

**Research Advisory Committee on Veterans' Gulf War Illnesses  
Subcommittee: Veteran Engagement Session**

**Subcommittee Meeting Minutes  
April 6-7, 2022**

**U.S. Department of Veterans Affairs  
Washington, DC**

Virtual VES meeting was held due to COVID-19 restrictions

**Veteran Engagement Session**  
**Subcommittee Meeting Minutes**

I hereby certify the following minutes as being an accurate record of what transpired at the April 6–7, 2022, meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses Subcommittee Veteran Engagement Session.



May 20, 2022

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Lawrence Steinman, M.D.  
Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

<b>Attendance Record</b>	
<b>RACGWVI Subcommittee Members:</b>	<b>Attendance:</b> (includes RAC staff/members)
Dr. Lawrence Steinman	<b>April 6:</b>
Dr. Karen Block	Online via Webex: 58
Retired Col. Richard Gaard	Telephone: 15
Dr. Drew Helmer	Total: 73
Ms. Jane Wasvick	
Ms. Barbara Ward	<b>April 7:</b>
Mr. William Watts	Online via Webex: 137
	Telephone: 33
	Total: 170
	<b>Two Day Total: 243</b>
<b>Designated Federal Officer (DFO):</b>	
Dr. Karen Block	<b>Invited Speakers:</b>
	Dr. Peter Rumm
<b>Alternate DFO:</b>	Dr. David Thompson
Ms. Marsha Turner	
	<b>Additional Attendees</b>
<b>Committee Staff:</b>	Dr. Erin Dursa
Mr. Stanley Corpus	Amy Lallier
Ms. Marsha Turner	
Mr. Daniel Sloper	
<b>Employee Education System (EES):</b>	
Brian Peplinski	

**Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses  
(RACGWVI), Subcommittee Veteran Engagement Session (VES)  
Department of Veterans Affairs**

**LOCATION: Virtual via Webex:**

**Agenda**

**April 6 and 7, 2022; 4–7 p.m. ET, 11 a.m.–2 p.m. ET, respectively**

<b>Meeting Purpose</b>	<b>The purpose of the Research Advisory Committee on Gulf War Veterans' Illnesses Subcommittee: Veteran Engagement Session is to listen to Veterans of the 1990 - 1991 Gulf War and engage with them about several talking points posed by the subcommittee concerning GWI research, health concerns and quality of life.</b>
<b>Meeting Focus</b>	<b>Veteran Engagement and Listening</b>
<b>Welcome/Opening Remarks</b>	<b>Dr. Lawrence Steinman, Committee/Subcommittee Chair</b>
<b>What health issues are of greatest concern to Gulf War Veterans?</b>	<b>Dr. Drew Helmer</b>
<b>How can research improve the treatments available to Gulf War Veterans?</b>	<b>Dr. Karen Block</b>
<b>VHA ORD Research Volunteer Program</b>	<b>Invited Guest: Dr. David Thompson</b>
<b>What health issue could the VA address to improve Gulf War Veterans' quality of life?</b>	<b>Ms. Jane Wasvick</b>
<b>What would you like the VA Secretary to know about the health of Gulf War Veterans?</b>	<b>Ms. Barbara Ward and Col. Richard Gaard</b>
<b>Public Comment</b>	<b>Mr. Bill Watts, moderator</b>
<b>Adjourn</b>	<b>Dr. Lawrence Steinman</b>

**Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses (RACGWVI),  
Subcommittee Veteran Engagement Session**

**April 6 and 7, 2022; 4–7 p.m. ET, 11 a.m.–2 p.m. ET, respectively**

**Committee Meeting Minutes**

*These minutes reflect the combined comments and questions for both days of the Veteran Engagement Session.*

**Welcome, Overview and Introductions**

**— Lawrence Steinman, M.D., Chair, Research Advisory Committee on Gulf War Veterans' Illnesses.**

Dr. Steinman called the subcommittee meeting to order, welcomed all 1990-91 Gulf War (GW) Veterans who were participating. He emphasized the purpose of these two Veteran Engagement Sessions (VES) is to listen to Veterans so the RACGWVI can make informed recommendations about research on Gulf War Illness (GWI) to the Secretary of Veterans Affairs (VA).

Dr. Steinman then asked the subcommittee to introduce themselves.

Col. Richard Gaard: A retired colonel, his last assignment was at the Pentagon as an assistant to Joint Chief of Staff. He continues to work with Veterans.

Dr. Drew Helmer: A medical doctor with a research focus on GWI and collaborates with several GWI research teams.

Barbara Ward: A Vietnam Veteran of the Airforce Nurse's Corps. She is a former Director of Center for Minority Veterans.

Jane Wasvick: A retired nurse. She worked in several nurse leadership roles both within and outside the VA.

William 'Bill' Watts: A 1990–91 Gulf War Veteran who continues to support and help his fellow Veterans.

The RACGWVI staff were asked to introduce themselves.

Dr. Karen Block, serving as the Dedicated Federal Officer (DFO) for the RACGWVI. She is a VA employee overseeing the GW research program.

Marsha Turner, she is the alt-DFO and Managing Director of the RACGWVI.

Dr. Steinman introduced Stan Corpus, RACGWVI program coordinator, and Dan Sloper, RACGWVI technical writer, and thanked them for their support.

Dr. Steinman introduced Dr. Peter Rumm.

Dr. Peter Rumm: A medical doctor specializing in preventive medicine along with GWI research experience. He is the head of VA's Health Outcomes Military Exposures (HOME) group. HOME administers various programs related to environmental and occupational exposures of U.S. Veterans during their military service.

Dr. Steinman emphasized that the RAC is not able to give medical advice. The purpose of the RACGWVI is not to speak for the VA, but to make recommendations to the Secretary of the VA. The purpose of the committee/subcommittee is to make informed GWI research options and initiatives to the VA Secretary.

Dr. Steinman turned the meeting over to Bill Watts so he could go over the meeting guidelines.

**Welcome and Rules of Engagement**

**— William (Bill) Watts, Moderator**

Mr. Watts welcomed the 1990-91 GWV to the meeting and read the rules of engagement (ROE) for the meeting:

This meeting must end promptly at the specified time

This is a public meeting, please be respectful

This meeting is being recorded for RACGWVI reporting purposes  
Everyone is on mute. The chat is available to talk freely with each other  
The moderator will call your name and unmute your line when it is your turn to speak  
Question and comments sent in advance will be taken first  
Please limit your comments to 3 minutes to allow time for others  
The purview of the RACGWVI is centered on understanding and treating the health consequences of military service in the Southwest Asia theater of operations during the 1990-91 Gulf War. We plan to address your question(s), comment(s), or concern(s) during the meeting; however, if they fall outside the purview, we will not be able to discuss them here.

Dr. Steinman: Thanked Bill for the going over the guidelines. He further emphasized the purpose of the meeting is for the subcommittee to listen to the Veterans. To start the question portion of the meeting he introduced Dr. Helmer.

**Question 1: What health issues are of greatest concern to Gulf War Veterans?**

Led by Dr. Drew Helmer. Dr. Helmer started this section by acknowledging that 30 years after the 1990-91 Gulf War, GWV are still experiencing chronic disabling symptoms that interfere with their daily lives and activities. Some of these health issues are known to medical science, some remain unexplained, and some symptoms are now just starting to manifest as the GWV population ages. The RACGWVI subcommittee wants to hear in your own words the health issues of greatest concern today.

Dr. Steinman: On day two, Dr. Steinman addressed the audience regarding Veteran comments made during day one regarding disease latency versus “just getting old.” He wanted to emphasize that the subcommittee understands and hears the Veterans when they speak about new problems they are now just experiencing. Those symptoms are a common part of medicine and termed latency and just because something comes up later in life does not mean it is taken off the table.

