

Research Advisory Committee on Gulf War Veterans' Illnesses (RAC-GWVI)

Report of the Veteran Engagement Subcommittee, Session #4

Date: February 17, 2021

Location: Virtual with Puget Sound VA Health Care System, Seattle WA

RAC Subcommittee: Larry Steinman, Karen Block, Richard Gaard, Drew Helmer, Barbara Ward, Jane Wasvick, Bill Watts

Talking Points: ❖ Health concerns ❖ Quality of Life ❖ Research issues
❖ What do you want the Secretary of VA to know?

Session Overview: Number of attendees: Adobe Connect 68; VANTS phone line 60

- Format: Virtual meeting using Adobe Connect and Call in, 1 day, 3 hours, 11-2pm ET
- First virtual meeting due to COVID-19 travel restrictions.
- The goal is to interact with Veterans, their advocates and caregivers to learn about their greatest concerns for health care and improvements needed in their treatments and quality of life.
- Rules of engagement: This is a public meeting so comments are posted, use first name only, be respectful, 3 minutes to speak to allow enough time for all, a Chaplain is available by chat and by phone.
- Desired outcome: Summary of Veteran messages and suggestions to translate into recommendations for the VA Secretary.

Abbreviations: GWV = Gulf War Veteran, GWI = Gulf War illness;

Talking Point Summaries

❖ What health issues are of greatest concern to Gulf War Veterans?

Veterans at this session described struggling with the following symptoms and conditions:

- Chronic diarrhea daily/every night for 30 years and can't get any rest, the VA has no answer for it; chronic pain in joints and muscles but can't get enough pain medicine, chronic bladder and urinary tract infections. Also afraid of catching COVID. Very sick after the first Pfizer vaccine.
- Sleep apnea
- Cerebral vasculitis
- ME/CFS, and COVID long-haulers with similar symptoms of ME/CFS
- Skin rashes, neurologic issues such as migraines and visual disturbances, including temporary blindness
- GI (gastroenterological) issues: acid reflux, IBS-C
- Severe chronic back pain
- Back portion of brain removed due to stroke
- GI colon polyps
- Spots on lungs, lung cancer
- Plural scarring, other obscure lung issues
- COPD
- Congestive heart failure, vascular disease, edema, hyperlipidemia
- Multiple granulomas in lungs
- Neuropathy
- Idiopathic edema, GI symptoms, chronic pain, rashes worsening over the years
- Constant chronic pain in feet, hips, arms, neck, fingers, and affecting voice box
- Half of colon removed, over 25 biopsies on skin and colon
- Skin rash, affects back, chest and arms and legs

❖ **How can research improve the treatments available to GW Veterans?**

– **Probiotics and fecal transplant**

GWV and underlying problems of GWV. Many symptomatic problems have been coming back to increased inflammation in the vascular system, in the colon, in the brain. People talk about the gut brain interaction. So how do you improve QOL for veterans? A few things found over the years that are making veterans feel better have been nutraceuticals that can reduce overall inflammation like CoQ10 and others that reduce antioxidants. Overall improved headaches and pain. There are looking at diet and microflora in the gut, and someone brought up fecal transplant. We do have several pre-clinical trial models going on right now looking at flora in animal models of GWV vs control. Also looking at GWV microbiota vs veteran health controls, and they're trying to understand the imbalance of the metabolites or things that can be given off so that they can try to put the system back into homeostasis.

– **ME/CFS (Myalgic encephalomyelitis/chronic fatigue syndrome)**

VA partnered with NIH to recruit GWV with and without GWV for a deep phenotyping study that should start in 2021. Veterans will go to NIH for a 10 day on site study looking at exercise, blood metabolites, functional assays and other measures to try to understand GWV in a way it's not been looked at before.

– **COVID long-haulers and COVID and symptoms similar to GWV**

NIH is going to bring some of the long-haulers into the deep phenotyping study. VA may partner with them to bring in GWV, to determine if GWV have higher risk or no change in the risk of developing COVID or symptoms that come along with COVID. VA Post Deployment Health and Research will be launching additional studies very soon.

