Date: 23 July 2013

#### A Thank You, and 1991 Gulf War Illness and RAC Changes: A Historical Perspective

Honorable Secretary Shinseki Department of Veterans Affairs Central Office (VACO) 810 Vermont Avenue, NW Washington, DC 20420 CC: US President; US House Committee on Veterans' Affairs; US Senate Committee on Veterans Affairs; US Senator Merkley; US Senator Wyden; and US Representative Defazio

To Whom It May Concern:

First, please do not stigmatize me because of my mental illness.

Next, I would like to thank the Indianapolis Regional Office for awarding me 100% Total and Permanent disability for my medical aliments, which includes the very disabling schizoaffective disorder. Sadly, my illnesses do not allow me to be employed as a chemical engineer, biological scientist, which I have a degree for both, or as an employee in any other environment. Since medication does not help me with most of my positive, negative, and cognitive symptoms of schizophrenia, I am considered a refractory schizophrenic. Also, I cannot handle a gram of stress any longer. Initially, and directly after the 1991 Gulf War, I was diagnosed with Generalized Anxiety Disorder (GAD), which, according to the US Veterans Affairs, is often a precursor to schizophrenic and bipolar disorders. GAD has been definitively connected to 1991 Gulf War Illness too[21]. Although I believe that some errors occurred and the claims process promotes suicidal thinking, most people at the Indianapolis Regional Office were friendly.

Sadly, I was denied compensation for my 1991 Gulf War Illness. I was denied even though I was diagnosed with 1991 Gulf War Illness by US Veterans Affairs War Related Illness and Injury Study Center (WRIISC). As you should know, the US Veterans Affairs usually touts the US VA WRIISC as the experts on 1991 Gulf War Illnesses. In fact, my WRIISC physician contacted the Indianapolis Chief of Compensation and Pension on my behalf because she could not understand why I had been denied. Sadly, I am a part of several 1991 Gulf War veterans groups on Facebook and the prevailing belief is that most 1991 Gulf War veterans are denied compensation even though presumptions exist. Because of financial security, I did not appeal the 1991 Gulf War Illness claim decision by the Indianapolis Regional Office. If I appeal, it is possible that I could lose my 100% Total and Permanent disability rating for my schizoaffective disorder, which would be detrimental to me financially and medically. As an example, I often throw away new food because I believe my food has been poisoned—I have olfactory and gustatory hallucinations, gag, and I cannot eat or drink. That is quite costly. Also, I have dental problems.

I hope I am not retaliated against for writing this letter to US Veterans Affairs Secretary Shinseki, my Congressional Representatives, and the US President. I hope I do not lose my 100% Total and Permanent disability rating. I say that because of the recent VA whistleblower and Senior Epidemiologist, Dr. Coughlin, and recent VA changes to Congressionally Chartered Research Advisory Committee On Gulf War Veterans' Illnesses (RAC). Also, it appears that the Veterans Affairs is operating as a rogue agency since it is ignoring US House Committee on Veterans Affairs requests[20].

# Many 1991 Gulf War Veterans Are Concerned About Congressionally Chartered Research Advisory Committee On Gulf War Veterans' Illnesses (RAC) Changes

Sorry, but the situation is complex and this is going to be a long letter. I should state now that I trust Congressionally Chartered Research Advisory Committee on Gulf War Veterans Illnesses (RAC) position on the issues mentioned in this letter.

First, thanks for your continued interest. The situation really is dire because time is of essence, and some veterans could, in the worse case, be denied future compensation and go homeless or commit suicide. I was on that route before receiving Veterans Affairs disability compensation in February 2013.

# Brief Political History of 1991 Gulf War Illness and RAC

During the 1991 Gulf War, I, like many soldiers, was given experimental medication and I had severe reaction to that medication. Also, I was attached with the 24th Infantry Division and chemical detector alarms sounded. We were told that the alarms were false-positive. Now, we know that our generals had decided to bomb chemical weapons manufacturing plants in Iraq, and the chemical detector alarms went off the days after that bombing[4;4a]. During that period, we were likely bathed in low-dose chemical weapons. Also, we were given pyridostigmine bromide during that period, which goes against FDA recommendation since pyridostigmine bromide can exacerbate the effect of nerve agent. In addition, large bunkers were destroyed with chemical weapons in place.

Many 1991 Gulf War soldiers experienced symptoms during the 1991 Gulf War. When we returned, the DOD and VA stated our symptoms were psychological and due to stress. During the 1990s the Senator Riegle report verified the chemical weapon exposure[5]. Because of the large number of veterans complaining of symptoms; CIA, DOD, VA denial, the Congressionally Chartered Research Advisory Committee on Gulf War Veterans' Illnesses was created by Congress in 1998[6]. Still, the Veterans Affairs stone-walled the creation and members were not appointed until 2002 by Secretary Anthony J. Principi[6].

After many frustrating years, the RAC decided to prepare and release a report, year of 2008, that, similar to a large peer reviewed journal article, scientifically proved that 1991 Gulf War Illness was real, debilitating, and likely connected to pyridostigmine bromide, overuse of pesticides, and possible other environmental exposures[7]. Prior to that release, the members of Congressionally Chartered Research Advisory Committee on Gulf War Veterans' Illnesses (RAC) testified before Congress, year of 2007. Here is a quote from Chairman James Binns who is a Vietnam veteran and Harvard lawyer:

*Year 2007 Quote:* "This government manipulation of science and violation of law to devalue the health problems of ill veterans is something I would not have believed possible in the United States of America until I took this job. Until this practice is stopped, the products of Gulf War illnesses research will be distorted, misleading the Secretary, Congress, veterans' doctors, and the scientific community." [Mr. James Binn, Committee Chair, Congressionally appointed Research Advisory Committee on Gulf War Veterans' Illness (RAC), Vietnam veteran, Harvard Law Graduate, 8]

Some members of RAC believe some Veterans Affairs bureaucrats were furious about the release of the RAC 2008 report[7]. Why? Because some bureaucrats at the Veterans Affairs have stoned walled 1991 Gulf War Illness research and Agent Orange research[1]. In fact, Veterans Service Organizations discuss such political relationships as well[22].

