

ADVISORY COMMITTEE MANAGEMENT OFFICE (ACMO)
Annual Assessment of Committee Activities

January 1, 2022 through December 31, 2022

Committee Name: Research Advisory Committee on Gulf War Veterans' Illnesses (RACGWVI)

Calendar Year 2022 Committee Goals: The Committee met the majority of projected 2022 goals.

VA Strategic Goals: 2022 committee goals and accomplishments:

Goal 1: Hold two RACGWVI parent committee meetings to examine current research and develop new and existing recommendations to advise the VA Secretary (SECVA).

The Committee held two parent committee meetings. The first meeting on January 28, 2022, was held virtually due to COVID travel restrictions. The second meeting held in Washington DC on September 21-22, 2022, was the first in-person meeting since 2019. Both meetings focused on the 1990-91 Gulf War environment and toxic exposures, genetics and epigenetics. See 'committee activities' for more information.

Goal 2: Hold two RACGWVI subcommittee Veteran Engagement Sessions (VES) to better understand Gulf War Veterans' health and quality of life concerns, increase trust and communication with Gulf War Veterans, enhance customer service and reinforce VA's commitment to excellence with the goal of understanding and treating the health consequences of military service in the Southwest Asia theater of operations during the 1990-91 Gulf War.

The committee held two virtual VES on April 6-7, 2022, and July 20-21, 2022 (3-hour sessions each day). See 'committee activities' for more information.

Goal 3: Continue to follow the status of the VA: National Institutes of Health (NIH) Deep Phenotyping Study on Gulf War Veterans' Illnesses, known as Project IN- DEPTH, and discuss progress with the VA Office of Research & Development (ORD), Senior Gulf War Program Manager.

This committee recommendation received concurrence in 2018. The study team expects to collect, build and maintain the project's deep phenotyping infrastructure to create a data- and biologics-repository overseen by VA and made available to VA- and non-VA Gulf War investigators for validation, discovery, and targeted clinical trials. Dr. Block informed the committee during her update at the September meeting that Project IN-DEPTH has exceeded enrollment expectations to date.

Goal 4: Follow planning for the second ORD Gulf War Illness State of the Science Conference planned for 2022 with the Department of Defense (DoD) and offer guidance on next steps.

Initial planning for the second GWI State of the Science conference has been delayed by the start of the DoD Toxic Exposures Research Program (TERP), which resulted in

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a change to the DoD GW program and personnel. This conference will be re-evaluated.

Goal 5: Develop a task force to increase interactions with other government agencies (e.g., FDA, CDC, NIH) to enhance communication, encourage collaboration and solidify common goals with these agencies in Gulf War Veteran research.

The goals herein have been refocused around new legislation, the PACT Act. Signed into law, 8/10/22, the committee is aligning with PACT Act activities, with emphasis on sections 501 and 509, to enhance new collaborative scientific directions by encouraging collaborations with other government agencies to leverage subject matter expertise, technologies, data and biorepository resources to enhance Gulf War Veteran research.

Goal 6: Initiate recommendations submitted and approved by the VA Secretary in 2021.

All four 2021 recommendations received concurrence in April 2022. The status of each of these recommendations are outlined below.

Recommendation 1: Fund research into key focus areas, examples below, to support the diagnosis and treatment of Gulf War Illness (GWI). 1) Emphasis on, basic and clinical studies on the role of the microbiome in the etiology and maintenance of GWI. 2) Emphasis on, basic and clinical studies to determine the effects of dietary manipulations on the quality of life for Gulf War Veterans (GWV) with GWI. 3) Emphasis on, basic and clinical studies to further evaluate the status and/or influence of mitochondrial function in GWVs, with and without, GWI. 4) Determine the utility of the Department of Defense Serum Repository as a resource for Gulf War (GW)-funded investigators. Among other utilities, the repository's samples may be useful in confirming a correlation between butyrylcholinesterase inhibition (itself and as a biomarker of acetylcholinesterase) and pyridostigmine bromide exposures as potential sources which cause GWI. 5) Conduct a prospective, double-blind randomized clinical trial to determine the effects of antioxidants, ubiquinol vs ubiquinone, on the quality of life for GWV with GWI.

