Research Advisory Committee on Gulf War Veterans' Illnesses

Committee Meeting Minutes
August 4, 2021

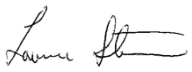
U.S. Department of Veterans Affairs
Washington, DC

Virtual meeting was held due to COVID-19 restrictions

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 August 4, 2021, meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses.



Lawrence Steinman, M.D.
Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

Attendance Record	
Members of the Committee:	**RACGWVI Subcommittee Members:**
Lawrence Steinman, M.D.	
James Baraniuk, M.D.	
Col. Richard Gaard, USA, Ret.	
Mr. Brent Casey	
Drew Helmer, M.D., M.S.	
Carey Pope, Ph.D.	
Barbara Ward, BSN, MPA.	
Jane Wasvick, R.N., BSN, MSA	**Invited Speakers:**
Mr. William Watts	Mark Miller, Ph.D.
James Woody, M.D., Ph.D.	Gary W. Miller, Ph.D.
	Michael Snyder, Ph.D.
Committee Chairman	J. Wesson Ashford, M.D., Ph.D.
Lawrence Steinman, M.D.	
Designated Federal Officer	
Karen Block, Ph.D.	
Alternate DFO	
Marsha Turner, M.S.	
Committee Staff:	
Mr. Stanley Corpus, B.A.	
Ms. Marsha Turner, M.S.	
Mr. Daniel Sloper, M.A.	
VA Senior Leadership	
Carolyn Clancy, M.D.	

Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses (RACGWVI)
Department of Veterans Affairs
LOCATION: Virtual via Webex:

Agenda
Wednesday, Aug. 4, 2021
11:00 a.m. – 4:00 p.m. Eastern Time Zone

11:00 – 11:05 a.m.	**Welcome/Opening Remarks**	**Dr. Karen Block, DFO** **Dr. Lawrence Steinman, Committee Chair**
11:05 – 11:25 a.m.	**VA Senior Leadership**	**Dr. Carolyn Clancy** **Deputy Under Secretary for Health for the Office of Discovery, Education and Affiliate Networks (DEAN)**
11:25 – 11:45 a.m.	**VA Gulf War Updates and Military Exposures Research Program**	**Dr. Karen Block** **Gulf War Research Program** **VA Office of Research & Development**
11:45 a.m. – 12:20 p.m.	**Recent Developments in the Identification of PTSD-Related Biomarkers**	**Dr. Mark Miller** **National Center for PTSD** **VA Boston Healthcare System** **Boston University School of Medicine**
12:20 – 12:55 p.m.	**The Exposome: Capturing Complex Exposures**	**Dr. Gary W. Miller** **Environmental Health Sciences** **Columbia University Mailman School of Public Health** **New York, NY**
12:55 – 1:30 p.m.	**Big Data, Health and Aging**	**Dr. Michael Snyder** **Professor and Chair of Genetics, Stanford University School of Medicine**
1:30 – 1:40 p.m.	**Break**	
1:40 – 2:10 p.m.	**Panel Discussion**	**Invited Speakers and Committee**
2:10 – 2:45 p.m.	**GWI Acetyl-Cholinesterase Inhibitor Withdrawal Hypothesis: Tardive Dysautonomia**	**Dr. J. Wesson Ashford** **WRIISC CA** **VA Palo Alto Health Care System** **Stanford University**
2:45 – 3:30 p.m.	**Committee Business**	**Committee**
3:30 – 4:00 p.m.	**Public Comments**	**Visitors and Invited Guests**
4:00 p.m.	**Adjourn**	**DFO/Committee Chair**

Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses (RACGWVI)

U.S. Department of Veterans Affairs

Wednesday, August 4, 2021

Committee Meeting Minutes

Welcome and Opening Remarks

— Karen Block, Ph.D., VA Office of Research & Development and Designated Federal Officer, RACGWVI

Dr. Block, Designated Federal Officer (DFO), is the Senior Program Manager for Gulf War Research at the Office of Research and Development in Washington, DC. Dr. Block opened the public meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses. She said this was a virtual, public meeting due to the COVID-19 pandemic, CDC guidelines and social distancing and VA travel restrictions. She noted a quorum for the committee was present via virtual and telephone attendance. She provided orientation, teleconference phone contact, and public comment. She welcomed Research Advisory Committee (RAC) members and Alternative Designated Federal Officer (Alt-DFO) and thanked RAC administrative staff for pulling the meeting together and introduced Dr. Lawrence Steinman, RACGWVI Chairman.

