

Research Advisory Committee on Gulf War Veterans' Illnesses

**Committee Meeting Minutes
September 18, 2018**

**U.S. Department of Veterans Affairs
Washington, DC**

Research Advisory Committee on Gulf War Veterans' Illnesses
Committee Meeting Minutes

I hereby certify the following minutes as being an accurate record of what transpired at the September 18, 2018, meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses.

Stephen L. Hauser, M.D.
Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

Attendance Record

Members of the Committee:

Dr. Stephen Hauser, Chair
Ms. Kimberly Adams
Mr. James Bunker
Dr. Fiona Crawford
Ms. Marilyn Harris
Dr. Stephen Hunt
Dr. Nancy Klimas
Dr. Katherine McGlynn
Mr. Jeffrey Nast
Dr. Stephen Ondra (not present)
Ms. Frances Perez-Wilhite
Dr. Scott Rauch
Dr. Caroline Tanner
Dr. Mitchell Wallin
Dr. Scott Young (telephone)

Committee Staff:

Mr. Stanley Corpus
Mr. John Rukkila
Dr. Jon Van Leeuwen

Designated Federal Officer:

Dr. Karen Block

Invited Speakers:

Dr. Matthew Reinhard, VA Washington, DC
Ms. Pamela Powers, VA Chief of Staff
Dr. Mitchell Wallin, VA Washington, DC
Dr. W. Ian Lipkin, Columbia University
Dr. Jim Breeling, VA Office of Research and Development
Dr. Nancy Klimas, VA Miami, FL
Dr. Peter Rumm, VA Office of Post-Deployment Health Services

VA Personnel

Dr. Joel Culpepper, VA Office of Post-Deployment Health Services, Deputy Director of Epidemiology
Ms. Marsha Turner, VA Office of Research and Development, Cooperative Studies Program

Veterans:

Ms. Denise Nichols
Mr. Curt Love (telephone)
Ms. Buddah Strouse (telephone)
Ms. Andrea Fremont (telephone)

**Meeting of the Research Advisory Committee on Gulf War Veterans’ Illnesses
U.S. Department of Veterans Affairs**

**LOCATION: Sonny Montgomery Room (Room 230)
810 Vermont Ave NW, Washington, DC 20420**

Call-in: (800) 767-1750; access code 56978#

Watch Online: <http://va-eerc-ees.adobeconnect.com/racgwvi-sept2018/>

**Agenda
Tuesday, September 18th, 2018**

8:00 – 8:20	Introductory Remarks (and DFO notes by Dr. Block)	Dr. Stephen Hauser, Chairman Res Adv Cmte on GW Veterans’ Illnesses
8:20 – 9:00	Project IN-DEPTH Update	Dr. Matthew Reinhard Veterans Affairs Medical Center, Washington, DC
9:00 – 9:30	Discussion with VA Leadership	Senior Leadership Dept. of Veterans Affairs
9:30 – 10:15	Warriors’ Health-Research Network	Dr. Mitchell Wallin Washington, DC VA Medical Center
10:15 – 10:30	Break	
10:30 – 11:15	Biomarker and Pathogen Discovery in Chronic Illnesses	Dr. W. Ian Lipkin Cntr for Infection and Immunity, Columbia Univ.
11:15 – 11:45	Committee Discussion	Dr. Stephen Hauser, Chairman Res Adv Cmte on GW Veterans’ Illnesses
11:45 – 12:45	Lunch	
12:45 – 1:30	Electronic Health Record Modernization	Dr. Jim Breeling VA Office of Research and Development
1:30 – 2:00	Gulf War Illness Common Data Elements Proposal	Dr. Nancy Klimas Nova Southeastern Univ. and Miami VAMC
2:00 – 2:45	Committee Discussion	Dr. Stephen Hauser, Chairman Res Adv Cmte on GW Veterans’ Illnesses
2:45 – 3:00	Break	
3:00 – 3:30	Public Comment	
3:30	Adjourn	

Following the meeting, the VA will hold a listening session to hear from GW Veterans. The VA listening session (3:45 – 5:00pm EDT) is not a RAC-GWVI event and is optional for members of the RAC-GWVI.

**Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses
(RAC-GWVI)**

U.S. Department of Veterans Affairs

Tuesday, September 18th, 2018

Committee Meeting Minutes

Introductory Remarks

—**Dr. Stephen Hauser, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses**

—**Dr. Karen Block, VA Office of Research & Development and Designated Federal Officer, RAC-GWVI**

Dr. Block, Designated Federal Officer for the RAC-GWVI, welcomed meeting participants and reviewed meeting facilities as well as guidelines for participation in meeting discussions. Dr. Hauser, Chair for the RAC-GWVI, welcomed participants and prompted Committee Member introductions. Dr. Hauser, reviewed the Committee's 2018 draft recommendations: (1) Form a working group, to include VA's Office of Research and Development (ORD) and Post-Deployment Health Services (PDHS), tasked with identifying steps to operationalize a pilot of the *Warriors' Health-Research Network* in coordination with VA's modernization plan; (2) Ensure that the VA is able to maximize its ongoing commitment to the deep phenotyping study of Gulf War illness (i.e., project IN-DEPTH) by taking steps in the next year that make ORD well positioned to sustain the ongoing study and further extend its research findings over the long-term; and (3) Pursue VA Modernization efforts with a view that VA's research mission is crucial and reciprocally beneficial to its mission to deliver world-class health care for Veterans; importantly, this principle should be applied to the new electronic health record (EHR) by developing it as a tool for both clinical and research use, which would bring tremendous potential to advance the health of Veterans. Dr. Hauser stated one of the goals for the meeting would be to discuss recommendations further as a Committee and approve final documents, including a white paper on the Warriors' Health-Research Network. Dr. Hauser noted the meeting agenda would include discussion with the new VA Chief of Staff to learn about VA priorities and to understand how the RAC-GWVI can be helpful while advocating for research. Dr. Hauser promised stimulating research presentations and then introduced the first presenter.

Session 1: Project IN-DEPTH Update—Deep Phenotyping of Gulf War Illness: A VA-NIH Partnership

—**Dr. Matthew Reinhard, Veterans Affairs Medical Center, Washington, DC**

Dr. Reinhard, a clinical neuropsychologist and Director of the War Related Illness and Injury Study Center (WRIISC) in Washington, DC, presented an overview of Project IN-DEPTH. He reviewed the original National Institutes of Health (NIH) study focused on chronic fatigue syndrome (CFS) and the partnership between NIH and VA to develop a sister protocol for Gulf War illness. Dr. Reinhard emphasized “the goal of these analyses is to identify physiological alterations for the purpose of hypothesis generation.” He noted that study results will guide the design of future studies to elucidate biologic mechanisms underlying Gulf War illness as well as identify potential mechanisms of intervention. Dr. Reinhard reviewed VA project specific aims, timeline, sites, subject recruitment and screening, and participant eligibility and inclusion criteria. He compared Gulf War illness case definitions and reviewed project methods, phenotype visit, stress test, and study outcomes. In response to Committee member questions, Dr. Reinhard reviewed study sample size and discussed Gulf War illness characteristics and Gulf War Veteran symptoms.

Session 2: Discussion with VA Leadership**—Pamela J. Powers, Chief of Staff of Veterans Affairs**

Pamela Powers, Chief of Staff of Veterans Affairs and senior advisor to the Secretary and Deputy Secretary of the VA, outlined four key-point priorities for VA Secretary Robert Wilkie: (1) emphasize customer service—the prime directive—that when Veterans come to VA, it is up to VA employees to be trained and equipped to achieve getting Veterans to yes; (2) implement the MISSION Act to fundamentally transform VA healthcare by consolidating community care into a single program that is easier for all to navigate and expanding family caregivers program to provide much-needed assistance to people caring for Veterans; (3) replace an aging electronic health record to modernize the appointment system, automate disability and payment claims systems, and connect VA to the Department of Defense (DoD), private healthcare providers, and private pharmacies through an ongoing, iterative process to build a continuum of care organized around Veterans’ needs; (4) transform business systems to modernize human resource management, finance and acquisition, and the supply chain with more leeway to manage budgets as well as recruit, retain, and relocate staff and develop more robust partnerships with state and local communities to address challenges such as Veteran homelessness and suicide prevention. Ms. Powers answered questions regarding VA commitment to Gulf War Veterans, referrals to the WRIISCs, training for VA leaders and personnel, research and clinical guidelines, and Veterans Benefits Administration denials made without explanation. She also reviewed the Veterans Experience Office website and noted the importance of educating and empowering women Veterans. In summarizing the solution to link research and clinical care, Dr. Hauser stated his belief that “bringing together the research and the clinical care with the holistic care of patients is going to be the answer...and the VA has the unique opportunity to link science and medicine the way that almost nobody else can.” Dr. Hauser emphasized that the recommendations from the RAC-GWVI this year identify actionable steps the VA can take to link research and care within the VA, and the Committee would soon send the Secretary an updated white paper that proposes details for how the VA can establish a model system called the Warriors’ Health-Research Network.

