

**Department of Veterans Affairs Advisory Committee on Gulf War Veterans
January 14 – 15, 2009**

**January 14, 2009
VA Puget Sound Health Care System**

Present:

The Honorable Charlie Cragin, Committee Chair

Committee Members (alphabetical order):

Martha Douthit

Mark Garner

Dr. John Hart

Rusty Jones

Kirt Love

Dan Ortiz

Dan Pinedo

LTG (USAR, RET) Tom Plewes

Valerie Randall

Randy Reese

Steve Robertson

Not Present:

Dr. Henry Falk

Dr. Lynn Goldman

Opening Remarks by the Honorable Charlie Cragin

Mr. Cragin called the meeting to order and began with noting for the record that when the Committee makes a request from the VA, it should receive a timely response as to allow time for review, comment, observation or request for additional information. While the Committee did receive a VHA response to Committee questions, it is still awaiting a response from VBA. Mr. Cragin explained that the VBA response is being held up in the VBA concurrence process. The Chairman used the VHA timeline explanation of the Gulf War Review Newsletter publication in the concurrence process to illustrate his concern with the lengthy process. He acknowledged the importance of stakeholder review/comment but stated a response should not take a month. He said information delayed is often information denied. The Chairman expressed that he suspects one of the issues the Committee may have at the end of its deliberations is the timeliness of information to the constituencies the Department of Veterans Affairs serves. Mr. Cragin then welcomed members of the public as well as those who phoned in through the teleconference line.

Welcome

DeAnn Dietrich, Deputy Director of VA Puget Sound Health Care System

Ms. Dietrich thanked the Committee for visiting VA Puget Sound not only to talk to the staff about what they are doing to help Gulf War Veterans but for also taking the opportunity to speak

with Gulf War Veterans about how the VA Puget Sound Health Care System can do better. In addition to presenting an overview of the agenda, presenters, and key programs that will be discussed over the next couple of days, she pointed out that various staff members will attend the two day meeting to assist Veterans with any issues that may be raised.

Ms. Dietrich told the Committee that VA Puget Sound Health Care System is somewhat unique in the VA health care system. Using the VISN 20 map to depict the geography of the Veterans VA Puget Sound serves, she explained that the VISN has Veterans that take great lengths to seek care. There are Veterans who take a dogsled to Barrow, Alaska, then a flight to Anchorage and then take another three and half hour flight to Seattle to get care. That is a role in the network the hospital takes very seriously. She pointed out that the care of Veterans in the VISN 20 network is far-reaching. Chairman Cragin shared with her that the Committee decided to visit Puget Sound because based on the information it has received to-date, it believes that Dr. Stephen Hunt and his colleagues clearly have some of the right answers. Mr. Cragin went on to say that the Committee would like to know if the care is systemic, institutional or simply personality driven by Dr. Hunt.

Post-Combat Care for Gulf War Veterans

Stephen C. Hunt, MD MPH

Dr. Hunt began his presentation by discussing how war affects people and how VA can improve the care of Veterans whose lives have been affected by war. He explained that the Deployment Health Clinic evolved from the Gulf War Veterans Clinic which was established to care for returning Veterans from Desert Shield and Desert Storm. It has been used as a model to apply the same principles and approaches to Veterans returning from the current conflict. The Gulf War resulted in certain types of risk exposures which led to outcomes seen differently in other wars. Dr. Hunt said that he framed his presentation around the fact that we do not fully understand what is going on with some of the Gulf War Veterans' healthcare issues. Therefore, he said he would talk about what VA does know about Veterans from the first war, what VA does not know, and what VA can do for Veterans knowing what it does know, and acknowledging what it does not know. In his multidisciplinary clinic where Dr. Hunt conducted 1500 GW Registry exams and 1600 exams for Veterans from Iraq and Afghanistan, his team consists of a social worker, primary care provider, and a mental health provider who initially evaluates the Veteran and provides ongoing care which is integrated in the same way. Veterans see the social worker first since most polled stated that their top needs are healthcare, help with claims, financial and vocational rehabilitation. The goal in the treatment of combat Veterans is to take their combat experiences and have the outcomes contribute to their development, growth, appropriate healing, with their experiences integrated into their lives in a way that takes them to a higher level of life.

