

**Department of Veterans Affairs Advisory Committee on Gulf War Veterans
May 6 – 7, 2009
Residence Inn by Marriott, Washington, D.C.**

May 6, 2009

Present:

The Honorable Charles L. Cragin, Committee Chair

Committee Members (alphabetical order):

Martha Douthit

Henry Falk, MD, M.P.H

Mark S. Garner

John Hart, MD

William R. “Rusty” Jones

Kirt Love

Daniel Ortiz

Daniel Pinedo

LTG Thomas Plewes, USAR, Ret.

Edward R. Reese

Not Present:

Lynn Goldman, MD, M.P.H

Valerie Randall

Steve Robertson

Opening Remarks by the Honorable Charles L. Cragin

Mr. Cragin called the meeting to order and began by outlining the Committee’s Operations Plan and stating that the Committee’s charter will remain in effect as set forth by former VA Secretary James Peake and reiterated by Secretary Eric Shinseki. The Chairman said he is optimistic that the Committee will accomplish its activities within the designated timeline. He then introduced the panel of VA outreach officials. He expressed that he was pleased to see such a broad representation from across the Department to meet with the Committee on such an important and greatly discussed issue.

VA Outreach Panel

Emily Smith, *Deputy Assistant Secretary for Intergovernmental Affairs (IGA)*

Karen Malebranche, *Executive Director, OEF/OIF Program Office*

Chris Scheer, *Public Affairs Supervisor, VA Office of Public Affairs*

David Connor, *Program Analyst, VBA, Compensation & Pension*

David Schettler, *Director, NCA, Communications Management Service*

Joyce Bounds, *Web Director for the Office of VHA Web Communication*

Emily Smith began the panel discussion by explaining that the IGA mission is to coordinate outreach efforts for the entire Department. IGA annually produces an outreach report to Congress. VA reports outreach accomplishments in the even years and reports planned outreach efforts in the odd years. Under the new Assistant Secretary for the Office of Public and Intergovernmental Affairs, The Honorable Tammy Duckworth, VA will use the annual report to better coordinate all outreach efforts across the entire Department. This collaboration should result in a coherent, cohesive, and integrated outreach plan. As part of that process, IGA will also consult with VA stakeholders to include Veterans, VA Advisory Committees, and Veterans Service Organizations to seek ideas on what the VA is doing right and wrong in communicating effectively with Veterans. Ms. Smith relayed that Secretary Shinseki has set outreach as a high priority for the Department of Veterans Affairs.

Chris Scheer explained that the VA Office of Public Affairs primarily handles media relations, develops such communication products as speeches and fact sheets, and manages other tools that are important to the VA outreach effort. Mr. Scheer said VA outreach is fragmented and in the past, research had not been done to determine the effectiveness of outreach to Veterans. He said this will be the first time that outreach will be centrally coordinated and part of a VA strategic communication plan. Mr. Scheer believes the top down approach of including outreach in the strategic management responsibilities will enhance VA's efforts in reaching Veterans.

Karen Malebranche began by sharing with the Committee that many of the VHA programs in place for OIF/OEF Veterans were derived from lessons learned from the Vietnam and 1990 - 1991 Gulf War era Veterans. She noted that while the Internet is an increasingly popular communication tool, not all Veterans use it. Therefore, VA also uses traditional communication means like newsletters, information letters, brochures, and posters. Ms. Malebranche emphasized that VA continues to explore a variety of additional mechanisms to reach Veterans and their caregivers. She also discussed outreach to Veterans in the criminal justice system as well as homeless Veterans.

Ms. Malebranche told the Committee about healthcare care initiatives that will help VHA better care for OIF/OEF Veterans. She discussed VHA's electronic medical record clinical reminders. She pointed out that the records now include traumatic brain injury and post traumatic stress disorder triggers. VHA has also opened the Gulf War Registry to returning OEF/OIF Veterans and offers a special depleted-uranium screening program for concerned Veterans. Ms. Malebranche told the members that VHA is improving staff education by providing information and training to VHA providers about combat Veterans' healthcare concerns. In addition to new healthcare protocols, she discussed benefits available to returning Veterans, including counseling services. Ms. Malebranche's slide presentation can be found on the Advisory Committee on Gulf War Veterans website.

David Connor told the Committee that one of the main VBA Compensation and Pension Service outreach vehicles is the *Gulf War Review Newsletter* which is mailed to more than 220,000 Veterans who are on the Gulf War Registry as well as other interested parties.

