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**Agent Orange/Dioxin
And
Other Toxic Substances Committee**

Birth Defects

Position Paper

1/14/2010

**Agent Orange/Dioxin &
Other Toxic Substances Committee
(AO/DOTS)
1/14/2010**

FOR DISCUSSION

Draft Proposed Position Paper: Birth Defects in Children and Future Generations of Veterans.

Children are our future. We have all heard that common saying. What is the future of the children of Vietnam veterans and other veterans with toxic, service-related exposures? There is a growing realization that both maternal and paternal toxic exposures play a role in the birth defects of the children and future generations of the exposed individuals. Research in the field of epigenetics also points toward toxic exposures turning on or off genes that, when passed on to the child, could lead to the onset of diseases later in life.

We now know that when we send service members in harm's way, battlefields toxins also place the future offspring of those service members in harm's way.

Background:

The VA recognizes only one birth defect, spina bifida, in the children of both male and female Vietnam veterans. The information below was taken from the VA's web site.

- “The National Academy of Sciences (NAS) concluded in its 1996 update to its report on *Veterans and Agent Orange – Health Effects of Herbicides Used in Vietnam* that there is limited/suggestive evidence of an association between exposure to herbicides used in Vietnam and spina bifida in children of Vietnam veterans.” .
- “In 2000, Dr. Han Kang and the VA's Environmental Epidemiology Service of the Veterans Health Administration published a study that found the risk of birth defects was significantly associated with the mother's military service in Vietnam.”
- “As a result of these findings, the VA now funds assistance programs for spina bifida in the children of male or female Vietnam veterans and for all birth defects without other known causes in the children of female veterans.”

Children born to female Vietnam veterans who meet the following requirements may be eligible for compensation, vocational training, rehabilitation, and health care benefits:

- “Are biological children of a woman Vietnam veteran who served in Vietnam during the period beginning February 28, 1961, and ending on May 7, 1975.”

- “Were conceived after the date on which the veteran first entered the Republic of Vietnam.”
- “Have a covered birth defect, which resulted in a permanent physical or mental disability.”

The VA web site clearly states that covered birth defects do not include conditions due to family disorders, birth-related injuries, or fetal or neonatal infirmities with well-established causes. The VA points out that inherited birth defects, birth-related injuries, chromosomal disorders, congenital malignant tumors, fetal or neonatal diseases, developmental disorders, and birth defects that are not permanent do not qualify. Appendix A gives a list of covered and non-covered birth defects.

The current IOM Veterans Agent Orange (VAO) Review 2008 provides a starting point for looking at the issue of birth defects and the future generational impact of herbicide exposures in Vietnam Veterans. The review makes some important recommendations.

“The assessment of any link between exposure of Vietnam veterans to the chemicals of interest and birth defects or developmental disease in their offspring presents distinct challenges. The Department of Veterans Affairs (VA) should review all the possible cognitive and developmental effects in offspring of veterans. Such a review should include the possibility of effects in grandchildren, which are of growing concern to veterans and their families. A recent review of the literature and meta-analysis by Ngo et al. (2006) noted a significant association for veterans, who served in Ranch Hand, pointing to the need to examine closely both the biologic plausibility of paternally mediated birth defects and existing epidemiologic evidence. In addition, reviews have focused on epidemiologic studies of data from birth-defect registries or parental reports of birth defects. Those studies often exclude alterations in function that could appear later in a child’s life, such as in neurologic function, endocrine function, or reproductive capacity. The findings of the Air Force Health Study (AFHS) on birth defects in veterans’ offspring have not yet been (and, if funding is not provided, may never be) formally and systematically integrated and analyzed in a longitudinal fashion.”

The 2008 VAO Review Committee makes it clear that the VA has failed to act on past recommendation that the committee included in its report.

“The committee notes that, despite the fact that its predecessors have made quite similar recommendations, there has been little or no action toward implementing several investigations that the committee regards as imperative. These projects need to be undertaken in order to address veterans’ concerns and to meet the scientific needs of future VAO update committees to resolve outstanding questions, particularly with regard to Parkinson’s disease, tonsil cancer, and melanoma. VA and DOD are in the unique position of being able to study the very population that is of concern. Focused study of Vietnam veterans themselves would be especially appropriate for extremely rare conditions like tonsil cancer, which anecdotally appears to be occurring at an unusual rate among Vietnam veterans and for which the study of surrogate populations (even with

a case-control design) might entirely exclude factors of importance for the military situation.”

The VAO Review also points us in a direction in looking for answers in paternally mediated birth defects.