*Year 2013 Quote:* "5. The individuals behind the recent staff pushbacks are some of the same people that Congress was concerned about in 1997, who have built their careers on minimizing the health consequences of toxic exposures. Dr. Michael Peterson, currently in charge of post-deployment health research at the VA Office of Public Health, was a principal investigator of the 1987 update to the Ranch Hand study that concluded Agent Orange had no adverse effect on the health of Vietnam veterans. Dr. Kelly Brix, currently DoD co-chair of the Deployment Health Working Group subcommittee that co-ordinates VA/DoD research policy, was a staff member of the 1995-1997 Presidential Advisory Committee that concluded the likely causes of Gulf War Illness was stress." [Dr. James Binns, Chairman of RAC, 1]

#### A Suggestion and RAC 1991 Gulf War Veteran Member

Sadly, the situation is quite complex and combines law, science, medicine, and politics. To help relieve the complexity, I suggest you read Dr. James Binns' 3 page letter[1] because it highlights some of the numerous problems that Congressionally Chartered Research Advisory Committee on Gulf War Veterans' Illnesses (RAC) has faced. The RAC June 2012 document is more detailed[2]. Also, I suggest you read the 1991 Gulf War Veterans RAC member letter to Secretary Shinseki[3].

Next, I can give my opinion, but I would like to suggest you speak to Gulf War Veteran RAC member, Anthony Hardie, because he has been involved for many years and has an outstanding understanding. As such, he can likely elaborate on the points I make. He has testified before US Congress, US House Committee on Veterans Affairs, on several occasions. Before you and Anthony communicate, you might want to read the 1991 Gulf War Veterans RAC member letter to Secretary Shinseki[3]. In fact, Anthony Hardie uploaded the letters[1;3;23].

## Some Points About RAC Changes

In addition to changing the charter and possibly relieving the Veterans Affairs of responsibility with respect to 1991 Gulf War veterans' illness research,

As an example, removal of: "The guiding principle for the work of the committee shall be the premise that the fundamental goal of Gulf War health-related government research, either basic or applied, is to ultimately improve the health of ill Gulf War Veterans, and that the choice and successes of research efforts shall be judged accordingly. The Committee shall assess the overall effectiveness of government research to answer central questions on the nature, causes, and treatments for health consequences of military service in the Southwest Asia theater of operations during the 1990-1991 Gulf War." [Removed from 6th RAC charter; 24]

the Veterans Affairs leadership, Secretary Shinseki, has made a decision to replace Congressionally Chartered Research Advisory Committee on Gulf War Veterans' Illnesses (RAC) membership. Part of that change is Dr. James Binns, Chairman of RAC, and six other members to be decided. Rotation and member changes have always been allowed in the charters, but have not occurred since the inception of RAC. Chairman Binns has long been a strong advocate for 1991 Gulf War veterans. Many 1991 Gulf War veterans are concerned about the sudden change[9].

Some RAC members believe the membership change is due to a scathing June 2012 RAC report that asked to have some VA bureaucrats removed from duty. Why? Because there are some VA bureaucrats that have consistently been a road block to needed research into 1991 Gulf War Illness. As an example, 2/3 of the research dollars were cut without RAC agreement. Once again, I suggest you read the letters: "Letter from Dr. James Binns, Chairman of Congressionally Chartered Research Advisory Committee on Gulf War Veterans' Illnesses (RAC) to Hon. Jose D. Riojas, Interim Chief of Staff of Secretary Eric Shinseki, US Department of Veterans Affairs (VA), May 29, 2013"[1] and "Letter From RAC-GWVI Gulf War Veteran Members--Anthony Hardie, Marquerite Knox, Joel Graves--to Secretary Eric Shinseki, US Department of Veterans Affairs, June 10, 2013."[3].

# A Year of 2013 Veterans Affairs Whistleblower

Please note that Dr. Coughlin, past VA epidemiologist and recent, March 2013, VA whistleblower verifies RAC concerns of VA incompetence.

*Year 2013 Whistle-blower Quote:* "Twenty to thirty percent of these veterans were also Gulf War veterans, and the study produced data regarding their exposures to pesticides, oil well fires, and pyridostigmine bromide pills. It also included meticulously coded data as to what medications they take. The Office of Public Health has not released these data, or even the fact that this important information on Gulf War veterans exists. Anything that supports the position that Gulf War illness is a neurological condition is unlikely to ever be published." [Dr. Coughlin, Senior Epidemiologist and Veteran Affairs Whistleblower, 10]

## Why is research so important in the 1991 Gulf War Illness case?

First, research should lead to understanding and treatment, and many, approximately 1 in 3, "250,000", deployed veterans are suffering from 1991 Gulf War Illness. If research dollars are spent in the wrong area, understanding of mechanisms will not be realized. From what I understand, RAC members believe the charter changes allow the Veterans Affairs to possibly research the role of stress in 1991 Gulf War Illnesses even though science and medicine has long proved that stress research is not the appropriate direction. As such, stress research spends precious dollars that could be used in other areas of research that might lead to understanding and treatment.

With that said, I am not saying that stress is not a factor. As an ill 1991 Gulf War veteran, I cannot handle a gram of stress. I was diagnosed with Generalized Anxiety Disorder (GAD) directly after the 1991 Gulf War, and I am now service-connected for schizoaffective disorder and 100% Total and Permanent disabled. As previously mentioned, GAD has been definitively connected to 1991 Gulf War Illness. As a pharmaceutical chemical engineer and whistleblower, stress from whistleblower retaliation exacerbated my 1991 Gulf War Illness and precipitated schizoaffective disorder. The VA notes that GAD is often a precursor to schizophrenic and bipolar disorders. Yes, stress chemicals are endogenous and can exacerbate 1991 Gulf War Illness, but stress is not the likely "cause". Rather, an exogenous chemical is likely the cause, chemical weapons; experimental medication; overuse of pesticides[7]. Why is that important?

Both VA medical doctors and VA researchers need to realize that exogenous chemicals are likely the cause of 1991 Gulf War Illness. In fact, all researchers should be aware. Like damage to the cutaneous skin organ from exogenous chemical burns, the human brain is susceptible to exogenous damage as well[11]. In fact, endogenous stress chemical can physically damage and change the brain as well[12]. Wait, didn't I just say that stress was not the cause! Yes, I said that research has shown that stress is not the likely cause.

In fact, research has shown a correlation between chemical detector alarms and 1991 Gulf War Illness symptoms, nerve death[13-13c]. Also, past and recent research has shown brain damage[7;14-15a] and correlation to symptoms. In addition, researchers are investigating the role of brain inflammation with respect to 1991 Gulf War Illness[16] Still, the actual "cause" of 1991 Gulf War Illness is not definitively known because it happened so long ago.

What is known is that we 1991 Gulf War veterans were a part of the most toxic war in US military history[17]. Also, 1 in 3 deployed veterans are experiencing symptoms. For many, the illness destroys an ability to work. Sadly, it appears that many are denied compensation too[17]. In fact, I was denied my compensation claim for 1991 Gulf War Illness even though Veterans Affairs War Related Illness and Injury Study Center (WRIISC) diagnosed me with 1991 Gulf War Illness. The US Veterans Affairs has said the WRIISC are the intra-institutional experts on 1991 Gulf War Illness. What was I compensated for?

