

Testimony for House Veterans Affairs Committee -Subcommittee Oversight and Investigation
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I am Montra Denise Nichols a Desert Storm Veteran and Gulf War Illnesses Advocate from 1992-2017 and giving testimony which gives the overview of the problem with gulf war illnesses claims. In order to cover this issue, one must understand it starts with when you walk in the door at VA seeking care and help. Our issue started with changes in our health and then progresses to benefits i.e. claims for compensation and answers and treatment which is now being found in research.

Since 1991 when we return from our service in Desert Storm, our group of veterans have been suffering without adequate health care and effective claims service. This has continue for going into our 26 year of returning home despite hearings, legislation, advisory committee on benefits, advisory committee on gulf war illness research, IOM contracted studies, GAO studies, countless committee hearings, countless meetings and task forces, and legislative actions leading to public laws but here we are still feeling as though nothing has changed! It appears DOD has not totally been forth coming to help and VA care and benefits has us feeling like third class citizens. Many have tried, many have given up, many have died in a younger age group than should have normally occurred to a group of service members that went into service fully healthy and accepted physically the only intervening factor was our service in a war theater during Desert Storm. Many years ago we had a law put in place to cover the undiagnosed illness, the chronic multi-symptom illnesses, chronic fatigue syndrome, fibromyalgia, Irritable bowel syndrome and numerous other health complaints as presumptive conditions. Still after all these years the VA Benefits, Compensation and Claims process is broken as each GAO study has documented. Others today in person and in written for the record testimony will discuss in detail with examples given from members of our community of veterans.

But in order to really understand the problem I believe you need an overview of the total problem that we Desert Storm Veterans have experienced because it all ties together one leads and impacts the other area of the VA. We in our overall community believe our government we swore to defend has not lived up to the due care and benefits earned by the giving of our services and our very lives. TOO MANY of our fellow veterans have died prematurely from Cancers especially brain cancers, heart disease i.e. Myocardial infarcts, pulmonary embolisms, and neurological conditions none of these have been added as presumptive conditions. They have been left without adequate care, no compensation for them or their surviving spouses, they have become homeless, families have broken over the health and financial distress, and some have given up leading to suicides. All of this has happened due to all portions of our government failing us the veterans of Desert Storm. This is totally UNACCEPTABLE and must have immediate real action no more promises, no more words, no more denial, no more ineffective responses, and no more excuses.

Others today will testify in person and on submissions for the record on details of the claims for desert storm veterans situation I am here to provide a total overview of the problems that have occurred and the total interwoven situation from our service in theater to approaching the VA for care to seeking answers and effective, appropriate treatment, to getting research that should answer the physiological damage done and methods of real treatment, to how the total government system has failed, to how care and documentation from VA health has direct implications to our claims and benefits, and how legislative efforts have failed the Desert Storm Veterans. This has impacted 1/3 to 1/2 of us Desert Storm Veterans. Many veterans took the systems missteps and gave up. Many were suffering quietly having been trained not to be gold brickers and not to complain. They struggle valiantly and heroically to go on and try to reach their own personal professional goals and to maintain themselves and their families. They gutted up ignore the symptoms and did not want to appear weak. Those that spoke up or continued pushing faced huge odds against them. Many were left in the dark totally and did not know to question and keep seeking care and help. Most of all they wanted to live their lives and not to be disabled and warrant a compensation. Many wanted to stay for a full 20 years or more in military service to their country and hid

their concerns in order to struggle on and serve in the intervening years and deployments into war time environments adding more exposures to their weakened physiological bodies.

This whole situation starts with inadequate records, maintaining military active records from in theater, inadequate maintaining of logs from headquarters down to lowest level of units on location changes, vaccinations given, preventive medicines recorded in individual records, inadequate and erroneous measurement of exposures levels at multiple locations throughout the theater. Then inadequate documentation of medical concerns of the symptoms as they occurred both while on active duty status and upon leaving the service. The majority of troops were kept in the dark on information on exposures and what symptoms they needed to report i.e. any changes they had in pre-deployment, deployment, redeployment home, and later throughout post-deployment for 26 years.

