## STATEMENT OF SHANNON L. MIDDLETON, DEPUTY DIRECTOR VETERANS AFFAIRS AND REHABILITATION COMMISSION THE AMERICAN LEGION TO THE

# SUBCOMMITTEE ON HEALTH COMMITTEE ON VETERANS' AFFAIRS UNITED STATES HOUSE OF REPRESENTATIVES ON GULF WAR EXPOSURES

## July 26, 2007

Mr. Chairman and members of the Subcommittee:

The American Legion appreciates the opportunity to offer our views on this very important issue. American military forces are currently engaged in combat operations in Iraq and Afghanistan and it is easy to forget that there are still thousands of veterans from the 1991 Gulf War still suffering from unexplained multi-symptom illnesses related to their service in Southwest Asia. We applaud this subcommittee for not forgetting these veterans and holding this hearing.

## History of Undiagnosed Illness Compensation

Shortly after the end of the 1991 Gulf War, thousands of Gulf War veterans began complaining of unexplained multi-symptom illnesses (headaches, fatigue, muscle pain, joint pain, gastrointestinal problems, neurological signs and symptoms, etc.). In most cases, doctors were not able to provide definitive diagnoses. As a result, compensation claims filed with the Department of Veterans Affairs (VA) were being denied outright since VA was prohibited by law from "service-connecting" conditions that could not be diagnosed. As result of strong lobbying efforts by the veteran service organization community and others to correct this problem, Public Law 103-446 (38 USC § 1117) was enacted in 1994, authorizing VA to pay compensation to disabled Gulf War veterans suffering from undiagnosed illnesses. The undiagnosed illness must have become manifest either while the veteran was in the Southwest Asia theater of operations or prior to January 1, 2012, if symptoms first developed after the veteran left Southwest Asia. Although PL 103-446 was clearly intended to compensate ill Gulf War veterans suffering from undiagnosed or medically unexplained conditions, vague wording in the final version of the law allowed VA to publish restrictive implementing regulations, resulting in a very high denial rate under the new law. Conditions such as fibromyalgia, irritable bowel syndrome, and chronic fatigue syndrome, although medically unexplained, were considered to be "diagnosed" conditions and were being denied under the new undiagnosed illness law.

The VSO community again turned to Congress for help. The result was Public Law 107-103, signed into law on December 27, 2001. Effective March 1, 2002, provisions of this law clarified and further expanded the definition of undiagnosed illness under the law to include medically unexplained chronic multi-symptom illness, such as chronic fatigue syndrome, fibromyalgia, and irritable bowel syndrome, that is defined by a cluster of signs or symptoms. Signs or symptoms that may be a manifestation of an undiagnosed or chronic multi-symptom illness include the following: fatigue, unexplained rashes or other dermatological signs or symptoms, muscle pain, joint pain, neurological signs or symptoms, signs or symptoms involving the upper or lower respiratory system, sleep disturbances, gastrointestinal signs or symptoms, cardiovascular signs or symptoms, abnormal weight loss, or menstrual disorders. A disability is considered chronic if it has existed for at least six months.

Despite the enactment of PL 107-103, clarifying and expanding the definition of undiagnosed illness, the denial rate for these claims remains very high (approximately 75 percent). The restrictive nature of VA's final rule, published in the Federal Register on June 10, 2003, implementing the Gulf War provisions of PL 107-103 has reinforced this pattern. As of May 2007, less than four thousand such claims, out of almost 15,000 that have been processed, have been granted service connection.

The American Legion urges the House Veterans' Affairs Committee to conduct oversight of the Gulf War-related provisions of PL 107-103.

## Compensation for Amyotrophic Lateral Sclerosis (ALS)

Preliminary findings of a joint Department of Veterans Affairs (VA) and Department of Defense (DoD) study, released in December 2001, of nearly 2.5 million veterans indicated that deployed Gulf War veterans (August 2, 1990 to July 31, 1991) are twice as likely as their non-deployed counterparts to develop ALS. The Secretary of Veterans Affairs immediately announced that he would explore VA's options for compensating Gulf War veterans who have been diagnosed with ALS. VA subsequently directed all VA regional offices to submit all Gulf War ALS cases to VA Central Office for expeditious adjudication. VA service-connected all Gulf War veterans (with service in Southwest Asia during the period of August 2, 1990 to July 31, 1991) identified with ALS at that time (approximately 40) on a direct basis, using the preliminary research findings as evidence to link ALS to the veterans Gulf War service.

