

ADVISORY COMMITTEE MANAGEMENT OFFICE

Annual Assessment of Committee Activities

FY2019

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

Committee Goals: The Committee met the projected FY19 goals:

1. **Committee meetings and activities.** In FY2019, the RACGWVI parent and subcommittee held three open public meetings, which were accessible in person, on line, and by phone. Two subcommittee meetings preceded a full parent RACGWVI meeting, which concluded with a visit from the SECVA and a Gulf War Veteran round table event. The National Academy of Science, Engineering, and Medicine released Gulf War and Health, Vol 11 entitled Generational Health Effects of Serving in the Gulf War was released November 2018. Subsequently, the theme of the RACGWVI for FY19 included the Intergenerational Effects of Military Exposures, ongoing health concerns and quality of life issues for Gulf War Veterans, and evidence-based research.

The Committee staff worked throughout FY19 organizing committee and sub-committee meetings and identifying and distributing current research alerts related to understanding and treating all health conditions affecting Gulf War Veterans to the committee members. The Committee staff also stayed in contact with Gulf War Veterans met at the sub-committee Veteran outreach meetings in person and by phone, furthering trust within this community.

2. ***Form a sub-committee and hold Gulf War Veteran Engagement sessions to better understand current Gulf War Veterans' health and quality of life concerns and trust issues.*** A RACGWVI subcommittee was formed January 2019 to support the VA's and committee's mission to provide clear information, build trust, and support world class customer service. The subcommittee included the RAC Chair, DFO, and committee managing director, VA-physicians with expertise on chronic multi-symptom illness, VA-researchers, a priest and women's advocate, and Gulf War Veterans. Two subcommittee meetings or "Veteran Engagement Sessions" were held at the Houston, TX and Cleveland, OH VAMCs. The VAMCs were chosen to bring the Gulf War Veterans to the VA, in a safe environment, where they could share their stories and interact directly with the subcommittee members. During these listening sessions, Veterans and family members were invited to describe existing and/or new health conditions and quality of life concerns. The sub-committee members educated the Gulf War Veterans and their families on the many historical VA-supported research breakthroughs and discussed the importance of research participation to drive evidence-based treatments and development of prognostic or disease markers. These sessions were open to the public and available by phone and online. The subcommittee chose 1-2 representative Gulf War Veterans from the outreach sessions to travel to the parent RACGWVI committee meeting in Washington DC where they again, shared their stories and had an opportunity to meet the Honorable Mr. Wilkie, Secretary of the VA who briefly arrived onsite for the FACA meeting. A truly special occasion for our Gulf War Veterans.
3. ***Reports and Recommendations.*** The RACGWVI committee received feedback from the VA on the 2018 recommendations. Recommendation 1) Form a working group to operationalize a Warriors' Health-Research Network. *Non-Concur.* This is the RACGWVI attempt to move from its research charter into directing clinical care. Notably, this recommendation lies outside of the Office of Research &

Development purview and implementation of recommendation 1 would remove significant resources from other Veterans and require realignment with multiple VA-intramural offices, external federal partners, and informational technology. Recommendation 2) Commit to supporting the Gulf War Deep Phenotyping Study short- and long-term between ORD and National Institutes of Health (NIH). *Concur*. Actions are underway to launch the first known VA:NIH partnership using intramural NIH clinical facilities. The goals are to generate data- and biologics-repository for subsequent hypothesis-driven projects funded by ORD and provide biological insights now to the scientific teams engaged in this endeavor. Recommendation 3) Aligning ORD (10X2) with VA modernization efforts to develop a tool within the electronic health record (eHR) for VA-approved researcher access. *Concur-in-principle*. VA actively utilizes integration of GW research into clinical practice through the War-Related Illness and Injury Study Center (WRIISC) at its three sites and in the future will create a research platform to access modernized electronic health care records for VA-funded researchers engaged in longitudinal and other evidence-based trials, which will overtime satisfy Recommendation 3 without the need of cost associated analysis and re-alignment. The Honorable Mr. Wilkie, SECVA, attended the RACGWVI meeting June 2019 and spoke with Committee members and invited special guests, Gulf War Veterans.

