

Written Testimony for Submission into Official Hearing Record for House VA Committee

Subcommittee on Oversight and Investigation March 13, 2013 Gulf War Care After 20 Years

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Good afternoon Committee members and Veterans. I am Montra Denise Nichols, Maj, Retired USAF NURSE, Gulf War veteran and Vice Chairman of National Vietnam and Gulf War Veterans Coalition. I am also one of the ill gulf war veterans. I have attended all but two of the VA RAC GWIR meetings except for 2, attended all the VA advisory committee meetings on Gulf War Health and Benefits, have attended in person or by phone the IOM NAS public meetings on GWI, served on the first DOD-CDMRP Peer review process at DOD CDMRP, PAC meetings, PSOB meeting, town hall meetings by OSIGWI meetings, CDC meeting in 1999, hearings on the hill and have testified in person or by written submission since 1994, and in addition have attended medical conferences that have direct connections to our illnesses. I have also participated in 8 research projects as a research subject for 6 researchers on gulf war illness. I also was listed as a coauthor on the Hypercoagulation peer reviewed paper published in 2000.

Over the last 22 years since our return home from Operation Desert Storm we have continued to advocate for all gulf war veterans that are ill. It has been a long trudge through this mass of activity and now our journey that seems to have a perpetual loop between VA, Institute of Medicine reports from the National Academy of Science, hearings here on the hill on an irregular basis, and the VA RAC GWIR. It is disappointing to say the least that the situation never seems to get on the Right Path to unify and address the real physical damage that veterans of Operation Desert Storm encountered after toxic exposures. The VA RAC GWIR and the DOD CDMRP has been the leaders in this effort to get answers thru real medical research to find the right diagnostic tests, biomarkers and finally real treatment options that are not palliative. The VA seems to be the road block over and over. The veterans of the gulf war are suffering because of the Actions of the VA or shall I say the INACTION. I have witnessed first hand how the VA RAC GWIR Advisory committee has labored since 2002 and have seen the intransigent activity of the VA. This is occurring at the top and seen clearly at the bottom re the clinical care of the gulf war veterans or the lack thereof and there is a problem that has not been solved for 22 years. I left the VA angry when my female hematologist primary care told me her hands were tied, and she even got tears in her eyes. I left because I both in the information on the hypercoagulation problem that I feel as a nurse can relate to early needless deaths of gulf war veterans who are ill. I had my own test results and she would not call the Drs and researchers that had done this study independently. They were concerned about my own elevated values and had suggested treatment that she refused to

consider. What really made me madder was when I found out the editor of that journal that published our peer review research was the head of the VA lab at the Denver VA the one I was going to for care. That was in 2000. Since then I have tried to go back to the VA and told during 2003-4 time period it would take 6 months to a year to get an appointment. I continued as many of us have to suffered and seek care when I could. I was lucky to have health care insurance through my husband but I lived in fear of loosing it if they the doctors deemed it war related. I certainly did not want to risk the insurance we had for my husband and my child. I struggle finding doctors that want to delve into this because they also do not have the knowledge on toxic exposure effects and they are hesitant to get involved when their might be government forces at work. I know the doctors that have suffered retaliation from the VA for trying to help, I know some of the researchers that are hesitant also because of that same potential, and we even had a county corner fired when she ruled a death of a veteran due to gulf war exposures. I have had a benefactor that helped several veterans get care through environmental medicine doctors, and I return to them when I can afford to travel and pay out of pocket for their fees and tests. I know of other civilian doctors I would like to get to but again it involves travel and cost factors. I was recruited for research at WRIIS at DC and received good research testing and caring doctors but yet they did not put me through the 2 day WRIIS protocol. I have said I will pay for my travel but I want to get thru that evaluation, I am being denied that until I can get back into the VA medical appointment system in Denver and get a doctor to refer me to WRIIS. And since what I got was research those test have not been entered in my record, I was told yes I failed the testing which to me was no big surprise. But it doesn't help with getting further care or a claim that is service connected.

