National Gulf War Resource Center
Operation Forgotten Warrior
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This is my statement for the record of the VA Research Advisory Committee on Gulf War Illness April 28, 2014 meeting, and is to be a part of the official minutes.

The 2014 edition of the *Gulf War Illness and the Health of Gulf War Veterans Report* produced by the VA Research Advisory Committee does an excellent job of cataloging myriad studies affecting Gulf War veterans. However, it also failed those veterans that it is to help. The committee produced a document that fell short, much like a baseball team that played a great game, only to quit after the 7th inning stretch.

That is because neither the primary report nor the executive summary recommended that the Secretary of the Department of Veterans Affairs conduct any kind of follow-up research in regards to the pilot studies cited within the report. While the CDMRP has conducted over 50 different research studies, the report does not comprehensively incorporate that activity into a single follow-on study. I believe the RAC should ask the Secretary to conduct such a larger study to move research and treatment forward.

This report also falls short by not giving the Secretary advice or tools to request increased funding for the much-needed research into diagnosis and treatment of Gulf War veterans. I do listen to those veterans, and I did try to get the report to include the precise recommendation on each pilot study that showed how it could be of benefit to Gulf War veterans. Many veterans know that trial studies do need to have a larger follow-up study validating the pilot studies, as many steps must be performed.

Moreover, the report does not point out to the Secretary the studies needing VA validation or which are the most important for follow-up; it only makes a blanket remark like the one on page 79 (entered in response to my public comments at the March 2014 meeting).

As a committee member, here is what I felt should have been a part of the Executive Summary. As I have said to the committee, we need to be direct in asking for the follow-on study(ies) that may really help sick veterans.

Statement for the record by James A. Bunker VA Research Advisory Committee on Gulf War Illness.
To be a part of the minutes of the meeting, April 28, 2014.

Gulf War Illness Treatment Research Recommendations

As of the Committee's report in 2008 until December 2013, there had been only four published studies of treatments for Gulf War illness. Of those four, we are able to recommend the following two for follow-up studies by the Department of Veterans Affairs:

1. **Baraniuk et al, 2013.** Irritable Bowel Syndrome (IBS) is one of the complaints of many Gulf War veterans -- and many non-veterans too. Dr. James Baraniuk's research found that administering an amino acid supplement containing L-carnosine reduced IBS associated diarrhea. We recommend to the Secretary that he conduct this cooperative follow-on study with Dr. James Baraniuk and Georgetown University. This treatment could not only help the Gulf War veterans with IBS, but many others that suffer from it too.
2. **Amin et al, 2011.** The CPAP treatment showed significant improvements in fatigue scores, cognitive function, sleep quality, and measures of physical and mental health. This type of research could lead to a treatment that would give back some quality of life without adding medications that can have dangerous side effects. We recommend that the Secretary conduct a follow-on study of this research to validate these findings.

Research Recommendations for disorders of concern reviewed:

1. **Wallin et al., 2012.** This study found that females of all races now have incidence rates for MS some three times those of their male counterparts. Dr. Wallin ended the research report by stating, "This study stated that more follow-up work is needed". This committee strongly recommends that the Secretary do a follow up study not only on the MS as per this study within the two years of this date; but this follow-up study needs to be conducted in such a way to incorporate the spirit of Public Law 110-389, 2008, Section 804. We recommend that the Secretary ask the Congress for the changes to Public Law 110-389, 2008, Section 804 to allow the VA to conduct the research. The research could then look at MS, MS type syndromes, Parkinson's disease, lung cancer, brain tumor / cancer and other neurological diseases with reports every 5 years.

2. **DYSPEPSIA; GERD vs. FUNCTIONAL DYSPEPSIA.** Since the 2008 report the Secretary made functional gastrointestinal disorders a presumptive illness for service in the Gulf War, but this was based on the lack of any proper research into the cause of the dyspepsia. While a number of surveys of Gulf War veterans showed that suffered from the symptoms of dyspepsia at a very high rate, there are no studies on veterans getting proper diagnostic tests to determine if they suffers from GERD or not.

   The clinical picture is further complicated because symptoms in GERD overlap with those present in functional gastrointestinal disorders (FGIDs), such as functional dyspepsia (FD) and irritable bowel syndrome (IBS). Currently, there is a need to determine if symptoms can be accurately and appropriately assigned to GERD or FGIDs and whether this is of any clinical value in determining assessment and management strategies. (E.M.M. Quigley 2006).

