Research Advisory Committee on Gulf War Veterans' Illnesses

Committee Meeting Minutes

February 12, 2024

Virtual Meeting

I hereby certify the following minutes as being an accurate record of what transpired at the February 12, 2024, meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses.

KAREN BLOCK

Digitally signed by KAREN BLOCK
Date: 2024.03.19 11:05:34 -04'00'

Karen Block, Ph.D.
Designated Federal Officer
Research Advisory Committee on Gulf War Veterans' Illnesses

Cheryl Lyn Walker, PhD

Digitally signed by Cheryl Lyn Walker, PhD
Date: 2024.03.19 11:02:46 -05'00'

Cheryl Walker, Ph.D.
Chair
Research Advisory Committee on Gulf War Veterans' Illnesses

Attendance Record	
Members of the Committee:	**Audience Members** (as entered in chat)
Dr. Cheryl Walker, Chair	Jimmy Arocho
Dr. Kenneth Ramos, Vice-chair	Stephen H. Boyle
Mr. Ronald Brown	Alice Nono Djosta
Dr. Drew Helmer	Olivia Frances
Mr. Thomas Mathers	Eva Fulton (DS Veteran, Army, 93rd Signal Brigade)
Ms. Delphine Metcalf-Foster	Clara Garcia (DS Veteran, Army)
Dr. Elaine Symanski	George Garner
Ms. Jane Wasvick	David Gray (US Army)
Mr. William Watts	Harold D. Hanson
Dr. James Woody	Jason Johnson
	Jester Jersey
Members Absent	Kirt Love
Retired Col. Richard Gaard	David Moline
Ms. Barbara Ward	Denise Nichols (USAF, 1611AES(P), Log Base Charlie, MASF13 Saudi-Iraq border, 32AEF USAF)
	Quandrea Patterson
Designated Federal Officer (DFO):	Alice Williams
Dr. Karen Block	
	Total Attendance = 142
Alternate DFO (Alt-DFO):	**Subtotals:**
Marsha Turner	Committee Members = 11
	RAC Staff = 4
Committee Staff:	
Mr. Stanley Corpus	**Total Audience Participants = 127**
Mr. Daniel Sloper	Phone 24
	Online 103
Invited Speakers:	
Ms. Sonya Smith, 1990-91 Gulf War Veteran	
Lisa Pape, Ph.D.	.
Elizabeth Ragan, Ph.D.	
LaTonya Small, Ph.D.	
Mr. Tom Mathers	

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

SEPTEMBER 7, 2023 **9:00am – 3:00pm ET**		
11:00-11:05	**Opening Remarks**	**Karen Block, PhD** Designated Federal Officer
11:05-11:15	**Welcome, Introductions and Meeting Overview**	**Cheryl Walker, PhD** RACGWVI Chair
11:15-11:20	**Veteran Shared Experience**	**Sonya Smith, MHA** **1990-91 Gulf War Veteran/Committee Member**
11:20-11:40	**PACT Act Sections 103, 405 and Gulf War Illness**	**Lisa Pape, LISW** Senior Advisor to the Deputy Under Secretary for Health Veterans Health Administration
11:40-12:00	**FACA 101 Brief**	**LaTonya Small, PhD** Program Officer, Advisory Committee Management Office
12:00-12:15	**RACGWVI Committee Overview**	**Dr. Karen Block**
12:15-12:30	**RACGWVI Veteran Engagement Session (VES) Restructure**	**Kenneth Ramos, MD, PhD** RACGWVI Vice-Chair **Mr. Tom Mathers** RACGWVI Subcommittee Chair
12:30-12:50	Break	
12:50-2:30	**Committee Discussion: Recommendations**	**Dr. Cheryl Walker and Committee**
2:30-3:00	**Public Comment**	**Mr. William 'Bill' Watts** Committee Member/Moderator
3:00	Adjourn	

Committee Meeting Minutes

Welcome, Introductions and Opening Remarks

Cheryl Walker, Ph.D., RACGWVI Chair

Dr. Walker welcomed and thanked everyone for joining the meeting. She then asked Dr. Block to give the committee its charge.

Welcome and Opening Remarks

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

Dr. Block, RACGWVI Designated Federal Officer (DFO) and Director of the Office of Research and Development (ORD) Gulf War Research Program in Washington, D.C., reviewed the committee charge and meeting guidelines. She noted the meeting was posted in the Federal Register, would be chaired by Dr. Cheryl Walker and vice-chair Dr. Ken Ramos, and met the required member quorum. The meeting was being recorded and with written consent, all materials would be publicly posted following the meeting. Anyone not speaking should mute their microphones. She thanked all participants for joining the meeting.

Dr. Block returned control of the meeting to Dr. Cheryl Walker. Dr. Walker asked each committee member and RAC staff to introduce themselves.

