

# GULF WAR: WHAT KIND OF CARE ARE VETERANS RECEIVING 20 YEARS LATER?

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HEARING  
BEFORE THE  
SUBCOMMITTEE ON OVERSIGHT AND  
INVESTIGATIONS  
OF THE  
COMMITTEE ON VETERANS' AFFAIRS  
U.S. HOUSE OF REPRESENTATIVES  
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## **GULF WAR: WHAT KIND OF CARE ARE VETERANS RECEIVING 20 YEARS LATER?**

**Wednesday, March 13, 2013**

U.S. HOUSE OF REPRESENTATIVES,  
COMMITTEE ON VETERANS' AFFAIRS,  
SUBCOMMITTEE ON OVERSIGHT AND INVESTIGATIONS,  
*Washington, D.C.*

The Subcommittee met, pursuant to notice, at 3:45 p.m., in Room 334, Cannon House Office Building, Hon. Mike Coffman [Chairman of the Subcommittee] presiding.

Present: Representatives Coffman and Kirkpatrick.

### **OPENING STATEMENT OF CHAIRMAN COFFMAN**

Mr. COFFMAN. Good afternoon. I would like to welcome everyone to today's hearing titled "Gulf War: What Kind of Care Are Veterans Receiving 20 Years Later?"

Yes, it has been over 20 years since the Gulf War. I remember it very well, having been there myself as a Marine Corps officer. Now, as Chairman of this Subcommittee, I am asking the same questions many fellow Gulf War veterans have; namely, how is this unique set of veterans being treated by the VA?

While it may be pretty easy to determine whether a veteran served in the Gulf War, it has been difficult for some time to accurately identify what constitutes Gulf War Illness; however, a lot of people, both in the veteran community and the medical community, agree that it exists. In fact, VA's current Chief of Staff John Gingrich once made the following comment about Gulf War Illness: Quote, "While commanding an artillery battalion during Gulf War I, one of my soldiers suddenly became quite ill. Despite the best efforts of our medical team, they could not diagnose what made him so sick. Out of 800 soldiers under my command, no one else was that sick. Now here we are almost 20 years later, and this veteran is still suffering and has been since the war. I have watched him when he could barely stand up, couldn't cross the room on his own. His legs were so weak. He has been in and out of hospitals many times, seen by some of the best doctors, and yet there is no explanation for his debilitating illness. And this veteran is not alone," unquote.

Chronic Multisymptom Illness, or CMI, is by its own definition not just one item that a VA physician can look for. However, there are certain things a VA physician can and should look for in determining whether a veteran likely has CMI that can be attributed to service in the first Gulf War. This should be a straightforward process; however, I am concerned that it is not happening in practice.

This hearing today is not about whether Gulf War Illness exists; this hearing is about how it is identified, diagnosed and treated, and how the tools put in place to aid these efforts have been used. For example, is the Gulf War Registry working as intended and being used properly? If not, what is VA doing to fix the problem, and what can this Committee do to help VA in that effort?

Are the findings of the Research Advisory Committee being put to use in identifying, diagnosing and treating those veterans suffering from Gulf War Illness? If not, where is the disconnect? How can this Committee help VA better assist these veterans?

We have learned a lot in the last 20 years. Science and research has identified unique medical issues for the veterans of the Gulf War and established baselines from which we can gain a better understanding of those unique issues. Gulf War Illness has significant physical effects on the lives and well-being of those veterans, and we need to make sure that VA can and does make every effort to accurately identify, diagnose and treat them in a timely fashion. To be sure, it should not take another 20 years for us all to get this right.

I look forward to hearing from today's witnesses on what is working in treating Gulf War Illness, where problems remain, and how the entire process can be improved.

With that, I yield to Ranking Member Kirkpatrick for a statement.

[THE PREPARED STATEMENT OF CHAIRMAN COFFMAN APPEARS IN THE APPENDIX]

#### **OPENING STATEMENT OF HON. ANN KIRKPATRICK**

Mrs. KIRKPATRICK. Thank you, Mr. Chairman.

Because we know that the deployment experience of our veterans is especially important in the world of research and the care and treatment of injuries and illnesses, I want to thank you for holding this hearing on Gulf War veterans and the progress or not of recognizing and treating these veterans for ill-defined and undiagnosed conditions.

It is estimated that up to 35 percent of veterans who have served in the Gulf War suffer from symptoms that are not readily identifiable or well understood. In the Institute of Medicine's report released just this past January, and on which this hearing is based, these conditions are called Chronic Multisymptom Illness, or CMI.

Veterans from the 1991 Gulf War have struggled for more than two decades to dispel the all-too-often accusation that "it is all in your head." Veterans of the Iraq and Afghanistan wars have recently presented to the Veterans Health Administration with similar symptoms and have joined their fellow veterans in the fight for effective treatments and legitimate recognition of CMI by providers.

Keeping the struggle of this generation of veterans in the forefront of this Subcommittee is not just important, but crucial for us as a Nation to finally look at service in combat not so narrowly as just that span of time served in combat, but to look at the whole experience of a servicemember from the perspective of

predeployment, deployment and postdeployment as the sum total of things that have happened to a servicemember.

Hopefully this hearing will provide us a better perspective and a more holistic approach in understanding their unique needs and the full toll that serving takes on everyone. In this way we are better able to contribute to their healing and readjustment.

I think it is incumbent upon us to learn as much as we can about what our Nation is asking from our servicemembers and families when they volunteer and raise their right hand. We must recognize and be prepared to address the consequences of that service and bring to bear our best efforts to ensure that they are thoroughly prepared to serve, and, when they return home, we commit to making them whole again.

Thank you, Mr. Chairman. I yield back.

[THE PREPARED STATEMENT OF HON. ANN KIRKPATRICK APPEARS IN THE APPENDIX]

Mr. COFFMAN. Thank you, Ranking Member Kirkpatrick.

I ask that all Members waive their opening remarks as per this Committee's custom and invite the first panel to the witness table.