In addition, the Compensation and Pension Service created a toll free helpline for Veterans. Established in 2003, the number of calls received is trending downward. The helpline received

more than 11,000 calls when it was established in 2003. By contrast, the helpline has received approximately twenty five hundred to date in calendar year 2009. Another resource for Veterans is the *Federal Benefits for Veterans Dependents Handbook*. The Compensation and Pension Service also generates fact sheets each time legislation changes about presumptive conditions. The fact sheets are communicated through the Public Contact staff in Regional Offices as well as through the VBA website. Mr. Cragin referred to this type of communication as “in reach,” meaning Veterans must take the initiative to go to VA in order to take advantage of the information rather than the information being pushed to the Veteran. Mr. Connor pointed out that there are instances when VA does direct mailings to specific Veteran cohorts.

David Schettler addressed the outreach program for the National Cemetery Administration whose customers are the Veterans’ family members, funeral home and cemetery directors, as well as living Veterans. NCA diligently strives to inform all Veterans of their burial benefits eligibility. Over the past seven years, NCA has conducted extensive surveys to measure the successes and failures of its outreach program and to solicit recommendations on how to strengthen its program. With only 12 percent of all Veterans buried in National Cemeteries and only 40 percent of deceased Veterans with VA provided headstones and markers, NCA continues to make outreach a priority. During 2008, NCA’s outreach activities included participating in a large number of ceremonies, events, and conventions. In 2007, the American Customer Service Satisfaction Index awarded the National Cemetery Administration the highest score ever awarded to a federal agency or private organization. Additional information about NCA outreach, benefits, and the new medallion benefit can be found under the Advisory Committee on Gulf War Veterans website.

Joyce Bounds discussed the overarching role of the Office of VHA Web Communication which is to provide oversight and accountability for the content on all of VHA’s websites. Approximately 80 percent of the content on the VA website belongs to VHA. In recent years, VA has moved to enhance the website by narrowing the scope of information and making the site Veteran focused--particularly on the outward facing sites--and to provide alternative outreach. She said if the Committee wanted a website for Gulf War I Veterans, she will help them establish it. She said there is not a specific Gulf War I Veteran website but rather pieces of Gulf War information in various locations on the VA website. To establish a specific Gulf War I website, it will be necessary to determine the content of the site, from where the content will originate, and who will manage the site.

The Office of VHA Web Communications will be participating in three VSO annual conventions to ask Veterans what they would like to see on VA’s website. She said it may be that certain Veteran cohorts need their own specific webpage. To further increase VA’s web presence, the VHA Web Communications Office also has been in discussion with the Iraq & Afghanistan Veterans of America (IAVA) about merging web efforts, with the goal of reaching as many Veterans as possible.

Ms. Bounds used the Returning Service Members (OEF/OIF) site, which was rolled out on January 20, 2009, to demonstrate VA website enhancements. She suggested that many of the website features can be used by Gulf War I Veterans. Easy to maneuver and esthetically appealing, the site was designed from the Veteran’s perspective with resources that include

information on benefits, family support, Guard and Reserve, and outreach. The site also includes a blog area. A copy of the presentation depicting the OEF/OIF Returning Service Members website can be found on the Advisory Committee on Gulf War Veterans website.

The Office of VHA Web Communications has also implemented mobile communication through the use of the iPhone, which VA has termed “Mobile VA.” VA’s mobile website uses existing content from www.va.gov and tailors it for display on the iPhone in a finger-friendly layout. iPhone users can access the site by going to m.va.gov. Veterans soon will be able to refill prescriptions and locate gravesites. VA is using capabilities that are available on the Internet but can be rolled over to the iPhone, with minimal cost to the Department. VA has also created a presence on such social networking sites as *Facebook*, *Youtube*, and *Second Life*. Ms. Bounds explained there are a myriad of legal, contractual, and policy issues that the Federal Government is considering regarding social media. As a member of the Federal Web Managers Council, she was one of the authors of the *Social Media and the Federal Government: Perceived and Real Barriers and Potential Solution* which explains some of the prevailing issues. A copy of the paper can be found on the Advisory Committee on Gulf War Veterans’ website.