Dr. Hunt stated that from each war, we learn how it affects people in global ways. Each war shows mental health issues, muscular skeletal problems, medically unexplained illnesses, hearing loss, and unique features from a particular war. Some examples from the Gulf War are exposure to environmental agents, chemicals, and potential nerve agents. The Gulf War is different in that there are more of these symptoms manifesting for which we do not know the origin. Additionally, while the rates of PTSD are lower in this group, there are more medically

unexplained symptoms amongst Gulf War Veterans. What experts do know is that this war was a very different conflict and the stressors were also very dissimilar. For instance, Veterans experienced hearing alarms at any given time, putting on and off MOPP gear at a moment's notice, thinking they were being exposed to environmental agents (whether they were or were not), and believing they would die as a result these agents.

Dr. Hunt said in his personal opinion healthcare officials should get away from the mind-body dualism notion. Somehow there are physical injuries and then there are mental health problems that are less real or less physical. Dr. Hunt purports that PTSD, depression, and panic attacks are physical conditions. Forty-one percent of the Veterans currently returning from Iraq and Afghanistan have had panic attacks and it would be wrong to state that this is in their heads or should be attributed to mental health issues. Dr. Hunt stated that the duality is deeply engrained into the Western philosophy and is a false dichotomy. He advocates that when physicians do not know exactly what is wrong with the Veteran, whether it is attributable to physical or mental health, those providers should tell the Veteran so and assure them the VA will help. Dr. Hunt agreed with the Chairman who said "we have allowed the process to drive the care as opposed to the care driving the process." Dr. Hunt went on to say that VA should provide care without labeling. There are Veterans who are not receiving the care and resources they need. He went on to point out that the low percentage of service connection for undiagnosed illnesses depicted in the briefing slide may not truly be reflective of Veterans with undiagnosed illnesses receiving care. In many cases, Veterans may be service connected for other illnesses or injuries and may also be receiving care for undiagnosed symptoms.

Committee Member Steve Robertson asked if VA has reached out to Veterans who originally sought care but were turned away and may have lost trust in the VA. Dr. Hunt replied the worse thing that could have happened is VA not taking care of those Veterans who did not receive care or support from the VA and are experiencing difficult times. His hope is that the debate of what is causing the symptoms does not get in the way of Veterans being able to come to VA to get what they need. That is why developing the combat care clinic is very important and life long for the Veteran. It will not only benefit current Veterans but Gulf War Veterans as well as all other Veterans. The hope is that through outreach and word of mouth, Gulf War Veterans will hear about the program and come back to VA. Dr. Hunt stated that most of the new people coming in for PTSD treatment in the VA Post Combat Care Clinic are not from Iraq and Afghanistan but are from the Vietnam era. He said he is encouraged that VA is doing a better job of providing care to combat Veterans and more Veterans are returning to receive that care. Combat Veterans have five years priority eligibility for care and are encouraged to come to the clinic when they return from war to be evaluated.

Multiple Sclerosis (MS)

Jodie Haselkorn, MD, MPH

Dr. Haselkorn gave an overview of MS. She stated that MS is a clinical disorder for which there is no one cause or cure for the disease. However, there are multiple treatments to modify the disease and treat the symptoms. MS can be insidious starting with a numb toe or some other sensory disturbance or can be acute and happen all of a sudden with paralysis. MS is progressive. It is the most common neurological disease in the world of young people in their

20's to 40's, appearing just when military personnel are starting their careers or when civilians are starting their lives and building their families. There are approximately four hundred thousand people in the United States with the disease, and it occurs more commonly in women than men. MS results in both visible and invisible impairments. The invisible are the most difficult for people to manage. Fatigue is the top symptom of this disease.

Dr. Haselkorn stated that research showed increased incidence and prevalence rates, particularly in the Kuwaiti natives, during the period of 1993 to 2000. The thought is that the increase is not due to migration but rather to something the native population experienced. Dr. Haselkorn discussed several studies involving GW Veterans, which are outlined in her presentation. She pointed out that VBA has identified almost three thousand service connected Veterans with MS. The presumptive period for MS is seven years unless the Veteran has experienced and documented some of the symptoms which can be associated with MS within the seven years.

The MS Center of Excellence is equipped to care for Veterans with MS by providing consistent high quality healthcare to all Veterans by using an interdisciplinary approach, integrated and evidence based. To provide the best care, the MS Center of Excellence uses the Chronic Care Model which involves the healthcare teams as well as the person and family members affected by the disease. More information from Dr. Haselkorn's presentation can be found on the Gulf War Advisory Committee website.

