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**U.S. Department of Veterans Affairs Advisory Committee on Gulf War Veterans**  
**January 14, 2009**  
**Seattle, Washington**

On behalf of the Veterans of Modern Warfare, for which I serve as their National President, I thank the Committee for the opportunity to present our concerns and recommendations regarding the ongoing plight of Gulf War veterans.

**Gulf War Veteran Health:**

Nearly 18 years after the end of the 1991 Gulf War, almost 175,000 of the approximately 697,000 Gulf War veterans who served in theater remain seriously ill as a result of their Gulf War service. Many are suffering from a complex, chronic multi-symptom illness, which is often severe and debilitating to the veteran and destructive to their family units. The diagnoses of several diseases have been at rates higher than comparable populations, including ALS (Lou Gehrig's Disease) and brain cancer. We believe that Gulf War veterans have elevated rates of other diagnosed conditions and multi-symptom illnesses as well, including cancers, Multiple Sclerosis, Fibromyalgia, and Chronic Fatigue Syndrome (CFS), Irritable Bowel Syndrome (IBS) and sleep apnea. Mortality rates among Gulf War veterans are not currently known. Nor are there any mechanisms monitoring the physical or neurological health of our children.

**Illness Validation:**

In November 2008, the Research Advisory Committee on Gulf War Illness formally acknowledged that Gulf War Illness is real. Scientific evidence strongly and consistently indicates that two Gulf War neurotoxic exposures are causally associated with Gulf War Illness: 1) Use of pyridostigmine bromide (PB) pills, given to protect troops from the effects of nerve agents and 2) pesticide use during deployment.

There are military reports dating back to at least 1981 noting the assumption of blood-brain barrier impermeability was not absolute with PB use. The Federal Drug Administration's (FDA) conditional approval of the Department of Defense's (DoD) request for a waiver in 1989 to approve PB was dependent on follow-up testing and reporting of adverse events and further reporting. The Department of Defense failed to meet its obligations under the FDA's direction and continues to not meet the current conditions for usage. Yet, PB is still being administered to our troops today.

PB was presumably given to us because the DoD believed that the protection it would provide troops would be greater than the harm it might cause. But that's not the way it has played out for 1 out of 4 Gulf War veterans. The risk was known, but there has been no accountability for the risk taken. Instead, it seems that we were looked upon collectively like an experiment gone

wrong without regard for our cohort as human beings. And only now, nearly 18 years later, have we been validated.

### **Continued Health Care for Gulf War Veterans:**

Gulf War illness has been widely described in government testimony, media reports, and scientific studies. It is typically characterized as a combination of symptoms such as memory problems, chronic headaches, widespread pain, extreme fatigue, mood changes, diarrhea, respiratory problems and skin rashes. One of the major challenges in identifying, treating and understanding Gulf War illness is that ill veterans often have no abnormal findings on clinical diagnostic tests.

The current presumptive enrollment opportunity for Gulf War veterans to file a claim for undiagnosed illness (UDX) is due to expire on September 30, 2011. We believe the delimiting date should be extended by five years, until 2016, for Gulf War veterans who are ill with a prescribed set of complex symptoms identifiable as “Gulf War Illness”.

Given the nature of neurotoxic exposures and the overall lack of treatment research, we believe that it is unreasonable to enforce the current time-constraints on illness development and treatment. We urge this Committee to include an immediate five-year extended delimiting date for undiagnosed illness claims as one of its final recommendations.

### **Standardized Screening:**

There are Gulf War veterans around this country who are still referred by their VA practitioners for psychiatric consultations because they present with chronic complaints and no abnormal findings on diagnostic tests. Rather than being treated for their physical symptoms as a consequence of neurotoxic exposures, they are being prescribed anti-psychotic medications. Their services to our Nation and their exposures have been essentially and sadly negated by many in the VA medical community.

We urge the VA to focus efforts on the development of a screening exam for Gulf War veterans that would become best practices nationally and we request the Committee’s support.