On this panel we will hear from Dr. Lea Steele, Research Professor of Biomedical Studies and Director of the Veterans Health Research Program at Baylor University; Dr. Steven S. Coughlin, Adjunct Professor of Epidemiology at Emory University; Dr. Bernard M. Rosof, Chairman of the Board of Directors at Huntington Hospital and Chair of the Committee on Gulf War and Health: Treatment for Chronic Multisymptom Illness of the National Academies; and, finally, from Mr. Anthony Hardie, a Gulf War veteran himself.

All of your complete written statements will be made part of the hearing record.

Dr. Steele, you are now recognized for 5 minutes.

**STATEMENTS OF LEA STEELE, RESEARCH PROFESSOR OF BIOMEDICAL STUDIES, AND DIRECTOR, VETERANS HEALTH RESEARCH PROGRAM, BAYLOR UNIVERSITY; STEVEN S. COUGHLIN, ADJUNCT PROFESSOR OF EPIDEMIOLOGY, EMORY UNIVERSITY; BERNARD M. ROSOF, CHAIRMAN, BOARD OF DIRECTORS, HUNTINGTON HOSPITAL, AND CHAIR, COMMITTEE ON GULF WAR AND HEALTH: TREATMENT FOR CHRONIC MULTISYMPATOM ILLNESS, INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES; AND ANTHONY HARDIE, GULF WAR VETERAN**

**STATEMENT OF LEA STEELE**

Dr. STEELE. Good afternoon. I am Lea Steele, Research Professor of Biomedical Studies at Baylor, where I direct a multidisciplinary research program on the health of Gulf War veterans with scientists from across the country. I have also served on several Federal committees that plan and advise government agencies on Gulf War research, including the Research Advisory Committee on Gulf War Veterans Illnesses, which we commonly call the RAC.

I have been asked to testify on the work of Federal agencies in addressing Gulf War Illness. By this we mean the serious, often disabling symptom complex resulting from military service in the

1991 Gulf War. I want to be clear, Gulf War Illness refers to a characteristic profile of symptoms, persistent cognitive and neurological problems, widespread pain, respiratory and other concurrent symptoms that are not explained by established medical or psychiatric diagnoses.

In recent years the government has made progress understanding Gulf War Illness, but there remain serious problems on a number of fronts at VA, including the need for adequate health care for Gulf War veterans.

Twenty-two years after the war, we know Gulf War Illness is not a stress-induced or psychiatric disorder. Rates of PTSD, for example, were much lower in the 1991 Gulf War veterans than in veterans from other wars, and studies consistently show that Gulf War Illness is not due to war trauma or serving in combat. Rather, studies identify links with a number of hazardous exposures during the war, and there is no disagreement among scientists working in this area that Gulf War Illness is a real and serious problem affecting 25 to 33 percent of the nearly 700,000 veterans who served in that war. Further, few veterans have recovered in the 22 years since the war, unfortunately.

This is an incredibly important time for Gulf War Illness research. Scientific advances have provided important insights into this problem, its causes and the biological processes that drive veterans' symptoms. At the same time, results are beginning to come in from treatment studies that show benefits for veterans with Gulf War Illness, with more treatment research in the pipeline and more results expected in the near term. After so many years of waiting, there is finally some hope for Gulf War veterans, hope that they will have answers that are long overdue, and hope that treatments can be found that meaningfully improve their health and their lives.

Those of us most involved in this research believe, based on recent progress, that these successes are within sight. But I regret to say that in some sectors within VA, there appears to have been backward movement with actions that seem intended to ignore the science and minimize this condition as a problem.

Fundamentally we have a situation where two Federal agencies sponsor very different scientific programs, both ostensibly to address Gulf War health issues. DoD's Gulf War Research Program is managed by the Office of Congressionally Directed Medical Research Programs, or CDMRP. This office has made great strides in a short time with about \$34 million in funding over 5 years between 2006 and 2011. This program began in 2006 by defining a mission, establishing priorities and enlisting the input and guidance of experts in the field and veteran stakeholders. This mission-oriented approach has yielded impressive progress, and the proof is in the results.

The highest priority research for Gulf War Illness are studies to identify effective treatments. Of the 50 projects approved for CDMRP funding between 2006 and 2011, 18 are treatment related, 11 clinical studies to assist treatments for ill veterans, and additional research on treatments in animal models of Gulf War Illness, a very impressive record.



In contrast to DoD's mission-oriented approach, VA has not managed an effective program that achieves targeted priorities for Gulf War veterans. Research programs at VA often run counter to the advice of scientific experts. The proof, again, is in the results. VA has reported spending over \$120 million for Gulf War research over the 10 years between 2002 and 2011. This includes a total of just five human and animal projects related to treatment for Gulf War Illness, two focused on stress reduction.

So, what happened? The devil is often in the details, of course, but there are two overarching themes. First, VA has been slow to clearly and accurately acknowledge the Gulf War Illness problem. VA continues to provide mixed signals and vague or inaccurate representations concerning the reality and the nature of Gulf War Illness. This generic representation of the Gulf War Illness problem as a constellation of disparate symptoms that overlap considerably with psychiatric disorders provided the basis for the recent IOM report on treatments, which others on the panel will be talking about. Unfortunately, the misrepresentation of Gulf War Illness by VA was amplified in this report, but we will hear more about that later.

There are many examples, large and small, of VA minimizing the Gulf War Illness problem. It is unbelievable, for example, that VA's current national study of Gulf War veterans conducted in 2013 does not even assess Gulf War Illness symptoms. This is the largest study of 1991 Gulf War veterans in the U.S. and targets 30,000 veterans. It includes scores of questions in many areas like psychological stress, substance abuse and alternative medicine, but not the basic symptoms needed to define Gulf War Illness by any case definition. This is a wasteful and inexcusable missed opportunity at best and something akin to scientific malpractice at worst.

Further, VA has never established an effective research program to address priority Gulf War health issues. There are two main reasons that I can talk about here, although many countless examples might be provided.