“The paternal contribution to a pregnancy is limited to the contents of the sperm that fertilizes an egg. Any damage would be conveyed as DNA mutations or epigenetic effects (that is, heritable changes in genome function that occur without a change in primary DNA sequences). Dioxins have not been shown to alter DNA sequences (they do not produce mutations), so the potential effects in offspring are limited to epigenetic effects. Two possible mechanisms could theoretically produce affected children: if sperm stem cells are altered by exposure, they could continue to produce altered sperm; and mobilization of dioxin from storage in adipose tissue (for example, due to weight loss) could continue to damage a man’s developing sperm, and thus interfere with conception and concept uses. In any case, any exposure of the father that could affect his children must occur before their conception.”

It is clear that the current VAO Review position is that dioxins have not been shown to produce mutations. This does not mean that it doesn’t but that the current review of evidence does not show it. The review points out the potential effects in offspring of male veterans are limited to epigenetic effects.

Discussion:

It is clear that the health impact of exposures on our veterans’ children, grandchildren, and future generations is of the utmost importance to VVA and its members. As such, it must be given the highest priority by our committee.

It is also clear that both maternally mediated and paternally mediated birth defects are equally important to the committee. While there is a large body of work on the impact of maternally mediated birth defect, there are limited studies on birth defect mediated by the fathers.

The committee has concerns about the VA’s limitations on the coverage of birth defects. For example, developmental disabilities are not covered, yet, over and over, veterans express their concern about this issue in their children.

The collection of meaningful data on the birth defects in the children of veterans who were exposed to toxins while in service is important to the better understanding of the health issues in these children. The United States does not have a national, federally required birth defect registry. However, most states have a state-required birth defects registry. The U.S. Center for Disease Control and Prevention (CDC) works with the states and compiles data on birth defects.

Under CDC is the National Center on Birth Defects and Developmental Disabilities. Their web site provides a wealth of information on various organizations that they work with on birth control. (Appendix B provides information taken from the CDC web site.) Below is their contact information:

Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities
1600 Clifton Road
MS E-87
Atlanta, GA 30333
800-CDC-INFO
(800-232-4636)

Another organization that has actually collected data on birth defects in the children of veterans is:

Birth Defects Research for Children.
800 Celebration Ave, Suite 225
Celebration, FL 34747
Tel (407) 566-8304
www.birthdefects.org

In 1982, Betty and Mike Mekdeci founded the Association for Birth Defects in Children (now Birth Defects Research for Children). Below is information from their web site.

“Birth Defect Research for Children, Inc. (BDRC) is a 501(c)(3) non-profit organization that provides parents and expectant parents with information about birth defects and support services for their children. BDRC has a parent-matching program that links families who have children with similar birth defects. BDRC also sponsors the National Birth Defect Registry, a research project that studies associations between birth defects and exposures to radiation, medication, alcohol, smoking, chemicals, pesticides, lead, mercury, dioxin, and other environmental toxins.”

“BDRC operates from offices in Celebration, Florida, with a staff and community volunteers under the guidance of a Board of Directors and a Scientific Advisory Board. Each year, BDRC responds to thousands of birth defect information requests from all over the world. BDRC's on-line environmental health updates provide thousands of parents, professionals, and organizations with daily news on the latest birth defect research. BDRC's birth defect information is also available by phone: (407) 566-8304, 9-5 EST, Mon-Fri or mail by writing to BDRC, 800 Celebration Ave, Suite 225, Celebration FL 34747.”

Betty is currently an advisor to the Agent Orange/Dioxin and Other Toxic Substance Committee. More importantly, BDRC collects birth defect information on Vietnam and Gulf War veterans' children. This is the only organization our committee knows of that

is involved in collecting this data. (Appendix C contains printouts of the information collected). The BDRC web site also has a page dedicated to veterans' research which is located at <http://www.birthdefects.org/research/veterans.php>.

The website has links to valuable information of interest to both Vietnam and Gulf War veterans. Some of those on the web site for Vietnam Veterans are:

- [Agent Orange and Birth Defects](#). A comprehensive review of the latest research on Agent Orange and birth defects.
- [The National Vietnam Veterans Birth Defects/Learning Disabilities Project](#)
- [Agent Orange and Birth Defects Blog](#). A special page which features new research and comments from veterans' families about their children's birth defects and disabilities.