Amyotrophic Lateral Sclerosis (ALS)

Greg Meekins, MD

Dr. Meekins gave an overview of Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's Disease. ALS is a progressive loss of both the upper motor neurons in the brain and the lower motor neurons in the spinal cord. It is purely a disease of motor weakness. Fifty percent of people with ALS will eventually develop some cognitive changes. The first thing that happens is a painless weakness. This can start in any area of the body. When it begins in the swallowing mechanism or muscles, it is typically called Bulbar ALS because of the degeneration of the motor neurons in the brain stem or mid-brain. With this type of ALS, there are lots of problems with regurgitation of fluids and choking. Bulbar ALS is the most rapidly progressive form of ALS. Twenty-five percent of cases start in the Bulbar region of the brain. The rest of the cases will start in the leg or an arm. The risk of developing ALS is very similar to developing MS. The difference with prevalence is people die from the disease very quickly. Ten percent of the cases are genetic. The most common age of onset is 40 – 60, and there is a slight dominance of males with ALS. The median time to death is 2 to 4 years from symptom onset, although ten percent of patients can survive for over 10 years.

Dr. Meekins also discussed the ALS DOD/VA timeline. He said that it became apparent in the decade after the conflict that there was a problem when a large number of young returning Desert Shield and Desert Storm servicemen and women started to come down with ALS. As a result VA and DOD commissioned a retrospective case ascertainment study of 2.5 million Veterans of those in theater and those out of theater to look at case rates of ALS. The study found a two times greater likelihood of developing ALS from Gulf War service. The original study identified 48 ALS cases in the Gulf War group. In December 2001, Secretary Anthony Principi announced

a connection between Gulf War service and ALS, conferring full disability and survivor benefits to Gulf War Veterans with ALS. Another key point that Dr. Meekins made was that all Veterans are at a higher risk of developing ALS than the general population. The cause of ALS in GWV is unknown. Further study of cluster and genetic data from Gulf War Veterans with ALS may identify environmental triggers and susceptibility genes.

The neuromuscular expert for Seattle VA and VISN 20, Dr. Meekins sees a population of Veterans and active duty personnel over a wide geography. His recommendations to the Committee were to ensure there is a seamless transfer of data to the VA and the establishment of ALS Center of Excellence. More information from Dr. Meekins' presentation can be found on the Gulf War Advisory Committee website.

Washington National Guard Support to Combatant Commanders – Post 9/11/01

Tom Riggs, Transition Chief

Mr. Riggs discussed the impressive partnership the Washington National Guard has with the VA Puget Sound. The National Guard holds regular information sessions at the Medical Center educating service members about their benefits and assisting them with claims processing. Similar MOUs have followed suit in 35 additional states across the country. The External Affairs Manager at the Washington National Guard was the first in the Nation to implement VA Benefits at Discharge Program for Guard and Reserve. This resulted in a reduction in claims processing from an average of 192 days to 79 days as well as a significantly reduced wait time for Vocational Rehabilitation and Employment (VR&E). Mr. Riggs also discussed the lessons learned from Gulf War I which have resulted in better response to the needs of activating and deactivating Guard and Reserve personnel in the current conflict. He also provided recommendations to help Gulf War Vets which included outreach. More information from Mr. Riggs' presentation can be found on the Gulf War Advisory Committee website.

Veterans Service Organization, Veterans of Modern Warfare

Julie Mock, President, Veterans of Modern Warfare

Ms. Mock discussed her organizations' concerns and recommendations regarding the care of Veterans who served in the Gulf War. She restated the Gulf War Illnesses Research Advisory Committee findings regarding Gulf War Illnesses and the effects of the pyridostigmine bromide (PB) pills. She emphasized the importance of continued health care for this cohort of Veterans as well as standardized screening. Ms. Mock asked the Advisory Committee "to advocate swiftly on behalf of Gulf War Veterans by recommending: presumptive service connections, a five-year delimiting date extension, records audit for Veterans with MS and demyelinating disorders, initiation of a DoD Comprehensive Clinical Evaluation Program (CCEP DOD) for children Gulf War Veterans, registries for birth, children and death and timely development of a primary web site resource." Ms. Mock's entire address to the Committee can be found on the Gulf War Advisory Committee website.