Iraq & Afghanistan Veterans of America (IAVA)

Patrick Campbell, Chief Legislative Counsel

Patrick Campbell talked about the mission and work of IAVA which is headed by Executive Director and Founder, Paul Rieckhoff. The organization’s mission is to improve the lives of Iraq and Afghanistan Veterans and their families. Mr. Campbell stated that IAVA does not include Gulf War I Veterans in its membership constituency because the current Global War on Terrorism Veterans have very different needs from the Gulf War I Veteran cohort. He said that IAVA did not want to include the Gulf War I Veterans unless it could be sure their organization could appropriately and effectively represent the cohort. Mr. Campbell did say that IAVA may consider including Gulf War I Veterans in its membership at sometime in the future. The IAVA presentation can be found on the Advisory Committee on Gulf War Veterans website.

Gulf War Research: Using Multiple Brain Imaging Approaches to Understand How the Brain is Failing When GW Veterans Have Symptoms

John Hart, M.D., Professor of Neurology and Psychiatry, University of Texas Southwestern Medical Center

Robert Haley, M.D., Department of Epidemiology University of Texas Southwestern Medical Center

Dr. John Hart and Dr. Robert Haley presented a very comprehensive presentation on Gulf War I Veteran research. Dr. Haley is the Professor of Internal Medicine and the originator of the Division of Epidemiology at UT Southwestern Medical Center. Under a program that he and Dr. Hart currently work, Dr. Haley started a large brain imaging program to explain aspects of Gulf War related illnesses and to develop a diagnostic approach and treatment.

In 1994 after receiving a generous research grant from Mr. Ross Perot, Dr. Haley began a study of 24th Naval Reserve Mobile Construction Battalion personnel which included 21 chronically ill Gulf War I Veterans and 17 well Veterans. After returning from the Gulf War, the chronically ill Veterans began experiencing unexplained illnesses. The research team designed the experiment to test areas of the brain that would have been damaged if their illnesses were caused by Sarin or pesticides. His research found that there is a correlation.

Dr. Haley began his presentation by describing the symptoms of Gulf War illnesses and the various environmental exposures Gulf War I Veterans experienced. He then discussed in great detail the methodology and results of the brain research that has been conducted which clearly shows damage inside the Veterans' brains. Even though his initial test began shortly after the Gulf War, Dr. Haley said he would not rule out Gulf War Illness in a Veteran who begins showing symptoms seventeen years later. He said it is normal for people to lose neurons over time and that it is likely that an illness will eventually unmask in a person with brain damage as he loses neurons. Dr. Haley's desire is to continue his research with an objective test to further prove his research theory.

Dr. John Hart, also a member of the Advisory Committee on Gulf War Veterans, is an expert in semantic memory—how the brain stores and accesses knowledge. He has more than twenty-five years of experience in the study of the brain. Dr. Hart began by discussing how the brain stores memory in separate parts. He explained that people have words and the association with them, and they have sound, vision, smell, emotion, movement and touch. He and his partner have mapped out and published how and where all of these parts are stored in the brain as well as how knowledge is stored about information in the brain. These parts are put together in the brain to get the memory and then the person says the word. The leading symptom of a problem with this process is inability to find words.

Dr. Hart used a simple picture of a camel in the slide presentation to describe his point. He explained that there is not a spot in the brain that has cells that has camels, dogs, etc. but rather a person builds these things “on the fly.” There is no way to store this much knowledge in the brain and keep learning and learning, he explained. There is one color brown and it is attached to all of the brown things and must all be put together. One does not store brown multiple times nor is it stored with the object itself. There are features and categories in the brain, and they are put together to come up with the memory in forming the word to be used. The categories must be located in different spots otherwise the words cannot be put together. Dr. Hart and his partner designed a test to see how people put the memory together in the brain and then retrieve the memory. They were able to learn how the brain is activated when one finds the memory. In Dr. Hart's research, he found that Veterans with Gulf War illnesses or related illnesses have a problem making choices and inhibiting wrong responses. This shows up in all of their neuropsychological tests. As a result, Dr. Hart and his partners created the Semantic Object Inhibition Test to show how the brain responds for one to select a correct answer. Dr. Hart and Dr. Haley's complete presentation may be found on the Advisory Committee on Gulf War Veterans' website.