First, VA's program has been scientifically ineffective. Despite strong urging from scientific experts, VA did not begin the process of developing a strategic plan for Gulf War research until 20 years after the war. A comprehensive process was finally undertaken in 2011 to develop such a plan with nongovernment experts and stakeholders from multiple institutions and offices, nine groups of at least six members each working over many months to craft and review the plan.

The draft plan was largely approved by two expert committees early in 2012, but in the next several months the plan was extensively changed by VA internal editors, who removed references to Gulf War Illness and substantially altered the program developed to define and treat this problem. The Federal Research Advisory Committee on which I serve had long urged VA to develop a plan of this type, but last June, the RAC withdrew its support of the plan and reported to the Secretary that, under current circumstances, the Committee had no confidence in VA's ability to develop an effective Gulf War research program.

Just one final point briefly. The other major issue related to VA's Gulf War research program relates to research funding. The RAC

was charged by Congress to review all Federal research programs that address Gulf War health issues. Our Committee staff review of Gulf War research expenditures each year invariably finds that a large portion of VA-identified Gulf War studies would not be considered Gulf War research by any other government or nongovernment program.

This is not a trivial problem. In many years, 60 percent or more of the millions of dollars identified for Gulf War research is actually used for other types of research, with no link in any important respect to 1991 Gulf War veterans. There are far too many examples to identify here, but they include high-dollar research items like the \$10 million used to fund a postmortem brain tissue bank, identified as the Gulf War Bio-Repository Trust. In reality, this program is a brain bank for veterans with ALS, or Lou Gehrig's disease. Despite its name and the \$10 million in Gulf War funding used for this program, it neither targets nor studies veterans in any important way. As of 2010, only 1 of the 60 contributors to this brain bank was a Gulf War veteran.

So, as always, the proof is in the results. Together VA's poor representation of the Gulf War Illness problem and failure to apply current scientific knowledge to develop a focused state-of-the-art research program have led to relatively little in the way of tangible benefits for ill veterans. From my perspective as a scientist who has worked in this area for many years, it is time to get this right, and certainly the many thousands of veterans who have suffered with Gulf War Illness for more than 20 years would say it is long past time.

Thank you.

[THE PREPARED STATEMENT OF DR. LEA STEELE APPEARS IN THE APPENDIX]

Mr. COFFMAN. Thank you, Dr. Steele.  
Dr. Coughlin.

#### **STATEMENT OF STEVEN S. COUGHLIN**

Mr. COUGHLIN. Chairman Coffman and Members of the Subcommittee, distinguished guests, thank you for the privilege of testifying today. I am Steve Coughlin. I have worked as an epidemiologist for over 25 years, including positions as a Senior Cancer Epidemiologist at the Centers for Disease Control and Prevention, and as Associate Professor of Epidemiology and Director of the Program in Public Health Ethics at Tulane University. I chaired the writing group that prepared the ethics guidelines for the American College of Epidemiology, and have authored or edited several key texts on public health ethics and ethics in epidemiology.

For the past 4-1/2 years, I was a Senior Epidemiologist in the Office of Public Health at the Department of Veterans Affairs. In December 2012, I resigned my position in the U.S. Civil Service because of serious ethical concerns that I am here to testify about today.

The Office of Public Health conducts large studies of the health of American veterans; however, if the studies produce results that do not support the Office of Public Health's unwritten policy, they

don't release them. This applies to data regarding adverse health consequences of environmental exposures, such as burn pits in Iraq and Afghanistan, and toxic exposures in the Gulf War.

On the rare occasions when embarrassing study results are released, data are manipulated to make them unintelligible. The 2009-2010 National Health Study of a New Generation of U.S. Veterans targeted 60,000 OAF and OEF veterans and cost \$10 million, not including the salaries of those who worked on it and were employed by the VA. Twenty to thirty percent of these veterans were also Gulf War-era veterans, and the study produced data regarding their exposures to pesticides, oil well fires, and pyridostigmine bromide pills. It also included meticulously coded data as to what medications they were taking.

The Office of Public Health has not released these data or even disclosed the fact that this important information on Gulf War veterans exists. Anything that supports the position that Gulf War Illness is a neurological condition is unlikely to ever be published.

I coauthored a journal article for publication on important research findings from the New Generation study having to do with the relationship between exposures to burn pits and other inhalational hazards and asthma and bronchitis in OEF/OIF veterans. My immediate supervisor, Dr. Aaron Schneiderman, told me not to look at data regarding hospitalizations and doctors' visits. The tabulated findings obscure rather than highlight important associations. When I advised him I did not want to continue as a coinvestigator under these circumstances, he threatened me.

Speaking as a senior epidemiologist with almost 30 years of research experience, there is no reason to work night and day for years on a complex data collection effort which costs U.S. taxpayers millions of dollars if you are not comfortable putting your name on publications stemming from this study or if no scientific publications are released.

Another example of important data that have never been released are the results of the Gulf War Family Registry which was mandated by Congress. These were physical examinations provided at no charge to Gulf War veterans' family members. I have been advised that these results have been permanently lost.

The Office of Public Health has also manipulated information regarding veterans' health through the questions included in their surveys. During the preparation of a major survey of Gulf War-era veterans of which I was principal investigator, the Follow-up Study of a National Cohort of Gulf War and Gulf War-era veterans, the Research Advisory Committee on Gulf War Illness made extensive recommendations regarding changes to the survey. I considered many of those changes as very constructive, and some were adopted.

The VA Chief of Staff, Mr. John Gingrich, directed my supervisors to send the Gulf War study scientific protocol and draft questionnaire out for additional objective scientific peer review. The OPH Chief Science Officer, Dr. Michael Peterson, contacted a long-time friend of his, who is dean of a U.S. school of public health. The dean identified a faculty member at his school, although the individual has no background in Gulf War health research.