**Veteran Comments Within RACGWVI Purview:**

- Submitted question: How will the VA address obvious over-exposure to hazardous elements when symptoms did not manifest before discharge?
- Submitted question: Veteran suffers from intestinal pain caused by being around burn pits. He would like to know if there are other health problems for GWV that are not associated with burn pits?
- (From the chat): Is TB (tuberculosis) part of GWI?
- Veteran asks if there are other health problems or symptoms experienced by GWV that are not linked to burn pits?
- Veteran speaks about his increasing GWI symptoms such as chronic fatigue, brain fog, which may have become worse following a COVID-19 infection, dizziness, neuropathy, psoriasis on feet, legs, hands and elbows, IBS, respiratory/congestions issues, common digestive issues, starting to develop vision problems, pain in joints, muscles and skin, phantom sensations like having a vibrating cellphone in the pocket. The GWV want to share his symptoms to let the other Veterans know he experiences them as well.
- Veteran states he has multiple GWI conditions such as irritable bowel syndrome (IBS), rapid eye movement (REM) sleep disorder, and Parkinson’s disease. Also, he was recently diagnosed with prostate cancer and asks, besides the previously stated presumptive conditions, is prostate cancer linked in any way to GWI or is it just virtue of age? He also spoke of being given multiple immunizations both pre-deployment and after arrival in-country, one of which was not officially recorded in his personal shot records. Has any research been conducted on immunizations given to GWV?
- Veteran addressed Veteran suicide rates. He states the current Veteran suicide rate of 17 deaths per day is skewed because the National Guard and Reserve personnel were no being longer counted. The true suicide rate is still 22 deaths each day and possibly going higher while the Department of Defense (DoD)

and VA claim the rate is only 17. He would like to know why the VA is playing a numbers game with the Veteran suicide risk/rate.

- Veteran asks if anyone knows how many Veterans have developed multiple myeloma or any other blood-based cancers after the Gulf War?
- The Veteran explains when there are drastic twenty degree or more temperature changes during the day, he experiences greater body pain and inflammation and increased fatigue. He asks if there has been any research on this issue?
- Veteran asks about dental issues and how many GWV are experiencing dental-related symptoms with their GWI? He also expressed frustration that the VA does not offer dental care unless a Veteran meets the VA accepted level of disability. He also agrees with previous comment about drastic weather changes causing an aches-and-pain effect on his body.

#### **Veteran Comments Outside RACGWVI Purview:**

- Veteran spoke about being in an area where chemical agent alarms sounded several times. He asks if there is or has there been any proof of chemical exposures?
- Veteran spoke about his difficulty having the VA acknowledge his GWI claims due to lack of actual time in the theater of operations. He was part of the flight crews that were constantly flying supply missions into and out of the area and is now suffering from GWI. He speaks about fighting the VA for over ten years to have his GWI claims accepted because they tell him he wasn't in the area long enough. He also stated that many of the Veterans he worked with have died before reaching 70-years of age. Veteran comments that the VA does not seem to have the time for GWV suffering with GWI.
- Veteran thanked the Committee for the meeting. He then spoke about after being discharged from the Marine Corps he did not know about the healthcare options or research services provided by the VA or how to navigate the paperwork. He further stated that until other Veterans at the Disabled American Veterans (DAV) and Veterans of Foreign Wars (VFW) told him to go to the VA, he did not know he had medical care options. He also spoke of having lack of treatment or diagnosis documented in his health record because while serving he did not want to be a "light-duty commando." He signed up for the Million Veteran Program (MVP); however, they did not ask him about his current medical issues and medications which include respiratory problems that require two different inhalers. He does not understand how to relate the health problems to receive GWI-related care if there is no mention of GWI-related symptoms in his health record.
- Veteran asks if there have been or will be any studies regarding the Camp Lejeune water contamination issues and its impact on GWI? The Veteran states he is 100% disabled because of the combination of GWI and environmental toxic exposure such as what happened at Camp Lejeune. He asks if there has been any research on this issue?
- Veteran asks if there have been any studies or links between GWV with GWI, particularly related to anthrax exposure, which may have been passed along to their children?

#### **Committee Responses**

##### Latent Symptom Appearance:

Dr. Helmer acknowledged that, yes, some symptoms or illnesses caused by environmental exposures could take years to manifest, and that is why the VA has presumptive service-connected conditions when there is evidence that some type of exposure occurred.

##### Other Health Issues:

Dr. Helmer listed common GWI symptoms which include fibromyalgia, IBS, abdominal pain, chronic fatigue syndrome; all of those are presumed service connected for GWV.

Tuberculosis:

Dr. Helmer responded that TB and sinus problems are not a symptom commonly reported with GWI and he will investigate it.

Dr. Peter Rumm stated that, because TB was considered an endemic infectious disease in that region, it is considered a presumptive of GWI.

Chemical Alarms:

Dr. Helmer responded that chemical weapon exposure is one of ongoing concern. Currently, he does not have access to objective data about if those weapons were deployed. However, there is well-documented low-dose chemical exposures to sarin and other nerve agents from munitions demolitions. There may also be a compounding effect caused by the combinations of exposures to pesticides, oil fires, burn pits, and other elements which may have caused some of the problems.

Regarding the Parkinson's disease, Dr. Helmer made a special note of that because there is some evidence to support Parkinson's is present in deployed GWV cohorts.

Regarding prostate cancer, there is currently no evidence linking prostate cancer and GWI, however, as the GWV population ages, some of those latent diseases may start to appear.

Disease/Symptom Latency:

Dr. Steinman responded that because studies into stated conditions have already been conducted does not mean those studies should not be repeated. As the GWV population ages, their symptoms may change and/or new diseases or symptoms may start to occur.

Flight Crew:

Dr. Helmer stated how struck he was that approximately 25% the Veteran's flight crew all died relatively young. He reiterated that GWI and research is not a mission accomplished situation. It is an ongoing concern and needs to be continually monitored and addressed to assure the health concerns and needs of GWV. We also need to share all this new information and updates with everyone. Dr. Helmer also acknowledged what Dr. Rumm mentioned the benefit changes being started by the VA.

Myeloma:

Dr. Helmer responded that although myeloma specifically was not immediately seen following the war, because it is more of an age-related disease, it may start to become a problem as the GWV population ages. It is a disease that should be monitored for any significant increases in diagnosis in GWV.

Chemical Weapons Exposure:

Dr. Steinman responded that a member of the full parent Committee, Dr. James Woody, was part of a team in the Gulf War and they were tasked with looking at all biological warfare agents. He would ask Dr. Woody if his team had any knowledge of chemical weapon use or known human exposures.

COVID-19 and Brain Fog:

Dr. Helmer responded there may be a correlation and/or exasperation of GWI-related brain fog symptoms and COVID-related brain fog. Due to the newness of COVID-related conditions that research is ongoing.

Service-Connected Claims:

Dr. Helmer responded that it can be difficult to connect current symptoms and health condition back to the time of deployment if no medical treatment was sought for at the initial time. That is a challenge for many other service-related claims.

Suicide Risk:

Dr. Helmer acknowledges there is an increased suicide risk among GWV. That increase could be increased by their physical pain and GWI symptoms along with the feeling of isolation that come from having GWI. This input



should be brought to the Secretary to help gain awareness of and help to prevent suicide among GWV and all Veterans. That suicide prevention research would include not just understanding of suicidal ideation and why people commit suicide, but also the research on getting actual interventions in place to reduce the numbers.