Welcome, Overview and Introductions

— Lawrence Steinman, M.D., Chair, Research Advisory Committee on Gulf War Veterans' Illnesses.

Dr. Steinman called the meeting to order, welcomed all participants and introduced members of the committee and guest speakers. He then introduced Dr. Carolyn Clancy, VHA Deputy Under Secretary for Health for the Office of Discovery, Education and Affiliate Networks (DEAN).

Session 1: VA SENIOR LEADERSHIP

— Carolyn Clancy, M.D., Veterans Health Administration (VHA) Deputy Under Secretary for Health for the Office of Discovery, Education and Affiliate Networks (DEAN).

Dr. Clancy congratulated all meeting participants for joining today's Gulf War Veterans' Illnesses presentation. Furthermore, she complimented the RACGWVI on their resourcefulness and continued support of Gulf War Veterans (GWV) during the challenges of the pandemic. She informed the committee that she learned of the success of the Veteran Engagement Sessions (VES) through Dr. Ramoni, the Chief of Research and Development, and how those sessions have provided key insight into new directions of research and recommendations to the Secretary of Veterans Affairs.

Dr. Clancy reaffirmed VHA's commitment to GWI related research and discussed key areas of research focus moving forward. She stated the RACGWVI committee is essential to guiding research for GWI research and noted this is also recognized by VA Secretary McDonough, who is dedicated to improving the health and care of Veterans suffering with GWI. As a critical first step, the VA is using a holistic approach, grounded in science, to determine toxic exposure presumptions. She discussed longer-term efforts aimed at developing evidence-based information to improve Veterans' health care, such as seeking out collaboration across research spectrums. In 2021 the VA funded more than 30 studies across four VA research services. Key areas of research focus include long-term efforts to increase the diagnosis and care of GWI. Several studies are in progress regarding Veteran aging and GWI. One of those is a clinical

study involving the relationship between toxic exposure during Gulf War deployment and Parkinson's disease. Dr. Clancy addressed how the VA will begin processing disability claims for respiratory issues due to chronic exposure to Middle East service; was reassured in the basic research approach in GWI, biomedical, and direct health care and spoke of improvements for Veteran care with the current modernization of electronic health care records. Discussing ongoing research projects such as the genetic research from the Million Veteran Program database which has become a ground-breaking research database that includes a subset of over 41K registered GWV that will assist the GWI case definition project as well as other GWI research efforts.

Dr. Clancy discussed Coronavirus (COVID-19) and its impact among those Veterans experiencing lung issues, saying research on that topic is ongoing. Currently Veterans have the same infection risks as the general population; however, those Veterans suffering from respiratory problems may experience an increase in symptom severity. The long-term health impact to Veterans who were infected with the virus that causes COVID-19 are still unknown.

Committee questions for Dr. Clancy:

Q: What are the priorities of the new administration related to toxic exposures?

A: President Biden and the House committees recognize the health concerns of Veterans and the need to increase the recognition of Gulf War related toxicity issues.

- The Biden Administration and Congressional Committees on Veterans' Affairs are focusing on legislation to support Veterans sickened by toxic exposures.
- Secretary McDonough is deeply committed to our Nation's Veterans, and especially focused on improving the health and quality of life for Veterans with toxic exposures.

Q: How does VA plan to communicate awareness of toxic exposures to Veterans, VA physicians and staff, community healthcare providers, caregivers and claim adjudicators?

A: There will be an outreach to all caregivers regarding health care issues and health outcomes for GWI Veterans.

- VA's Office of Patient Care Services, Health Outcomes Military Exposures (HOME) (formerly Post Deployment Health Services) administers various programs related to environmental and occupational exposures of U.S. Veterans during military service.
- HOME develops educational and outreach materials for various environmental issues and health outcomes related to military exposures for all stakeholders.
- VA-funded researchers are required to publish their research in the open access public domain. Available for all to read.

Q: What is the VA doing to get an ICD-10 diagnostic code for Gulf War Veterans with GWI?

A: Currently there are ongoing studies to better identify a clinical case definition for GWI. There are two ongoing VA Gulf War CASE DEFINITION PROJECTS. Both projects have clinical over-sight teams and subject matter experts.

- WRIISC study using advanced charting techniques in several databases.
- VA HOME collaborating with academic Institutions using big data and predictive analytics.

