Research Advisory Committee on Gulf War Veterans' Illnesses

Meeting Minutes

August 21–22, 2024

U.S. Department of Veterans Affairs

Washington, D.C.

I hereby certify the following minutes as being an accurate record of what transpired at the August 21–22, 2024 meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses.

KAREN BLOCK

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Date: 2024.10.17 16:28:30 -04'00'

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

Cheryl Lyn Walker, PhD

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Date: 2024.10.22 11:37:02 -05'00'

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

Attendance Record	
Members of the Committee:	**Invited Speakers:** in order of speaking
Cheryl Walker, Ph.D., Chair	James Woody, MD, PhD, Capt. (Ret)
Kenneth Ramos, M.D., Ph.D., Vice-chair	Karen Block, PhD
Ronald Brown	Thomas Mathers
Retired Col. Richard Gaard	Megan Lafferty, PhD
Drew Helmer, M.D.	Elizabeth Yano, PhD, MSPH
Thomas Mathers	Shakeria Cohen, PhD, MSCR
Delphine Metcalf-Foster	Karen Goldstein, MD, MSPH
Sonya Smith, MHA	Stacey Whitbourne, PhD
Elaine Symanski, Ph.D.	Maheen Mausoof Adamson, PhD, MHL
Barbara Ward, BSN	Stephen Hunt, MD
Ms. Jane Wasvick, BSN, MSA	Javad Razjouyan, PhD, MSc
William Watts	Brian Walitt, MD, MPH
James Woody, M.D., Ph.D., Capt. (Ret).	Apostolos P Georgopoulos, MD, PhD
	Donna White, PhD, MPH
Designated Federal Officer (DFO):	
Karen Block, Ph.D.	
Marsha Turner (Alternate DFO)	**Special Consultant**
	Jeffrey Moragne, Director, Advisory Committee Management Office (ACMO)
Committee Staff:	
Stanley Corpus	
Daniel Sloper	**Attendance:**
	Aug. 21, 2024
	Call in: 10
	Staff/ Committee: 17
	Online: 78
	In-person: 6
	Total: 111
	Aug. 22, 2024
	Call in: 1
	Staff/Committee: 17
	Online: 56
	In-person: 1
	Total: 65
	Two Day Total = 176

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

Agenda		
AUGUST 20, 2024		
9:00 (Mountain Time)	**Opening Remarks**	**Karen Block, PhD** RACGWVI Designated Federal Officer
9:00-9:15	**Welcome, Introductions and Overview**	**Cheryl Walker, PhD** RACGWVI Chair
9:15-9:25	**Veteran Shared Experience**	**James Woody, MD, PhD, Capt. (Ret)** 1990-91 Gulf War Veteran
9:25-9:35	**Message from VA Senior Leadership**	**Secretary Denis McDonough** (video)
9:35-10:00	**Update and Committee Discussion on RACGWVI Recommendations**	**Karen Block, PhD** Director of Gulf War, Senior Scientific Program Manager VA Office of Research & Development
10:00-10:20	**RACGWVI Subcommittee Veteran Engagement Session Report and Future Direction**	**Thomas Mathers** RACGWVI Subcommittee Chair
10:20-10:40	**Women of the Gulf War: Understanding Their Military and Health Experiences Over 30 Years**	**Megan Lafferty, PhD** Qualitative Methodologist Center to Improve Veteran Involvement in Care VA Portland Health Care System, Portland, OR
10:40-11:00	**Break**	
11:00-11:20	**What Drives Women Veterans' Trust in VA Health Care?**	**Elizabeth Yano, PhD, MSPH** National Director, VA Women's Health Research Network Director, VA HSR Center for the Study of Healthcare Innovation, Implementation & Policy VA Greater Los Angeles VA Healthcare System
11:20-11:40	**VA Office of Research and Development (ORD) Diversity, Equity, and Inclusion (DEI) Initiative**	**Shakeria Cohen, PhD, MSCR** Co-Chair, DEI Work Group VA Office of Research and Development
11:40-12n	**Women's Enhanced Recruitment Process (WERP)**	**Karen Goldstein, MD, MSPH** Co-Director, Evidence Synthesis Program Co-Lead, Women's Health Research Network Durham VA Health Care System, Durham NC
12n-12:20	**Overview of Efforts to Increase Women Enrollment in the Veterans Affairs Million Veteran Program**	**Stacey Whitbourne, PhD** Director, Cohort Development and Management Million Veteran Program Coordinating Center VA Boston Healthcare System, Boston, MA
12:20-12:40	**Women's Operational Military Exposure Network Center of Excellence**	**Maheen Mausoof Adamson, PhD, MHL** Director for Research, Women's Operational Military Exposure Network Center of Excellence (WOMEN CoE) VA Palo Alto Healthcare System
12:40-2:00	**Lunch**	

2:00-2:30	**Committee Planning**	**Cheryl Walker, PhD**
2:30-3:00	**Public Comment**	**William "Bill" Watts** Moderator
3:00	**Adjourn**	
AUGUST 21, 2024		
9:00 (Mountain Time)	**Welcome and Overview**	**Kenneth Ramos, MD, PhD** RACGWVI Vice-Chair
9:05-9:20	**PACT Act Sec. 405. Improving Compensation for Disabilities occurring in Persian Gulf War Veterans**	**Stephen Hunt, MD** Persian Gulf Registry Physician VA Puget Sound Health Care System Seattle
9:20-9:30	**Constructing a Clinical Gulf War Illness (GWI) Case Definition Using Natural Language Processing and Advanced Machine Learning Algorithms**	**Javad Razjouyan, PhD, MSc** Assistant Professor of Medicine Health Services Research Michael E DeBakey VA Medical Center, Houston TX
9:30-9:40	**Committee Discussion with Drs. Hunt and Razjouyan**	**Kenneth Ramos, MD, PhD** Moderator
9:40-9:45	**Leveraging Research from Other Diseases to Inform Studies on Gulf War Illness**	**Drew Helmer, MD, MPH** Deputy Director, Center for Innovations in Quality, Effectiveness and Safety (IQuESt)
9:45-10:05	**Deep Phenotyping of Post-Infectious Myalgic Encephalomyelitis / Chronic Fatigue Syndrome**	**Brian Walitt, MD, MPH** Supervisory Physician/Interoceptive Disorders Unit National Institute of Neurological Diseases and Stroke (NINDS) Bethesda, MD
10:05-10:25	**Persistent Antigens Inflicting Chronic Damage on the Brain and Other Organs in Gulf War Illness, Long-COVID-19, and Chronic Fatigue Syndrome**	**Apostolos P Georgopoulos, MD, PhD** Director, Brain Sciences Center Veterans Affairs Health Care System Minneapolis, MN
10:25-10:45	**Cooperative Studies Program (CSP 2006) Million Veteran Program: Deployment, GWI and COVID Health Outcomes**	**Donna White, PhD, MPH** Investigator, Clinical Effectiveness & Population Health Program, IQuESt
10:45-11:00	**Committee Discussion with Drs. Walitt, Georgopoulos and White**	**Drew Helmer, MD, MPH** Moderator
11:00-11:10	**Break**	
11:10-11:15	**RACGWVI Membership Updates**	**Kenneth Ramos, MD, PhD** RACGWVI Vice-Chair
11:15-11:30	**Parting Thoughts from RACGWVI Members**	**Richard Gaard, Col. (Ret.)** **Barbara Ward** **William "Bill" Watts** **James Woody, MD, PhD, Capt. (Ret.)**
11:30-12:00	**Public Comment**	**William "Bill" Watts** Moderator
12:00	**Adjourn**	

Committee Meeting Minutes

Welcome, Introductions and Opening Remarks
Karen Block, Ph.D., Designated Federal Officer (DFO)
Dr. Block welcomed and thanked everyone for joining the meeting. She presented the rules for the meeting and noted that a committee quorum was present. She then turned the meeting over to RACGWVI Chair, Dr. Cheryl Walker.

Welcome and Opening Remarks
Cheryl Walker, Ph.D., RACGWVI Chair
Dr. Walker thanked the committee for all their work and traveling to Denver for the meeting. She thanked the RACGWVI DFO and support staff and asked for the committee members and staff to introduce themselves.

Session 1: Veteran Shared Experience
James Woody, MD, PhD, Capt. (Ret), 1990-91 Gulf War Veteran
Dr. Woody spoke about his time in the 1990-91 Gulf War and working with the U.S. Naval Medical Research Unit-3 (NAMRU-3), stationed in Cairo, Egypt. The mission of NAMRU-3 was surveillance for any infectious disease and biowarfare agent(s) in the area. The group reported to U.S. Naval Forces Command (in theater), as well as Naval Medical Research Institute and other military and civilian research and health organizations (outside theater).

Session 2: Message from VA Senior Leadership
Secretary Denis McDonough (video)
Veterans Affairs produced a Secretary McDonough video message. Message content was directed at VA Federal Advisory Committees and how they support the VA mission and Veterans.

Session 3: Update and Committee Discussion on RACGWVI Recommendations
Karen Block, PhD, Director of Gulf War, Senior Scientific Program Manager
VA Office of Research & Development
Dr. Block updated the committee on the status of the 2023 and 2024 Committee Recommendation packages along with the RACGWVI member nomination package.
A discussion was initiated during this presentation that was specific to the 2023 recommendation: "*The RACGWVI Chairs and committee unanimously request the SECVA support the adoption of International Classification of Diseases-Clinical Modification (ICD-CM) codes for Gulf War illness (GWI).*"
The basis of the discussion was regarding the length of time that had passed from the original submission date. Normal response time for submissions is approximately four months. For the recommendation under discussion it has been 12 months. The committee was told the recommendation is currently pending review at the executive level:

- Office of Public and Intergovernmental Affairs (OPIA)
- Office of Communications and Legislative Affairs (OCLA)
- Office of the General Counsel (OGC)
- Senior Advisor
- Secretary of Veterans Affairs (SECVA)

A response on this specific package is expected at any time. Dr. Block recommended an administrative meeting before the end of September 2024 to inform members of the final outcome.
Discussion:
Cheryl Walker asked if the five levels of review are concurrent or sequential.

Karen Block explained there were 15 offices who reviewed the package before the executive review. The reason the package has taken so long is because CDC did not support the adoption of the ICD-10 code in the first submission. Because of that, the entire submission process had to restart. At this time the resubmitted package went through the various programs, and it is now pending decision at the executive level. Dr. Block did her best to respond to the questions and comments from the committee but because the majority of questions were outside her area of knowledge (i.e., "*Had the SECVA actually seen any of the RACGWVI recommendations?*"), she could not give any specific answers.

Committee member comments include:

Tom Mathers expressed his opinion to the committee. Stating, "*This is an utter disgrace … I have zero confidence that the original recommendations will make it to the Secretary* [SECVA] *unadulterated … this committee should dictate that these recommendations be made to the Secretary without levels of concurrence … it's just an utter disgrace.*" Mr. Mathers further commented that the VA Office of Research and Development should "*take up arms on our behalf*" to help move the RACGWVI recommendations forward and to ensure these types of situations never happen again.

