

VETERAN ENGAGEMENT SESSION #2

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

Report of the Subcommittee for Veteran Engagement Sessions (VES)

Date: April 16 and 17, 2019

Location: Cleveland, Ohio, Louis Stokes VA Medical Center

RAC Subcommittee: Larry Steinman, Karen Bock, Steve Hunt, Kim Adams, Brent Casey, Bill Watts, Stanley Corpus

Talking Points: ❖ Health Issues of Greatest Concern ❖ Quality of Life ❖ Research
❖ What do you want the Secretary of VA to know? ❖ Local and National Resources

Session Overview: Number of Gulf War & family/caretaker attendees: 8 in person on Day 1, 18 in person on Day 2, and 30 by phone each day.

- 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.
- Session was held in the Cleveland Louis Stokes VA Medical Center Administration Building, where Gulf War Veterans could park across the street and follow signs to the meeting room. Announcements were made over the public address system right before the meeting that brought Gulf War Veterans and their family members/caretakers into the sessions.
- The mission of the RAC-GWVI Subcommittee is to hear directly from Gulf War Veterans about their current health issues and quality of life and discuss ways VA research could help improve their health. This information informs the parent RAC-GWVI objective to provide advice and make recommendations to the VA Secretary on proposed research and strategies related to understanding and treating the health consequences of military service in the Southwest Asia theater of operations during the 1990-1991 Gulf War (Operation Desert Shield and Desert Storm). This interaction with the Gulf War Veterans and their family members allowed learning not only about their greatest concerns for their health, but also the health of their family members, improvements needed in research and research participation, access to quality clinical care and treatments, and quality of life for the Veterans and their families.
- Education occurred between the Gulf War Veterans and the Subcommittee with powerful messages to take back to the parent RAC-GWVI Committee. Lack of trust about VA continues as a major issue with Gulf War Veterans feeling ignored from deployment through the present and noted Desert Storm as "the forgotten war." However, attendees noted it was a "sacred experience" for Gulf War Veterans to have the opportunity to share and connect with experiences affecting their lives. In addition to individual testimony, a Gulf War Veteran and his spouse described their issues related to his deployment and related physical and mental health conditions, and several Gulf War Veterans in person and by phone described the unexplained and/or unusual health concerns of their children they believe to be caused by their exposures during deployment. The generational effects of Gulf War Illness will be explored in future meetings.

Talking Points Summaries

❖ What health issues are of greatest concern to Gulf War Veterans?

Gulf War Veterans raised ongoing health concerns related to burn pits and oil well fire exposures, anthrax and botulism toxoid vaccinations, depleted uranium, embedded shrapnel, their continuing health effects and complications, and symptoms occurring even with Gulf War Veterans non-deployed. Along with the most predominant symptoms of chronic fatigue syndrome, fibromyalgia, and irritable bowel syndrome, the following symptoms and conditions were noted:

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- prostate cancer
- major depressive disorder
- sleep apnea
- cognitive problems
- hearing problems
- chronic inflammation
- chronic anemia
- changes in energy metabolism.
- aneurysms
- endothelial issues
- Issues with prescribing too many medications and medication availability
- Birth defects and other health issues with their children

❖ What health issue could the VA address to improve GW Veterans' quality of life?

The Veterans again noted that the VA does not recognize exposures, does not officially recognize health problems unique to serving in the first Gulf War, and denies specific care for Gulf War illness. To improve quality of life, the following recommendations were made:

- VA should acknowledge and say that in the Gulf War “there were toxic chemicals and we’re not sure what effects they have had.”
- Educate doctors to listen to Gulf War Veterans to understand problems unique to the first Gulf War.
- Provide specialized treatments for Gulf War illness.
- Provide full services for Pre-9/11 Veterans similar to those of post 9/11.
- Too many medication pills are prescribed, and medications are often not equally available across VA VISNs.
- Improve the limited VA formulary for necessary medications that have shown to be helpful in research (ie: CoQ10 not available on VA formulary).
- Improve uniformity in provision of health care.
 - Balance resources at all VAs for consistency of care and accept treatment plans from outside providers.
 - Ensure availability of health care providers who understand what Gulf War 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.
 - Have one-on-one counseling, all appointments in one day, less travel, all resources available.
 - Facilitate registry exams and referrals to the WRIISCs for those who were not deployed but also had the anthrax vaccinations.
 - Provide resources for spouses and address children’s quality of life issues.
- Resolve the lack of outreach to the Gulf War Veteran community.
 - Realize the best support is often from other Veterans— “I talked to a lot of older Vets that kept me sane.”
 - Acknowledge chaplains are a resource—they build relationships and listen to stories without judgment.
 - Develop a Gulf War website that lists Veteran-sponsored websites.
 - Consider having a Facebook page interface for review of websites relevant to Gulf War Veterans.

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- Create a database to reach out to Gulf War Veterans (research, but also clinical).
- Hold a Gulf War Town Hall Meeting.
- Reach out to Veteran organizations to coordinate concerns about Gulf War Veterans.
- Veteran Engagement Session attendees learned a lot through hearing from and interacting with the Gulf War Veteran community—a very big unmet need was served.
 - The engagement session was overall very emotional and powerful.
 - Attendees noted it was a sacred experience for Gulf War Veterans and their families or caregivers to have the opportunity to share and connect with experiences affecting their lives.
 - Gulf War Veterans wanted to know when the next engagement session will occur.
 - List on the RAC-GWVI website and post in the session minutes the local and national resources discussed and reviewed about outreach for Veterans.
- Continue Gulf War Veteran Outreach Sessions! Someone needs to listen to their stories—they need to be listened to and heard: “What was your experience? Tell me what you’ve done and what you’ve been through.”