Session 2: GULF WAR RESEARCH PROGRAM UPDATE

— Karen Block, Ph.D., Director of Gulf War, VA Office of Research and Development

Due to the COVID-19 pandemic, CDC guidelines of social distancing, and VA travel restrictions, all participants were welcomed to the virtual RACGWVI meeting. Dr. Block reviewed the agenda, discussed Veterans Affairs leadership and presented information on VHA Office of Research and Development (ORD). ORD is the only research program that focuses entirely on Veterans' needs. There are over 100 VA Medical Centers with the capacity for research. More than 60 percent of VA researchers are also VA clinicians who provide direct patient care. For 75 years the VA has partnered with U.S. academic institutions for education, training and research. The ORD has five research and development services: Biomedical Laboratory, Clinical Science, Cooperative Studies Program (CSP), Health Services Research and Development (HSRD). Under ORD the VA has initiated several new research programs: Precision Oncology Program (POP), Suicide Prevention, Traumatic Brain Injury Program (TBI), and the Military Exposures Research Program (MERP).

Dr. Block described ORD-MERP as a multi-disciplinary and multi-agency approach. The mission of the MERP is not only to initiate and continue toxic military exposure research, but to re-build trust with Gulf War Veterans and let them know that the VA does recognize GWI and is putting effort into understanding the cause of, and accelerating treatments for this disease.

The mission of the MERP is to advance military exposure assessments and to understand the effects of military exposures on Veterans' health outcomes to inform care and policy. The MERP program will have a committee governing board, which will oversee the program, ensure that program goals are met, and provide direction in its outside partnerships. A dedicated scientific steering committee will be important for helping guide the program in a priority-specific manner, and to include and/or introduce subject-matter experts from our field. The MERP program will include 3-CORES to provide support services to MERP and investigators. There will be an administrative core, a scientific data and repository core, and an exposure assessment core. These cores will be put together so the investigators can have access to regulatory documents, specimens and data, and standardized data collection, common data elements, to allow data sharing for future meta-analysis. The exposure assessment core will assist investigators with establishing and validating new procedures and technologies to be used for understanding and capturing signatures of exposure and novel methods of exposure assessment.

Session 3: RECENT DEVELOPMENTS IN THE IDENTIFICATION OF PTSD-RELATED BIOMARKERS

—Mark Miller, Ph.D., Senior psychologist/clinician investigator at the National Center for PTSD at the VA Boston Healthcare System, also a professor of psychiatry at Boston University School of Medicine.

Dr. Mark Miller presented his research on the discovery of biomarkers for increased accuracy and treatment of Veterans' with GWI. Biomarkers are specific biological molecules found in the various tissues of the body. Dr. Miller further defined biomarkers as an objectively measured biological parameter that is used as an indicator of normal biological processes, atherogenic processes, that is, processes that lead to the development of disease, acute or chronic illness and/or recovery. These markers can be used to assess health, sickness, and efficacy of treatment. A good biomarker is one that will track the course of a disease, and depending on the disease biomarker, shows how biomarker concentration of the disease increases or decreases

depending on the severity of the condition, and theoretically also as a function of recovery from the disease. This research builds upon previous studies on traumatic stress, oxidative stress, and post-traumatic stress disorder: neurodegeneration and the accelerated-aging hypothesis; oxidative stress, inflammation, and neuro-progression in chronic PTSD. Dr. Miller's research has shown there are genetic factors involved with PTSD. Those genetic factors affect body mechanisms such as epigenetic changes, oxidative stress, and inflammation. Those changes in mechanisms lead to the consequences of accelerated aging, neurodegeneration, and metabolic syndrome.

The focus of Dr. Miller's research is on the idea that trauma exposure, which is an adverse environmental exposure, psychological trauma and PTSD is associated with the development of oxidative stress and inflammation in the body, specifically in the brain. That stress can lead to an accelerated aging process leading to neurodegeneration. This research includes working with Gulf War Veterans in the identification of GWI biomarkers. Some of the disease biomarkers being researched are for metabolic syndrome, which includes abnormal aging, obesity, elevated blood pressure and cardiovascular and degenerative brain disease.

Once these biomarkers are fully identified and their function understood, the discovery research will be able to transition to treatment research. By monitoring the abnormal or disease-state biomarkers, doctors will be able to accurately treat and monitor a disease.