Drew Helmer commented the fight for the GWI ICD-10 code has been going on for years. In his practice as a doctor and researcher, he relies on ICD-10 codes and the lack of a GWI ICD-10 code is, "*one of the biggest stumbling blocks and barriers to improving our research and ongoing public health surveillance of the effects of deployment and GWI on the health of our Veterans.*"

Committee members Ron Brown and Sonya Smith also expressed comments of disbelief and frustration at, what they felt as, the VA's and/or SECVA's seemingly negligent dereliction of duty toward the RACGWVI's recommendations. Because of that disregard for the committee's actions, as Mr. Brown stated, "*…pretty much hamstrings this committee.*"
Ms. Smith told Dr. Block the committee's fierce response was not directed at her, but at VA leadership and their lack of action on the committee's recommendations for over a year. She also stated that, "…*she will continue to be an advocate for GWV, and she will not simmer down!*"

Col. Richard Gaard supported Ms. Smith's comment and agreed the situation was fault of VA leadership.

Barbara Ward shared with the committee her experience from previously working with the VA as DFO for the Advisory Committee on Minority Veterans. Ms. Ward commented during that time ACMO had approximately 30 different advisory committees with similar charters. Some of the recommendations from her committee ran for ten years if not longer before receiving a satisfactory response. She explained how recommendations would be sent back to her committee for rewording or how that recommendation fell under another center.

All committee members addressed the situation and provided their varying degrees of frustration, disgust, and some anger at VA leadership for their handling of the RACGWVI recommendation, especially the request for VA support of a GWI ICD-10 code. Mr. Brown pointed out a probable reason for the situation is the recommendation path is a bottom-up process. The corrective action would be to invert the recommendation pathway and make it a top-down process; to start with the SECVA and then send the recommendation on the concurrence review pathway. Dr. Ramos pointed out there is a lack of efficiency in the concurrence process that needs to be looked at and corrected.

Further questions and comments from committee members:

- Does the original phrasing/wording of the RACGWVI recommendations remain or were

they altered/watered-down by each office in the concurrence process that reviewed them?
- A request was made to speak with an ACMO representative (at the current meeting) to ask why the RACGWVI recommendation package was not reviewed in the established timeframe and if the recommendations were altered.

Committee Chair Dr. Walker agreed with earlier comments, stating she supported Dr. Block and knew she was an advocate for the RACGWVI and GWV. The committee comments were directed at the VA concurrence process. Dr. Walker then asked Dr. Block to continue with her presentation on the status of RACGWVI recommendation packages.

2024 Recommendations to build collaborative efforts with outside federal partners/non-VA funded research to leverage increased GWI research; engage other federal partners in encouraged multidisciplinary research; and establish GW innovation centers under PACT Act.

RACGWVI Member Nominations: Several committee members had reached their term-limit and were leaving the RACGWVI. New members are being appointed, and the Vice-Chair, Dr. Ken Ramos, was nominated as new committee chair. The nomination package was currently pending signature.

Committee Chair Dr. Walker asked for a non-scheduled ten-minute break.

Session 4: RACGWVI Subcommittee Veteran Engagement Session Report and Future Direction
Thomas Mathers, RACGWVI Subcommittee Chair
The Subcommittee on Veteran Engagement held two Veteran Engagement Sessions (VES) in 2024, one in Phoenix, AZ the other in Tampa, FL.
For his efforts in Tampa, Bill Watts was recognized as a true local champion for the subcommittee. He along with Dr. Precious Leaks-Gutiérrez (Tampa VAMC staff member) broadcast and advertised the VES throughout the local GWV community and at the Tampa VAMC. The RACGWVI staff also supported the effort with advertising and outreach. Despite all the outreach effort there was a lack of in-person turnout at the meeting (approximately 20 people over two days) and the majority of online participants were GWV who generally participated in RACGWVI events.

This year a change to VES format was introduced. It included the inclusion of staff members from the Veterans Benefits Administration (VBA) and Dr. Peter Rumm, Director of Policy, VA Health Outcomes Military Exposures (HOME). At the Tampa VES a local VBA staffer was in the room and helped GWV with any questions on their benefits or claims in real time. Addressing the GWV who attended the event, they were active with the subcommittee and appreciative of the subcommittee coming to Tampa. The inclusion of VBA at both the Phoenix and Tampa VES was appreciated by GWVs and helped them feel heard.
Other observations include how the PACT Act has changed the benefits process for the better, but GWV who were previously denied must now reapply via the PACT Act portal, which can be frustrating.
Local investigators and participants commented how an GWI ICD-10 code would improve GWV care.
There were discussions about updating the clinical care guidelines.
At the Phoenix VES the subcommittee had the opportunity to speak with former RACGWVI chair Jim Binns. Mr. Binns commented how his subcommittee was able to circulate amongst the RACGWVI chair/vice-chair the 2014 RAC final report. Despite the heavy lift of getting that report out, there seems to have been no further action taken by subsequent RACGWVI committees, which makes the committee appear to the GWV community as powerless.

Based on conversations with subcommittee members and other GWI/GWV experts (such as Peter Rumm) associated with the RACGWVI and subcommittee, the lack of in-person turnout at VES, and all the effort that goes into preparing one, it was suggested the VES are a drain on time and resources,

especially when the majority of the comments are about benefits.
Based on those conversations and observations, Mr. Mathers recommended restructuring the VES. His suggestion would be to create and send a smaller contact team (one subcommittee member, a VBA representative, and RACGWVI staff member), and those smaller teams go out several times per year to more remote/select GWV population centers; with the hope that smaller and more frequent VES could be equally if not more impactful.

Ron Brown commented he did not want the VES impact to be lessened or lost by the proposed changes. The purpose of the VES is to ensure GWV voices are being heard, to take notes about issues that are important to GWV and present that information to the parent committee. Also, the VES has previously helped GWV during VES sessions including getting a GWV a new wheelchair.

Sonya Smith commented how she has benefited from engagement in the VES. Ms. Smith stated how it is important for the subcommittee to continue to meet GWV where they are and to hear their concerns. It is also important for the subcommittee to continue to figure out the best way to conduct that engagement; to figure out what does and does not work and continue to improve the process.

Jane Wasvick spoke of her time as a subcommittee member; how it was incredibly important for the committee members to hear directly from GWV, and how those conversations have had a big impact on her.

Bill Watts commented that he appreciated the committee/subcommittee for acknowledging the work he and Dr. Precious Leaks-Gutierrez, put into the Tampa VES. Mr. Watts spoke about being part of the subcommittee when it was first initiated. At that time the subcommittee heard from GWVs, their parents, children, and spouses and how GWI impacted all of their lives. He also added that along with getting a Veteran a wheelchair, the subcommittee was able to help three female Veterans, who were being physically abused placed into shelters. Mr. Watts concluded by saying "*VES is more than just hearing about illnesses. It is about helping those that are out there, … and it is a great way for Veterans to release their anger towards the VA, it's a mental release. They know physically somebody has heard them and knows what problems they are having. … It's not only about benefits, it's about psychologically helping.*"

Drew Helmer suggested that a way to maximize GWV outreach and conserve resources would be to leverage other VA advisory committees and outreach programs; to coordinate the engagement efforts into combined events.

Further discussion on the topic included:

- Identifying and coordinating a VES with future VA Veteran-centric events
- Consider holding VES during non-work hours, such as Friday evenings or Saturday
- Creating smaller outreach teams that will reduce travel expense, travel to more remote areas where GWV live, and increase the number of VES per year
- Coordinate efforts through Veterans' Experience Offices

The Committee agreed all of the suggestions were applicable to improving VES and asked members to consider approaches to initiating those efforts.

Agenda Segue:
Jeff Moragne, Director of the VA Advisory Committee Management Office (ACMO), joined the meeting to specifically address the status of the RACGWVI recommendations.
Mr. Moragne thanked the committee for their hard work and dedication to GWV. Addressing the recommendation process, he referred the committee to the Committee Member Handbook that contains a diagram of how the recommendation process officially works. He added, as a VA committee, according to that diagram, the RACGWVI followed the standard operating procedure. In more detail he explained, once

the committee's recommendations are submitted, those recommendations are sent to the DFO's program office. It is then "*the responsibility of the program office to look across the VA enterprise to figure out what part of the enterprise needs to answer each and every one of the recommendation(s).*" which depending on the complexity of the recommendation(s), could span several different program offices. Each of those program offices must then review the recommendation(s) and determine a response to the originating committee.
Mr. Moragne addressed the comments that alleged submitted recommendations are changed or "*watered-down*," and/or put on a "*slow road*." He said those allegations were not only false but would actually violate multiple laws (e.g., National Records Act, Federal Advisory Committee Act, The Sunshine Law).
Once all the support agencies have crafted a response, they then send that response to the submitting program office who then submits the package for further review and concurrence across the VA enterprise, which can include, depending on the nature of the recommendation, various undersecretaries, assistant secretaries, executive directors, Office of General Council, and/or Office of Congressional Legislative Affairs.
All of those processes take time. Currently the VA goal is 120 days from time the DFO releases the report. If that report exceeds 120 days for completion, the senior executive person in the submitting office must answer in writing as to why the response/report took so long.

Tom Mathers appreciated Mr. Moragne's explanation of the process, but directly asked him why the RACGWVI recommendation for the VA to support the adoption of a GWI ICD-10 code is still pending a year after it was submitted. Mr. Mathers further added, "*I know everyone is working hard. … It's not about effort, it's about achievement. It's* [the length of time] *unacceptable …*"
Jeff Moragne responded that the ownership and accountability is in the chain of command of the submitting organization, along with the other enterprise groups, and/or at the undersecretary level.

Cheryl Walker asked Mr. Moragne if the SECVA has ever read or is aware of the RACGWVI recommendations, and second, if there has been any feedback?
Jeff Moragne replied that if a report goes up to the SECVA and he/she responds to it, that report is now available to the public. If the SECVA concurs with a recommendation a VA action plan is implemented. If it is not implemented the committee needs to contact the office of their DFO.
The committee thanked Mr. Moragne for taking the time to answer questions.

Session 5: Women of the Gulf War: Understanding Their Military and Health Experiences Over 30 Years

Megan Lafferty, PhD, Qualitative Methodologist, Center to Improve Veteran Involvement in Care. VA Portland Health Care System, Portland, OR.

Dr. Lafferty's presentation was on the healthcare experiences of Veterans, and specifically pertaining to the focus of this meeting, the healthcare experiences of female GWV. The project was supported by VA teams in Portland, OR., and Salt Lake City, UT. The aim of the project was/is to amplify and expand GWV voices. By doing so, that helps in understanding their illness, and clinical care experiences along with learning about their patient preferences in VA care. Second, the project's aim was/is to improve VA's understanding of symptoms and functional problems that are specific to GWV with GWI and to help identify potential treatment in care at VA medical centers.

