Research Advisory Committee on Gulf War Veterans' Illnesses

Committee Meeting Minutes
November 20–21, 2024
Houston, TX.

I hereby certify the following minutes as being an accurate record of what transpired at the November 20–21, 2024, meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses.

Karen Block, Ph.D.

Designated Federal Officer

Research Advisory Committee on Gulf War Veterans' Illnesses

Kenneth Ramos, M.D., Ph.D.

Chair

Research Advisory Committee on Gulf War Veterans' Illnesses

Attendance Record		
Members of the Committee:	Audience Members	
Dr. Kenneth Ramos, Chair	November 20	
Dr. José Manautou, Vice-chair	In Person = 6	
Dr. Laila Abdullah	Online = 55	
Mr. Ronald Brown	Phone = 3	
Brig Gen (R) Gracus Dunn	Total = 64	
Dr. Drew Helmer		
Harvey L. 'Boe' Marshall, Jr	November 21	
Mr. Thomas Mathers	In Person = 7	
Ms. Delphine Metcalf-Foster	Online = 68	
Dr. Cheryl Walker	Phone = 9	
Ms. Jane Wasvick	Total = 84	
Dr. Ken Wickiser		
	Total Attendance = 148	
Members Absent		
Ms. Sonya Smith		
Dr. Elaine Symanski		
Designated Federal Officer (DFO):		
Dr. Karen Block		
Alternate DFO (Alt-DFO):		
Marsha Turner		
Committee Staff:		
Marsha Turner		
Mr. Stanley Corpus		
Mr. Daniel Sloper		
Invited Speakers:		
Melissa Tursiella, PhD		
Invited Guests:		
LaTonya Small, Ed.D., ACMO		

# Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses (RACGWVI) Department of Veterans Affairs

November 20, 2024		
9:00-9:05am Central Time (CT)	Opening Remarks	Karen Block, PhD RACGWVI Designated Federal Officer (DFO)
9:05-9:10	Welcome	Kenneth Ramos, MD, PhD RACGWVI Chair
9:10-9:40	Committee Member Introductions	Kenneth Ramos, MD, PhD
9:40-10:00	VA Gulf War Research Program Update	<b>Karen Block, PhD</b> VA Director of Gulf War Research
10:00-10:30	ICD-CM for Gulf War Illness Update	Karen Block, PhD
10:30-11:00	Veteran Shared Experience	1990-91 Gulf War Veteran Committee Members
11:00am	Adjourn	

November 21, 2024			
9:00-9:05am CT	Open Meeting	Karen Block, PhD Designated Federal Officer	
9:05-9:15	Welcome and Introductions	Kenneth Ramos, MD, PhD RACGWVI Vice-Chair	
9:15-10:00	The Congressionally Directed Medical Research Programs' Toxic Exposures Research Program	Melissa "Missy" Tursiella, PhD Program Manager, Congressionally Directed Medical Research Programs, U.S. Army Medical Research and Development Command	
10:00-10:30	RACGWVI Recommendations: Updates and Options for Paths Forward	Karen Block, PhD Director of Gulf War VA Office of Research & Development	
10:30-10:45	Break		
10:45-12:15	RACGWVI Recommendations: Next Steps	Committee Discussion	
12:15-1:30	Lunch		
1:30-3:30	Committee Planning	Ken Ramos, MD, PhD	
3:30-4:00	Public Comment	Tom Mathers Moderator	
4:00pm	Adjourn		

#### **Committee Meeting Minutes**

#### Welcome, Introductions and Opening Remarks

# Karen Block, Ph.D., RACGWVI Designated Federal Officer

Dr. Block reviewed the meeting agenda and focus. She extended a thank you to RACGWVI staff for their hard work in coordinating the meeting. Dr. Block turned the meeting over to RACGWVI Chair, Dr. Ken Ramos.

#### **Welcome and Opening Remarks**

#### Ken Ramos, M.D., Ph.D., Chair, RACGWVI

Dr. Ramos welcomed everyone to the meeting and thanked them for joining in person or online. He asked the committee members to introduce themselves. After the introductions Dr. Ramos reviewed the agenda for day one of the meeting. He then asked Dr. Block to begin her presentations.

#### Session 1: VA Gulf War Research Program Update

### Karen Block, Ph.D., VA Director of Gulf War Research

Dr. Block provided the committee with a background and current status of the ORD Gulf War Research program. She briefly reviewed the history of the 1990-91 Gulf War (GW) and the suspected origins of Gulf War Illness (GWI) and how the program was created and reviewed the funded programs. As an example, in 2023 the program received 13 proposals from which five were funded. The proposals were broken into several categories: Clinical Trials Implementation, Biomarkers/Mechanisms, Model Systems/Preclinical and Other Resources.

Dr. Block closed her presentation by showing the active, VA-funded research projects which include the Million Veteran Program and biomarker repositories.

#### Questions:

Ron Brown: Will the ILER (Individual Longitudinal Exposure Record) include 1990-91 GWV information or will that information only be left at Operation Iraqi Freedom (OIF), Operation Enduring Freedom (OEF), Operation New Dawn (OND) levels? Specifically, will all the listed exposure information be available and applicable to GWV?

Karen Block: The ILER is still having information input into the database. The majority of electronic records have been updated back to 2006. Other hardcopy records are being added as available. Many of the original health records for 1990-91 GWV are not available; however, current GWV health information, such as from the WRIISC (War Related Illness and Injury Study Center) and the GW Registry, are in the ILER.

Tom Mathers: How does the GW Program allocate funding across all the studies in a given year? Karen Block: Each project has a budget path that is followed.

Tom Mathers: Do you think the role of the RACGWVI, from a governance perspective, is to comment upon award for grants and/or project funding?

Karen Block: The program has an established peer-review process conducted by subject matter experts. That process involves several layers of VA vetting.

Tom Mathers: To that point, are the recommendations and opinions of the RACGWVI part of the conversation when those research projects are selected?

Karen Block: Yes, suggestions by the RACGWVI are part of the conversation.

Drew Helmer: Supports Tom Mathers input that the RACGWVI should be an active voice in the grant/research selection process. After the VA-based review process, the RACGWVI should be given a chance to look at some of those projects.

Karen Block: That is not how the system currently works; however, there are subject matter

experts that are part of the peer-review process, and all the applications/submissions are vetted at the highest-level of those experts and committees. If the RACGWVI wants to be part of the research funding/review level it would be at the request for application (RFA) process.

Tom Mathers: Supports the idea of the RACGWVI being part of the VA research RFA process.

Drew Helmer: Supports the idea of the RACGWVI being part of the VA research RFA process.

Cheryl Walker: Agrees that an outside review panel would be a great idea.

Ron Brown: Comments that as a Veteran and a Veteran representative he has served on several such research committees and helped that panel of doctors steer the direction of the research focus.

José Manautou: Have previous VA research grant recipients presented research updates to the committee?

Karen Block: Yes, it has happened.