My direct supervisor Dr. Schneiderman spoke with the peer reviewer and told him that the Research Advisory Committee comments were politically motivated; i.e., not objective in nature. The reviewer responded that he would certainly try to help out. Not surprisingly, the reviewer's comments were highly favorable. The Chief of Staff Mr. Gingrich was never informed that the outside reviewer worked for a friend of Dr. Peterson.

My supervisors also made false statements in writing to the Chief of Staff. For example, they falsely stated that putting the study on hold long enough to further revise the questionnaire would cost the government \$1 million, delay the study for a year or longer, and potentially result in contract default. None of that was true.

The contract for the study was specifically worded in a way that the contractor was only paid for each deliverable as they completed that piece of the work product. As a result, the Chief of Staff ordered the survey to proceed without the changes.

The Office of Public Health also handles the VA dealings with the Institute of Medicine, which is part of the National Academies of Science. Congress and VA leadership rely on the IOM for authoritative objective information on medical science. I have personally served on IOM committees and workshops having to do with public health ethics.

Last year the Department of Veterans Affairs contracted with IOM for a congressionally mandated study of treatments for Chronic Multisymptom Illness in Gulf War veterans. Many Gulf War veterans were distressed that five speakers selected to brief the IOM committee presented the view that the illness may be psychiatric, although science has long discredited that position. My understanding is that Dr. Peterson identified the speakers the IOM should invite.

I wish to close with a subject of particular importance to me. Almost 2,000 research participants from the National Health Study of a New Generation of U.S. Veterans self-reported that they had thoughts in the previous 2 weeks that they would be better off dead; however, only a small percentage of those veterans, roughly 5 percent, ever received a callback from a study clinician. Some of those veterans are now homeless or deceased.

I was unsuccessful in getting senior Office of Public Health officials to address this problem in the New Generation study. I was successful in incorporating these callbacks in the Gulf War survey, and they have saved lives, but only after my supervisors threatened to remove me from the study and attempted disciplinary action against me when I appealed their refusal to provide for callbacks to a higher authority.

I urge this Committee to direct the VA to immediately identify procedures to ensure that veterans who participate in VA large-scale epidemiologic studies receive appropriate follow-up care so that this tragedy is not repeated. I also urge you to initiate legislation to cure the epidemic of serious ethical problems in the Office of Public Health, I described to you today.

In view of the pervasive pattern where some of these officials failed to tell the truth even to VA leadership, VA cannot be expected to reform itself. These problems impact the balance of risks

and benefits of federally funded human-subjects research costing tens of millions of dollars and which fail to serve the interests of the veterans they are intended to benefit.

The VA mental health professionals who made callbacks for the 2012 Gulf War follow-up survey, who are over at the VA medical center here in D.C., saved lives and ameliorated human suffering. They helped vulnerable research participants get access to health care benefits to which they are entitled to by acts of Congress.

When you are suffering from a neurologic condition such as Gulf War Illness or traumatic brain injury, or a psychiatric condition such as major depression or post-traumatic stress disorder, it can be extremely difficult to navigate the bureaucratic procedures for getting access to health care benefits. That is why it is essential to have clinical psychologists, licensed clinical social workers, and other mental health professionals as coinvestigators on these large-scale national surveys.

The quality of measures to assist research participants who are experiencing pronounced psychological distress varies widely across epidemiological studies conducted by the Department of Veterans Affairs, studies that are targeting hundreds of thousands of U.S. servicemen and women and U.S. veterans. In some studies, such as the National Health Study for a New Generation of U.S. Veterans, only a small percentage or none of the research participants who self-report suicide ideation receive a callback from a study clinician. This practice is unethical and should be strongly discouraged.

[THE PREPARED STATEMENT OF DR. STEVEN S. COUGHLIN APPEARS IN THE APPENDIX]

Mr. COFFMAN. I am going to have to try and remind the witnesses to try and keep it to 5 minutes—you are at 10 minutes right now—because we are going to have to return to vote in a little while, so we want to get through as much as we possibly can.

Dr. Rosof.

#### **STATEMENT OF BERNARD M. ROSOF**

Dr. ROSOF. Good afternoon, Mr. Chairman, Ranking Member Kirkpatrick, and Members of the Subcommittee. My name is Bernie Rosof. I am Chairman of the Board of Directors of Huntington Hospital, part of the North Shore LIJ Health System in Huntington, New York. I am a specialist in internal medicine and gastroenterology, and professor of medicine at the Hofstra North Shore-LIJ School of Medicine. I also served as chair of the Institute of Medicine's Committee on Gulf War and Health: Treatment for Chronic Multisymptom Illness.

The Institute of Medicine, or the IOM, as you know, is the health arm of the National Academy of Sciences, an independent nonprofit organization that provides unbiased and authoritative advice to decision-makers and to the public. The IOM was asked by the Department of Veterans Affairs to comprehensively review, evaluate and summarize the scientific and medical literature regarding treatments for Chronic Multisymptom Illness, or, as you have heard, CMI, among Gulf War veterans.

The IOM assembled an expert committee of which I was chair to address this task. We met in person five times over a 9-month pe-

riod to gather evidence, deliberate on our conclusions and recommendations, and write our report. That report underwent a rigorous, independent, external review before being released in January of this year. More detailed information on the committee's recommendations is included with my longer written statement.

CMI is a very serious condition that imposes an enormous burden of suffering on our Nation's veterans. It is a very complex condition. Veterans who have CMI often have a combination of physical symptoms and cognitive symptoms, along with comorbid syndromes, such as chronic-fatigue syndrome, fibromyalgia and irritable-bowel syndrome. Other clinical entities such as depression and anxiety may occur as well.

There is no consensus among physicians, researchers and others as to the cause of CMI. The range of unexplained symptoms experienced by people who have CMI could result from multiple factors, but the etiology remains unknown.

We didn't attempt to identify the causes of CMI. As laid out in the charge, we evaluated treatments for CMI and made recommendations for improving health care for veterans who have this condition. We conducted an extensive systematic assessment and review of the evidence on treatment for CMI. We also assessed treatments for a number of related and comorbid conditions to determine whether any of those treatments may be beneficial for CMI.