Public Comment Period

Public comments were received from the following Veterans and Veterans family members:
Denise Nichols, RN Major USAFR (Ret), National Vietnam and Gulf War Veterans Coalition
Pam Johnson, the mother of Gulf War Navy Veteran, David McKay, who died in April 2006
Edward Bryan, Staff Sergeant, U.S. Army (Ret)
Donald Overton, Army Veteran representing Veterans of Modern Warfare
Thomas Overy, Gulf War I Veteran from Whitman, MA

Closing Comments by the Honorable Charlie Cragin

In closing, Mr. Cragin asked the members to refer to the draft report which was included in the briefing packages. He asked the members to bring their five top recommendations to the next day's meeting. The Committee will deliberate on the recommendations as it begins to finalize their report.

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May 7, 2009

Present:

The Honorable Charles L. Cragin, Committee Chair

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Opening Remarks by the Honorable Charles L. Cragin

Mr. Cragin began the session by mentioning the absence of four of the Committee members but pointed out that there were enough members present to form a quorum. He told the members that Dr. Gordon Schectman would speak later in the afternoon about the VA strategic plan for the Post Deployment Integrated Care Initiative. The Chairman said prior to discussing Committee recommendations, he wanted to share with the members comments he received from David McKay's sister, Melanie. She had asked to speak to the Committee on May 7th about her brother's illness and death. Because a public comment period had not been announced in the Federal Register Notice for May 7th, Mr. Cragin said it would not be fair to others who would have otherwise asked to speak had they known of such an opportunity. However, he assured David McKay's sister that he would relay her comments to the Committee. She said that during her brother's illness and death, there were no family support mechanisms in place by either the military or the Department of Veterans Affairs. She did add that he was no longer affiliated with the military during his illness and at the time of his death. The Chairman relayed that there may have been some eligibility issues involved. However, he did mention that as the Committee had heard on the previous day, the Department of Veterans Affairs has now been a little more flexible in working with families and caregivers, particularly with psychiatric oriented issues, in order to help Veterans.

The Chairman then asked the Committee if there were any points of observation or issues members would like to discuss. Dr. Falk responded by asking how the Chairman foresaw the Committee proceeding after the meeting. The Chair said the Committee must produce a product that will be given weight. The Committee must be selective in the number of specific recommendations it makes and provide specificity in the recommendations. He said that there is nothing that says the Committee cannot express its concerns or make observations that are not necessarily specific recommendations. However, he suspects that the Secretary will want a metric of what the Committee wants accomplished. In addition, recommendations put forth by any of the members must be justified on the basis of relevance to the Committee's jurisdiction. He said that the Committee's tasking should be treated with the highest level of respect. The Chair went on to say that as the Committee begins its discussions, the members may require additional information from VA staff. He said that he would like to believe that VA would be responsive in a timely basis. However, if experience would be the indicator of responsiveness, he would not be optimistic that the Committee would receive the information in a timely basis. He said that the Committee has encountered what many Veterans have encountered—dilatoriness or a lack of responsiveness. He said that VA has a large coordination chain that takes months. The Chairman also said the Advisory Committee on Gulf War Veterans has waited months on information from VBA that has been moving along in the coordination process.

The Chair then explained that the reason why he asked everyone to come up with their top five recommendations is because it is important for the members to hear what each believes are the most important issues or recommendations. Mr. Cragin asked each member to opine their own top recommendations. The Chair stated that Committee Member Tom Plewes was unable to attend the second day of the meeting but sent his recommendations for consideration. The VA staff captured the recommendations and will synthesize them into a final report and deliver to the Committee in July. A brief summary of the recommendations are captured below:

- Reinstatement of Public Law 103-210 which allowed Gulf War Veterans to enroll into VA Health Care Priority Group 6.
- Identify the cohort of Gulf War I Veterans in healthcare and benefits databases for useful tracking and analysis.
- Focus on Gulf War I Veterans as a distinct cohort/group (other than Gulf War Registry).
- Apply the same objective diagnostic criteria to the VHA diagnosis/treatment aspects and the VBA rating of disabilities.
- Continue research to include providing a follow up exam for each Veteran who participated in the original registry exam. Use the information to chart the course of illness over time and research value to understand what has happened over time.
- Expand the Post-Deployment Care Model to serve all Gulf War era deployed personnel and support the nationwide rollout of the model.
- Bring back the Spouse and Children Registry.
- Implement training programs to ensure that all compensation and pension examiners, primary care clinicians, and contractor medical personnel/examiners (e.g. QTC) have a complete understanding of the ongoing research, decisions, health care risks and unique needs of Gulf War I Veterans.