The project created the Database of Individual Patient Experiences (DIPEx) to capture each person's story regarding their health, illness, and treatment. The interviews could last up to two hours and were video and audio recorded, along with a transcription. The interviewee determines what format is publicly shared, and all findings are shared via modules on publicly available websites. . The modules serve as a resource for patients and families who may feel alone or uncertain in dealing with their illness and can also help healthcare providers improve communication as well as patient centered care. Results from the study support improvement in several areas: Women-specific care with dedicated space for women Veterans; improved service connection process and tone of denial letters; mandatory provider

education/training about GWI; more alternative therapies and treatments; creation of GWI/GWV support groups.
All the modules can be found at www.healthexperiencesusa.org

Questions:
Bill Watts: *Did your department explore any issues concerning female family member where exposures from the spouses transferred to them and possibly their children?*
Megan Lafferty: *Yes, impact on family, including partners and children were part of the study; that included things for women specifically like challenges with reproductive issues and family planning. The website will have a specific section on that topic.*

Sonya Smith: *Were there any Veterans on your committee to help guide the process?*
Megan Lafferty: *Yes, the study group included a GWV advisory group that helped through the entire process to include developing interview questions, interpreting results, and information dissemination.*

Shannon Nugent, Ph.D. (Principal Investigator, Portland, OR.): Dr. Nugent added to the discussion that the study spoke with Veterans along with Veteran family members and caregivers. Those discussions included spousal/partner discussion regarding relationship and family (children) challenges.

Session 6: What Drives Women Veterans' Trust in VA Health Care?
Elizabeth Yano, PhD, MSPH, National Director, VA Women's Health Research Network Director, VA HSR Center for the Study of Healthcare Innovation, Implementation & Policy, VA Greater Los Angeles VA Healthcare System
Dr. Yano presented a quantitative overview of women Veteran characteristics. The data she presented numerically showed women Veterans represent a minority among VA users, however, they are also the fastest growing segment of new users. They are younger in age than male Veterans and represent a greater racial-ethnic diversity. Results from the study showed it is essential for VA at a nation-wide level to offer comprehensive services at VA facilities to address the increase in female Veteran care. Several women Veteran specific health issues presented included significant comorbid physical and mental illness issues, higher rates of service-connected disabilities, and high rates (between 52–62%), of military sexual trauma (MST). Reports show women Veterans who experienced MST were nine-times more likely to develop PTSD with greater severity, and also to experience higher rates of alcohol and drug abuse issues and/or eating disorders. Women Veterans also report uniquely personal, social, political and occupational contexts, such as institutional betrayal and chronic environmental strains. Because of the increase in women Veterans seeking VA care, the VA has increased emphasis on women-centered care models including, women's clinics and specialty care services with additional specialized training that focuses on safety, security and dignity in VA settings. The training is designed to improve women Veteran care and trust, and to fill-in health care gaps in VA facilities.
The presented information was part of a 12-VAMC randomized controlled trial of an evidence-based quality improvement approach to gender. Overall, 40% of women Veterans had a complete trust of 100 on a 100-point scale, and two-thirds had a trust score >90 on a 100-point scale. However, women Veterans with mental health multimorbidity had a much lower level of trust in VA care.
Dr. Yano explained this study was part of the VA Women's Health Research Network which continues to engage with women Veterans and frontline VA provider/staff to continually improve women Veterans care across the VA network. Dr. Yano concluded her presentation by introducing the new VA guide, *Sourcebook: Women Veterans in the VHA, vol. 5: Longitudinal Trend in Sociodemographics and Utilization, including Type, Modality, and Source of Care*.

Questions:

Tom Mathers: *Has the VA ever conducted a study from the provider's point of view? How the different health care providers (i.e., doctors, nurses, staff) view their patients, especially from the GWV population?*
Elizabeth Yano: *No, that approach has not been explored, although that is an interesting question and should be part of a study.*

Sonya Smith: *For the study, why were those locations (VISNs) selected?*
Elizabeth Yano: *The study sites included the Women's Health Practice-Based Research Network* (WHRN*). The Midwest/East Coast were selected because a similar study had already occurred on the West Coast; the facilities had to be willing to help do the study (no funding was available).*

Ron Brown: *In the millennium cohort female GWV were a small number, correct?*
Elizabeth Yano: *That study has been around for about 25 years and the numbers would have to be verified with the principal investigator. The information isn't current.*

Cheryl Walker: *Can you elaborate more where you think the high-level of trust from women Veterans in the VA is coming from?*
Elizabeth Yano: *The (non-specific) overarching answer could be that women Veterans immediately get plugged into VA women's healthcare, which are often designated women's health providers who are trained and experienced in women's health care.*

Session 7: VA Office of Research and Development (ORD) Diversity, Equity, and Inclusion (DEI) Initiative

Shakeria Cohen, PhD, MSCR Co-Chair, DEI Work Group,
VA Office of Research and Development

Dr. Cohen thanked the committee for inviting her to speak. Dr. Cohen's presentation covered the background and the need for a VA diversity, equity, inclusion (DEI) committee. The purpose of the committee is to promote a culture of inclusivity with ORD and among VA researchers. DEI helps to ensure the VA workforce and researchers reflects the Veteran population it serves. The program also builds a training pipeline for exposing student and junior investigators to potential careers in the VA through volunteer and mentoring programs. The program helps senior investigators with their grantsmanship and career development. The DEI program also ensures VA peer review panels reflect a diverse population. The DEI program is not specific only to racial, ethnic, or gender guidelines but also regional locations; it helps to ensure individuals from rural area are represented, which again, helps to reflect the VA Veteran population. Dr. Cohen pointed out that a diverse workforce helps Veterans coming to VA facilities feel represented and welcomed.

Questions:
Delphine Metcalf-Foster: *Has the DEI program looked at recruiting at Historically Black Colleges and Universities (HBCU)?*
Shakeria Cohen: *Yes, the VA does work with/recruit at HBCU, however, there is work to be done and this DEI program is relatively new and as it grows it will start more collaborations with those institutions.*

Col. Richard Gaard: *On the DEI Summer Research Program Sites map, there are a number of awardees on the upper East Coast/Vermont area, how did that happen?*
Shakeria Cohen: *Those VA facilities had an infrastructure already in place to initiate those DEI programs and collaborations.*

Sonya Smith: *Do you see an opportunity for the DEI committee and the GWI committee to*

collaborate?
Shakeria Cohen: *Yes! Please reach out to me after the meeting.*

Session 8: Women's Enhanced Recruitment Process (WERP)
Karen Goldstein, MD, MSPH Co-Director, Evidence Synthesis Program Co-Lead, Women's Health Research Network, Durham VA Health Care System, Durham, NC.
Dr. Goldstein spoke to the VA's Cooperative Studies Program process improvement project, which works to increase recruitment and inclusion of women into VA clinical studies. The key reason for strong female representation in a clinical study is because men lack a generalizability to women for reasons such as differences in pathophysiology around hormone levels, pharmacokinetics of medications, and prevalence of certain conditions like migraines and fibromyalgia. Therefore, it is important that research reflects and delineates those differences Regarding recruitment, Dr. Goldstein explained, that to conduct, for example a heart/cardiovascular study, one VA site would have enough male volunteers; however, to conduct that same study using female Veterans, multiple VAMC/study sites would be required to enroll the same number of subjects, which could have adverse implications for the study. Furthermore, many women Veterans seek care at women-specific providers and clinics therefore some study coordinators may not be recruiting at the right locations, along with other social and caregiving responsibilities all of which impact women recruitment and participation.
To address those issues the Women's enhanced Recruitment Process (WERP) was started. WERP's purpose is to create enhanced opportunities for women Veterans to participate in VA clinical trails through facilitating study design choices and study team actions that promote the inclusion of women. Dr. Goldstein included several clinical studies and resulting reports that emphasized the differences aforementioned difference between men and women and therefore the need for greater women involvement in clinical studies. Enhanced recruitment techniques included focusing on women's clinics, working with local program managers, and effective/targeted messaging. Based on initial success, WERP expended the program to more centers across the nation. WERP also works with other women-centric and DEI committees at the VA to leverage all available resources.

Questions:
Tom Mathers: *How many women have been pre-consented to be contacted by their primary care physician about clinical research opportunities versus noticing a flyer on a wall and then seeking out the study?*
Karen Goldstein: *Current regulations do not allow for a cold call; an initial letter must be sent to notify the person of the study and that they may be contacted. There have been conversations about building a registry, but currently nothing like that is available.*

Session 9: Overview of Efforts to Increase Women Enrollment in the Veterans Affairs Million Veteran Program
Stacey Whitbourne, PhD, Director, Cohort Development and Management Million Veteran Program Coordinating Center VA Boston Healthcare System, Boston, MA.
Dr. Whitbourne gave the committee and invited guests a brief overview of the Million Veteran Program (MVP) and its importance to research. In November 2023 the MVP reached its goal by enrolling one million Veterans. To reach the one million Veteran milestone the MVP team employed various techniques to include standard e-mail notifications along with snail mail flyers. The MVP base demographics are 10% female, 90% male, both groups are comprised of Veterans across race, gender, age, ability and service branch. The MVP demographic represents approximately 25% racial minorities; approximately 80K/8% Hispanic; 180K+/18% African American; average female age is 50.5 and male is 62.5 years old. Among the women Veteran participants, they are represented from across the entire country, with the greater numbers reflecting states/areas with greater Veteran populations, and those numbers are reflected in the

age and race/ethnicity categories.
The success in enrolling the large number of women Veterans resulted from working with multiple women Veteran stakeholders. That initiative is part of the VA's larger focus on improving care for women Veterans. Some of the campaign methods included using multimedia, outreach activities (press releases, blogs, podcasts), along with direct mailing/e-mailings. Over a seven-month campaign 4,700 women Veterans enrolled in the program, which was a significant amount for the MVP program. The MVP continues to look to the future and enroll Veterans to reach the next million Veteran milestone.

Questions:
Ron Brown: *Are the Veterans broken down according to era-of-service or military campaign (e.g., Desert Storm, OIF, OEF)?*
Stacey Whitbourne: *Yes, that information is part of the demographics and can be shared as requested.*

Karen Block: *Are Veterans being consented to be recontacted by other VA researchers to take part in other studies outside MVP?*
Stacey Whitbourne: *In a limited fashion, yes; however, it comes under the MVP umbrella. But the group acknowledges the MVP subject data base has the possibility to be an amazing resource and the goal is to try and develop a consented recontact database.*

Cheryl Walker: *What did you find to be the most effective way of reaching out and contacting Veterans?*
Stacey Whitbourne: *Unfortunately, from a cost and time perspective, it was snail mail.*

Session 10: Women's Operational Military Exposure Network Center of Excellence

Maheen Mausoof Adamson, PhD, MHL, Director for Research, Women's Operational Military Exposure Network Center of Excellence (WOMEN CoE)
VA Palo Alto Healthcare System

Dr. Adamson presentation was an overview of the Women's Operational Military Exposure Network Center of Excellence (WOMEN CoE). In the U.S. military there are approximately 1.6 million women Veterans with a median age of 49 years old. As of 2022, women comprised nearly 18% of all active duty service members, 17% enlisted, 20% officers. Further data showed there are over 500,000 female GWV and of those, 40,000 were deployed to the Middle East. What WOMEN CoE does is look at military environmental exposures to include airborne hazards and open burn pits, endocrine-disrupting chemicals, fuels, heavy metals, herbicides and pesticides, ionizing radiation, volatile organic compounds, and others and look for the adverse health conditions they cause, such as COPD and reduced lung function, cardiovascular disease, adverse pregnancy outcomes, and cancers to name just a few. The Pact Act gave millions of Veterans expanded care for military environmental exposures (MEE). As Veterans are seeking MEE care different approaches to diagnosis and treatments need to be addressed because MEE, for a number of anatomical/physiological reasons, may affect women differently than men. In addressing MEE health conditions, it is difficult to determine a cause and effect due to variation in exposure types, duration, concentration as well as individual adverse health effects may vary due to genetic vulnerability, gene-environment, and/or any ongoing health conditions. The goal of MEE research is to target the underling mechanisms of the risk and improve outcomes by innovative treatments. Several commonly reported problems in women GWV include skin rash, cough, depression, unintentional weight loss, GWI-related symptoms. Furthermore, GWI is more common among women GWV than men. In comparison deployed female GWV, using VA healthcare, are frailer and have more health deficits than deployed male GWV and non-deployed female GWV. The mission of the WOMEN CoE is to combine a comprehensive clinical care program with cutting edge research to purse answers to military

exposure effects on women who served. The center is organized into three groups/approaches: Education, clinical care, and research.

