

Research Advisory Committee on Gulf War Veterans' Illnesses

2017 Recommendations

*The Committee recommends the VA:*

- **Partner with the National Institutes of Health to conduct a deep phenotyping study of Gulf War Illness and Chronic Fatigue Syndrome.** Gulf War illness (GWI) is the signature health issue from the 1990 – 1991 Gulf War and today, nearly 30 years later, much remains unknown about this vexing condition. Within the past few years, a true scientific revolution in molecular diagnostic capabilities has occurred – based on progress in next generation sequencing, bioinformatics, neuroimaging, microbiome biology, and epigenetics, among other advances – that make it possible to pinpoint abnormalities associated with disease with previously unimaginable resolution and power. For sufferers of GWI, these advances create, for the first time, an outstanding opportunity to uncover the roots of this disorder. The Committee believes that we must take full advantage of these recent conceptual advances in biomedicine; the proposed study represents not only the highest possible research priority, but is also an ethical obligation owed to our warriors. We propose a comprehensive study using the very best technologies to thoroughly examine the biological underpinnings of GWI. Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) shares many similarities with GWI, both in clinical presentation and gaps in our understanding of its physiology. To elucidate the underlying biology of ME/CFS, the National Institute of Neurological Disorders and Stroke (NINDS) at NIH is undertaking a comprehensive deep phenotyping study at its world-renowned Clinical Center. Today, the VA has an opportunity to partner with the NIH on this study by adding a GWI population and a control group. By aligning research across GWI and ME/CFS, both of which afflict Gulf War veterans, this Committee is confident that meaningful progress toward the identification of biomarkers and effective therapies for both conditions are likely to result. The VA should name a leadership team that would work closely with the Principal Investigator of the ME/CFS study at the NIH to help manage and direct the study, and the VA should also establish an advisory board to help guide the GWI portion of the study and interpret its results. The partnership should ensure data sharing across agencies. Furthermore, the VA should apply findings from the study to inform future research directions and clinical approaches. The VA should formally enter into this partnership in 2017 and continue through the life of the study.
- **Commit to piloting and establishing a coordinated system of centers and expertise focused on complex chronic conditions of post-deployment, and operationalize the beginning stages of such a system by 2019.** The Committee continues to believe there would be great value in pursuing a demonstration project for how research and clinical

efforts can interface more seamlessly throughout the VA system. We plan in the coming year's deliberations to provide advice on one potential model that would align research more closely with a stepped clinical care approach. Many of the challenges facing Gulf War-related research, and scientific investigation of complex chronic conditions more generally, could be meaningfully addressed by more closely integrating research with a stepped model of clinical care. This Committee recommended in 2016 that the VA establish a coordinated system of centers to realize the goal of a learning health-research system. After a year of consideration and continued discussion, the Committee has identified key areas that should be further explored by the VA. These include: a) conducting a needs assessment of post-deployment health services throughout VHA to estimate potential demand on the system; b) identify potential sites at the national and local levels where the system could be piloted; c) identify "local champions" and a means for them to engage on policy centrally, such as by creating a national council of local champions; d) determine what a specialty PACT for post-deployment health would consist of, including the number of personnel needed, the required level of effort, and what specialties would be most useful; e) identify integration points between research and clinical care that can facilitate continuous communication at the local-level and with national centers; f) developing strategies for coordinating and standardizing relevant registry exams and Environmental Health Coordinator activities to support local- and system-level research and clinical care; g) assessment of data infrastructure and opportunities for interoperability between EHRs, research data, VA databases, as well as biorepositories and brain banks; h) engaging veterans to make them partners in research and health. The Office of Research and Development and the Office of Post-Deployment Health Services should work collaboratively with each other, and in consultation with this Committee, to explore these issues. Additionally, an actionable item the Committee identified as part of its recommendation last year was for the VA to produce a cost estimate for establishing this coordinated system of centers. This should be followed up on as no such estimate has been shared with the Committee. The RAC-GWVI looks forward to working with the VA to further develop these ideas and consider how best to implement solutions that serve our veterans.

In addition to the recommendations above, the Committee encourages the VA to continue work already underway related to past recommendations. For example, this group recommended in 2016 that the VA Office of Research and Development (ORD) update its Gulf War Research Strategic Plan for 2018 – 2022. The VA has worked closely with members of this Committee as well as various members of the research community to develop a draft strategic plan. Expediently approving this plan and effectively implementing it should remain an ORD priority. When considering its strategic plan, ORD should prioritize pragmatic directions that have the possibility to improve or maintain the health of Gulf War veterans in a timeframe that would allow them to benefit from the biomedical advances being pursued. Furthermore, the VA

should identify targeted goals that are achievable by the strategic plan end date. This Committee would welcome continued consultation on the development of the Gulf War Research Strategic Plan and throughout its implementation.