

VETERAN ENGAGEMENT SESSION #3

Research Advisory Committee on Gulf War Veterans' Illnesses (RAC-GWVI)

Report of the Subcommittee for Veteran Engagement Sessions (VES)

- Date:** February 03 and 04, 2020
- Location:** Atlanta, Georgia, VA Medical Center
- RAC Subcommittee:** Larry Steinman, Karen Block, Drew Helmer, Steve Hunt, Kim Adams, Brent Casey, Marilyn Harris, Bill Watts
- Talking Points:** ❖ Health concerns ❖ Quality of Life ❖ Research issues
❖ What do you want the Secretary of VA to know? ❖ Local and National Resources
- Session Overview:** Number of attendees called-in & in-person: Day 1—20 & 6 and Day 2—32 & 13 respectively.

- Format: 2 days, 3 hours each day, Day 1 from 4:00 pm to 7:00 pm, Day 2 from 10:00 am to 1:00 pm local time.
- Held in the Atlanta VA Medical Center with some confusion and a conflicting access about the meeting site; however, after announcements over the public address system walk-in attendees began to show up.
- The goal to interacting with Gulf War Veterans was achieved. Discussions focused on current health- and quality of life-concerns, in addition to National Gulf War research efforts focused on treatments and mechanisms underlying Gulf War illness.
- Dialogue occurred between the Gulf War Veterans and subcommittee members of the Research Advisory Committee on Gulf War Veterans' illnesses with the goal of taking the Gulf War Veterans messages to the parent committee for discussions and actions.

Talking Points Summaries

- ❖ **What health issues are of greatest concern to Gulf War Veterans?**
 - Exposure issues include burn pits and oil well fires, chemical exposures, vaccine injury and poisoning, and symptoms occurring in a subset of Gulf War Veterans despite being non-deployed.
 - Clinical concerns discussed included breast cancer, gastrointestinal problems, irritable bowel syndrome, neurological problems, immunodeficiency, hypersensitivity to medications, degenerative joint disease, blood pressure problems, metabolic issues, and depression.
 - Internal organ-related issues included deterioration of functioning organs and body systems such as thyroid, liver, urinary bladder, and endocrine problems.
 - Gulf War Veterans felt too many medication pills are prescribed, but also that medications are often not equally or fully available across VA VISNs.
 - Concerns about premature aging and reinjury resulting from lack of VA caring about health issues were raised.
 - Concern by Gulf War Veterans over their children having some of the same exact issues that they are having.
- ❖ **What health issue could the VA address to improve GW Veterans' quality of life?**
 - Gulf War Veteran engagement sessions allow us to directly listen and to Gulf War Veterans and investigate the system failure issues that continue to mediate mistrust within the VA.
 - We continue to get feedback on the need to do a better job of educating primary providers about Gulf War illness.