Session 1: Veteran Shared Experience

Ms. Sonya Smith, 1990-91 Gulf War Veteran and RACGWVI Committee Member

Ms. Smith served as a medic with the 13th contingency Air Force Hospital detachment (det)-2 out of Langley Air Force base. During her deployment from the United States to the Middle East the military situation transitioned from Operation Desert Shield to Desert Storm. That action resulted in the grounding of the troop plane multiple times due to high-volume of military air traffic and military threats. In Oman, Ms. Smith was stationed at Camp Nacirema (American spelled backwards). Ms. Smith at that time came to understand that she and the other warfighters in her unit and serving their country might not make it back home alive. She discussed exposure to burn pits, sandstorms, and through discussions with friends with whom she deployed, emotional elements that needed to be acknowledged. Ms. Smith finished by saying that as a RACGWVI committee member she will work to be an advocate for all GWV. She also thanked all those GWV for their continued support of the committee and their comments to help guide committee actions and thanked the RACGWVI for their hard work in supporting GWV.

Session 2: PACT Act Sections 103, 405 and Gulf War Illness

Lisa Pape, LISW, Senior Advisor to the Deputy Undersecretary for Health Veterans Health Administration (VHA).

Ms. Pape has been with the VA for approximately 30 years. Currently she is the Senior Advisor to the Deputy Undersecretary for VHA. Her previous experience includes the VA homeless program, caregiver support, chaplain and social work services and care management. As part of her current role, Ms. Pape works on efforts to improve VA care and benefits for Veterans suffering with toxic exposures.

Ms. Pape presented to the committee a PACT Act overview. The key points of her presentation included: The PACT Act is a law that requires VA to improve health care and benefits for Veterans exposed to toxic substances by expanding eligibility and available health care services and other benefits. Immediate impacts of the PACT Act are to expand eligibility for VA health care for toxic-exposed Veterans and Veterans of the Vietnam era, Gulf War era, and Post 9/11 era. The PACT Act has 53 substantive sections. The VA is managing those sections by spreading them across VA and other agencies. Department-level integration is being led by VA Office of Enterprise Integration. Veterans Benefits Administration (VBA) and VHA are working collaboratively to

address all sections and identify areas with cross-administration impacts. The PACT Act is one of the largest expansions of Veterans benefits and health care in VA's history and could impact generations of Veterans and their survivors. The VA recognizes the complexity and broad demographic cross-section of Veterans the PACT Act will affect and will ensure that a "Veteran-centric" approach to the timely and efficient delivery of health care and benefits is available. Ms. Pape presented several specific sections of the PACT Act.

Section 103 expands VA responsibility to provide hospital care, medical services, and nursing home care for any illness to Veterans who participated in a toxic exposure risk activity, were assigned to a duty station in certain locations, including airspace above, and Veterans deployed in support of designated operations and how they fit into the VA priority groups. For a complete overview visit the VA's Public Health website.

Section 405 improves compensation for disabilities occurring in Persian Gulf War Veterans. As part of this section the VA is required to develop a disability benefits questionnaire (DBQ) for Gulf War Illness (GWI). This section also addresses improvements and changes to clinician education and training to improve their awareness and understanding of GWI.

Questions:

Cheryl Walker: Regarding the Veteran Questionnaire, will it provide an overview of clinical research opportunities and give the Veteran an option to enroll or be contacted regarding studies at the time they are competing the questionnaire?

Ms. Pape: She would need to take that question/point back and present it [to her group] as a point of discussion because the primary care doctors will be the ones who are doing/giving the questionnaires.

There is an opportunity for the development of a brochure or flyer to give to Veterans to inform them of research opportunities.

Cheryl Walker: The RAC would be open to working with their group on creating and/or further developing such a brochure/questionnaire.

Bill Watts: Mentions many VA doctors retire or rotate out of the VA (high turn-over rates).

How much additional training will doctors receive or be required to complete that is specific to 1990-91 Gulf War (Desert Shield/Desert Storm) Veterans under section 405, subsection E of training?

Ms. Pape: Primary care provider in the system are always striving to ensure they are fully educated, but that may not always happen. There is training that is ongoing for toxic exposures as part of Section 405.

Elizabeth Ragan, Ph.D., Senior Advisor to the Deputy Under Secretary for Health (Lisa Pape colleague): Told the Committee that there is always room for improvement. Their group is focusing on the implementation of section 405 as an opportunity to provide extremely systematic education across the entire VA. Also, to help document and hopefully connect people with benefits. The education will need to be for both Veterans, helping them understand the benefits process, and for doctors on how to medically treat Veterans with health consequences of toxic exposures. This initiative is a top priority for their group not just from an implementation perspective to make sure the questionnaire and education are being provided, but to ensure providers are getting systematic education on GWI.

Bill Watts: Has anyone from Lisa's group reached out to CDC in support of the ICD-10 code for GWI/Gulf War Syndrome?

Ms. Pape: Not that she is aware of, but she will make a note to bring this back to her group for discussion; it is a good suggestion.