Based on our assessment, we cannot recommend any specific therapy as a treatment for veterans who have CMI. We concluded that a one-size-fits-all approach is not effective for managing these veterans. We recommend that the VA implement a systemwide, integrated, multimodal, long-term management approach.

In our report we make a number of additional recommendations aimed at identifying veterans who have CMI, bringing them into the VA health care system, and improving the quality of their care. The VA should commit the necessary resources to ensure that veterans complete a comprehensive health examination immediately upon separation from active duty. To improve coordination of care, the results should become part of a veteran's health record and should be made available to every clinician caring for the veteran, whether in or outside the VA health care system. Additionally, the VA should include in its electronic health record a pop-up screen to prompt clinicians to ask questions to ascertain whether a patient has symptoms consistent with CMI.

Once a veteran has been identified as having CMI and has entered the VA health care system, the next step is to provide comprehensive care for the veteran not only for CMI, but also any comorbid conditions. Existing VA programs, such as post-deployment patient-aligned care teams, or PACTs, could be adapted to best serve veterans who have CMI. The VA should commit the resources needed to ensure that PACTs have the time and the skills required to meet the needs of veterans who have CMI as specified in the veterans' integrated personal-care plans; that the adequacy of time for clinical encounters is measured routinely; and that clinical case-loads are adjusted in response to the data.

A major determinant of the VA's ability to manage veterans who have CMI is the training of clinicians and teams of professionals

in providing care for these patients. The VA should designate CMI champions to serve as an internal resource at each VA medical center. These individuals should be integrated into the care system to ensure clear communication and coordination among clinicians. The VA also should develop peer networks to introduce new information, norms and skills related to managing veterans who have CMI.

Finally, many studies on treatments for CMI reviewed by the committee have methodological flaws. Therefore, future studies funded and conducted by the VA to assess treatments for CMI should adhere to well-accepted methodologic and reporting guidelines for clinical trials. We can't emphasize that too much.

We identified several interventions that may hold promise for treatment of CMI. Although this is not an exhaustive list, the VA should consider funding and conducting studies of interventions, such as biofeedback, acupuncture, aerobic exercise and multimodal therapies.

Numerous opportunities exist for the VA to improve and expand its health care services of veterans who have CMI. Our veterans deserve the very best health care.

Thank you very much for the opportunity to testify. I certainly would be happy to answer any questions.

[THE PREPARED STATEMENT OF DR. BERNARD M. ROSOF APPEARS IN THE APPENDIX]

Mr. COFFMAN. Thank you, Dr. Rosof.

Mr. Hardie for 5 minutes, please.

#### **STATEMENT OF ANTHONY HARDIE**

Mr. HARDIE. Thank you for today's hearing, and thank you to the Gulf War veterans who are here or watching from home or from the hospital in the case of at least one. I myself am a veteran of the 1991 Gulf War as well as Somalia and four other deployments. I developed health issues that began in the gulf that have plagued me ever since. My experiences are far from unique, and we now know roughly one in three of us Gulf War veterans are similarly afflicted.

In 2010, a landmark IOM report confirmed what we Gulf War veterans already knew. Gulf War Illness is likely the result of environmental agents plus other factors. It is not psychiatric, and it is likely that treatments and preventions can be found. Though such a renewed national effort has not yet fully happened, special thanks to Congressmen Miller, Michaud, and Roe and others for helping fund the Gulf War Illness CDMRP, the only Federal research program in the last two decades aimed at improving the health and lives of us ill Gulf War veterans. I'll provide more detail in my written statement.

VA's past Gulf War research failures have previously been well documented, much of it focused on stress, psychological and other irrelevant issues, little of it aimed at developing Gulf War Illness treatments. As we just heard Dr. Coughlin, such failures have not been by accident. VA staff misdeeds continued with the recent IOM Treatments Committee, and last year, as we also have already heard, VA staff effectively killed the first-of-its-kind strategic plan

finally aimed at improving the health and lives of veterans suffering from Gulf War Illness. VA staff unilaterally whitewashed the plan. Participants, including myself, felt betrayed in having wasted a year and a half.

The Research Advisory Committee on which I serve unanimously rejected VA's whitewash, declared no confidence in VA's handling of Gulf War Illness research, and described even more issues: secret VA cuts to the Gulf War Illness research budget; VA staff misrepresentations to VA leadership and Congress; blatant violation of statutory mandates; prioritizing research not on treatments, but on, quote, "whether Gulf War veterans' illnesses are linked to Gulf War service." And the RAC has not been allowed to hold a public meeting since then. There are more issues with details in my written submission.

VA staff have initiated a process to create a new case definition for Gulf War Illness via a literature review, unprecedented, from what I am told, and in opposition to the strategic plan mentioned earlier. VA staff refused to provide the RAC with more information.

VA's medical surveillance of serious Gulf War health outcomes remains broken. VA refuses to implement a 2008 law mandating an MS prevalence study. VA is still not doing obvious infectious disease workups, as exhibited by a recent Iraq War veteran who after a 4-year battle was finally diagnosed and treated with Q fever.

VA's Gulf War Task Force ignores—includes only VA staff. It operates in secret, and it asks for, but ignores, veterans' input. VA has failed to publish its quarterly Gulf War and OIF/OEF newsletters and claims data reports since 2010. The VA continues to exclude Gulf War veterans whose service was in Turkey or Israel. VA continues to exclude from Gulf War veterans' benefits Afghanistan war veterans, yet includes Iraq War veterans.

VA still hasn't fixed rating problems for fibromyalgia and chronic fatigue, with up to 100 percent ratings for one, but only 40 percent ratings for both. Yes, you heard that right. And these conditions are presumptive for Gulf War and Iraq veterans, but not Afghanistan veterans. DoD and VA continue to find no evidence for other serious military health issues like burn pits, vaccination injuries and more.

VA staff routinely ignore Congress, the law and expert advisers, wasting more precious years squandering experts' time and energy, and further alienating not just the most engaged advisers, but also the very Gulf War veterans they are supposed to be helping.