The Gulf War Research Program Manager will update requests for applications (RFAs) in FY23 to support incoming applications with inclusion of these priorities. Incoming applications will be peer-reviewed by a special emphasis committee and recommendations will be considered.

Recommendation 2: Establish one or more Gulf War-Military Exposure Research Innovation Center(s) (GW-MERIC). The RACGWVI recommends that VA ORD establish one or more GW-MERIC(s) with a two-part mission: 1) To expedite and implement evidence-based clinical treatment and diagnostic research for GWV with GWI, and 2) Build upon existing collaborations and establish new VA and non-VA

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partnerships to leverage and expand subject matter expertise, data and specimen resources, and technology.

In progress: An overview of the “Gulf War Implementation MERIC: Accelerating the translation of research and evidence-based practices into care” was presented to the committee by the project Co-Principal Investigator, Dr. Lisa McAndrew, along with presentations on the 4 funded projects under the MERIC already in progress:

- Project 1: Enhancing Quality of Care for GWI through Clinician Awareness and Support
- Project 2: Evaluation of Veterans Exposure Team-Health Outcomes Military Exposures (VET-HOME)
- Project 3: Concordant Care and Problem-Solving Treatment for GWI
- Project 4: Optimization of a Web-based Approach for Treatment of GWI

Dr. McAndrew and team have written and submitted an application to include all of these projects to the Office of Research and Development. This application will be peer-reviewed by a special emphasis committee and recommendations will be considered.

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

In progress: ORD approved additional research funding on CSP 2006 to specifically address this question. CSP 2006 is a subset of the Million Veteran Program (MVP), the largest well-characterized and validated GWV cohort to date. This addendum will address important questions such as, analyzing data for:

- Risk of contracting COVID 19 in GW Veterans vs ERA Controls
- Risk of contracting COVID 19 in GW Veterans with and without GWI
- Symptoms or hospitalization of GW Veterans vs ERA Controls who got COVID
- Symptoms or hospitalization of GW Veterans with and without GWI
- Mortality of GW Veterans vs ERA Controls who got COVID
- Mortality of GW Veterans with and without GWI who got COVID

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

In progress: VES continue to meet twice per year as described above, with plans to continue a hybrid format (both in-person and virtual) going forward.

Committee Activities: The activities of the Committee in 2022 fully supported the committee accomplishing its mission:

Parent Committee Meetings

January 27, 2022. This meeting focused on the effects of environmental and military exposures on genetics, epigenetics and Gulf War Veteran health. Dr. Cheryl Walker, Director of the Center for Precision Environmental Health, Baylor College of Medicine, and newly appointed RACGWVI Chair effective October 1, 2022, presented research on environmental epigenomics. In line with this theme, additional presentations

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included gene x environment interactions and genetic susceptibility. Together, these studies model the genetic basis of individual differences in susceptibility to toxicants. A fireside chat with committee members and invited speakers was held each day after the presentations.

September 21-22, 2022. The meeting focus included the 1990-91 Gulf War environment, recently published research related to the causation of GWI, post exertion malaise in GWI-Brain autonomic and behavioral interactions, and GWI and similarities to myalgic encephalomyelitis/ chronic fatigue syndrome and long-haul COVID-19. The September meeting also included a subcommittee report on the Veteran Engagement Sessions (VES), a powerful testimony by a VES GWV participant, and an update on the VHA ORD Research Volunteer Registry that is under development. Gulf War Veteran 'topics of interest' were added to the agenda. First, Dr. Stephen Hunt, Director of the VA Post-Deployment Integrated Care Initiative, described the importance of the clinical guidelines for chronic multisymptom illness. Secondly, Dr. Raymond Christian, a 1990-91 Gulf War Veteran and nationally recognized storyteller, delivered the keynote address: "The Lived Experience of a Black American Gulf War Veteran."

Subcommittee Veteran Engagement Sessions (VES)

Subcommittee VES aims to educate Veterans about the importance of research to inform care and policy, build trust, and show transparency. As this Veteran population ages, there are new health concerns emerging that need to be identified for proactive interventions.

• VES virtual meeting April 6-7, 2022.

Questions discussed during meeting:

As a Gulf War Veteran:

- What health issues are of greatest concern to Gulf War Veterans (GWV)?
- How can research improve the treatments available to GWV?
- What health issue could the VA address to improve GWV quality of life?
- What would you like the VA Secretary to know about the health of GWV?