Water Contamination and Temperature Change:

Dr. Helmer responded that there is a compounding effect of environmental toxic exposures, such as the causality relationship between asbestos exposure and smoking, and there could certainly be a relationship between environmental contamination and GWI. Regarding the water contamination and GWI, that would require a research study to make any substantive claims. As for the rapid temperature changes having a physical effect, there could be a relationship and that would also need to be looked at. Dr. Helmer noted that several other GWV mentioned in the chat that they also experienced temperature change effects.

Dental Coverage:

Dr. Helmer responded that yes, dental coverage does seem to be a chronic problem among GWV, and it is an issue that can be brought forward by the RAC.

Intergenerational Effects:

Dr. Helmer responded that the VA commissioned a report from the National Academy of Science on the possibility and what is known about the possibility of passing on health effects caused by exposures from parent to child. That report was released, and results showed there were no demonstrated relationships between deployment and birth defects. However, the VA has been looking at some priority areas identified in that report and that issue still remains an area of high concern and researchers are still looking into it.

**Question 2: How can research improve the treatments available to Gulf War Veterans?**

Led by Dr. Karen Block. Noting the importance of research in understanding cause and effect of military exposures. There are multiple environmental exposures experienced by people when they deployed, but also there were occupational exposures for those who did not deploy or remained in garrison. Dr. Block addressed VA research stating it is the only program in the US focused entirely on improving Veterans' health needs, and the majority of VA researchers are also clinicians directly involved in patient care. There are over 172 VA medical centers in the U.S. that have the capacity to conduct research; over 90% of the medical centers are affiliated and/or partner with medical schools. Examples of VA research were given such as the first liver transplant, the relationship between smoking and lung cancer, the implantable cardiac pacemaker, and the an-aspirin-per-day among others.

Addressing comments regarding concerns about GWI research ending now that the CDMRP (Congressionally Directed Medical Research Programs) is being phased out. This is not the case. A new toxic exposure research program is being instituted and GWI research will continue and there is funding for it. These programs and research opportunities are not going away completely. Regarding clinical trials that have already been started, those will not be affected and are still being supported and/or covered.

A Webex poll was conducted asking the guests if they ever participated in any research study.

Have you ever participated in a research study?

Day 1:

- A. Yes 18%
- B. No 32%
- C. Not answered 43%

Day 2:

- A. Yes 23/97, 24%
- B. No 32/97, 33%
- C. Not answered 47%

If not, why not? (Check all that apply).

- A. I am not interested 3%
- B. I am interested, but never contacted 26%
- C. I do not know how to join 13%
- D. I am afraid it would interfere with my VA benefits 8%
- E. Other 13%
- F. Not answered 53%

Dr. Block: The results suggest that people are interested in research studies but are never contacted. Part of the problem about being contacted for a study involves the research study's inclusion/exclusion conditions. Even though your name is on the list, you might not fit the established study parameters. Also, COVID-19 has hindered travel and in person contact, which mean some studies had to be put on hold. The location of the study can also be a factor especially if routine in-person contact is required. Those are just a few reasons why a person might not be contacted to participate. However, there are many studies that do not require routine in-person meetings and with improvements in telemedicine and working with home healthcare workers, there remain many options and opportunities for Veterans to participate in research studies. Research is critical for advancements in understand and developing treatments for GWI and that research cannot happen without willing participants.

#### **Veteran Comments Within RACGWV Purview:**

- Veteran said he was reluctant to join in a research study because he didn't fully understand the purpose of the study and those study researchers, in the Veteran's opinion, did not explain to his satisfaction, the study-risks or the possible impact of the experimental drugs on his health. He was very concerned that the experimental drug could cause further health issues.
- (Comment sent in advance) Veteran who did not deploy overseas but is currently suffering from numerous health to include non-Hodgkin's lymphoma, fibromyalgia, pulmonary embolisms, reflex sympathetic dystrophy and rheumatoid arthritis. She wonders if those issues were caused by occupational toxic exposures from her military job.
- A Veteran commented that research may be overlooking other non-combat occupational toxic exposures. The Veteran talked about toxic exposures while staying on-base caused by environmental contamination issues. Veteran asked if research could look at possible amplification of, or other health impact those exposures could have on GWI?
- Veteran asks if any study been done on GBM (glioblastoma multiforme) or other brain cancers?
- A Veteran suffers with an autoimmune disease, limbic encephalitis, that is affecting his cognitive brain functions. He was told by his primary care physician (PCP) if such a condition was linked to GWI it should have presented within a year of initial infection/exposure; however, in his case the disease remained latent. He wants to know if other Veterans have contracted this disease. He has seen both VA and private doctors for his condition, and they state his condition is Gulf War related.
- Veteran asked who to contact or how to get information about neurological conditions study.

#### **Veteran Comments Outside RACGWV Purview:**

- Veteran supports the compensation of Veterans for their travel and other expenses for participation in research studies. The Veteran also commented that the VA needs to ensure they are including civilian, non-VA, researchers as part of conducting those studies. There should be Veteran input on the CDRMP panel. The pre-9/11 data needs to be updated. The child-health registry needs to be reinstated so the VA can track their health issues. All Veteran research and health evaluation forms need to be filled out by the Veterans and ensure there is follow-up with those Veterans.

## **Committee Responses:**

### Flight Crews and Jet Fuel Exposures, other Toxic Exposures:

Dr. Block: In her opening comments Dr. Block asked Dr. Rumm about research on jet fuel exposure and if there are any links to cancers or other disease mentioned.

Dr. Peter Rumm: Replied that yes there is a proposed study to look at air pilots and risk of diseases, especially cancer. Regarding jet fuel and toxic exposures, Dr. Rumm said there was an initial study conducted by VA toxicologist Dr. Terra Sullivan and he would try to locate that information and put it in the chat. He further said one of Dr. Sullivan studies is concluding and she should soon have the results from that fuels and solvents study and will be able to share them. Dr. Rumm added that Dr. Sullivan's research pertains to post-9/11 toxic exposures and health and not specifically to GWI.

Dr. Rumm continued to state the jet fuel and pilot study was done with the Air Force in San Antonio, TX. The study looked at fuels and solvents and their impact on humans. There is an interest in fuel and solvents and studies are being developed. The study was conducted by Terra Sullivan; Dr. Rumm recommended her as a RACGWV guest speaker.

Dr. Block: Supported Dr. Rumm's comments stating that environmental toxicity and occupational exposures also happened in garrison to non-deployed service members. She further encouraged GWV to keep pushing their GWI health claims because latent forms of GWI are now starting to manifest in the GWV population.

### Clinical Research:

Dr. Block: Addressed the concern about participation in research studies and reassured the Veterans that VA research and researchers are vetted and will work with the Veterans to ensure their current health conditions will not be impacted by the study. Also, participating in VA research studies will not impact VA health benefits.

Dr. Block: Stated the VA research office has partnered with the National Cancer Institute (NCI) and other medical research centers sponsoring a precision oncology study to research tumors and rare cancers, genomics and the aspects of precision medicine healthcare. There is also the MVP research program that collects Veteran blood samples that are then used for environmental exposures and gene interaction research studies within and between population groups and individuals. A current project is the development of an exposure questionnaire to help design research experiments to better understand genomic and environmental interactions.

### Occupational Solvent Exposures:

Dr. Rumm responded that the National Academy reviewed the data and did not find any evidence of association with any chronic diseases including cancers and Gulf War service. Dr. Rumm went on to say that just because the initial findings did not show anything, cancer takes time and as the GWV population ages an increase in cancer cases may manifest. The VA Secretary does have an interest in rare cancers so this topic will remain on the VA radar. Dr. Rumm also encouraged all GWV to get a registry exam.

