Veteran Engagement Session (VES) Roundtable Discussion

Agenda

1:00 – 1:10 Roundtable Overview and Instructions

1:10 – 1:30 Roundtable Overview: VES Meetings

Houston VAMC:

Cleveland VAHCS:

1:30 – 1:50 VES Key Topic Reports

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

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

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

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

1:50 – 3:00 Veteran Attendee Experiences

• Chaplain Barrington Malcolm, Houston

• Randy Harrod, Cleveland

George Coates and wife Ruth

Brian Davis and daughter Haley

3:00 – 3:30 Discussion / Questions

RACGWVI Committee address VES

Audience address VES

• Phone / Facebook / other address VES

Larry Steinman, MD

Marylyn Harris

Kimberly Adams

Steve Hunt, MD

Karen Block, PhD

Bill Watts/Marylyn Harris

Larry Steinman, MD

Roundtable Guidelines

DISCUSSION FORMAT

GUIDELINES

- One question to allow others to speak
- Direct questions to the RAC Subcommittee and invited guests
- Questions in person, by phone, or submit in writing

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

DESIRED OUTCOME

A summary of suggestions/recommendations for the VA Secretary

Veteran Engagement Session Overview Houston VAMC

Marilyn Harris, R.N.

Gulf War Veteran

Subcommittee Member, RAC-GWVI

Lessons Learned--Houston

- Houston is the fourth largest city in the United States.
- The Houston area is home to over 300,000 Veterans, (Spouses and Dependents). The City of Houston has a Department of Veterans Affairs, a Houston (Harris) County Veterans Service Office and a State of Texas Veterans organization, the Texas Veterans Commission.
- The Houston area is home to over 30,000 Women Veterans. Texas is home to the largest amount of Women Veterans in the U.S., over 171,000 (2018, Center for Women Veterans).
- The Michael E. DeBakey Medical Center (VA Hospital) reports treating 113,000 Veterans annually. The Houston VA sits on 119 acres and is 3 million square feet. (Including the outpatient clinics in Beaumont, Conroe, Galveston, Katy, Lake Jackson, Lufkin, Richmond, Texas City, and Tomball, Houston VA outpatient clinics log nearly 1.4 million outpatient visits annually). Houston has 3 Vet Centers, one Regional Office and a National Cemetery (2019, Houston VA Website).
- Approximately 700,000 Gulf War Veterans were deployed during the Gulf War, over 30% are projected to have Gulf War Illnesses. (Attendees onsite at the Houston VES and others called in to discuss their current Gulf War Illnesses, conditions and questions).

Lessons Learned—Houston

(CONTINUED)

- Gulf War Veterans in Houston expressed feeling INVISIBLE, DETACHED from the VA System and expressed degrees of ANGER towards the VA.
- Gulf War Veterans in Houston do not have a "CHAMPION or Subject Matter Expert (SME)" to ask questions, receive or share Gulf War information, nor are they aware of a trusted portal to access information specifically for Gulf War Veterans (and their Families). *Gulf War Veterans report that Houston VA Clinicians never ask about their Service during the Gulf War when they come in for appointments. Gulf War Veterans expressed that the Houston VA Clinicians are not educated about the Gulf War and Gulf War-related Illnesses.
- Gulf War Veterans in Houston are UNAWARE of ongoing Gulf War Research. Houston VA, (and peripheral outlets, CBOCS, Vet Centers, etc.), DO NOT consistently post available Research Studies online or on bulletin boards/monitors. Gulf War Veterans reported that available Gulf War Research Studies discussed at clinic visits.
- Gulf War Veterans in Houston are skeptical about participating in research, getting treatment and/or unsure to pursue compensation for their Gulf War Related Illnesses.
- Some Gulf War Veterans, Military Family Members and VSOs are open to EDUCATION about Gulf War Veterans' environmental exposures and available Research Studies and Treatment for Gulf War Illnesses.

Veteran Engagement Session Overview Cleveland VA Healthcare System

Kimberly Adams, J.D.

Veterans Legal Advocate, United States Air Force-Desert Veteran

Subcommittee Member, RAC-GWVI

Takeaways Cleveland VES #2

Kimberly M. Adams, J.D.

Veterans Legal Advocate-Community Legal Aid Services

Akron, OH

United States Air Force Veteran-Desert Storm

Louis Stokes Cleveland VA Medical Center

- Provides Healthcare and Social Services to 112, 589 Veterans throughout NE Ohio (24 Counties)
- Has 18 Locations of Care including: 13 outpatient clinics (CBOC's), 2 community resource and referral centers (CRRC's), a psychosocial rehabilitation and recovery center, a chronic dialysis center, and an outpatient surgery center.
- Part of VISN 10 which provides services and support to over 685,000
 Veterans throughout the lower peninsula of Michigan, Ohio, Northern Kentucky, and Indiana.