Dr. Miller has two research approaches. The first was conducted at the National Center for PTSD Behavioral Science Division Cohort. The study had approximately 750 Veterans of various eras and include some GWV spouses, approximately 200 participants followed over ten years. The median age of participants is 65. The study measured: 1) Genotyping: Illumina 2.5M single nucleotide polymorphism (SNP) array. 2) DNA methylation: Illumina 450K and 850K arrays. 3) Plasma Biomarkers (SIMOA inflammatory and neurology markers, in process). 4) Clinical: Clinician-Administered PTSD Scale (CAPS) and Structured Clinical Interview for DSM - IV (SCID).

The second approach was conducted at the Translational Research Center for TBI and Stress Disorders (TRACTS). The study had approximately 650 U.S. Veterans of conflicts in Iraq and /or Afghanistan, approximately 300 with two or more longitudinal assessments at approximately two-year intervals. Average current age is approximately 45 years old. The study measured: 1) Neuroimaging: Structural Morphology, Diffusion Tensor Imaging, Functional Connectivity; 2) Genotyping: Illumina 2.5M SNP array; 3) DNA methylation: Illumina 450K and 850K arrays; 4) Plasma Biomarkers (SIMOA inflammatory and neurology markers); 5) Clinical: CAPS and SCID; 6) Neurocognitive Battery; 7) Emphasis on mTBI assessment and analysis.

Dr. Miller discussed individual genes involved in neurodegeneration, cardiovascular disease, inflammation and PTSD all of which produce potential biomarker proteins. His study presented promising research in the monitoring of DNA changes due to structural chemical changes. Basic conclusions of the research suggest panels of relevant biomarkers in the future could aid in a PTSD diagnosis and assessment. Due to the nature of PTSD, initial research suggests no individual PTSD biomarker has shown sufficient diagnostic sensitivity or specificity. However, studies support the combining of biomarkers for increased diagnostic accuracy.

Blood-based biomarker research has shown that many biomarker associations with disease are modified by the genetic variation, and that meaningful associations between the disease and a biomarker can be missed if the genetic background of patients are not considered.

Finally, biomarkers hopefully will inform the development of therapeutics. However, there may always be a disconnect between our diagnostic phenotypes and the targets of those therapies. Dr. Miller's research supports the conclusion that PTSD seems to be associated with a variety of systemic health conditions including oxidative stress and inflammation. Future research on blood-based biomarkers might identify new targets for therapies that do intervene in some of these more basic processes, like inflammation, oxidative stress, and even perhaps accelerated aging.

Session 4: THE EXPOSOME: CAPTURING COMPLEX EXPOSURES
— Gary W. Miller, Ph.D., Environmental Health Sciences, Vice Dean for Integration and Research, Columbia University, Mailman School of Public Health, New York, NY

Dr. Gary Miller's research is based on the concept of exposome exposure affecting the health of the body. The term exposome was established by Chris Wild, [Christopher Wild, Ph.D.], who is the director of the International Agency for Research on Cancer (IARC) at the World Health Organization. He defined it as all environmental exposures from conception onwards, and in many ways is referred to as the totality of our exposures throughout our life span. Dr. Miller presented as an example, if a person smoked cigarettes 20 years ago and then quit ten years ago, he could tell that from the epigenetics. Exposomes are a way of seeing a person's biology and what past exposures have done. Working from that definition Dr. Miller studies how the human body absorbs environmental chemicals and how those chemicals remain in the body and affect a person's general health. His research has been able to develop a database of not only known chemicals but also discovered new intermediate chemicals that result from the breakdown of the original parent compound.

Advances in this type of research are being conducted in conjunction with the Mayo Clinic on a type of liver disease named primary sclerosing cholangitis (PCS). Initial results showed highly specific chemicals were associated with alterations in various biological pathways.

Similar research has been done on Alzheimer's disease. That research, using an untargeted approach, measured endogenous metabolites. One of those was the metabolite of the pesticide/herbicide DDT, called DDE. Banned from use in the United States in 1972 this chemical was thought to no longer be present in the modern environment. However, Dr. Miller's exposome research can still detect it in everyone. Published research showed DDE was elevated in people with Alzheimer's disease. This finding supports not just looking at the drugs people take to treat their disease, but also environmental chemicals. Further controlled laboratory experiments are being performed using a model organism Caenorhabditis elegans (C. elegans) that replicates similar physiological responses as seen in humans.