   We as a committee must make a recommendation to the VA to undertake a survey to determine true rate of GERD in the following subsets of veterans, showing the veterans location in subgroups as per combat and the March 5-20 dates due to Khamisiyah. The study needs to be using an Endoscopy to check for damage. Barium swallow is not good method to use, as it would miss 2/3 of the veterans with the GERD. We also request that the Gulf War registry exam be changed so that if a veteran has a complaint of dyspepsia he will be tested with endoscopy to check for damage.

I wholeheartedly believe that without these types of recommendations in the report, we will have failed sick Gulf War veterans like the thousands of veterans the National Gulf War Resource Center helps. This is but a shortened list of what I was seeking.

Respectfully,

James A Bunker

James A. Bunker
Executive Director, National Gulf War Resource Center
Committee Member of the Research Advisory Committee on Gulf War Veterans' Illnesses

Comparison of topics raised in James Bunker March 19, 2014 statement for the record with Committee report

The topics raised in the statement for the record are all addressed in the report. Most were in the report prior to March 19, and others were added following the submissions of comments and discussion by committee members. As in the case of all member submissions, it was not deemed necessary or appropriate to include every detail proposed.

1. Follow-on study about sleep dysfunction/sleep apnea

Historically, studies reporting on sleep dysfunction find that Gulf War veterans report greater rates of sleep and circadian disturbances relative to controls (Haley et al., 2004; Peacock et al., 1997; White, 2003). Sleep apnea results from two previous studies were inconsistent: Peacock et al. (1997) reported increased sleep apnea in Gulf War veterans, while Haley et al., 2004 did not. Animal studies modeling exposures experienced by Gulf War veterans showed sleep abnormalities in depleted uranium (Houpert et al., 2005; Lestaevel et al., 2005) and sarin exposed groups (Burchfiel et al., 1976; van Helden et al., 2004).

One study published since 2008 addressed sleep disturbances in symptomatic Gulf War veterans compared to age and obesity-matched asymptomatic Gulf War veteran controls (Table 6). Amin et al. (Amin et al., 2011a) found a significantly increased occurrence of sleep apneas, hypopneas and mild inspiratory airflow limitation in symptomatic veterans. Treatments utilizing continuous positive airway pressure (CPAP; see Treatments section) have shown early promise as treatments in symptomatic veterans with sleep disordered breathing (Amin et al., 2011b). p. 26

When a pilot treatment study funded by VA or CDMRP shows promising results and is judged to have scientific merit (such as the CPAP intervention in Gulf War veterans with sleep apnea), VA should follow up with a larger trial or other systematic assessment of the treatment's potential benefits. p. 79

[Comment: Competently-designed research studies take into account the medications a subject is taking. Many other factors are equally important. It is not necessary or appropriate for the report to prescribe this level of detail.]

2. Follow-on studies of GERD.

Research since 2008 continues to indicate that Gulf War veterans report being diagnosed with a variety of medical conditions at significantly higher rates than nondeployed era veterans. These include chronic digestive disorders, respiratory conditions, heart disease and skin disorders. Although consistently reported by Gulf War veterans, these conditions have not been further evaluated or characterized by epidemiologic or clinical studies. p. 36

VA's longitudinal survey can be effectively used to assess rates of physician-diagnosed medical conditions in Gulf War and era veterans. Survey data should be used to flag conditions of possible importance and followed up with detailed investigation, including any clinical evaluations that are required to determine specific medical diagnoses affecting Gulf War veterans at excess rates. p. 14

[Comment: Studies show that other digestive problems occur in Gulf War veterans at equal or higher rates than GERD, including irritable bowel syndrome and diarrhea. A general statement encouraging

further evaluation of digestive disorders, rather than one singling out GERD, is more far-reaching and appropriate. VA's longitudinal survey contains eighteen questions concerning digestive symptoms and disorders. The committee has not reviewed literature concerning detailed methodology for conducting digestive studies, and cannot make a scientific recommendation based on the unsupported statement of one member. These judgments would be made by the principal investigator proposing the study, who would be an expert in the field.]

