

ASSOCIATES OF VIETNAM VETERANS OF AMERICA

AVVA Presentation Before the IOM Committee to
Review the Health Effects in Veterans of Exposure
to Herbicides

On Paternally Mediate Birth Defects

January 16, 2013



Together Always

I am Elayne Mackey, National Health Committee co-chair for the Associates of Vietnam Veterans of America (AVVA), and I want to thank you for the opportunity to represent our 8,000 members today.

In the IOM's Update 2010, Veterans and Agent Orange Update, the Committee has concluded that it is plausible that exposure to the herbicides sprayed in Vietnam could cause paternally mediated results in offspring. Pursuant to the Committee's recommendation that more research be conducted, we recommend examining the data found in the National Birth Defect Registry.

The National Birth Defect Registry maintained by National Birth Defect, Inc., maintains an existing registry that should be examined by the Committee for statistical relevance regarding the incidence of birth defects in children of Vietnam veterans. The National Birth Defect Registry was established in 1990 with the collaboration of an advisory board of seven prominent scientists in addition to input from the University of South Carolina and the New Jersey Agent Orange Commission. Since that time, the registry has collected data on birth defects and disabilities in the children of veterans. The registry questionnaire has special sections with identifiers for the veteran's military service, duty stations, deployments, and possible exposure to toxic substances to facilitate research into the particular health effects of specific exposures. This registry will continue to collect data on birth defects (functional and structural) in children of veterans who have been exposed to toxins during military service.

Further, the committee recommends the development of epidemiological protocols to address the logistical challenges in the adult children and grandchildren of Vietnam veterans as a result of paternal exposure.

AVVA recommends the creation of Centers of Excellence to provide for research, treatment, and social services for the offspring of veterans of all eras who have been exposed to toxins while in service to our country. The Centers would provide the following:

a) A registry of birth anomalies, modeled after the National Birth Defect Registry, to collect and analyze data on health conditions that affect these children. Such a registry shall have identifiers for the veteran's military service, duty stations, deployments, and possible exposures to toxic substances to facilitate research into the particular health effects and exposures.

b) The Centers shall track and report annually to Congress the extent and nature of care provided, on current and completed research, unmet needs, as well as an update on the Centers' Birth Defects Registry.

c) The Centers shall function as an incubator for scientific research on the possible trans-generational effects of toxic exposures and shall be the fulcrum for investigation into the genetic and epigenetic impacts from paternal and maternal toxic exposures.

d) To ensure the confidence of veterans, all research conducted at the Centers shall not be open to individuals or organizations associated with chemical manufacturers or others with inherent conflicts of interest. Additionally, data from research shall be made available for additional study only with the informed consent of participating families, while safeguarding the personal information of the veterans and their children and grandchildren.

e) The Centers Collect data on the most frequently reported conditions in the children, grandchildren, and great-grandchildren of veterans. Collect data with sufficient rigor and detail so that it will be considered "scientific" and not dismissed as "merely anecdotal" or "just self-reporting."

f) Specialists shall be identified in areas most relevant to these conditions; i.e. immunologists, geneticists, cardiologists, psychologists, internal medicine, etc. Find these specialists at centers with experience in environmental illness and invite them to participate in the new center.

g) Services will be provided in centralized location(s) in order to allow easier access and provide greater participation in the centers.

h) The Centers will be have access to state-of-the-art diagnostic equipment.

i) The offspring's primary care physician will be provided with a report with diagnosis and treatment recommendations.

j) A method for the Care Centers to receive periodic reports from the offspring's primary home physician will be instituted.

j) Conferences between the Centers and the offspring's primary care physician will be facilitated.

k) Recurring follow-up visits to the Center will be arranged as often as needed to stabilize the offspring's condition and to facilitate research.

l) Annual reevaluation of each offspring enrolled at the Centers will be conducted.

m) The data collected will be made available for researchers within and outside of the VA to facilitate meaningful scientific search.

Why do we ask for this? In 2009, our organization convened the first of a series of Agent Orange Town Hall Meeting on the transgenerational effects of Agent Orange. Over 200 Vietnam veterans and their families attended. Since then, over 30 Town Hall meetings have been held across the country. Over and over again, we have heard the pleas of our veterans and their families. We have heard heart-wrenching stories of children who have suffered. We have listened to grown men cry, as they confess they have always felt in their hearts that their exposure during their service is the reason for their children's sometimes fatal health issues. We have heard mother's tell of how they have, over the

years, suspected that their child's ill health is due to their spouse's exposure while in service.

Our families are suffering. When our young men and women serve in defense of our Constitution, they willingly risked life and limb, but they did not expect their children and grandchildren to suffer as well.

From the beginning, we have suspected that there is a connection between our veterans' service and the health problems of our children and grandchildren. Given the recent research on epigenetics and paternally mediated birth defects, we are hopeful that there is ample science to show a direct connection between the service of the veteran and the health of their offspring and future generations.

Multiple sclerosis, spinal deformities, hip dysplasia, learning disabilities, heart problems, unspecific multiple tumors, cancers, bones in feet not complete, ocular cancers, ear problems, cleft lip, infertility, undeveloped sexual organs, lupus, lymphomas, Hodgkin's disease, juvenile diabetes, and pituitary tumors--these are just a few of the health challenges facing our children.

In closing, I thank you for the courtesy you have shown AVVA, and I ask that the same courtesy be accorded to our children who through, no fault of their own, unnecessarily suffer the wounds of war.