Tom Mathers: How can this committee give Dr. Block feedback or advice on a research project when the committee doesn't know what research projects are being proposed. The committee should be in that initial review process.

Drew Helmer: Agrees with Tom Mathers.

Ken Ramos: Asks Dr. Block to give the committee work and let it help in the RFA process.

Cheryl Walker: Suggested that if the committee were able to be part of the VA RFA process there should be an established research focus that helps guide the decision-making process that will advance and benefit the entire GWI field. And as an ongoing agenda item, the committee should have an update about the current cycle of research proposals.

Ken Ramos: That could help align the initiatives the committee would like addressed with the current/upcoming research proposals.

## Session 2: ICD-CM for Gulf War Illness Update

#### Karen Block, Ph.D., VA Director of Gulf War Research, RACGWVI DFO

Dr. Block reviewed the RACGWVI 2023 recommendation that the Secretary of VA (SECVA) issue a statement of support for International Classification of Diseases (ICD)-10 codes Z77.3 and T75.830 to the CDC/National Center for Health Statistics (NCHS). The committee also requested the SECVA enable accelerated system wide education and implementation of Z77.3, and T75.380 ICD-10 codes pending their adoption by CDC/NCHS. The committee felt, and continues to feel, a GWI ICD-10 code will be of great benefit to GWV healthcare and research.

Dr. Block reviewed the history of GWI, its associated health concerns, and the development of the GWI criteria, e.g., CDC criteria and Kansas criteria. The purpose of an ICD code is for reporting health conditions and diseases. It is a series of letters and numbers used by healthcare professionals that identifies a patient's medical diagnosis. ICD codes are needed because they are useful for recording, reporting, and monitoring diseases across healthcare settings. They are also crucial for accurate billing and insurance reimbursement.

She also pointed out that ICD codes are not necessary for a healthcare provider to treat a patient. Also, research diagnostic category and clinical diagnostic codes are not the same.

Dr. Block also emphasized that not having an ICD code has not inhibited GWV from receiving care as there are clinical ICD codes for fibromyalgia, irritable bowel syndrome (IBS), and other GWI-associated diseases.

Several committee members responded to Dr. Block's statement.

Dr. Drew Helmer clarified the situation by stating that an ICD code is not necessary for a patient's treatment or diagnosis. An ICD code helps with pharmacy/prescription management and insurance billing. However, an ICD code gives a provider a means to chart a patient diagnosis quickly and accurately.

The VA and DoD do have clinical practice guidelines for treatment of, and general management approaches, for chronic multi-symptom illness (CMI)/GWI and those guidelines have been updated.

The ICD codes are set by the World Health Organization. In the United States the CDC and NCHS are the nation's principal health statistics agency for Clinical Modification (CM) of ICD codes. An external group of subject matter experts submits an application to the CDC/NCHS requesting an ICD-10 diagnostic code for Gulf War illness. The RACGWVI Chair, Vice Chair, and committee unanimously recommended the SECVA to support adoption of the GWI ICD code in the form of a written email to the NCHS open public comment forum.

To date, the status of the RACGWVI recommendation package in support of the ICD-10-CM code for GWI is pending. Dr. Block elaborated that the SECVA must consider the entire VA, which includes healthcare, administration, benefits, and the other supporting offices and oversight boards; the SECVA decision is based on how that decision impacts the entirety of the VA not just one aspect of it.

Dr. LaTonya Small, Advisory Committee Management Officer, addressed several of the administrative questions the committee presented. Dr. Small told the committee they did their job, and Dr. Block, as DFO, did her job. The ICD recommendation presented by the committee went through the correct channels. However, the recommendation had legislative impacts that would impact all VA, so those needed to be addressed. The process is not simple and must be vetted and documented at each step by each of the groups involved in the process. Currently, the ICD recommendation presented by the committee will continue through the concurrence process with the goal of reaching the SECVA.

If, and when, the RACGWVI recommendation for the SECVA to support the GWI ICD-10 code is approved and signed, the letters of support, already prepared, will go to the agencies responsible for making the ICD code approval/denial decision.

Dr. Block added that if, and when, the recommendation is approved, it includes an execution/implementation plan.

Dr. Ramos, on behalf of the RACGWVI, officially thanked Dr. Karen Block for her unwavering and persistent efforts to ensure this recommendation was followed through to completion.

#### Session 3: Veteran Shared Experience

#### 1990-91 Gulf War Veteran Committee Members

During this session each of the Veteran committee members shared their personal experiences of being involved in the 1990-91 Gulf War.

#### **Session 4: Closing Comments**

#### Dr. Ken Ramos

Dr. Ramos thanked everyone for joining the meeting and asked them to join again on the twenty-first

Dr. Ramos called the meeting adjourned.

#### November 20, 2024 meeting adjourned.

#### November 21, 2024 meeting opened.

#### **Welcome, Introductions and Opening Remarks**

# Karen Block, Ph.D., RACGWVI Designated Federal Officer

Dr. Block reviewed the meeting agenda and meeting focus. She extended a thank you to RACGWVI staff for their hard work in coordinating the meeting. Dr. Block turned the meeting over to RACGWVI Chair Dr. Ken Ramos.

#### **Welcome and Opening Remarks**

#### Ken Ramos, M.D., Ph.D., RACGWVI Chair

Dr. Ramos welcomed everyone to the meeting and thanked them for joining in person or online. He made some simple housekeeping announcements then introduced the day's first presenter.

## <u>Session 1: The Congressionally Directed Medical Research Programs' Toxic Exposures</u> <u>Research Program</u>

Melissa "Missy" Tursiella, PhD

# Program Manager, Congressionally Directed Medical Research Programs, U.S. Army Medical Research and Development Command

Dr. Tursiella presented an overview of the Congressionally Directed Medical Research Programs' (CDMRP) Toxic Exposures Research Program (TERP). The mission of the CDMRP is to responsibly manage collaborative research that discovers, develops, and delivers health care solutions for service members, their families, Veterans and the American public. The CDMRP was started by Congress in 1992 with a focus on managing and funding biomedical research. The CDMRP funding is part of the DoD budget and of that funding, in 2024, 30 million dollars was allocated to the TERP. All research applications go through a two-tier review process to ensure the project has merit, will advance topic knowledge, and fits the CDMRP mission.

Dr. Tursiella addressed the TERP, which is under the CDMRP. Its vision is to prevent, minimize, and mitigate the impact of military-related toxic exposures and improve the health and quality of life of those affected. The mission is to support impactful research aimed at identifying the cause and understanding the health outcomes, comorbidities, and pathological mechanisms associated with military-related toxic exposures to facilitate the prevention, diagnosis, and treatment of the visible and invisible diseases and symptoms impacting service members, their families, Veterans, and the American public. GWI is one of the topics of research interest and funding. The TERP research portfolio includes research on toxic exposures and health outcomes. VA GW and TERP already work together to share information and advance Veteran care and research.