3. Follow-on studies of cancers, skin diseases and mortality, by location, etc.

Since 2008, research using state cancer registries has suggested that there may be an increased rate of lung cancer in Gulf War veterans. Brain cancer mortality has been shown in two studies conducted by VA to be significantly increased in the subgroup of Gulf War veterans with greatest exposure to oil well fire smoke and to low-level nerve agents released by the destruction of Iraqi facilities at Khamisiyah. In general, cancer risk remains unknown and understudied. p. 36

Lack of current information on overall and disease-specific mortality among U.S. Gulf War veterans is an important issue. No comprehensive information has been published on the mortality experience of U.S. Gulf War era veterans after the year 2000. The 14 years for which no mortality figures are available represent more than half of the 23 years since Desert Storm. Mortality information from the last decade is particularly crucial for understanding the health consequences of the Gulf War, given the latency periods associated with many chronic diseases of interest. Despite specific recommendations over many years from both the current Committee and Institute of Medicine panels, federal research efforts to monitor the mortality experience of 1990-1991 Gulf War veterans remain seriously inadequate. p. 36

Ongoing monitoring and surveillance of the Gulf War veteran population is critical as this veteran group ages. . . Such surveillance should include outcomes described in this document, including Gulf War illness; neurological disorders, including Parkinson's disease; autoimmune conditions such as multiple sclerosis; brain, lung and other cancers; cardiovascular disorders and dysfunction; sleep dysfunction; adverse reproductive outcomes and birth defects; general ill health and disability; mortality and other disorders and outcomes that emerge as important during the surveillance process. p. 38

A study on the prevalence of "multiple sclerosis, Parkinson's disease, and brain cancers, as well as central nervous system abnormalities that are difficult to precisely diagnose" in Gulf War and recent Iraq/Afghanistan war veterans was required by Congress in 2008 (Public Law 110-389, 2008, Section 804) and should be carried out. These assessments should be repeated and published at a minimum of 5-year intervals.

A large national VA survey, currently underway, will provide some insight concerning the degree to which Gulf War veterans are affected by excess rates of neurological diseases. This longitudinal survey of VA's national sample of 30,000 Gulf War era veterans will, for the first time, include a more comprehensive assessment of physician-diagnosed neurological diseases, as reported by Gulf War and nondeployed era veterans. A second national survey, recently funded by DoD, will also query veterans about physician-diagnosed neurological and other diseases. Neither of these surveys, however, is a substitute for the rigorous epidemiological study ordered by Congress or recommended by past RACGWVI and IOM reports. p. 24

Research since 2008 continues to indicate that Gulf War veterans report being diagnosed with a variety of medical conditions at significantly higher rates than nondeployed era veterans. These include chronic digestive disorders, respiratory conditions, heart disease and skin disorders.

Although consistently reported by Gulf War veterans, these conditions have not been further evaluated or characterized by epidemiologic or clinical studies. p. 6

Systematic assessment of overall and disease-specific mortality in all Gulf War veterans and in specific subgroups of interest is essential. The results of these assessments should also be published at 5-year intervals. p. 38

Evaluation of health outcomes in Gulf War veterans in subgroups of potential importance is critical as some health outcomes are related to specific exposures and experiences in theater. These subgroups can be defined by suspected or documented exposures in theater, geographical locations in the Gulf War theater or other predictors. p. 39

It is important that VA work with the DoD Congressionally Directed Medical Research Program (CDMRP) to establish guidelines for improved methodology in Gulf War research that can be included in requests for proposals and subject to research application reviews. Such guidelines should include the following:
- Systematic methods for assessing symptoms and other health outcomes in Gulf War veterans.
- Evaluation of health outcomes in Gulf War veteran subgroups of importance—for example, subgroups defined by relevant exposure history or location in theater.
- Consideration of subpopulations with multiple health outcomes. p. 37

4. Follow-on study regarding CPAC

When a pilot treatment study funded by VA or CDMRP shows promising results and is judged to have scientific merit (such as the CPAP intervention in Gulf War veterans with sleep apnea), VA should follow up with a larger trial or other systematic assessment of the treatment's potential benefits. p. 79

5. Follow-up of Wallin study of the rate of multiple sclerosis in veterans from 1990-2007, and by subgroups.

[Comment: The report criticizes the Wallin study because it did not address whether 1990-1991 Gulf War veterans have higher rates of multiple sclerosis:] Despite concerns raised by veterans' groups in relation to MS rates in Gulf War veterans, as well as Congressional directives and previous RACGWVI and IOM recommendations, the only MS study that included veterans of this era was not designed to determine if Gulf War veterans are affected by excess rates of MS. . . The study did not . . . distinguish 1990-1991 Gulf War veterans from veterans who did not serve in a warzone or those who served in other periods through 2007. p. 24