– **Preventive research**

The VA Registries provide preventative health exams: Exams are free, include diagnostic evaluations and notate the symptoms Veterans are describing. If you haven't accessed the VA or accessed the VA in a while, this is an opportunity to come in and get your concerns checked out. The Airborne Hazards and Open Burn Pit Registry includes an online questionnaire portion and links to the medical record. This is an opportunity to use this information for surveillance -looking for problems and looking at the data to see if we can detect these health concerns and see that people get the treatment they need.

– **Concerns with cancer and not being able to participate in Gulf War research**

Inclusion and exclusion criteria: the study design will decide what types of underlying conditions might affect the interpretation of the study. If you have an underlying health condition that may exclude you from the study, talk to the research team. They might know another study where you can participate.

– **Brain and headaches**

There is research going on looking at repetitive transcranial magnetic stimulation. This is a multisite trial out of San Diego and other VAs that is working on reducing overall pain, PTSD and depression. These can be found on clinicaltrials.gov. Put GWV or GW syndrome into search to find all trials in the US sponsored by VA, DoD and others.

– **“Research does work”. I participated in Dr. Klimas’s study in Miami. The first two to three weeks after taking the medication I did not feel that great but as time moved forward I started feeling brand new like I was 15 years younger than I had felt in a long time. A few months later I fell into some cold water and the shock to my body reversed all changes that were made. But for that short time people were commenting on how much better I looked and a better attitude. Others should try it and hopefully will have better results.**

– **“I’m proud to participate in research”**

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- **Million Veteran Program (MVP): Did they categorize Desert Storm veterans? Did genetics show interesting findings? Are they reopening sites (e.g. Denver)? Are they collecting blood from offspring? When will million vet program do more blood collections again!?**

MVP is a VA program trying to recruit a million veterans to donate blood to understand genetic or gene x environment interactions that can give rise to disease processes. Over 850,000 have enrolled at this time, and out of these Dr. Helmer is looking at DNA from GWV. To date, the Gulf War genomics analysis team got data from MVP, data has been cleaned, and they've come up with the definition of GWI. They are finalizing the deployment status of participants. About 45,000 responded with surveys, not all are deployed, not all within service, but cleaning this data up. This is the largest cohort of GWV ever assembled and will have genetic information and medical record information from all that volunteered to be in the MVP program and spend their time and energy on the GW survey. Primary analysis will look at GWI and genetic risk factors of GWI for those deployed in 1990-1991. Results from the primary analysis are expected soon.

It's important that GWV feel comfortable donating blood for MVP so investigators like Dr. Helmer and others can understand more about the epigenetic and gene x environment interactions that make some people more susceptible and some people more resistant to diseases. We know that in GWV about 35% have CMI (*chronic multi-symptom illness*). The big question is why? Were some exposed to different toxicants and in different combinations and different doses? Is it the diversity of the DNA that protects some and makes others more at risk? There are a lot of genetic and physiological aspects that we can't rule out and rule in so we're able to look at all the different components.

Regarding collecting blood from children of GWV: This is a very important subject that VA is attending to at the moment. VA does not have the ability to see children in the VA and at this particular time we do not know what the best approach is to evaluate generational effects of military exposures but these discussions are ongoing and we will be getting some answers for you on that.

MVP has an online service to go online and sign up. Everything is getting more user friendly. Link to MVP online enrollment and the COVID questionnaire: [MVP Online - Home \(va.gov\)](https://www.va.gov/mvp/)

- **Gulf War News publication: Used to receive this in the mail. It was a great tool to keep GW veterans in the know for latest news, research, etc. Anything specific being done digitally for GW veterans now? The last GW Newsletter was published Fall 2019. Did it stop because of COVID, will it be published in the future?** The VA has converted the Gulf War Newsletter to an exclusively electronic newsletter. <https://www.publichealth.va.gov/exposures/gulfwar/publications/newsletter-archive.asp> This should be sent to all on the Gulf War Registry. Contact Dr. Block at karen.block@va.gov and she will be sure you get the publication.