#### Questions:

Ken Ramos: Several of the presented research awards were larger than the number of projects. Do those awards represent multiple awards to the same program?

Dr. Tursiella: The larger funding awards are when applicants have the ability to partner-up and combine their individual research projects into one overarching project.

Dr. Ramos thanked Dr. Tursiella for speaking with the committee and hopes in the future she will return to update the committee on CDMRP projects.

# Session 2: RACGWVI Recommendations: Updates and Options for Paths Forward Karen Block, PhD. VA Director of Gulf War Research, RACGWVI DFO

Dr. Block presented a synopsis of the RACGWVI 2024 recommendations.

Recommendation 1: Establish regional research units (GWI-RRU) to facilitate GWI research designed to facilitate both clinical and academic GWI research.

Recommendation 2: Establish mechanisms that facilitate interagency GWI research to increase

and leverage aligned research efforts withing the VA, DoD, and other institutions that will encourage interagency GWI and toxic exposure research and increase research funding. Recommendation 3: Continue efforts and increase funding for 1990-91 Gulf War Research Innovation Centers (GWRIC).

Dr. Block also presented possible ways forward to address the recommendations. Several examples included investigator initiated research, program-directed research, transdisciplinary research, collaboration, and reciprocity of resources. All of the various research programs could be spread out across the 23 different VA Veterans Integrated Services Networks (VISNs).

Dr. Ramos thanked Dr. Block for differentiating between process-related activities and strategic-related activities. The challenge for the committee will be to review each of the different activities and group them accordingly. He then asked to again review the recommendations presented to start looking at them through the lens of the group and prioritize those that are low-hanging fruit versus those that will take longer to accomplish.

Dr. Block suggested starting with recommendation 3. It is the easy, low-hanging fruit.

Tom Mathers commented that with all the bio-sample repositories, knowledge, areas of toxic exposure in the Gulf War epoch, there is still no way to connect those with individual medical records, yet we are excited about ongoing research proposals for underlying mechanisms of GWI. Is there a way to have all the various agencies combine their efforts to upload all the GWV medical records into the ILER system or has this already happened?

Dr. Block replied that the ILER is managed by the DoD, and they leverage what information is added. The primary problem is that medical records before 2006 were not in a digital/electronic format and not easy to load into the system.

Ron Brown commented that according to a letter/statement from DoD, that many if not all the medical records were destroyed in country.

Tom Mathers requests that all meeting slides be sent to committee members several days before the meeting date, which will allow committee members to formulate questions for a given speaker. Second he would like the ILER to be updated with GWV medical records and any environmental monitoring records.

Dr. Block explained that environmental monitoring records are already in the ILER and, regarding GWV medical records from that time, many of those records were lost or destroyed as Mr. Brown had just noted.

Dr. Ramos pointed out, that for better or worse, whatever GW and GWV data that still exists is in the ILER and, unfortunately, it would seem that the majority of the information from that time period was either not accurately recorded or if it was recorded it is now lost. Regarding the lack of accurate patient healthcare records, especially for GWV, in the ILER system, that is a similar problem being faced across the entire U.S. healthcare system. Based on that understanding the committee should prioritize its efforts in a direction that intersects with existing resources, such as guiding and funding of GWI research funds as outlined in RACGWVI recommendation 3.

Dr. Helmer commented that putting together all the record information will be beyond any one investigator.

Dr. Ramos called the session to an end. He addressed some time changes to the agenda and

then called for a break.

#### **Session 3: RACGWVI Recommendations: Next Steps**

#### **Committee Discussion**

Dr. Ramos reconvened the meeting.

Dr. Ramos set a direction for the committee discussion by asking the members to think about the RACGWVI priorities and how as a research advisory committee the RACGWVI can advance research and programs that provide benefits to GWV.

Dr. Ramos reminded the members that the actual mechanics of recommendation execution fall internally within the operations of the ORD GW Research Program. With that understanding, Dr. Ramos asked the members to embrace two concepts:

- 1: To empower the committee in terms of how it influences the direction of the research portfolio for the GW Research Program.
- 2: The RACGWVI should review its recommendations and, with assistance from Karen Block, consider which of those research projects are actionable and can come to fruition in a shorter time, or simply said, let's pick the low-hanging fruit.

As these are considered and discussed the committee must also remember how Dr. Block interfaces with other groups within the VA; we, the RACGWVI need to make sure our recommendations and suggestions will work with those other agencies and move forward.

Ron Brown put forth a request for the VA to look at, and increase research into, health issues that are of higher prevalence in the deployed GWV population. The VA's post-deployment health reports show GWV have a higher prevalence for several conditions than other Veterans who were deployed to the same Middle East area.

Dr. Ramos supported Ron's request and suggested the committee review the ideas and suggestions that were presented at the Boston meeting.

Tom Mathers commented on the importance of reviewing previous recommendations and reports to learn what has already been recommended and if those recommendations are still relevant. Also, the committee needs to determine what its role is, meaning that if the SECVA isn't going to take the time to review our suggestions/recommendations why have any advisory committee.

- Dr. Ramos agrees that a review of previous RACGWVI recommendations would benefit the committee. A recommendations review would identify the status and/or progress of previous recommendations and identify any gaps the current committee could fill.
- Dr. Ramos asked Dr. Block to add as an agenda item for the next RACGWVI meeting to review previous and current recommendations and items discussed at the Boston working-group meeting.

Dr. Helmer supports Dr. Ramos' proposal. As part of that recommendation review, he also suggested to look at how the grant money was being used and the extent to which those funded projects advance the GWI body of knowledge.

Boe Marshall asked if the Veteran Engagement Sessions (VES) are the only pipeline for GWV to come and talk about their experiences as a GWV and their struggles with GWI.

Tom Mathers, current chair of the VES, asked to table that question until his VES update later in the day and he will then address it. However, Mr. Mathers briefly replied to Mr. Marshall that, to the best of his knowledge, the RACGWVI is the only collective forum for GWV to present not only their GWI health issues, but also their struggles with trying to get their Veterans' benefits.

Dr. Manautou asked, regarding Dr. Tursiella's presentation, how is all that information being used? Have any actionable steps been taken to use that information other than for publication purposes?

Boe Marshall, asked if anyone on the committee knows how many GWV participate in GWI clinical research studies and what are the dropout numbers? Karen Block responded those numbers are available and several clinical studies were unable to continue because of participant drop out, and unfortunately, that happens more often than not.

Tom Mathers asked if there is a reason for the issue, such as ineffective screening and/or low participation and recruitment? Karen responded that the problem encompasses all of the issues.

Dr. Abdullah commented that regarding clinical trials, not only are fewer people/centers submitting trial studies, but many of those studies, which are submitted, are not clinically translational. Dr. Abdullah added she would like a committee recommendation to support funding for clinical translational GWI research studies over basic research projects.

Dr. Helmer pointed out that two of the biggest problems about GWI clinical research are that GWV are spread out across the country and clinical research studies cost a lot of money. And currently many centers (i.e., government agencies, public/private universities) lack money to fund those studies.