Session 3: Warriors’ Health-Research Network: A Model for an Integrated Health-Research Network**—Dr. Mitchell Wallin, Washington, DC, VA Medical Center**

Dr. Wallin, Associate Professor of Neurology and Director of the VA Multiple Sclerosis Center of Excellence-East as well as a member of the RAC-GWVI, provided an overview of the RAC-GWVI recommendation for a coordinated system of centers focused on chronic conditions of post-deployment and development of the newly titled integrated Warriors’ Health-Research Network. Dr. Wallin noted that this concept has developed within the RAC-GWVI for the last few years and that annual recommendations since 2016 have progressively built on the idea of a hub-and-spoke network, which the Committee suggests calling by the new name of Warriors’ Health-Research Network. Dr. Wallin discussed that VA leadership concurred in principle with the 2017 RAC-GWVI recommendation with the provision that “Piloting a project like this will have to be coordinated with VA’s modernization plan.” He summarized key points, such as benefits to research and clinical care, key features of the network at all levels, and opportunities for implementation. These details are described in a white paper written by the RAC-GWVI this year to support the Warriors’ Health-Research Network concept and the relevant 2018 RAC-GWVI recommendation. During discussion, Dr. Wallin answered questions about the integrated network and Committee members made comments related to timeline, rollout, and partnerships.

Session 4: Biomarker and Pathogen Discovery in Chronic Illnesses**—Dr. W. Ian Lipkin, Center for Infection and Immunity, Columbia University**

Dr. Ian Lipkin, Director of the Center for Solutions for ME/CFS, the Center for Research in Diagnostics and Discovery, and the Center of Infection and Immunity with the Mailman School of Public Health at

Columbia University, is internationally recognized for his contributions to global public health in infectious diseases diagnosis, surveillance, and discovery. He discussed how the integration of genetic background, the environment (e.g., microbes, toxins and other elements), and timing impact the manifestations of particular exposures, such as infectious agents. Dr. Lipkin provided general background on identification of viruses, bacteria, and other infectious agents and evolution of high-throughput sequencing. To frame the context for his talk, he outlined the Center for Solutions for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) organizational structure, recruitment process, and history as well as reviewed projected aims for sampling, profiling, and networking. He reviewed ME/CFS analyses of metabolites, profile tracking, and data integration as well as reviewed improved diagnostic performance and common treatment modalities. Dr. Lipkin answered questions pertaining to approaches the VA might consider for Project IN-DEPTH, such as household controls for microbiome studies and integrating serology processes.

Committee Discussion

—Dr. Stephen Hauser, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

The scheduled separate morning discussion session was overtaken by questions and extended discussion from previous sessions.

Session 5: Electronic Health Record Transition for RAC-GWVI

—Dr. James Breeling, VA Office of Research and Development

Dr. Breeling, Director of Bioinformatics at VAs Office of Research and Development and a leader in VA information technology strategic planning, discussed the VA transition to a new electronic health record (EHR) system. He stated that VA data is an important national resource. In past meetings, the RAC-GWVI had discussed how EHR systems have potential to be a useful tool for research and an opportunity exists for the VA to develop its new EHR system as an invaluable tool for both its clinical and research missions. Dr. Breeling presented guiding principles and benefits of EHR management in sharing data and described stages of interoperability with the Department of Defense. He discussed levels of interagency governance, outlined strategies for technology uniformity and data collection, and reviewed workflow involvement at national, VISN, and local levels. Dr. Breeling noted Cerner as the state-of-the-market EHR solution for phased enterprise-wide implementation. He pointed out that VA Office of Research and Development is involved to assure VA investigators will continue having access to longitudinal Veteran data for research purposes. Dr. Breeling answered questions about projected timeframe, security, structured data, and computational problems.

Session 6: Gulf War Illness Common Data Elements Proposal

—Dr. Nancy Klimas, Nova Southeastern University and Miami VAMC

Dr. Klimas, a clinical immunologist and a RAC-GWVI member who is also leading on the VA effort to develop Common Data Elements (CDE) for Gulf War illness (GWI), updated progress on development of the core CDEs for GWI. Dr. Klimas reviewed goals for the CDE project, listed CDE working group members, and outlined the processes for the GWI CDE project. She discussed challenges to advance and methods to improve understanding of GWI. She reviewed the National Institute of Neurological Disorders and Stroke (NINDS)/Centers for Disease Control and Prevention ME/CFS common data element project that developed CDEs for CFS and served as the inspiration and foundation for the GWI CDE project. Dr. Klimas discussed development and presented details of the GWI CDE instruments, terminology, and benefits. She discussed VA engagement with the DoD funded Congressionally Directed Medical Research Program that has been supportive of the GWI CDE effort and calls for its investigators to use the platform. She noted that the draft modules of CDEs for GWI completed by November will be made available for public comment and revision in December, and a final document will be posted on

VA, CDRMP, and NIH websites by February 2019. Dr. Klimas concluded by noting ongoing efforts to establish a GWI research case definition.

