

TESTIMONY OF MONTRA DENISE NICHOLS

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**To THE INSTITUTE OF MEDICINE
TREATMENT OF GULF WAR SYNDROME
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Good Afternoon,

I am Denise Nichols, Vice Chairman of the National Vietnam and Gulf War Veterans Coalition. I served in Operation Desert Storm as a Nurse and was located on the border of Saudi Arab and Iraq. I have a master's degree(MSN) and 20 plus years of nursing experience. Sadly, I have had to retire from active nursing due to my health changes since the war.

Since 1992, I stepped forward to work on the issue of Gulf War illnesses. I have testified, networked with other gulf war veterans stateside and internationally, networked with doctors and researchers, and educated congressional and senatorial staffers of the problems that gulf war veterans are experiencing.

The testimony today is to talk about treatment options for gulf war veterans. But, in order to treat Gulf war veterans, one must first diagnosis them appropriately by doing a complete and comprehensive physical examination and order appropriate diagnostic testing directed towards neurological and immunological abnormalities This is NOT Being- Done!

The VA and Military Comprehensive examination is faulty. I have included in my testimony, a copy of the comprehensive examination protocol being utilized at the VA and military medical facilities. You will not see any of the speciality tests that have been identified as markers of the damage we gulf war veterans have experienced in this protocol. The deficits that we are finding is that they are not using appropriate testing such as Spect Scans, Viral screening, specialized MRIs, and specialized testing by means of laboratory tests that can show the damage to the neurological and immunological systems of the body. Tests that have been documented, published, and testified to the Shays Government Reform Committee, Presidential Advisory Committee, Presidential Oversight Cormmittee (Dr Ari Vjordani), IOM, CDC, and other committees by Dr Ari Vjordani, Hailey, Baumzweiger, Callender , Hyman.and Nicholson are not being ordered for all veterans of the Gulf War through the VA hospitals or any other military hospital. Dr Nicholson's tests and treatment for mycoplasma infections is currently in research for a limited number of the gulf war veterans as is Dr Hymen's. I am asking why at least the testing for these infections has not been instituted for all Gulf War Veterans? Even widespread testing for Leischmaniasis has not been performed.

These tests are the ones that are consistently showing the immunological and neurological damage not only on the deployed ill gulf war veterans but also the nondeployed but deployable ready veterans who are showing the same symptomology.

How do we fix this glaring disconnect? It is CRITICAL that we do so immediately, Because until all available laboratory and diagnostic testing are performed for each veteran who has reported in ill, we will never get diagnosed

We need this committee to immediately report this problem to the full chain of command and request that all comply throughout the VA and DOD medical system. Until this is done, we will all suffer from inadequate physical assessment and omission of appropriate diagnostic procedures and coding leaving the gulf war veterans in a true Catch 22 position. We can not move to treatment until the system is corrected throughout.

The tests that are being shown that prove the damage are avoided at all costs by the government. The research findings that are being found for example Dr Hailey's findings are not being utilized or included in the workup provided by the VA or DOD. The independent testing that has found results from Dr Baumzweiger, Dr. Ari Vjordani, and Dr. Berg is not being funded or utilized in anyway to assist the Gulf War veterans to even get adequate diagnosing. SPECT Scans as documented as useful by Dr. Callender and other doctors are not being ordered for the veterans seeking care at the VA or military medical facilities.

Neurological, Immunological, viral testing, urine testing (Dr Hymen), mycoplasma testing are all being avoided. Is this medical malpractice? Omission of appropriate diagnosing and care and ignorance of published medical testing could very definitely be considered malpractice.

In Feb 1999, at the CDC conference on Gulf War syndrome, Dr Bill Baumzweiger was asked by the Georgia veterans to examine a veteran who had been special forces and led the way into Iraq. Dr Bill Braumzweiger agreed to perform a physical assessment of the person in his hotelroom. What I observed then and numerous times before and after that session, was no hocus pocus it was a detailed history taking and a detailed physical assessment with particular emphasis on the neurological system. This veteran like so many of the tens of thousands of veterans showed clear and unmistakable neurological damage. When the assessment was completed, I asked the veteran if he had gone through the VA system to get help. He replied yes to three different VAs with three different neurologists but NONE of them had done such a detailed and complete physical assessment.

I myself can validate that this in fact is true. I have tried through the VA to receive diagnosis and care and what occurs is a very minimal physical assessment and no referral to specialist in the fields of neurology, immunology, infectious disease, rheumatology, etc. I have had to send my blood off to speciality labs throughout the

country to get answers. I have had to go independently to get a Spec Scan. All of these have shown definite physical abnormalities.

