

VETERAN ENGAGEMENT SESSION #1

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

Report of the Subcommittee for Veteran Engagement Sessions (VES)

- Date:** February 5 and 6, 2019
- Location:** Houston, Texas, VA Regional Office
- RAC Subcommittee:** Larry Steinman, Jon VanLeeuwen, Karen Bock, Drew Helmer, Steve Hunt, Kim Adams, Marilyn Harris, 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: 50 per day—20 in person and 30 by phone on both days.

- 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 Houston VA Regional Office auditorium. Announcements were made in advance by VA Public Affairs and local VA representatives brought additional attendees to the session.
- The RAC Subcommittee felt an in-person meeting would allow more visibility with a face-to-face open dialogue allowing a better understanding of Gulf War Veterans' concerns. Authentic and necessary dialogue was experienced leaving a significant impact on subcommittee members. Free-style format of the session and flexibility on talking points allowed a deeper dive into the talking points.
- Gulf War Veterans expressed deep feelings of Institutional betrayal of trust and subsequent pain. They were able to verbalize stories of their deployment and exposures, their long-term suffering and frustrations, as well as current health and health care concerns that research and the VA Secretary could potentially address. Powerful information and ideas were offered to help drive the direction of Gulf War research and improve the experience of Gulf War Veterans within the VA.

Talking Points Summaries

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

Gulf War Veterans raised ongoing health concerns related to exposures during the 1990-1991 Operation Desert Shield/Desert Storm including vaccinations, chemicals, smoke from burn pits and oil well fires, depleted uranium, and again noted veterans' anger upon return from deployment and their long-term suffering. The following past and current health concerns were noted:

- Neurological problems, chronic fatigue, myelinated autonomic disease, seizure disorder
- Connective tissue issues, Bell's palsy (face droops)
- Skin burns and breakdown, open sores, lesions, rash, photosensitivity
- Joints and lower back pain, swelling in back, legs and feet hurt, muscle spasms, knot on arm from vaccinations
- Chronic continuing pain, painful headaches, migraine
- Impaired glucose levels, blood sugar, weight gain, type 2 diabetes (caused by weight gain?)
- Sleep problems, sleep apnea, bad asthma
- Increase in blood pressure, hypertensive, hypercoagulation, aneurism, congestive heart failure
- Intestinal issues, irritable bowel syndrome, diverticulitis
- Vision photosensitivity, teeth rot, balance problems, hair falling out, vitamin E deficiency
- Uterine fibroids, bone in ears bleeds

RAC-GWVI: Veteran Engagement Session #1 in Houston, Texas—Report of the Subcommittee for VES

- Sexual trauma, burning semen syndrome, semen foul order and yellow discolor
- Miscarriages, infertility, premature hysterectomy, birth defects

❖ What health issues could the VA address to improve Gulf War Veterans' quality of life?

In addition to addressing the health concerns above, the following ideas were suggested to improve their health care and well-being, and restore trust in the VA.

- Outreach to get Gulf War Veterans back and restore trust in the VA.
- Acknowledge Desert Storm as a real war.
- Have a Gulf War Champion in the VA system or Administration.
- Have a Gulf War deployment health champion at every VA medical center location.
- Train and educate doctors about health issues of Gulf War Veterans.
- Address feelings of Institutional abandonment and lack of recognition.
- Allow access to same services as Post 9/11.
- Address and reduce isolation of Gulf War Veterans and validate symptoms.
- Allow collaboration between major facilities from coast to coast.

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

Attendees expressed concerns that research has been undertaken in the past, but no findings have been made available, no services have come out of it, and additional research was not undertaken even after successful pilot studies. One reason Veterans are unwilling to take part in research is because participation in studies tends to lead to excessive prescription of more unwanted medications. The following suggestions were offered to improve research and research participation:

- Provide feedback about research findings.
- Describe the benefits (not just the risks) of research. The key question is “What is in it for the Veterans to take part?”
- Pay travel and other expenses.
- Desire for more treatments as well as treatment studies.
- Concern for family members and generational affects.
- Include childhood health problems or abnormalities not apparent at birth
- Spouse and families need clinical care programs to include learning and behavior disorders.
- Research to improve quality of life should lead to superior health care and consistency of care across VAMCs.
- In addition, it was acknowledged that frustrations are not always directly related to research (e.g. clinical care).
- Government/VA needs to clearly acknowledge the effects of exposures to all sorts of chemicals, oil spills, and vaccinations.
- VA should provide combined services that address chronic multisymptom illnesses / unexplained medical conditions together.
- Acknowledge deployment health clinics and integrated health services emerged from review of individuals who came back from the Gulf War.