[The report recommended VA immediately conduct the study of the prevalence of MS in 1990-1991 Gulf War veterans ordered by Congress in 2008:] A study on the prevalence of "multiple sclerosis, Parkinson's disease, and brain cancers, as well as central nervous system abnormalities that are difficult to precisely diagnose" in Gulf War and recent Iraq/Afghanistan war veterans was required by Congress in 2008 (Public Law 110-389, 2008, Section 804) and should be carried out. These assessments should be repeated and published at a minimum of 5-year intervals. p. 38

Evaluation of health outcomes in Gulf War veterans in subgroups of potential importance is critical as some health outcomes are related to specific exposures and experiences in theater. These subgroups can be defined by suspected or documented exposures in theater, geographical locations in the Gulf War theater or other predictors. p. 39

Gulf War theater exposures, age and other variables likely moderate pathobiological effects and should be carefully addressed in research. p. 12

In some studies that have included female Gulf War veterans, it appears that gender differences may play a role in the pathobiological expression of Gulf War illness and its effects. Gender should be considered whenever possible in mechanistic and treatment research on Gulf War illness. p. 12

6. Follow-up studies of seizures, nerve pain, strokes, and migraines.

Although neurological conditions are a prominent concern for Gulf War veterans and research has found an elevated incidence of amyotrophic lateral sclerosis (ALS), rates of multiple sclerosis, Parkinson's disease and other neurological diseases (e.g., seizures, stroke, migraines) in Gulf War veterans are currently unknown. Research studies on the prevalence of neurological diseases have not been conducted despite repeated recommendations by this Committee and the Institute of Medicine and explicit legislation by Congress. The prevalence of these disorders is particularly important because they can be expected to increase as the Gulf War veteran population ages. p. 6

[Comment: Training for caregivers is not within the Committee's statutory and chartered role.]

7. Follow-up studies of immune dysfunction.

Six of eight studies conducted on immune system alterations in Gulf War veterans since 2008 showed immune dysregulation. Research in this area appears to be narrowing in on changes occurring to the expression of certain cell lines. Additionally, changes occurring during or following exercise reiterate that immunological (and other) manifestations of Gulf War illness may only become apparent in specific experimental or clinical settings under "challenge" conditions.
The Committee recommends that research on the pathobiological underpinnings of Gulf War illness and ill health in Gulf War veterans continue to focus on the central and autonomic nervous systems and on immunological and neuroendocrine outcomes in this population in order to identify targets for treatment interventions and outcomes that should be improved during such treatments. p. 12

Increased emphasis should be placed on the study of alterations in regulatory dynamics both within and across the principal regulatory axes, including the endocrine, immune and nervous systems. These should include response to standardized challenges at different time scales, i.e. acute response to exercise, circadian rhythm, and monthly cycles as well as long-term illness progression. Statistical analysis should be integrative and deployed across these interacting systems whenever possible using methodologies that formally acknowledge regulatory control. pp. 12-13

Studies that evaluate systemic immune and endocrine parameters in animal models, with an emphasis on those parameters that sensitize ill veterans to Gulf War illness, should also be informative. p. 11

Since the 2008 Committee report, the immune-related outcome studies in Gulf War veterans have been primarily performed by Klimas, Broderick and colleagues. p. 68

[Comment: The immune system is receiving close attention. Additonal human studies are already funded at four locations, including follow-on work by Dr. Klimas, plus animal studies.)

8. Improvements in methodology of research studies.

It is important that VA work with CDMRP to establish guidelines for improved methodology in Gulf War research that can be included in requests for proposals and subject to research application reviews. Such guidelines should include the following:

1. Systematic methods for assessing symptoms and other health outcomes in Gulf War veterans.
2. Evaluation of health outcomes in Gulf War veteran subgroups of importance—for example, subgroups defined by relevant exposure history or location in theater.
3. Consideration of subpopulations with multiple health outcomes. p. 9

9. Inclusion of a subgroup of southern watch veterans that would have some exposures but not all, to control for certain exposures.

