provided well-informed consumer representatives to serve on committees at the Institute of Medicine and Department of Health and Human Services. During the past decade, we have also been committed to public engagement and participatory democracy initiatives facilitated by the Keystone Center that have explored new ways for the public and government to address vaccine safety science and policy issues through a shared decision-making process.

Public trust in vaccine safety is paramount to public trust in public health policies. The people's support of national vaccine policies begins with their confidence in the integrity of the infrastructure within which vaccine science, regulation, recommendations and safety oversight is conducted. Despite the good intentions of those staffing health agencies within the Department of Health and Human Services, whose careers are devoted to protecting the public health, their jobs are made very difficult, if not impossible, when they are charged with fulfilling competing roles and responsibilities.

It has long been the position of the National Vaccine Information Center that existing federal health agencies congressionally funded and charged with the responsibility for:

- (1) conducting scientific research into the development of new vaccines; and

- (2) creating and implementing federal licensing and testing regulations for vaccine manufacturers; and
- (3) making national recommendations for vaccine administration and use;
- (4) promoting universal and mandatory use of government recommended vaccines, and
- (5) playing a major role in determining who does and does not receive federal vaccine injury compensation,

should not also be simultaneously charged with responsibility for vaccine safety oversight.

NVIC is not alone in taking this position and there are precedents in other areas of product safety oversight and assurance that confirm the validity of treating product or consumer safety as a separate function. These include the National Transportation Safety Board and Consumer Products Safety Commission, which are independent Executive Branch entities outside of the Cabinet Department structure and obtain funding from Congress and are managed through the Executive Office of the President.

This independent entity would provide oversight on, but not necessarily operation of, the federal Vaccine Adverse Event Reporting System (VAERS). It would take the lead in setting priorities for and oversight of vaccine safety research into the biological mechanisms and high risk factors for vaccine injury and death for the purpose of minimizing vaccine risks for individuals and populations.

Today, the federal government recommends 69 doses of 16 vaccines from day of birth through age 18 and there are laws in every state that mandate the use of a majority of these vaccines by children. There are hundreds of new vaccines being developed, many of which likely will be recommended by government for universal use by children and adults in the future. Two out of three vaccine injury claimants are turned down for federal vaccine injury compensation and, on February 22, 2011, the U.S. Supreme Court shielded vaccine manufacturers from civil liability even if they could have made a safer vaccine.

Therefore, with regard to Recommendation 8 for Assurance and Accountability, NVIC does not support a further enhanced role for the National Vaccine Advisory Committee, the Immunization Safety Task Force (ISTF), the National Vaccine Program Office (NVPO) or other existing DHHS entities in lieu of Option 3 under Recommendation 8: the creation of an independent entity charged solely with the responsibility for vaccine safety oversight that reports directly to the President and Congress.

The issue of independent vaccine safety oversight is so key to public trust in the transparency, accountability and integrity of the vaccination system that, without it, the other seven recommendations are effectively neutralized.

As some of you, who have worked with me since the 1980's know, I have always been as honest with you in these public engagement forums as I am in other public forums. I have been committed to the participatory democracy concept because I believe that citizens should be actively and constructively engaged with government and government should be actively and constructively engaged with citizens. When we honestly, and with good will, inform each other, it can lead to wise public policy that deserves the confidence and support of the people.

However, after many years of actively engaging with government, in 2011 I am deeply concerned about the effort by some in the public health, medical and pharmaceutical communities to marginalize and persecute a growing minority of citizens with vaccine damaged children and those defending the ethical principle of informed consent to medical risk taking. During the past decade, I have witnessed the public discourse on the subject of vaccine safety and informed consent become so poisonous that it is resulting in the persecution of families, whose only crime is trying to protect their children from further health deterioration after vaccination.

It is becoming a civil and human rights issue that threatens to jeopardize public trust in the integrity of government health policy in general. Where there is fear, there can be no trust.

When a child is injured or dies from an infectious disease, we rightly mourn their loss. Yet, when a child is injured or dies after vaccination, too often their injury or death is viewed as collateral damage in our nation's "War on Disease." Worse, it can be quickly dismissed by vaccine administrators as a "coincidence" and never counted at all. If grieving parents speak up and ask for acknowledgement, they are belittled. If they stand up and try to protect their other children from harm by exercising a conscientious belief or religious exemption to vaccination, they are threatened, denied medical care and called selfish or child abusers.

The crisis of trust in vaccine safety today has everything to do with basic science knowledge gaps about vaccine side effects and implementation of inflexible one-size-fits-all vaccine policies that do not respect biodiversity and place an unequal risk of harm on some. The strident calls by doctors inside and outside of government for an elimination of all non-medical vaccine exemptions, raises the specter of mandatory vaccination policies that destroy the informed consent ethic and result in a de facto selection of the genetically vulnerable for sacrifice.

If there has been a failure to communicate, it can begin to be repaired with a recommitment to the informed consent ethic and an affirmation that every human life is important, including the lives of those for whom the risks of vaccination are 100 percent.

Thank you for holding this open public meeting and for soliciting public comment on a health care reform issue that touches the lives of all Americans.

