

ADVISORY COMMITTEE MANAGEMENT OFFICE

Annual Assessment of Committee Activities

January 1, 2018 through December 31, 2018

Committee Name: Research Advisory Committee on Gulf War Veterans' Illnesses

Calendar Year 2018 Committee Goals: The Committee fully met its goals in 2018. It held three meetings in open public session that featured experts in a broad range of fields, which helped inform the Committee's recommendations and created a forum that fostered discussion among the Committee, VA representatives, Veterans, and other stakeholders. Additionally, each meeting was held in different cities that spanned the continental U.S., and was accessible online and by phone to allow for greater participation from experts and Veterans across the country. Throughout 2018, there was continued discussion on the RACGWVI's two highest priorities: Project IN-DEPTH and the Warriors' Health-Research Network. Updated recommendations were made for each in 2018. Project IN-DEPTH is the new name for the deep phenotyping studying of Gulf War illness conducted in partnership with the National Institutes of Health (NIH) that followed from a past RACGWVI recommendation. The Warriors' Health-Research Network, previously referred to as a coordinated system of centers that integrates research with clinical care for chronic conditions of post-deployment, has been under consideration since 2016. In 2018, the Committee offered guidance on initial steps to operationalize the network after the VA concurred-in-principle with the related 2017 RAC-GWVI recommendation. Due to retirement of the Committee's longstanding Designated Federal Officer and transition to a new Chair in 2018, updating the ORD Gulf War Research Strategic Plan was put on hold until new leadership was in place.

VA Strategic Goals: The activities of the Committee in 2018 aligned with several VA Strategic Goals. The Committee provided advice and made 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 Gulf War. All of these activities were aimed at improving health care for Veterans. The Committee worked closely with VA on developing an approach to operationalizing the Warriors' Health-Research Network, which would function as a coordinated system that integrates research and clinical care. This system would promote continuous learning throughout the VA, thereby leading to more informed and consistent care for many Veterans and thus supporting Goal #2: Veterans receive timely and integrated care. Collectively, the activities of the RACGWVI to advance understanding and treatments for Gulf War Veterans contributes to Goal #1 relating to improving customer service and making the VA a place Veterans actively choose. Additionally, the last recommendation the RAC-GWVI made in 2018 specifically addressed VA modernization efforts and the electronic health record, which supports Goal #4: VA will modernize systems.

Committee Activities: Committee activities for the year fully supported the Committee accomplishing its goals in 2018. Over the course of the year, the RAC-GWVI remained focused on its two highest priorities: Project IN-DEPTH and the Warriors' Health-Research Network. These topics were discussed at each public meeting in order to develop updated recommendations in 2018 for how the VA can continue to move these efforts forward. The Committee held three public meetings this year. The first meeting followed the VA-sponsored Gulf War Illness (GWI) Common Data Elements (CDE) meeting held in Davie, Florida. Issues raised at the GWI CDE field-based meeting were brought for discussion at the RACGWVI meeting and invited speakers shared lessons that could be learned from efforts related to Chronic Fatigue Syndrome. Another topic of focus for this meeting was VA registries and exploring how to maximize their utility for research and clinical care. At the second meeting, a main area of focus was on GWI patients and the health conditions they suffer from. An ongoing GWI clinical case series was presented and Veterans shared their personal health experiences and receiving care at the VA. The meeting also addressed treatments and emerging technology pertinent to health conditions affecting Gulf War Veterans. The final meeting of 2018 began with a conversation between Committee members and the VA Chief of Staff, Pamela Powers, on priorities for the new VA administration and opportunities identified by the

RACGWVI. The meeting also featured presentations on pathogen detection in chronic illness and implications for research with modernization of VA's electronic health record. By the end of the meeting, the Committee unanimously approved three recommendations for the VA Secretary and an accompanying white paper to further support one of the recommendations. This meeting was the last for several RACGWVI members, including the Chair. In 2018 there were also intermittent working group calls to discuss and develop the draft white paper on the Warriors' Health-Research Network. Additionally, the Committee staff did a terrific job throughout the year organizing Committee activities and keeping the Committee informed, such as by sending weekly alerts about new research related to understanding and treating health conditions affecting Gulf War Veterans.

Reports and Recommendations: In September of 2018, the Committee sent SECVA a focused set of three actionable recommendations along with a white paper from the Committee (Warriors' Health-Research Network: A model for an integrated health-research system) to further support one of its 2018 recommendations. The Committee looks forward to hearing from Secretary Wilkie and his administration on these issues, and to continue working with VA representatives, Veterans, and other stakeholders to move towards solutions that serve our Veterans.

Senior VA leadership Participation: At the last meeting of the year, held in September in Washington, DC, the VA Chief of Staff (Pamela Powers) attended and spoke with Committee members. The VA Secretary initially planned to participate in this meeting but later withdrew.

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. Meetings included presentation of results from VA:DOD 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. Meeting 3, pathogen detection in chronic illnesses and implications for research with modernization of VA's exposure and electronic health record.

General Comments: Dr. Karen Block, was named as the new Designated Federal Officer for the RACGWVI to replace Dr. Victor Kalasinsky. Several RACGWVI members rotated off of the Committee in 2018 and four new members were appointed, including a new RACGWVI Chair (Dr. Larry Steinman).

Signatures:

Karen Block 12/11/2018

DFO's Signature and Date

Larry Steinman 11/30/2018

Chair's Signature and Date

Program Office Signature (SES or SES Equivalent) and Date