Despite the Secretary's announcement and subsequent action, VA did not have plans to draft a regulation establishing an ALS presumption under current law guaranteeing compensation for Gulf War veterans who develop ALS in the future. The joint VA and DoD study was published in the scientific journal "Neurology" in September 2003, resulting in the Secretary publicly announcing that this "final study" supports his 2001 decision to compensate Gulf War veterans stricken with ALS. Despite this public announcement and the Secretary's initial decision to expeditiously service-connect, on a direct basis, Gulf War veterans diagnosed with ALS, VA informed The American Legion that it would be "premature" to create a regulatory presumption of service connection for

Gulf War veterans with ALS. Bottom-line, although VA expeditiously service-connected a small number of veterans diagnosed with ALS, it has not established ALS as an official Gulf War presumptive disability and it has no plans to do so at this time based on its responses to specific American Legion inquiries. Without an actual presumption in place, there is nothing to ensure that Gulf War veterans diagnosed with ALS in the future will receive the same treatment as those discussed above. Due to the media coverage of VA's actions to expeditiously service-connect Gulf War veterans with ALS in December 2001, many people are under the erroneous belief that ALS is a Gulf War presumptive disability.

Additional studies have shown that military veterans in general have a greater likelihood than non-veterans of developing ALS. A study published in 2005 in the journal "Neurology" titled "Prospective study of military service and mortality from ALS," [M.G. Weisskopf et al., 2005; 64:32-37] evaluated ALS risk for veterans from World War 2, and the Korean and Vietnam Wars. This study concluded that these veterans were at significantly higher risk for ALS compared to civilians. In November 2006, the Institute of Medicine (IOM) released a report concluding "there is limited and suggestive evidence of an association between military service and later development of ALS." We understand that VA has finished its evaluation of the November 2006 IOM report in order to determine if any changes in VA health care or disability compensation policies are warranted but has determined that more research is needed and a presumption is not warranted at this time. Although IOM also noted that additional research is needed regarding a link between military service and ALS, we submit that IOM's finding of "limited and suggestive" evidence between ALS and military service is sufficient, under current law, for VA to move forward and establish official ALS service connection presumptions. Even though veterans can, in theory, establish service connection without a specific military presumption, it is extremely difficult in most cases for the veteran to meet the burden of proof required by VA for establishing direct service connection and many veterans will be precluded from establishing entitlement to service connection for ALS without an actual presumption.

### **Gulf War Presumptive Disabilities**

Research is inextricably intertwined with an ill Gulf War veteran's ability to receive VA compensation for specific conditions he/she believes are related to his/her Gulf War service. 38 USC § 1118 (PL 105-277), allows the Secretary of Veterans Affairs to establish presumptions of service connection for specific diagnosed conditions/diseases when scientific research supports a positive association with a known Gulf War exposure (vaccines, nerve agents, depleted uranium (DU), oil well smoke, etc.). The Secretary relies primarily on the IOM literature reviews and subsequent reports (Gulf War and Health) to determine whether a positive association exists to justify the establishment of a presumption. IOM's reports to date (Volume 1: Depleted Uranium, Pyridostigmine Bromide, Sarin, Vaccines; Volume 2: Insecticides and Solvents; Volume 3: Fuels, Combustion Products, and Propellants; Volume 4: Health Effects of Serving in the Gulf War; Volume 5: Infectious Disease), and an August 2004 updated literature review of sarin have not provided the scientific evidence necessary for VA to establish

presumptive disabilities for any of the exposures looked at by IOM so far. As a result, not one presumptive disability has been established to date under this law.

Congress directed IOM's reports to be based on findings from the full range of human and animal studies that provide information on the effects of Gulf War-related exposures, as well as both diagnosed and undiagnosed illnesses affecting Gulf War veterans. IOM's "Gulf War and Health" series of reports, as commissioned by VA, have not adhered to requirements set forth by Congress in mandating the reports. As a result, they have not comprehensively addressed key questions regarding Gulf War-related health conditions in relation to Gulf War exposures. IOM's reports to date have not considered findings from epidemiologic studies of Gulf War veterans (i.e. association of Gulf War veterans' illnesses with exposures), nor have they considered animal studies in drawing its conclusions. A perfect example of this is the August 2004 updated literature review of The Secretary of VA commissioned this review because studies published subsequent to IOM's September 2000 report (Volume 1), that addressed sarin, showed that exposure to sarin even at levels too low to cause immediate/acute effects can still have long-term adverse health effects (brain damage). Even though these studies were the reason the Secretary wanted IOM to look at sarin again, IOM did not even consider this research when drawing its conclusions because they were animal-based studies.