Initially, I was 70% compensated for schizoaffective disorder and awarded 100% Individual Unemployability with my 1991 Gulf War claim deferred. A second rater and compensation evaluator denied my 1991 Gulf War Illness claim, but he called me and told me that he was increasing my schizoaffective disorder claim to 100% Total and Permanent because the first rater grossly underrated me. How is this connected to the above? Brain inflammation and white matter disease has been implicated in schizophrenic symptoms[18], schizophrenia and bipolar are suppose to be highly genetic, and I cannot find

any present or past family members with schizoaffective, schizophrenia, or bipolar disorders. As such, I personally believe my schizoaffective was caused by my 1991 Gulf War Illness. Why is that important?

As an example, I have been told by a eminent 1991 Gulf War researcher that epidemiological researchers are investigating if there is a higher prevalence of schizophrenic and bipolar disorders as compared to the US population on average--There might be a sub population of ill 1991 Gulf War veterans suffering from schizophrenia or bipolar disorders. Please note that the US National Institute of Mental Health lists schizophrenia as the most devastating severe mental illness known. The World Health Organization lists schizophrenic disorders as 1 of 10 worse diseases known to man. Often, schizophrenics are homeless. Is there a possibility that some 1991 Gulf War veterans are schizophrenic because of their service and homeless? Only research out of the research group of stress is, in my opinion, likely to determine that factor. Such research is important for compensation purposes too. Wait? I was compensated. Yes, I was also diagnosed with Generalized Anxiety Disorder (GAD) while in the military. As such, I had a service connection, and many veterans might not be that lucky. Remember GAD is often a precursor to schizophrenic disorders.

I realize I said 1991 Gulf war researchers are investigating if there is a statistically likely increased prevalence of schizophrenic and bipolar disorders among the 1991 Gulf War veteran population. As such, an answer might be found. That answer will be determined because something other than stress has been considered.

Also, I believe now is a good time to mention that combat PTSD is lower in the 1991 Gulf War population as compared to other veteran populations. It is well known that combat PTSD is due to combat stress. With that said, I do not minimize those veterans that did see combat during the 1991 Gulf War. Many Iraqis died, such enormous numbers of death are not natural, and we must respect the death of any human being. I know because I was a part of some battles during the 1991 Gulf war as a member of the 24th Infantry Division. I have also been diagnosed with combat PTSD by two US VA psychiatrists but claim denied. Once again, I am not appealing the decision since I have 100% Total and Permanent disability for schizoaffective disorder. Like 1991 Gulf War Illness, I would appeal based on principle, but I cannot afford to lose financial and medical security. Still, I am advocating for less fortunate and ill 1991 Gulf War veterans. Please do not reduce my 100% rating.

## **RAC Changes**

The Veterans Affairs change the regulations based on scientific research. In fact, the law requires the Veterans Affairs to use the National Academies, or comparable Institute, to evaluate the scientific research and make decisions. Once the evaluation is accomplished, the Secretary has a period to decide if he will make regulatory changes based on the National Academy findings. The National Academy findings are based upon available research. When the National Academies perform their evaluation, they eliminate many studies from the evaluation because the studies do not meet their criteria. As such, funds are often wasted in research-hate the word "wasted" because such research might have revealed important results. For this reason, a unified "case definition" is needed. Also, research is mostly dependent upon Government funding-Ross Perot has actually funded some of Dr. Haley's research, and research dollars are precious. As such, Congressionally Chartered Research Advisory Committee on Gulf War Veterans' Illnesses (RAC) would like to concentrate VA research in the appropriate direction that is most economical and scientific. It makes no sense to continue an investigation into areas that provide no substance. In fact, the National Academies Institute of Medicine found that 1991 Gulf War Illness is not due to any "psychiatric" illness. With that said, 1991 Gulf War illness can cause psychological problems, Chronic Fatigue, Irritable Bowel Syndrome, Fibromyalgia, Undiagnosed Illnesses, etc[19].

The RAC charter is a legal document and is intended to guide the RAC in a direction of investigating the research direction of the Veterans Affairs. In the past, the RAC looked at other Government research as well. To RAC, it appears the Veterans Affairs has manipulated the charter to eliminate RAC's ability to effectively investigate the research direction. Remember, the US Congress created the RAC as an entity to evaluate the US Government research into 1991 Gulf War Illness because parts of the US Government were stone walling. Sadly, VA politics have come into play and the RAC believes VA has purposefully retaliated against the RAC because the RAC did their job[2;7].

#### Wouldn't membership change be better since it brings a new set of eyes?

In most cases, change would be beneficial. In fact, I will go as far as to say that it might be beneficial if there is political gridlock too. With that said, political gridlock should not be created as a means to cause change for nefarious purposes. In other words, politics should not affect the outcome of science. Let properly directed research science speak for itself[19].

#### **Personal Statement**

Well, that is my take. I could have made some errors. I am sorry for the long letter, but the situation is complex as it involves many agencies. More importantly, it involves people.

Also, I want all to know that I realize the US Veterans Affairs is a very large organization. Like any large organization, there are stars, average, and dead-beats. Sadly, each person represents the US Veterans Affairs. As such, we 1991 Gulf War veterans will often generalize to Veterans Affairs. With that said, we are often reminded about our positive experiences too.

For me, my life has been saved twice by the US Veterans Affairs. I was saved when I had a large liver abscess, and when I was awarded compensation. Instead of going homeless, I would have likely committed suicide. If you don't know, suicidal ideation is common among schizophrenics[25].

I now beg you to properly investigate Dr. Coughlin's, Senior Epidemiologist and VA whistleblower, allegations. Also, I ask that an investigation ensue regarding RAC changes. Finally, I believe both investigations should be accomplished in the public eye.

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I hereby certify that the information I have given is true to the best of my knowledge and belief.

Have a nice day!

Chris Harding, 100% T&P Disabled 1991 Gulf War Veteran Email: <u>harding.cb@gmail.com</u> Dr. David D. Hatfield

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January 7, 2014

Research Advisory Committee - Gulf War Veterans Illnesses

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Re: Comments on Discussion During Morning RAC-GWVI Session - January 7, 2014

Chairman Binns and members of the Committee,

Someone from the Veterans Administration (VA) (identity unknown) made a comment not long before the lunch break, in response to the discussion about an article in the *Journal of Military Medicine* written by doctors at the New Jersey War Related Illness and Injury Study Center (WRIISC) discussing how Gulf War Illness (GWI) followed a pattern from the Civil War to Operations Iraqi and Enduring Freedom (OIF/OEF). A follow-on comment was made that a C&P reviewer had actually quoted this article in denying service-connection for a Gulf War veteran's illnesses, saying it was "all in his head." The unidentified VA person said that was not the position of VA and she said if you asked veterans, researchers, or clinicians they would tell you that isn't the position of the VA (to paraphrase her comments).