### **Research on Demyelinating Diseases:**

PB was administered to Gulf War veterans as, essentially, a myelin defense shield. For years, Gulf War veterans have been presenting with symptoms of demyelination and we believe that an elevated rate of Multiple Sclerosis (MS) occurs within Gulf War veterans. Others have been diagnosed with Demyelinating Disorder NOS. On one internet forum, there are over 400 Gulf War veterans who have come together, either diagnosed with one of these illnesses or symptomatic of demyelization, looking for answers while they provide support to each other. In fact, there has been such a large response from Gulf War veterans with MS that Senator Patty Murray introduced legislation in 2006 to presumptively service connect Gulf War veterans diagnosed with MS, without the restriction of the current 7-year delimiting period. This issue was the reason that Senator Craig promoted and gained a five year extension for Gulf War veterans in 2006. Multiple requests made to the VA to mine and sort their current diagnosis codes in order to determine the rate of MS and they have apparently been ignored because this

data has not, to our knowledge, been released.

We believe that it is plausible for there to be an MS that is characteristic of Gulf War veterans. A norm, if you will, for our cohort that does not adhere firmly to the McDonald criteria used as a tool for diagnosing MS. We ask this Committee and the scientific community to consider the consequential potential of an MS induced as a result of blood-brain barrier permeability from PB ingestion. In fact, there are veterans here today who have been diagnosed by a civilian neurologist with Multiple Sclerosis who have been discharged from the MS Center of Excellence because they do not, in the Center's opinion, meet the McDonald criteria. They have been diagnosed with a demyelinating disorder and provided no follow-up protocol given to these veterans regarding their neurological care.

Multiple Sclerosis is service connected when a veteran can prove that symptoms presented within 7 years of discharge at a base rating of 30%. To our knowledge, there is no rating for a demyelinating disorder, even when the symptoms can be proven to have existed within the 7 years after discharge. Ratings are determined based on individual symptoms, even when the level of illness is equal to that of someone who carries the diagnosis of MS. This change of the diagnostic code also removes any opportunity the veteran may have to utilize medications specific to MS treatment to prevent further demyelination.

We urge the Committee to support an immediate mandate that would require the VA to audit its records and determine the number of Gulf War veterans who are diagnosed with Multiple Sclerosis and Demyelinating Disorders NOS. This task must be completed in a defined and enforced time frame and made public to the VSO community.

### **Brain Bank:**

We are pleased with the establishment of the Gulf War veterans' brain and spinal cord bank and we have hope that knowledge will be gained through this research.

I had the personal privilege of working with the family of the first Gulf war veteran to donate his brain to research. He emphatically believed that through the research of his brain, he would not die in vain. I pay respects to him today and honor him for his strength and courage.

We believe that the **Department of Defense (DoD) Comprehensive Clinical Examination Program (CCEP)** must be reinstated for the eligible children of Gulf War veterans. Additionally, there must be a mechanism to collect the data regarding the neurological and physical development of our children. This data must be monitored for trends and patterns.

Over the years, we have received reports from many parents whose children have been born with clusters of neurological and/or physical abnormalities: Autism and autism spectrum disorders, severe hypotonia, kidney and bladder issues, unusual physical defects, hydrocephalus, severe apraxia of speech, Tourette's Syndrome, bipolar disorder, double aortic arches and dramatic sleep apnea conditions. All of these have been reported by both male and female veterans of the Gulf War who are themselves ill.

We understand that as soldiers we take risks with our safety, our bodies and our health. But for those of us who are parents of children who plausibly suffer as a result of our exposures, our grief and devastation simply cannot be expressed. We ask that you consider the potential of this biological consequence as we ask you to immediately support a Gulf War Birth and Child Registry.

**Birth registry:**

We believe that an epidemiological registry must be created immediately in order to begin tracking trends in the neuro and physical health of our children. Parents must be allowed to submit their children's medical records. Please, let's learn as much as we can from veterans and their affected children.

**Gulf War Registry:** There are currently over 100,00 Gulf War veterans enrolled in the Gulf War Registry. VMW supports continuation of the Registry. However, we believe that amendments must be made to the VA Form 10-9009A by adding the following questions and that Gulf War veterans who have previously completed the Registry be resurveyed with a questionnaire to also answer the following:

*Do you have children born before deployment and/or after deployment?*

*Do your children conceived post deployment have any physical or neurological defects?*

*Is your spouse also a Gulf War deployed veteran?*

*Did you receive vaccines for chemical and biological warfare?*

*Did you have an acute reaction to vaccines?*

**MS Registry:**

The cause of MS is not yet known. We promote studying MS and demyelinating disorders in veterans to further research efforts to find a cure for this debilitating disease.

We believe that all of society will benefit by the creation of an MS Registry. An MS Registry should be inclusive of all veterans who have MS as well as demyelinating disorders, but enable the ability to sort for specific queries.