Public Comment Period

The Committee heard from Dr. Bridget Cantrell, WDVA PTSD Provider, CEO/President of Hearts Toward Home International, Non-profit organization.

Veterans Panel (Gulf War Veterans)

- Elizabeth Burris, LTC (Ret) US Army Reserve
- Mark Nieves, Calvary Scout, US Army
- Lee Christopherson, USN, BM/PS, Port Security Unit 303
- Beckie Wilson, Retired USN Officer

The Committee members ended the first day of the meeting by touring the VA Puget Sound Medical Center and talking with primary care physicians as well as touring the Post Deployment Clinic. The Committee spoke with Dr. Joyce Wipf about the care of Women Veterans. She explained that over 3,000 female Veterans receive care at the facility. The clinic provides a full range of inpatient, outpatient, mental health services, and medical surgical, including maternity care. Dr. Wipf explained that primary care is available through the Women's Clinics in Seattle and American Lake and Community-Based Outpatient Clinics. The female Committee members toured the Women's Clinic. The Advisory Committee ended the day by touring the newly opened Fisher House located at VA Puget Sound. The House has twenty-one guest suites which provide a comfortable home-like setting for family members of Veterans receiving care at the hospital.

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Claims Processing Tour

On January 15, 2009, the Committee began the day by touring the VA Regional Office to gain a better appreciation of what is involved with the claims process. Assistant Director, Bill Borom, gave the Committee an overview of the Seattle RO. He estimated that there are 17.5% Gulf War Veterans in the State of Washington of 622,263 Veterans in the State. Renaye Murphy, the Veterans Service Center Manager, explained the general claims process and specifically how Gulf War I Veterans' claims are processed. She said the Seattle RO generally has the more experienced raters review Gulf War Veterans' claims. Ms. Murphy's discussion was followed by the Vocational Rehabilitation and Employment (VR&E) Officer, David Boyd, who talked about the VR&E benefits. He shared FY 2008 job placement statistics and various outreach programs in the state of Washington. The Seattle RO presentation can be found on the Gulf War Advisory Committee website.

Seattle Vet Center

The Committee traveled to the Seattle Vet Center and met with Mr. Ron Boxmeyer and his colleague, Dr. Michael Colson. Mr. Boxmeyer, a decorated combat Veteran himself, explained that the Seattle Vet Center, like all other VA Vet Centers, provides readjustment counseling and outreach services to all Veterans who served in a combat zone. The Seattle Vet Center is

community based and is staffed with a small multi-disciplinary team of dedicated providers. Mr. Boxmeyer and Dr. Colson discussed various outreach programs his office employs. One of those includes prison outreach. Mr. Boxmeyer said that he treats each Veteran entering the facility with respect and gives the benefit of the doubt on their eligibility. If it is later found the Veteran is not eligible for services, he or she is directed to the proper officials for claims assistance. The Seattle Veterans Center also provides bereavement counseling to family members.

Community Based Grant and Perdiem Program

The Committee visited a homeless shelter in Shoreline, WA. Dr. Ann Shahan gave the Committee an overview of the VISN 20 Homeless Programs, which includes VA Supported Housing, Contract Residential, the Homeless Women's Program, Homeless Domiciliary Programs and other programs. She also discussed the VISN 20 homeless Veterans demographics. Dr. Shahan also educated the Committee on the overall VA Homeless Program. Dr. Shahan's entire presentation can be found on the Gulf War Advisory Committee website.

Committee Discussion Summary

The Advisory Committee reconvened in open session to deliberate after touring the various sites. The members reflected on the content of the presentations given over the past two days. Randy Reese reminded the Committee that Congress has not ended the period of the Gulf War. He said there should be a systemic change in which VA cares for Veterans. He reiterated what Committee members have previously said that the care should drive the process instead of the process driving the care. A Veteran should not have to wait until he is service connected to receive care. Mr. Reese also suggested that perhaps the term undiagnosed illnesses should be changed to something more acceptable to Veterans and better understood by healthcare officials.

Dr. John Hart stated that Compensation and Pension doctors and specialty combat care doctors should be trained. He expressed concern that not conducting ongoing training results in inconsistent and lack of care for Gulf War I Veterans. He said that because the Gulf War was seventeen years ago, some of the physicians do not have any experience with the cohort of Veterans. He also emphasized the importance of knowledgeable C&P doctors since they are the first stop for the Veterans. There should be a standardized screening document for Gulf War Veterans that enable doctors to focus on similar medical issues and to draw similar conclusions. He said the Committee has recognized after talking with various C&P doctors that understanding and diagnosing Gulf War Undiagnosed Illnesses varies throughout VA. There should be a consistent model that VA doctors should follow.