Now... The Takeaways-Part I

- **Exposure Issues**: Exposures to Burn Pit and Oil Fire Residues, Effects from Anthrax, Botulism, and other Vaccinations Gulf War Veterans were made to take, Depleted Uranium, and Effects of Shrapnel in body.
- <u>Health Care Administration Issues</u>: trust, Trust, TRUST with the system, Ignoring our health and other concerns, No official recognition of Gulf War (GW) health issues, No recognition for exposures and denial of targeted care for Gulf War Illness (GWI), Lack of services for Pre 9/11 Veterans, and Lack of outreach to Gulf War Veteran Community.
- <u>Clinical Symptom Issues</u>: Concerns about genetic effects of GW exposures passed down to children, Too many medications prescribed vs more holistic therapies, Limited formulary for necessary medications (i.e. CoQ10), Inconsistencies of medications across VISN's.
- <u>Research Issues</u>: Explore intergenerational effects of GW exposures, Increased contacts and outreach to GW Veterans to participate in research studies, Provide travel and other supports to allow GW Veterans to participate in research studies.
- Education Issues: Disseminate research information to health care providers, Electronic Medical Record (EMR) needs to be updates with alerts and red flags for GW health issues, <u>MORE</u> Training for primary care providers about GW medical issues

The Biggest Takeaway... DESERT STORM IS THE NEW FORGOTTEN WAR!



Final Thoughts, Questions, and Thank You!

"Twenty-seven years later, Operation Desert Storm continues to be a shining example of 'getting it right.' We won that military battle by building international and domestic support through transparent diplomacy, having the clearly defined objective of liberating Kuwait and executing the plan with the world's besttrained military. This formula delivered a resounding victory on a scale we could never have imagined. I am very thankful that the National Desert Storm Memorial in Washington, DC will allow future generations to learn and draw inspiration from this epic event along with the brave men and women who made it all happen." January 26, 2018 James A. Baker, III

Secretary of State

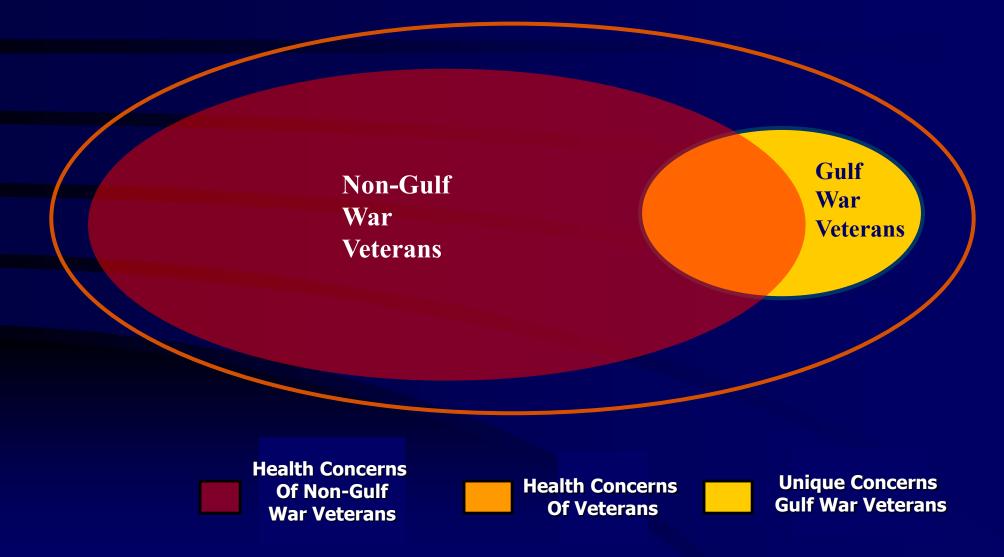


What health issues are of greatest concern to Gulf War Veterans?

Steve Hunt, MD.

National Director, VHA Post-Deployment Integrated Care Initiative

Health Concerns of Veterans



How can research improve the treatments available to Gulf War Veterans?

Karen Block, Ph.D.

Designated Federal Officer, RAC-GWVI

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

Bill Watts / Marylyn Harris
Gulf War Veteran, Subcommittee Member, RAC-GWVI

What would you like the VA Secretary to know about the health of Gulf War Veterans?

Lawrence Steinman, M.D. Chair, RAC-GWVI

To submit questions to the subcommittee and invited guests

PHONE

(800) 767-1750; access code 56978#

RAC-GWVI email:

varacgwvi@va.gov