Ron Brown pointed out that many of the initial clinical trials, even the ones with positive results, never get refunded or replicated. All that investment can go to waste.

Both Dr. Ramos and Tom Mathers agreed with Mr. Brown that not only does there need to be a better return on investment for the clinical trials that are funded, but also those studies need to be better vetted to ensure the research approach is both applicable for treatment and using current methodology and techniques.

Dr. Walker agreed with the conversation and added from her own experience in conducting clinical trials that there are one-off studies, meaning that the study was never intended to go to a second study. Because of those studies her group then started a better vetting process to ensure any study they were funding was looking forward to an actual clinically translational process, in other words a positive return on investment.

Dr. Helmer suggested revisiting recommendation one to rephrase some of the strictly worded items to a more open interpretation. Dr. Ramos suggested that instead of revisiting a recommendation already approved, maybe add language about how the research center would conduct/fund the research.

Ron Brown asked Dr. Block if the VA would increase funding for GWI-specific research over Veterans of other Middle East conflicts.

The committee discussed approaches to increasing GWV participation in GWI clinical research. Several points were discussed on that topic that included more effective and wide-spread advertising of the trial, a simpler approach in the recruitment language, increase in recruitment collaboration between VA and non-VA researchers/facilities, inclusion of, and/or increase in financial compensation (including lodging and transportation) for trial participants.

During the discussion Dr. Wickiser pointed out that from a DoD perspective both active duty and Veterans are a protected population group and therefore special care is required by the IRB for authorization of a study. Furthermore, in his experience, some clinical trials compete

against similar trials which causes participant exclusion; in some of those cases an IRB called for a forced collaboration between the studies.

Dr. Helmer responded by saying each VA facility does have a coordination board, which is independent of the IRB, to help prevent research overlap and facilitate recruitment. He also explained there are several offices in the VA such as Health Outcomes and Military Exposures (HOME) and those agencies do collaborate on clinical research methodology and sample collection, such as wearable monitoring devices, and clinical studies.

Ron Brown directed a question/comment to Dr. Block regarding the toxic wound questionnaire (PACT Act Toxic Exposure Screening) and if that questionnaire could be expanded to include/ask more detailed and specific questions about the type of toxic exposure, where it happened, and when. Mr. Brown asked if that could be included as a committee recommendation or initiative. Dr. Block responded saying the questionnaire was developed by the VHA clinical care team and she thinks for PACT Act section 405 there will be a succession questionnaire and that would be where the committee could provide input/guidance on the questions. Dr. Block suggested to the committee, if they were to suggest updated questions, one of those should ask Veterans if they want to be contacted about clinical research opportunities.

The committee discussed how to overcome the difficulties and increase not only inter-agency clinical research collaborations (CDC and VA) but outside/non-VA researchers and the sharing of all that information/results. The group discussed the idea of including a collaboration incentive as part of the grant award (i.e., if CDC collaborates with VA, x-amount of dollars will be added to the grant).

Dr. Ramos called the session to an end.

# Session 4:Committee Planning

### Ken Ramos, MD, PhD, RACGWVI Chair

Dr. Ramos opened session 4 of the meeting. He asked Mr. Tom Mathers, VES Chair, for the VES report and update.

Mr. Mathers reported that the VES subcommittee met twice over 2024, in Phoenix, AZ and Tampa, FL. The subcommittee panel had been restructured to consist of either GWV and/or GWV healthcare provider (currently Sonya Smith, Drew Helmer, and Ron Brown), and Veteran Benefits (VBA) representatives. The majority of GWV comments were in the areas of Veteran benefits and access and delivery of care in the VA system. Mr. Mathers also addressed the problem that despite the extensive outreach/promotion of a VES the actual turnout, both in person and online, remains low. Responding to a comment made by a GWV at the Phoenix VES and how that GWV had to drive several hours to the VES location, Mr. Mathers determined a change to the meeting structure was needed. He presented to the full committee several VES subcommittee changes.

First would be to reformat the VES from the larger, full subcommittee meeting twice a year to a smaller subcommittee group (two members and two support staff) traveling to the remote locations where the GWV live and work several times a year. He suggested it would be a better use of resources and increase GWV outreach.

Second would be to work with VA events and contact regional Veteran Service Organizations (VSO) and similar Veteran-centric organizations and piggyback or team-up with existing or upcoming GWV events. Mr. Mathers then recognized Mr. Ron Brown to speak.

Mr. Brown agreed that partnering with VSOs, such as attending the national VSO convention, would be a more effective approach to GWV outreach. Also, VA leadership usually attends those conventions, which would give the subcommittee a chance to speak with them. Mr. Brown returned the floor to Mr. Mathers.

Mr. Mathers asked the committee to consider the feasibility, administrative and logistic, to send a VES team consisting of two subcommittee members, one or two support staff, no online/virtual component, to more remote locations four to six times a year. He opened his comment for group discussion.

As the DFO and ORD representative Dr. Karen Block provided the VA-ORD response; as long as there is a DFO present at the meeting and that by holding four to six VES in one year the cost does not exceed the allotted budget, then the answer is yes, the subcommittee can hold an increased number of meetings.

Drew Helmer added to the discussion that he agreed the VES have become rote and losing some of their value. He added that each VA facility has their own in-house, Veteran Outreach team that plans and hosts Veteran events. Dr. Helmer suggested the committee/subcommittee reach out to those teams and try to plan events with them.

Dr. Ramos responded that Mr. Mathers identified several issues and solutions for the issues. He noted that one problem that was not addressed is stakeholder involvement. The subcommittee has held several VES but only a few Veterans participate. From his prospective the corrective action would be to not change the VES format but to increase outreach and partnership with a location's Veteran event stakeholders, such as a VSO, and by working with them could increase local Veteran involvement. There was strong support to contact the National VSO leadership and inquire about how the RACGWVI could hold a VES during their next national convention.

Brig. Gen. Dunn suggested the subcommittee actively pursue outreach to Veteran groups, such as VSO, DAV, VFW and leverage their local expertise in organizing VES events. Tom Mathers asks how to start working with a local VA to develop and promote an event.

Stan Corpus (RACGWVI Staff) responded that when the RACGWVI plans an event at a selected location one of the staff's first actions is to reach out to the local VA Public Affairs Officer (PAO). That PAO then sends all RACGWVI/VES meeting information to their stakeholders. The staff also reaches out to the local VSO, VFW organizations and they send out the meeting information, and the staff also posts the information on official VA websites and social media accounts. Mr. Corpus informed the committee that if they wanted to make something like a YouTube commercial, he knows support people at the VA who could help make it happen. He just needs to know what the committee wants.

Marsha Turner (RACGWVI Staff and Alt-DFO) added to the discussion that at a previous meeting a presenter from the Million Veteran Program told the committee that from all of their marketing and outreach formats the most effective was a physical flyer sent by mail.