Questions:
No questions were asked.

Session 11: Committee Planning
Cheryl Walker, Ph.D., RACGWVI Chair
Cheryl Walker initiated the committee planning session. The committee had four points to discuss: Recommendations update, further discussion with the VES subcommittee, meeting travel issues, and possible next meeting dates.

Karen Block: The RACGWVI 2024 recommendations package was signed.
Recommendation 1: Establish regional research units (GWI-RRU) to facilitate GWI research designed to accomplish:

- 1A. Increasing participation of Veterans in GWI-related clinical trials, observational studies, and basic research. **Concur-in-Principle**
- 1B. Building capacity for GWI clinical trials and other research by enabling access of researcher and clinicians to repository and research resources. **Concur-in-Principle**
- 1C. Leveraging past, current and future VA research investments by enabling protocol approval and subject recruitment by non-VA investigators. **Concur-in-Principle**
- 1D. Increasing diversity of participants in clinical trials involving Veterans. **Concur**
- 1E. Assisting with harmonization of (clinical/research) Case Definition and International Classification of Diseases (ICD)-10 code for GWI clinical trial capacity. **Concur.**

Cheryl Walker asked for clarification because the actual recommendation was the establishing of the research units and those each individual point were what would be accomplished. So, the question becomes whether the goals of the research units have been agreed upon, but the research units themselves have not? Or has the recommendation been looked at in aggregate? How/where does this recommendation actually stand?

Karen Block explained the establishment of research units is the easy part, but what can or can't happen at those research units falls under the facilitating agency. Also, the initiation of research units will require oversight, budgets, and other administrative details; ultimately, regarding the request, the final answer of yes or no will depend on the partner agency. For example, if the DoD is a requested partner agency and they say, "*No, we will not be a partner on this project,*" then there is no project. Also, the actual establishment of the regional research units lies outside the committee purview if it is clinical in nature.

Cheryl Walker commented that the described research facilities would require another arm of the VA infrastructure to stand-up those facilities as they lie outside the committee purview. Also, further details need to be clarified such as what/where is a region.

Ron Brown commented how the recommendations are concurred-in-principle by the SECVA, but the current SECVA has announced he is stepping down in January which means a new SECVA will be appointed, and that secretary may have different priorities. It could become that all of the committee recommendation will just fall by the wayside.

Drew Helmer added that, as he understood Jeff Moragne to say, once there is a concurrence or response from the SECVA it is then possible for the committee to ask the responsible people within the organization to come in and describe how they would initiate/set-up the plan. As a next step, the committee should probably identify those individuals.

Dr. Block asked to continue presenting the full VA response statements results before the committee discussion went too far. Dr. Block summarized the response statements by saying the response are something the committee can work with. None of the recommendations were denied; they all had a level of concurrence that can be addressed and resubmitted to achieve a full concurrence response.

Dr. Walker addressed an earlier statement made by Jeff Moragne, that when a recommendation receives concurrence an action plan is drafted. Her question is, who drafts that plan, someone at ORD or does the committee do it?

Recommendation 2: Establish mechanisms that facilitate interagency GWI research to increase and leverage aligned research efforts within the VA, Department of Defense (DoD), and other institutions that will:

- 2A. Actively encourage intra-VA and interagency collaborations to expand research into GWI and toxic exposures promoted under the PACT Act. **Concur-in-Principle**
- 2B. Increase matching funds for jointly funded programs between the VA and other entities (e.g., CDMRP conducting GGWI and toxic exposure research. **Concur-in-Principle**

Ken Ramos commented that the committee understood the concurrence language and as a committee they can work together to figure out a path forward. That will also include such issues as funding and cross-agency collaboration/funding.

Cheryl Walker concluded the discussion by confirming, as it was explained, with the concurrence of the recommendations and it is now up to the committee to start to develop an action plan.

Session 11: Public Comment

Visitors and Invited Guests

Denise Nichols: *I'm a flight nurse, Bachelors and Master's degree. I came in throughout to finish my master which was unique at the time. What I have to say is I networked in all the states with VFW posts, Legions, DAV, Marine Corps league, and various groups. I got the word out about the meeting. We have a problem that we didn't meet at the hospital, so parking is a problem with having to pay for it, but, nope, I'm the only one in the room. I'm sorry. I worked it and I worked it through Facebook and notifying everybody to come. I was willing to help in any way possible. So again, we have that problem, but I want to continue to recommend use the VA facilities. We did have some of the nurses come from the VA, which was unique, and I spent some time with them. So, they learned a lot and had a lot of discussion. I'll try to write it up and share with the rest of the committee. A couple of them were reservists out of the four or five that were here.*

The one thing I want to bring out is we need a VES versus a RAC meeting because then you really hear from Veterans, and I would recommend you all come to Denver, and we can go to the VA auditorium, and I will help with getting reduced rates for Veterans for overnight [lodging] if they need. I would really love to have the VES here versus the scientific research group. I think they need to be kept separately and I've mentioned having a Zoom meeting once a month during off hours, not during business day hours in case some of the Veterans are still trying to live a normal life to some degree. So, that's what I wanted to bring up. Rember our national parade happens with the [GWV] *memorial, and the ground was broken, and I know the first year I tried to get some the people from the WRIISC in D.C. to be there for their meetings and maybe some of the committee members might take advantage of that national time. The parade occurs and I think they have 500 again that showed up so that's a key time to be there and to have a session with the events.*

To have session with the Veterans, I think we have to look outward to getting material out to them in the mail and what have you. The national VSO meetings, the state Veterans Affairs Committee needs to have materials that they can hand out. The benefits regional office had nothing like we have from the VBA and Ron [Ron Brown] *have developed, that I'm gonna try to get a whole stack of those to take over to the benefits area. We had two of the benefits people that were Desert Storm Vets, the one that checks you in was intel, the other was a Navy Veteran that I talked to that works there and he said there are other*

others. We also have one of our Veteran advisors over at the VA that is a Desert Storm Vet. He knew about this; he was trying to get free to come. I did get a staffer from Jason Crow's office [Representative Jason Crow, CO-06], *who is a Veteran of OIF, so I did get that accomplished. He was here earlier, so I'm trying to connect also with the representatives and senators, and they were notified. I was hoping to see more, maybe they'll show tomorrow.*
I want to mention one thing that all of you individually could help with; you know the National Parade and everything that goes on in D.C? Have you noticed if you've ever listened to that, they never mention GWV except for when Powel [Gen. Colin Powell] died, they mentioned it, but they don't mention GWV or Desert Storm. So, a lot of y'all could write individual letters to the memorial group in D.C., not to our Desert Storm, but the overall concert to maybe have that happen. Maybe one of y'all on the committee could be one that's called out of the audience that they focus on.
Some other outside ideas: the other thing is the BBrain, I want to mention is, the DOD congressional directed, they ran out of travel funds. Not that bring me up to how can we figure out research and connecting points. We need to maybe have a way that VA could help with the travel that is required for BBrain in Boston, which is an exceptional institution. I've tried all kinds of things. I found Angel Flight would help us nationally, because I had contact with Veterans who are pilots and have their own planes. So, there are ways, I've tried to be creative to get people to go to BBrain in Boston. So that might be something the VA committee here could maybe work with for travel funds when CDMRP funds run short I covered some of the high points and I'll come back tomorrow an let you all finish. I want, again, we need rules on the chat because it is a problem.

Jimmy Arocho: *Thank you. I am a Veteran of the Persian Gulf War in 1990-91 Desert Shield/Desert Storm. I was in the 101 Airborne Assault for seven months in the deployment. That's my introduction. I just want to share to some of the newer people in the committee. I've been at GWI research for about seven years. I work for Dr. Nancy Klimas at the Institute for Neuroimmune Medicine, Nova Southeastern University. I want share there was one acronym that went unidentified, and I want to identify it. It's GWICTIC, known as Gulf War Illness Clinical Trials and Interventions Consortium. That is something that was built with the work with Congressionally Directed Medical Research Program (CDMRP). Now there is some interpretation to the CDMRP that I think it is interesting. The water is very warm folks. During the years here, the years that have passed, the last seven year, what I've observed is the CDMRP research, which is by the way, which is hundreds of clinicians, many of them with VA assignments, today is under the CDMRP itself, under GWICTIC, two VA entities, very high-level entities. The war related illness and injury study center (WRIISC) in Palo Alto with West Ashford and the WRIISC at New Jersey with Helena Chandler, so there's already a number of professionals in the VA that have already been doing the work. I don't think that the bureaucratic component is caught up and I'd be very respectful here because there is funding and there are protocols to be achieved. I get that part. What has been happening all along; I've been right here all along. I was in Tampa sitting right up front and what has been happening is that we CDMRP researcher have been all along building community. We have been building relationships with Persian Gulf War Veterans. We have been very kind and caring and committed in our approach. Not to ruffle the waters up too much, we understand that there's a little push and pull between dot govs. I understand that it's a little bit frustrating for others, just so you know, again, this congressional directed medical research program peer reviewed research committees can far compliment what the VA is doing, much deeper, mech better. The community is already built. I believe that most of what maybe, maybe frightening in these, in this relationship opportunity are solving much faster, things like this ICD conversation we had this morning. And moreover, what better role than to fill the gap with, with GWI mitigation then having tow massive dot gov organization that essentially can complement one another. We need one another to succeed and to proceed. And when you sit back where I'm sitting, this is my living room at my home where I work remotely every single day talking to Persian Gulf War Veterans from Desert Shield/desert Storm. It kind of invites another 34 years. My gosh, that's like mitigating agent orange. It's been 60 years since the Vietnam war. We don't need those added years. I think that the fine people here could get through the bureaucratic stuff quickly, I say that respectfully, but the folks that can move GWI mitigation forward in understanding what causes GWI and how to intervene, how to treat, complimentary medicine, all of the modalities that we've learned along the way, let's get together because*

the message is there, the Gulf War Veterans, the cries for help, who are there. We need to move beyond these hurdle ladies and gentlemen, that the real deal. And that's all I have to say about that.