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

- Consider Veteran-inclusive research not as separate endeavors but as integrated elements in a coherent system of support and care for our Veterans, including:
 - Strong stepped care system with informed clinical teams as the initial point of contact.

RAC-GWVI: Veteran Engagement Session #1 in Houston, Texas—Report of the Subcommittee for VES

- Clinical teams that meaningfully engage Veterans and are accessible and responsive to them.
- A program to help Veterans and their families recover, reintegrate, and thrive in their lives following service.
- Allocate more funding for specialty clinics.
- Consider specific research topics, such as the concerns of Gulf War Veterans about intergenerational effects on the health of their children.
- Make research more successful by raising awareness about research and research participation.
- Fund transportation for research to include specimen collection.
- Fund research that includes not only pathophysiological research but also implementation services research and clinical services research.
- Consider implementation research studies and therapies.
- Research that is more beneficial to aging Gulf War Veterans in their forties and fifties and beyond.

❖ Local and National Resources for Veterans

The RAC Subcommittee also wanted to highlight services that could help Gulf War Veterans and their families. The Gulf War Veterans on the subcommittee shared the following resources for the local Houston and surrounding areas as well as national resources, some of which they have found exceptionally helpful to themselves personally.

Local Houston Area Resources

Harris County Veteran Services Office: <https://vso.harriscountytexas.gov/>

- Assists Texas Veterans to apply for compensation, pensions, hospitalization, and benefits.
- Will do home visits and transportation for disabled Veterans.

Michael E. DeBakey VA Medical Center in Houston: <https://www.houston.va.gov/>

- Has free Veterans Legal Advice Clinic.
- Emergency Room is open 24 hours a day.

Veteran Centers: Serve Veterans and their family members.

- Houston West Vet Center: <https://www.va.gov/directory/guide/facility.asp?ID=672>
- Houston Southwest Vet Center: <https://www.va.gov/directory/guide/facility.asp?ID=671>

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

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

METRO Transit Authority Veterans Pass: <https://www.ridemetro.org/Pages/VeteransPass.aspx#>

- Houston's METRO's fares include The Qualified METRO Veterans Pass (MVP).
- MVP provides qualified U.S. military veterans with free, unlimited rides on light-rail, local bus, and Park & Ride service.

YMCA and Local Community Center Aquatic Therapy Programs:

- Houston 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.
- Houston T.W. Davis Family YMCA: <https://www.ymcahouston.org/locations/tw-davis-family-ymca/programs>

Recreational Outdoor Activities:

- Houston VA Medical Center Recreation Therapy: https://www.houston.va.gov/services/Recreation_Therapy.asp

RAC-GWVI: Veteran Engagement Session #1 in Houston, Texas—Report of the Subcommittee for VES

- 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.

Texas State Resources

Texas Veterans Commission: <https://www.tvc.texas.gov/education/>

- Connects Texas Veterans to higher education and technical training opportunities.
- Provides grants for general assistance, housing, and services.

VA National 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.

Additional Resources

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:

RAC-GWVI: Veteran Engagement Session #1 in Houston, Texas—Report of the Subcommittee for VES

<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>

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:

RAC-GWVI: Veteran Engagement Session #1 in Houston, Texas—Report of the Subcommittee for VES

- 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/>

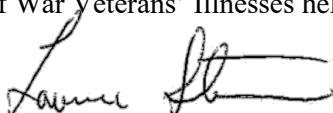
Veterans Treatment Courts: <http://www.courts.ca.gov/11181.htm>

- 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.

I certify this report is an accurate summary of the Veteran Engagement Session of the Research Advisory Subcommittee on Gulf War Veterans' Illnesses held in Houston, Texas, VA Regional Office February 5 and 6, 2019.



Lawrence Steinman, M.D.

Chair, Research Advisory Committee on Gulf War Veterans' Illnesses