Dr. Ramos directed a question to Dr. Helmer as a practicing healthcare provider at a VA hospital, wanting to know how a VA hospital organizes its engagement activities. Dr. Helmer explained that every facility is required to have a community engagement board, and usually there are members of local Veteran organizations serving as members on those committees. Dr. Ramos suggested working with those committees to promote VES events. He also summarized the discussion into two points of thought and consideration:

First will be sustainability of the investment. That sustainability is realized by appropriately engaging the local individuals and Veteran groups.

The second piece is actionability of what is being presented or discussed; you have to make something happen otherwise it is just talk.

Ron Brown asked if and how does the VA use any information the VES gathers. Karen Block

replied that yes, that information is made available to VA, but how or if they use it she cannot say.

After further discussion about the various outreach approaches and consideration for how to move forward with the subcommittee on Veteran engagement, Tom Mathers ended the conversation and returned the floor to Dr. Ramos.

Dr. Ramos recognized Dr. Karen Block and asked her to speak to the RACGWVI about its next parent meeting.

Dr. Block told the committee that the next RACGWVI meeting is (tentatively scheduled) for May 2025 in Washington, D.C. The meeting will coincide with the VA ORD Research Week 100<sup>th</sup> Anniversary, which according to the VA ORD website, the week of May 12-16, 2025. There will be a presentation on toxic exposures and Veteran health outcomes. Currently RACGWVI staff are working on the agenda, identifying and coordinating RACGWVI events. The subcommittee could also consider holding a VES during the event.

Tom Mathers asked if members of the committee could take time to speak with members of Congress and advocate for the RACGWVI.

Dr. LaTonya Small replied that it would be possible, but her office would want to be contacted beforehand to ensure and emphasize what can and cannot be said. Dr. Block agreed to work with Dr. Small on a set of ACMO rules regarding what, any and all, RACGWVI members are permitted to say when speaking as a RACGWVI member versus as a private citizen.

Dr. Ramos asked Dr. Block to gather more information about the Research Week agenda so the committee can determine how to integrate itself into the event. Such actions could be a RACGWVI poster, or possibly putting together a discussion panel with VA senior leaders.

General Dunn suggested the committee put together an outline of five plans they would like to enact at the event, understanding that probably only three of them will be approved. But when those three plans are approved, the committee will already have the details for each one worked out. In short, don't wait for the VA event planners to tell the committee what to do, the committee needs to start planning now and then it will be able to tell the event planners what the committee wants to do.

Dr. Ramos seconded Brig. Gen. Dunn's suggestion. Additionally, he would like to put together a discussion panel, about 90-minutes long.

Dr. Helmer suggested finding out if any of the VA senior leadership or members of Congress are GWV and inviting them to participate.

Tom Mathers offered to help identify and invite elected representatives.

A RACGWVI poster was suggested and supported by the committee.

Dr. Ramos emphasized that the committee would need a common script of talking points that adhere to ACMO/FACA guidelines. Dr. Small agreed with that statement and would work with the committee to ensure all committee talking points are correctly phrased.

Ron Brown asked if doctors Steele and/or Chau could be invited to speak at the upcoming meeting. Dr. Ramos moved to table that request, because of unknown time constraints, until an agenda outline is developed. Once an agenda is developed Dr. Ramos said they would revisit inviting the doctors to speak.

Dr. Ramos called session four to a close and moved the meeting to the Public Comment session.

<u>Session 5:Public Comment</u> Tom Mathers, RACGWVI member, 1990-91 GWV Tom Mathers opened the public comment section. He provided an overview of the rules and direction of the public comment.

Tom Mathers recognized Kirt Love to speak first as Kirt had attended the meeting in person. Although Mr. Love left before the public comment portion, he was online and asked to unmute. He did not respond to the request, so Tom asked for the next Veteran who wanted to speak.

Kevin Simon: This is actually one of the best meetings that y'all have done. I really liked it. I really enjoyed it. Last two days and as y'all, it's done really good. I was in the Navy from '89 to '93. I served on board the USS San Jose. I was stationed in Guam, went to Desert Storm. I have neuropathy, tremors, IBS, all, everything and my healthcare is getting because now they're starting to learn a little bit more about it. And, you know, that's all I want to say. I just really want to tell y'all did a good job. I really enjoyed it. I was diagnosed with GWI back in 1997. At first they called it Environment of the Gulf War. Then a little bit later, they called it GWI. I receive care at the Houston VA. I have no complaints about my doctor or anything. They don't know a lot about it yet because we still need research. I also host a effects of GWI podcast and anytime y'all want to advertise, y'all can advertise on my podcast. I think I have around seventy thousand listeners worldwide. So, thank y'all very much. I really enjoyed this, and I will have nothing but positive things to say about this.

**Denise Nichols:** Due to chronic technical difficulties (reverb/feedback) Denise was unable to speak at this meeting.

Alice Saddler: Kudos to the committee. This has been an excellent meeting. I served with the 35th signal brigade. I was the signal officer in the rear area operations center, so I had a full view of the battlefield, and I was the signal officer that sent all of the signals to inter-link with Turkey, so I was the point of connection with the world. We received a lot of incoming SCUDs over 50, and so our exposures as a signal site were great. We were at King Faisal [name garbled] airport, and that was a high value target for, for the Iraqis. But they didn't hit us, they came close, you know, and when I say close, I mean the ground shook and that we could taste the change in the air. So, danger close. My comment today, refers back to yesterday, with the digitization of the medical records that didn't include the Gulf war.

I understand that and it's not a can't do situation. I believe the National Guard still has the capability to activate into Title 10, key personnel update, upgrade, I'm not sure what the acronym is now, but I used them a lot when I was on active duty to bring on to active duty a Tiger Team that could digitize these records in reasonably short order, just a couple of PAs and a couple of data entry people could turn that into a digitized form and then include the Gulf war Veterans. Just a thought. Thank you.

Sara Boyd: [bad connection that made hearing her exact phrasing difficult.]

Okay, thank you. I just wanted to tell everyone thank you for this great meeting and introduce myself. My name is Sarah Boyd. I am a non-deployed Army Veteran. I am confident to share the possibility of proposal for much. Needed funded research on autonomic neuropathy. Yeah, I don't know if you can tell what I'm currently having a neuropathy flash and the reason I know that autonomic neuropathy is causing this [several words garbled and unable to understand] happens to be the leading research at the illness study centers at the Palo Alto facility and he presented the same hypothesis in 2021 that he believes every patient with a toxic exposure has a form of autonomic neuropathy that perhaps we can either increase funding toxic exposure research or for the CDMRP through a large group funding. Perhaps what this correlation is that with autonomic neuropathy with the exposure, we are seeing this behavior in our civilian toxic exposure

demographics, so I believe that it could have a global impact, not just a Veteran and service member impact. Thank you for your time, and I appreciate what you are doing for all our Veteran patience demographics.

**Tom Mathers:** As a side question, do we know the prevalence of autonomic neuropathies in the Gulf War cohort. This condition has been mentioned twice now.