Session 7: Update of the PDHS Environmental Health Services (Related to the Gulf War)

—Dr. Peter Rumm, VA Office of Post-Deployment Health Services

Dr. Rumm, a preventive medicine physician who serves as the Director of Pre-911 Era Environmental Health Services/Post-Deployment Health Services at the VA, presented an update of VA Post-Deployment Health Services. Dr. Rumm updated status of registries and outreach related to the Gulf War. He outlined progress on efforts by the VA to develop a single case definition for Gulf War illness/chronic multisymptom illness. He discussed implementation and aims of two VA research studies—the first is a sophisticated chart review of symptoms and the second is an EHR data-driven analysis of case definitions—with the primary objective of identifying clinical and health service characteristics associated with Gulf War era deployment status to determine GWI prevalence and to validate GWI case definition. Dr. Rumm concluded with an update on analyses of Gulf War-related topics in Gulf War Registry and other databases, forthcoming National Academy of Medicine Gulf War series reports, and epidemiology program studies that include medical records collection from Veterans' private medical providers.

Session 8: Committee Discussion

—Dr. Stephen Hauser, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

Dr. Hauser and Dr. VanLeeuwen reviewed the three draft RAC-GWVI recommendations for 2018, and after brief discussion the Committee unanimously approved the recommendations. Dr. VanLeeuwen introduced the draft of the White Paper on the Warrior's Health-Research Network and noted its content was reviewed by Dr. Wallin during his presentation earlier in the day. The white paper moved to a vote and was approved unanimously by the Committee. Dr. Hauser reviewed and thanked outgoing Committee Members completing their membership terms this year. He discussed the importance of the Warriors' Health-Research Network proposal and the future focus of the RAC-GWVI. Dr. Hauser noted VA Secretary approval of the new Chair and Committee members. Dr. Hauser thanked Dr. Victor Kalasinsky former Designated Federal Officer for the RAC-GWVI; Dr. Karen Block the new Designated Federal Officer for the RAC-GWVI; fellow RAC-GWVI members; Dr. Rachel Ramoni; Directors of the WRIISCs and Post-Deployment Health Services for their support; and Dr. Jon-Eric Van Leeuwen, Stanley Corpus, and John Rukkila for their RAC-GWVI administrative support; and Veterans for all their support and service. In follow-up, Dr. Block announced Dr. Larry Steinman had been appointed as the new Chair, named the new Committee members, and presented an award to Dr. Hauser.

Public Comment

Participants in person and on the phone line made public comments covering a wide range of topics. There was a brief delay due to technical difficulties with the VA conference phone line. Dr. VanLeeuwen moderated the public comment session and also announced that the VA would hold a public listening session immediately following the conclusion of the RAC-GWVI meeting.

Denise Nichols, Gulf War Veteran attending the meeting, stated the necessity to include and recognize spouses in research studies and Veteran celebrations, increase the education level of care providers, develop standing orders for health care providers, plan a future RAC-GWVI meeting in a central location such as Colorado, and retain former RAC-GWVI Committee members in an active emeritus status.

Curt Love, Gulf War Veteran on the phone line, discussed his family difficulties in coping with his health issues, need for provision of follow-up spouse and family counseling for Veterans, difficulties in getting care through the VA, and lack of recognition of his problems through the WRIISC programs.

Buddah Strouse, Gulf War Veteran on the phone line from Illinois, related various medical problems and diagnoses possibly related to genetic mutation and her deployment exposure to petroleum products, questioned the lack of genetic and neurological specialists available in the VA, expressed frustration at frequent switching of her doctors at the VA, confirmed her participation in the Million Veteran Program, and responded favorably to a suggestion by Committee Member Dr. Klimas to participate in research studies.

Andrea Fremont, Gulf War Veteran on the phone line, reviewed health problems that she believes are related to her deployment work with jet fuels, described long-term frustration in resolving her health problems through VA managed care, said she is looking into paying for private health care, expressed interest in participating in research, and responded favorably to a suggestion by Committee Member Dr. Klimas to participate in research studies.

Public comment participants responded favorably to Dr. Karen Block, RAC-GWVI Designated Federal Officer, who requested their participation on the same phone line in a follow-up VA Listening Session that continued with Veterans, Committee Members, and representatives of VA leadership after adjournment of the RAC-GWVI meeting.

Adjourn

Dr. Hauser, Chair for the RAC-GWVI, adjourned the Committee meeting and announced the Committee will meet again in 2019.