**Death Registry:**

We receive 'Taps' reports from around the country; obituaries of veterans far too young to die of natural causes who have reportedly been suffering with Gulf War illness. Far too often these reports tell of how the veteran was chronically ill, became suddenly worse and died in a short time.

The mortality of Gulf War veterans must be monitored. A registry would create a mechanism to collect information from the veteran's survivors as well as monitor future mortality rates. This information is essential for tracking mortality trends.

**Benefits Claims:** Neurotoxic exposure have now been recognized by the scientific community. Therefore, we believe that, given the nature of neurotoxic exposures, Gulf War veterans who are diagnosed with chronic multi-symptom illness (UDX) should immediately be granted presumptive service connected benefits, both for health care and compensation. While the law allows for the granting of service-connection for UDX claims, the convoluted rules have led to the denial of most UDX claims. VMW supports the continuation of current provisions that allows for service connection of ALS, Brain Cancer, Fibromyalgia, CFS and IBS. We believe this should be an area of focus for the Committee during its 18-month charter.

VMW asks that the Committee support Gulf War veterans who have been ill and suffering for nearly two decades by immediately recommending presumptive service connection for UDX claims.

**Outreach:**

There are hundreds of medical and research projects that have either been completed or are currently being conducted. There are numerous GAO and other DoD reports on subjects such as chemical plumes that should all come together in one centralized location for everyone to use as a reference resource.

Information for Gulf War veterans is often difficult and discouraging to locate. We urge the development of a VA Gulf War Illness/Gulf War Veteran website to serve as a unique and unparalleled communications tool to inform the scientific, medical, veteran's communities, the public, those suffering from Gulf War illness and their loved ones. Information about each of the registries I mentioned here today should be accessible as well.

We support the initiation by VA of a direct, proactive, systematic outreach to Gulf War veterans. We urge the reestablishment of the defunct Gulf War Review newsletter, which was VA's only communication to Gulf War veterans with health concerns related to their Gulf War service.

We ask that the Committee support our call for an inclusive Gulf War Resource web site that will be must developed and maintained as a premier resource for Gulf War veterans, their families and their providers.

In conclusion, the recent Research Advisory Committee on Gulf War Illness report has provided Gulf War veterans with an appreciated "reality upgrade". It has been officially reported "...that Gulf War illness is real, that it is the result of neurotoxic exposures during Gulf War deployment, and that few veterans have recovered or substantially improved with time."

One of the lessons I learned preparing for the meeting was why DoD gambled with an experimental medicine that could have rendered its Army useless. The answer was they didn't believe they had a choice. They believed then much like they did in 2003: "You go to war with the Army that you have", but that may not be an Army that is fit for the fight. Therefore, they believed they were 'armoring up' for a protection that was not suited for the warrior, but was appropriate for the war.

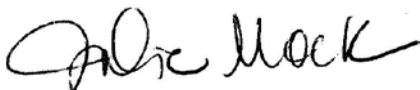
Sometimes in medicine one drug developed for..... hair loss is also effective for ... reducing enlarged prostate glands. But the use of a medication for all chemical warfare agents in a hostile environment that was developed to treat gravis may not have been the best defense for a limited offense.

In the case of the human experimentation with PB and the Gulf War veteran a clear understanding of the benefits was absent. The experiment was driven by fear and a lack of respect for the individual. The evidence to support that conclusion is overwhelming. The Rand Corporation found that DoD did nothing to fulfill its promise to the FDA to be as safe as possible in its use of PB as a vaccine.

Now is the time to provide relief to those who are essentially the victims of this experiment. Aggressive research programs must be initiated in order to develop a treatment protocol for these veterans affected by PB contamination. The time to provide Gulf War veterans the acceptance, the service-connected medical care and compensation that they earned by serving their Nation is long overdue. We ask this Committee to advocate swiftly on their behalf by recommending: presumptive service connections, a five-year delimitating date extension, records audit for veterans with MS and demyelinating disorders, initiation of a DoD CCEP for children of Gulf War veterans, registries for birth, children and death and timely development of a primary web site resource.

Thank you again for this opportunity to present this Committee with our recommendations to aid in the plight of our Nation's Gulf War veterans.

Respectfully submitted by

A handwritten signature in black ink, appearing to read "Julie Mock". The signature is fluid and cursive, with the first name "Julie" written in a larger, more prominent script than the last name "Mock".

Julie Mock  
President  
Veterans of Modern Warfare, Inc.