

ROUND TABLE DISCUSSION AND RECOMMENDATIONS FOR VA RAC GWIRP
MEETING
28 APRIL 2016

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Recommendations:

1. The VA RAC GWIR recommend to the Secretary of the VA that he orders the VA get the DATA from the Social Security Death Data on a complete match of all Gulf War Veterans that served in theater to include Name, Age, and Cause of Death within 180 days. This full list should be made public and online within 180 days to 360 days.
2. A. The VA RAC GWIR recommend to the Secretary that the VA commissions a study concerning the health and symptoms of gulf war illness of Spouse and offspring conceived after the Operation Desert Storm of the veterans that served in theater. Timeline 180 days
B. The VA RAC GWIR actively seeks input from the spouses/family members of Desert Storm Veterans by way of the federal registry and an electronic questionnaire to be filled out on line. Timeline 90 days.
3. The VA RAC GWIR actively seek input from those that served in theater post Desert Storm but prior to 911 by way of the federal registry and an electronic questionnaire to be filled out on line within 180 days.
4. That a VA epidemiological study be commissioned for the deployed in theater post Desert Storm but prior to 911. The second VA epidemiology study would be for those post Desert Storm but prior to 911 that were not deployed but worked on equipment returning from the gulf war and received vaccines that gulf war deployed veterans received. These studies should have a timeline of 360 days.
5. The VA RAC GWIR should mandate that the Secretary of the VA initiate through cooperation with other agencies be it State Department and DOD to have active involvement with all coalition forces in order to gather all data and studies done in the past 25 years. This involvement must be activated with all coalition forces starting within 60 days.

An international conference should be set up within 180 days to meet in DC sponsored by the VA to bring all government, civilian, medical, scientist and biomedical professionals to share and compile a manuscript of all international studies that would be available on line to the public within 180 days.

The participants needs to include all relevant scientific professionals, researchers, public

health officials, and experts in all areas including but not limited to biomedical, genetics, neurology, oncology, etc.

The goal of this conference would be to involve all coalition partners of Desert Storm, the Saudi and Kuwaiti military and civilian health officials to share/review past studies over 25 years and studies currently funded within all agencies. The main objective would be to formulate future plans to develop cohort studies involving epidemiological and morbidity/mortality studies with 360 days.

A long term plan with timelines developed thru working groups identified at the conference and follow up dates in conjunction with the international conference to replicate any diagnostic studies and treatment studies that have been done by DOD CDMRP or VA Studies or coalition forces and host nations involved ie Kuwait and Saudi Arabia. The start date of these coalition replicated studies needs to be within 360 days.

6. The VA RAC GWIR should recommend that the Guidelines for Clinical practice should be immediately thrown away by direction of the Secretary of VA and Undersecretary for Health. The guidelines effectively addresses mental health and stress instead of physiological damage and preventive screening procedures for All cancers, neurological diseases, autoimmune diseases, Cardiovascular diseases, Hematology diseases, respiratory diseases, gastroenterology diseases, dermatological diseases, mitochondrial diseases, endocrinology diseases, infectious diseases and immunological diseases.

A separate committee should be establish for this task that includes veterans with medical backgrounds to be directly involved. All drafts must be available and subject to review and comment utilizing the Federal Registry. All meetings must be televised live as proposed also for the VA RAC GWIR in recommendation #8

Timeline immediately discard the Guidelines for clinical practice. Develop new guidelines within 180 to 360 days.

7. Recommend that the VA RAC GWIR activate the strategic plan for GWIR needs to be immediately utilized and followed without further delay.

8. The VAC RAC GWIR must recommend to the Secretary of the VA and to all within the VA headquarters that Communication and Education on to all levels of the VA from headquarters to the primary health care providers and adjudicators must be a priority immediately on Gulf War Research and all gulf war related programs.

The VA RAC GWIR must recommend to the secretary of the VA that all meetings of the VA RAC GWIR should be conducted using active live web conferences that include live video of proceedings and including veteran participants. This live web conference must be available to all veterans and VA facilities. This recommendation must be accomplished by the next scheduled VA RAC GWIR meeting.

The education being done thru the WRIISC education program should also be provided via live web conferences to all interested parties and to all VA facilities immediately.

Video recordings of all research or scientific presentations should be done and utilized by the VA on their VA Website immediately.

9. VA RAC GWIR must recommend that The Secretary of the VA mandates that All printed materials on Gulf war benefits, registries, WRIISC, and research studies VA AND DOD CDMRP must be sent and placed in every VA hospital, clinic, VARO, and VSOs offices should be provided the same materials to be freely distributed. A authority and accountability person at each facilities should be identified and named so that accomplishment ongoing can be fulfilled.

There should be one named person at each VA facility should be posted online and on site so that veterans can seek out a named person if materials or not readily available. That person's title should be gulf war illness coordinator.

Timeline for accomplishment within 90 days.

10. The VA RAC GWIR recommend to the VA Secretary that at one VA hospital ideally within each state a primary care doctor, nurse, social worker, and a gulf war veteran advocate be identified and trained to be the Gulf War Illness Expert team. (this has been previously suggested by DR Ashford WRIISC CA and veterans during VA RAC GWIR meetings and at listening sessions with veterans). This should be done within 90 days.

This team should be the ones to have listening session town hall meetings with the Gulf War Veterans and their family members with VA facilities representatives throughout the state to attend along with VA VARO personnel and VA health care providers. This should be timelined to start in 130 days and should be conducted quarterly.

The team should work with the WRIISC and Veterans input to define their role and duties within a 150 days.

11. VA RAC GWIR should recommend to the Secretary of the VA to have one central posting of all gulf war illness related meetings on one site on the official VA government website.

Timeline within 60 days. The person in charge of this needs to be identified and have phone contact and email address posted.

Additionally there needs to be one central calendar on the VA government website for all scheduled town hall meetings at all VA hospitals. Again the named individual to perform this duty needs to be named and phone and email contact provided . Timeline within 40 days.

12. The VA RAC GWIR should recommend to the Secretary of the VA that the team

identified in Recommendation 10 become the resource team and the trainers for train the providers within the state on gulf war illness. This team should then develop a plan to be published within 160 days on their plan to train the providers throughout the state. Education for this resource team must be mandated by the VA Secretary and Undersecretary of health and benefits. Education for the providers should likewise be mandated! Oversight for this function must be part of the Undersecretary of Health and Benefits role, responsibility, accountability and duties and with Gulf War Veteran involvement at headquarters and within each state. The training should be implemented as soon as possible but fully functional within 180 days.

Training should occur on an ongoing basis using video recordings, minutes, live video conference abilities, slide presentations, and be open to gulf war veterans to observe and take part in through public comment and participation. Documentation of those attending and dates should be recorded and noted in their job performance reviews and listed in public documents. Training should be at least on an annual basis with intermin quarterly updates.

13. The VA RAC GWIR must recommend to the Secretary of the VA that any meeting concerning Gulf War illness be totally open and transparent to including any working groups or coordination groups. Minutes and Presentations should be available on line to all. Timeline Immediate or within 45 days.

14. The VA RAC GWIR must recommend to the VA Secretary to immediately mandated that VA Research and Development involve veteran peer reviewers for any and all VA funded Gulf War illness Research Studies Grant reviews. Timeline 60 to 90 days.