Most importantly of all, VA still has no proven effective treatments for Gulf War Illness patients who walk through VA's doors, where they frequently are still thought to be psychosomatic. VA has only Band-Aids for symptoms and to help cope. Today we are hearing why.

I encourage this body to take—to help right these ongoing wrongs, including comprehensive legislation to help force solutions, reallocation of funding from these nonperforming entities, further investigation of their misdeeds, and criminal sanctions for such behavior.

We Gulf War veterans have been fighting with VA and DoD for what is right for most of the last 22 long years. We have had count-



less congressional hearings like this one on Gulf War veterans' issues with more empty VA promises. We have seen laws pass only to see VA staff circumvent them or ignore them with impunity. I hope today's hearing will be different.

Thank you, Mr. Chairman, Madam Ranking Member, Members of the Committee, and I am happy to answer any questions you may have.

[THE PREPARED STATEMENT OF ANTHONY HARDIE APPEARS IN THE APPENDIX]

Mr. COFFMAN. Thank you, Mr. Hardie, and thank you so much for your service to our country.

Doctor—and if you all could do your best to keep your questions down to a minimum in terms of time so we can get to the second panel, and our Ranking Member has questions as well as I do.

Dr. Coughlin, your written testimony stated that, quote, “on the rare occasions when embarrassing study results are released, data are manipulated to make them unintelligible,” unquote. Please explain and cite an example.

Dr. COUGHLIN. Several examples can be cited. The best example that comes to mind is we set out to analyze data from the National Health Study for a New Generation of U.S. Veterans looking at self-reported exposure to burn pits, oil well fire smoke, other inhalational hazards, in relation to physician-diagnosed asthma and bronchitis.

The initial exposure analyses, which were produced by the writing group and the statistician, showed that a sizable percentage of the deployed veterans had been exposed to burn pit smoke, and burn pit fumes were associated with asthma and bronchitis. Then in a later iteration of the tabulated results, those results were set aside or discarded, and the focus was instead on deployment, deployment status in relation to asthma and bronchitis.

Well, those 30,000 deployed vets and 30,000 nondeployed vets included veterans who served on ships in the Indian Ocean, or in the Philippines, or in Germany in hospitals. In other words, people were deployed OEF/OIF and served in the War on Terror, but were never in Iraq or Afghanistan on the ground and had no potential exposure to burn pits. So the way that the refined results were tabulated, it obscured rather than highlighted the associations of interest. And I could elaborate if you would like.

Mr. COFFMAN. Okay. Mr. Hardie, can you explain in your opinion why the Research Advisory Committee in their latest Institute of Medicine report is flawed?

Mr. HARDIE. Yes. Thank you for that question.

First I want to recognize that I believe that the researchers, distinguished researchers like the gentleman sitting next to me, who served on that committee were well intentioned. However, VA staff issued a scope of work and committee charge that radically diverged from the law, that effectively prevented—and also effectively prevented what the committee could consider. I believe that these helped to prevent—prevented the IOM committee from meeting the expectations of the law.

VA staff directed the panel to do a literature review rather than, as the law directed, focusing on physicians experienced in treating

Gulf War Illness. VA staff knew little such literature exists, because VA's two decades of failures to develop treatments have helped to ensure that fact.

Additionally, most of the presenters to the panel focused on psychosomatic issues, stress as cause and things like relaxation therapies as treatments. Our Gulf War veterans who called in to listen to that meeting were naturally outraged. VA staff were among the presenters to the committee, including at least one sitting here today. VA staff muddied the waters by directing IOM to include not just 91 Gulf War veterans as the law directs, but many others.

And finally, all of this involvement by VA staff is a far cry from previous claims that these panels operate independent of biasing influence from the contracting agency.

Mr. COFFMAN. Thank you, Mr. Hardie.

Dr. Rosof, the law required that VA's agreement with the Institute of Medicine was to, quote, "convene a group of medical professionals who are experienced in treating individuals who served," unquote, "in the Southwest Asia theater of operations of the Persian Gulf War during 1990 or 1991, and who have been diagnosed with Chronic Multisymptom Illness or another health condition related to such service," unquote.

Of the members of your committee, how many have experience in medically treating Gulf War veterans?

Dr. ROSOF. Well, I can't answer as to the number of members of my committee who had experience, but all of the members of the committee had experience in dealing with Chronic Multisymptom Illness, some directly with veterans who served in those theaters of war.

In addition, there are members of the committee, including myself, that have been on other IOM committees that have dealt with the issues of Gulf War Chronic Multisymptom Illness or illnesses of that sort. So there was considerable expertise sitting around the table in addition to methodical expertise to evaluate the literature on best treatments.

Mr. COFFMAN. Thank you.

Ranking Member Kirkpatrick.

Mrs. KIRKPATRICK. Mr. Hardie, can you enlighten the Committee on the role of the Research Advisory Committee on Gulf War Illness in the preparation of a major survey of Gulf War-era veterans that Dr. Coughlin was talking about in his testimony? Were the recommendations that the Research Advisory Committee made regarding the changes to the survey ignored, and what has happened to the survey?

Mr. HARDIE. Thank you very much for that question, Madam Ranking Member.

The Research Advisory Committee made a number of recommendations early on when the committee first became aware that the survey existed. Many of those Office of Public Health staff, including Dr. Aaron Schneiderman that was mentioned earlier, refused to provide the Research Advisory Committee with answers to whether or not that the requested changes had been made. If any changes had been made, they refused even to tell our chairman where his office was so the chairman could come and have a private meeting with him.

I was frankly shocked, and candidly I expressed at that meeting that I hadn't seen such a display of arrogance and insolence, and that I thought that he should be fired. I was absolutely shocked.