Ron Brown: Regarding 405, why does the DBQ not incorporate the Kansas definition, which is the closest definition to the GWI symptoms and put that definition onto a DBQ like the existing

chronic fatigue syndrome criteria and apply it as part of the GWI diagnosis. It seems that VA is waiting for the perfect case definition when there is a good one ready to be used to get the diagnosis for GWI.
Ms. Pape: VHA, under 405, allows them to do a successor questionnaire to identify symptoms. The DBQ [Ron] mentioned is for VBA, and it is believed they are using the Kansas definition referred to, but Lisa would need to take that questionnaire back to VBA subject matter experts (SME) for discussion.
Ron Brown: If that is the case, under section 603 of PACT Act, why could VHA not have the examiner ask the Veteran about any toxic exposure at the time of screening? At that point the Veteran could be put into toxic exposure treatment/examinations.
[*Cheryl Walker interjected that to maintain schedule and also allow for further questions, she requested Mr. Brown send his further questions to Ms. Pape.*]

Drew Helmer: How will the group evaluate the roll out of their approach to section 405?
Elizabeth Ragan: They are actively building out not only a sort of baseline evaluation plan, but a process for evaluation of impact of the plan. They are reviewing it to ensure it is operating like it is supposed to and addressing several specific questions:

- Is it capturing the target group for which it is intended?
- How is it impacting the system?
- What are the metrics of success?

Concluding that there is an evaluation plan for all of those questions, but their group is not at liberty to discuss it.

Session 3: FACA 101 Brief

LaTonya Small, PhD, Program Officer, Advisory Committee Management Office (ACMO)

Dr. Small presented the committee with their annual Federal Advisory Committee Act (FACA) training for 2024.
This training included the definition of FACA, when FACA applies and Federal Advisory Committee requirements. Additionally, Dr. Small discussed the rules and regulations that all FACA committees and members must follow, where, when, and how those rules and regulations are applied, and FACA best practices.

Session 4: RACGWVI Committee Overview

Karen Block, PhD, Office of Research and Development

Dr. Block presented a structured overview of the RACGWVI that included:

- RACGWVI Charter and purview
- Veteran Engagement Session (VES) subcommittee guidelines
- Parent meetings, public comments and committee correspondence
- Recent solicitation for new members.

The scope of activity for the RACGWVI is to provide advice and make recommendations to the Secretary of VA (SECVA) on proposed research studies, plans and strategies related to understanding and treating all health consequences of military service during the 1990-91 Gulf War. All reports and recommendations must be approved by the Committee in an open public session. The Committee is expected to meet at least once and up to three times annually. The committee will be comprised of up to 16 members, but 12 is more common. The majority of the Committee membership will be special Government employees. The Committee membership will include, but is not limited to, GWV, representatives of such Veterans, and members of the medical and scientific communities representing appropriate disciplines.

The committee Chair shall notify the Secretary of the establishment of any subcommittee, including its function, membership and estimated duration. Such subcommittees may not work

independently and must report their recommendations and advice to the full committee for full deliberation and discussion. The VES subcommittee shall assemble to host a series of Veteran Engagement sessions to hear directly from GWV about health issues most relevant to their well-being and consider ways VA research could help improve their health. The parent Committee shall oversee and guide the subcommittee's activities. The subcommittee shall submit a report (if applicable) to the Committee detailing its activities, findings and recommendations. The subcommittee will be comprised of a chairperson and not more than six additional members. The budget will not exceed ten thousand dollars per in-person meeting. Subcommittee membership will be drawn from parent Committee members, GWV, representatives of such Veterans and members of the medical and scientific communities representing appropriate disciplines, in accordance with the membership balance plan for the Committee.

The RACGWVI is currently soliciting new members. The membership information is posted in the Federal Register: Solicitation of Nominations for Appointment to the Research Advisory Committee on Gulf War Veterans' Illnesses. The deadline is March 1, 2024.

Questions:
Ron Brown: Could a caregiver of a GWV with GWI serve on the Committee?
Dr. Block: Yes, they can serve on the committee. A balanced Committee membership should include SMEs and such a person would be considered an SME.

Cheryl Walker: Is the VES a standing or an ad hoc subcommittee?
Dr. Block: Yes and no; usually there is not a standing subcommittee, there are terms around them; however, this subcommittee was part of the 2022 SECVA recommendations and is in an extended form.

Tom Mathers: Is it worth the time of the Committee/subcommittee collaborating with a special medical advisory group regarding access to benefits or healthcare? Also, what previous interactions have there been to include clinical research and development committees which serve as a type of internal review board (IRB) as it applies to GWI?
Dr. Block: We can collaborate and invite speakers from those various organizations, which in collaborating with them can help to ensure action items have accountability.
Sonya Smith: Collaborations with other committees and organizations was part of a previous committee discussion, to invite other organizations to help with committee/subcommittee action items.
Dr. Block: Outside committees can present and suggest ideas to the committee/subcommittee, but the final decision of any action item will always be determined by the Parent Committee.
Dr. Walker: Increased engagement with GWV, especially for research projects, is a great suggestion and a reminder for committee action.