**Drew Helmer:** There were some early comparisons between deployed and non-deployed GWV and there were some detectable abnormalities and some, not, diagnostic in nature, but some detectable differences between deployed and non-deployed and autonomic function. Some of that work came from the D.C. WRIISC. We, we did a chart review looking at some symptoms of autonomic dysfunction and the WRIISC cohort from New Jersey and saw higher rates of symptoms that could be attributed to autonomic dysfunction, but we were unable to really rule out some of the other potential causes of autonomic dysfunction. And so, I think it's an open question. But there's definitely some clues in the literature that there may be a broader issue of autonomic, dysfunction in Veterans, not, not yet attributed to a specific cause or exposure, but in general. Thank you.

Eric [no last name provided]: I'm dealing with, this for many decades and, also working for the Department of VA for 25 years and watching their bureaucracy from the IT on the inside which it adds to my resignation. But I was in the 1st Tiger Brigade, in the mechanized infantry with the 2nd Marines wound in the Kuwait City and had the Mutla Ridge. I guess one thing I want to bring up about that I always bring up is we had our CO come out and order us to take two injections and sign a non-disclosure, saying we wouldn't divulge having received it. And of course we're told imminent chemical attack. Is coming and, you know, we're all scared so you do it, but I like to add that to the record because such things really need to get addressed and along that line, the Dr. Apostolos Georgopoulos [speaker, RACGWVI meeting Denver, CO. Aug. 2024] who he shared on the last meeting with the Anthrax antigens, I'd really like to see that picked back up as a central effort. I think it was one of the most tangible pieces of evidence ever discussed. I got well over a dozen other vaccines, and as Sarah [Boyd, previous speaker] pointed out I've always held the idea that, you know, if we have a common denominator between deployed and non-deployed that share the same symptomologies. The vaccines are what, are shared by both of those groups. And then of course working here for VA I had to endure coercion of vaccine mandates once again. For my employment with this so called pandemic, which I'd like to highlight again for the record that this is what the VA is doing to its employees, which was had more than an impact than I like to admit, to be quite honest, kind of recreating a belligerent defiant reaction to being injected with things. And I believe the result of those injections are, you know, these, these pains, these, myalgias that I have, they can pop up in less than an hour like the one I had on Saturday night in my foot after a sweat lodge and I got home and I'm unable to put weight on my foot and, I would call it excruciating and I deal with that all the time in my hands, in my knees, it interrupts my physical activity, my playing musical instruments, a lot of things, and my main concern is this could be quite debilitating. It did debilitate me back in the nineties, when I was at the University of Texas I thought I had both bone cancer when this was assailing a lot of my joints and my knees and my feet. So, and back to the other point, I'd really like to see a goal four newsletter every six months. I would say, you know, over the years, having worked in IT and been around VA, that Gulf War newsletter. Was the largest, had the largest impact on me in terms of the VA cares about me. I'm interested in reading this, I'm seen, and I have many copies from years past that I've kept, and I haven't received anything from the VA and the mail, I quess except for my last intent to file, which I'm doing almost every year because I just never get around because I don't want to deal with any of this to be honest, it's how I deal with it, so. But that's all. I do appreciate everyone's work and sharing of experiences. We I think we are to a large degree isolated from one another. I really don't identify as a Veteran. I think

some of the moral injury and some of my experiences in the Gulf with some very dear Iraqis, really affected me in what we were doing and why we're doing it. It's atrocious and not worth it. And that's all I have to say. And again, my thanks to everyone for all your time.

William Worley: Good afternoon. Can everyone hear me ok? First off, I'd just like to say thank you to the committee and, to the countless advocates, like Denise [Nichols] and several others who continue to make these meetings without fail. I am an Army Veteran of the Gulf War I served with the 1st Infantry Division, and Mechanized Infantry. And if the host would shut off their microphone it'd be great. Okay thank you. The, just getting feedback. There's several comments. I want to echo Eric's comments about the Gulf War newsletter. I too, have many copies that I've maintained throughout the years, not just because I'm a that potential hoarder, it's just because I want my children, my wife and my family to know a lot of information from my time in the Gulf up to present. I have been to the world related illness and injury study center twice. I'd like to thank the work of Dr. Helmer and others, the many clinicians who continue to, give me hope that someday. These things will be addressed for all Veterans. The one recommendation I would make two is that we do have a VBA representative present because so many GWV are, are being denied even with the PACT Act and the many laws that have been put into place since the early 1990s, just today, I worked for the VA in a healthcare for homeless Veterans program and I was interviewing a navy Veteran who was, in the Navy Sea-Bees on the ground, in the areas that I know have been in the areas of the Khamisiyah incident and so on who was just denied by the VBA, mainly because they can't prove that he was in those areas, but I know the units that he was attached to and that kind of thing. So, I think it would be, I think it would be beneficial for them to hear the effects of the continuous denials to Veterans who are not service connected, even though the law says certain conditions are presumptive. With that said, I again, I want to say thank you to the committee. Thank you.

[Regarding Gulf War Newsletter: The newsletter has shifted to a digital/online format. It can be found at <u>VA Publications & Reports on Gulf War</u> or by copy/paste the following link: <a href="https://www.publichealth.va.gov/exposures/gulfwar/publications/index.asp">https://www.publichealth.va.gov/exposures/gulfwar/publications/index.asp</a>

There is also a Dept. VA GWI Facebook page: <a href="https://www.facebook.com/VeteransAffairs/posts/gulf-war-illness-committee-provides-advice-to-the-va-secretary-meetings-can-be-a/1584366212208046/">https://www.facebook.com/VeteransAffairs/posts/gulf-war-illness-committee-provides-advice-to-the-va-secretary-meetings-can-be-a/1584366212208046/</a>]

Alice Saddler: I don't mind sharing it all, my journey with, with disability claims. When I was diagnosed I was in the pack of, people who exited well actually my original exit was with SSB and VSI folks that were downsized, and I received a 10% disability rating for seizure disorder. They all thought I had epilepsy, and I knew I didn't have epilepsy, although I would have a big seizure but then I wouldn't have one for a really long time. An epilepsy is sudden reoccurring seizures. So, they were giving me Tegretol. Which if you don't have absolute epilepsy causes epilepsy and it also has impact on childbearing. So, there's this thing called Fetal Tegretol Syndrome which is the same basically as fetal alcohol syndrome. And so, my decision to get off active duty was based on the fact that I did not want to surrender my childbearing capability to active duty. So, when I had the opportunity to get out, I did get out and become a reserve officer for a period of time and had my children and then hook up with mobilizations and nobody knew the difference. So, it was just fine but then, I also had some severe sinus issues and had, some sinus surgery, so that went up to the 15%. I was simply not paying attention to it because it was not important to me. I already had a bachelor and master degree, so it didn't matter for insurance purposes. So, I kind of tooled along with that kind of stuff for a while, and the thing was I had fibromyalgia, and it should have been service connected according to the 1999 ruling, but it was not service connected. And I've fought that and finally with the PACT Act, I submitted it as a clear and unmistakable error, but it

only backdated to the beginning of the PACT Act, not back to 1999, c'est la vie. Okay you know it's c'est la guerre really. So, we go on and I did open claims about the backdating of the fibromyalgia and all of them were denied. I stayed not service connected, and that's just the way it is, you know, and unless you keep that open every year you are not going to guess the backdating and I didn't so that's how the ball rolls. But I am in in the 2013 ruling that I got when I finally left active duty in 2010, there was a three-year delay at that point for the 2013 ruling to come out. I was in a gray area because I did take the separation bonus and so I paid that back with my, with the years intervening, I didn't get any compensation then until 2016, and then it was at 90%. Okay, that's fine, but then again, when I retired, they took the whole \$46000 out the second time. And that has still not been resolved.