- **Genetics: I have seen a few articles discussing the possibility of us passing this on to our children. Are there any VA studies on this?**

The VA commissioned a review by the National Academies of Science, Engineering and Medicine (NASEM) about "generational effects" to explore the state of the science about passing effects of exposures on to your progeny. The science is very early in its development. The VA will be working with other federal agencies to advance our understanding in this area.

There are studies that are looking at this from an animal model point of view, this has not been looked at in humans. There are discussions going on between VA and other federal partners about how best to approach these kinds of studies. It's probably not going on through genetics so we need to understand epigenetic regulation and gene expression and physiological function to see if there's any kind of changes passed to children. But we can look at different agents and toxicants. The NAM has looked at that and Dr. Helmer just mentioned about generational effects, but it's still early in development and we're still working on that.

- **Research to correlate immunizations/inoculations given to military personnel serving in the Gulf and GWI?** Very important question that many veterans have asked us even over the last year and a half, during these VES. We're going to be having a detailed discussion by presenters in our upcoming RAC meeting on March

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10 . We've had a few presenters talking about vaccines in our RAC meetings. We've tried to get the DoD to come on and talk to us directly and we were not able. We had an expert from the CDC talk about the anthrax vaccine that was given to civilians that were exposed but we've not been able despite strenuous efforts to bring on board someone to talk to us about anthrax vaccine in the military. We'll keep trying to get a straight answer. We received flak for getting a speaker from the CDC, but this was the best we could do at the time. Obviously, it's an area of high interest to us and all of you. We'll keep trying our best.

- **Non-users of VA: There's concern that Desert Storm veterans that are not in the VA system for care are not being counted. High income, like officers, and also those that had federal service after military, use civilian insurance or Tricare are not counted.**

That's correct. We need the researchers to try and recruit outside the VA user healthcare system to try and bring in more of their information. A very important point.

- **Treatments that have been studied for GWI, like COQ10 and Turmeric, are not being recommended by VA healthcare providers. There's a lot of great research being done, but it doesn't seem to be transferred to actual treatments from our VA PCPs.**

The updated chronic multi-symptom illness clinical practice guideline will include an evidence review of treatments for CMI/GWI. Many treatments have only advanced to the pilot stage and the evidence is not considered strong enough to recommend them except on a case-by-case basis. The CoQ10 study recently closed enrollment and the results should be known soon. If the findings are strong, CoQ10 may make it into the VA formulary.

Research is working with VA pharmacy to find out if drugs that look promising for helping veterans, CoQ10 for example, can get on the formulary so they may be available to GWV. They can be purchased over the counter, so we don't know why they're not being recommended. Is it because they think they're harmful, or are they not recommending them because they think the research isn't strong enough?

- **Neuropathy**

We have a lot of GWV with neuropathies. It's a subject of research interest and one of the issues is the comorbidities. Type II diabetes is one of the major causes, and obesity, and are those problems directly or indirectly related to serving in the GW. Those are open questions and we're far from any definitive answers.

- **Reporting cause of death: The brain tumor studies failed on two levels. One, they shut down the AFIP which never provided researchers with a catalog of Gulf War vets samples over the first 10 years. Two, most gulf war vets could not get VA care and died in private care sector. That information was not forwarded to VA as no system existed to poll for that data. If a vet died of pulmonary edema with brain tumor - it was not listed or listed as cause of death. This is a game of technicalities in reporting systems.**

Fully agree. Sometimes the technicalities on how things are listed on a death certificate are not always clear cut. But the VA is cross communicating with the National Cancer Institute and cancer registries, so there is more cross checking with different agencies and registries and different information than just the VA health care system.

There are birth registries that are nationwide where different agencies report different birth defects differently. You're right, there need to be better ways that collect data from both sides to get the all the information to get the best picture possible.