So my understanding when we finally saw the survey that went out, the expert—I am simply a Gulf War veteran on the panel that has had a lot of experience with these things, but I look to many of the scientists that I find to be brilliant, and experts in their field had put together a comprehensive survey list and focusing on the important issues to veterans like Gulf War—frankly, Gulf War Illness issues, and it did not appear that those issues were being included in the survey. And when we finally saw the survey, it was extremely troubling that much of it was focused on psychological and psychiatric issues. Frankly, it was extremely upsetting for Gulf War veterans.

Mrs. KIRKPATRICK. Do you know where the survey is now?

Mr. HARDIE. I think that others may be better suited to answer that question.

Mrs. KIRKPATRICK. Okay. Dr. Coughlin.

Mr. COUGHLIN. The Research Advisory Committee on Gulf War Illness provided scientific critiques as part of the formal Office of Management and Budget's regulatory process. We published an announcement in the Federal Register as required by OMB about this national data collection, and the public can indeed provide written comments, which VA is obligated to respond to.

The false statements and other ethical problems that I mention in my testimony, those problems may well have compromised the integrity of the OMB regulatory process. So I just wanted to reinforce Mr. Hardie's comments.

Mrs. KIRKPATRICK. Thank you.

This question is for the entire panel. What do you believe are the top three challenges the VA faces in addressing the inadequacy of the Gulf War veterans research programs and the lack of effective treatment? So what are the three reasons, challenges, that they are unable to address this?

Dr. Steele?

Ms. STEELE. Yes, thank you. I briefly outlined that in my testimony, and I can just summarize them very quickly.

The top reasons have to do with lack of expertise in this area among the people who are designing and executing the program. So it is almost as if they are designing a program that is well suited to the mid-1990s, soon after the Gulf War, when we didn't know anything about Gulf War Illness.

But a lot has changed since then. We have learned a lot, and certainly there is a lot of scientific promise now and scientific information now that could be built on to develop an effective research program to address Gulf War Illness, as the Department of Defense has done in recent years.

So is partially the lack of expertise. It almost appears to be the lack of will, just in looking how Gulf War Illness is typically portrayed on VA Web sites and VA literature, how the studies appear to be designed to actually ignore Gulf War Illness for the most part, or minimize it as an important problem. So some of it probably has to do with political will, and some of it has to do with expertise.

But I would also say that just the use of funding is totally inappropriate. So much of the funding is used for studies that have nothing to do with Gulf War veterans or Gulf War Illness.

So, you know, it is sort of a three-pronged problem; lack of expertise, lack of intention to address the problem and misallocation of funds.

Mrs. KIRKPATRICK. Thank you, Doctor.

And, Mr. Chairman, I have almost used up my time, so I will yield back.

Mr. COFFMAN. Thank you, Ranking Member Kirkpatrick.

Dr. Rosof, on the monitors in this room, there are slides from five presentations from different speakers who appeared before your committee on February 29th of last year. As you can see, these speakers appear to be giving the committee the message that this illness is psychiatric, stress, PTSD and so forth.

Who selected these speakers to present to the committee?

Dr. ROSOF. Let me correct some of the statements that were made initially. The selection of the speakers to the committee was done by our committee. It was not done, as indicated previously, by Dr. Peterson or any other individual. It was selected by our committee.

The committee wanted to better understand the treatment modalities that would affect positively the veterans and their health. We reviewed, identified—

Mr. COFFMAN. Excuse me 1 second. Did VA or DoD have any input into the choice of these speakers?

Dr. ROSOF. The committee made the decision on what speakers to choose, clear understanding on the part of the committee. We reviewed in addition 6,541 unique references, enabling us to make some decisions about the treatment of veterans. So our conclusions were not based solely on the people who you saw; in addition, there were others. And if you read—if our report is read clearly, you can see our conclusions were not that this was a psychological or psychosomatic disorder.

We clearly make the statement we do not know the etiology. No one treatment will be able to affect positively the treatment for patients with CMI, Chronic Multisymptom Illness. It requires a group of physicians, a team-based approach, who understand the patients, who enable the patient to have a decision in the care he or she receives, and at the same time better understand the satisfaction of the veterans in their care. We strongly believe that this is an illness that has and requires a multimodal therapeutic intervention.

Mr. COFFMAN. All right. Dr. Coughlin, on October 23rd this Subcommittee asked VA how many veterans have self-identified as suicidal and later committed suicide in the Follow-up Study of a National Cohort of Gulf War and Gulf-era veterans. On February 19th, VA responded stating, quote, “VA has no evidence to date that any veteran in this study has committed suicide,” unquote. Are these the same results you saw in your study?

Mr. COUGHLIN. Yes. Fortunately, we did not lose any of the research participants. As I mentioned in my testimony, my efforts to identify mental health professionals to get involved with the study as coinvestigators, to place these callbacks to vulnerable research

participants were initially blocked by my supervisors, and that is why I contacted the IRB chair in writing and also the VA Office of Inspector General.

After a delay of 2 or 3 months, we were able to start the callback process, and a team of mental health professionals at the Washington, D.C., VA Medical Center did a fantastic job of reaching out to the veterans.

We had vets who had been told by their local VA clinic or hospital that they were not eligible for free health care, but when they called the toll-free number and reached somebody in VBA and the VA central office, they were told the opposite. So the social workers were able to sort this out and get them into health care.

These were vulnerable veterans, men and women, who had major depression or other medical and psychiatric conditions, and they needed assistance to get into health care to save their lives.

Mr. COFFMAN. Thank you.

Ranking Member Kirkpatrick, any other questions before we go to the next panel?

Mrs. KIRKPATRICK. Any other questions I'll submit in writing in the interest of time.

[THE INFORMATION APPEARS IN THE APPENDIX]

Mr. COFFMAN. Very well. Thank you very much for your testimony.

I now invite the second panel to the witness table. On this panel we will hear from Dr. Victoria Davey, Chief Officer of VHA's Office of Public Health and Environment Hazards. Dr. Davey is accompanied by Dr. Maureen McCarthy, Deputy Chief of VHA's Patient Care Services Office; Dr. Stephen Hunt, Director of VA's Post-Deployment Integrated Care Initiative; Dr. Gavin West, Acting Chief Medical Officer of the Salt Lake City VAMC and Special Assistant in the Office of the Assistant Deputy Under Secretary for Health for Clinical Operations; and Mr. Tom Murphy, Director of VBA's Compensation Service.