[Comment: The idea behind this proposal is that veterans who served in the same theater in the mid-1990's should also be included in research studies because they would have had the same "background" exposures as the 1990-1991 Gulf War veterans (heat, sand, disease, etc.) but not the exposures particularly associated with the war (pyridostigmine bromide, overuse of pesticides, low-level nerve agents, oil well fires, etc.) However, it has already been possible to rule out these background factors as potential causes on the basis of studies already done. In deed, it was possible to rule them out on the basis of the studies conducted prior to the 2008 RAC report. Thus, there is no need to study this additional cohort and incur the fifty percent additional cost of having a third cohort.]

10. Follow-on study regarding Baraniuk L-carosine treatment findings.

In a study on symptomatic Gulf War veterans, Baraniuk (2013) found that administering an amino acid supplement containing L-carnosine reduced irritable bowel syndrome (IBS)-associated diarrhea (Baraniuk et al., 2013). p. 73

When a pilot treatment study funded by VA or CDMRP shows promising results and is judged to have scientific merit, VA should follow up with a larger trial or other systematic assessment of the treatment's potential benefits. p. 14

11. Deletion of "Pre-Decisional Draft Strategic Plan for Gulf War Illness Research," formerly Appendix A.

[Comment: This appendix has been deleted, based on comments from several committee members.]

12. Follow-on studies of treatments where research shows potential benefits.

When a pilot treatment study funded by VA or CDMRP shows promising results and is judged to have scientific merit, VA should follow up with a larger trial or other systematic assessment of the treatment's potential benefits. p. 14

My name is Glenn Stewart. I participated in Desert Shield & Desert Storm with 13 Signal Battalion, 1st Cavalry Division. My symptoms are and have been confirmed by the WRIISC in Washington, DC of which I participated on March 10, 2014, IBS, Fibromyalgia, Chronic Fatigue Syndrome, Mental Cognitive dysfunction, Sleep Apnea, etc... These are ailments by which I submitted claims with the VA and are considered presumptive conditions to Gulf War Illness. However, every single item has been denied on the claims request and are in appeal status with a hired attorney working the case. My appeals started in 2012 and have yet to be resolved. So in essence the Veterans Administration will say these health issues are presumptive to GWI, but at the local level they are still denying claims for such either intentionally or failure to educate local raters and reviewers on current policy. Why do I say intentionally? Because as you can see on the last C&P many of the items missed, errors made and downright lies I have highlighted in red with bullet comments indicating what is wrong with the entry.

We have all heard this story told over and over. I have gone as far back to view video footage of veterans like Brian Martin testify before hearings back on September 20, 1996 and still to this day Gulf War Illness has not been resolved and we have been brushed under the carpet just as the VA did with Vietnam veterans afflicted with Agent Orange. Watching the footage has shown me, that you can practically play the first hearing and just hit the rewind button and play it all over again. Same story and same disregard for veterans suffering from Gulf War Illness, both by the Veterans Administration and our President.

I want to tell you a story.

Please close your eyes & picture this - I want to tell a story of a veteran of the 82nd Airborne Division & veteran of operation Just Cause in Panama & veteran of operations Desert Storm & Desert Shield. Timothy Gable was my brother's name. A husband, a father & great patriot who loved his country.

In 2010 Timothy submitted claims with the VA due to health issues related to Gulf War Illness (Joint & muscle pains, CFS, sleep disorder, etc...). Then came the wait, the denial, the appeals and still waiting for the VA to help this brother & his family. He had to quit his job as a correctional officer in December 2012 due to health issues.

On May 28th, 2013, he seemed okay, but that night around 6 PM he said he felt really bad and was going to go to bed and try to sleep it off. He came downstairs from the bedroom but seemed really disconnected (it's hard to describe, but like he wasn't really with it). His wife goes upstairs to check on him. She talks to him for a minute, but gets a sense that he is not even aware he is talking to her. She says "I am going downstairs to eat". Suddenly she hears the horrifying sound & can smell the burning in the air. She yells "Tim what was that?" However her heart already sinks before she even ask and runs to his side of the bed, as she already knows the answer. She runs to his side of the bed just to see his eyes flutter & her suspicions confirmed. Tim is gone, another victim of the VBA red tape.

He left behind a loving wife & a beautiful young daughter which was 16 at the time & how was & will always be "Daddy's little girl". Timothy wanted & fought to live for his family. However as his ailments progressed & mental cognition deteriorated, his body & mind were done fighting. GWI on this day claimed another victim & left behind loved ones to deal with the emotional scares.