That is simply not accurate. First, the VA's own research agenda predominantly has been focused and continues to focus on stress as a cause and mindfulness and mental wellness as treatments, and other psychological and psychiatric aspects of GWI, something both the RAC and Gulf War veterans have complained about for years. Second, a VA clinician at the Baltimore VAMC personally told me with an insulting, dismissive wave of his hand, "There is no such thing as Gulf War Illness. It is nothing but a somatoform disorder." Third, many claims adjusters in the VBA still believe there is no such thing as GWI, witness the thousands of denied GWI claims that are stuck in the BVA appeals system logjam today.

The Primary Care Physicians simply do not know what to think, because most of them seem not to have received, did not understand, or do not remember the GWI training, nor do they have the pocket cards they should have to explain exposure-related issues to them (which were not very thorough to begin with). So I am convinced the WRIISC article's authors' opinions are more prevalent in both the VHA and the VBA than the unidentified speaker believes.

Please make this letter part of the official record for the January 7-8 RAC-GWVI Meeting.

Thank you.

Very Respectfully,

//signed//

David D. Hatfield, D.M., M.S.

SGM, US Army (Retired)

Dr. David D. Hatfield

1620 Old Bay Ln

Severn, MD 21144

January 8, 2014

Research Advisory Committee - Gulf War Veterans Illnesses

Boston University School of Public Health

715 Albany Street, T4W

Boston, MA 02118

Re: Comments on Discussion During Morning RAC-GWVI Session - January 8, 2014

Chairman Binns and members of the Committee,

Chairman Binns, I appreciate your coming into the control room to try and capture comments from those of us remaining on the line, and am sorry it did not work any better for you than it did. I do not believe it was intentional on the part of the VA, but it does seem odd that it happened when it did. In any case...

After listening to the rest of the testimony on 7 and 8 January, it became more clear than ever to me that the VA, even after all these years, has absolutely no intention of listening to the needs of ill Gulf War Veterans, no intention of obeying either the letter or spirit of the legislation enacted by Congress in regard to the health of ill Gulf War Veterans, no intention of returning the RAC's authority to oversee federal research that promotes the health of ill Gulf War Veterans, and has little sense throughout the organization of where it even stands on issues related to ill Gulf War Veterans.

Despite the best efforts of you and all the previous members of the RAC-GWVI, and those of all the people who have tried to work with the VA, Congress, and DoD to promote issues related to the health of ill Gulf War Veterans, the VA is simply not interested enough to take the necessary actions. The time for attempting to work with this monolithic behemoth who flouts the law, flouts the will of Congress, belittles the very Veterans it is charged with caring for, and refuses to listen to those responsible for providing it with the information it needs to perform its mission is over.

Bureaucratic power only responds to power in return. For government bureaucrats, their biggest fear is losing their funding and their jobs. Congress exercises the power of their funding and the administration exercises the power of their jobs. Congress and the administration respond to political pressure from people. Nothing gets the public and the resultant political pressure going like hundreds of thousands of ill veterans marching on Washington, phoning their Senators and Representatives every day, showing their faces and telling their stories in the media every day, all across the country.

It's time for action by an enraged constituency to force Congress and the Administration to answer for the sins of the VA. The VA must know what it feels like to suffer from the pressure the ill Gulf War Veterans have been feeling for over 22 years. I promise to do everything within my power to make this happen, and to make it happen now!

Please make this letter part of the official record for the January 7-8 RAC-GWVI Meeting.

Thank you.

Very Respectfully,

//signed//

David D. Hatfield, D.M., M.S.

SGM, US Army (Retired)

From:	<u>Glenn</u>
To:	rac; <u>"WRIISC.DC"</u>
Cc:	<u>"Zoellner, Erik"; tony.grant68@gmail.com; "Angela Gable"; pwdalt@gmail.com; robert.cliburn@gmail.com;</u> dlashell@comcast.net; tgmccullough70@gmail.com; dsvet91@outlook.com
Subject:	RAC meeting Jan 7 & 8. Also WRIISC examination.
Date:	Friday, January 10, 2014 12:01:53 PM

To members of the VA Research Advisory Committee:

I am very disappointed with Dr. Nancy Klimas last remarks at the end of the RAC meeting on January 8, 2014, when she stated – they have been using some of her methods for over a decade, but none of them have been disseminated throughout the VA system for use in other clinics. She request that the veteran be their own advocates because many physicians (within the VA) don't believe the illness is anything but psychiatric. Others, she said, don't have time to read the training manual VA put out to help them care for Gulf War veterans, they don't have more than 15 minutes to deal with each patient, or they don't know how to refer sick veterans to specialty clinics where they can get care — and some simply don't care to learn.

How can sick Gulf War veterans be their own advocate, when many of us are suffering from severe mental cognition problems? That is like asking a 3<sup>rd</sup> grader to complete their parents tax return. I mean please let us get real.

One thing I stated during the comment section is the fact that submitting a request to register for a WRIISC examination is practically impossible. You want proof? See all the correspondence between myself, my PCP office via My HealthVet & the WRIISC. I have been asking for months to submit my name to the WRIISC just to fall on deaf ears. The instruction outlined for the PCP to make the request via the VA IFC system as so clear & they even provide pictures. Seriously the information I provided on how to make the request is step by step & so simple. I myself could make the request one eye blindfolded, hand tied behind my back & only using a pencil to hit the keys.

The VA states they have several presumptive conditions added for Gulf War Illness. However in the real people world chances are if you submit a claim for IBS, TBI, etc you will get denied just as I was. Also when the VA deny your claims they will always say over and over again "We could not find a service connection". Now the question is 1) What doctor on active duty or even civilian world had any clue as to what was happening to us? Did any GWI veteran ever get a clear dx saying "I Dr Thor of Asgard proclaim YOU to have IBS, TBI, etc...? Common sense, you are not going to find any direct diagnostics rendered for Gulf War service and as a matter of fact to include today.

