

Research Advisory Committee on Gulf War Veterans' Illnesses

**Committee Meeting Minutes
September 28, 2021**

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

Virtual meeting due to COVID-19 restrictions

Research Advisory Committee on Gulf War Veterans' Illnesses
Committee Meeting Minutes

I hereby certify the following minutes as being an accurate record of what transpired at the September 28, 2021, meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses.



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

Attendance Record	
Members of the Committee:	Data on Participant Logins
Lawrence Steinman, M.D.	WebEX Count: 38 online, 14 dialed = 52
James Baraniuk, M.D.	
Col. Richard Gaard, USA, Ret.	
Mr. Brent Casey	
Drew Helmer, M.D., M.S.	
Carey Pope, Ph.D.	
Barbara Ward, BSN, MPA.	
Jane Wasvick, R.N., BSN, MSA	
Mr. William Watts	
James Woody, M.D., Ph.D.	
Committee Chairman	
Lawrence Steinman, M.D.	
Designated Federal Officer	
Karen Block, Ph.D.	
Alternate DFO	
Marsha Turner, M.S.	
Committee Staff:	
Mr. Stanley Corpus, B.A.	
Mr. Daniel Sloper, M.A.	
Ms. Marsha Turner, M.S.	
Absent	
Mr. Brent Casey	
Ms. Marsha Turner	

**Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses
(RACGWVI)**

Department of Veterans Affairs

**LOCATION: Virtual via Webex:
Agenda**

Tuesday September 28, 2021

12:00 – 1:30 p.m. Eastern Time Zone

12:00 – 12:10 p.m.	WELCOME / OPENING REMARKS	Dr. Karen Block, DFO / Dr. Lawrence Steinman, Chair
12:10 – 1:00 p.m.	COMMITTEE BUSINESS	Committee
12:10 – 12:20 p.m.	Recommendation 1	Carey Pope
12:20 – 12:30 p.m.	Recommendation 2	Drew Helmer
12:30 – 12:40 p.m.	Recommendation 3	Barbara Ward
12:40 – 12:50 p.m.	Recommendation 4	Lawrence Steinman
12:50 – 1:00 p.m.	Recommendation Concurrence	Committee
1:00 – 1:30 p.m.	PUBLIC COMMENTS	Bill Watts
1:30 p.m.	ADJOURN	DFO/Committee Chair

**Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses
(RACGWVI)**

**Department of Veterans Affairs (VA)
Tuesday, September 28, 2021**

Committee Meeting Minutes

Welcome and Opening Remarks

— Karen Block, Ph.D., VA Office of Research & Development and Designated Federal Officer, RACGWVI

Dr. Block, Designated Federal Officer (DFO), is Director of the Office of Research and Development Gulf War Research Program in Washington, DC. Dr. Block opened the public meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses (RACGWVI). She said this was a virtual, public meeting due to the COVID-19 pandemic, CDC guidelines, social distancing and VA travel restrictions. She noted a quorum for the committee was present via virtual and telephone attendance, and as required, the meeting had been entered into the Federal Registry. Orientation was provided regarding teleconference phone contact, and public comment. She welcomed RACGWVI members and informed the participants that Alternative Designated Federal Officer (Alt-DFO) Marsha Turner and committee member Brent Casey were unable to attend due to personal/family emergencies. She thanked the RACGWVI administrative staff for pulling the meeting together and introduced Dr. Lawrence Steinman, RACGWVI Chair.

Welcome, Overview and Introductions

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

Dr. Steinman called the meeting to order and welcomed all participants. He explained why the RACGWVI exists and that one of its purposes is to present recommendations to the Secretary of Veterans Affairs to help bring and continue awareness of Gulf War Illness (GWI), and guide GWI research and treatments. Dr. Steinman introduced each committee member. He explained the purpose of this meeting was to publicly present and discuss the four recommendations the RACGWVI will submit to VA Secretary Denis McDonough. Each recommendation will be presented by a different member of the RACGWVI, time will be given for committee discussion, and after all recommendations have been presented a committee vote will be called. Following the vote, the meeting will be open to public comment.