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

- Develop research themes that improve quality of life through superior health care and consistency of care and treatments across VAMCs.
 - Do a study with endpoints so it translates to quality of life (e.g., studies of the smart drug modafinil show that for some people it improves performance on long and complex tasks and enhances decision-making and planning skills).
 - Look at Gulf War Veterans’ entire anatomy from head to toe (including dental).
 - Disseminate research information to health care providers.
 - Refuse to let Gulf War Veterans be forgotten.
- Veterans returned with unpredictable health consequences and unique health issues related to specific deployments.
 - Explore what Gulf War Veterans have done and what they have been through.
 - Perform evidence/outcome studies to get effective drugs on the VA formulary.
 - Provide contact and outreach to Gulf War Veterans about research participation.
 - Develop travel support and research access scheduling that make it easier to participate in research.
 - Allow weekends and evenings research participation to avoid hardship for some.
- Conduct research on settings of care—each Veteran and cohort is unique and participants can shape research.
 - Accommodate Gulf War Veterans as they’re getting care.
 - Resolve why Gulf War Veterans are not being contacted for research.
 - Solve problem of lack of budgets for research.
 - Get research results into the VA electronic health record so providers can read it.
 - Convince study participants that taxpayer money is not just being thrown away to experiment on people.
 - Include studies of intergenerational issues in Gulf War health care treatment research.
- Researchers are now beginning to review generational health issues and gather information.
 - Explore generational effects to help current children, not just new enlistees.
 - Generational health studies don’t yet show certainty of relationships.
 - There is still a lack of understanding and evidence is unclear even with research.

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- Rigorous studies need to be conducted before conclusions can be made.
- The levels of proof versus possibilities depend on degrees of certainty regarding exposure effects.
- Is the generational health issue outside the mandated focus of the RAC-GWVI?
 - How much can the RAC focus on review of generational issues?
 - RAC subcommittee members were a first-responder team in the engagement session and Gulf War Veterans expressed appreciation for their comments.
 - Involve the Secretary of the VA to determine the most-efficient approach.
- As part of every RAC meeting we should say to Gulf War Veterans: “We’re glad you’re here. You’ve been through a lot that we don’t understand but what we do know NOW is you’ve come back with unique health consequences related to specific deployments.”

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

- Develop research themes that improve quality of life through superior health care and consistency of care and treatments across VAMCs.
- Recognize Gulf War Veteran exposures, provide specific care for Gulf War illness, and officially recognize Gulf War health problems.
- Consider specific research topics, such as the concerns of Gulf War Veterans about generational effects on the health of their children and involve of the Secretary of the VA to determine the most-efficient approach.
- Resolve the lack of outreach to the Gulf War Veteran community:
 - Provide Gulf War Veterans with recognition and validation—hold a 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, qualify for WRIISC referral).

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❖ Available Local and National Resources for Veterans

Local Cleveland Area Quality of Life Resources

Cuyahoga County Veterans Service Commission (CCVSC): <http://cuyahogavets.org/locations/>

- Assists Ohio Veterans to apply for compensation, pensions, hospitalization, and benefits.
- Offers bus tickets to assist veterans with transportation to their VA medical appointments.
- Also assists with paratransit special transportation services for Veterans with disabilities.

Louis Stokes VA Medical Center in Cleveland: <https://www.cleveland.va.gov/>

- Leader in geriatric care: The Geriatric Emergency Department Collaborative (GEDC) selected the Louis Stokes Cleveland VA Medical Center to be its first VA partner institution.
https://www.cleveland.va.gov/features/VANEOLS_Recognized_as_Leader_in_Geriatric.asp
- Innovative program to enable disabled Veterans to perform everyday tasks independently with new technology. https://www.cleveland.va.gov/features/New_Technology_Empowers.asp

Veteran Centers: Serve Veterans and their family members.

- VA Cleveland Regional Office: <https://www.benefits.va.gov/cleveland/>
- Cleveland State University Veteran and Military Resource Center:
<https://www.collegefactual.com/colleges/cleveland-state-university/student-life/veterans/>

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

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

YMCA and Local Community Center Aquatic Therapy Programs:

- Cleveland local YMCAs offer a range of physical and rehabilitation therapy services such as aquatic therapy as well as strength, treadmill, and balance and gait training.
- Cleveland Area YMCAs: <https://www.clevelandymca.org/>

Recreational Outdoors Activities:

- Cleveland 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.

Ohio State Quality of Life Resources

Ohio Department of Veterans Services: <http://dvs.ohio.gov/main/county-veterans-service-offices.html>

- County offices connect Ohio Veterans with higher education and technical training opportunities.
- Provide grants for general assistance, housing, and services.

VA Northeast Ohio Healthcare System—list of health services: <https://www.cleveland.va.gov/services/index.asp>

VA National Quality of Life Resources

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

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- 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>
- LinkedIn offers Veteran caregivers enrolled in the [Department of Veterans Affairs' stipend program](#) 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>

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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 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

- 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:
- 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/>

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- 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/cfbnpartnerships/>

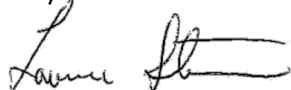
Veterans Treatment Courts: <http://www.courts.ca.gov/11181.htm>

- 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.

I certify this report is an accurate summary of the April 16 and 17, 2019, Veteran Engagement Session of the Research Advisory Subcommittee on Gulf War Veterans’ Illnesses.



Lawrence Steinman, M.D.

Chair, Research Advisory Committee on Gulf War Veterans’ Illnesses