Dr. Helmer: Can the Committee be given a list of committee/subcommittee members and their start-end dates?
Dr. Block: Yes.
Tom Mathers: Suggests that the Committee, to maintain continuity, develop a broad succession plan, ensuring a GWV replaces a GWV, a doctor replaces a doctor.
Dr. Block: The replacement process is based on the applicants and the Committee does its best to maintain continuity and diversity.
Dr. Walker: Tom has a great suggestion, and it should be discussed at the next meeting as an administrative item.

Session 5: RACGWVI Veteran Engagement Session (VES) Restructure
Kenneth Ramos, MD, PhD, RACGWVI Vice-Chair. Dr. Ramos provided a welcome and

introduction for newly appointed subcommittee Chair, Mr. Tom Mathers.

Mr. Tom Mathers, RACGWVI Subcommittee Chair
Based upon Veteran feedback/comments at previous VES, RACGWVI members determined a restructure was warranted. There remains great enthusiasm and support for the VES as it provides the only public forum currently available for GWV to voice their health concerns through the entirety of the VA. The Committee recognizes an overwhelming majority of feedback from GWV has centered on issues outside the RACGWVI charter, specifically healthcare delivery and denial of GWI presumptive claims.
Proposed changes to the VES structure include:

- Appointment of a VES Chair by the RACGWVI Chair(s)
- The VES composition should be three RACGWVI Veterans, one DFO/Alt-DFO, one RACGWVI staff, and senior VHA and VBA representatives.
- As possible, other non-Veteran RACGWVI members, invited Veteran Service Organizations (VSO) should be included.
- Held as both in-person and virtual open events.
- Disconnect the VES from Parent meetings by:
    - Holding VES on separate days before/after RACGWVI meetings; or
    - Hold the morning of and preceding the RACGWVI meeting; or
    - Hold VES in another city as its own stand-alone event.

Suggestions to RACGWVI Chair(s) and Committee include:

- A non-VAMC location to avoid Veteran apprehension of repercussions from senior VA leaders.
- RACGWVI managing director and staff to coordinate meeting locations with local VSO offices to advertise VES and to ensure VBA, VHA, and Homeless Veteran Offices are notified.
- The VES subcommittee chair shall provide an after-action report/meeting minutes to the RACGWVI DFO within 30 days post-VES (as required).

New VES members:

- Mr. Tom Mathers (Chair), 1990-91 GWV
- Mr. Ron Brown, 1990-91 GWV
- Ms. Sonya Smith, 1990-91 GWV
- Dr. Drew Helmer, GWI Researcher
- Dr. Karen Block, DFO and/or Ms. Marsha Turner, alt-DFO (required).
- RACGWVI support staff (required)
- VHA and VBA invited senior leadership (varies, depending on location).

Questions:
Bill Watts: Appreciates the new direction and structure of the VES and as a founding member of the VES, he poses a challenge to Tom that he and the new members live-up to their presented goals.
Tom Mathers: Agree, and there is a strong incentive to work with the RACGWVI staff and DFO to do as much as possible to advertise the VES and maximize participation by both GWV and VA senior leadership.

Session 6: Committee Discussion: Recommendations
Dr. Cheryl Walker and Committee
Karen updated the committee on the status of the GWI ICD-10 code. The code is under further review. The CDC will discuss on March 19, 2024, for a later implementation date.

Implementation dates occur on April 1 or October 1.
Dr. Beatrice Golomb, invited speaker at the meeting on September 7, 2023, was informally available at this meeting to speak as a SME on the status of the GWI ICD-10 code. She informed the group of the reasons for the postponement of the GWI ICD-10 code:

- Somebody suggested a broader super code and the GWI code would be part of it.
- Somebody suggested a war-related illness code that would be an umbrella code with several exposure-related diseases under it, which included GWI.
- Somebody suggested adding Agent Orange under the illness code.

Those suggestions led to discussions that caused a delay in the approval/denial of the GWI ICD-10 code. Pending any further delays, the GWI ICD-10 code go-live is estimated for autumn of 2025.

Ron Brown: Can the RACGWVI, through proper channels, send a letter of support to the current ICD-10 committee?
Dr. Block: Yes, we will try.
Dr. Golomb: A supporting letter/comment from the Committee could be beneficial to the process; however, do not suggest any revisions to the code as that would only cause further delay.
Tom Mathers: What can the Committee do to support Dr. Golomb at the March 19, 2024 CDC/ICD-10 meeting? Also, would it help if committee members acting as private citizens contact their local elected representatives to express support of the code, stating that GWV cannot wait until March 2025?
Cheryl Walker: As a committee we are following the formalized channels and we can ensure the SECVA knows about the March 19 meeting. As private citizens everyone has the ability to express their personal opinions.
Dr. Golomb: Confirmed the reasons for the code approval delay:

- Coupling Agent Orange to the GWI code
- The position of both the exposure and the illness code under the umbrella code
- Reorganization to move GWI and other exposures under an umbrella code

The biggest concern is the attempt to add Agent Orange to the GWI code which could cause even further delays. Those problems aside, there was no actual opposition to adopt the GWI ICD-10 code.