Recommendations Executive Summary Statement

— Lawrence Steinman, M.D.

The Research Advisory Committee on Gulf War Veterans' Illnesses (RACGWVI) presents the following four recommendations to the Secretary of Veterans Affairs.

These four recommendations and the following suggested focus areas are largely based on current GWI research and concerns voiced by Gulf War Veterans (GWV) during the RACGWVI subcommittee, Veteran Engagement Sessions (VES).

Group Discussion Summary Statement:

No comments.

RECOMMENDATION 1: Fund research into key focus areas, examples below, to support the diagnosis and treatment of GWI.

— Carey Pope, Ph.D.

Basic and clinical studies on the role of the microbiome in the etiology and maintenance of GWI.

- Basic and clinical studies to determine the effects of dietary manipulations on the quality of life for GWV with GWI. Examples include low-glutamate and low Fermentable Oligosaccharides, Disaccharides, Monosaccharides And Polyols (FODMAP) diets used clinically to reduce gastrointestinal and other symptoms.
- Basic and clinical studies to further evaluate the status and/or influence of mitochondrial function in GWV, with and without, GWI.
- Determine the utility of the Department of Defense Serum Repository as a resource for investigators studying GWI. Among other utilities, the repository's samples may be useful in confirming a correlation between butyrylcholinesterase inhibition (itself and as a biomarker of acetylcholinesterase) and pyridostigmine bromide exposures as potential sources which cause GWI.
- Conduct a prospective, double-blind randomized clinical trial to determine the effects of antioxidants, ubiquinol vs ubiquinone, on the quality of life for GWV with GWI.

Group Discussion:

Dr. Steinman: Asks how much emphasis should be put on a preclinical or animal study which may not translate to an actual clinical study? Should not there be more emphasis on actual clinical research?

Dr. Pope: Explains his background is as a preclinical researcher and principally works with animal models. By complementing animal models and clinical research the process helps to refine both the preclinical and clinical research. This process improves basic research and animal models making future studies more accurate leading to higher efficacy of clinical studies and treatments.

Dr. Steinman: Commented further to support Dr. Pope's response, stating that by conducting both human and animals studies a more precise mechanistic approach to the disease can be acquired. By looking at specific mechanisms of disease, specialized model animals such as gene-specific knockout or knock-in mouse can be developed.

Dr. Helmer: Seconds the recommendation for the reasons of not only developing clinical treatments, but for the exploration of the preclinical and animal mechanistic approach.

Dr. Steinman: Concurs with Dr. Helmer.

Dr. Woody: Agrees a mechanistic research approach is needed to discovery and understand the etiology of GWI. He also concurs regarding the need for both clinical (human) and preclinical (animal) studies.

Dr. Steinman: Further supports and elaborates on Dr. Woody's statement.

Dr. Baraniuk: States he has a conflict of interest on this recommendation due to submitted grants. He has previously conducted, and published, animal research which could be translated into an applicable clinical study. He feels the VA can step up and support the research leads and start studies to help GWV suffering GWI. He feels these studies could be conducted within several years.

Dr. Steinman: Asks for further comments; upon hearing none, asks for the second recommendation to be presented.

RECOMMENDATION 2: Establish one or more Gulf War-Military Exposure Research Innovation Center(s) (GW-MERIC).

— Drew Helmer, M.D., M.S.

The RACGWVI recommends that VA Office of Research and Development (ORD) establish one or more GW-MERIC(s) with a two-part mission: 1) To expedite and implement evidence-based clinical treatment and diagnostic research for GWV with GWI, and 2) Build upon existing collaborations and establish new VA and non-VA partnerships to leverage and expand subject matter expertise, data and specimen resources, and technology.

GW-MERIC projects should include diverse team-based approaches through supporting multi-investigator, multi-institution partnerships and recruiting new and junior investigators into the field to advance translation of research. The GW-MERIC(s) would coordinate a strategic approach supporting GWI-focused, program-directed projects and a learning healthcare system model to integrate research into clinical care.