4. ***Offer guidance on the development of the Office of Research and Development's (ORD) Gulf War Research Strategic Plan.*** The Chief Research & Development Officer (CRADO) for ORD has outlined strategic goals that are in line with the SECVA's top priorities, which include: Increase Veterans' access to quality clinical trials, make VA data a National Resource, and increase the real-world impact of VA research. The Committee's work directly addresses these goals through inviting VA-funded research and subject matter experts to describe their on-going research studies and noting the importance of participating in research to influence health, healthcare and policy, and traveling to gather input directly from Veterans during the open meeting sessions. These Veteran outreach sessions aim to improve communication around future research opportunities and improve participation by leveraging Veteran engagement.

5. **VA Strategic Goals:** The activities of the Committee in 2019 aligned with VA Strategic Goals:

Goal 1: Veterans choose VA for easy access, greater choices, and clear information to make informed decisions: The Committee and subcommittee efforts to engage Gulf War Veterans has reconnected Gulf War Veterans to their VA health care centers and reenergized conversations between them. This is important, as the biggest feedback we get from our Gulf War era veterans is the lack of trust for VA. The outreach exercise has exceeded its expectations with the Committee, preparing targeted agendas geared toward the underlying topics of Gulf War veteran concerns. Notably, we have seen a tripling of Gulf War veterans participating in RACGWVI meetings and providing feedback.

Goal 2: Veterans receive highly reliable and integrated care and support and excellent customer service that emphasizes their well-being and independence through their life journey. The Committee and sub-committee are dedicated to understanding the health consequences of military service in the Southwest Asia theater of operations during the Gulf War, and the impact on their quality of life. Veteran engagement sessions are planned to continue in FY20.

Goal 3: Veterans trust VA to be consistently accountable and transparent. The FY19 agendas were formed based on the feedback of Gulf War Veterans. Two major themes were noted: 1) Intergenerational effects of

military toxic exposures while serving in the Gulf, and 2) Health concerns mediated by the Anthrax Vaccine. Accordingly, the RACGWVI Chair invited special speakers to provide support on VAs transparency and trust mission, such as the Chair of the National Academy of Science and Engineering (NASEM), MILCO family study (VA:DOD effort), Gulf War subject matter expert investigators of the longitudinal National Health Survey and their families and topic specific interests that are supported by Cooperative Study Program (CSP), in addition to the Center for Disease Control (CDC) experts on vaccines.

Goal 4: *VA will transform business operations by modernizing systems and focusing resources more efficiently to be competitive and to provide world-class customer service to Veterans and it's employees.* The Honorable Robert Wilkie attended the RACGWVI Committee meeting and spoke about the VA priorities of ending suicide and the VA Mission Act and it's goal to provide world-class care to Veterans. Activities of the RACGWVI facilitating communication and understanding of Gulf War Veterans concerns, reaching out to Veterans in more rural areas, contribute to this goal of providing excellent customer service and making the VA a place Veterans actively choose and trust. The RACGWVI staying abreast of current efforts to address research needs with the modernize of the electronic medical record will directly affect the quality of their health and health care.

6. **Program Office Assessment:** Each of the three committee meetings has focused on different aspects of research aimed at the health problems of Gulf War Veterans. Both meetings included presentation of results from post-deployment health efforts to form research common data elements with the goal of unifying data interpretation from Gulf War research studies and exploring VA registries and how to maximize their utility for research and clinical care. Treatments and emerging technology pertinent to health conditions affecting Gulf War Veterans.
7. **General Comments:** The committee had 2 members whose terms expired, and 1 member resigned. Dr. Karen Block, Designated Federal Officer and Chair, Dr. Larry Steinman of the RACGWVI, nominated 4 new Committee members, experts in the field of Gulf War and the Veteran experience.

Signatures:

Karen Block November 28, 2019

DFO's Signature and Date

Larry Steinman November 27, 2019

Chair's Signature and Date

Program Office Signature (SES or SES Equivalent) and Date