BDRC's National Birth Defect Registry was also cited in an article (page 443) on Environmental Factors in Birth Defects in the October issue of *Environmental Health Perspectives*, the journal of the National Institute of Environmental Health Sciences. <http://www.ehponline.org/members/2009/117-10/EHP117pa440PDF.PDF>

AO/DOTS Committee position:

There is a growing valid concern in veterans that their military service impacts the health of their children, grandchildren, and future generation of offspring. This issue is very personal and emotional. Given the lack of research, there are real concerns that the birth defects issue in the offspring of Vietnam veterans' children will still be debated forty years from now. We cannot let this happen. In forty years, none of us will be around to fight for our children, our grand children, and our great-grand children. This is an important "NOW" issue.

The position and recommendation of the AO/DOTS Committee are:

- That VVA make every possible effort to get birth defects included as part of the recently VA announced longitudinal study on Vietnam veterans.
- That VVA make every possible effort to get VA to fund a study to formally and systematically integrate and analyze the Air Force Health Study on birth defects in veterans' offspring, as recommended in the 2008 IOM/VAO Review.
- That the VVA take action to facilitate the passage of legislation that would create centers to provide for research, treatment (funded by ChampVA), and social services for offspring of Veterans of all eras who were exposed to toxins in service.
 - These Veterans' Offspring Centers of Care and their programs should include provisions to:

- 1) 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." Collect longitudinal data and think intergenerationally.
 - 2) Identify specialists 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.
 - 3) Provide the needed services in centralized location(s) in order to allow easier access and provide greater participation in the centers
 - 4) Provide state-of-the-art diagnostic equipment.
 - 5) Provide free travel vouchers for parents or guardians and the offspring to come to the center.
 - 6) Provide room, food, and transportation vouchers during the stay. Have the Center staff include a Social Worker who can provide information about: (a) Social Security and any other relevant Federal programs; (b) various state programs for the disabled; and (c) access to resources that may be helpful for the family or the offspring.
 - 7) Provide the offspring's primary care physician with a report with diagnosis and treatment recommendations.
 - 8) Provide a means for the Care Centers to receive periodic reports from the offspring's primary home physician.
 - 9) Fund and facilitate conferences between the Centers and offspring's primary care physician.
 - 10) Provide for recurring follow-up visits to the Center as often as needed to stabilize the offspring's condition and to facilitate research.
 - 11) Provide and offer an annual reevaluation of each offspring enrolled at the Centers.
 - 12) Make data collected available for researchers within and outside of the VA to facilitate meaningful scientific search.
- That VVA use media resources to promote Birth Defect Research for Children and encourage veterans who have offspring with birth defects to register them on BDRC's National Birth Defect Registry.
 - That the AO/DOTS Committee

- explore the opportunities to get other Veterans Service Organizations and military associations to promote BDRC's National Birth Defect Registry.
- explore more fully the CDC resources and associated organizations in regards to birth defects.
- compile scientific information and research on the association between birth defects in offspring when there is maternal or paternal exposure to toxins.

Alan Oates
Chairman AO/DOTS Committee

Appendix A: VA Covered/Non-Covered Birth Defects

Below is a list of birth defects that the VA recognizes for children of female Vietnam veterans.

List of Covered Birth Defects

The following birth defects usually qualify a child unless other people in the family have had the condition:

- Achondroplasia (abnormally short stature)
- Cleft lip and cleft palate
- Hallerman-Streiff syndrome (malformations of the skull and face, hair, dental and skin changes, short stature)
- Congenital heart disease
- Esophageal and intestinal atresia (atresia: Absence of a normal opening or failure of a structure to be tubular)
- Hip dysplasia (dislocation)
- Hirschprung's disease (congenital megacolon)
- Hydrocephalus due to aqueductal stenosis (a narrowing of a channel in the brain that connects two ventricles preventing the flow of cerebral spinal fluid)
- Hypospadias (abnormal opening of the male urethra)
- Imperforate anus (born without normal anus opening)
- Neural tube defects (including spina bifida, encephalocele, and anencephaly)
- Poland syndrome (one-sided malformation of the chest muscles and webbing of the fingers)
- Pyloric stenosis (narrowing of the stomach leading into the small intestines)
- Syndactyly (fused digits)
- Talipes equinovarus (clubfoot), congenital
- Tracheoesophageal fistula (connection of the breathing and swallowing tubes)
- Undescended testicle
- Williams syndrome (abnormalities of the face, heart and blood vessels, dental, kidneys, hearing and musculoskeletal problems)

Types of Birth Defects That Don't Qualify

- Inherited Birth Defects
- Birth-Related Injuries
- Chromosomal Disorders
- Congenital Malignant Tumors
- Fetal / Neonatal Diseases
- Developmental Disorders
- Birth Defects That are NOT Permanent

Inherited Birth Defects (not covered)

The following birth abnormalities are inherited from family members and are not covered by the Children of Women Vietnam Veterans Program:

- Albinism
- Alpha-antitrypsin deficiency
- Crouzon syndrome
- Cystic fibrosis
- Duchenne's muscular dystrophy
- Galactosemia
- Hemophilia
- Huntington's disease
- Hurler syndrome
- Kartagener's syndrome (Primary Ciliary Dyskinesia)
- Marfan syndrome
- Neurofibromatosis
- Osteogenesis imperfecta
- Pectus excavatum
- Phenylketonuria
- Sickle cell disease
- Tay-Sachs disease
- Thalassemia

- Wilson's disease

Birth-Related Injuries (not covered)

The following injuries that happen during birth aren't covered:

- Brain damage due to anoxia during or around the time of birth
- Cerebral palsy
- Facial nerve palsy or other peripheral nerve injuries
- Fractured clavicle
- Horner's syndrome

Chromosomal Disorders (not covered)

The following chromosomal disorders aren't covered:

- Down syndrome and other Trisomies
- Fragile X syndrome
- Klinefelter's syndrome
- Turner's syndrome

Congenital Malignant Tumors (not covered)

The following conditions aren't covered:

- Medulloblastoma
- Neuroblastoma
- Retinoblastoma
- Teratoma
- Wilm's tumor

Fetal / Neonatal Diseases (not covered)

The following fetal / neonatal diseases aren't covered:

- Asthma and other allergies
- Effects of maternal rubella, toxoplasmosis, syphilis, or other maternal infection during pregnancy
- Fetal alcohol syndrome or fetal effects of maternal drug use
- Hyaline membrane disease
- Maternal-infant blood incompatibility
- Neonatal infections
- Neonatal jaundice
- Post-infancy deafness/hearing impairment (onset after one year)
- Prematurity
- Refractive disorders of the eye

Developmental Disorders (not covered)

The following developmental disorders aren't covered:

- Attention deficit disorders
- Autism
- Epilepsy diagnosed after infancy (after one year)
- Learning disorders
- Mental retardation (unless part of a syndrome that is a covered birth defect)

Birth Defects That Are NOT Permanent (not covered)

The following birth defects aren't covered because they don't cause permanent physical or mental disability:

- Conditions that are non-disabling through treatment
- Congenital heart problems that have been surgically corrected or resolved without disabling residuals
- Heart murmurs associated with a diagnosed cardiac abnormality
- Hemangiomas that have resolved with or without treatment
- Scars (other than head, neck, or face) as the only residual of corrective surgery for birth defects

Appendix B: Information from CDC web site on tracking birth defects.

<http://www.cdc.gov/ncbddd/bd/monitoring.htm>

Tracking Birth Defects

CDC believes that it is important to have a system to track birth defects to see when and where they happen. CDC uses different systems to look for changes and then tells the public about these trends. We base our research studies, for example causes of certain birth defects, on what we learn from tracking. In addition, our systems guide how we plan and evaluate ways to prevent birth defects.

CDC is driven by our vision—to promote optimal health and development for all children. More specifically, we work to prevent or reduce the adverse consequences of birth defects. We have several major systems that track birth defects in the United States. CDC also partners with other groups in the U.S. and the world to share information and to work on projects that will help prevent birth defects throughout the world.

- [The Metropolitan Atlanta Congenital Defects Program \(MACDP\)](#)

CDC has been tracking birth defects closely for over 40 years. Established in 1967, MACDP is a population-based surveillance system for birth defects that was established in 1967 by the CDC, Emory University, and the Georgia Mental Health Institute

- [State Birth Defects Surveillance Systems](#)

CDC guides and fund states to set up and improve their systems to track birth defects.

- [National Birth Defects Prevention Network \(NBDPN\)](#)

CDC supports the mission of the National Birth Defects Prevention Network (NBDPN). The mission of the NBDPN is to establish and maintain a national network of state and population-based programs for birth defects.

- [International Clearinghouse for Birth Defects Monitoring Systems \(ICBDMS\)](#)

CDC supports and collaborates with the ICBDMS as a way to gain knowledge and expertise on birth defects information worldwide and to further our goals and those of the international community.

- [The Health and Environment Linked for Information Exchange \(HELIX-Atlanta\)](#)

CDC supports and collaborates with the Health and Environment Linked for Information Exchange (HELIX-Atlanta). HELIX is a local level project of environmental public health tracking. The HELIX-Atlanta birth defect team works to develop strategies to be used in environmental public health tracking by state birth defects program

Content source: National Center on Birth Defects and Developmental Disabilities

Appendix C: Printout of questions and information collected in BDRC's birth defect registry.

Note printout starts on next page.