

'We're not crazy'

Gulf War illness is real — deal with it, veterans tell national panel

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STREET NEWS SERVICE

In the final days of the first Gulf War in Iraq, Mark Nieves was a soldier in a unit assigned to destroying munitions dumps. When the war was over, he came home to Seattle and started college, joining Reserve officers' training to further his career in the military.

His body, however, had other plans. As a junior in his 20s, Nieves began to notice that he couldn't exercise without becoming unusually winded. He became drowsy and lethargic, saw blood in his stool and, after exercising, he started breaking out in head-to-foot hives the size of dollar bills — a condition for which he sought help early on from the Seattle veterans hospital, only to regret it.

Because no welts were visible during his first visit, "one resident doctor became irritated with me... yelling at me and kicking me out of the treatment area. I was humiliated in front of everyone," Nieves told a national panel of doctors and veterans who visited the Seattle hospital in January. He went in a second time, he said, and was simply given a common anti-allergy medication.

"From that day," Nieves said, "I gave up on the VA." He never went back — a problem that, 17 years after the war's end, the U.S. Department of Veterans Affairs is finally trying to address.

This past May, at the urging of veterans' advocates, the secretary of Veterans Affairs appointed the 14-member Gulf War Veterans Advisory Committee to make recommendations on what the VA can do to help veterans such as Nieves, 38, who suffers from Gulf War illness, a collection of symptoms that includes skin rashes, mood changes, memory and respiratory problems, chronic headaches, fatigue, and all-over body pain.

After years of dispute about the existence and cause of the illness, a VA research committee that has been studying Gulf War symptoms since 2002 issued a report in November that not only officially recognized the illness and its prevalence for the first time — one in four of the 1991 war's 697,000 veterans is affected, the report says — but linked it to two neurotoxins used during the conflict: pesticides and PB, or pyridostigmine bromide, which was administered experimentally to U.S. troops to counteract possible nerve agents.

PB has been used to treat muscular disease since the 1960s, but, in 2006, a report by the Rand Corp. revealed that the Department of Defense disregarded Food and Drug Administration recommendations for further testing and administered PB off-label in tabs of packaged pills given to roughly 250,000 Gulf War personnel.

"PB was presumably given to us because the Department of Defense

believed that the protection it would provide troops would be greater than the harm it might cause. But that's not how it played out," Julie Mock, president of Veterans of Modern Warfare, told the Gulf War Veterans Advisory Committee.

Mock and Nieves were among five veterans who testified Jan. 14 during a two-day fact-finding visit that the committee made to Seattle. The panel, chaired by retired Navy Capt. Charles Cragin, has made previous VA site visits in Washington, D.C., Baltimore, and Indianapolis. At the end of the two days here, however, many of its members said the work that one local doctor is doing with Gulf War



PHOTO BY
SHERRY LOESER

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PRESIDENT OF VETERANS OF MODERN WARFARE

veterans is a model that should be rolled out nationally — one of the possible recommendations that the group is due to make by year's end.

Dr. Stephen Hunt is the director of the VA Puget Sound Deployment Health Clinic, which gives veterans a comprehensive work-up and multidisciplinary care to address symptoms related to exposure in particular wars, including Vietnam, the Persian Gulf's Desert Storm mission, and the occupation of Iraq.

"Dr. Hunt is the one that has gotten people to start listening that there are (specific) conditions with Desert Storm," says Navy veteran Beckie Wilson. "He has got a really good network of people there that work with him for Desert Storm and the guys coming back now."

It's an integrated approach that didn't exist at the end of the Gulf War, in which Wilson, 58, served aboard ships as a data processor. Today, she suffers from a mysterious shaking disorder, bone disease in her back, and post-traumatic stress disorder. But the last time she tried to get help at the VA six years ago, she said, they sat her down with yet another psychological test — a common response that has led VA doctors to put many Gulf War veterans on anti-psychotic medication, Mock said.

But "I'm not crazy," Wilson told the panel. "I do have these problems."

Wilson says the jerking started during her service in the Indian Ocean, first with what she thought was merely a restless foot. Now there are nights, she says, when she can't keep her body still in bed.

Compared with the general population,

Mock told the panel, Gulf War veterans experience higher rates of certain diseases, including brain cancer, Lou Gehrig's disease and multiple sclerosis. MS symptoms are a particular concern, Mock and retired Army Col. Liz Burris said, because the VA often treats them differently than civilian doctors would, diagnosing the symptoms as demyelination because they don't meet the classic medical definition of MS.

Like MS, demyelination disrupts nerve function. The bureaucratic difference between the two, said Burris, who was diagnosed with multiple sclerosis in 2001 and later discharged from the Seattle VA's MS care clinic with a diagnosis of demyelination, is that MS is considered a service-connected disability if it appears within seven years of discharge. Demyelination is not.

Mock urged the VA to correlate its data on diagnoses of demyelination to determine whether a PB-induced form of multiple sclerosis should be recognized. In the meantime, she called on the VA to recognize Gulf War symptoms as service connected, and to extend the current deadline for related disability filings by five years, from Sept. 30, 2011, to 2016.

"The risk [of PB] was known, but there has been no accountability for the risk taken," Mock said. "It seems that we were looked upon collectively like an experiment gone wrong without regard for [us] as human beings."

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