### Research Program:

Dr. Block: Thanked the Veteran for her comments. She acknowledged that there is a travel compensation for research participants, also the VA does its best to partner with outside investigators, however, CDRMP investigators can be collaborator or co-investigators, but they cannot be full investigators of a project through VA research.

### Brain Cancer:

Dr. Block: Responded that cancer was also discussed in the day 1 VES and remains a top concern to GWV. In areas where chemical weapon demolition was being done a two-fold increase in brain cancer was observed; however, since that initial spike there has been no observable difference between deployed GWV, non-deployed GWV and the general population. This is not to say a correlation does not exist, but further research and surveillance is needed. Part of the new military exposure and research program is working with the VA and are looking very closely at those possible GWI-related cancers.

### Autoimmune Limbic Encephalitis:

Dr. Block: Responded that she had never heard of the disease the Veteran spoke of but knows that autoimmune disorders are commonly associated with GWI. She asked for Dr. Rumm and Dr. Steinman to weigh-in on this question. Dr. Block also emphasized that GWI was also caused by occupational exposures; a '90-91 Veteran did not have to deploy overseas to be exposed to the chemicals and toxins that were being brought back on the equipment. She also reinforced that every GWV should sign up for the Gulf War and Burn Pit Registry.

Dr. Rumm: Mentioned there is a researcher in his office that is currently doing research on GWI neurological problems. Dr. Rumm provided his email address for Veterans to contact him regarding some of the rare neurological problems. He further spoke about a HOME neurologist who is currently doing neurological conditions between deployed versus non-deployed GWV. He further spoke to being the head of the HOME program and how this group is trying to improve telemedicine and telehealth capabilities across the nation and also how all GWV need to register for Gulf War health and Burn Pit exams.

Dr. Rumm also went on to mention that there is a new model for assumptions currently working its way through the agency and the White House; it was mentioned in the President's State of the Union address. It will contain nine rare cancers associated with the Gulf War, rhinitis and asthma. And regarding VA provider education, other VA updates include that every provider in the system, by the end of the year, has to take a 90-minute module on military exposures. There are also two-level certification for an advanced certification in environmental medicine for all providers, not just physicians within a year.

### **VHA ORD Research Volunteer Program**

Led by Dr. David Thompson, Director, ORD Research Volunteer Program.

Dr. Thompson informed the attending GWV guests that the VHA is starting to develop a VA-wide, centrally managed, program to link research volunteers to VHA research resources and opportunities. This service will be provided via a VA-managed website, which is scheduled to launch autumn 2022. The program goals are to improve Veteran healthcare and well-being; put Veterans in touch with VHA research that matters to them; create a sustaining a modernized connection between VHA Research and Research Volunteers. He emphasized that Veteran VA benefits are not affected by participation in a clinical study and the Veteran can opt out of a study at any time.

Dr. Thompson included two Webex poll questions as part of his presentation:

Day 1:

How often do you receive information about VA healthcare?

- A: Never 6%
- B: Rarely (1x year) 2%
- C: Occasionally (2x year) 2%
- D: Sometimes (monthly) 13%
- E: Frequently (weekly) 18%
- F: Not answered 59%

What kind of messages are you most likely to respond to?

- A: Social media, 6/93 (6%)
- B: Emails, 37/93 (38%)
- C: Texts, 19/93 (22%)
- D: Brochures at VA facilities, 5/93 (13%)
- E: None, 0/93 (0%)
- F: Not answered 54%

Day 2:

How often do you receive information about VA healthcare?

- A: Never 5%
- B: Rarely (1x year) 5%

- C: Occasionally (2x year) 2%
- D: Sometimes (monthly) 18%
- E: Frequently (weekly) 17%
- F: Not answered 54%

What kind of messages are you most likely to respond to?

- A: Social media, 6/93 (6%)
- B: Emails, 37/93 (39%)
- C: Texts, 19/93 (20%)
- D: Brochures at VA facilities, 5/93 (5%)
- E: None, 0/93 (0%)
- F: Not answered 54%

There was limited audience response to these questions; however, Dr. Thompson still considered any collected data to be good data for developing the VHA Research Volunteer Program.

#### **Veteran Comments Within RACGWVI Purview:**

- Veteran asked about being appropriately compensated for participating in research.
- Veteran asked if reasonable time accommodations can be made regarding appointment scheduling for working Veterans who want to participate in a research study?
- Veteran asked who is the point of contact for VHA research programs conducted throughout the country?

#### **Veteran Comments Outside RACGWVI Purview:**

- Veteran comments after returning from the Gulf War he registered for the Gulf War and Burn Pit registries. He further commented that he has lost trust in and is afraid of the VA because they tell him they do not know what is wrong with him and/or will not treat him. He was also told by some of those providers that, “it’s all in your head.” This forced the Veteran to seek private healthcare that he must pay for out of his pocket. He also feels that participation in research studies provides the VA with information that can be used against Veterans.

#### **Committee Comments:**

##### Compensation:

Dr. Thompson: Responded by stating that in some studies compensation is possible; however, compensation of any kind is strictly controlled by the specific research protocol and by congressional law to prevent the coercion of participation in research studies.

##### Appointment Scheduling:

Dr. Thompson: Explained that there are multiple research studies that use telemedicine and other alternatives over going into a physical office. When actual physical appointments are needed, the research group is usually able to work with the participant to schedule an acceptable time.

##### VA Recognizing GWI:

Dr. Block: Responding she is sorry to hear how bad the Veteran was treated by the VA. She cannot speak to his direct experience, but the VA as a whole does recognize GWI as an actual medical condition and treats it as such; GWI is not “all in your head.”

Dr. Steinman: Commented that he was emotionally moved by all the comments he has been hearing from the Veterans. Directly addressing the “it’s all in your head” comment, he states of course many of these are all in your head because there is a relationship between psychiatric and physiologic disorders; ALS, MS, sleep disorders, chronic fatigue, epilepsy these all involve the brain. There is research that is addressing these diseases and looking at them in both manners.

#### **Question 3: What health issue could the VA address to improve Gulf War Veterans’ quality of life?**

Led by Jane Wasvick, Committee Member. Quality of life (QOL) is a very personal subject. It means something different to each individual and includes how each of you live your life, your expectations and ability to obtain the

goals you've set for yourself. QOL can be improved by optimizing physical, emotional and social functioning in the home, community and workplace. We really want to hear your story. So, please tell us what health issues could the committee address to improve your QOL?

**Veteran Comments Within RACGWVI Purview:**

- Veteran spoke about her brother, suffering from GWI. How he was repeatedly denied care at his VA and eventually committed suicide. Because of what happened to her brother and because she felt the VA wasn't doing enough, she started her own Veteran support group to help prevent Veteran suicide. Ultimately, she would like the VA to address Veteran mental health issues such as post-traumatic stress disorder (PTSD) and suicide rates, and for the VA to investigate new or improved mental health and suicide prevention measures.
- Veteran asked if the VA could provide a Veteran-focused exercise program at VA facilities or provide a stipend for Veterans to go to a gym or fitness center?
- Veteran responding to comments made in the chat. He says acupuncture and massage therapy can help with some GWI symptoms and that therapy should not be discounted as ineffective; however, those treatment options are not covered by the VA benefits. The Veteran also stated he used to get the National Cohort of Gulf War Veterans questionnaire back in '95 but it seemed to have stopped around 2015. Is that program still active?
- Veteran address the topic question; his biggest health issue is not being able to think and process information and has difficulty concentrating. He would like research on how to help people learn to think again. He took neuro-feedback classes, and he thinks those may have helped. He further comments that he doesn't feel the VA has actually helped him, but he did find proper care from a civilian doctor. He further comments that he suffers from central sleep apnea. He feels his GWI was caused by occupational toxicity exposure issues from washing and cleaning vehicles returning from the battlefield.
- Veteran comments that he agrees there is something going on neurologically with all the GWV with GWI. He speaks about his symptoms and problems experiencing neurological and concentration issues along with hypothyroidism. Specifically addressing the topic question, the GWV states he thinks that research is doing an excellent job, but his thought is what good all the research if the VA does not listen to the research and that directly impacts his quality of life. Due to his neurological issues, the Veteran is currently at 60% disability and is afraid to seek further disability claims because he thinks the VA will take away all his benefits and that also impacts his quality of life. Addressing the topic question, he says research is excellent, but feels the VA is not listening to the results of the research and if the VA isn't listening to the results what good is the research. He would like the committee to ask the VA about how the VA will use or apply GWI research in the care of GWV?
- Veteran comments that he is happy that the VA gave preemptive sinus issues, but those issues needed to be recorded in a health record within ten years of being discharged. He is frustrated because many doctors do not have health records from 30 years ago, "How can anyone make this presumptive claim"? He is currently suffering from a chronic cough and bladder issues. He is also experiencing slow processing of his VA health benefit claims.