Dr. Block: Is the adopting of the GWI ICD-10 code new or are there previous military service-related ICD-10 codes?
Dr. Helmer: GWI ICD-10 code is new. When working with patients there are codes that are related to a condition, such as radiation exposure, but there is no code specific to a condition such as GWI.

Through further discussion it was determined that members want the Committee and senior VA-leadership to support the ICD-10 code, however, due to time constraints and going through proper channels, that process might prove difficult. The other approach is that as private citizens any committee member can contact their elected state/federal representatives and ask those officials to support the code. It was also suggested that a representative from the National Center for Health Statistics (NCHS) speak to the Committee at a future meeting about the amendments to the ICD-10 code.

From the Federal Register (added post meeting):

> *The Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Classifications and Public Health Data Standards*

> *Staff, announces the following meeting of the ICD–10 Coordination and Maintenance (C&M) Committee.* ***This meeting is open to the public, limited only by the number of audio lines available. Online registration is required.***

National Center for Health Statistics, Meeting of the ICD-10 Coordination and Maintenance Committee

ICD-10-CM Topics: Number 9. GWI

To keep with the meeting agenda times, Dr. Walker tabled the ICD-10 discussion until after discussion of the agenda topic, Committee Recommendations.

Ron Brown: Would like to recommend the VA further its research on GWV sleep apnea issues.
Cheryl Walker: Thanked Ron for his point but in the current recommendations the emphasis was on how to best engage with GWV and how to encourage them to support and participate in GWI clinical research projects. Recommendation one addresses the establishment of regional research units (GWI-RRU) to facilitate GWI research; Recommendation two is to establish a mechanism that facilitate interagency GWI research to increase and leverage aligned research efforts with the VA, DOD and other institutions; Recommendation three addresses continued efforts to increase funding for Military Exposure Research Innovation Centers (MERIC).

Tom Mathers: What does the Committee need to do to get to a specific research-based question about sleep apnea for GWV?
Cheryl Walker: As previously discussed by the Committee, there is a body of research to support sleep apnea research and there are other working groups in the VA to help direct and influence that research. Based on that information the Committee is positioned to take next steps to look at the sleep apnea and GWV topic.
Ken Ramos: The Committee fully supports the investigation of sleep apnea; however, in the previous meetings and discussion there was no clear understanding on how the Committee could provide adequate guidance on a meaningful research agenda that could move sleep apnea research forward. And in some ways writing a generic recommendation on sleep apnea would actually be as inadequate and inefficient as not even writing it at all. The best option is for the Committee to discuss a sleep apnea research recommendation at the next meeting and ensure the language is specific and stated in a manner that moves the needle forward.

Drew Helmer: Regarding recommendation 1D, should it read, “Increasing diversity *of participants* in clinical trials …” instead of “Increasing diversity of clinical trials …”?
Cheryl Walker: Yes. [correction made].
Tom Mathers: Would like to have VA doctors talk to Veterans about clinical research opportunities instead of the Veteran have to go out and look for it.
Cheryl Walker: That language has been included in the recommendation language. The Committee should invite Lisa Pape to come back and present/discuss the VA questionnaire.
Ron Brown: How will that DBQ be used and how will it improve Veteran care?
Sonya Smith: Agrees with Dr. Walker, she also would like to have Lisa Pape come back for a more in-depth presentation on the questionnaire.
Cheryl Walker: Based on feedback on Lisa Pape’s brief presentation, the Committee will ask her to come back for a longer presentation time. Dr. Walker also asked committee members to write down their question(s) so they can be sent to Ms. Pape for her to

specifically address in her talk.
Ken Ramos: An action item list should be created from this meeting for follow-up and accountability reasons; Dr. Walker agrees.

Cheryl Walker: Asks each member if there are any final questions or comments on the recommendations.
Drew Helmer: No further comments.
Elaine Symanski: No further comments.
James Woody: In Recommendation 1A, he would like language that includes the clinical trials that are being conducted by biotech and pharma companies outside the VA system.
Cheryl Walker: That language is included in the appendix.
Bill Watts: No further comments on this set but wants to make sure sleep apnea and COVID-19 vaccine research are part of the next set of recommendations.
Delphine Metcalf-Foster: No further comments but, regarding 1D, would like to make sure diversity includes female Veterans.
Jane Wasvick: There seems to be no language regarding timelines and accountability.
Cheryl Walker: The Committee can only be prescriptive on many of the recommendations, so timelines can be problematic.
Tom Mathers: No further comments.
Cheryl Walker: Asks for a motion to forward to the recommendations to SECVA.
Bill Watts: Makes the motion to forward the recommendations pending the change to recommendation 1D.
Sonya Smith: Seconds the motion.
Karen Block: Proposes the Committee change the language of Recommendation 3 from MERIC to *1990-91 Gulf War Research Innovation Centers (GWRIC).* [change made]
Bill Watts: Makes a motion to forward the recommendation pending the corrections discussed.
Sonya Smith: Seconds the motion.
Cheryl Walker: Calls for any member to oppose. There was no opposition to the recommendations. All recommendations are, pending the discussed changes, accepted and will be sent to SECVA.