Just recently their daughter attended her Prom & it is heartbreaking, because I can only imagine how much Tim would have loved to have been a part of this event. The given right of all fathers to stare down their daughters prom date with a glaring look that says it all "Get out of line young man & there will be trouble".

RIP Timothy Gable RIP.

As a veteran suffering from this illness and new to advocating for fellow veterans, I will be pushing forward for the following changes to the VA system

1) The RAC should NOT report to the VA & have its members appointed by the VA. This is totally illogical. Would the dog ever bite the hand that feeds it? In doing so the VA is at full liberty to ignore any recommendations by the RAC or simply say "At ease that noise". And force the RAC into compliance.
2) The RAC needs teeth. A dog with just a bark and no bite has no validity for protection. The RAC needs to report directly to The House Committee of Veterans Affairs with its own budget. The RAC makes recommendations to the house; these get passed into laws and then the RAC police and would report violation of the laws and push for prosecution.
3) The request for Gulf War veterans to participate in WRIISC research needs to be made available online so that veteran can submit their own request to participate. Currently at the local level the referral process is not working. It took me 9 months to get a referral to the WRIISC and that is only because I printed out all the documents, e-mails and MyHealthyvet messages and walked into the patient advocate's office. It is NOT OUR job to educate the local PCP's on the procedures and current policies.
4) The practice of using the term of CMI and the push by Under Secretary Allison A. Hickey must stop. I and other veterans I have spoken with find this terminology highly offensive. We view this as another attempt by the VA to camouflage Gulf War Illness and lump everything under one umbrella. In the past the term of Gulf War Syndrome was used. This is no longer acceptable since the term is an implied condition. Several researches have blown the myth of syndrome and the ideology that this is a psychosomatic condition in nature away. This is in fact an illness and as such the correct term must be referred to as "Gulf War Illness".

Thank you,

Glenn Stewart

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RAC Meeting
April 28 - 29, 2014

Thank you Dr. Jesse and all committee members for allowing me to speak to you today about Gulf War Illness and health care issues affecting veterans from the 1990-91 Persian Gulf War (Desert Shield/ Desert Storm).

My name is Mike Jarrett, CW2 USA retired. In early August 1990, I deployed to Saudi Arabia with a small rapid deployment advance party with the 703rd Provisional Watercraft Company, 7Th Transportation Group in support of operation Desert Shield. Our advance party was the third plane to land at Dhahran airport. As Soldier-Mariners our mission was to provide waterborne Logistics which is offloading U.S. combat power from sealift ships and placing that combat power ashore in a ready to fight configuration. I sailed on a U. S. Army ocean going tugboat between the ports of Dhahran, Al Jubayl, and Khafji in support of logistical operations. My unit redeployed state side in August 1991.

The 7Th Transportation Group's watercraft assets are the most deployed units in the U.S. Army so it wasn't long before I was deploying again, this time to Panama to support construction projects in Central and South America. During the deployment process I had an adverse reaction to dental treatment. Afterwards, I felt as if I had some type of flu that just wouldn't go away. I felt less energetic, and experienced frequent headaches, painful joints, severe diarrhea, numbness in my extremities, and chest pains. I was sick and felt ashamed, I was unable to pass the Army physical fitness test, and spent more time seeking medical care than performing my military duties. I was diagnosed with a sliding type hiatus hernia, acid reflux (GERD), Irritable bowel syndrome, migraine headaches, carpal tunnel syndrome, and spinal stenosis. I requested an early retirement, and retired from active military service in March 1996.

I've decided to maintain a positive outlook. I wish I could stand here today and tell you about the excellent healthcare that I have received from the VA. There are many excellent people in the VA who have bent over backwards trying to help me. Unfortunately the reality is Gulf war Illness is controversial and our symptoms are mysterious, they don't fit known medical criteria. There is no cure. Unfortunately, there are many VA physicians who still view our symptoms as psychological. I'm hopeful my remarks will lead to positive improvements in VA healthcare.

In 2003, thinking that the VA would have a better understanding of Persian Gulf War health issues, my family physician (whom I had been seeing since retirement) recommended that I seek treatment from the VA to find answers to the causes of my symptoms. My employer was requiring yearly FMLA forms because of the lack of control associated with Irritable bowel syndrome, unexplainable neurological symptoms, and numerous medical appointments were interfering with my performance at work. I was experiencing severe muscle & joint pain and right-sided neurological events for a lack of better words.