Group Discussion:

Dr. Steinman: Because the Gulf War was over 30 years ago, the impact of the war and GWI, how do we expect the samples will still be viable and where can they be obtained?

Dr. Baraniuk: Development of the non-VA partnerships is essential to access those samples, partnering with DoD investigators is especially critical. Outside investigators need those inside [DoD] investigators in order to get access to the DoD sample repository. A creative group of VA investigators will be needed to establish the centers and they will need non-VA partnerships. When new grants and research proposals are submitted, they will require specific wording to ensure a junior investigator will be able to access the DoD sample repository.

Dr. Steinman: Asks Dr. Baraniuk to please explain exposomes and epigenetics for those listeners unfamiliar with these topics.

Dr. Baraniuk: Explains epigenetics and exposomes: Epigenetics are changes in DNA due to exposures, anything from childhood stress to Gulf War battlefield experience and exposures. Epigenetic research can examine changes in the DNA from deployed GWV with GWI and deployed GWV who did not develop GWI. Exposome refers to all changes in proteins and metabolites involved in cellular growth and function processes. Such examples include exposure to pesticides altering the mitochondrial function. There are studies looking at differences between GWV suffering with GWI and GWV without GWI.

RECOMMENDATION 3: Initiate research on the relationship between COVID-19, long-haul COVID-19, and their impact on GWI.

— **Barbara Ward, BSN, MPA.**

The long-term effects of COVID-19 on the health and quality of life for GWV already suffering from GWI are of critical interest and warrant further study. The RACGWVI recommends initiating studies on COVID-19 and persistent symptoms of long-haul COVID-19 including examining the similarities and differences between GWI and long-haul COVID-19 symptomology.

This research could utilize existing cohorts of GWV such as the Million Veteran Program (MVP) and data resources such as the COVID-19 supplemental survey or the VA Informatics and Computing Infrastructure (VINCI). The studies could yield insights into the characterization and management of both GWI and COVID-19.

Group Discussion:

Dr. Steinman: Asks for questions and comments from the committee regarding recommendation three. He feels this is a timely research project because many GWV during previous Veteran Engagement Sessions (VES) repeatedly voiced their concern regarding the impact of COVID-19 and its effect on GWI. This research may help in future understanding and treating GWI due to long term effects.

Dr. Helmer: States this is an urgent and important study. Being able to leverage already existing VA research and resources would make this study easy to initiate.

Dr. Steinman: Comments he is currently encountering patients [in his practice] concerned about how long-haul COVID-19 may affect their chronic fatigue and respiratory issues.

Dr. Baraniuk: “Get your vaccine”! The doctor presents evidence stating those who are vaccinated are less likely to get long-haul COVID-19. The VA has done a good job of collecting the information, now it is up to the community to utilize the data. He feels that long-haul COVID-19 sufferers will have increased cardiovascular/respiratory problems than seen in GWV with GWI. The two of them combined, will only make the situation worse. Research focusing on disease mechanisms will help in developing specific treatments.

Dr. Steinman: Supports the information that there are fewer reports of long-haul COVID-19 in vaccinated people. He asks about the booster situation with compromised immune systems and GWI? Stating we need more data to support.

Dr. Woody: Comments that a way to identify those individuals susceptible to long-haul COVID-19 would be beneficial. Also, Veterans are skeptical of vaccines because of the anthrax vaccine; however, other COVID-19 treatment methods may prove to be better trusted by GWV. Dr. Woody elaborates on some of his background experience in the Gulf War as part of a team looking for biological agents. He did see evidence that some agents had been buried, but nothing was found. His team also conducted before and after blood draws on 1,000 Marines involved in the Gulf War.

Dr. Baraniuk: Asks Dr. Woody if those samples are still available for research studies?