Session 7: Public Comment

Mr. William 'Bill' Watts, Committee Member/Moderator

Mr. Watts noted the public comment portion of the meeting is important and gives Veterans the opportunity to share their voice with the committee. To hear from as many Veterans as possible all public comments were limited to five minutes. Members of the public who submitted comment(s) in advance were called upon to speak first. Time permitting other speakers would then be called on to comment.
All comments were captured and presented as faithfully as possible and without censoring or redacting of language used.

Valerie Mullikin:

The question that I have is there's already been so much research that's gone into this, but we don't seem to have any answers. I mean what kind of research do we actually do and being a female, it seems that maybe even, our, I the way, but the way this is affecting us is a little bit different. So, we're kind of underrepresented. I mean what in the future are we doing as far as research even the levels of people that are used and the testing, it's not enough for sample size. So how can we get true answers to what we can do with this with the treatment is I mean even doctors don't even recognize it because they don't know what it is. I mean good Lord; most people don't even know that there was a Gulf War. It's not even taught in schools, so it's just, where are

we with this? Any or what kind of research can we do to actually show something to give us some answers as far as treatment and doctors aren't knowledgeable about this because nobody is. This is the greatest kept secret.
Tom Mathers response:
To make one comment, I think one of the reasons why you heard such passion with the committee member speaking about the adoption by CDC of an ICD-10 code specific for Gulf War Veterans illness is because it allows us now to better aggregate. All these conditions and diagnosis in this super important cohort of people that enables research to the level you're talking about.
Ms. Mullikin, cont.
Yes, Sir. But what about the research that's already been done? You know, I mean there's a lot of universities that are asking for blood samples, you know, saliva samples, urine samples. So, what are they doing with that information, you know, I mean, why aren't there any answers to what their findings are?
Tom Mathers response:
Ma'am, I can't speak to the specifics of each individual university and or programs which have looked at different research questions that may or may not impact this cohort of soldiers like myself. Sorry, I can't specifically answer that question.
Ms. Mullikin, cont.
I just had one more question if I could ask. Because we keep focusing on, you know, when it first began. So, what about the rest of us after the fact? Because nobody ever seems to talk about the rest of us. It's only focused on that one point when so many of us have been affected. I mean right now we have a third, right that's the number. But we know that number is not true because not all that's recognized that are affected with this. I mean, it took me 15 years with symptoms. What I mean when people say that we're called crazy or we are, it's all in our heads, OK? Like the code to go with it. So, you take this to a doctor. Do you think they're gonna take us seriously? They don't.

[*Mr. Watts reminded everyone the Public Comment was a listening session only, and there should be no response*.]

Jester Jersey
Thank you. Good afternoon to the Research Advisory Committee on Gulf War Veterans Illnesses. Thank you for allowing me the opportunity to speak to the committee. Thank you as well for those on the committee who have served. My father, Joseph, served 20 years in the United States Navy, joining in 1967 and serving honorably before retiring in 1987 and the early 1990s during the Gulf War era. My father was once again called back into service as a reservist, he worked as a munition's depot near Eskan Village in Riyadh, Saudi Arabia. At the end of the Gulf War conflict, he returned home, working as a dietary aid for local hospitals before retiring for good around the same time I entered college. During his two decades of service, he had already served in the Pacific theater during the Vietnam conflict. Seven years ago this month, in February, he experienced a massive stroke while he was home alone. When my mother returned home from work in the evening, she called 911 to have my father taken to the hospital. The last seven years we have been caring for dad at home with the help of caregivers, my mom and myself. We cared for him from the summer of 2017 until the spring of 2020. During that time, we applied to the VA for help because we believe that my father's health conditions was service connected. We were not approved. When the COVID-19 pandemic happened, we tried to take care of my father once more, except without the help of some caregivers that my mom paid to help us as we were forced to shelter in place as lockdowns happened nationwide. Later that year, my mom lost her job and was forced to retire early. Shortly after, me and my mother started taking care of dad by ourselves. We received a letter from the VA in 2020 saying that if we were previously turned down. We could now reapply this the recent authorization of the fact that could help facilitate plans for service-

related injuries. We also took dad to several military health facilities to substantiate our service-related claims. Since then, last August we received information we are now eligible for some compensation as my father's diagnosis for hypertension exposure to Agent Orange were acknowledged. However, our plans for stroke. PTSD and dementia were denied. We feel that the non-approved conditions were exacerbated conditions he was approved for. Since some of these conditions often coexist with diagnosis other Veterans have been approved for. Today I urge the committee to consider additional emphasis on longitudinal studies to look at long-term service personnel who have served in multiple theaters of operations if that is not already being considered. With the higher cost of living, expensive these days, and negative health conditions servicing more often and presenting challenges to our Veterans, retired service members and their families, more research efforts should be devoted on ways to help our Veterans. Our service members have given their all to serve their nation and our people, sacrificing their health and well-being to keep us safe. The least we can do is be there for them in their time. You can help them face the health challenges they may face after the time-of-service ends. Thank you.