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- Interaction provides Patient Aligned Care Teams the insight to better support Gulf War issues.
- Most Gulf War Era Veterans do not trust the VA and even though they are suffering they do not want to deal with the VA system.
 - Desert Storm is the forgotten war.
 - Full services are provided for Post-9/11 but not for Pre-9/11 Veterans.
- VA does not fully recognize deployment exposures, denies specific care for Gulf War illness, and often does not officially recognize Gulf War health problems.
 - Doctors lack codes to record the variety of symptoms and health issues specific to the Gulf War.
 - Doctors don't listen to Gulf War Veterans and don't understand problems that Gulf War Veterans voice.
 - Routine physicals overlook Gulf War Veteran health issues.
 - Primary care consults do not cover severe problems.
 - Specialized treatments are lacking for Gulf War illness.
 - Sexual assault is not addressed.
 - Not enough is being done to help homeless Gulf War Veterans.
- VA must improve uniformity in provision of health care.
 - Ensure availability of health care providers who understand what Gulf Veterans have been through.
 - Train primary care providers about Gulf War health issues.
 - Update the electronic health record with alerts and flags for Gulf War health issues.
 - Specific Gulf War issues are not understood when receiving care outside of VA.
 - Mission Act confusion needs to be examined and procedures redefined.
 - Facilitate access to and completion of registry exams and referrals to the WRIISCs.
 - Provide resources for spouses to address children's quality of life issues.
- The Veteran Engagement Session provided interaction with the Gulf War Veteran community—a very big unmet need was served.
 - Significant personal therapeutic response occurred with Gulf War Veterans who were willing to share their concerns, problems, and treatments.
 - As we send more Gulf Veterans into the community to get their VA care, what are we doing about ensuring care for Gulf War illness?
 - VA providers, as well as providers outside of the VA, do not know enough about Gulf War illness.
 - Women Gulf War era Veterans and their care are overlooked and not engaged at the VAs.
 - Evident lack of knowledge of the resources available to the Gulf War Veterans and their families.
- Regarding systemic concerns in the VA, most centers do wonderful good work at least as good or better than the community.
 - The concern is how to standardize the system so that wherever a Veteran enters the system they get the care they need and deserve.
 - We can't just say a lot of our VA centers are doing really well.
 - We have to focus to say we as a system have to do a good job and we have to figure out how to do it in simplest terms.
 - Some centers just don't do good work and that is a big challenge in the VA.
 - Problematic conditions in which some VAs are being run need to be looked into.
- Red-flag issues at Atlanta were cancer, homelessness, and the vulnerability of women Veterans.
 - Many issues came out from the women Veterans and were felt if not verbalized.

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- Women here are having strong challenges of homelessness with the VA system.
- We may have seen homeless problems elsewhere but have not heard from Veterans so strongly.
- A lot of personal help and assistance was provided by the RAC Committee to Gulf War Veterans with individual separate attempts to engage with people who needed help.
- Subcommittee member discussions provided very significant answers to Gulf War Veterans' questions.

❖ How can research improve the treatments available to GW Veterans?

- Resolve the stumbling block in the lack of translation of research to clinical issues.
 - Get research results into the VA electronic health record so providers can read it.
 - Facilitate coordinated research and care with academic institutions.
 - Solve the problem of lack of budgets for research.
- Develop research themes that improve quality of life:
 - Emphasize superior health care and consistency of care and treatments across VAMCs.
 - Develop information about absorption of medicines.
 - Investigate why infertility clinic research only serves married women?
 - Include studies of intergenerational issues in Gulf War health care treatment research.
- Recognize that Veterans returned with predictable health consequences related to specific deployments.
 - Referring to Gulf War illness as chronic multi-symptom illness is confusing.
 - What issues are specific to combat-related later deployments.
 - What are the timelines for health conditions related to Gulf War illness?
- Provide contact and outreach to Veterans about research participation.
 - Develop travel support and research access scheduling that make it easier to participate in research.
 - Make research available after Veteran working hours and on weekends.
 - Make records available from previous CCEP (Comprehensive Clinical Evaluation Program) studies.
- Resolve limited support for participation in research.
 - Accommodate Veterans involvement in research as they are getting care.
 - Resolve why Veterans are not being contacted for research.
 - Facilitate studies through Facebook groups and Veterans Centers.

❖ What would you like the VA Secretary to know about the health of GW Veterans?

- Develop a plan of action and commitment to continuity of care that improve quality of life through superior health care and consistency of care and treatments across VAMCs.
- Emphasize not only recognition of Gulf War Veteran exposures and Gulf War health problems, but also provide specialists and specific advocates of care for Gulf War illness.
- Consider specific research topics, such as the concerns of Gulf War Veterans about intergenerational effects on the health of their children.
- Resolve the lack of outreach to the Gulf War Veteran community:
 - Provide Gulf War Veterans with recognition and validation—hold a pre-9/11 Gulf War town hall.
 - Bridge the gap between Veterans Service Organizations and Veterans Affairs.
- Facilitate health care resources for Veterans who were not deployed (e.g., registry exams and referral to WRIISCs).
- Provide referral access to holistic care through non-VA facilities