**Tom Mathers:** Col. Sadler, thank you for sharing your story. I think we have a few members on the research advisor committee who are new, and I think it's important for them to understand sort of, not only the health conditions that, that our vets are suffering with, but also some of the frustration in and around getting, service connection and also, getting benefits paid clearly a VBA issue that we're not expert in speaking to.

Alice Saddler: I'll go to the medical. I did manage to get a hundred percent. Yep. I still have PACT Act, things pending. Major health issues are ME/CFS of fibromyalgia, daily migraines, IBS. Drew Helmer might be able to help me with this, but it's like an issue that is throughout my body, it's not neuropathy, but related to connective tissues. It is always lit it up, so that's excruciating and doesn't seem to be a medication that addresses that, so I just checked. Then on top of that I have tinnitus, but it appears to be related to nerve damage from the exposures and that's really about it. There's, there seems to be some neuropathy in my lower joints, and I've had total knee replacements so I can't really walk at this point.

Thank you.

Jason Johnson: Hi, my name is Jason Johnson. All my conditions are getting worse. I was in the Navy. I was abord ship deployed in the north for the majority of the conflict until we cleared all the mines so the fleet can go north as well and then we followed them of them up north, as well I've been exposed to many things that are not even and, the echoing and feedback's really confusing me. Thank you. When you have disabilities you don't even realize you have them in at least with these, at least with me, and I think that's the case with a lot of other people especially the cognitive impacts, and I'm sorry I'd switched gears there, but I just think it's important to let the committee know that we need our voices to be accessible, we need to be heard. Our entire experience has been one of isolation, blame, denials even attacked and told that we're the bad quy because we're begging for help. I speak to you now as a Desert Storm Veteran who had probably more exposures than most and I'm not trying to, you know, measure up against anybody or anything, but what I'm trying to say is, is I was sick right away. I was offered an early out to keep everything un-service connected, in my view. And everything since has been to push us away, minimizes, even the research dollars have been minuscule, "piddly-winks" I call it, and many of the exposures that many of us had, especially in the Navy specifically, aren't even included in the known exposures such as oil in the gulf. We were detonating mines and who knows what was in those. We would sit out on the flight deck and watch it happen from a hundred and two-hundred yards away, you know. I wish I knew now what I, I wish back then I knew what I knew now. I would be heading it inside the ship and putting on MOPP gear as quickly as possible. I wouldn't be demasking when they tell me everything's ok. And the alarms are just false, which they still maintain today, blows my mind. We have been pushed away, we've been minimized, we've been forgotten. We've been swept under the carpet. I feel research is very important. I'm a very scientific minded individual and I was very, very intelligent before all this happened. Now I'm not so much. I have lots of issues and I had issues with my whole adult life. I have five partially failed organs, brain, heart, liver, lungs, I have,

oh, I knew there was another one in there. This is a problem when you have GWI-brain is you forget a lot of things. And if you just are reminded of them, they're still there. It's not like the memory's gone. It's weird. It's like the brain shuts off access to it like "screw you, I don't have energy. That's not important." That kind of thing is what I think is happening there. And the researchers really do need to listen to those of us that can articulate what's going on with us. Those of us that understand more what's going on with this because I was in denial for a long time, the VA put me into denial because I was forgotten, it, you know, ignored piddly-winks, research. I was told it was all in my head. I was told it was all my lifestyle. I was told it was this and that and everything else besides the war. I too, had been diagnosed with GWI by three different environmental medicine doctors, big doctors in the VA including the researcher, the director of the Palo Alto WRIISC. Dr. Ashford himself, who also said I have dysautonomia and I think a lot of us have that. It only makes sense because when the, the stuff is crossing the blood brain barrier, that's the first thing in the brain that gets hit from my understanding. And I do have lots of issues and my organs are failed in ways that there is no treatment, there is no—they don't even understand why. I have a partially collapsed left lung that is from my expert, in my opinion, civilian community care pulmonary doctor is pretty sure it's from 33 years of shallow breathing. And that's the thing. These many of these exposures are organophosphate based and organophosphate, for the Vets. I know the committee understands this and stuff, but organophosphates are neurotoxins, and neurotoxins cause problems with your nerves. What one of my first impacts was the nerves in my lungs, which caused my shallow breathing, my dyspnea or whatever for 33 years, and normally people die in this situation from what I understand, but my body adapted. And I was very healthy, and I was very smart before all this happened and I I'm confident that's the only reason why I'm still alive. I'm not very smart and I'm not at all healthy at all. I have so many CMI and muck me. I have a medically unexplained venous insufficiency that's happening. Pipes look good, but the valves aren't working right. This is neurological damage, and it really concerns me that we're wondering if neuropathy is a component of GWI at the research advisory committee of the United States of America when we know that organophosphates are neurotoxins and it's in our food. The very chemicals the base chemicals that made a lot of us sick, the petroleum air, you know, another thing in the oil and the gulf that, that we're breathing 24/7 until we from when we happened until we left, though, the another thing is the ships water systems that we were preparing food with and showering in, which I think I remember we were told not to shower anymore at one point and things got really stinky, there's just so much and there's so much complication. There's so much deception and leaving us out it's just beyond the scale and when I say that what I'm talking. Now is there's been a lot of research already done on all this stuff and it was done to design this, these chemical weapons, and somehow these chemical weapons are ending up in our food. And for some weird unknown strange reason, there's an epidemic of metabolic disorders in the United States of American where catching things like coronavirus, which we never caught before and many other things apparently that we're really starting to affect the human population. 'Hey Jason' [Tom Mathers]. All that stuff. Sir, can I, can I just wrap it up? I understand I'm taking a lot of time, so thank you. And so, so I just want the record and research committee to know in case you're not aware that there is a lot of research already done and none of it is being looked at or implemented in claims or care and according to Dr. Golomb, she says that the research into what's going on with us, the long study of GWI is not only beneficial to maybe help Veterans, but it's beneficial to help everybody. And I like research. I don't think that there has to be a lot of research done to figure out what's wrong with this. I think that's gaslighting and a lie in my personal opinion, and the facts back that up by all the research that's already been done on all this stuff and none of it is implemented and none of it is, you know, it's all still in our heads.