**Veteran Comments Outside RACGWVI Purview:**

- Veteran spoke about how he is tired of being told his GWI is just "old age."
- Veteran spoke about the Vet Center and how they provide emotional support for Veterans both individual and group meetings to talk.
- Multiple GWV responded in agreement and support of Jason's speech to the committee (Noteworthy Veteran Comments)
- A Veteran spoke of his experience in the GW and told other GWV if they are in a dark spot mentally to reach out to a Vet Center. They are experienced Veterans helping other Veterans and available 24/7 to help.

- Veteran spoke about how the RACGWVI and the VA has lost the trust of the Veterans they are supposed to be helping. The VA is not doing enough research on other exposures. She also said he has lost trust in the VA and in order for the VA to gain back the trust of Veterans the committee and the VA need to listen better to the Veterans. She mentioned how VA is cutting research funding or not fully supporting existing GWI research studies. She said the VA PCPs need training on how to work with GWV suffering with GWI, calling the doctors, “deer in headlights.” She stated that GWV need to know how to navigate the VA healthcare system and what tests and other specialty exams they need to ask for. There also needs to be increased communication between GWI researchers and doctors at the VA. The VA needs to improve the claims denial process.
- Veteran thanked the committee for putting the VES together. He also speaks to having a central neuropathy condition affecting his entire body and is currently on the high-dose levels of medication; however, a VA doctor reported that his tremors are not caused by neurological problems. Seeking further medical opinions, another assessment by another VA doctor did report his tremors being caused by neurological problems but listed him at 0% disability. His comment to the committee is that the VA doctors don't seem to understand and/or accurately document the conditions they are treating as being caused by GWI. He feels the VA doctors just do not care.
- Veteran addresses the comment that their health issues are “all in their head.” Saying the VA seems to have a pattern and practice of denying GWV symptoms/conditions, which he reinforced by speaking of his personal experience with GWI and the VA. His conclusion was that because of his experiences with the VA system and doctors, he does not trust the VA to take care of him and feels that many other Veterans feel the same way.
- Veteran thanked the committee for the VES. Addressing the question, she feels the VA could improve Veterans' quality of life by doing a better job at expediting Veteran health claims and not be so quick to deny Veteran health claims. She also feels the providers at the VA could improve their sensitivity and bedside manner. She based that statement on her military judicial record and the development of anxiety issues. She currently suffers with bone loss and sleep-loss issues.

### **Committee Comments:**

#### General Comments:

Ms. Wasvick: Thanked everyone for their comments and suggestions. She reenforced the statement that the committee hears you and we will do our best to help you.

#### Neuropathy:

Ms. Wasvick: Responds that she is writing down these comments and can sympathize with the Veteran as her husband deals with a similar tremors and neurological problem. She understands how these conditions impact quality of life.

#### Loss of trust in the VA:

Ms. Wasvick: Responds that she understands the Veteran's point of view, but overall, there seems to be a loss of focus about the RACGWVI's mission and purpose of the VES, both of which are to help determine what GWI research and health issues the RACGWVI can recommend to the Secretary VA. This committee cannot address VA GWI education and/or benefits and claims issues.

Dr. Steinman: Again, spoke to the understanding that there is a psychiatric component to GWI; he takes that very seriously and will be sure to address that idea in the next gathering of the full committee.

#### GWV Questionnaire:

Dr. Block/Dr. Erin Dursa: Responded that the questionnaire was last sent out in 2012 and several papers were published based on that information. There is a plan to conduct another survey with a tentative start date in 2023. The data they have collected has demonstrated that deployed GWV are suffering from increased health issues over those Veterans who did not deploy to the 1990-91 Gulf War or the general population. She thanked all the

GWV who participated in that study because that study did show statistically significant differences between GWV and non-GWV as well as changes in the GWV population overtime. She added information links in the chat.

#### **Question 4: What would you like the VA Secretary to know about the health of Gulf War Veterans?**

Led by Barbara Ward and Col Richard Gaard, Committee/Subcommittee Members. Barbara: What health related issues would you like us to bring forward to the VA Secretary. We hear the frustrations that so many GWV experience and we do value and are about these issues and concerns that you have related regarding GWV healthcare. What would you say/share if you could talk to him directly today? Col. Gaard: Concur with Ms. Ward and opens the floor to comments.

Ms. Ward and Col. Gaard recapped the comments from the first day of the VES:

1. Lack of trust in the VA and the VA needs to rebuild Veteran Trust
2. Position training for physicians, compensation doctors and raters specifically focused on GWI and GWV; GWI is not in the Veterans' head or caused by old age
3. Veteran eligibility in terms of exclusions if the Veteran is a cannabis-using patient
4. Limited dental coverage

#### **Veteran Comments Within RACGWVI Purview:**

- Veteran asks if there is a single point of contact to whom he can speak to about processing his VA claims and getting care. He speaks of being mentally and physically tired of trying to navigate the VA system to get help.
- Veteran spoke of chronic chest pain and mishandling of his early medical issue (chest pain/lung scaring) while serving. His request is that the VA Secretary know that not every Veteran knew when they first developed their problem, and the VA should recognize that situation and change their attitudes regarding caring for Veterans.
- Veteran wants the Secretary to set up an advocacy budget and establish a GW advocate at the VA hospital. The purpose of the VA GW advocate would be to help the Veterans press for their claims and benefits. These advocates would also be a resource for the Veterans to talk with about the problems they are experiencing dealing with the VA bureaucracy and doctors. The Veteran would also like the VA to do another GWI questionnaire health study to ensure continuity of health issues, and exposure studies for Veterans who did not deploy but were still exposed to hazards; the example given was personnel who washed and cleaned all the contaminated equipment returning to the U.S. from the Persian Gulf.
- Veteran wants the VA Secretary to know how the VA system is probably adding to Veterans' health issues through all the additional stress caused by the doctors who do not necessarily believe what the Veteran is telling them, or if appropriately diagnosed by the doctor, the Veteran then must deal with stress of the VA claims process. The Veteran wonders if there is a central website or database that GWV can go to, to learn about all the research studies?
- Veteran speaks about how GWI affects female Veterans. She speaks about how female GWV experience early menopause, reproductive issues and female organ loss. Some of her personal symptoms include light sensitivity and other eyesight-related issues. She would like to see an increase in reasonable accommodation requests for Veterans suffering with GWI. Furthermore, she would like to see an increase in GWI education provided to healthcare providers. The focus of the education should be that GWI is not a one-off disease or simple health problem, but a whole multi-symptom illness.