Dr. Woody: Is currently unsure of those samples' location. Dr. Kenneth Craig Hyams published research using those samples and Dr. Woody feels he may know where those samples currently reside, and they have stayed in contact with him.

RECOMMENDATION 4: Continue the RACGWVI subcommittee, Veteran Engagement Sessions (VES).

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

A RACGWVI subcommittee, called VES, was established in January 2019 to support the Committee's mission to provide research education to GWV, to better understand the Veteran's experience of living with GWI and to build trust with the GWV community. Members of the subcommittee include the RACGWVI Chair, Designated Federal Officer, VA clinician and non-clinician researchers with expertise on chronic multi-symptom illness, GWV and other VA and non-VA subject matter experts with community leadership backgrounds. The outcomes of the VES have been highly successful. Feedback from these interactions have directly led to newly funded research projects in areas not previously examined. Additionally, participation by GWV in the VES and parent RACGWVI committee meetings have increased fivefold.

The RACGWVI recommends:

- RACGWVI staff continue to work with VA and non-VA partners to facilitate maximum outreach to the 1990-91 GWV community. These communication partnerships include, but are not limited to, VA Public Affairs, VA Communications, Employee Education System (EES), War Related Illness and Injury Study Centers (WRIISC), Health Outcomes Military Exposures (HOME, formerly Post Deployment Health), Post-Deployment Integrated Care Initiative (PDICI), GWV Facebook and other Veteran social media groups.
- The RACGWVI VES subcommittee resumes in person meetings twice per year as COVID-19 travel restrictions are lifted.
- The RACGWVI VES subcommittee continue to maintain a virtual meeting platform simultaneously with in-person meetings to allow nationwide attendance to continue.

- The RACGWVI VES subcommittee pinpoint rural areas as well as areas with a high population of 1990-91 GWV.
- The RACGWVI VES subcommittee support Diversity, Equity, and Inclusion (DEI) to the VES team.

Group Discussion:

Dr. Steinman: Feels the VES is positive and needs to continue; furthermore, he would like to see a greater increase in connectivity with each VA facility and other GWV outreach groups to ensure the RACGWVI and VES are reaching the rural or underserved areas. Also, he wants to ensure these sessions include families of GWV.

Mr. Watts: Describes how the VES do their best to coordinate and promote the meetings before the scheduled date. They work with The RACGWVI and VES work with the VA hospitals, VA public affairs officers, and public outreach groups and resources; they are doing their best to reach everyone and understand they need to keep looking for new ways of contacting to make sure all GWV know about the meetings. Mr. Watts also pointed out the RACGWVI and VES are not only about discussing GWI but helping all GWV; as examples he cited how at a meeting, they were able to help a Veteran get a new wheelchair. They also helped other GWV get into a group home.

Dr. Steinman: Commended the VES for the efforts to reach the Veterans and knows they will continue to do their best to reach as many GWV as possible. He further reiterated about inviting all GWV spouses and children to join the sessions because they have experience living day-to-day with family members with GWI and their observations and input are insightful.

Conclusion and Committee Concurrence of Recommendations

— Lawrence Steinman, M.D.

In conclusion, the RACGWVI suggests these four recommendations will improve the health and quality of life for GWV. The RACGWVI wishes to thank the Secretary for his continued support in addressing the healthcare needs of GWV suffering with GWI.

Dr. Steinman: Calls for a vote on the recommendations. All committee members responded with “Aye” and the recommendations were approved.

PUBLIC COMMENT

— Bill Watts (moderator)

At 12:22 the public comments portion was started. Mr. Watts provided the rules of engagement regarding questions and comments; asking the public to keep their questions to three minutes or less, to be respectful of the time limits and everyone in the meeting.

Male GWV: Asks if the CoQ10 study (ubiquinol vs ubiquinone), is that a new study or a continuation?