I know that several veterans have already sent their e-mails expressing their views. I want to first thank the RAC for taking this time to hold this meeting & I also want to apologize if this

e-mail comes off as crude. With my mental cognition problems, I do not have the mental capacity to write eloquent letters as others have. My letter are straight to the point. This is the year things MUST change for Gulf War veterans. NO MORE EXCUSES. I have on several occasions requested the VA to join me via Google+ hangouts for a live interview, but have never received a single response. Just in case anyone is having a hard time opening any of the images, you are more than welcome visit my Gulf War Syndrome page via the link below. In there you will find a album titled "My request to War Related Illness and Injury Study Center (WRIISC)". Here is a direct link to the album & post - https://plus.google.com/110321549524619427432/posts/SkJciTmgJsc

Thank you, Glenn Stewart US Army & NG retired Gulf War Illness casualty and advocate Phone: 918-876-3249 E-mail: <u>gstwt1960@gmail.com</u> or <u>gulfwarillness1@gmail.com</u> Webpage: <u>https://plus.google.com/110321549524619427432/posts</u> YouTube channel: <u>http://www.youtube.com/user/GulfWarIllness1</u> August 26, 2013

Robert L. Jesse, M.D. Principal Deputy Under Secretary for Health Veterans Health Administration U.S. Department of Veterans Affairs 810 Vermont Avenue, NW Washington, DC 20420

Dear Dr. Jesse,

Thank you for taking the time to meet with me on Friday, August 9, 2013. This letter memorializes our meeting, describes the serious government failures that continue to harm hundreds of thousands of Gulf War Veterans, and outlines specific and immediate reforms expected by Gulf War Veterans related to Gulf War Illness.

I look forward to meeting with you again in September as we agreed, with the expectation that the Department of Veterans Affairs (VA) will by then have made substantial progress remedying the specific, significant concerns we discussed and which are further described in detail in this letter as well as the documents listed below.

Please be mindful of history. Because of widespread corruption within the Veterans Administration after World War II, President Harry Truman named retired Army General Omar Bradley to clean house at the beleaguered agency. His wise quote below should provide guidance to leaders at the Department of Veterans Affairs:

"We are dealing with Veterans, not procedures; with their problems, not ours."

During our meeting, you asked me to describe the "disconnects" within VA that prevent the agency from providing healthcare and benefits to the more than 250,000 Veterans who deployed to the 1991 Gulf War and who remain ill due to toxic exposures in Southwest Asia. In summary, VA has failed Gulf War Veterans for more than two decades and continues to fail our generation at every turn. VA itself is entirely disconnected from the needs of ill Gulf War Veterans.

As you are aware, VA intentionally blocks meaningful scientific research. This lack of meaningful government research then blocks the search for answers, treatments, and

appropriate disability compensation plus other benefits. VA's failures on this issue start at the top, and they permeate the entire department.

As we discussed, though VA may not want it, VA desperately needs independent and objective input as well as to listen carefully to the needs of Gulf War Veteran patients. Without significant outside input, VA's current leaders, including you, will remain unable to lead the department on these issues for several reasons. Nearly all of VA's leaders lack a clear understanding of the many issues raised by Gulf War Veterans and the Research Advisory Committee on Gulf War Veterans' Illnesses (RAC), Gulf War scientific research, and the suffering and needs of the more than 250,000 ill Gulf War Veterans.

And for you personally, you are further hindered by your lack of military training or experience, lack of war theater deployment, and lack of experience with toxic exposures, which are disconcerting given your new role as VA's "point person" on Gulf War Veteran health and benefit issues. Reaching out to me is appreciated, yet there are so many more actions VA must take on the issue.

In preparation for our August 9 meeting, I e-mailed you vital reading materials, including:

- September 7, 1997, "Bi-Partisan House Report on Gulf War Veterans' Illnesses" that led to the passage of the "Persian Gulf Veterans Act," Public Laws 105-277 and 105-268 in 1998, including the creation of the RAC.
- December 4, 2012, "Statement for the Record," by 14 leading Gulf War Veteran advocates to the House Veterans' Affairs Committee listing specific reforms.
- June 10, 2013, letter to VA Secretary Shinseki by all the Gulf War Veterans on the RAC objecting to his effective termination of the RAC's mission.

For our nearly two-hour meeting, you and Dr. Madhulika Agarwal had no apparent agenda beyond what is described in the next paragraph, and you both admitted you were not prepared to understand VA's rampant, continuing failures or the practical recommendations previously made by Gulf War Veterans and the RAC. You appeared to be unaware of key reports, investigations, and participants, especially those impeding scientific research, and you showed a lack of preparation for our meeting.

Worse than being unprepared, you repeatedly attempted to shift the focus of our meeting to your apparent ultimate objective: how could I help you to improve VA's

tattered reputation. I remind you now as I did during our meeting that VA's tarnished reputation among Gulf War Veterans was caused by VA's ongoing failures. For example, when I discussed restoring the RAC to the correct 2010 version, you stated it would be an embarrassment to Secretary Eric Shinseki to change it.

The goal of Veterans remains unchanged and momentum is growing: to restore the RAC and enhance the RAC's abilities to provide recommendations to the Secretary that will be heeded. You, VA, and Veterans need the RAC, which faithfully executes the mission intended by Congress in 1998.

The best way to fix VA's wholly deserved negative public image problem is to promptly and adequately address the underlying issues. If you attempt to continue VA's ineffective efforts and merely spin these issues away, without long overdue meaningful fixes benefiting a large group of ill Veterans VA was created to assist, then you can rest assured you will be personally responsible for further tarnishing VA's image.

In an apparent effort to deflect from the travesties current VA leaders are inflicting on Gulf War Veterans, you brought up the Secretary's 2010 favorable decision to provide healthcare and disability benefits for hundreds of thousands of surviving Vietnam War Veterans sickened by Agent Orange/dioxin while deployed to Southeast Asia. The scientific evidence and laws justifying the decision were overwhelming and clear. The Secretary made the right decision, and I strongly supported it.

However, VA's tardy decision came only after four decades of bureaucratic VA delays and denials while untold thousands of Vietnam War Veterans suffered and died without VA treatment and benefits.

I am concerned that you apparently failed to grasp that VA's decision regarding Vietnam War Veterans does not impact the more than 250,000 ill Gulf War Veterans that were the subject of our meeting. Tragically, some of the same former VA and Department of Defense (DoD) officials responsible for delays in providing Vietnam War Veterans their earned healthcare and benefits now delay inquiries into Gulf War Veterans' illness.

Gulf War Veterans are newly reinvigorated, increasingly unified, and will not wait decades for answers, care, or benefits. Gulf War Veterans reject VA's vicious attempt to delay care and benefits by kicking the can down the road to the next Secretary and President to review in the future. We remain firmly committed to the development of effective treatments, and demand change at VA *now*. VA must not repeat the delays

that harmed so many Vietnam War Veterans, nor continue the denials and delays that continue to harm Gulf War Veterans. We do this in part so Afghanistan and Iraq War Veterans do not suffer the same fate.