Kristi Mogen: *Hi everyone, this is Christy Mogan. I'm a caregiver of a person, of a Desert Storm Veteran. He is too ill to participate. First, I want to bring up with the fact that this is a research committee with their mindset to that. In region 23, we do not have a Gulf War clinic or any specialty to a Gulf War, Desert Storm GWI clinic or resources to that. We do not have, we have a hard time participating in research for GWI because we do not have labs that can do our testing for the research required on, basically, the coasts, is where this research is being done. And we are here in the Midland, and we have no resources. It's a five-hour drive for us to drive to a Quest lab. We have tried to source a local nurse or someone to do those labs and there is just nobody who can do it to the quality and the level required for research. So, there are some hurdles out here for, in the, in the Midwest. And I, I just, the urgency I, I don't know how nobody can feel this sense of urgency. I am in a community where Vietnam Veterans saw their 50th anniversary of the Vietnam war. And I am surrounded by 70- and 80-year-old Veterans, Vietnam Veterans, who are in the same shape as my 53-year-old husband, who will not see his 50th anniversary of his war. He will not see, if it's going the way it is, maybe even his 35th anniversary. The sense of urgency needs to happen. This fire needs to be lit. I am asking for you to investigate the delay of twelve months on this ICD code when we are hearing that it's normally a140 days. I want that investigation and action as swift as our Congress did in their investigation of the secret service earlier this year. Our guys and women who served and received invisible battlefield injuries and their families need this and they needed it yesterday. I'm asking that you please start that investigation, and you take action. This is too far and too long. I cannot impress the urgency and the fact that our, our children are all on impacted and we know it and they know it, and nobody is doing anything about it.*

Kirt Love: *Hello. The audio is going to be a little distorted, we're having a solar storm and my cell phone's really acting up right now. Okay, I've got a problem with a lot of things that have been going on because my frustration is what I used to watch a long time ago in the beginning, what people could do, what they could get away with. There are people that predate this, this committee and this crowd in this room. We were there at the formation; we were there at the beginning of the RAC. We watched what we could do with VA, the things that we pushed. When the committee got together, they did things, they walked up and stormed the secretary's office, Principi [Anthony Principi, SECVA 2001-2005] was willing to listen. When they didn't like the way of something, they wrote a joint letter together and took it upstairs. They waited till they were at 810 Vermont Street to do things. It was a different era. VA got really mad at them and by 2012, they ran the bulk of these people off that used to do these things. When Jim Binns met with the secretary of VA with their recommendations, he stood by them. He challenged the Secretary of VA. He asked him questions. I know what I've talked to Jim for years about the things that they used to do and what they could and couldn't do, and how the committee wrote joint letters, how a lot of this worked. And one of the things that I wish that people would do, is go back and bring back the old crowd and seek them as an asset, seek them as consultants, and work with them to show, because back then, from 2002 to 2012, we did get things done. And the biggest things that got done was the CDMRP. The brain bank, all these other one of things that exist now, we were part of that group, and I was part of that group back then, that made these things happen. When I went to the secretary of VA through Congress, one person, the chairman of the appropriations, let me draft the letter. He signed it, sent it to the secretary of VA—Boom, we had the committee. Never been done before. People forget executive privilege does work. You can get things done.*
PL 105-368 is stagnant. It doesn't work. It hasn't worked. It hasn't changed since 1998 and it governs all this, the WRIISC, the RAC, everything. Back then we weren't afraid of VA and would challenge them, and the secretaries knew us, but over time that has changed, and they've gotten more and more to the point where they don't even know anybody's names or care, there's NO fear factor. If I, if this meeting would have been mine today, I wouldn't have held it in Colorado, I would have held it on Vermont Street and I would have taken everybody upstairs on the elevator and we would have gone up and challenged the executive staff, not the secretary himself, but the people that work underneath him. And if we had made enough of an impression, they would have passed it on to him. Something would have happened today. It

didn't have to be accepted.
The secretary's video to the committee was insulting. It should have been spot specific. There should have been things that he knew by name and people he knew by name. That thing could have been created by artificial intelligence.
I'm absolutely insulted by all of this today, and it's because I've been around and watched what it used to be like when people did get things done. And if you guys would just, you know, Denise Nichols, in the room today, you should have asked her some questions. How to get things done? She does know. Beatrice Golomb knows how to get things done; Roberta White, all these others that were part of the old crowd and knew how to get things done because they had to implement them, they created them. And you guys could stand to benefit from kind of digging in the past and asking the old crowd because some of us actually are subject matter experts, and I get terribly frustrated having been a part of all this for 26 years and just treat me like a guy in the crowd, like, who's he? Why should we care? Why should we talk to him? Because he's the old guy. Well, I'm gonna tell you what, when you've been off the committee three years and you're not with the RAC anymore, watch how VA treats you. Every damn one of you, because when you leave, they're not gonna let you back and they're not gonna let you comment and they're gonna do to you what they did to Anthony Hardy and all the others.
You have a chance to unite and do things as a group. You have a chance to unite the people in the room. You have a chance to vote on things and make it work as a collective. But these letters that you're writing right now are gonna get ignored because the secretary feels no pressure. Every secretary VA since the beginning has ignored them, but we've gotten things done through other channels. And I'm asking you to become true advocates step outside the norm, change it. Policy and planning will let you. OMB will let you. You know, you're taking certain things as verbatim, it's not. And if you ask the old crowds some of us from the old days, we could tell you the things they used to get away with. And so, I'm deeply perplexed and frustrate all this because I can't comment, I can't do things. I have to wait till the end of the day in situations like this and I'm so angry by the end of the day it's hard to focus. Especially now with my new health problems, the new my tumor on my lung just shows how bad everything is right now and what I'm trying to get done with that. Use some imagination, listen this old people, ask for help on the outside. Thank you for your time.

Connie Hunter: *I'm very glad to be here today. I'm glad, very glad to come after the people who have just spoken so passionately because of the influences in having been in the Gulf War.*
I'm an auntie of a GWV, but I've been working with Veterans since Vietnam when I worked in a Veteran Service Office and my husband was a Vietnam Veteran.
My son passed away from birth defects very high likely caused by his father's agent orange exposures. My family is also a gold star family as we lost a family member Sergeant John Kyle Daggett in Iraq, he was one of the youngest men to ever be an Army Ranger. I don't know, know better than to be on these kinds of opportunities to speak my mind. What I wanted to say is, I've been working, and I mentioned it a little bit in the chat box with Dave Cracky (sp?)*, the brain injury advocate for service members and Veterans for the state of Oregon. He's contracted with the Oregon Health Authority at University of Oregon Center for brand injury research and training, and Dr. Doug Goman* (sp?) *VA defense, a suicide prevention conference in Portland, which I was able to attend. I live in Oregon.*
One of I am noticing in this conversation we're seeing PTSD, but what I've learned over working with Dave Cracky for approximately five years in the area of mention and noting that brain injury screening is suicide prevention, that PTSD cannot be appropriately evaluated without the 1st approach, which includes brain injury screening. Medications such as Xanax are contraindicated and Veterans with traumatic brain injury maybe more sensitive to medications such as lithium. So, I see a missing layer of planning across the landscape of VA services to include brain injury screening.
In all of this effort to find the right way to approach many brain injuries and issues associated with, different depressions and different anxieties and PTSD in general.
Without brain injury screening and appropriate emphasis on brain injury screening, you're missing the boat, and we may be causing more harm than good. In addition, having the opportunity to be here today, I want to thank very much the Veterans Engagement. Without community engagement, we don't get things done. Our VA Roseburg Healthcare Network has two engagement and partnership coordinators, one who

is responsible for our county in Southern Oregon. Has not been to our county and has been onboarded with the VA for seven months. We recently had our suicide Awareness and prevention council's strategic planning meeting, and that person was invited and did not attend.
I can't tell you how grateful I am to see community engagement, but also know that we believe in our real areas that the VA is not gonna fill the gaps in care and that it's going to be up to community-based providers. So, thank you for that emphasis. I appreciate everybody here today on probably the biggest disc appointment that I've had in the. This conversation is understanding the disconnect with VA secretary. Thank you so much.

Jason Johnson: *Hello, can you hear me ok? We got you. Okay, great. I just want to I said some of this in the chat, but I just, you know, I want to get into the record and the people that aren't wearing, hearing the chat can hear what I I'm saying here. I would like to encourage that research of root problems are being done and a real concerted effort on what is causing all the, the barriers and delays to things getting done, because, as you hear from any vets that do participate, the ones that still can, you know.*
Things are bad, and they're getting worse. And if you're healthy and you haven't hit these walls and this toxic exposure, cascade of failures in the body, which is not just cancer, not just diabetes, not just the heart issue. It's all the issues and, about to cry what I just saw from, that amazing woman that just spoke. Thank you ma'am. We suffer every day; we wake up suffering.
And our families are affected, and we're affected, and all our relationships are affected, and people don't understand us. It's hard for us to communicate, and against all odds with what's going on in my body. I'm able to even accomplish that at all. It's a miracle I don't understand why the delays of research being implemented in the health care system.
It it's not happening, and the only thing I can think of seeing all the other information if you follow the science and the facts and the history, there's a large scale cover up of all toxic exposures and if you aren't killed by whatever you're exposed to in the moment, you're fine. You're, you're absolutely fine. No physiological effects at all unless you can see an arm melting off. So, this affects us, it affects our friends, it affects our families, it affects our employment, it ruined, my whole adult life has been ruined, ok? And, and I've been struggling to survive and miraculously have survived all of a sudden depth event.
That are not included in service connection, like heart attacks and strokes. I've had I've had an eye stroke that could have went to my brain and we wouldn't even be talking right now.
So, I know I'm going long. I'm gonna end it now. I would just encourage more research being implemented, ASAP, we are in trouble. And, and these chemicals being covered up across the board East Palestine, Ohio train Wreck alone says specifically that those people fit the Kansas criteria for golf war illness among other things. There's comparisons, the long COVID and golf war illness, the chemicals in our food and water and everywhere are becoming rampant and it's affecting everybody now. This is beyond like warning, this is coming stuff, this has been going on.
And it's all getting worse. So, I'm gonna end right now. Thank you for letting me speak.

Closing Remarks:
Cheryl Walker: She thanked all the speakers and Veterans who participated and asked the GWV and speakers to join the continuation of the RACGWVI meeting the next day, August 22, 2024, and closed the meeting.

Meeting Adjourned.

Day 2: August 22, 2024

Welcome, Introductions and Opening Remarks

Karen Block, Ph.D., DFO

Dr. Block welcomed and thanked everyone for joining the meeting. She presented the rules for the meeting and noted that a committee quorum was present. She then turned the meeting over to RACGWVI Vice-Chair, Dr. Ken Ramos.

Welcome and Overview

Kenneth Ramos, MD, PhD, RACGWVI Vice-Chair

Dr. Ramos welcomed everyone to the meeting and asked the committee members to introduce themselves. He then then introduced the first speaker of the day and started the meeting.