#### **Veteran Comments Outside RACGWVI Purview:**

- Veteran, medically retired Army Staff Sergeant. She talked about having to put together her own non-profit research group because she feels the VA is not effectively researching vaccine-based toxicity issues in Veterans. She comments that she has lost trust in the VA system and asks for more in-depth research to be conducted on toxic exposure damage caused by vaccines/vaccinations and the chronic illnesses



resulting from that damage. She spoke of having to seek private medical care, and medical cannabis because the level of treatment she received from the VA for her chronic pain management did not meet her needs.

- Veteran speaks about the VAs' lack of proper care and listening to the Veteran regarding his health issues and needing to seek outside the VA for healthcare. He feels the VA doctors are either unaware or don't care about GWV suffering with GWI. What the Veteran would like the VA Secretary to know is that VA doctors need to be better educated about GWV and GWI.
- Veteran speaks about how the GWV community, including GWV from the coalition nations, and they all share the same set of very similar symptoms. The VA needs to recognize GWI is not just PTSD or caused by the decline in health because of age.
- A former Veterans' advocate from the Veterans of Foreign Wars (VFW) wanted to let Veterans know that there are non-VA advocacy options available such as the VFW. Furthermore, he would like to see a reduction in the amount of time it takes to file a VA claim and get it through the system. He would like to have more doctors, instead if nurse practitioners or physicians' assistants, involved in the patient care. He would like more information on presumptive cases for GWI sent out to the GWV.
- Wife of GWV comments that her husband is suffering from cancer, possibly caused by his service, and would like the VA to ensure there is enough research being done to improve the treatment and quality of life available for those affected by GWI.
- Veteran comments there seems to be a lack of responsive care for GWI within the VA.

#### **Committee Comments:**

##### Veteran with vaccine toxicity issues.

Ms. Ward: The Veteran made some very good points and suggestions for us to take forward to the VA Secretary regarding building trust with Veterans and funding research not just for GWI, but also vaccine reactions.

Col. Gaard: Reiterated and added to Ms. Ward's comments regarding bringing comments to the VA secretary and research.

##### Veteran with chest/lung issues.

Ms. Ward: Thanked the Veteran and agrees improvement in the early diagnosis and recognition of symptoms for Veterans. The comments regarding PCP care and consideration for GWV with GWI are being documented and will be passed along.

##### Lack of proper care comment.

Ms. Ward: Responds she hopes to prove the Veteran wrong. That the RACGWVI can help the GWV community and raise awareness and/or resolve the physician training issues and improve patient-doctor communication.

Col. Gaard: Agrees, the RACGWVI will continue to advocate for GWV and their health needs.

##### Patient Advocate

Ms. Ward: She recognizes the patient advocacy role and understands what was suggested would be an expanded and/or specialized role for the advocate. Regarding continuing the studies, those are something the RACGWVI can present, and the Secretary can seriously consider.

##### VFW advocate:

Col. Gaard: Asked if the VFW advocate had actually helped Veterans with their claims. Yes, the advocate did; his office was inside the VA, and he attended training classes with the doctors. He again emphasized that Veterans can seek non-VA advocates and guidance by contacting either the VFW or Disabled American Veterans (DAV).

##### Research Links

Dr. Block: Responded with weblinks for the Veteran.

Reasonable Accommodation:

Ms. Ward: Thanked the Veteran for calling into the VES and for their suggestion. No one had yet mentioned the need for reasonable accommodation for Veterans with GWI and that suggestion can certainly be forwarded to the Secretary.

**General Discussion and Comments**

**Veteran Comments Within RACGWVI Purview:**

- Veteran would like the Secretary to know about Veteran mental health issues and how the constant fighting with the VA bureaucracy is contributing to Veteran depression and stress. The Veteran would like the Secretary VA to find funding to better train VA mental healthcare staff on how to work with Veterans. This Veteran also spoke about denial of claims because she uses cannabis as a therapeutic for her GWI. The Veteran moved states seeking better healthcare.
- Veteran wants the VA Secretary to listen to this VES recording as she feels it will be more impactful if he hears all these comments directly from the Veterans. She wants the VA Secretary to remove time limits for presumptive medical conditions; wants a standard set of medical orders from physicians for diagnostic testing such as blood work or body scans; insists that every GWV receive a neuro-cognitive testing.
- Veteran and former committee member comments the reasons some providers deny GWV GWI claims are because a doctor calls them a diagnosed condition, or the condition is being caused by other prescribed medications. Furthermore, even if a Veteran has a presumptive condition such as fibromyalgia or IBS, a contract examiner will say there is no evidence in their military records and disqualify the claim because it does not have a nexus to their service. The best way to circumvent that denial process is to include a well-written nexus letter stating that reason why the condition exists and the research to support the symptoms. He stressed the wording is very important when making the claims. He further comments that, “the VA has people doing crappy work” and the VA needs to know the biggest problem are the contract examiners. Furthermore, not all of a Veteran’s medical records are included when they are sent to the examiners, which usually results in a claims denial. The Secretary needs to know all of this information—“The claims side sucks and it has only gotten worse.”

**Veteran Comments Outside RACGWVI Purview:**

- Veteran speaks about multiple physical problems, but the worst problem is dealing with chronic pain. Eventually the VA doctors implanted a nerve stimulator; however, there were constant problems with the stimulator and it is no longer an option for pain management. The Veteran is also on pain management narcotics via a pump but wants to stop taking the drugs because they exasperate other GI symptoms. She has gone through all the VA channels and programs for pain management, but nothing seemed to be helping. Her therapist told her there were no other options for her. The Veteran said at that moment she understood the 22-a-day [Veteran suicide rate] and the therapist recorded in her chart the Veteran is doing ok. The therapist also told her maybe the VA isn’t for her. The Veteran went outside the VA system to seek better healthcare and is now doing better. The VA continues to deny her claims for benefits or claims because she went outside the VA system for care.
- Veteran talks about how the top comment made by Veterans in the meeting is the VA’s lack of caring and sometimes belief regarding GWI. How the VA’s current standard of care for GWI, such as mindfulness, yoga and tai chi do not seem to be reasonable treatments. The toll of GWI is not just on the GWV but also on their families and livelihood. The VA still doesn’t seem to listen and even if they do listen the VA takes years before they act.
- Wife of GWV speaks to how she is having problem caring for her GWV husband. How they keep trying to figure out when his various symptoms started. He has become physically disabled to the point where he is unable to feed or bathe himself. They have been in the VA claims and denial process for ten years.
- Veteran comments GWV must constantly fight claim denials to get a presumptive illness status on their claims.

- Veteran comments that a previous speaker [Veteran advocate] helped him navigate the VA and he was able to get a 100% disabled claim; however, a short time after getting his 100% disabled rating he received a letter from the VA stating they re-evaluated his status and because his history does not completely meet their requirements the VA is dropping him to 60% disabled. He speaks to having hit a low point in his life because after fighting the VA system for 30 years for his disability status, suddenly the VA takes it away from him. Not only has he lost trust and faith in the VA, but he is afraid to push his claims because he fears further reprisal from the VA, that they will either further reduce his disability status or rescind the VA-based aid provided to his family. He wants the VA Secretary to know how the VA is treating Veterans.
- Veteran would like to know how long it will take for his retirement benefits and his VA claims to go through? He has been appealing his claims since June 2020.

### **Committee Comments:**

#### Veteran with multiple physical problems and chronic pain:

Karen Block: Asked the Veteran if they had reached out to the Veteran Experience Office? Karen then gave the Veteran her contact information to try and help the Veteran get in contact with the appropriate people.

#### Presumptive illness/claim denial:

Ms. Ward: Thanked the Veteran and ensured him that the RAC has taken note of the claims denial problem and will include it in the recommendations to the Secretary.