There was no SOPs to medical personnel to truly take complete physical history details, documenting locations and specifics of duty positions that may be factors to consider, no physical assessments were done completely in evaluation of exposures documented or undocumented, medical personnel were not educated on exposures potential or what symptoms to assess and report in medical records, vaccine records went missing, medical items were not documented, the standards and regulations of maintaining all documents from every level of command were neglected.

Non-documented verbal directives seem quite realistically to have been given to turn a deaf and mute response to our concerns when we returned. Some doctors at the VA even said they could not help or their hands were tied. I know this lead to professional dissatisfaction to many of these health care providers. But MUM was the Standard operating procedure or else they were left totally uninformed due to the DOD actions. A few VA physicians and civilians researchers stood up for us since the beginning many were disciplined in many ways or found themselves out of jobs for speaking up. If they weren't told, or given written information, or given documentation from the DOD that VA accepted, or educated -then that was just it. WE as veterans would end up and continue to surmise the why. Was it money, budget, cover, negligence, geopolitical, personal reputations of our leaders, politics, just ignorance, or blind obedience to orders not valuing the service members health and wellbeing, or even our commanders in the field and supervisory ranks also affected by the ill effects of exposures that their abilities and common sense were affected and degraded their leadership and responsibility to their troops.

Have no doubt they have suffered for 26 years now. They have been treated with no honor, no care, no celebration of their service. They have been treated as third class citizens not as valued service members and war time veterans. Their service is forgotten in every national veterans ceremony or memorial day ceremonies.

Another factor is inadequate education and knowledge to health care providers both military, VA, and civilians in regards to each exposure or multiple exposures with synergistic and overlaying physical damage. (whether documented and acknowledged by DOD or not!) None of the doctors and health care providers have ever had education in medical schools, internships, residencies, continuing medical education, or medical conferences, or in VA employment as mandatory training on our exposures or the greater area of military toxic materials and the effects thereof to physiological body systems. The majority of health care providers are whole fully uneducated on even our presumptive conditions of chronic fatigue syndrome, fibromyalgia, Irritable bowel syndrome, or the mirage of our other health problems listed under ill defined chronic multi-symptom or un-diagnosable conditions. WE still get health care providers that get that look like a deer in the headlights, or how fast can They turf this to mental health and behavior medicine, or how can I avoid the veterans questions, or avoid real concerns, or avoid the good patient doctor communications, or how fast can I get them out the door. WE take in research articles and reports to help give them the info and tools but they are too busy and not required to receive and read and question. They do not even seem to know what information is available if they pull up VA gulf war health, WRIISC, VA RAC GWIR, gulf war public health information on the computer sitting in front of them. They just follow the template as provided by VA on medical documentation for a health visit.

The battle on a term for diagnosis for us and definition has been talked about for 26 years! Name it gulf war illnesses or military toxics conditions define it by symptoms and findings so far in research and give it a code and use the code! Quit running around in circles and in the process denying our physiologic changes and symptoms and denying claims for whatever purpose or reasons. You disrespect the veterans service totally and do not give the veterans any benefit of doubt that was caused by all the factors I am covering in this testimony. You Dishonor our service and sacrifices. You do not give due trust in the honesty of each veteran. A result of that loss of trust it leads to future generations of civilians questioning joining the military if their health and lives are not protected and given full priority attention and benefit of the doubt!

The first step was a Gulf War Registry that became a rushed questionnaire and very brief physical with very little physical assessment except yep breathing, pulse, Bp. No full physical, no complete detail history taking, no documentation of what the job was that the veteran did and what exposures needed to be documented i.e. fuels, tanks, flight duties, sanitation practice, noise levels exposed to, medicines, vaccines given in theater, where were they located from entrance to exit from theater, what unit and type of unit, what did they handle, did they handle dead bodies or injured EPWs or friendly casualties, or casualties showing symptoms, what symptoms no mater how slight occurred and when, what did they take note of in theater?, what did they observe as strange, what has changed head to toe.