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❖ Available Local and National Resources for Veterans

Local Atlanta Area Quality of Life Resources

Regional Veterans Services:

- Atlanta Regional Benefit Office: <https://benefits.va.gov/atlanta/>
- Atlanta Vocational Rehabilitation and Employment Office: https://www.va.gov/find-locations/facility/vba_316a

Atlanta VA Medical Center: <https://www.va.gov/directory/guide/facility.asp?id=38>

- Atlanta VAHCS is one of the national VA Rehabilitation Research and Development Centers of Excellence with research programs focused on medical and clinical problems, rehabilitation medicine and engineering, as well as health services and outcomes research: <https://www.rehab.research.va.gov/>
- The mission of the Atlanta VA Medical Center Rehabilitation R&D Center for Visual and Neurocognitive Rehabilitation (CVNR) is to foster the health and well-being of veterans through uniquely synergistic research impacting visual and/or neurocognitive function: <http://www.varrd.emory.edu/>

Veteran Centers: Serve Veterans and their family members.

- Atlanta Veterans Center: <https://www.va.gov/directory/guide/facility.asp?ID=651>
- Georgia Tech Veterans Resource Center: <http://veterans.gatech.edu/>
- Georgia State University Military Outreach Center: <https://military.gsu.edu/>

Veterans Service Organizations: <https://www.benefits.va.gov/ROATLANTA/veterans-services-orgs.asp>

- Atlanta Regional Office counsels about eligibility for VA benefits and how to apply.
- Atlanta Regional Office provides information about VA health care and memorial benefits.

YMCA and Local Community Center Aquatic Therapy Programs:

- Atlanta local YMCAs offer a range of physical and rehabilitation therapy services such as swim lessons, sports and wellness classes, educational opportunities, and senior programs.
- Atlanta Area YMCAs: <https://www.ymcaatlanta.org/locations/>

Recreational Outdoors Activities:

- Atlanta Area Recreation Centers: Google search reveals over 100 sources for recreational organized sports, fitness training, and seasonal activities.
- National VHA Recreational Therapy Services: <https://www.prosthetics.va.gov/rectherapy/aboutus.asp>
 - Get outdoors to move and be active.
 - Primary Care doctors can refer VA patients to medical center services.

Georgia State Quality of Life Resources

Georgia Department of Veterans Service: <https://veterans.georgia.gov>

- Assists Georgia's veterans in all matters pertaining to veterans' benefits.
- Informs veterans and their families about veterans' benefits.
- Directly assists and advises veterans and their families in securing the federal and state benefits.

VA Georgia Facilities: https://www.va.gov/directory/guide/fac_list_by_state.cfm?State=GA&dnum=All

VA National Quality of Life Resources

War Related Illness and Injury Study Center (WRIISC): <https://www.warrelatedillness.va.gov/>

- A VA national program dedicated to Veterans' post-deployment health concerns and unique health care needs:
 - Develops and provides post-deployment health expertise to Veterans and their health care providers through clinical care, research, education, and risk communication that is fundamental to VA's mission and is rarely found outside of VA
 - Partners, as a tertiary care center, with referring providers and their health care teams to support the care of Veterans.
- The WRIISC is part of VA's Post Deployment Health Services, a VA Delivered Foundational Service.

Gulf War Newsletter: <https://www.publichealth.va.gov/exposures/publications/gulf-war/gulf-war-2019/index.asp>

- Combined Gulf War and Post-9/11 Vet Newsletters published twice a year.
- Information for Veterans who served in Operations Desert Shield and Desert Storm and their families.

General Quality of Life Resources List

Easter Seals Programs: <https://www.easterseals.com/our-programs/military-veterans/>

- **THRIVE Financial Program, Veterans Therapy (Mental Health Treatment):** Easter Seals Veterans Programs work to break down barriers, engage organizations and communities, and connect veterans and military families with what they need for meaningful education, employment and job training, and overall wellness, rehabilitation, and caregiver services.