I have participated in research projects and even recruited others to participate and know the researchers are finding clues and when their papers are published –those results will help hopefully to better diagnosis and treatment potentials. But when doctors are not being educated on those findings then the interface with research and care is failing.

We the veterans see the continued battles that have occurred thru the years. It is a shame and a disgrace that the VA has not taken the advice of the RAC GWIR. That interference has stymied for years the beneficial work of scientific researchers, doctors, and researchers. It has blocked actively the improvements that could of have been made over the last 22 years in the actual clinical care that could have made a difference in the quality of care, diagnostic abilities, and yes real treatment. And yes they could have saved countless lives of gulf war veterans that have died in an early age group under the age of 50!

I was one of roughly 20 fellow veterans that took part in the public meetings of the last IOM/NAS report. Each offered public comment and offered the IOM committee real insight into our situation. ALL of us were in anguish listening to their first public meeting that concentrated on the psychology-stress aspect yet again! After listening, then offering public comment, and debriefing with my fellow ill

veterans and spouses that were on line, I immediately called the chairman of the VA RAC GWIR, Mr. Binns. I wanted to give him our feedback, what had been covered, and our very deep concerns that this marked yet again a back tracking effort on the part of the VA that institutes the charter and guidance when they contract a literature review from the IOM/NAS. It was like all the work that had been done on gulf war illness research had not even been considered.

Our input seemed to not even be heard. These committee members I wonder if they have ever seen and cared for even 100 of the gulf war vets with the multitude of health issues. After 22 years and excellent research from outstanding doctors and researchers that had proven that physical damage has occurred to hundreds of thousands of veterans it appeared we were back to step one all over again. The IOM/NAS never ever in their hearings heard presentations from the doctors and researchers that have studied us or group of gulf war veterans to be able to comprehend their findings. This is wrong.

Their definition the IOM committee used is so broad that it creates confusion yet again. Patients that have had chemotherapy could easily fit the definition and have had no military exposures much less other categories of patients. This definition does not even have relevance to the definitions already being used for the RAC GWIR reports of 04-thru current year. They did not even utilize guidance that the DOD CDMRP process has used since 2006 in peer review and awarding of gulf war illness research. Their definition truly creates havoc in the work that has been developed by researchers over the past 10 years. The IOM NAS committee did not hear from the range of researchers that have been involved thru the years examples include UTSW Medical , Wright State, University of Miami, to name just a few.

Again and again the VA and IOM/NAS work seems to set us further behind in the goals to get better diagnostic testing of gulf war veterans who have suffered for 22 yrs. The goal of getting true treatment gets pushed back yet again. Right now we basically have COQ10(that the VA hospitals will not provide) and CPAP (used in sleep apnea) as real physical treatment. I put acupuncture and cognitive behavior techniques as supportive palliative treatment. As an analogy I would use a cardiac patient with significant blockages of the cardiac arteries that need stents/bypass/ medications being ordered to just use exercise, acupuncture, and stress reduction as their total care. The situation is dire.

More and more of the results from research are showing significant damage to the brain and the autonomic nervous system. This should help make sense of what health care providers are seeing at each VA hospital. When you have brain and autonomic nervous system and hypercoagulation of the blood involved it affects every other organ in the body.

The care of our gulf war veterans is impacted by the VA that still resists the significance of the damage done to hundreds of thousands of gulf war veterans. When the doctors and health care providers are not updated/educated on all the significance findings of this effort in research it is truly unacceptable. When the veteran patient/client is even providing hand carried copies of the reports and research papers to their health care provider at the VA and for those efforts to be ignored is truly showing some type of mind set to ignore, delay, and deny. The VA even when they have misspent money on conferences in the past number of years have not even focused on education for the clinicians on what is being found in research on gulf war illness and seeking to institute a true intergradation of research into the clinical practice of health care providers that are seeing the gulf war veterans who are ill daily. Legislation is needed.