Steve Robertson thanked the Seattle staff for their sustained commitment in taking care of Veterans. He noted that VA implementing the Post-Deployment Health Care Model across VA is a step in the right direction. He also acknowledged that war does change everyone. Mr. Robertson expressed his concern that Veterans who came to VA for care but were turned away may not come back but genuinely need the help. VA must make great efforts to reach out to these Veterans to get them back into the system. Mr. Robertson said VA must be proactive and

the culture must change. He said that VA doctors should treat the incoming Veterans as if he/she were their kid coming to VA.

Martha Douthit stressed the importance of families being supported through the VA. She also stated that she would like to hear more about programs available for family members.

Valerie Randall summarized what she had learned over the course of the two day meeting. She expressed that she was impressed with Dr. Haselkorn's work in MS and the efforts to identify women who served during the Gulf War.

Tom Plewes pointed out that while the RAC report may be considered controversial, it is valuable and has brought about awareness to Gulf War Veterans and others. He expressed concern of what steps should be taken next in institutionalizing learning and implementing what Dr. Stephen Hunt is doing with the Post Deployment Integrated Care Initiative. Mr. Plewes recommended that VBA trace the characteristics and status of GWI Veterans, paying particular attention to the Guard and Reserve. He acknowledged the VA will require support from the Guard and Reserve (VA with the National Guard Bureau) to furnish records but insists there needs to be more systematic ways of obtaining information.

Rusty Jones stated that VA must move forward with caring for Gulf War Veterans based on the information that is available to-date. He talked about pursuing outreach activities to get this cohort of Veterans back to VA and when they return VA must make every effort take care of them. He agreed that the process should not drive the care but rather the care should drive the process.

Mark Garner expressed his interest in how Dr. Hunt's Post Deployment Integrated Care Initiative is being rolled out across VA. He thought the multidisciplinary approach used as a best practice throughout VA is in the best interest of all Veterans in particular the Gulf War I Veteran population.

Dan Pinedo stated that the services available and the services received by Veterans are not congruent. He advocated for reaching out to those Veterans who were turned away. Mr. Pinedo believes VA is now very proactive by using lessons learned from other wars to take care of Veterans. He said that many Veterans suffer from the bureaucracy of getting into the VA system, but went on to say that VA does not hear from the millions of Veterans that are happy and satisfied with VA.

Kirt Love expressed his disappointment with the VA Puget Sound Hospital not having publicly displayed information about the Gulf War, like the Gulf War Review publication and information about the Gulf War Registry exam. He asserted that VA should inform Veterans of programs available to them. Mr. Love also proposed that the first 30,000 Veterans who completed the Gulf War Registry exam be called back to ascertain how they are and whether they are receiving VA healthcare and benefits.

Mr. Cragin told the Committee they should start thinking about honing their recommendations to the Secretary. He applauded the VA for acting upon lessons learned from previous wars and

taking care of the current Veterans. He said it is critical that Veterans who decide to give VA another chance not get the feeling they are being rejected again. The Chairman went on to say that if VA is nationally implementing the Post Deployment Integrated Care Initiative, the Committee should hear from the person leading these effort to learn the strategic plan for the rollout to include the comprehensive timeline of all VISNs. Mr. Cragin said that he and the other Committee members were very impressed with VA Puget Sound staff's positive, can-do attitude of taking care of Veterans. He questioned, however, whether Veterans' care is being managed by personality or by institutional protocol.

Mr. Cragin commented that he was happy that the Committee was able to visit the Regional Office, particularly since the majority of the members had never been to an RO. He was dismayed that VA has not moved into the paperless age. He noted there must be a paradigm shift. The Chairman also expressed his concern with the treatment of the RAC Report. He said now that the research report is completed and has identified a Gulf War Illness, the report must either be debunked or validated. He went on to say that perception is the report was definitive and we must deal with it. Systemically, process drives care; care is not driving the process.

Closing Remarks

Chairman Cragin thanked everyone for their participation in the meeting to include those who called in through the teleconference. He said he looked forward to seeing the members in Atlanta, February 18 – 19, 2009.