Imbedded in the question was a comment that it's a game. It's not a game for healthcare providers and researchers, it's a real problem. When one asks a question about cause of death with associated findings and there are different databases and different systems, you'll have different entry criteria. We've seen that with COVID deaths. Are we understating or overstating, if a person dies of a heart attack did they also have COVID. We're dealing with problems that on the surface seem simple to solve but if you drill down it becomes really complex to capture in a single diagnosis. Something as obvious as a cause of death, where the heart stops beating and blood is not circulating, but what caused that? Most healthcare researchers are doing their best to answer this question. When it gets to a political level there may be reasons to argue if

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there are any other ulterior motives. It's very hard to answer simple questions with research so cut some slack to the researchers who are really trying hard. We don't look at it as a game - it's dead serious.

In regard to reporting, each state reports differently. Sometimes the data that's coming in, is coming in different ways and is interpreted differently. So it seems like a simple thing but it's very complicated. Everybody is doing their best.

- **VA providers have no idea about Gulf War illness. What is being done to educate VA providers about gulf war illness? Especially should be in orientation and there should be required updates.**

When we pursue evidence based research, we also pursue implementation based research through the Health Services Research & Development program at ORD. We have funded studies that look at education to providers that have been very successful and are concluding now. There are other webinars by Post Deployment Health that talk about GWI, airborne hazards, open burn pits, and other exposures and providers get continuing education credits for these. There are a lot of efforts out there, but I agree with you that it's difficult. Even though it seems like some are getting it at one VA, you go to another and they don't understand it. It needs to be more uniform and more widespread.

- **Vaccinations: I would like to know the 21 vaccines I got. I know most of them.**
- **Is he talking about the secret injections? I'm in a wheelchair because of those injections**
- **Any studies on viral infections from human herpes 6 vaccine most likely given to most desert storm vets?**
- **No studies have been done on ganged vaccines in this arena. Due to the waiver that vaccines and contacting them about VAERS (*Vaccine surveillance program of the FDA Center for Biologics Evaluation and Research*) was ignored to this day by deployment health. What happens when you give a cluster of vaccines to people over 6 types has never been studied in depth. That much simultaneous proteins and MRNA over lapping in the blood stream and its effects.**
- **With so many veterans committing suicide each day. what is being done within system to make sure veterans aren't being shunned by VA docs when trying to get recognized for illness due to service in gulf war? Especially those vets in more rural areas or those without the proper resources to do so?**
- **Resistance to COVID vaccines because of experience with GW vaccines. Because of experience with GW vaccines, anthrax vaccine, they say nothing is going to touch me. Veterans are resistant to masks and not wearing masks. Concerns me as a RN. I am and I do tell people to wear a mask.**

We're very lucky in the U.S. Two vaccines presently approved are a class of RNA vaccines, the spike protein that most everyone is familiar with. Produced in record time and results are 95% effective. Better than what anyone hoped for and better than the influenza vaccine. Few side effects. We don't have to worry about a lot of diseases in 2021. Vaccines work. Now with COVID, those who are not professional immunologists now know more about immunology in the general public. Talk about antibodies and mutations in the virus, these are upper level discussions that the general public is vitally concerned with. So the simple answer is everyone should get a vaccine if you can get it. The rollout is a work in progress, but people are stepping up to make sure it's covered. We want to get vaccines to everyone in the U.S. Some vaccines like RNA require a booster shot. Some are coming online that require a single shot.

Other than vaccines, simple measures will make a difference. Following the guidelines - wear a mask, pay attention to social distancing and don't do anything foolish. People on this call who are members of the armed services, who risk their lives and gave for the nation - you should be the leaders in telling others that 'we did it.' You're not going to get shot or killed in combat for wearing a mask to protect the country. Wear a mask, protect the country. The Veterans should be in the lead on this - we sacrificed; we took a lot higher risk to protect the country. Now it's a lot easier to protect the country. Wear a mask.

VA/MVP is working with Operation Warp Speed on trying to do the clinical trials for the pharma to get these out. They looked for volunteers and within 1-2 days they had over 50,000 veterans step up. I (Dr. Block) just want to say thank you to the veterans that participate and help move the science forward. Overall COVID

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is a new thing but we're learning more about it, especially Dr. Steinman, who's been in the middle of all this. Research is what brought the vaccines forward.