Kirt Love
The committee got my letter, so you know my position. I'm going to surrender the rest of my time to doctor Jim Moss.

Dr. Jim Moss
Yes. I just have one comment and it's about the ICD codes. It seems that there's a lot of attention and effort to having a unique code, but I haven't seen much attention lately, anyway. To all the other excessive illnesses that Gulf War Veterans have, a concrete example I can think of is Lou Gehrig's disease, but there's the list is endless cardiovascular system problems that are they have codes already. Why aren't we talking about that more? Anyway, that's all I have.

George Garner
I first wanted to thank you as an advisory committee for your work. As a chaplain, I was the type of person that would take care of my own stuff, and I did that for years, even after I got out of the service. Till one day a great doctor, Dr. Mossop at James Haley [James A. Haley Veterans Hospital, Tampa, FL] said chaplain, I see that you have some serious PTSD issues you need to address. I started addressing them, and I'm so thankful I did. But there's an issue that is not being even acknowledged, really, by the VA yet. And that's the impact of sarin gas. On those of us in Desert Storm. I was part of a 50-man team. The first people to deploy from Fort Hood, Texas for Desert Shield, and having had a number of trips to the National Training Desert Warfare Training Center. I served really as a circuit-ride preacher and ran into number of areas, some have been acknowledged as low-level, but some have still not been acknowledged, such as Hofer Albata [sp.?], which the University of Texas Medical School Study clearly identified through the weather satellite imagery, it hung right over where I was for a week at the local level. I'm pleased with the VA care, but you folks are in a position to address the higher-level personnel. One issue of course when you already mentioned is diversity. How about diversity of us older guys? I was in top shape, forty-six years of age and there were those that were active and in key roles. Beyond me that I know we were exposed to sarin gas. I was considered for a study and when they learned that I was at that time I was 77 years old, they said, oops. The study that the VA and National Institutes of Health are going to do will only consider people up through age 70. That's interesting since other studies, including University of Texas Medical, showed that those that were older at the time were more susceptible to the long-term effects, some of whom I have no doubt I have. And I would hope that that could be considered. A cardiac doctor at Tampa General Hospital that was referred to me had his theory. That my problem was neurological and caused most likely by the saran gas. He said he didn't know if it ever be known or acknowledged, but that was his clear theory. Hope that y'all will be cognizant of that and seek to address that as well. Thank you so much for giving

me this time for these brief comments. I trust that you received my written comments that e-mail to you.

Denise Nichols
Thank you, Bill, for noticing me and others have been involved for 33 years. Going up to the Hill, working on the bill that gave this committee the authority to have the committee. I worked that Hill bill so it wouldn't get lost, so it couldn't go away. And I also brought up the Veteran engagement session as a public comment when we were in San Francisco at the Mark Hawkins hotel. And so, I've been trying to feed into Veteran Engagement Session. I've been begging to have y'all come to Denver ever since. I want to go through my list here real quick. I want to back up the person on the age. You're deleting myself and many others that are over the age of 70. We came home, we had problems early. We've been there all along. I've spoken up and I thank the chaplain for bringing that up, I'm a little bit younger than he is. But you're neglecting probably every general that served over there—Franks, all the generals that are still alive would be deleted and that's not right. It should include every Veteran no matter the age because you need to take that into account. They served. We were there. Usually a little older age group—Right chaplain? I can see you nod your head. The other thing is ALS/Lou Gehrig's is covered because we brought the two first ones that I found which was a Michael Donley, the F16 pilot who is no longer with us in Randy Aveer [sp.?], the Marine. We got it. We got it for Gulf War Veterans and then the general that worked the issue from South Carolina I think who is not with us anymore, but he worked it so that every Veteran that has Lou Gehrig's gets service connected, gets all the help they need. I want that clarified; it is there already. Now what the problems we have, we have a research advisory committee that should be sticking to research. OK? And we had problems with benefit and health. Now Kirt Love was very outspoken and got to go to the secretary of the at the time we had it under his authority for only for 18 months. We have a big problem we need y'all to speak up and say listen—We should be just dealing with the research. We need the benefits Committee for GWI for Desert Storm. We need a health care committee just for Gulf War. OK. That's where a lot of the problems are coming in and we have so much coming in at us, you get confused. Number one. What happens if we don't get any reports on what the patient advocates are being brought forward on GWI and I know that people have gone to them. There is no reports put in to headquarters to know what's going on. We have the White House. People have to call the White House line to get help at healthcare VA benefits or complain on research. We need customer service, look at IT headquarters and we need those divisions of somewhere at headquarters to call with problems with healthcare, with benefits. Research should be separate. That's why I push for research committee and got all the cosponsors. Now when we look at benefits, we need to look at life or death issues. Cardiovascular is now number one, high blood pressure which could lead to strokes and other serious death producing problems. We need to take care of the vets at the highest risk factor, and I know there was a heart association that. doctor Helmer worked on research that came out and so that's really important to me. Sleep apnea could fall under that because if you have cardiovascular problems, it could relate to what I started talking on the hypercoagulation, sleep apnea leading to a heart attack in your sleep. And other things that are aimed at duress, such as thyroid and DDD [degenerative disk disease] as soon as. Yes, problems with the disc in the back. I wanna report we have one vet that I know of that now has suffered an amputation in the past couple of weeks. He probably had COVID hyper coagulation problems. Doctor Ron Bach out in Minneapolis, VA needs to be brought in and he needs to go through his research with y'all because this relates to cardiovascular and blood pressure. Yes, Vietnam vets have those already. They have cardiovascular, high blood pressure and other things. We're 33 years in. OK, aneurysms would be a cause of death. Now the last thing I want to bring up is training. Our providers are still not educated on GWI. I've dealt with it myself with my own new doctor and so the providers, we need something that the providers are getting updates on what the research is, quick and fast for them, so they know and can apply it to the people they're seeing. One last thing