The clinicians on the whole don't even know of the WRIISC and the referral method that shows you why most veterans give their health care provider a D or F in grading. The clinicians could also be asked to give feedback to the RAC GWIR or headquarters VA Health care on information and findings they are finding on their gulf war veterans but that is not done. There is no interface between the VA health care providers and the Researchers and Doctors that have worked with gulf war veterans in civilian or VA practice. This needs urgent action at the highest priority!

It is unconscionable to see that some gulf war veterans have found civilian doctors and resources that can do testing and help gulf war veterans but the majority of gulf war veterans cannot pay out of their pocket to travel and get to these doctors and pay those civilian doctors. WE know there are places like the Mayo Clinic that can provide autonomic nervous system testing but 99% cannot get that important testing. The VA has not had training programs or the equipment in order to perform this testing. There is now a commercially available test for the hypercoagulation problem that was first researched and published in 2000, and we have research currently on that area by Dr. Bach at VA Minneapolis on this topic. Again a critical need that could possibly save gulf war veterans lives from pulmonary embolism, cardiac incidents, strokes, deep vein thrombus, and other death potential diagnoses. Where is the priority to truly help gulf war veterans and get the diagnostic testing and lifesaving treatment? Legislation is needed.

Then we have only 3 WRIIS serving as second opinion but there are hundreds of thousands of gulf war veterans not getting the highest quality of care that should be available at each VA hospital or at least one in each VA region. The majority of the veterans asked said their VA primary care personnel had no knowledge of gulf war related illnesses and physical problems. The veterans that gave an A or a B were the ones that had gotten to the WRIIS or had struggled to get a change of doctor or a referral to a specialist like rheumatology. (these are still in the low minority , seeing that the WRIIS only see limited number of gulf war veterans(2 a week)) . When asked to grade the education of the providers on exposures and effects, gulf war illness, and care from the VA providers the grades given were predominately D and F.

Additionally care also involves helping the spouse or loved one trying to take care of the veteran at home. Unfortunately, although we served in Iraq as did the current OIF, OEF veterans no provision was made to cover caregivers for the Operation Desert Storm Veterans of 1990-91. A percentage of our veterans need that help too! The spouses are suffering and trying to be the bread winners of the family while caring for their adult veteran spouse that have become housebound to varying degrees. With the significant neurocognitive, the debilitating CFIDS, or development of MS, Cancers, or other devastating illnesses in a group of younger veterans below the age of 50 there needs to be consideration to including the spouses from 1990-91 who may still have young children school age at home(and some of these have developmental type problems.) The door to caregiver assistance needs to be consider for these cases including ALS veterans. Legislative effort will be needed to amend that law.

The need is there for the providers of health care in the VA to have the gulf war veterans seen by designated trained physicians at each VA hospital/clinic. WE need our gulf war clinics back that we had in the nineties. WE need to have support groups at each VA hospital for gulf war veterans and their spouses with care providers and social workers. WE need gulf war veteran task forces at each VA or at least at one VA hospital in the state to have the interaction that is needed to be heard and improvements made. Legislation will be needed.

WE need an active sharing of data on deaths, age, unit, cause of death and statistics in comparison to the normal non- military age groups. This is needed for our researchers and for us the veterans. This will need legislation.

WE need a robust accounting like we had with GWVIS data that is produced every three months. The data needs to show diagnoses and ages. Again researchers and veterans need this information. Legislation will be needed.

WE need to have you all reconsider registry for the family members that feel their symptoms are the same as the veterans. WE had that in the ninties but it was allowed to expire time wise. Again legislation needed.

WE need the VA to hire consultants in the area of environmental medicine and integrative medicine to be involved in updating the VA system in dealing with exposures effects. Again legislation will be needed.