The Fisher House: <https://www.fisherhouse.org/about/>

- The Fisher House Foundation builds comfort homes, located at military and VA medical centers around the world, where Military and Veteran families can stay free of charge, while a loved one is in the hospital.

Give an Hour — Free Mental Healthcare: <https://vetsvites.com/give-hour-free-mental-health-counseling-veterans/>

- Give an Hour provides free, confidential mental health counseling for individuals, couples, and families of Veterans and active military.

Kohls 15% Military Monday Discount for Veterans:

- Kohl's Military Mondays is a 15 percent in-store discount valid in-store every Monday — all year long — when customers show a valid Military ID, Military Dependent ID or Veteran ID at the point of purchase. <https://corporate.kohls.com/news/archive-/2019/April/kohl-s-launches-military-mondays---a-new-15--off-discount-every->

LinkedIn FREE for Veterans Caregivers:

- LinkedIn offers U.S. veterans a free one-year Premium Careers subscription, including access to LinkedIn Learning: <https://www.linkedin.com/help/linkedin/answer/14803/linkedin-for-veterans-free-premium-career-subscription-and-eligibility?lang=en>
- LinkedIn offers every military spouse a one-year Premium Career subscription with each permanent change of station, career change or job loss: <https://socialimpact.linkedin.com/programs/veterans/milspouses>

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- LinkedIn offers Veteran caregivers enrolled in the [Department of Veterans Affairs' stipend program](https://www.military.com/militaryadvantage/2019/04/03/linkedin-premium-now-free-veteran-caregivers-fry-scholars.html) and students using the Fry Scholarship a free year of LinkedIn Premium: <https://www.military.com/militaryadvantage/2019/04/03/linkedin-premium-now-free-veteran-caregivers-fry-scholars.html>

The Mission Continues — a VSO that provides service projects for Veterans nationally and beyond:

- The Mission Continues is a national, nonpartisan nonprofit that empowers Veterans to continue their service, and empowers communities with veteran talent, skills, and preparedness to generate visible impact. <https://missioncontinues.org/about/>
- The program connects Veterans with under-resourced communities in cities across the country to deploy Veteran volunteers alongside nonprofit partners and community leaders to improve educational resources, increase access to parks and green spaces, foster neighborhood identity, and more.

National Military Family Association: <https://www.militaryfamily.org/about-us/>

- **The National Military Family Association**, NMFA, provides programs and resources geared toward helping **military** service members, their spouses, and their children fund their education, career, or business goals as well as providing a voice for their legislative concerns and issues.

National and State Park Access for Veterans:

- The National Park Service provides disabled military Veterans with any disability rating from the Department of Veterans Affairs a [free lifetime pass](https://www.military.com/militaryadvantage/2018/04/06/got-va-rating-you-can-get-free-lifetime-national-parks-pass.html) to national parks and other recreation areas, as well as discounts on some fees. The passes provide free entrance to more than 2,000 national parks, wildlife refuges, national forests, and other federal recreational areas. <https://www.military.com/militaryadvantage/2018/04/06/got-va-rating-you-can-get-free-lifetime-national-parks-pass.html>
- State-operated parks provide various park passes, discounts, and other benefits to Veterans and/or disabled Veterans. <http://www.usvetcamper.com/veterans/state-park-passes/>

Operation Family Caregiver: https://www.operationfamilycaregiver.org/about_us/

- Operation Family Caregiver coaches the families of returning service members and veterans to manage the difficulties they face when they come home. OFC is a personalized program, tailored specifically to the struggles of each family. Through proven methods, the program teaches military families how best to navigate their challenges, resulting in stronger and healthier families.

USO — United Service Organizations: <https://www.uso.org/about>

- The USO strengthens America's military service members by keeping them connected to family, home, and country, throughout their service to the nation.