No neurological exam, no follow on consults re sleep study, no referral to dermatology for skin samples are just a few examples. No history taking on changes noted in memory, multitasking, comprehension, executive management tasking, change of IQ, school or duty performance impacts. They did not document exposures to oil fires smoke and follow up with complete respiratory function test and challenge substance respiratory functions. No EEGs, EMG, no assessments by specialties like immunology, endocrinology, infectious diseases, otologist(hearing) testing, no visual acuity testing were some of the items neglected.

If you are going to do a registry then a full, complete, through history, complete physical, complete testing of blood hematological, immune factor, neurological transmitters testing, virus, infectious testing, viral testing, testing for endemic diseases, complete urine testing for Depleted uranium, metals and known toxins like a forensic toxicology screen must be done.

These tests are needed in relation to confirmed, suspected, or unknown toxins.

The registry records were never maintained from the start and data collection has been missing.

The early specialty centers set up for gulf war veterans by the VA, the early CCEEP by the military, and the follow on VA WRIISC were more complete in this aspect but the majority of veterans who had symptoms were not able to obtain these services. These services would have provided much more in depth evaluations and testing and medical reports to assist in the later application for claims and compensation from the start.

The health care within the VA for Gulf war illness and exposure assessment and medical reports is totally lacking on the physical symptoms and changes that occur after exposures to any military toxic exposures. The difficulty experienced in getting the diagnoses of Chronic Fatigue Syndrome, fibromyalgia, and irritable bowel syndrome that are so prevalent much less the other complaints and symptoms addressed in the regulations is another problem that has not been solved. Again the Doctors and health care professionals in the military, VA, and civilian health care areas do not receive education, continuing medical education, and training in military toxins. I wonder why when service members receive training in NBC why is the medical profession so lacking in knowledge? This is not covered in curriculums for medical schools, internships, or residencies.

The total emphasis on claims should be focused on Desert Storm Veterans and gulf war illnesses because we happened prior to 911, OIF, OEF, etc, or the world trade center exposures. WE have waited too long! Where was the preparedness planning for medical professions? What if this happened within the continental US with massive civilians exposed? Would the medical professionals know what to do? In the GAO reports they state 1.1 million claims and 40% with claims. How many of those are Desert Storm Veterans? Many Desert Storm veterans were also Vietnam Era and mistakenly listed under Agent Orange, yes we have documented cases of that too! And why does the GAO not include every VARO in

their reviews why only a small number of VAROs are reviewed to get a really complete review? Why not pick out those with high rates of approvals and find out the best practices?

Without adequate Gulf War Registry Exams and with VA uneducated health care providers providing our health care then adequate medical records and medical progress notes and medical testing is interwoven in the failure of successful claims adjudications ! The proof is in the medical records, progress notes, diagnoses lists, medications list, laboratory studies. Without proper mandatory training, education , CME and credentialing and Standard Procedures(SOP), standing orders it was destined to fail us the veterans in our claims process. The requirements of proof and documentation is the necessary steps for a successful claim. WE can not meet the requirements needed when we deal with VA Benefits/Claims.

Without the right credentialed specialists Drs it is next to impossible to get the presumptive conditions diagnosed. Then the VA thru the Choice or fee basis programs for Desert Storm Veterans to get to experts in the civilian medical profession does not work. When the Desert Storm Veterans do go on their own expense to civilian experts i.e. Rheumatology, Immunology, Dermatology, Neurologist, Endocrinology with definite expertise and credentialed by specialty boards then the C and P examiners and VA adjudicators ignore these experts diagnoses, history, medical testing, and DBQs. The doctors at the VA may diagnose but out right refuse to fill out DBQs for the veterans to help aid in the claims process.

The medical providers, C and P examiners, and VA adjudicators need mandatory and credential training to handle Desert Storm/Gulf War illness/ military toxins issues. We were told by VA headquarters personnel that all the adjudicators and examiners would receive mandatory training! They lied to several of us. The GAO study proves that fact!