Session 1: PACT Act Sec. 405. Improving Compensation for Disabilities occurring in Persian Gulf War Veterans

Stephen Hunt, MD, Persian Gulf Registry Physician, VA Puget Sound Health Care System Seattle

Dr. Hunt introduced himself along with an occupation and environmental medicine fellow who is working with him. Dr Hunt thanked the committee for inviting him to speak. Dr. Hunt is a primary care provider and occupational and environmental medicine doctor in Seattle, WA., and has been working with GWV and the RACGWVI for many years. Dr. Hunt's presentation focused on two parts of the PACT Act. First was section 405: "*(d) If a Persian Gulf Veteran at a medical facility of the Department presents with any one symptom associated with Gulf War Illness, the Secretary shall ensure that health care personnel of the Department use a disability benefits questionnaire, or successor questionnaire, designed to identify Gulf War Illness, in addition to any other diagnostic actions the personnel determine appropriate.*"

Another relevant section of the PACT Act is Section 603 which deals with toxic exposures and mandates the VA to screen all enrolled Veterans for potential health concerns related to exposures during their time in the military. According to Dr. Hunt, the VA has screened approximately 5.7 million Veterans. The PACT Act, from Dr. Hunt's experience, has been successful and transformed the approach to care for Veterans with exposure concerns.

Dr. Hunt provided an overview of the VA's approach on the matter, which is called precautionary principle in occupational environmental medicine. That means if you are in an area and there is no exposure data it is called an unquantified exposure, and the VA then falls back on establish policies and mission statement and values. In the VA, the policy is based on, what is called, the precautionary principle. Which means if there is any evidence of potential harm, the VA gives the benefit of doubt to the Veteran, which is about 85% of exposures. For the other 15%, the VA uses the classical approach of occupational environmental medicine, which means you have to have evidence supporting the exposure and for exposure length of duration.

Speaking specifically to Section 405, it covers any Veteran deployed to any Persian Gulf region from 1990 to present date. What is common to all of the Veteran's deployed to that region is they have higher rates of unexplained symptoms that, during a medical exam, a doctor will not find a diagnosable condition that would explain the pathophysiology. The VA approach is to be as inclusive as possible in supporting that Veteran cohort. That means if a Veteran, within the established cohort, comes to a VA seeking care and presents with the unexplained symptoms, the doctor is to complete Public Disability Benefits Questionnaire (DBQ), or its successor form, the completed form is put in the Veteran's medical record and the Veteran is advised they may meet criteria for service connection for GWI/CMI.

Session 2: Constructing a Clinical Gulf War Illness (GWI) Case Definition Using Natural Language Processing and Advanced Machine Learning Algorithms

Javad Razjouyan, PhD, MSc, Assistant Professor of Medicine Health Services Research Michael E DeBakey VA Medical Center, Houston TX

Dr. Razjouyan introduced himself and thanked the committee for the invitation to speak. Starting in October 2024, his team will begin constructing a clinical GWI computer model. The overarching goal of the application is to develop a case definition of GWI for application in the Veterans Health Administration electronic medical record (EMR) using artificial intelligence (AI) such as advanced machine learning, natural language processing (NLP), algorithms based on large language models (LLM). Dr. Razjouyan gave Chat GTP is an LLM/NLP as an example. The basic design of the model is, as he described, a sophisticated flow chart the computer program will follow to make decisions that are based on the established definitions (e.g., CDC, Kansas) of GWI. The program will be modeled on real-world data and evidence gathered from EMR. The current cohorts include WRIISC (531 participants), CSP585 (977 participants), Other (271 participants selected from ~410,000 VHA users). All of that data is input using three different aims that will build from the data model sets to help identify and/or establish hot spots at VA facilities and to help improve care and quality of life.

Session 3: Committee Discussion with Drs. Hunt and Razjouyan
Kenneth Ramos, MD, PhD, Moderator
Ron Brown (for Dr. Hunt): *According to your presentation, it's going to be very open as to be what is included as GWI, which now includes age-related conditions.*
Dr. Hunt: *The VA is trying to honor and include all Veterans deployed to the Persian Gulf.*

Ron Brown (for Dr. Razjouyan): *Do you know when your machine learning model of a GWI case definition will be available?*
Dr. Razjouyan: *Approximately four years if the work and funding stay on course.*

Tom Mathers (for Dr. Hunt): *As more of a comment than question, as chair of the Veteran Engagement subcommittee the GWV who have spoken at those events don't seem to share the same level of enthusiasm as you presented in your talk, and I would invite you to come to or join virtually to hear what GWV are saying about benefits and claims.*
Dr. Hunt: *I would love to be part of those. Please contact me.*

Tom Mathers (for Dr. Razjouyan): *How easy will it be to "trick" the computer program into making a decision? How confident are you that you will have the sensitivity and specificity in the diagnosis and case definition for GWI?*
Dr. Razjouyan: *The programmers are ensuring the accuracy of all medical records/notes that are being input into the program to ensure that information meets the established gold standard of information. The test models/data sets will ensure that good data input equals good data output.*

Sonya Smith (for Dr. Hunt): *Do you have any idea what percent of presumptive claims have been approved for disability benefits?*
Dr. Hunt: *Not in front of me, no, but I can get those numbers and send them to you.*

Ron Brown (for Dr. Razjouyan): *How does machine learning work when there are no established biomarkers, it's only process of exclusion, how does the machine know?*
Dr. Razjouyan: *That is part of the NLP that is documented in the patient notes/records in the EMR.*

Drew Helmer (for Dr. Hunt): *Hypothetically a Veteran comes to the clinic suffering from sleep problems; who makes the determination that that symptom needs to be included? Furthermore, when does the rating for that symptom happen?*
Dr. Hunt: *That is a complex question and many of the symptoms are covered by a law and by VBA review boards for rating. Bottom line is the group is trying to be as inclusive as possible.*
Karen Block (for Dr. Hunt): *Dr. Block spoke to Dr. Hunt's tireless work as a Veteran advocate*

and all the hard work he is doing to care for the Veteran community.

Session 4: Leveraging Research from Other Diseases to Inform Studies on Gulf War Illness
Drew Helmer, MD, MPH, Deputy Director, Center for Innovations in Quality, Effectiveness and Safety (IQuESt)
Dr. Helmer introduced the next sessions by stating that there are some obvious overlapping symptoms and situations with other conditions of what is typically put under the umbrella of GWI/CMI.
The next speakers will address what is known about those conditions individually and then what might we learn from comparing and contrasting them.
Dr. Helmer explained his personal take on overlapping symptoms varies over time, "*Sometimes I'm a lumper and sometimes I'm a splitter and sometimes it depends on the context."* He was looking forward to hearing from the presenters and learning a little bit more about each of these conditions and then having a chance to talk with them about what can be learned by cross condition comparisons.

Session 5: Deep Phenotyping of Post-Infectious Myalgic Encephalomyelitis / Chronic Fatigue Syndrome
Brian Walitt, MD, MPH, Supervisory Physician/Interoceptive Disorders Unit
National Institute of Neurological Diseases and Stroke (NINDS) Bethesda, MD
Dr. Walitt introduced his research saying that in 2015 the NIH announced a new two-component approach to tackle chronic fatigue syndrome (CFS). One approach was an extramural effort to provide funding for scientists in the community. The second approach, which was led by Dr. Walitt, was to establish an intermural NIH program on the NIH campus to study CFS. The protocol his group developed was named Post Infectious ME/CFS at the National Institutes of Health. The research hypothesis was that the post-infectious ME/CFS was triggered by an infectious illness, an exposure that resulted in immune mediated brain dysfunction. To test the hypothesis the team conducted a cross sectional study that deeply phenotyped ME/CFS to find its pathophysiology. The study recruited individuals meeting experimental criteria and all underwent detailed clinical evaluations, and collection of physiological measures and biological samples; each subject underwent a case adjudication, and then underwent an exercise stress visit.
Test results showed that an infection leads to alterations in immunity that alter immune function and the microbiome function of the gut. Those changes influence the central nervous system (CNS), leading to CNS metabolite alterations. The altered CNS metabolites then affect the temporal-parietal junction of the brain, which impacts motor function and output. Multiple tests were conducted, such as blood based (i.e., biomarkers), imaging (i.e., MRI), physical (i.e., exercise performance), and if there are any sex-based differences. The study concluded that ME/CFS may have an underlying treatable disease; some patients spontaneously recover; multiple biological systems are involved; there are multiple targets for interventions.

Session 6: Persistent Antigens Inflicting Chronic Damage on the Brain and Other Organs in Gulf War Illness, Long-COVID-19, and Chronic Fatigue Syndrome
Apostolos P Georgopoulos, MD, PhD, Director, Brain Sciences Center, Veterans Affairs Health Care System, Minneapolis, MN
Dr. Georgopoulos thanked the committee for inviting him to speak. His presentation focused on persistent toxic anthrax vaccine antigen in GWI. Dr. Georgopoulos defined persistent antigens as proteins or protein fragments that cannot be removed from the body. They come from microorganisms following infection and/or vaccination. They persist because the immune system cannot get rid of them for two possible reasons, the immune system is compromised and/or lack of suitable immunogenetic makeup to eliminate them by killing the class that contain them and/or making antibodies against them.
Persistent antigens can cause harm by various mechanisms, alone or in combination, by inflicting direct cell damage, disrupting cell structure and function, inducing chronic inflammation, continuous immune system stimulation, and/or inducing autoimmunity.
Dr. Georgopoulos's research showed the protective antigen portion of the anthrax vaccine become a persistent antigen that leads to cell damage and as well as cell/system dysfunction that, in the opinion of

the study, is a major contributor to GWI. That opinion is supported by earlier published research that, in rodent cells, showed the persistent antigen from the anthrax vaccine was found to be toxic in CHO-TEM8 cells. A follow-up study, "Anthrax Protective Antigen 63 (PA63): Toxic Effects in Neural Cultures and Role in Gulf War Illness (GWI)." In that study his team found that when the PA63 toxin was added to human neural cell cultures, it led to decreased cell spreading and cell aggregation, leading to cell death. Additional results from the study showed mitochondrial membrane potential was impaired in specific assays.

From that research, another study was conducted to learn what would happen to cells if the toxin was removed from the cell culture. The results showed the cell function improved and the cells stopped dying. In his newest study, Dr. Georgopoulos's team showed the presence of anthrax vaccine antigen in the blood of GWV suffering from GWI to this day. Data from the study showed the severity of GWI symptoms reported corresponded to level of the anthrax vaccine antigen; mild symptoms = lower antigen levels, severe symptoms = higher antigen levels.

To summarize, Dr. Georgopoulos stated the anthrax vaccine antigen (AVA) is toxic. It is present in the blood of GWV with GWI to this day. The AVA damages a variety of cellular functions and causes cell damage and death. The conclusion is that the continuous presence of the AVA can explain much of the diverse GWI/CMI symptomatology. Dr. Georgopoulos hypothesized that an approach to treating GWI would be to clear the AVA from the blood of GWV. He presented several options, but they are either under FDA safety review or expensive.

Session 7: Cooperative Studies Program (CSP 2006) Million Veteran Program: Deployment, GWI and COVID Health Outcomes

Donna White, PhD, MPH, Investigator, Clinical Effectiveness & Population Health Program, IQuESt

Dr. White thanked the committee for inviting her to speak. The focus of her presentation was a study overview, and preliminary findings update from CSP 2006. As the study relates to COVID-19, current global data showed that 776 million COVID cases and 7.1 million COVID deaths were officially reported. The United States has the highest numbers at 103 million cases and 1.2 million deaths. Dr. White pointed out that despite vaccinations and improved treatments/level of care, COVID remained in the top 10 leading causes of U.S. deaths in 2023. Also, severity of COVID is greater in people with comorbidities and/or the elderly.