I have those reports with me today for each of you to review. These tests results show simultaneous immune suppression and autoimmunity not characteristic of most diseases studied in medicine. These findings were originally theorized and found by Dr Bill Baumzweiger and validated by Dr Hailey's team in Dallas, Texas where a full medical university has been activated to get to the true diagnosis of gulf war syndrome. The SPEC Scan demonstrates the damage that is consistently being found on these veterans that shows immunologically caused coagulation perfusion problems. The Specialized MRI MRS being done by Dr Hailey and Fleckenstein lends even more documented data to the brain stem damage that we gulf war veterans have sustained. Unfortunately, I have not been able to obtain that study yet.

I have taken these same results in to the VA Primary Doctor that I have and that Doctor refused to study them or to get in contact with the Drs or the lab research specialists that provided these tests even when given the names and phone numbers and directly asked to contact them and discuss the findings in order to better provide care not only to myself but thousands of other gulf war veterans who are suffering. This VA doctor without even studying the tests results said: Oh you can get SPURULOUS Lab Results. The VA Doctor instead ask me if I would like a referral for a psychiatric consult but no referral to neurology or immunology.

I have physical medical damage to my body and this is what an educated injured retired gulf war veteran medical professional gets as far as diagnosis and treatment?

This is the evidence of the nonwritten VA policy to do nothing, to not pursue independent medical assessment ideas and thoughts, to not find or even consider looking for answers to the diagnostic needs of gulf war veterans.

It is outright medical malfesance to allow at least 220.000 veterans to walk around begging for help with this extensive of neurological immunological damage. How would you like to live with the effects of this damage? Overwhelming debilitating fatigue, memory problems so bad that one of my veterans couldn't even remember his wife of 20 years name, memory and visual problems that force veterans to not be able to drive or participate in normal life functions, decreasing mental intellectual abilities, irritability and lack of understanding from family, other friends, or health professionals, and absolutely no support mechanisms in place!

This is criminal neglect when testing, appropriate diagnostic procedures and physical assessment, and treatment could effectively be saving lives and improving their functional abilities. So help us now to make a huge change in the system and become proactive with us in calling for these appropriate actions with funding to be made available immediately not in ten more years. Make these tests and diagnostic

realities commonplace in every VA and military facility for every gulf war veteran. We can do this with this IOM's committee's report. Shorten your deliberations and study techniques and cut the bureaucratic government foot dragging denial approach. Rise up, to the moral and ethical duties and DO IT NOW.

We also need to consider the veterans who were nondeployed to theater but deploy ready who are ill that Dr Baumzweiger and other doctors have evaluated and performed diagnostic testing that show they too have physical damage. We need to examine those who have received the anthrax vaccine or other vaccines and reported reactions and ill health consequences. Every committee we have had involved pointedly avoids considering a vaccination related problem. WE urgently need this put on to the list as a number one priority in order to STOP more troops from becoming ill.

We also need to aggressively get answers to the problem of transmissibility to family and close friends... it is absolutely outrageous that the government has not approached this as the number one health problem since the war. Also we need to address and find answers to the question that the gulf war veterans both male and female are experiencing sexual functional abilities disruption.

These are critical issues! It is a wonder that more violence has not occurred with this group of veterans that have been so poorly treated over the last ten years. We are not study guinea pigs we are real live people that put our lives on the line for our country.

It is not right that our family members that have become ill who did not sign that same contract as we did are not being more directly assisted.

Those of us who are ill consider the number one priority to be finding appropriate testing (diagnosing) and treatment to correct these problems. WE are the ones that have taken a proactive stance in order to teach you the lessons learned. It is not the DOD or VA that is leading. We have done this by paying out of our own pockets to get these tests. The costs for tests may run to an estimated 5,000-10,000 dollars for each veteran. But this sure appears to be much cheaper than the millions of dollars spent on research funded by the government designed in the wrong direction, designed to find no association or help, and designed to protect the status quo.

While this delay continues, more veterans are becoming more severely disabled, losing jobs and family, filing for bankruptcy, filing for disability, and yes Dying. We received news the other day that veterans who served in Kosovo and Bosnia will be studied for

20 years for changes in their health. Is this any different than the Tuskegee Syphilis study that our nation has finally acknowledged? What are the other costs to name a few: loss of fully functional individuals that could be producing economic income instead of being a debt burden, loss of confidence and trust in the Government we believed and served, and loss of personnel for recruitment and retention for our

government's military services. The choices now seem to be squarely in the face of the IOM to set the government straight and to correct the errors of the past. We hope you stand up and start issuing immediate reports to the chain of command that brought us all here today in order that this deplorable situation can immediately be rectified.

Thank you and I sincerely hope that each of you on the committee have questions for me and others today, so that we can have a true open exchange of information and scientific inquiry today and make that huge turn that is so desperately needed.