In conclusion, Dr. Miller thinks exposomes present a good opportunity for the military [DoD] and the VA to look at complex exposures in a systematic and unbiased fashion. By leveraging existing and new technologies and utilizing existing bio-bank samples there is an opportunity to follow existing patient studies and gain information about environmental drivers of human disease, resulting in a faster and more effective treatment.

Session 5: BIG DATA, HEALTH AND AGING
— Michael Snyder, Ph.D., Professor and Chair of Genetics, Stanford University School of Medicine

Dr. Snyder's research is based on the idea that modern medical practice is reactive, not proactive. Instead of monitoring the body for initial signs of illness before a disease or sickness happens (what he calls precision health), standard medical care treats a person only after they become sick (known as precision medicine).

To change that approach, Dr. Snyder's research is trying to understand what it means to be healthy, and how health changes over time and varies between individuals. Part of that study approach involves using advanced technologies to better manage people's health. This first started with looking for specific DNA sequences related to disease. Using a form of artificial intelligence or machine learning, his research team was able to identify genes involved in a lethal cardiovascular mutation. Further use of this model may help identified genes that are or could become pathogenic mutations. Dr. Snyder's research determined that people generally age along several biological pathways in the body: metabolic, immune, hepatic (liver) and nephrotic (kidney). People who are metabolic agers, for example, might be at a higher risk for diabetes or show signs of elevated hemoglobin A1c, a measure of blood-sugar levels, as they grow older. People with an immune ageotype, on the other hand, might generate higher levels of inflammatory markers or be more prone to immune-related diseases as they age. But the ageotypes are not mutually exclusive, and a metabolic ager could also be an immune ager, for example. When this type of research is combined with the use of biomarkers (see above, Dr. Mark Miller), and wearable smart-devices, (i.e., Fit Bit, Apple smart watch), medical practice becomes proactive and focuses on individual-based health care.

When applied to GWI, ageotype studies will allow for a comparison of normal aging pathways versus abnormal (disease-state) aging pathways possibly experienced by Gulf War Veterans. In conclusion Dr. Snyder envisions a proactive or constant medical monitoring form of medical care. People would have genome sequencing even before birth, and then together with these deep molecular measurements and wearable technology, individuals can actually better monitor their own health and receive precise medical care.

Session 6: PANEL DISCUSSION
— Invited Speakers and Committee

The following portion of the meeting was opened to questions for the guest speakers from the Committee (Q & A).

Q: What approaches are being used to diagnose and treat GWI and can any of the described methods be used as part of that diagnosis and treatment? Are there any testing approaches currently available to GWI Veterans'?
A: All the current projects discussed are in basic research at this time. Any move to clinical testing is by permission of the U.S. Food and Drug Administration (FDA). One of the challenges to moving forward with clinical testing is the size of the study database and currently there are no clinical studies looking for disease using healthy people.

Q: How would you describe or present research to the head of the VA to drive GWI research?
A: There are several items needed to drive GWI research. First is data regarding GWI and all the Veterans suffering from it. Second is an established disease baseline to extrapolate the symptoms and treatments. Currently there is still a need to define the phenotypes and diagnosis for GWI. In short, a new or better classification system is needed.

Q: What do you see as the most promising class of biomarker(s) for GWI?
A: By using big data it will be possible to identify suspect biomarkers. The process will come down to the collecting of the data and identifying how those biomarkers are directly and indirectly involved in GWI.

Q: Due to similarities, how will it be possible to differentiate between PTSD and GWI?
A: If the root cause is the same, as identified by biomarkers and symptomology, then there would be no real reason to distinguish between the two as the treatment would be the same.

Q: Would different tissues provide different results and what is the best tissue for sampling?
A: Currently the easiest and most common tissue studied is blood/serum.

Q: Can other tissues be more exact for disease biomarkers?
A: Yes, specific/target tissues could provide more exact information; however, collecting those tissues can be invasive. Blood is still the best tissue type to start with and remains the initial focus in biomarker identification.

Session 7: GWI ACETYL- CHOLINESTERASE INHIBITOR WITHDRAWAL HYPOTHESIS: TARDIVE DYSAUTONOMIA

— J. Wesson Ashford, M.D., Ph.D., WRIISC CA, VA Palo Alto Health Care System, Stanford University

Dr. Ashford brought a multi-focused presentation that covered how GWI is diagnostically and clinically defined; how GWI affects the body; the possible environmental and chemical exposures that may have caused the disease; specific symptoms and areas of the body affected by GWI.