My first appointment with the VA healthcare system was with the Harrisonburg VA CBOC. The primary care nurse that I seen was excellent, she bent over backwards trying to help me. She referred me to neurology and rheumatology. Unfortunately my symptoms don't fit known medical criteria. At one point the Rheumatologist at the Martinsburg WV, VAMC called me and told me it would be a waste of my time to come to my appointment because they had done every test known to modern medicine, and they couldn't find anything wrong. I honestly believe those doctors were simply frustrated – I base this opinion on the following remarks transcribed in my medical records:

- "He seems to simply have a propensity for developing such pain. I cannot say that he has classic fibromyalgia, although I do find similar complaints among many of my FM patients. I

certainly cannot find any evidence of underlying autoimmune disease."

- "Possible somatiform disorder."
- "Patient is encouraged to seek evaluation by a local neurologist since he seems convinced that he has a "nerve problem". Apparently he believes he was exposed to a "nerve gas" while serving in the gulf war."
- "He is concerned about his legs; at times the legs don't seem to follow brain commands (paraphrased). Unfortunately I have nothing to offer to evaluate his leg complaints. Should I be of service in the future he may return."

My family physician is also frustrated. He has witnessed the neurological "events" and believed that I had classic Multiple Sclerosis. He sent me for a MRI of the brain. The MRI showed mild diffuse cerebral atrophy, but failed to demonstrate a demyelinating process. In writing he has stated that I have a "not yet formally recognized disease process that mimics Multiple Sclerosis."

The Harrisonburg, VA CBOC sent me back to the Martinsburg WV, VAMC for another MRI of the brain, but the MRI results was normal (?).

In 2012 I had another neurological "event" and even though I didn't have an appointment I went to the Harrisonburg, VA CBOC hoping they could see the "event." I was told they would record it in my medical files, but I needed to go see my doctor because my blood pressure was high and they didn't have a doctor available to see me. Unfortunately, the "event" was not recorded in my medical files, only a follow up call the next day. After this "event" I have developed new symptoms that I did not have before such as recurring skin rashes and fluctuating blood pressure. Symptoms that I had previously have worsened especially the fatigue. My family physician believes these "events" are a MS like flare.

Last year, I transferred from the Martinsburg, WV VAMC to the Salem, VA VAMC hoping for better care and a firm diagnosis. My new primary care doctor sent me to a dermatologist for treatment of my skin rashes. Also, she got me a new MRI of the brain. The MRI revealed bi-frontal lobe atrophy mostly within the cephalad aspect of the frontal lobes. The report suggests the atrophy is on a congenital / developmental basis or reflects neurodegenerative changes.

I've received all MRI images and reports at the request of my family physician. He plans to send me to the University of Virginia Neurology Department so they can compare the images.

I requested through my new primary care team, a referral to the War Related Illness and Injury Study Center (WRIISC). Unfortunately, the Staunton CBOC doesn't have the computer program needed to make the referral; the Inter Facility Consult (IFC) process in Computerized Patient Record System (CPRS). My new primary care doctor is working on the issue.

I've participated in a couple of studies at the NJ WRIISC. In order to do so I had to pay for my travel and lodging expenses. I was willing to do so because part of the research included a neuropsychological evaluation from the Kessler Foundation that shows my cognitive executive function (resistance to interference) is impaired and cognitive executive function (verbal fluency) is borderline. Many veterans are willing to participate in research, but don't have the financial means to do so.

As I said earlier, I'm hopeful my remarks here today will lead to positive improvements in VA healthcare. Here are suggestions I would like to put out to this committee:

- Improvement in communication between VA facilities is desperately needed. Physicians that treat ill Gulf War Veterans at the WRIISC or anywhere else should be able to share knowledge with primary care providers at the CBOC level. Referrals to specialty clinics (WRIISC) should not take six months or a year.
- Each state needs at least one clinic that specializes in research based treatments for GWI.
- Ill Gulf War veterans need to see one primary care physician long term, in the past I've been bounced back and forth between PCP's.
- Travel and lodging needs to be a part of the funding for research.
- Agree on a definition for Gulf War Illness, chronic multisymptom illness is too confusing.
- Affected Veterans need the benefits they earned.

Thank you.