- **Look at skin cancers**
- **Look at hypercoagulation and Desert storm veterans. Concern with the problems seen in COVID ICU getting heparin to deal with similar problems.**
- **Encourage info sharing be done by separate video presentations on VA website or facebook pages...etc.**
- **Suggest that providers be given updates on GWI research electronically as soon as they are published. Include VA and non-VA research.**
- **Restart publication of pre 911 reports and DBQs based on last legislation that made it into law in Dec 2020.**
- **Advertise re email list subscription for RACGWIR**
The RAC-GWVI does have an email list. To be added, send a message to VARACGWVI@va.gov.

❖ What health issue could the VA address to improve GW Veterans' quality of life?

- **Develop a diagnostic code ICD-10 to identify Veterans diagnosed with GWI.**
We're developing a case definition. Clinicians use symptom codes for GWI symptoms. In the VA medical record, there's a way to create an indicator to inform MDs. At a policy level, a summary of the call will be discussed by RAC and can be advocated to VA Secretary.
People have been trying to do this for a while because that is one of the ways that record keeping happens in the health care industry in general. Feedback from the organization that manages the ICD codes consistently says that it's not a well-defined condition and you need to have a better defined condition in order to get an ICD code. ME/CFS is a similar situation. There is a code for chronic fatigue, but it is not actually a code for CFS. Clinicians tend to use it for chronic fatigue syndrome because fatigue is usually a symptom of that condition. Clinicians tend to use symptom codes for veterans with GWI because there's not a specific code for GWI. In the VA medical record, we plan to create an indicator that would denote the presence of GWI or chronic multisymptom illness. Those are the plans for the projects going on right now around the case definition.
- **What dept or level within the VA is responsible to create that indicator (*that denotes presence of GWI symptoms*). How can vets with GWI advocate to push this process forward.**
Every individual veteran, whether getting care in the VA or outside of the VA, can talk with their doctor about documenting their symptoms using ICD codes. On a policy level, by participating in this call, the summary of this call will be discussed by the entire Research Advisory Committee to determine recommendations to make to the VA Secretary. Just by having this conversation and raising it here you are effectively advocating.
- **Or Congress. Veterans need to have movement on this issue.**
Congress is a very effective way of getting things done. Within the VA, we can use ICD codes to document the symptoms present and we can work with the policy offices to create an indicator that is internal to VA. The right leaders, a combination of Post Deployment Health and Patient Care Services, are working on that.
- **Advocacy and awareness for small fiber neuropathy in Veterans with GWI: There have been many studies given research money from DoD to research small fiber neuropathy in veterans exposed to neurotoxins. Dr. Oaklander at Harvard University - this research needs to be passed along to VA neurologists and practitioners. Mary Louise Oaklander at Harvard: <https://connects.catalyst.harvard.edu/Profiles/display/Person/88803>**