The WRIISC staff at Palo Alto has done some clinician training both in person and by web training. How many no one seems to have a full data collection on that aspect. This has been a very small number I am sure. Again No mandatory education has been done! The scheduled session by phone and computer web is not known about at all by medical professionals at each VA hospital much less the clinics. The VA care providers have no knowledge on what WRIISC is, what they provide, how to make referrals, how to find all the basic educational materials and brochures, pamphlets, newsletters, magazines that the WRIISC have developed. These materials are seldom if ever seen in the VA Waiting Rooms or Doctors offices! The veterans get educated by other veterans of where to find these materials and they hand carry the info to their doctors. Then if they are lucky and do get referred the doctors at their home VA have problems with follow thru with the results and suggested plan of care. Again the documentation by WRIISC can help significantly in the success of claims being approved due to their documentation.

The VA RAC GWIRP since the turn over of committee members started under Secretary Shinseki, then McDonald has deteriorated that advisory group. The Presentations are not 100% applicable to what the mission of the RAC is. There are no short term and long term goals for each presentation made to the VA RAC GWIR. The RAC went to San Francisco a year ago but did not seek a presentation by Dr Golumb at UCSD and VA SD who is a prior committee member and gulf war illness funded researcher! When they went to Boston on their last meeting the funded DOD GWIRP Researchers at BU and Mass General were not invited to present past and current research findings on GWI.

Personally, I have communicated in writing and verbally at each meeting and to their staff coordinator the shortfalls of the RAC as the veterans see them. They do not provide full interactive video conferencing of their sessions. The example role model would be the HHS Civilian CFS/ME Research Advisory Committee which has excellent web based audio visual interactive meetings. They do not provide printed notebook materials for the attendees to reference even on a back table.

I have suggested and encourage the committee to consider and use VA facilities auditoriums like at Minneapolis VA where we have had MEG research studies done and hyper coagulation research and a treatment trial occurring! I suggested using Miami VA or the medical universities there to have DR Klimas and Roskamp Institute to review their funded gulf war illness research that is finished and ongoing. But no to that too. Then there is a Stanford University Researcher expert in civilian CFS/ME research and now

funded at University of Alabama Birmingham for a gulf war treatment trial research. Then there is Salt Lake City VA funded studies on treatment trials for IBS. Then there is the gulf war illnesses researcher at Georgetown Medical University here in DC another expert in civilian CFS/ME that I recruited who has had funded GWIR studies on MRI DT, Spinal Proteomics who has not been invited to present to VA RAC GWIR when in DC for their meeting.

Why are we not using VA hospital auditorium and the Medical Universities that are directly involved with VA hospitals as facilities for these RAC meetings. Certainly it would help cost wise much less drawn in more experts in the Medical Universities and their students! WE need the different locations throughout the country utilized so more veterans, Drs, researchers, and medical universities can be involved to further research and get answers and help to Desert Storm veterans. I would give the VA RAC GWIR at D in grade. All of us that fought for the introduction and passage of the law for the VA RAC GWIR and served as members of the committee or as attendees to the meetings have been distressed by its decline in productive goal and mission directed fulfillment. WE need a new RAC on a different set up model and covering military toxic exposures.

The VA is still looking at our gulf war illnesses as a psychological and Behavior Problem or Mental health problem. They are treating with anti-depression medications and psychological medications. Many of these have side effects impacting further our immune system of the body. They frequently are using multiple anti-depressant drugs at a time for a patient. And to use these drugs as pain control is not appropriate. Some of our Desert Storm veterans have been diagnosed with bipolar disease but never evaluated by MRI DT or MEG or other advanced neurological techniques. Is it possible that they have been misdiagnosed?

Genomics is what is needed NOW. That is the direction we are headed in many areas of medicine to include Gulf War illnesses. Dr Klimas, Golumb, DR Baranuck(Georgetown) and the researchers at Minneapolis are headed now in that direction! The VA MVP could recruit more Desert Storm Veterans rapidly and make that a priority now on GWI. Then we can rapidly move to individualized genomic treatment and in the process have more definitive evidence for the claims proof.