to the last thing, two last things. Number one we've never had a death account that's appropriate complete of those of us that served in theater by Social Security number. The DoD should help and VA to give us a complete listing of numbers of death on Gulf War and cause of death in the age of the occurred. This would definitely help everybody to know that. The other very last thing, travel funds. We have an issue right now with our congressionally directed medical research program with Boston. They've run out of travel funds now. VA should be able to help with providing travel funds. They do it for the risk and you know for urgency with that. That's a critical connecting point for CDMRP. The Boston based, right? So that's an urgent issue. They're out of money for travel. How can the vets be? I tell them to go and beg up the VFW and all. That's ridiculous. OK, I'm tired of this. I'm sorry. Covered everything.

Olivia Frances
Great afternoon, everyone. Thank you for giving me the chance to speak. I recognize what a privilege it is to have everyone's attention here today. I'm speaking on behalf of my precision health data science company, Cogitativo. Our organization focuses on the development of machine learning. Battles for disease prediction resulting in earlier diagnosis, treatment, and preventative care. One of our top priorities is using these models to identify Veterans most vulnerable to exposure related conditions, including GWI. First, I'd like to thank the committee for fostering these discussions and researching endeavors. While GWI should be a top public health priority, especially given Veterans high disease risk resulting from protecting our country, the prevalence and severity of GWI is often forgotten. Additionally, I want to emphasize the value of applying the most sophisticated and advanced technology, namely machine learning and artificial intelligence, to pressing health issues such as GWI. Veteran Healthcare received a major win with the Packed Act signed in August 2022. However, we must acknowledge that even this act focuses more on benefits than optimized testing and care for high-risk Veterans. This dilemma raises 1 main question for Veterans service members and the Cogitativo team. Why are we not addressing the issue of military exposures using the best technology available? The number of Veterans reaching old age, the average Veteran now is 58 years old and almost half of the of the Veteran population is over 65. As risk of exposure related conditions increases with age improving, our approach to monitoring and mitigating these illnesses becomes more pressing these Veterans deserve. Not to date information on their disease risk as well as timely diagnostic testing and comprehensive treatment for any exposure related condition. After completing their service, there is no greater health risk to Veterans than lack of knowledge and care for their high-risk illnesses. Thank you all and if you have any further questions regarding Cogitativo and our machine learning work, please feel free to reach out to me. Thank you.

Ed Bryan
Thanks, Bill. Yeah I just want to I sent a paper in for you guys. Like I emailed the statements for you, but I wanted, I want to still check. I go on to the tap test [finger tapping test] because that seems to be severely overlooked and a lot of the for the VA's across the nation. And the pocket card that goes hand in hand, that's what the community has to rely on, is that pocket card for the doctors, for environmental exposures, very good tool put out in 2012. The other thing is that the Kansas they gave you the letter, Doctor Clapp pointed out early in the 2000s. He said in 25 years after the Desert Storm, we should be looking at cancer screenings in 2015 and were in 2024 so we that's not on our radar yet. That should be the number one doctor said a thing of doing a blood cancer screening. The other thing VA said back in the early 2000s, there was a 1990-91 war was the most toxic bowl of chemical soup. Now this committee should be going off of that toxic bowl of chemical soup. I mean, everybody knows it was really toxic over there and we need to be looking at environmental doctors down the road and that should be on our list and it's not there. But I'd rather leave you with that because there's a lot to digest over 33 years. I appreciate the committee letting me speak today. And you know, we need to be taking care of the Veterans just

the notch above the rest. Appreciate your time.

Session 8: Closing Comments

Dr. Cheryl Walker:

Dr. Walker asked to review the set of action items that were discussed/raised during the meeting.

- Sending member term dates to committee to help inform new member selections
- Set up admin meeting to discuss new member selections
- Set up meeting with Tom to discuss inviting VHA, VBA leadership for VES
- Inform SECVA office of March 19 ICD-10 deadline
- Send questions to Lisa Pape; include her at the next meeting; include questions about the timeline
- Invite NCHS and VA to the next meeting to report on the CDC process for ICD-10 code approval.

Dr. Walker thanked everyone for joining the meeting and called it adjourned.

Meeting adjourned