Gulf War Veterans were encouraged by the Institute of Medicine 2010 Gulf War panel, which stated that, with the proper research, effective treatments, cures, and preventions are likely to be found for the chronic multi-symptom illness that afflicts more than one-third of Gulf War Veterans. For VA to continue to deliberately refuse to pursue the right research is unconscionable. We are frustrated and irate that VA does nothing when there is the real probability that effective treatments can indeed be found, as the IOM stated in 2010.

During our meeting I took notes. However, I remain troubled that you and Dr. Agarwal took no notes at all, suggesting your lack of interest in anything I had to say on behalf of my fellow Gulf War Veterans or my two decades of experience uncovering toxic exposures, testifying before Congress, drafting legislation, and working at VA on this subject.

I remain deeply disappointed that you and Dr. Agarwal refused to admit any VA current or past error during our meeting, specifically:

- VA's failure to acknowledge the widespread extent, neurological nature, and toxic causes of Gulf War illness and corresponding failure by VA and DoD to conduct meaningful scientific research into Gulf War Illness treatments for more than two decades (with the exception of the Congressionally directed, treatment-focused Gulf War Illness research program run *outside* regular DoD and VA research efforts).
- VA's failure to provide effective medical care and appropriate disability benefits to hundreds of thousands of disabled Gulf War Veterans suffering from Gulf War Illness.
- VA's failure to honestly and properly contract with the Institute of Medicine to review matters related to Gulf War Illness.
- VA's failure to address or even respond to RAC recommendations and letters by Gulf War Veterans.
- VA's failure to address key toxic exposures, including, but not limited to the radioactive and toxic heavy metal depleted uranium and chemical warfare agents such as sarin, cyclosarin, and mustard poison gases.

 VA's failures in flouting the law (PL 105-368) by essentially killing the RAC in May 2013, which was in blatant retaliation for the RAC's June 2012 unanimous vote of "no confidence" in VA's staff and the RAC's apparent role in a March 13, 2013, Congressional oversight hearing that provided an important glimpse into the metastasizing cancer that afflicts VA's research and affects all eras of Veterans on issues ranging from Gulf War Illness to burn pits and beyond.

Therefore, in addition to the 1997 Congressional report, other Congressional hearings on Gulf War illness, several IOM reports citing a lack of DoD and VA research into the health effects of toxic exposures, the Veterans' statements to Congress, and the Veterans' letter to the Secretary, I restate Gulf War Veterans' legitimate and reasonable expectations, some of which we discussed during our meeting and other parts of which are fully described in testimony, reports, and correspondence to VA leadership, all of which remain wholly unaddressed by VA:

- 1. VA must adopt the recommendations made by the RAC since 2002. Nearly 16 years after Congress condemned VA and created the RAC in response to abject VA failure of an entire generation of Veterans, the VA still has a "tin ear, cold heart and closed mind" with regards to Gulf War Veterans. VA must respond in a timely, complete, professional, and public manner to the recommendations made by the RAC by fully implementing the RAC's recommendations; or, VA must fully and publicly justify in writing why full implementation is not possible. VA must fully address the series of issues raised in the RAC's many reports, including the RAC's June 12, 2013, "no confidence" report.
- VA must fully address the recommendations from Gulf War Veterans contained in other documents: the December 4, 2012, Statement for the Record; the March 13, 2013, hearing of the House Veterans' Affairs Committee; and the June 10, 2013, letter to Secretary Shinseki.
- 3. The Obama Administration must address the cancer inside VA and DoD by rooting out and permanently removing all VA and DoD staff abusing their positions by working against the interests and health needs of Gulf War and other Veterans injured by toxic exposures and other deployment health hazards. For years, these individuals abused their positions and influence, including through the Deployment Health Working Group, to spin rather than address legitimate deployment health issues, much as you and Dr Agarwal sought to do during our meeting. These personnel include but are not limited to: Dr. Kelley Ann Brix, at DoD's Office of Force Health Protection and Readiness; Dr. Michael R. Peterson and Dr. Aaron Schneiderman, at VA's Office of Public Health; Dr.

Timothy O'Leary at VA's Office of Research & Development; Dr. Charles Engel, at DoD's Deployment Health Clinical Center; Dr. Frances Murphy, at the Institute of Medicine; Dr. Mark Brown, previously at VA but now within DoD's deployment health field.

- 4. VA must immediately terminate the IOM panel on creating a case definition for Chronic Multi-symptom Illness in Gulf War Veterans. This expensive panel was neither directed nor authorized by Congress. With the current and recently expanded psychosomatic focus of many of its panelists, this specific IOM panel is detrimental to the legitimate health interests of Gulf War Veterans. In its place, VA must fully heed and implement the RAC's recommendations for creating a new Gulf War Illness case definition as specified in the original VA Strategic Plan on Gulf War Illness research, prior major detrimental edits by wayward VA staff.
- 5. VA must take the necessary actions to correct the definition of the Southwest Asia theater of operations (war zone) so it accurately includes deployment to Israel, Turkey, and adjacent areas (38 Code of Federal Regulations § 3.317). This is fully described in detail in the Gulf War Veterans' December 4, 2012, Statement for the Record to the House Committee on Veterans' Affairs. The military recognizes these geographic areas as eligible for receipt of the "Southwest Asia Service Medal," and these Veterans were also exposed to toxins while deployed. VA's continued unjust refusal to include these Gulf War Veterans denies them their justly earned healthcare and disability benefits.
- 6. VA must restore public accountability on Gulf War Veterans' disability claims by reinstituting the quarterly claims reporting reports. These Congressionally mandated quarterly public reports were formerly known as the Gulf War Veterans Information System reports, and later as the Pre-9/11 reports (PL 102-585 § 702). The RAC provided important recommendations on these reports in a February 1, 2012, report to VA. The RAC's report was ignored by VA. The RAC's recommendations must be addressed and the quarterly public reporting a demonstration of a commitment to public transparency about the consequences of war and VA's response to Veterans' needs must be restored.
- 7. VA must restore the VA-DoD project for the creation and maintenance of the Virtual Lifetime Electronic Records. Without accurate record collection, retention, and access to confirm toxic exposures or other military events, Veterans are often denied essential VA healthcare and disability benefits. The lack of records often prevents scientists as well as IOM literature reviews from determining the impact of toxic exposures on service members and Veterans. The military admits records were destroyed during the 1991 Gulf War as well as subsequent military operations in Afghanistan and Iraq, placing an unreasonable burden on Veterans

to find evidence of medical conditions that began in or were exacerbated by service.