You know, the clinical guidelines have not changed at all. The claims processes are still, they improved a few percent post PACT Act. I love research. I didn't hear the meeting, I recorded and I'm gonna listen to it later because I have a lot of life issues and I haven't even really been able to attend both days because of all the problems that are going on in my life right now and I'm hanging

on by a thread.

**Tom Mathers:** Thank you. Jason, thanks for sharing your experience and obviously we've heard, you know, heard your progress over time and thanks for calling in to share your experience. At the Veteran Engagement Session back in Tampa where you shared your concerns about updating the clinical guidelines. That's something we've discussed as a research advisory committee yesterday and today. So, your point was well taken in Tampa, so just know that your participation is appreciated and thanks for sharing.

Edward Bryan: Yes sir, I'm definitely from Massachusetts. You can tell with the voice. I appreciate it. I thank everyone for the meeting. My name's Ed Bryan. I was in the U.S. Army. I was in the regular Army Reserve and Army National Guard. I was in the Reserve unit during Desert Storm, I retired in 2000 from starting in 1974. I was loading the ships for Desert Storm, Middle East, 1988-89 down in Jacksonville, Florida. We got called up to go overseas that we bring the stuff back in April of '91. We turned back home in December in '91. It was just nasty over there. I can't, I don't understand how they didn't come up with a measurement of how much oil well fires and nerve agent was released. The DoD doesn't have a clue; all the way to the CIA they don't have any measurements. I studied the oil well fires as a subject matter and I gave my information to the presidential oversight board. As a stakeholder, we need to change the outcomes of the VA RAC [RACGWVI], need to start working on getting more funding. Let me talk to you a second about that. I'll be sending written documentation too. A Gulf War clinic and center should be a mandatory in 2024. You should start the foundation to piece together.

Science not being done. The biomarker study is in limbo in-field because we were very interested in the research and the clinical trials in 2012 timeframe, not done. The Gulf War Clinic would bring together research and find it foundational layering of research to clinical trials nationwide. There must be a foundation planning and focus groups open to the public VA RAC.

Must give more interactions with Veterans and Veterans groups. We need a focus group with round tables, info to get the information out to the committees to get that point across to the congressional committees on Gulf War. We need to update all public laws. We need to go back to 105-368.

We need to find treatments at work. There are two findings from Gulf war research. Alzheimer's, breast cancer, and ALS. It's their signature diseases from Desert Storm. The VA RAC knows this, and the CDC knows this Gulf War research must stay away from research failures. The more funding is needed outside the box. If I was on the VA RAC committee as a member, I would be requesting at least a \$10 billion dollars in funding to get better answers and not under funding. In testing less than 1% of the total subject matters that, that were you that you have on record today. Less than 1%. We get over 1.7 million Veterans nationwide with signatures for GWV.

My son's a GWV. He gets medical treatment, and I don't. I mean I'm his father. He's my son. He's 32 years old. He's an Iraqi Veteran. He gets all the treatments. I don't. Doesn't make sense, but I'm gonna stay positive and focus on my health and not his. If I was a member of the RAC, I would be requesting \$10 billion for Gulf War research today as a stakeholder for Gulf War. Issues and all GWV as stakeholders should interact with the VA RAC at a public discussion like we're doing now with written testimony. I'm requesting this committee to place this item of the Gulf War research clinic center with the \$10 billion budget to be placed on the agenda as soon as possible. Like if you can make a meeting tonight quick, just to put it on the meeting for the for May, we'd be going somewhere. Otherwise, we're not getting no job done. That's why Robert's Rules of Order is important. When I was a commander of the DAV up in Massachusetts, I'll tell you, we always had the Robert's Rules, and we had the business ready for the next meeting. So, this ain't being done with the VA RAC, so we appreciate that if you clear up that discrepancy and if you don't get \$10 billion, at least put \$5 billion, something, you gotta put some more money other than the CDMRP and the VA, the two are minimizing, we need to do maximize to get better outcomes. Less than 1% of 1.7 million. I don't know what that number is, but it's not good. We could at least be getting—

I see a lot of GWV down here in the North Carolina. I was in Tennessee 101st Airborne, going to the past days, but it's a shame they're treating Veterans like they're doing.

**Tom Mathers:** Mr. Bryan, I appreciate it and we hear your call to action to request an appropriation to, you know, better fund Gulf War research. We're all about that. We're obviously here not to make recommendations for appropriations, but we certainly feel the same.

**Ed Bryan:** So, I think like Denise and Kirt and all these other people that interact with me. I'm just stepping out of my thing. I'm a combat engineer and refrigeration guy, firefighter, Boston bound. I'm giving it what I can.

Tom Mathers: Yeah, we appreciate your participation and advocacy. We really do.

Mr. Mathers concluded Public Comment by asking Denise Nichols to speak with the committee once again; however, due to the continuation of technical issues she was unable to speak. Mr. Mathers thanked all the Veterans who spoke and those who posted online. He returned the meeting to the committee chair.

Ken Ramos thanked the Veterans for sharing their comments and called for a fifteen-minute break.

After the break there was extra time and Ken Ramos invited Denise Nichols to try once again to speak with the committee. Ms. Nichols technical issues continued and, once again, she was unable to be clearly heard.

With all committee business having been conducted/discussed, Dr. Ramos moved to close the meeting. He thanked all the Veterans for joining and sharing their comments and all the hard work and input from the committee members.

Dr. Ramos adjourned the meeting.

#### **Action Items:**

- 1. Review and prioritize current RACGWVI recommendations; which ones are short-term and can be easily accomplished (low-hanging fruit), and which ones will require more work.
  - A) Recommendation 3 was discussed as the starting point
  - REF: Recommendation 3: Continue efforts and increase funding for 1990-91 Gulf War Research Innovation Centers (GWRIC).
- 2. Review previous RACGWVI recommendations to:
  - A) Help guide future recommendations (fill in gaps)
  - B) Determine which ones have been completed
- 3. Stay updated on VA-ORD Research Week in May 2025 to:
  - A) Put together a GWI/Toxic Exposure discussion panel with committee members, GWV-elected officials (if possible), VA representatives
  - B) Make and present a RACGWVI poster.
  - C) Determine feasibility of holding a VES
- 4. For the RACGWVI to help guide/provide input on ORD GWI research grants (at the RFA level) for the purpose of ensuring the research will:
  - A) Not be a one-off study
  - B) Move the body of GWI knowledge forward
  - C) Move the research from lab/bench to active clinical treatment
  - D) An ongoing agenda item, the committee should have an update about the current cycle of research proposals.
- 5. Review the committee discussion at the Boston meeting and act on those suggestions
- 6. Plan VES in conjunction with other GWV events. Suggested examples were:
  - A) National VSO conference (VA senior leadership usually attends)
  - B) Army VII Corps GWV reunion