July 2022, the subcommittee questions were revised to capture GWV feedback on anecdotal remedies that have improved their symptoms and quality of life. These discussions have led to research concepts for consideration.

• VES virtual meeting July 20-21, 2022.

Questions discussed during meeting:

As a Gulf War Veteran:

- What health problems concern you most about the 1990-91 Gulf War?
What treatments have helped you manage your Gulf War health problems?
- What aspect of your Gulf War illness most affects your quality of life? (e.g., interference with daily life, work, and family activities or social interactions)
What helps you most to manage these interferences?

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- If you could tell the VA Secretary one thing about being a Gulf War Veteran with Gulf War illness, what would it be?

This change led to new insights such as changes in diet, exercise routines and other activities that have helped lessen their GWI symptoms. For example, after noting how scuba diving alleviated GWI symptoms for several days, one GWV started hyperbaric chamber therapy and continued to experience a decrease in his symptoms. This was new and valuable information for the committee and others.

Committee nominations and appointments

Dr. Lawrence Steinman completed his tenure as Chair in October 2022 after an outstanding 4-year term. His successor, Cheryl Walker, PhD, is the committee’s first Chairwoman. At her request, Kenneth Ramos, MD, was appointed as the first Vice-Chair, ensuring a strong and balanced leadership in both basic and clinical science.

RACGWVI has sought to attract diverse candidates for nomination to the committee in accordance with its Charter and Membership Balance Plan. The diversity, equity and inclusion of the committee is defined as a membership that parallels the diversity of the 1990-91 Gulf War Veterans the Committee serves that account for: gender, race, geographical reach, branch of service, service occupation and deployment and non-deployment status. With the fluidity of membership tenures, the current committee underscores the balance of the GWV we serve (see table below).

2022 Committee Members Total	15	RACGWVI %
VET DATA (Persian Gulf deployed)		
White 67% (70%)	11	73%
Black 19% (23%)	3	20%
Hispanic 4%	1	7%
Asian 4%; Native American 1%, other 5% (6.7%)		
VETERANS ON COMMITTEE (Persian Gulf deployed)	9	60%
BRANCH Army (51.8%)	6	67%
BRANCH Navy (21.9%)	1	11%
BRANCH Air Force (11.5%)	2	22%
BRANCH Marines (14.8%); BRANCH Reserves (10.1%)		
GENDER (Persian Gulf deployed)		
Women (7%)	6	40%
Males (93%)	9	60%

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Highlighted activities in alignment with VA:VHA Strategic Goals:

Goal 1: Veterans choose VA for easy access, greater choices, and clear information to make informed decisions

- The committee continues to engage, support and listen to voices in the GWV community to understand their experiences and needs to improve health outcomes and satisfaction.
- Meeting topics are chosen that are relevant to current GWV concerns.
- The committee has included contact information for the VA Crisis Line, Vet Center, Homelessness and Chaplain Service on rotating slides before each meeting and on the RACGWVI website. The committee email address is posted as an additional resource for Veteran feedback.
- All documents on the committee website are 508 compliant.
- Invited speakers/scientists are asked to provide a summary in laymen's terms for understandability as well as the relevance of the topic to GWV with Gulf War Illness (GWI).
- During the committee's open meetings, chat allows GWVs to directly ask questions to the subject matter experts, physicians and engage in discussion with their brothers and sisters in arms.
- Committee staff have enhanced parent and VES meeting participation by engaging with national VA public affairs officers, VA Insider and ORD calendar announcements. Other VA and non-VA partners and past VES attendees who have enlisted their social networks are also used for meeting solicitation.
- The virtual meeting platform allowed enhanced participation of over 1300 GWV stakeholders during 2022. Attendees included policy makers, congressional leaders, GWV and family members interested in both scientific topic areas and the public comment session which allows direct communication of GWV concerns.
- Parent and subcommittee meetings have developed into a positive synergetic committee/veteran partnership to communicate clear and pertinent information in both directions.
- The committee collaborates with partners that deliver benefits, healthcare services and policy to allow all stakeholders to stay abreast of current information and ensures committee awareness of GWV issues.