8. Finally, VA must immediately restore the RAC's 2010 Charter and retain James Binns as RAC Chair. VA flouted the law and its publicly stated intent by gutting the RAC's treatment-focused oversight mission. Your claim to me that VA needs to have streamlined procedures for advisory committees is not only false, but it flies in the face of the publicly stated intent of Congress that in 1998 created the RAC as a watchdog oversight body intended to keep then entire federal government on task to develop effective treatments for ill Gulf War veterans, a task at which VA has utterly failed and continues to fail. I am truly disappointed in your lack of historical understanding regarding the creation of the RAC for the benefit of Veterans, VA, Congress, and objective scientific inquiry.

I recognize that you, Dr. Agarwal, and I agreed to a meeting in mid-September. However, it should go without saying that a meeting with only more talk, no notes, and no follow-through actions by VA shall not be enough. VA must demonstrate substantive action *prior* to our next meeting. If there are no substantive VA improvements as well as ongoing dialog with the RAC and Veterans, then the meeting will be yet another empty VA gesture that only serves to demonstrate VA's continuing demonstrated intent to further delay research, treatment, and benefits for an entire generation of Veterans.

In the time leading up to the landmark legislation that created the RAC and provided a foundation for Gulf War Veterans' research, healthcare, and benefits, Congress concluded in September 1997, after 19 months of hearings, that VA's efforts were fatally flawed. In the prelude to creating the RAC to help oversee and watch over VA's breathtaking failures of Gulf War Veterans, Congress described VA:

We find [VA's] efforts hobbled by institutional inertia that mistakes motion for progress. We find those efforts plagued by arrogant incuriosity and a pervasive myopia that sees a lack of evidence as proof. As a result, we find current approaches to research, diagnosis and treatment unlikely to yield answers to veterans' life-or-death questions in the foreseeable, or even far distant, future.

In plain English, Congress concluded VA was saying a lot, but doing little to nothing to actually improve the lives of Gulf War Veterans ill due to wartime toxic exposures. Today, we Veterans find ourselves "back to the future," and dealing with this exact same mentality throughout a VA more concerned about image than substance, more concerned about words than achievements, and more concerned about procedures than Veterans.

With or without you, Gulf War Veterans will work to ensure that VA complies with adhering to our nation's solemn obligation to leave no Veteran behind. Rest assured that the public image issues about which you seem so single-mindedly concerned will only worsen should VA fail to make long-overdue and substantive improvements.

VA needs to earn the trust of Veterans. I hope you will take this opportunity to work *together* with me, fellow Veterans, and the RAC for the benefit of our ill Gulf War Veterans, whose interests and needs are clear, legitimate, and unfulfilled. A list of Gulf War veteran leaders who read and support this letter appears below. I look forward to hearing from you soon about our next meeting date as well as verifying the concrete steps VA is taking to *now* improve the lives of our nation's Gulf War Veterans.

Sincerely,

nuliar

Paul Sullivan Gulf War Veteran 913 Saddlebrook Circle Cedar Park, TX 78613

Joined by fellow Gulf War Veterans: Brent Casey, Daniel Fahey, William Fuzi, Joel Graves, Peter Greene, Erik Gustafson, Anthony Hardie, Marguerite Knox, Chris Kornkven, Vera Roddy, Charles Sheehan-Miles, and David Winnett.

- CC: The President
  - The Honorable Bernie Sanders
  - The Honorable Richard Burr
  - The Honorable Jeff Miller
  - The Honorable Michael Michaud
  - The Honorable Jason Chaffetz
  - The Honorable John Tierney
  - The Honorable Mike Coffman
  - The Honorable Ann Kirkpatrick

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National Gulf War Resource Center 3725 Jordan Circle Roanoke, VA 24012 Toll Free (866) 531-7183 Fax: 785-235-6531 President@ngwrc.org

www.ngwrc.org

# January 7, 2014

Chairman Binns, distinguished members of the Research Advisory Committee, and members in attendance. My name is Ronald Brown and I serve as the President of the National Gulf War Resource Center.

I would like to speak to you about the Forgotten Warriors II Program. This program is a work in progress created with the purpose of helping the Veterans Administration to better serve the needs of us sick Desert Storm Veterans and to better the relationship between these Veterans and the Veterans Administration. One can find it at ngwrc.net our sister site.

The NGWRC has set out to fix this by going to the veterans of Operations Desert Storm who are sick and asking them to help us by telling what they felt were the main issues they found at the VA hospitals they used. The foremost issue that kept arising was a need for better education of the primary care physicians on the illnesses specific to service in the Gulf War.

A sick veteran should not have to educate their primary care physician on their illnesses, the current research, or the programs available to them.

One example of this need for education of the physicians that

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recently happened after veteran had gone thru Dr. Baraniuks' study and the results from the study were released, the veteran took them into his primary care doctor to share with them. The physician glanced over it, and threw it in the trash stating it was only 28 veterans who went through it. Well this veteran was one of the 28 those results were based on, so did it matter to this veteran? Yes it did.

Another example is when one of these sick Desert Storm veterans ask their primary care physician for a referral to the War Related Illness & Injury Study Center (WRIISC) which is a VA program originally set up for our sick veterans from Operation Desert Storm. Often, the primary care physicians tell them they do not have a clue what the program is, and when the veteran brings in a copy of the brochure on this program, the primary care physician then says it's only for our current veterans. Because the brochure now only mentions OIF/OEF veterans and TBI injuries, naturally the physicians do not think this program applies to the sick Desert Shield/ Desert Storm veterans. Unfortunately, this happens quite often.

I cannot tell you how many times I myself have had to take studies in to my doctors who had no idea that the research had even been done. Some were open to using them in the treatment of my illness; others never even bother to get around to reading them. Research is only good if the medical professional will

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take the time to read it and apply it. Only then will it perhaps help in the treatment of these sick veterans, but it should not fall to the veterans to have to bring these studies to the doctors.

The point here being why do we spend millions upon millions of dollars on research if the results are not read by our medical professionals and applied to treating the sick veterans? What good does it do?