- Conduct a twenty-year anniversary recall (outreach) to Gulf War Veterans: “Become a part of the second largest agency – come back to VA for healthcare services and benefits.”
- Through collaboration with DoD, develop a comprehensive list/database of GWI Veterans and then communicate with those Veterans. Include information that addresses family member issues, benefits, and resources.
- Accept the unanimous body of Gulf War Illness research, update the presumptions to be consistent with IOM findings, and make the presumptions indefinite.
- Replace term Undiagnosed Illness with Gulf War Illness, institutionalized by meaningful training, outreach, policy, and practice oversight.

Veterans Affairs’ Strategic Plan for the Post Deployment Integrated Care Initiative Model (PDICI) Roll-out

Gordon Schectman, MD, MPH, *National Director for Primary Care*

Dr. Schectman presented the VA strategic vision and background of the PDICI. He told the members that VA has been gearing up in primary care since the mid 1990’s and has assumed a national leadership role in terms of defining what primary care is, expanding primary care, and making primary care an essential element in the VA healthcare architecture. Close to seven million Veterans are currently enrolled in primary care. Dr. Schectman told the Committee that the objective of the PDICI is to provide comprehensive care to returning Veterans by using an integrated team of health care professionals who are knowledgeable in post combat medical, behavioral, and psychosocial problems. The integrated care team is comprised of a mental health provider, a social worker and primary care medical provider who work as a team to provide care that is tailored to the specific post combat healthcare needs of the individual Veteran.

The Chair shared with Dr. Schectman that one of the Committee’s considerations is to include the Gulf War I Veteran cohort into the Post Deployment Integrated Care Program. Dr. Schectman responded by saying that this Initiative provides the opportunity to do so. He went on to say that VA primary care staff are poised to provide the fulcrum to reevaluate Gulf War I Veterans with the same sensitivity, understanding and insight as they are now training themselves to address the OIF/OEF Veterans. Dr. Schectman said while the symptomatology might be different, fundamentally the concepts are the same. He went on to say that even amongst the OIF/OEF Veterans some of the illnesses are not clearly defined under standard medical diagnoses. Dr. Schectman commented that background in military medicine is very important to primary care and must be part of the training.

Mr. Cragin told Dr. Schectman that VA recently published a study that indicated that Gulf War Veterans who had certain symptoms when they came home from the Gulf War continue to have those symptoms. He said the Committee is concerned that many of the Gulf War Veterans were driven away from VA. They initially came to VA because they were sick but were told that their illnesses were psychological. He said the Committee wants the VA to recognize that there is a cohort of Veterans who went to war in good mental and physical condition but shortly after returning home began to hurt and their entreaties for care in many cases fell upon deaf ears. The Chairman said that when VA encourages these Veterans to come back, the Department needs to somehow ensure that they will be welcomed home seventeen years later as warriors—like the OIF/OEF Veterans—and not be sent home again telling them their illnesses are all in their heads.

Mr. Cragin called this “Sensitivity 101” because the primary care physician may have seen this Veteran more than once and may want the Veteran to express something new. Mr. Cragin also expressed his concern about the primary care physician’s reaction to a returning Gulf War I Veteran who says he does not have something new but the same illness as previously expressed. The Chairman went on to say that as VA undergoes this culture change, it must inculcate this sensitivity as the Secretary welcomes these Veterans back home. Dr. Schectman said he fully understands the Committee’s concerns. He reiterated that it is imperative that all healthcare professionals have background and training in this area and need to be prepared when Veterans do come back with undiagnosed illnesses that they are properly treated. Dr. Schectman’s full presentation is included on the Advisory Committee on Gulf War Veterans’ website.

Closing Comments by the Honorable Charles L. Cragin

The Chairman said that the Committee has now determined its top recommendations. He asked the VA Policy staff to put together a document that is ready for real substantive discussion which incorporates much of what has been said that has substance. The Chair would like for the document to have a metric for the Secretary to send to the Under Secretaries to implement along with implementing recommendations. Mr. Cragin said the document could also include a section with the things the Committee has heard and as well as Committee concerns. The report should also have discussion and justification and be succinct and to the point. Mr. Cragin asked Committee Member Randy Reese to draft some proposed language for the Committee to consider regarding presumptions for Gulf War Veterans. He then told the members the next meeting will take place July 15 – 16, 2009 and a final meeting on September 16, 2009 as outlined in the Committee’s Operations Plan. Mr. Cragin adjourned the meeting.