VA Chaplains Department: [https://www.patientcare.va.gov/chaplain/What Do Chaplains Do.asp](https://www.patientcare.va.gov/chaplain/What_Do_Chaplains_Do.asp)

- The VA Chaplains Department ensures that Veteran patients (both inpatient and outpatient) receive appropriate spiritual and clinical pastoral care as desired or requested by the Veteran. VA Chaplains provide comfort, support, leadership, advocacy, counselling, mediation, and education to Veterans and ensure Veteran religious practices and spiritual concerns are known and met.

VA Crisis Line: <https://www.veteranscrisisline.net/about/what-is-vcl>

- The Veterans Crisis Line connects Service members and Veterans in crisis, as well as their family members and friends, with qualified, caring VA responders through a confidential toll-free hotline, online chat, or text-messaging service responders standing by to help 24 hours a day, 7 days a week:

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- If you're a Veteran in crisis or Service member in crisis — or you're concerned about one —the crisis chat is a free, anonymous, confidential resource available to any Service member, including members of the National Guard and Reserve, and any Veteran, even if you're not registered with VA or enrolled in VA health care.

Vet Centers: <https://www.vetcenter.va.gov/>

- Vet Centers are community-based counseling centers that provide a wide range of social and psychological services, including professional readjustment counseling to eligible Veterans, active duty service members, including National Guard and Reserve components, and their families.

VetTix — FREE Concerts, Sporting Event, Theater Tickets, etc., for Veterans:

<https://www.vettix.org/>

- Vet Tix provides free tickets (for a small delivery fee) to sporting events, concerts, performing arts, educational, and family activities across the nation for all branches of currently serving Military and Veterans, including immediate family of troops killed in action.

Veterans Caregiver Support Line: https://www.caregiver.va.gov/Care_Caregivers.asp

- VA Veterans Caregiver Support Line—Telephone number 1-855-260-3274—is a call-in support phone line that provides caring licensed professionals staffing to connect Veterans with VA services, a Caregiver Support Coordinator at your nearest VA medical center, or just listen if that's what you need right now.

Veterans Local Ministries — at Communities of Faith:

- Local Communities of Faith provide resources for Veterans and the Military community and military supporters. <http://www.operationwearehere.com/ForChurches.html>
- The Department of Veterans Affairs (VA) Center for Faith and Opportunity Initiative (CFOI) is an office located in the Office of Public and Intergovernmental Affairs (OPIA) to engage, educate, and inform faith-based, community, and non-profit organizations about the VA tools and resources that will equip them to better serve the Veterans, their families, survivors, caregivers, and other beneficiaries within their organizations. <https://www.va.gov/cfbpartnerships/>

Veterans Treatment Courts: <http://www.courts.ca.gov/11181.htm>

- The Veterans Treatment Courts **program keeps Veteran individuals out of jail and on the road to a healthy, law-abiding lifestyle.** The Veterans Court unique program focuses on **Veterans who are currently in, or entering, the Criminal Justice System** to provide a better understanding of the Veteran's problems and target the root causes of Veterans' criminal behavior. Each participant in Treatment Court is assessed for a wide variety of supportive services, primarily drug and alcohol and/or mental health treatment.
- The Court creates and supervises treatment plans to address the underlying causes of the Veterans' behavior and substance abuse issues. Because a Veterans Treatment Court judge handles numerous Veterans' cases and is supported by a strong, interdisciplinary team, he or she is in a much better position to exercise discretion and effectively respond than a judge who only occasionally hears a case involving a Veteran defendant.

VSOs — Veteran Service Organizations:

<http://www.operationwearehere.com/VeteransServiceOrganizations.html>

- VSOs are “partnership agencies” that help service members in a variety of ways including assisting with claims and benefits, lobbying or other political work on behalf of the VSO's members to raise awareness about the issues they address, plus providing scholarships, training, counseling, and related programs.

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I certify this report is an accurate summary of the February 03 and 04, 2020, Veteran Engagement Session of the Research Advisory Subcommittee on Gulf War Veterans' Illnesses.

A handwritten signature in black ink, appearing to read "Lawrence Steinman", written over a horizontal line.

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