I would like to mention an example from my own experiences regarding a service connected illness many Desert Shield/ Desert Storm Veterans have. I suffer from severe Fibromyalgia. I asked my primary care doctor to be referred to Rheumatology for better treatment of my illness since they are the experts on this illness. I waited and waited, and I eventually got a letter from them stating there was nothing they could do for me and because of the current backlog of new patients, I would not be seen. Because of the backlog and inability of the VA to provide care for me on this issue, I have to travel to DC every 6 months, out of my own pocket, to be seen by Dr. Baraniuk who is a Rheumatologist. I can assure you I am not the only sick veteran this has happened to. I have spoken to many sick veterans from other VA hospitals that have had similar experiences. This expense is heartbreaking because I have to seek treatment outside the VA, at my own expense, for a service connected illness. The primary kind of issue that the VA was created to

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help veterans deal with.

Another issue Desert Shield/ Desert Storm Veterans have is with the guide to social workers that the VA uses. This publication lists all the medals for every war from World War II, Korea, and Vietnam, then it Jumps to our current wars OIF and OEF. It has pictures of all the medals veterans of these wars are authorized to wear; however there is one missing. The <u>Operation Desert</u> <u>Storm awards</u> are not even listed in this VA manual. This is part of why this project is called the Forgotten Warriors II Program. Very often, as mentioned previously, within the VA Literature on available programs, health issues, and benefits, we are forgotten.

When our nation called on us we stepped forward without hesitation to do whatever our country asked us to do. Today, 23 years later, we are still fighting for adequate care because we became ill from our service in Operations Desert Shield/ Desert Storm and the veterans of Southern Watch.

The forgotten warrior II project is not about bashing the VA which is where many of us get our health care, it's about building a better relationship between the VA and the sick Desert Shield/ Desert Storm veteran. There is no room for finger pointing in finding a solution that benefits both parties. I do feel this can be achieved through better education of our primary

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care physicians on the illnesses we the Desert Storm veterans suffer from because no warrior should ever be forgotten no matter which war they served their country in.

Thank you for your time.

Ronald E. Brown President National Gulf War Resource Center Appendix C Sep 15, Public Gomment 6 - Ronald Brown Jan 7, 2014 RAC-GWVI Meeting Minutes January 7-8, 2014 Page 199 of 204

Mr. Ronald Brown 3725 JORDAN CIR ROANOKE, VIRGINIA 24012

Dear Mr. Brown:

I submitted the consult for Rheumatology evaluation yesterday as you requested. Thi morning I received the following response:

RHEUMATOLOGY CLINIC (NO RESTR. - MD REVIEW) Orderable Item: Is the person entering this request a Resident/Student? No REASON FOR REQUEST: DIFFUSE JOINT AND PAIN ISSUES. REQUESTS TO SEE RHEUM FOR FURTHER OPINION ON THIS. KRAMES ON DEMAND INFO ABOUT FIBROMYALGIA TREATMENT HAS BEEN GIVEN IN THE PAST, HAS TRIED NUMEROUS NSAIDS W/O IMPROVEMENT IN PAIN. Inter-facility Information This is not an inter-facility consult request. DISCONTINUED Status: Last Action: PRINTED TO Facility Date/Time/Zone Responsible Person Entered By Activity GODMAN, DIANE GODMAN, DIANE 09/14/10 18:35 CPRS RELEASED ORDER 09/14/10 18:35 PRINTED TO SAM HP SUBSPEC\$ P 09/15/10 07:51 PENDLETON, JOHN W PENDLETON, JOHN W DISCONTINUED

Have reviewed chart, nothing to suggest inflammatory condition, I have nothing ot offer and in view of present back log of consults, will not schedule.

Sincerel Godman, PA-C ne Toom D

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# January 8, 2014

Chairman Binns, distinguished members of the Research Advisory Committee, and members in attendance. My name is Ronald Brown and I serve as the President of the National Gulf War Resource Center.

The Gulf War Review was an informative newsletter sent out to veterans of the Gulf War that provided information on Gulf War related issues. This informative newsletter was stopped quite a few years back and veterans now are left wondering what new advancements are taking place concerning Gulf War illness.

The Gulf War Review newsletter was a great idea when it started and it still can be. This is just another example of how the Gulf War Veteran feels like a Forgotten Warrior. The newsletter that was designed to keep them informed was stopped with no explanation. If the cost of sending the letters out was an issue, then why not put it directly on the VA web site every 3 months. The VA already has people who update its site, why not just keep the newsletter updated on the web page too? We can read all of the past reviews there now.

We at the NGWRC would like to see the Gulf War review restarted to help keep veterans informed of the current research taking place around the country related to Gulf War illness. Not

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only should the new Gulf War Review include the research taking place, where it is happening, and how to become a part of these studies; but it should also include the results of research that has been completed and published, written in layman terms, so the veterans can read it and understand it.

Research is a vital part of finding causes and hopefully cures to the illnesses that affect some 250,000 sick gulf war veterans. There should never be a lack of veteran participation in the research studies, and one of the ways to ensure that this research gets the exposure and participation from sick veterans is thru the Gulf War review.

The NGWRC has had the Minneapolis VA contact us to advertise their research studies so that gulf war veterans could participate in it. This is a primary example of why we need the Gulf War Review newsletter.

With millions of dollars being spent on research, veterans should be informed preferably every 3 months, or at least every 6 months, of what is happening and where so that they can participate in studies being conducted close to where they live.

It makes no sense to spend millions on research with very small groups when often; the studies are small simply because those who could participate are unaware of them. Research facilities

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have little to no participation from the veterans the studies are intended for because veterans cannot participate if they don't know about them.

The Veterans also need to make sure they step up and actively participate in said research that is being done close enough to participate in.

That said though, at this point, many veterans feel that being a guinea pig for a study that never changes treatment protocols or makes it to the desks of their physicians for implementation in their care, is pointless. There is a huge disconnect between the veterans and the research studies because for many years now, the VA has conducted studies showing we are sick, showing that this or that helps, but when we go to our primary care physicians, they are unaware of the studies, unaware of treatment protocols that may help us, and many times, unaware that they could implement them in the care of their patients.

We at the NGWRC feel that the VA could do much more to help veterans and their physicians understand why research is important, and how it will hopefully lead to either a cure or better quality of life for all sick veterans. The Gulf War Review is one tool that should be used to accomplish just that.

In conclusion, I would like to thank the Veterans Administration

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and Research Advisory Committee and all members in attendance for the opportunity to present the Forgotten Warrior Project II to you. We at the NGWRC will continue to work for a solution that will benefits our sick Gulf War Veterans this I can promise you. Because, we will let no Gulf War Veteran get left behind to become a Forgotten Warrior II.

Thank you for your time.

Ronald E. Brown President National Gulf War Resource Center

Appendix C Public Comment 7 - Ronald Brown Ja	n 8, 2014	<b>/ledical</b> Salem, V/		rs r.	AC-GWVI Meeting January 7 Page 20	
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