Dr. Block: There was a VA study that looked at ubiquinol study that lacked participants and did not finish. VA did a ubiquinone study, and some Veterans say one version of the drug works better than another, so a double-blind study has been suggested. Recruitment is a problem but there are still problems getting Veterans to participate. There is a recruitment resource being developed to get out to Veterans to join clinical trials. No clear answer or study to make a claim about which one works. The VA is also working to develop a clinical study recruitment list to be able to contact GWV for participation in clinical studies.

Male GWV: Responded that he received a flyer, responded to it, but has not heard anything from the VA [study organizer] regarding the study.

Dr. Block: Says she is sorry to hear that.

Mr. Watts: Bill prompts a [medical] coding question from the caller. Bill has previously spoken with this GWV about some of the problems he has encountered.

Male GWV: Says there is no all-encompassing GWI ICD code for a primary care doctor to refer to. Can the committee do something to change the ICD coding for GWI?

Dr. Helmer: States getting an ICD code added is outside the VA's power. Feedback from the institution [World Health Organization/National Center for Health Statistics] who establishes these codes says that GWI is not clearly defined as a clinical case definition. The Health Outcomes Military Exposure team is currently trying to change and advance the process.

Male GWV: Asks Dr. Helmer if there is a way to monitor the progress of GWI receiving an ICD code?

Dr. Helmer: Explains that process is under the Health Outcomes Military Exposure group. That group will be reviewing that information, but as he is not part of that group, he has no knowledge of when that will happen.

Mr. Watts: [Reads an online comment/question from Male GWV] How can we as Veterans help you get more monies to reach more Veterans who are suffering? If you are Federal, you should be able to reach so many GWI Veterans, correct? Why is recruiting a problem; are you utilizing web technologies to the max?

Dr. Steinman: This is the purpose of these meetings. We are working with the Gulf War groups, hospitals, and other places. Emphasizes that there is a need for more transparency in clinical studies; how many participants, how the study is conducted (blind, double-blind), and participants should be notified of the results. Feedback should be given to all the participants. The problem is the RACGWVI is a research committee, not the actual researcher. The purpose of the RACGWVI is to ensure there is actual research and that there are results and the Veterans are informed to what is going on.

Mr. Watts: States he posts GWV information on various social media websites, GW-social groups and he and the RACGWVI are doing their best, but if people won't participate, they can't force them.

Female GWV: She has several comments and questions to the RACGWVI. Her first comment was regarding COVID-19 vaccination. Veterans, having been given an anthrax vaccine that had no research or safety studies, are wary of the COVID-19 vaccine. What is being done to address this problem?

What about the children of GWV? Is there a plan to get their families and offspring into research groups? Will there be a research program or health initiatives to help those children; is the RACGWVI going to help them or do those family's need to look elsewhere? Where do GWV go to get help for their children?

Is there a way to get independent healthcare providers to participate in studies? And is there anything that can be done to help them with that research.

She asked about research published by Dr. Ronald Bach at the Minneapolis, MN VA on hypercoagulation. She mentioned another study regarding lipid problems and how a diet study had results. She also mentioned circulatory studies, specifically cardiac function, and the ability to circulate oxygen through the body? Rhetorically asking how many heart attacks have these people [GWV] had?

Shifting comments to address GWI and diets. She mentioned there are two diets with good results, these could be informative to clinicians at the VAs. She would like primary healthcare providers to involve dieticians to start GWI-suffers on those diets.

Male GWV: Thanks the committee for their hard work. Describes how he is GWV and suffers from GWI. He reads, as it is published, GWI-based research. He asks how does the current research on diets and nutrition become incorporated into a provider-based therapy at the VA? Comments on having some success with low-glutamate and ketogenic diet-based foods, CoQ10, and intermittent fasting. He also adds that he has participated in multiple research studies, but he must constantly follow-up with the study coordinator.

Dr. Helmer: Responds, mentioning that one of the purposes of the MERICs is to introduce the research into the VA.

Male GWV: Further comments, he comments that there is a sense of urgency to not only have the VA recognize GWV health concerns, but to work on a fixing the problem.