Dr. Ashford defined his tardive dysautonomia hypothesis as the effect of cholinesterase inhibitor withdrawal that either causes or exacerbates GWI. Dysautonomia is a disorder of the autonomic nervous system (ANS) function that generally involves failure of one or both parts of the ANS, the sympathetic or parasympathetic nervous systems. Forms of dysautonomia are common in fibromyalgia, chronic fatigue syndrome, and irritable bowel syndrome, all common diagnoses associated with GWI. This raises the possibility that such dysautonomia may be caused by a clustering underlying pathogenesis. Some of the possible causes considered are chemical weapons exposure, infectious disease, multiple vaccinations, depleted uranium rounds and pyridostigmine bromide (PB) pills.

Dr. Ashford further explained the role of PB pills in GWI, explaining there is a rebound effect from the neurotransmitter acetylcholine caused by taking PB. The PB bills inhibited acetylcholine, and when the pills were stopped, the reduced levels rebounded to a higher-than-normal amount. He presented brain scans of Veterans with GWI which show similarity to brain scans of people diagnosed with Alzheimer's disease. This was not to suggest GWI and Alzheimer's disease are related; however, it was to point out how both of those diseases have developmental and symptomology similarities. Many GWI symptoms experienced by GWV are common to the parasympathetic and autonomic nervous system, all of which are controlled in some manner by the brain stem. In further elaboration Dr. Ashford explained the brain stem is a primary source of energy, feelings of motivation, fatigue, sleep patterns; in total the brain stem touches almost all body activity to some degree. And the brainstem receives chemical signals from neurotransmitters such as acetylcholine, thus any disruption will impact all body functions.

Dr. Ashford suggested a variety of treatments for treating specific aspects or symptoms of dysautonomia. If a person suffers from irritable bowel syndrome treat the diet. He showed how

exercise changes the body focus from chronic pain issues. He suggested swimming and aerobic exercises. That yoga can help control the brain stem. Dr. Ashford specifically addressed how yoga helps because it is basically an exercise in trying to control the brain stem. It changes the whole concept of what a person is trying to do.

In conclusion Dr. Ashford said there is a need to figure out how to get people to use techniques like yoga, exercise, diet, even some medications to try to help the Veterans with the terrible symptoms they have because of GWI.

Session 8: COMMITTEE BUSINESS

— Parent Committee

Dr. Steinman: Thanked the presenters for taking the time to talk with the group and present their research. He then presented an open invitation for people interested in joining the committee. If interested in becoming a committee member, contact the RACGWVI at varacgwvi@va.gov.

Veteran Engagement Subcommittee Report

— Drew Helmer, M.D., M.S.

The Veteran Engagement Sessions (VES) subcommittee report was presented to the parent committee.

Two VES were held in 2021. Both sessions were held virtually due to COVID-19 travel and safety restrictions from the VA and CDC.

- Feb 17, 2021. Sixty-eight participants via Adobe Connect: 60 on VANTs telephone line. This VES was followed by a 30th Anniversary Tribute to Operation Desert Storm in collaboration with VISN 20 and VA Puget Sound Healthcare System, Seattle, WA.
- May 19, 2021. Seventy-five participants via Webex platform.

VES Format:

1. What health issues are of greatest concern to GWV?
2. How can research improve the treatments available to GWVI?
3. What health issue could the VA address to improve GWV quality of life?
4. What would you like the VA Secretary to know about the health of GWV?

Veterans, caregivers and advocates responded via the audio and chat features on the virtual Webex platform.

- Major themes discussed or presented:
    1. Health concerns
        - Diverse, both common and esoteric, potent negative health impact of GWI.
        - Difficulty accessing expert health care in VHA and elsewhere
        - Some concerns about special vulnerability to COVID-19 and COVID-19 vaccine side effects
        - Difficulty navigating the service connection process for GW-related benefits
    2. Research Role
        - Some positive testimonials about participating in research
        - More widespread unawareness of research opportunities and/or barriers
        - Imperative to communicate research results to Veterans and health care providers
        - Need to fund appropriate infrastructure to facilitate clinical research related to GWI