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- **I had a VA doc tell me if she couldn't diagnose me out of her books then what I have doesn't exist. When I pushed her about gulf war syndrome and VA studies, she told me to go ask the VA.**
Speaks to the same issue. Stays on list as an important thing.
- **Despite all my preparation over 2 weeks, I lost both vehicles, the plumbing in my house, and my security camera system to a record 0 degree cold snap in central Texas. Yet, I'm here on the phone with you while you berate and belittle my efforts. Give me credit for being here while at the same time I'm trying thaw my pipes and patch them. Even with my largely ignored health problems and suggestions.**
Speaks to QOL right now. Can't say enough about how the Committee appreciates how you're staying on the line with us and sharing your ideas. We are very grateful that you are here.
- **Understanding and awareness of GWI symptoms in VA clinics: The VA drops you from clinics if you miss 3 appts. If I have diarrhea all night, chronic pain in all joints and muscles that never leaves, I can't go to an early appt at a VA clinic that have appts only until 11am. If I exercise, then the next day I can't do anything. Regarding quality of life there are serious issues with the VA hospitals. I can't go to an early appt at the VA, then I get dropped from the clinic because I missed my appt for that very reason.**
- *Veteran comments regarding Gulf War Veteran claims*
- **For Veterans who were deployed for Desert Shield/Desert Storm and worked the flight line in Germany. In Germany, I was a deployed veteran who worked the flight line off loading of casualties, their personal belongings, medical equipment, etc. and was exposed to the dust and what-ever else was brought from the Theater of Operation. I feel many of my health issues are coming from that. These issues include "idiopathic edema", GI Symptoms, chronic pain, and rashes that have become worse over the years. I was not physically located in the Theater of Operation, but my symptoms are from my Gulf War Era. Am I eligible for compensation?**
You would have to go through the benefits process. You can sign up for the Registry and have the exam, and talk to the environmental health coordinator at your VA. Then your physician at your VA should be able to help you with some of those questions as well.
- **How does VA know so much about gulf war illness and approve a vet for skin, gastro, and headaches then turn around and deny a vet for chronic pain syndrome which is completely acknowledged as a major symptom of gulf war illness.**
It's debilitating no question.
- **Veteran on phone; Combat vet In Gulf War on ground. Have PTSD, but will talk about physical right now. About 6-7 years ago started feeling a lot of neuropathy, pain in my legs. Sent to the GW exam. It was a long process, about a year or so, and included a lot of exams. Condition worsened while going through that process. Words from MD at the time – you will go to cane, crutches, wheelchair, then die. As the pain worsened, decided no opioids, only IB, Tylenol, and meditation. Trying to resist using heroin. At pain clinic now, using RSI with neurosurgeons online and like that a lot. Have been through all other devices. Now in a wheelchair, in constant chronic pain that has gone from feet, hips, up to arms, neck, fingertips, and voice box. Constant neuropathy, the explosion, pain nonstop. Have to find something. 55 years old, no diabetes. As 27 year old lieutenant, decided to go to combat for my country, received all the secret injections over there. I want to know what was in those needles, what they did to my body. Appreciate all you're doing, but all I'm hearing is a bunch of research and algorithms. As a combat vet, it sounds like a bunch of wasted time and tax dollars. 55 years old and I'm going to go home in chronic pain and you'll all go home to your nice warm beds." We're all dying. That research won't get done; nothing is going to happen. That's our QOL out here. Chronic pain, in a wheelchair, trying to stay away from heroin.**

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- **VA approved me for multiple conditions related to gulf war illness and continues to deny for chronic pain because of no proof it was service incurred. I am living that man's nightmare as well and haven't worked in four years due to this and I'm only 48. I just got denied this past week.**

Gulf War Veteran that specializes in GW claims and is involved with laws/regulations since the early 1990s.