Dr. Block: Responds, stating how it is a problem that people want to participate in research studies, but are not contacted by the research group. Several problems with clinical research studies are not all studies are VA-based, so the VA has no control over how an independent study is conducted or in what time frame. Also, clinical trials are based on previous preclinical research. Another problem affecting many clinical studies is the need for a large and diverse study population to conduct, not only an initial clinical study, but if necessary, enough people to repeat the study. Dr. Block explained that those are some of the extenuating circumstances involved in the process. That is the purpose of recommendation 2, by establishing and using MERICs the studies would be centralized providing better control of the entire process. Further stating that the RACGWVI understands the need for urgency to get the GWI studies conducted and effective treatments into the system to help GWV.

Male GWV: (Bad Connection) Speaks of lasting benefits to protect GWV. [connection breaks up.]

Mr. Watts: Interrupts the caller, telling him there is a bad connection and it is difficult to hear his comments and questions. Asks the GWV to please post the comment in the chat and he will read it to the committee or email the RACGWVI and they will respond with an answer.

Male GWV: Explains he is a GWV with GWI, saying he appreciates what the committee is doing, but questions what the committee members actually do for a living and what organizations do they represent?

Dr. Block: Explained that all the members of the committee have medical and/or biomedical research backgrounds and some are also GWV. They are knowledgeable experts in the field of GWI. Some of them, like herself, work directly for the VA, while others are members of the committee.

Male GWV: Interrupts Dr. Block to ask several questions, “Are you getting what you need to do your job? Are you actually reaching Gulf War Veterans? What are you doing to reach more vets?” He suggests the RACGWVI is not doing enough to reach all the GWV. Questions whether the RACGWVI is trying to reach more GWV or is the RACGWVI roadblocked in some way?

Dr. Block: States the RACGWVI works with various VAs and registry groups at the VA. The registry contains the names of GWV and it possible we could use those names; flyers and information could be mailed but that can become cost prohibited. The RACGWVI is constantly looking for new ways and opportunities to contact GWV about not only research opportunities but also the RACGWVI meetings.

Male GWV: Again, interrupts Dr. Block, comments on how he has had problems participating in the VA research studies. He speaks about a need for the committee and researchers to work directly with the VA bureaucracy to effectively reach more GWV and get them involved in the GWI studies. Further commenting that priorities need to change; the VA needs more money; the VA needs to prioritize contacting GWV and get them involved in clinical research.

Dr. Block: Explains that only after a research study has an approved institutional review board (IRB) can the committee post it. However, many studies are run by independent contractors and they, not the VA, are responsible for contacting study participants.

Mr. Watts: Says he will respond to Male GWV.

Dr. Block: Also tells this GWV she will follow up and understands there is a problem with the clinical studies and will investigate.

Male GWV: Speaks of previous problems of getting diagnosed with GWI. After seeing multiple doctors, he ended up seeing a pain management doctor who was able to successfully treat him. Only after a long time did he learn of the Veteran research group. He feels there is a lack of information getting to the GWV regarding GWI, treatments, and research studies. He feels there even seems to be a lack of connection and communication inside the VA; that the VA doctors do not talk to each other regarding patient care. Further stating he feels that after 30 years, there still seems to be a lack of solid medical evidence and treatments for GWI throughout the entire medical field. Speaks that his fellow GWV look to him for information and answers to their questions; he is the person to tell them of new studies, when RACGWVI meetings happen, that the VA and non-VA medical community is not speaking or reaching out to GWV. Closes his comment by saying the VA is failing to get this information out to the GWV and failing all Veterans.

Mr. Watts: Closes the comment portion of the meeting and provides contact information for the Veterans to reach the RACGWVI with any of their concerns or questions. Turns the meeting over to Dr. Steinman.

Closing Remarks

Dr. Steinman: At 1:30 p.m. Dr. Steinman ended the meeting as scheduled. In closing he stated that the RACGWVI committee is always available for further discussion or questions via email. He thanked the committee, presenters and all the Gulf War Veterans and their families that participated in the meeting.

Meeting adjourned.