#### Military records for claims:

Dr. Block: Asks the Veteran Advocate what a Veteran should do if they cannot find their records, or if their records are missing?

Veteran Advocate response: Some conditions can be covered by a “Buddy Record” which falls under 1155B; for a presumptive condition. A Veteran does not need a record because the condition timeframe has not ended. Sometimes those records are not at a local/regional office, the Veteran will have to go to the board for the records. [multiple requests for that information to be put in the chat.]

### **Talking Point Responses:**

The RACGWVI posted the four VES questions online before the meeting. Any GWV who sent an email response was informed they would be given first opportunity to address the VES subcommittee. A full transcript of this VES can be found on the RACGWVI website: [April 67, 2022 VES](#)

### **Noteworthy Veteran Comments:**

GWV Jason: I feel like I’m speaking for many Veterans and what I’m about to say, there are tens of thousands of us in Facebook groups. What I witness and how we all feel and experience in these groups is very disheartening, but it is also very empowering because we finally see that we are truly not alone as the VA would like us to believe. We are all getting much worse as we get older. And we all have very similar, horrific, and also much different experiences with the VHA concerning our issues. I know from personal experience with the loss of ability to achieve work and support my family that so many vets are denied benefits and care with unsatisfactory care claims and appeal times that ruins relationships, creates homelessness and suicides from all the various implications of these issues. This is why there are 22 lives lost today on some VHA property, is a statement from my understanding. This illness has wrecked my relationships. It’s changed the entire trajectory of my life in very significant negative ways. I’ve answered all four questions with deep thought (see appendix C). You haven’t heard from me before all these years because of all the VA pushback and ultimately giving up because I viewed it as a futile cause to try and fight. Something I noticed that so many of us vets have done, which is reflected in the numbers of our initial claims in the 1990s compared to now and also participation in these events or research opportunities. You see that waning participating because it is the frustration and people giving up. It is hard for us to get through the day much less having to fight.

Question number one: What health issues are the greatest concern for GWV. In my view most of us have a neurological system immune system, cell damage, cytokines storm damage, especially of organs no matter how little, sleep issues—not allowing body to have restored of sleep and exhaustion all day; cumulative post-service organophosphate and other toxic exposures throughout our food, water, environment, and product supply which the FDA and everybody approves, continue to make things even worse. The VA also really needs to provide treatments—Let me back up; I'm sorry. I need to add something in there, and the general population is also being exposed to all these things, which muddies the research waters. It doesn't give you a clean group, does it? In my case, the neurological damage includes my automatic [autonomic] system such as heart rate—the muscles that push my blood around my veins. I have medically unexplained venous insufficiency; I have low oxygen levels intermittently. My life is a hell and every day. I keep hearing about biomarkers on a disease that isn't a syndrome meaning that it's all the same, because we all have different exposures levels of exposures, durations of exposures, combinations of exposures, and also different untested emergencies medications. Some of us got PB pills and all the vaccinations, others didn't also each of our individual body reactions to all of these reactions to all of these based on our genetics come into play. I even have a two GW syndrome ICD codes in my records recently that isn't supposed to exist, and the syndrome terminology is supposed to be corrected long ago with VHA clinician training. Some of us were even exposed to things not even included in the admitted GW exposures, like the oil in the gulf itself; for us Navy guys, which I think is the primary cause of many of my issues. My ship had to go into dry dock after the war in order repair all the damage from the oil we were floating in for that duration. I was working topside for the duration and refueling helicopters up close and personal with no breathing protection, breathing in petroleum, heavy metals and toxins in every breath; or the mines that we detonated to clear the way for the fleet, none of that is talked about. Many are already dead for my ship many more are sick and battling surgeries and VHA denials and some [crew members] on my ship are so far gone cognitively that they don't even know that their illnesses are connected to the gulf at all. The VA is not tracking or reaching out to us and the old number that is estimated about forth of us have GWI. That's an old number and so many more of us have signed up yet. The VA continues to look for every other cause of these diseases, even the presumptive. Which I think is a violation of the law. That's probably my three minutes. I'm on question two and the rest of it gets shorter. Can I conclude what I have to say? [Committee response: Yes, I would like you to continue.]

How can research improve the treatments available to GWV question number two. Research is just starting to get to some of the mechanisms and possible treatments that can help us Gulf War Veterans. I'm sorry, but the funding was just cancelled a few weeks ago. I'm sorry. This is destroyed the morale of so many of us who have been told for decades. The VA is looking into our illness, to find the mechanism so we can possibly find some treatments to ease are suffering and are suffering has been long for 31 years now. How is canceling the research going to benefit any of us as the researcher are currently doing trials of a possible system reboot or a cure in my opinion GWI seems to be a lot like long COVID with its cardio fatigue, cognitive, central nervous systems, brain damage, gastro and pulmonary problems. They're all similar. I'm hopeful that the massive effort of on the planet working on long COVID research compared to our barely funded and recently canceled research will ultimately and quickly benefit GWV. But I'm also worried that decades of GWV/GWI research already done is not being looked at by the larger long COVID community. I can imagine that the cytokine storms that our bodies likely endured trying to remove the toxins from our system, which are, like a virus, gave us organ and other system impacts, like my personal gastro central nervous system, heart and pulmonary issues I experienced right away. Were they that bad back then? No, I was very young, healthy, 21-year-old adult and I had been active all my life and I don't have these problems in my family and now I have every system in my body breaking down. I had been active all my life and I don't have these problems in my family and now I have every system in my body breaking down.

Question 3: What health issues could the VA address to improve GWV quality of life? My number one is sleep. If possible, I don't get sleep. None of us get sleep. It isn't just sleep apnea, even though we have sleep apnea events, this is the neurological problem. I don't get into deep sleep. I don't think many of us do. I have heard other people talk about REM (Rapid Eye Movement) problems; this is not looked into enough. Also addressing cardio issues that so many of us have. We die of stroke or heart attack in many cases it can be detected early

and possibly resolved preventing death. Yeah, we can't be cured of all this other oxidative stress damage, but we may get a stent, or we may get some sort of cardio procedure that can help extend our lives and maybe even make us feel a little bit better. Mental health issues are grossly under addressed. They are also exacerbated greatly by the VA's behavior and denial, lack of care, lack of understanding and willingness to look deeper into our issues that are already difficult to understand or what is commonly referred to as medically unexplained.

Question number four: What would we like the VA Secretary to know about the health of GWV? I see the forums, tens of thousands of us share our health issues and experience with the VHA and how many of us are dead already and/or getting much worse and dying every week. There are new deaths posted of people in their fifties and sixties. Boston University studies have shown the extreme oxidative stress and we injured has caused us to age faster so we are all approaching the end of our lives quickly as we're in our fifties and sixties. I see posts every week, and more of us dead and I'm 100% certain that not everyone is counted in that. In fact, the VA doesn't even seem to count, and it should. My conclusion, very sure, I'm sorry the VA needs mandate providers to listen to our issues and take them seriously. My provider tells me they have done everything they can and there is no treatment or cure for us, and they also say there's no time or resource to triage all our chronic multi-symptom illness, or even read or lean about it. My current PCP (primary care physician) is even a Gulf War Veteran, he's in denial of his own issues and he thinks everything is in my head or exaggerated. The VA standard practice is to differ all our issues as being mental illness. That's how it's been in the past, and I understand that is starting to change, and I'm glad to see that change. The recent research has shown that the damage to most all of us is the oxidative stress, which is basically aging. We can't reverse this. We understand this. We suffer every day and in my personal experience, I have combinations of many major diseases, such as MS (multiple sclerosis), Parkinson's, it's intermittent, they're all worsening. My daily life is getting worse and worse and so, and the VA has been telling Congress and everybody that they're going to train, they're going to help us and that just doesn't happen. I mean I was watching the congress thing in the nineties with Denise Nichols and all the GWV pushing for all of us when the VA was denying that this even existed at all. And here we are 31 years later, and while on paper and in law things are in writing, in black and white, but we're still having 80% presumptive denial and health as well, if you have no, if you have no money, you have stress, that stress impacts us, that's why we're homeless, suicide and dead. We need to change this now. This is what causing all the issues and it has been kicked aside way too long. And I'm done. I thank you for granting me this all this time. I know I speak for many, many vets when I say these things that I do.