3. Quality of Life
    - A need for clear indicator of GWI in the medical record to target appropriate, high-quality care
    - Providers (especially VHA) need to treat the whole person and work with the patient to alleviate impact from chronic symptoms of GWI
    - Service-connected benefits are critical to improving quality of life given tenuous or unemployment and financial insecurity caused or worsened by GWI symptoms
4. Information for the VA Secretary (Denis McDonough)
    - Listen to Veterans with GWI-acknowledge them and their suffering
    - Understand the Veterans with GWI are not getting high-quality care and change the system to prioritize that care (e.g., provider education, GWI expert at every facility, whole health approach, complementary & integrated health, accelerate clinical research into practice)
    - Make the service-connection process for GWI-related claims more transparent and efficient

Conclusions and Implications:

- Veteran Engagement Sessions continue to provide important and evolving information to the RACGWVI and the research and research policy communities
- Participation continues to be high, even with the virtual-only platform
- Content from the VES's informed the draft RACGWVI recommendations to the VA Secretary (to be discussed at this meeting)
- The VES discussions inform future RACGWVI parent committee meeting content

Dr. Steinman reiterated the importance of VES and how these sessions continue to engage GWV and work towards improving their quality of life. Committee member opening comments included the need to consider new approaches to increase the number of Veterans attending each VES.

Further committee comments were regarding the presentations, noting they were informative and provided new ideas about how to promote that type of research, but more information is needed on how that research can transition into a clinical trial and be used directly to help treat GWI Veterans. A GWV committee member noted some of the material presented was too complex for some of the audience members and reiterated the purpose of the RAC is to support GWI Veterans. A recommendation for a new committee member was also provided.

SECVA Recommendations

The Committee presented three purposed recommendations to be presented to the VA Secretary.

1. **To establish a GW Military Exposures Research and Innovation Center (GW MERIC). Purpose of the center would be to focus on GWI research and drive research to clinical studies and finally into actual GWI treatments. Increase visibility of GWI research.**

   Comments: Dan Sloper: Suggested a partnership with the U.S. Food and Drug Administration's National Center for Toxicological Research (NCTR) for the purpose of conducting GWI research. That facility is established and fully equipped to perform research on biomarkers, toxicity studies, machine learning, and translational treatments.

Dr. Pope: Regarding Dr. Block's presentation on the MERP, comments on how quantification of exposures needs to be included in the recommendations.

2. **Initiate research on COVID-19, Long-COVID and GWI.**

   Comments: Dr. Baraniuk: Parts of infectious disease research is ongoing on COVID-19. It would be easy to include GWI to look for similarities between the two diseases and if they build on each other. Recommends everyone receive vaccination for COVID-19.

3. **Continue Subcommittee Veteran Engagement Sessions.**

   Comments: Dr. Steinman: States he feels the VES are effective and bring good input to the committee.

Proposed 2022 Meeting Schedule – not yet confirmed.

- Jan 27-28 (Parent Committee) Tucson, AZ and virtual
- April 6-7 Subcommittee VES
- July 21-22 Subcommittee VES
- Sept. 21-22 (Parent Committee)

Session 9: PUBLIC COMMENT

— Mr. Bill Watts: At 3:28 public comment is started. Mr. Watts as moderator provided the rules of engagement for questions; asking the public to keep their questions to three minutes or less to be respectful of others who would like to comment.

Male GWV: Sergeant Major (SGM) Gulf War Veteran was blinded by an IED and suffers from depleted uranium exposure. He represents the group Gulf War Baby and Parents United, a group of GWV whose children are experiencing the same health issues as their GWI-suffering parents. He, and other families, want a Gulf War child registry established for the purpose of tracking and testing children of GWVs with GWI so these children can, in the future, be treated and compensated for inherited-GWI. He asks for further support and members for this group and asks for this groups information to be forwarded to the VA Secretary.

Dr. Steinman responds: Thanked the SGM and noted this situation can be complex and can be considered.

Female GWV: Gulf War Baby and Parents United member. Strongly requests a child registry to be established. She also emphasized the need for Veterans to have more input and education about COVID-19 vaccinations and vaccine hesitancy and mistrust due to previous military vaccinations such as the anthrax vaccine. She feels that other non-VA vaccine experts, such as those doctors seen on television news shows, are needed to explain to the Veterans the need for COVID-19 vaccination. She also wants to know how many Gulf War Veterans outside of the VA medical system have died due to COVID-19.

Dr. Helmer responds: There is ongoing research about vaccinations and Gulf War Veterans' vaccinations, illness and fatalities.

Female GWV responds: Professionals need to handle the situation, not Facebook chat groups.