Dr. White then presented how GWV, who were known to have been exposed to hazardous airborne and neurotoxic agents, are developing/have developed respiratory issues because of those exposures.

For those reasons the VA's ORD Gulf War Research Program (GWRP) provided COVID supplemental funds to conduct first study to evaluate potential GWV vulnerability to COVID by employing the largest nationwide U.S. GWV cohort VA CSP2006.

The CSP2006 program collected genomic data from GWV with GWI through the MVP to conduct research on GWI and other military toxic exposure related illnesses and Veteran health. Currently the CSP2006 cohort has 136,871 GWV members. All MVP participants are users of the VA healthcare system and gave their consent to use their EMR data for the study. The VA's COVID Shared Data Resource (CSDR) to identify COVID testing/outcomes began in March 2020. The CSDR applies large data informatic methods and pre-defined algorithms to VA health and administrative record databases to identify all VA-users tested for COVID, diagnosed with COVID, treated/hospitalized for COVID, and risk factor data on any Veteran ever tested or diagnosed with COVID.

Preliminary provisional results showed that deployment was not associated with increased risk of COVID. However, outcomes evaluated after accounting for other risk factors, although suggestive, show a possible shift toward relatively younger ages developing severe COVID in 2020. Deployed GWV with GWI had suggested potential increased risk for only one COVID outcome; given small numbers further studies were suggested.

Other ongoing COVID research in CSP2006 includes COVID vaccine effectiveness and safety, along with long-COVID burden.

Session 8: Committee Discussion with Drs. Walitt, Georgopoulos and White

Drew Helmer, MD, MPH, Moderator

Drew Helmer (to Dr. Walitt): *Do you think the identification of a diagnostic marker for ME/CFS is close and do you think that can lead to one for GWI?*
Dr. Walitt: *Finding a biomarker is still a fair bit off. Current research suggests the best place to look is in the cerebral spinal fluid, which is not the easiest place to look clinically. Looking at blood, there doesn't seem to be a particular disease signal.*

Tom Mathers (to Dr. Georgopoulos): *Are there any HLA restrictions associated with presence of vaccine antigen in the blood of GWV? Furthermore, you spoke of several treatment options, how do you move forward?*
Dr. Georgopoulos: *Yes, in the original work we identified 100% discrimination between the test and control groups. There were six, class-2 alleles that were identified that had a protective effect. The plasmapheresis would be the simplest approach, but it is also expensive. The antibody approach requires further testing and safety guidelines.*

James Woody (to Dr. Georgopoulos): *You mentioned autoantibodies. Do you have any specific issues?*
Dr. Georgopoulos: *No, none that have been noted.*

Ron Brown(to Dr. Walitt): *Is your study a follow-on to a study conducted by a Dr. James Baraniuk?*
Dr. Walitt: *No, this is not a follow up study.*

Ron Brown (to Dr. White): *Why did you use the CDC GWI definition over the Kansas definition of GWI?*
Dr. White: *The Kansas definition is too exclusive, while the CDC, although has exclusion criteria, it is more open to age-related symptoms and less severe.*

Session 9: RACGWVI Membership Updates

Kenneth Ramos, MD, PhD, RACGWVI Vice-Chair

There were no further membership updates to discuss. Dr. Ramos turned the session over to Dr. Block to provide further updates from the previous day that were not discussed.

Karen Block: Dr. Block discussed updates to the PACT Act, specifically addressing Section 501: Toxic Exposure Research Working Group (TERWG). The TERWG is a legislative requirement to establish a federal-wide working group consisting of employees from VA, DoD, EPA, HHS and other entities involved in research activities regarding the health consequences of toxic exposures experienced during active military duty.
The TERWG team consisted of many high-level subject matter experts from across 8 agencies and several departments.
The TERWG team recently completed their year-two goal of submitting a five-year strategic plan for congressional review and to the Executive Office of the President.
The current implementation and planning phase consists of three categories: A) Characterizing the military exposome, B) Linking military exposures to toxicity and adverse health outcomes, C) Mitigation of military toxic exposures and improved screening for associated health outcomes.

Ron Brown: *Is there anyway the VA can do a more extensive toxic exposure screening process?*
Dr. Block: *Yes*.

Session 10: Parting Thoughts from RACGWVI Members

Richard Gaard, Col. (Ret.); Barbara Ward
William "Bill" Watts; James Woody, MD, PhD, Capt. (Ret.)

Richard Gaard: *Thank you. I just like to say a few things about it's been an honor for me to be a member of this committee right from the start and, you know, after I retired, you know, I've said this before, but from the Pentagon my superiors there said go back home and help Veterans. So that was my goal to do that and to help them as much as I could. So, this committee work has really inspired me during the time*

listening to during some of the Veterans during the engagement sessions. It really hit home to me and so I tried to get as many contacts with Veterans as possible. [Back home] *The Veterans, a lot of Veterans came to me because I'm on the park and recreation board and the chairman wanted to find a spot for a Veteran's memorial. And it was, it was pretty difficult on our town of 8000 to find a spot for a memorial. So, we found a spot in the park and put in the memorial and now they have over 8000 names placed on the, on the various stones that they had various, you know decades various wars. So that was really quite an accomplishment that we achieved there. One more thing that as far as honoring Veterans, I wanted to honor some way the Veterans in Northeast Iowa. And so, on top of that, the middle pole on the Veteran's memorial, we put an American flag. My wife and I endowed that, so that flag will always fly, and also we endowed a flag that they will always fly over the hospital at Winneshiek hospital* [WinnMed, Decorah, IA]*. And both those flags are sent to the Pentagon and flown over the Pentagon in honor of all the Veterans in Northeast Iowa men and women, and then sent back to Decorah; that was another thing that we tried to get accomplished with my wife and I hope the RAC committee will continue to do its mission and continue to help our GWV and get the message to the SECVA. Always cheers our friendships here that we've had and hope that we can meet sometime down the road again. Thank you to our leadership. I know Larry Steinman when I first came on the committee. Then later on Cheryl and Ken, Marsha, Karen, Stan, and, and Dan, we can't, we couldn't be without all of you without you know making it happen. So, thanks again*.

Barbara Ward: *I could just start out by saying you did such a great job. Anyway, I would like to thank everyone on the committee for giving me this opportunity to serve alongside, very talented researchers. It's been a very rewarding experience, especially to me, being a Vietnam-era Veteran. It has given me the opportunity to contribute and hopefully make a difference in bringing visibility and recognition to GWV. The one thing that has really inspired me the most by serving on this committee are the Veterans that I got to hear their personal stories from how they've been impacted and what their continuing issues are. So, it has inspired me to the point that I do plan to continue to try and bring greater visibility to GWV. And if you recall when we had the opportunity to talk with the director of the ACMO. He did emphasize the possibility for collaborating with the other 27, advisory committees and I do think that there are advisory committees that for those of us who are leaving the committee that we could push to become a member of. I'd like to personally push to become a member of anything that's related to benefits because I feel that is one of the core issues facing the GWV. And also, I'd like to say to all of the Veterans that continue to participate and attend these meetings, I relate to their frustrations from the standpoint that oftentimes they feel that the committee is not doing as much as it could or what they expected it to.*
But just to remind everyone that the focus of this committee is research and research can definitely impact policies, but that's not the purpose, so the committee from the standpoint of formulating policies for the VA. So, I think that's an ongoing challenge from that perspective. So once again, I'd like to say thank you. Many of you will continue to hear from me and I will definitely commit to trying to provide greater. Visibility to the cause of all the GWV. Thank you.

James Woody: *Thanks. I've been on the committee for several years doing two administrations and so I have learned a huge amount from our colleagues from the go forward area. And I'm impressed by the dedicated organization's scientific leadership of, of our DFO Karen Block and Marsha Turner, they handle a huge number of huge number of issues, that's for sure. That's being carried on now managed by Cheryl Walker and Ken Ramos, so that's really good.*
I greatly appreciate Stan Corpus and Dan Sloper and the rest of the RACGWI team have been mission control over all these times and the input from the eleven members of the committee. And I have to say Bill Watts, Ron Brown are fervent advocates for the GWI Veterans. I'm just absolutely impressed with them, and Drew Helmer and Peter Rumm are both right at the epi center of all these things and provide us with real genuine insights so congratulations to them. I think Tom Mathers and I both agree with the community would be great to work with more biotech companies. And we're disappointed the ICD-10 didn't get through yet, but there needs more energy and need more expansion of opportunities going forward. So, thanks for allowing me to participate in this honorable activity I appreciate it.

Bill Watts: *All right, I normally speak from the heart when I had to write this one. After many years of*

service to this committee. I would like to thank everyone for the time we spent together, the Veterans, the VA officials who oversee the committee and the doctors themselves. Dr. Drew, Dr. Steinman, Dr. Woody. As well as many of the others. It's been a pleasure and heartbreaking at times for me while serving on this committee.
I know Rome was not built in a day, but we're right around the corner of 34 years since the start of Desert Storm. And it feels like we've only just broken ground in the Gulf War Veteran health care. Being one of the Veterans who suffers from many of the symptoms of GWI, I joined this committee in hopes of bringing about movement and treatment and awareness for the Desert Storms Veterans and their families. Desert Storm Veterans are victims of our own success. There's so few service members died in combat, so our needs were just pushed to the side and as time has gone on, we're just added into the mixing pot of everyone else who served in the same region.
My parting thoughts to this committee is listen to those who came before you and learned from the past. Do not reinvent the wheel and review past committees' documents and what is the status of past's recommendations and if any action was taken. Look at the research materials that prove successful because most of them were pilot studies and recommend trying and recreate the beneficial findings on a larger research scale. As one day it maybe benefit all that served.
Listen to the Veterans and be their champion. Because where there is hope, there's light. Remember the VA motto: "To care for him who shall have borne the battle … " and use my motto: "Quality of life begins with quality of care. No Veteran left behind."
Thank you.