Goal 2: Veterans receive timely and integrated care and support that emphasizes their well-being and independence throughout their life journey

- The committee consistently communicates with stakeholders to assess and maximize performance, evaluate needs and build long-term relationships and trust.
- The committee is focused on improving quality of life for underserved GWV; reaching out to rural and other underserved areas that lack information and access regarding current VA-based GWV/GWI opportunities nationwide.

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- The committee has included contact information for the VA Crisis Line, Vet Center, homelessness and chaplain service at each meeting. Committee staff have assisted GWV in crisis with the VA Crisis Line and VA partner HOME.
- The committee engages GWV family members (spouse, children) to understand the whole health perspective and quality of life concerns in the context of the outside environment (family, work/life balance, friends, etc.).
- The committee has maintained VA partnerships to promote resources outside the committee's purview. This partnership allows more information on resources and tools for GWV.
- The committee stays informed of the DoD toxic exposures research efforts to ensure gaps in knowledge can be identified and implemented.

Goal 3: Veterans trust VA to be consistently accountable and transparent

- The committee is committed to a culture of trust and accountability and strives to provide clear information and transparency. For example, all meeting minutes, presentations and recordings are posted for public review within 90 days. Meeting minutes include an appendix containing local and national resources.
- The committee staff ensures all RACGWVI members receive Advisory Committee Management Office (ACMO), Federal Advisory Committee Management (FACA) and Office of General Counsel (OGC) training. OGC is consulted as needed to ensure and validate no conflicts of interest or other issues are present.
- Committee membership aligns with the GWV we serve allowing a broader understanding of GWV needs.
- Topics are included that address GWV concerns.
- The committee responds promptly to Freedom of Information Act (FOIA) requests.
- The committee will continue hybrid meetings (in-person and virtual) to promote broad attendance, clear information sharing and transparency.

Goal 4: VA will modernize systems and focus resources more efficiently to be competitive and to provide World Class capabilities to Veterans and its employees

- The committee applies a Veteran centric approach by aligning research activities to meet GWV needs and to empower a collaborative culture that promotes information sharing, diversity, equity and inclusion and a competent, high-performing workforce that attends to privacy and regulatory requirements to confidently serve Veterans and their families.
- ACMO policies and procedures are followed to promote member nominations, recommendations to the SECVA, charter renewal, and other committee activities.
- Committee Chair and members are chosen for their leadership, knowledge, diverse backgrounds and expertise.
- Committee staff provide relevant resources and information to stakeholders and bridge VA research.

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Reports and Recommendations: Committee recommendations to the VA Secretary received full concurrence in 2022, as described above. The new Chair and Vice-Chair will be leading the committee towards future recommendations.

Senior VA leadership Participation: Secretary Denis McDonough addressed the committee via a prerecorded video message. In his address he congratulated all federal committees for their hard work and dedication to ensuring the VA is keeping its promise of support and care for Veterans. The committee will request in-person participation from the SECVA in 2023.

Program Office Assessment: Historically, finding treatments and informing policy has been challenged by sparse knowledge in understanding the etiology and pathological underpinnings of Gulf War Illness. The complexity of multiple toxic exposures, the lack of individual exposure assessment, and the multiple possibilities of health outcomes from exposures has hindered our ability in creating ICD codes, a clinical case definition, and policy. However recently, the RACGWVI advisory committee in concert with VA and other stakeholders is demonstrating progress in these critical areas.

The VA, for the first time, has concurred on 100% of recommendations that were put forth by the RACGWVI. Additionally, several of those recommendations have been initiated and are underway. The productivity of this committee in overseeing completion of ongoing recommendations is outstanding. Moreover, the participation and engagement of the Gulf War Veteran community has risen over 500-fold allowing more health concerns to be identified. We expect these actions and future recommendations to be fruitful and productive for improving health outcomes and satisfaction for ill Gulf War Veterans.

General Comments: The Research Advisory Committee on Gulf War Veterans' Illnesses committee will continue to provide advice and make recommendations to the Secretary of Veterans Affairs on proposed research studies, plans, and strategies related to understanding and treating the health consequences of military service in the Southwest Asia theater of operations during the 1990 - 1991 Gulf War.

Signatures:

DFO's Signature

Date