#### Research

In the Research Advisory Committee on Gulf War Veterans' Illness (RACGWI) initial report released in November 2004, it was found that, for a large majority of ill Gulf War veterans, their illnesses could not be explained by stress or psychiatric illness and concluded that current scientific evidence supports a probable link between neurotoxin exposure and subsequent development of Gulf War veterans' illnesses. Earlier government panels concluded that deployment-related stress, not the numerous environmental and other exposures troops were exposed to during the war, was likely responsible for the numerous unexplained symptoms reported by thousands of Gulf War veterans.

Gulf War research is moving away from the previous stress theories and is actually starting to narrow down possible causes. However, research regarding viable treatment options is still lacking. The American Legion applauds Congress for having the foresight to provide funding to the Southwestern Medical Center's Gulf War Illness research program. The Center, headed by Dr. Robert Haley at the University of Texas Southwestern, was awarded \$15 million, renewable for five years, to further the scientific knowledge on Gulf War Veterans Illnesses research. This research will not only impact veterans of the 1991 Gulf War, but may prove beneficial for those currently serving in the Southwest Asia Theater and the Middle East during the Global War on Terror. The purpose of the research is to fill in the gaps of knowledge where there is little, yet suggestive, information. Dr. Haley's research will further this knowledge about Gulf War veterans' illnesses and hopefully help improve the lives of ill Gulf War veterans, and their families who suffer beside them. We owe ill Gulf War veterans our exhaustive efforts in finding treatments for their ailments. The American Legion believes that VA

should continue to fund research projects consistent with the recommendations of the Research Advisory Committee on Gulf War Veterans' Illness (RACGWI). It is important that VA continues to focus its research on finding medical treatments that will alleviate veterans' suffering as well as on figuring out the causes of that suffering. The American Legion also recommends that the Subcommittee thoroughly review the RACGWI's second report, which will be released this fall.

## **Health Care**

Public Law 103-210, which authorized the Secretary of Veterans Affairs to provide priority health care to the veterans of the Persian Gulf War who have been exposed to toxic substances and environmental hazards, allowed Gulf War Veterans to enroll into Priority Group 6. The last sunset date for this authority was December 31, 2002. Since this date, information provided to veterans and VA hospitals has been conflicting. Some hospitals continue to honor Priority Group 6 enrollment for ill Gulf War veterans seeking care for their ailments. Other hospitals, well aware of the sunset date, deny Priority Group 6 enrollment for these veterans and notify them that they qualify for Priority Group 8. To the veterans' dismay, they are completely denied enrollment because the VA has restricted enrollment for Priority Group 8 since January of 2003. Even more confounding is the fact that eligibility information disseminated via internet and printed materials does not consistently reflect this change in enrollment eligibility for Priority Group 6. The American Legion has been assured by VA that this issue will be rectified.

The American Legion believes priority health care should be again extended to Gulf War veterans seeking treatment for ailments related to environmental exposures in theater. Although these veterans can file claims for these ailments and possibly gain access to the health care system once a disability percentage rate is granted, those whose claims are denied cannot enroll. According to the May 2007 version of VA's Gulf War Veterans Information System (GWVIS), there were 14,874 claims processed for undiagnosed illnesses. Of those undiagnosed illness claims processed, 11,136 claims were denied. Because the nature of these illnesses are difficult to understand and information about individual exposures may not be available, many ill veterans are not able to present strong claims. They are then forced to seek care from private physicians who may not have enough information about Gulf War veterans' illnesses to provide appropriate care.

Since VA doctors would be more knowledgeable about the exposures Gulf War veterans experienced in theater, it is important that VA keeps Gulf War Continuing Medical Education (CME) updated to reflect current science. It is equally important that, once updated, VA makes Gulf War CMEs a requirement, not an option, to better serve this population of ill veterans. Although reputable research committees have shown that Gulf War veterans are sicker than those who did not deploy to the Southwest Asia theater, The American Legion is still contacted by veterans complaining that some VA doctors do not know how to treat their Gulf War illnesses. In fact, some ill Gulf War veterans are still being told that their illnesses are all in their heads.

## Outreach

It is The American Legion's understanding that VA has stopped mailing out printed copies of the Gulf War Review and is now only posting it on-line. We are concerned, not only because not all Gulf War veterans have internet access, but the VA's Gulf War veterans page is difficult to locate from VA's main web page. Only those who know where it is located, or that it even exists, will have access to the information. The American Legion has had several calls from those who inquired about the printed newsletter, as well as those who were interested but had no internet access. We urge VA to resume mailing out printed versions of the Gulf War Review in addition to posting it on the web.

Again, thank you Mr. Chairman for giving The American Legion this opportunity to present its views on such an important issue. We look forward to working with the Subcommittee to address this and other issues affecting veterans.