Jane Wasvick response: I want to thank you so much for taking the time to look at the topics, organizing your responses, and addressing each of the questions. We appreciate your effort in telling us about you and your story. We are all listening; we want you to know the committee is listening.

**Regarding claims and comments (*out of scope for the Research Advisory Committee, but an important GWV priority*)**

- Veteran requests GWI awareness training for VA PCP.
- Veteran asks for improvement in the processing of benefits, service claims/reduction of denial of claims. "How will the VA address the concerns of obvious exposure to hazardous elements with some symptoms not manifesting prior to discharge"?

Dr. Helmer response: This is a common situation; exposures can produce immediate, acute or chronic, symptoms while other exposures can be latent, sometimes for year which makes them very difficult to prove. This is why the VA has presumptive service-connected conditions when there is evidence, such as a service-related exposure has occurred.

- Veteran states the VA PCP do not have the proper or updated training/education to work with GWV and GWI.
- Veteran states the VA needs to improve and/or restructure the health claims system; an 89% denial rate is too high.

**VES Closing Remarks:**

Dr. Steinman: Dr. Steinman thanked all the Veterans for participating in the two-day VES event. The subcommittee was very moved by their stories and comments, and they will take all of that information back to the full committee and make decisions to pass along to the VA Secretary. Furthermore, the subcommittee cherishes what was said and wish the Veterans and their families the best in dealing with all of those very tough problems.

**Meeting adjourned.**

## GULF WAR RESEARCH RESOURCES

(provided by participants and Committee members during this session)

- **Airborne Hazards and Burn Pit Registry:** <https://veteran.mobilehealth.va.gov/AHBurnPitRegistry/#page/home>
- **Birth Defects Information from DoD:** [Birth defects in infants born in 19982004 to men and women serving in the U.S. military during the 19901991 Gulf War era \(dtic.mil\)](#)
- **Clinical Trials (database of private and public funded clinical studies):** <https://clinicaltrials.gov>. Search by keyword 'Gulf War illness' or 'Gulf War.'
- **CSP 2006 'Genomics of Gulf War Illness.'** For more information: <https://www.vacsp.research.va.gov/CSPEC/Studies/INVESTD-R/CSP-2006-Genomics-Gulf-War-Illness.asp>
- **Denise Nichols, retired RN and GWV resource,** at [DSNurse1@yahoo.com](mailto:DSNurse1@yahoo.com). Help locating research.
- **DoD-funded GWI Clinical Trials Consortium (GWICTIC):** <https://www.nova.edu/nim/GWICTIC/gwictic-studies.html>
- **'Gulf War Illnesses' Facebook group:** <https://www.facebook.com/groups/125208941896/>
- **Gulf War Follow-up Study:** <https://www.publichealth.va.gov/epidemiology/studies/gulf-war-follow-up.asp>
- **Health Outcomes Military Exposures (HOME):** <https://www.publichealth.va.gov/about/postdeploymenthealth/index.asp#:~:text=As%20part%20of%20VAs%20Office.Enduring%20Freedom%2FOperation%20Iraqi%20Freedom%2F>
- **Individual Longitudinal Exposure Record (ILER)** (ILER records go back to 2005): [www.publichealth.va.gov/exposures/publications/military-exposures/meyh-1/ILER.asp](http://www.publichealth.va.gov/exposures/publications/military-exposures/meyh-1/ILER.asp).
- **Information on MS and GWI,** provided by Dr. Lawrence Steinman: [https://www.va.gov/MS/Veterans/about\\_MS/Combat\\_Related\\_Chemical\\_Exposure\\_and\\_the\\_Link\\_to\\_Multiple\\_Sclerosis\\_and\\_Other\\_Neurological\\_Diseases.asp](https://www.va.gov/MS/Veterans/about_MS/Combat_Related_Chemical_Exposure_and_the_Link_to_Multiple_Sclerosis_and_Other_Neurological_Diseases.asp)
- **Mindfulness:** <https://www.va.gov/WHOLEHEALTH/circle-of-health/mindful-awareness.asp>
- **Naval Medical Research Center (maintains the birth defect registry):** <https://www.med.navy.mil/Naval-Medical-Research-Center/Naval-Health-Research-Center/Core-Research/Military-Population-Health/DOD-BIRTH-AND-INFANT-HEALTH-RESEARCH/>
- **RACGWV email:** [VARACGWV@va.gov](mailto:VARACGWV@va.gov); **RACGWV website:** <https://www.va.gov/RAC-GWV/>
- **RACGWV Gulf War Illness Research Alerts:** [www.va.gov/RAC-GWV/Recently\\_published\\_Gulf\\_War\\_Illness\\_related\\_Research\\_Articles.asp](http://www.va.gov/RAC-GWV/Recently_published_Gulf_War_Illness_related_Research_Articles.asp)
- **Research Volunteer Program (Dr. David Thompson/Amy Lallier):** [VACOORDResearchVol@va.gov](mailto:VACOORDResearchVol@va.gov)
- **VA Chaplain Service:** [www.va.gov/chaplain/index.asp](http://www.va.gov/chaplain/index.asp)
- **VA Home Front for Homeless Veterans:** 1-877-424-3838, [www.va.gov/homeless](http://www.va.gov/homeless)
- **Vet Centers:** 1-877-927-8387
- **WRIISC research opportunities:** <https://www.warrelatedillness.va.gov/WARRELATEDILLNESS/research/volunteer/index.asp>
- **VA Funded Gulf War-related Research Studies:** VA: <https://www.research.va.gov/topics/gulfwar.cfm>  
DoD: <http://cdmrp.army.mil/gwirp/awards/awards>
- **VA Public Health—Gulf War Veterans:** <https://www.publichealth.va.gov/epidemiology/publications.asp#gulfwar>
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# **Appendix A**

## **RACGWVI Acronyms**



**RACGWVI Acronym List**

<b><u>Acronym</u></b>	<b><u>Name</u></b>
CDMRP	Congressional Directed Medical Research Program
COVID-19	Coronavirus disease of 2019
CSP	Cooperative Studies Program
DFO	Designated Federal Officer
DoD	Department of Defense
DAV	Disabled American Veterans
EES	Employee Education System
GI	Gastrointestinal
GW	Gulf War
GWII	Gulf War Illness
GWV	Gulf War Veteran(s)
HOME	Health Outcomes and Military Exposures
IBS	Irritable Bowel Syndrome
ICD	International Classification of Diseases
MVP	Million Veteran Program
NCI	National Cancer Institute
ORD	Office of Research and Development

PTSD	Post-Traumatic Stress Disorder
PCP	Primary Care Physician
QOL	Quality of Life
RAC	Research Advisory Committee
RACGWVI	Research Advisory Committee on Gulf War Veterans' Illnesses
ROE	Rules of Engagement
SECVA	Secretary VA
TB	Tuberculosis
U.S.	United States
VA	Veterans Affairs
VES	Veterans Engagement Session
VFW	Veterans of Foreign Wars
VHA	Veterans Health Administration
VoIP	Voice over Internet Protocol
VSO	Veteran Service Organization
WRIISC	War Related Illness and Injury Study Center