Female GWV: Gulf War Baby and Parents United member. Tells how GWI children are suffering from similar issues as their parents. GWI is now being recognized in Veterans, but not being recognized in their children; this situation needs to change. She then reads a mission statement and the groups directives. She again asks for a GWI Veteran's children registry be

established and asks for such a registry to be included in the recommendations to the VA secretary.

Mr. Watts responds: [To Dr. Steinman regarding recommendation 2: Initiate research on COVID-19, Long-COVID and GWI, also to previous female GWV who commented on COVID-19.] Mr. Watts says he believes there is a COVID-19 study happening at the Miami VA that people could investigate. [In response to Mr. Watts' reference, the link to that study has been included as a resource. https://www.research.va.gov/studies.cfm?Facility=Bruce%20W.%20Carter%20Department%20of%20Veterans%20Affairs%20Medical%20Center]

Female GWV: Gulf War Baby and Parents United member. She wants people to understand that the children being spoken about are not small children, but adults with children of their own. She also asked for the registry to be established. She then asks for depleted-uranium dust studies and research. She tells of how contaminated dust was prevalent and invasive in all aspects of life in the affected combat areas. She said at a previous meeting she asked for these studies to be conducted, citing specific case files and studies regarding depleted uranium dust particles, which a short time after the meeting, all the cited materials disappeared from the database.

Male GWV: Thanked the committee and fellow Veterans. He was a corpsman during the Gulf War and stayed for several tours. After returning to the U.S., he started experiencing [GWI] symptoms and experienced a lack of continuity in medical providers. He said clinics kept losing the doctors he [and other Veterans] had been seeing and being treated by, then having to start over again with a new doctor who was unfamiliar with their case history. Due to constant turnover of specialists at the VA, is it possible to improve continuity of care.

Dr. Helmer responds: Agrees that the continuity of care is critical. However, that is not always possible due to patients and/or doctors moving. Dr. Helmer spoke to several solutions such as the electronic medical record system also, tele-medicine which will allow patients and doctors to maintain a relationship and allow for sharing of a patient's case history, both of which will help to maintain a continuity of patient care. He concludes by again acknowledging the need for continuity of care.

Female GWV: Talks about her immune reaction issues. She is an Army GWV and received the anthrax vaccine and now has an autoimmune disorder. Elaborating further, she talks about a genome research project and noted vaccines being a common denominator in GWI. Besides autoimmune disorders, she is also experiencing cardiac issues due to her GWI.

Mr. Watts responds: Thanked her for her service and participating in the meeting. He further comments that vaccines have been discussed in previous meetings.

Dr. Steinman responds: Comments that the DoD will not speak about the vaccines. The CDC is also not forthcoming to speak of the vaccines in an open forum.

Male GWV: Asks the committee why do so many Gulf War Vets die of ALS?

Dr. Steinman: Comments that research into the high incident of Gulf War Veterans developing ALS is ongoing.

Female GWV: Thanked the committee for inviting her to participate. She is a former First Sergeant, and a member of multiple Veteran outreach and support groups. She asked if any research is being done specifically for women suffering from GWI?

Dr. Helmer responds: Says that is an article that he will put into the chat, and that yes, there was study specific for women. In other VES, female Veterans have commented on how GWI has affected then differently than the men. [In response to this question further references have been included below.]

1. A Review of Epidemiologic Studies of the Health of Gulf War Women Veterans. **https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5635858/pdf/nihms905048.pdf**
2. The Gulf War Women's Health Cohort: Study Design and Protocol. **https://doi.org/10.3390/ijerph17072423**
3. Prevalence and Patterns of Symptoms Among Female Veterans of the 1991 Gulf War Era: 25 Years Later **https://doi.org/10.1089/jwh.2019.7705**
4. Sex-Based Differences in Plasma Autoantibodies to Central Nervous System Proteins in Gulf War Veterans versus Healthy and Symptomatic Controls **https://doi.org/10.3390/brainsci11020148**
5. Neurotoxicant exposures and rates of Chronic Multisymptom Illness and Kansas Gulf War Illness criteria in Gulf War deployed women Veterans **https://doi.org/10.1016/j.lfs.2021.119623**

Closing Remarks

Dr. Steinman: Ended the meeting and stated that the RACGWVI committee is always available for further discussion or questions via email. He thanked the committee, presenters and all the Gulf War Veterans and their families that participated in the meeting.

Meeting adjourned.