WE need all data from the DOD declassified. It has been 22yrs and some of that massive data could possible provide insights into the potential causes. This may have a direct impact on our health. Again legislation is needed.

WE need newsletters that are not just PR pieces for the VA but informative and that includes all research findings and recruitment not just from VA research but DOD CDMRP research or other civilian research that might match conditions/diagnoses that the veterans are receiving. Legislation is needed.

WE need our records clearly identified as Gulf War in theater or non-deployed and unit assigned to in order to also have data that would show if particular units are more ill or have a higher death rate. Legislation will be needed,

Our veterans are actively seeking a means to relocate their fellow veterans that served in the same unit. There should be a means to help veterans to find each other to facilitate buddy letters if needed. And this would also assist our researchers. Legislation is needed.

The other item is to provide fee basis to get the testing that is commercially available ie hypercoagulation test . The need for autonomic nervous system testing that the VA cannot provide needs to be funded not only for those in the VA system but those other gulf war veterans not being seen at the VA. Specific legislation is needed.

There needs to be another time period extended for gulf war veterans that missed the initial time period allowed after operation desert storm or those that got fed up and left the VA and have struggled to find help in the civilian medical field. Currently I am living through that and have had a number of veterans communicate with me this past week of not being allowed in VA if they did not meet the means test. Much less those with insurance that they paid for being billed for health effects of service while they continue to try to get their claims through the system. Legislation is needed.

The VA still wants to label this with a name or diagnosis that does not even relate to military, war time, or hazardous exposures and that in itself is viewed as an insult to the veterans! The VA still wants to push treatment that centers on Psychological and stress, we deserve better. We started out with many VA gulf war clinics in the nineties and then they were closed! Legislation is needed.

The gulf war veterans when they try to discuss their exposures and relationship to their service and effect on changes in their body systems with their health care provider they are verbally or nonverbally shut down. We gulf war veterans have guided other veterans experiencing these problems to ask for change of doctors or provider at VA and we have provided the education to the veterans about the WRIIS program and guided them to inform and educate their doctor of the information on the VA's own website about the WRIIS and how the doctors are to refer them electronically. Legislation is needed for mandatory CME education for our health providers seeing ill gulf war veterans. Legislation is needed.

We have provided the flow of information even the actual research papers and RAC GWIR reports to our fellow gulf war veterans and encouraged them to share it with their VA health care providers. We have done the outreach to the veterans not the VA, we do this as our continued duty to each other as former military personnel that do care for each other even when we have not met them in person. WE listen and read what they are experiencing and their frustrations at getting sicker and having less quality of life and do our best to try to help our fellow gulf war veterans even as we are also ill and struggling to get care that we deserve.

WE have tried but as you see after 22 years we need firm legislative efforts and laws that will be enforced to make a difference!

And most of all the VA RAC GWIR needs to be recognized and VA must be held accountable for their intransience that has led to poor diagnostic testing, biomarker development, care and potential breakthroughs for treatment. This must stop. And the cycle ongoing between VA and IOM NAS must be but under great scrutiny.

WE also need hearings more frequently with the House and Senate VA committees. I suggest joint hearings to elevate the priority and to gain unity on the hill on this effort. I also suggest that other gulf war veterans and a few spouses be allowed to testify to truly give more insight to our elected representatives of what we are living through. WE also need an ongoing VA advisory committee on health and benefits for gulf war veterans in law so it is not a one time 18 month advisory committee. These issues need just as much attention as the Research. Legislation similar to the legislation that set up the VA RAC GWIR is needed. Until the situation is improved we need this effort. WE need transparency and reports publicly available for any and all Task Force activities concerning gulf war veterans' illnesses that VA has conducted! Please legislate and enforce these efforts so direly needed. Our claims are likewise in poor condition because VSO's and VA rating officials have not been trained to adequately deal with the claims of gulf war illnesses. WE need urgent help 22 years is too long to have waited.