Session 6: Public Comment
Visitors and Invited Guests
Jason Johnson: *So, this is all research specifically, you know, my mind spins of all the millions of things I can talk about, and I do understand. Thank you for ringing it in that this is just a research committee and nothing else, and I'm really quite frustrated with all of the research, the whole history, the research, the very, like I posted in the chat for those who didn't see that the very existence of this committee.*
Is, is it the early on the VA and DOD were denying any chemicals at all in the theater, that any illness was occurring there, and we're being told it's all in our heads. And so that was debugged fairly quickly in the 1996 hearing on 10 December 1996 when the Fox vehicle people and the CIA analyst Patrick Eddington who spoke at the end, proved that there were chemicals being used and then things started to change a little bit and then, you know, the CIA analysts Patrick Eddington said himself during that hearing, I encouraged people to watch that. At the very end, the, the CIA knew about a lot of the chemicals that we were exposed to and some of those effects that he named were brain specific, like memory impairment, language and communication skills, ability to connect dots and critically think, you know, the logic impairment and the brain. And so, they already knew these things and I imagine, I'm just guessing here. My logic and connecting the dots has been severely impaired, that that research known of these effects was already done to make these chemical weapons in the first place. So, I would encourage the research advisory if you haven't done so to look at, at chemical weapon research and see how that can apply. I would also like to suggest that the research advisory committee look at long COVID and all the studies that have been done on that because, even though I'm scared to death of long COVID or COVID in general because of long COVID and death and only death was emphasized, not the long COVID where long co COVID is the more common result of getting COVID. But even though I'm scared to death of it, I view it as a blessing because suddenly everybody is having this threat that we live with. And so now we matter because it matters to everybody else. And so, I would very highly encourage the research advisory committee to look into long COVID research and how that relates to and applies to the GWI research that's been done. Also, all the research that's been done, none of it's implemented. Doctors still have this group take across the board, VA and private care that if you were exposed to some chemicals such as sarin, anything else and you didn't die.
And you're walking and talking, and you make sense, then you're fine. There's nothing wrong with you. You have, you know, nothing more than a common cold, nothing to worry about, and anything else is mental illness. So, it would be really great. I mean research obviously is needed. Lots of research has been done. I've had to become a doctor, a researcher, a media person, advocate, activist, all these, all these things as

a very disabled, toxic exposed individual that is still being ongoing toxic exposed after the battlefield and so I would just really highly encourage that there's some accountability and some action on implementing this research because research is great if you can look at it on paper, but if it doesn't do any good, you know, if the results are ignored, it's useless and it's just a waste of taxpayer money and that's the end of my comment. Thank you. Oh, oh sorry one more thing. Research on the families is not even being looked at and that really. Thank you

Edward Bryan: *Yeah, I'm just looking at some of the stuff. I was a DAV commander up in Massachusetts for a few years. We used Robert's Rules of Order to get the old business versus the new business out of the way. That's not being followed with the RAC.*
Number two, what happened to all the Gulf War research from 2000 and present? We need to be referred out for environmental doctors, industrial doctors. These doctors in the VA don't know what a doctor is. Environmental doctors is that for exposures, the chemicals, multiple chemical sensitivity, chronic fatigue, fibromyalgia, this has been along 34 years. Look at Committee reports. Oil well fires, nerve gas released under each oil well. 1200 or more oil wells of blaze, that was significant. Some of the people that are on the RAC weren't even born there yet. Hey, they weren't born, so we need to be looking a little closer with a magnifying glass, we need to be thinking outside the box.
The committee should go back to Congress and update the committee's charter and start enforcement on research to treatments to clinics. We need a treatment; 34 years without a treatment. The returning Veterans use the power of research, Gulf War research, and got their treatment. How did they do that? You have to change seven four, you have to change public law 103-446 to combine with PL 105-368 reset the 9/11 public law of 107 back to '94 and we will get treatments. Otherwise, we are denied at VA for medical treatments.
The number five, the VA rack session on August 20, yesterday in Denver, had very little on GWI or CMI. Women's research has been leading the way since 2000 and a speed of lightning. Now it's stopping GWI at CMI or CMI. All of 8/20/2024 was about just women, not about Gulf War. Dr. Megan Lafferty said it best. This is why we need Robert's Rules of Order to play a part so we can focus on getting the treatment out of the clinics. Just look at the past documents focusing on 2010 to 2014. Plenty of treatment to send to the clinics.
You need to be looking at that under Robert's Rules of Order, I kind of hope you get your eyes open and your ears listening. I could put a little postscript on this monkeypox virus and GWI or CMI have a common issue not being looked at. Colorado in the area of the mountain range at prairie dogs that get the monkeypox virus. The state of Colorado on the on the federal side refused to look at that. So, it's just a, it's an ongoing process and I kind of hope that the committee will do a little extra and get the Robert's Rules of Order out.
And at least start looking at treatments to get, think outside the box. Don't be thinking that there's no effective treatment because there is. We need to get past that. The doctors that used to say that, that they couldn't find the cause of Alzheimer's disease and it sat right in front of them. And that's another marker. Alzheimer's disease is no longer available. It's not, not in the books no more. They've thrown it out there to trying to keep it but. They discontinued it. That was the cancer.
I that that's all I had to say. I put it all in print, but I'll send it to you guys. Thank you have built, you have for all the work you've done and all the, you and Ron Brown. Tom Mathers, you guys are doing a super job. We just need to get the chairs to correct how to deliver the message to get a treatment. I appreciate it.

Kirt Love: *Alrighty. I want to kind of follow up to Ed to try to help summarize for him a little bit. It's one thing to seek a treatment, it's quite another to have a clinic that works with you on specialty items to help get anything done. The last two years I have been fighting savagely with my primary care. And their attitude is we can't do certain blood labs, we can't do certain imaging, we can't do certain procedures, we have to get a referral, we have to get this, we have to get that. The doctor is overloaded, he doesn't have time for me. The nurses, half of them have an attitude and are trying to not get me care. I put in requests for variety procedures that will drag out up to two years depending on the circumstances and you cannot get a current medical baseline being seen twice a year at 15 minutes a pop, the doctor doesn't have time for you. He's got an attitude. And that you if you go and settle for another doctor on the team in that floor you're gonna*

see the worse. Waco [TX.] is down to nine doctors at this point, which is not enough for all the people they're dealing with. They're overloaded all the time. They just, the one thing they say is that they don't have time. Or they schedule you out. My colonoscopy is scheduled in April to tell you how far things were scheduled out. It should have been done a year and a half ago and I'm a high-risk person. I'm trying to get other procedures done. They're, they're putting it way, way out. I can't get blood labs to find out where I'm at currently. And so, some of you have known, you've seen the CT scan of this basically what is a 4-inch x 3-inch x 1.5-inch tumor in the back of my lung. We still don't have a biopsy to verify it. I've been to the medical consult. The doctor really kind of blew me off. The surgeon kind of blew me off. Now Peter Rumm [Peter Rumm, M.D., WRIISC] *is involved. Peter Rumm is gonna try to get me a referral. What it comes down to is we need a specialty clinic. We need someone where a GWV go, that was what was originally the WRIISC was supposed to be. You go in and they stay with you, and they follow you through on diagnostics. And a variety of other procedures, we need a toxic exposure pathology center that specializes in doing the autopsy before your dead.*
And so, without a place to go, once this meeting is over, I've got nowhere. I gotta sit here and hurry up and wait and hope that Peter Rumm or somebody else can get something through, and I could at least get a biopsy and find out if I'm about to die of this damn thing or if it's just a standard lipoma. Now the thing is, in the Gulf War crowd, we don't know how many are out there with these with these type of soft body masses because we don't have a specialty program following it. We don't even know if they're out there because it takes special imaging even to find it. And it could very well be the TCDD (2,3,7,8-Tetrachlorodibenzodioxin) and TCDF (2,3,7,8-Tetrachlorodibenzofuran) furans and dioxins, which aggravate the body fat, might play some part in this. And then it might be finally a cluster at this point of all these, benign or inert tumors that are surfacing that are reacting to these forever compounds in the body fat. We would know there's no place to go and no one to report it and in the autopsies is not gonna surface because it's a secondary or tertiary. It didn't kill you. So, we're not gonna be able to follow it that way either. So, I agree with Ed, we need special treatments, but we also need special clinics. Conventional care is not working. Thank you for your time.

Kristi Mogen: *Hi, this is Chrissy. I do want to second that call for learning Robert's Rules of Order, you know, every high school debate it knows what that is and how to use them. Secondly, I'd like, I'd like to know yesterday I called answers on that delay for the ICD code, and we hear nothing just crickets today and I think I think it needs to be addressed on this board. So, I'd like some answers.*

Denise Nichols: *Basically, I wanted to hear from all of you on-line and emphasize that, you know, we're dwindling on the people that even tune in to the RAC. And it happened and that's why I suggested Veteran engagement sessions way back in California, because the Veterans have a lot to say, and I wanted to hear them today. And again, we have to have a way.*
And I'm gonna suggest we set up a Zoom meeting with one or two of y'all to host it but do Zoom meetings once a month because we've got some people out there really hurting, and I'll tell you one thing.
I'm a hypercoagulation was out of Minneapolis also and Dr. Ron Bach up in Minneapolis [Ronald Bach, Ph.D., VAMC, Minneapolis, MN.]. *And I want to tell you a sad story I won't use the person's name. There's the GWV that participated from Nevada all the way to Texas with Dr. Steel in one of our congressionally directed medical research program researchers and he's been taken care of as far as compensation. But he was having circulation problems in his legs. No one was evaluating him. Give me a break. If I had known earlier I would have yelled and screamed at him to get to the ER. He's now an amputee because of that. Let that sit in. He's still alive. He's raising his son, who's in finishing high school. I hear all of the stories they get to me. I was a nurse out there. I want to help him. I want y'all to help him. I want you to hear them.*
And I want to remind the Vets there is a way to write to the committee and hopefully they would document what you write. The second thing is, I don't know about the other Veterans, but I would like the slide presentations to go up almost immediately. Because they're suffering with neural cognitive and trying to watch the slides and take notes and do the chat. Please, I mean, I don't see any reason you couldn't put the slide presentations up even before the conference, much less maintain them. Then you can have the minutes later, ok? But I think that would help the vets to have the slides out and know what y'all are doing.
And I want to encourage, I want to encourage the vets to keep the fight going.
It gets hard. I've been involved since I came home 33 years of it and people know that. A lot of us that were

there in the beginning Joe Jad(?)*, another nurse, Air Force nurse died many years ago, Steve Robins Robertson*(?)*, that was very involved on the office's special investigation.*
It was finishing up active duty who was really involved even with the post 9/11 group going out to bases, meeting with him and fighting for their benefits. He died of the sudden heart attack. We don't have any accurate data on our deaths, who they were, what their age, at death, cause of death. Many of them may not even be using the VA at all, going to civilian doctors. That's terrible. We have a memorial that's being built right now, the ground-breaking was over a year ago and I'm tired of even the concerts that are given on Veterans Day Memorial Day, not even mentioning Gulf War, Desert Storm, Desert Storm. It's like we're dead already.
I'm letting my emotions get to me, I'm taking more than five minutes, but my fellow vets don't give up, reach out and grab other Vets. The best thing you can do is to get him involved. To watch the hearings like you have now and watch for the minutes of this meeting. Do not give up. Okay reach out to each other if there's an episode that needs help, reach out to any of our committee members that are Veterans, myself, you know. I cry for what is going on with my fellow Veterans. Thank you. Thank you for everything that you've done for the Veterans.

Closing Remarks:
Ken Ramos: Thanked the four departing committee members and asked them to stay in contact with the committee. He turned the meeting over to Dr. Walker for her final closing comments.

Cheryl Walker: Dr. Walker also thanked the departing members, saying it was an honor to have worked with and gotten to know them. They are all wonderful Veteran advocates, and she hopes they continue with their efforts. She said the next job the committee has is to work on getting the recommendations through the VA system and getting VA concurrence or concurrence in principle on those recommendations.
She thanked the committee for allowing her to be the chair, and said, although she is stepping down from the leadership role, she will remain with the RACGWVI as a member.
Dr. Walker thanked the committee members and staff for all their work, the invited guests for their presentations, and a thanks to all the GWV who joined the meeting

Meeting adjourned.