- Regarding symptoms from handling equipment outside of the presumptive areas: By the regulations, Germany, Egypt, Italy, Turkey -the regulation does not apply to you. It applies to the airspace and the countries listed within section 3.317 unfortunately. The only way to change that is to get Congress to change that regulation within statute 38.117 and .118.
 - Presumptive end date: The end date is Dec 31, 2021. Need to push Congress to end it all together.
 - Regarding the Veteran on the phone in constant pain, neuropathy: The only way you can get that service connected is if the symptoms started while you were still in service. For neurological conditions, starting within 1 year out of service. That's a presumptive condition, it includes migraines and neuropathy. Or if the MD wrote a NEXUS statement that there's high research showing something.
 - Chronic pain disorder: Don't know why you didn't get service connection for this. A lot of veterans had chronic pain disorder or fibromyalgia as a presumptive that they didn't know what was causing it, that was service connected. Chronic pain disorder can also get service connected under mental health. If they call it 'idiopathic' chronic pain disorder, meaning unknown causes, and you're still fighting it after being deployed to the war. That's what your service officer should know.
 - Migraines: A lot of migraines get denied. Dr. Erin Dursa's research has shown that migraines occur at a much higher rate in GWV. You can get a NEXUS, a letter stating that due to the exposures of the Gulf War, according to Dr. Dursa's study of (use the reference), it's likely that the pain disorder that the veteran has been suffering from since 1991 is due to the environmental exposures they had while serving in the Gulf War. That's how you get it granted. Having good research behind it, it was from service in the Gulf War, undiagnosed idiopathic syndrome or causes.
 - Regarding neuropathy: The same. It's called idiopathic neuropathy. The regulation is clean on this.
 - Contact info: Use Jim@kansasvets.org or jim@ncwrc.org. There's a self-help guide at www.Kansasvets.Org. You can ask for help on the form through the site.
- **Veteran from chat: Info on who qualifies for Gulf War benefits:**
<https://www.benefits.va.gov/persona/veterangulfwar.asp#:~:text=This%20means%20that%20anyone%20who,considered%20a%20Gulf%20War%20Veteran.&text=Therefore%2C%20any%20Veteran%20who%20served,meets%20the%20wartime%20service%20requirement>.
 - **This post is from the VA Website prev posted. It's unclear and misleading as to who qualifies for benefits.**
Gulf War Veterans More than 650,000 Service members served in Operation Desert Shield and Desert Storm from August 2, 1990 to July 31, 1991. For VA benefits eligibility purposes, the Gulf War period is still in effect. This means that anyone who served on active duty from August 2, 1990, to present is considered a Gulf War Veteran. For example, the Veterans Pension benefit requires service during a wartime period. Therefore, any Veteran who served on active military service for any period from August 2, 1990, to the present meets the wartime service requirement.
 - **I was turned down multiple times for fibromyalgia. The exam doctor laughed at me and asked the clerk what he should put down for me. This was at Tampa VA for C&P exam. They also laughed when I told them I have diarrhea all night for 30 years.**
 - **How do we find someone to write a NEXUS? Private docs are afraid to write them, and the VA mental health doctor says she can't write one.**
 - **Who is going to pay my mortgage? Quality of life? As my condition worsens, I can't work.**

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❖ What would you like the VA Secretary to know about the health of GW Veterans?

- The President and VA Secretary should have a focus group of 1990-1991 GWV who are ill.
- Need a White House veteran liaison, a key person on the line and on these sessions
- Make GWV a top priority. This is an invisible disability. Needs to be recognized as a physiological, physical disorder. Stop telling us it's all in our heads
- I would ask them to read my medical records.
- Need to accommodate clinic hours to be more understanding about GWI symptoms and sick GWV.
- Mandatory training for physicians and on boarding of residents on GWI. Get providers to go to the GW Conferences. Some of these physicians weren't even born when we were standing in a war zone.
- Transparency with the findings being made with GWI and exposure to neurotoxins
- Have an immediate course of action to get a diagnostic code to identify Veterans with GWI.
- Get needed prosthetics and other accommodations (e.g. wheelchair van, ramp).
- Recognition: Gulf War Veterans are never mentioned at Memorial Day and other Veteran events
- Eliminate the presumptive end date in 38 USC 1117 / 38 CFR 3.317. There should be no deadline for symptoms to show in your medical records.
- Why not send the new VA Secretary a link so he or his senior staff can listen to this call in its entirety?
- Create a GWV Center in every VA like the OEF/OIF centers where the vets can come together for socialization, etc. and receive information.
- Help us focus on the physical problem and cause. For example, with peptic ulcer disease, they said you shouldn't do this and that, and it was later discovered that the cause was a very specific bacteria.
- Senators not addressing VA concerns based on political party
- Action to protect survivor benefits if a Desert storm vet who is rated dies from COVID
- Regarding claims
 - Establish a VA Advisory Committee on GWI claims benefits.
 - Veterans dying from glioblastoma from Desert Storm should be granted their claims regardless of research, like ALS.
 - Claims should be evaluated based on veteran symptoms/illness and plausibility of connection to service, rather than putting the onus on the Veteran to provide evidence of direct cause (example-any neurologic or immunological condition as they typically have NO known cause)
 - Ensure VA and C&P claims examiners are properly trained on GWV and GWI issues. Outside examiners should be trained and qualified per VA standards. Also, vets use private and VA med records. Examiners can't see private records. Can't see within C file and other med records.

I certify this report is an accurate summary of the February 17, 2021, Veteran Engagement Session of the Research Advisory Subcommittee on Gulf War Veterans' Illnesses.



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