Serotonin and neurotransmitters have not been tested on Desert Storm veterans that would provide more definitive proof of physiological damage and symptoms of gulf war illnesses. Again this would provide more definitive proof for claims to be approved. Dr Terry at the VA has mention the neurotransmitters as being key to Gulf War illness but no testing or data is available because that has not been done.

Again, areas that could provide proof of exposures and physiological damage that could help with diagnose, proof for claims, and treatment avenues has not been meeting the urgent need. The other is that of biomarkers coming from the animal models and correlated with biomarkers from a small sample size of ill Desert Storm veterans that matched! Again proof from the desert storm veterans physical bodies that show exposures and proof that could be used individually in claims or by extending the benefit of the doubt rule. These developments in biomarkers and genomics can lead to true treatment of Desert Storm veterans.

There has been a lack of coalition forces' governments to interact in solving the medical problems and compensation issues. WE had UK veterans attend RAC meetings to take an active role by fellow Desert Storm veterans to set an example for the RAC but so far no action taken by the RAC to seek out known experts in coalition countries.

There needs to be an urgent priority by all entities in the US government from legislative branch, to health care VA and Civilians, to researchers, and to VA Adjudicates on the Gulf War illnesses. WE have not learned from the past of WWI, Atomic Veterans, Agent Orange Veterans, Gulf War Illnesses Veterans, the WTC contaminated responders, Camp Lejune Environmental exposures, Pesticide exposed agriculture workers, and other toxic environmentally contaminated military bases. There has been no Standardized Operating Procedures, standing medical orders, regulations, education, training, credentialing of all that were needed to be involved. Failures in the areas of documentation, tracking mechanisms, effective leadership and management at all levels that have direct impact on the effectiveness of claims adjudication and thus failure approval of claims at a higher percentage.

Who is hurt most? The Veterans! It has been evidence that 26 yrs of effort has failed not only in health care documentation but equally assuring the claims process is fair, rapid, and effective to serve tens of thousand, even hundred of thousands of Desert Storm Veterans.

WE need Toxic Exposure centers in each region of the country located close to VAROs. If doctors give a presumptive diagnosis there is no excuse for denial of the claim!

It seems to all of us Desert Storm veterans that it is the saying: Same ##### Different Day. What is need is SOPs, Leadership, Expertise, Outstanding Management, Creative thinkers and researchers to truly be effective and solve the problems for Desert Storm Veterans with Gulf War Illnesses. Enough delay has occurred!

WE hold all US Representatives, Senators, DOD officials, VA officials from every VA area, VA Headquarters, VA administrators, each VA hospital administrator, chief of medical staff, VARO director, and VA claims adjudicators, each committee or entity that has been involved as failing to provide for the health and well being in all ways to those Desert Storm Veteran dealing with Gulf War illnesses both with presumptive categories and yet to come the diagnosable illnesses/diseases that are leading to early age based diseases death rates.

I say again it is all interconnected and interwoven failures that have led to the extremely high denial of claims for Gulf War Illnesses and to correct this problem all areas have to be reviewed and revamped now. I hope my testimony offers you the overview of the interconnected failures. One of the reasons I pushed to cover the overview is because US Representatives and Senators change every election cycle and many elected after 1991 do not have the institutional knowledge of the problems and delays we have faced. New doctors and health professionals enter the profession, the military, and the VA constantly and are not aware. New VA claims adjudicators and new C and P examiners get hired without adequate or mandatory training.

WE need new legislation and laws now. No more delays fix this problem as the highest priority that it truly deserves.

Look at our past lessons in exposures in war and compare presumptives by war and exposure similarities and really look to the urgent need to add Brain Cancers, other cancers, myocardial infarctions, pulmonary emboli , hyper coagulation resulting connections, neurological diagnoses, immune-endocrine related diagnoses, Parkinsons Disease, early appearing Althemizers Disease,, and many other diagnosed conditions.

It is wrong to deny claims and leading to widows and widowers left high and dry after living thru their veterans deterioration and deaths. We veterans know each other and see those left with nothing due to serving this nation and having one of those life altering diagnosed illness in too early of an age group compared to like population of civilians at different age ranges. Maybe review the 911 workers at the World Trade center program and legislation as a model to follow.