Dr. Davey, your complete written statement will be made part of the hearing record. You are now recognized for 5 minutes.

**STATEMENT OF VICTORIA DAVEY, CHIEF OFFICER, OFFICE OF PUBLIC HEALTH AND ENVIRONMENTAL HAZARDS, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS, ACCOMPANIED BY MAUREEN MCCARTHY, DEPUTY CHIEF, PATIENT CARE SERVICES OFFICE, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS; STEPHEN HUNT, DIRECTOR, POST-DEPLOYMENT INTEGRATED CARE INITIATIVE, U.S. DEPARTMENT OF VETERANS AFFAIRS; GAVIN WEST, ACTING CHIEF MEDICAL OFFICER, SALT LAKE CITY VAMC, SPECIAL ASSISTANT, OFFICE OF THE ASSISTANT DEPUTY UNDER SECRETARY FOR HEALTH FOR CLINICAL OPERATIONS, U.S. DEPARTMENT OF VETERANS AFFAIRS; AND TOM MURPHY, DIRECTOR OF COMPENSATION SERVICE, VETERANS BENEFITS ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS**

**STATEMENT OF VICTORIA DAVEY**

Ms. DAVEY. Mr. Chairman, Madam Ranking Member and Members of the Subcommittee, thank you for the opportunity to submit my written testimony for the record.

I am accompanied today by Dr. Stephen Hunt, who flew overnight to be here today because he didn't want to cancel his clinic appointments yesterday; Dr. Maureen McCarthy; and Dr. Gavin West; as well as Mr. Tom Murphy. The three physicians I just referenced have extensive experience treating Gulf War veterans.

Mr. Chairman, this is our message: VA has learned a great deal about identifying, diagnosing and treating Gulf War veterans over the past 22 years. We will continue to improve our abilities to provide world-class health care for Gulf War veterans, better educate our health care providers, and possibly most of all, in reference to the speakers that preceded me, expand the evidence base for the treatments we provide for these veterans, indeed for all veterans.

Let me provide you with a summary of where we are. We agree with Dr. Steele. As you know, a debilitating cluster of medically unexplained symptoms affects many Gulf War veterans. We refer to the illness that these veterans have as Chronic Multisymptom Illness, or CMI. Our present thinking is that a complex combination of environmental exposures and individual genetic characteristics may be behind this illness.

Veterans with CMI, like all veterans enrolled for VA care, receive personalized, proactive, patient-driven care. In addition, VA offers a number of programs and services uniquely designed to meet the needs of Gulf War veterans with CMI.

VA links our patient-aligned care teams, or PACT teams, working with Gulf War veterans with specialty-care capability that focuses on treating the unique health requirements of these veterans. The program includes teaching aids, referral networks and other types of collaboration. Frontline clinicians have been educated through our monthly community of practice conference calls, informational messages, pocket cards and Web sites.

Another program specifically for Gulf War veterans is our registry program, which offers a health examination at any of our health care facilities to any veteran with Gulf War service. To date,

about 130,000 Gulf War veterans have undergone a registry exam. The comprehensive health exam includes an exposure and medical history, laboratory tests and a physical exam. VA health professionals discuss the results face to face with veterans. This provides us an opportunity to partner with the veteran to develop an individualized care plan. An individual is very important to this discussion.

Since 2001, the War-Related Illness and Injury Study Centers of the VA Office of Public Health, known as the WRIISC, have supported specialized care for Gulf War veterans and conducted cutting-edge research, clinical education and a veteran referral program. VA's three WRIISCs have teams of clinicians ready to evaluate Gulf War veterans with deployment-related concerns. Based on a comprehensive evaluation, the WRIISC team develops an individual, holistic treatment plan for veterans with CMI or other ill-defined conditions through our referral process based on geographic location.

VA's Office of Public Health holds quarterly conference calls with environmental health coordinators and clinicians throughout VA. The calls provide coordinators and clinicians with ongoing training, and allows them to share patient questions, challenges, administrative issues and solutions that have come up at their facilities.

VA recently engaged the Institute of Medicine, as you heard, to convene a committee to comprehensively review, evaluate and summarize the available scientific and medical literature regarding the best treatments for CMI among Gulf War veterans. The report, as you heard, was released on January 23rd.

IOM made recommendations to VA in five categories, including how to treat CMI, how to improve systems of care and management of care, how to provide information about care, improve the collection and quality of data on care outcomes and satisfaction with care, and how to conduct future research. VA is already taking actions, and these include a program to provide every servicemember with a health care assessment upon separation from service; improvements in systems of care and management of CMI in Gulf War veterans, including the use of clinical reminders and streamlined consults for specialty care; and the innovative PACT program I described earlier that integrates and coordinates personalized care for Gulf War veterans.

We are improving communication among VA health providers and between them and the patients they care for. We are modifying our patient satisfaction measurement tools and training our staff to better recognize CMI. We are also developing a champions program and Webinars on this subject and taking steps to strengthen our research protocols.

Mr. Chairman, we appreciate the opportunity to discuss with you this important issue. We are proud to continue evaluation and treatment for the 700,000 deserving men and women who served in Operations Desert Shield and Desert Storm.

My colleagues and I are prepared to answer your questions. Thank you.

[THE PREPARED STATEMENT OF DR. VICTORIA DAVEY APPEARS IN THE APPENDIX]

Mr. COFFMAN. Thank you, Dr. Davey.

Is Gulf War Illness a psychological condition?

Ms. DAVEY. Gulf War Illness is not a psychological condition. Gulf War Illness is a group of chronic multisymptom—multiple symptoms. We do not believe that it is psychological.

Mr. COFFMAN. Dr. Hunt, I understand you made a presentation to the IOM Treatment Committee on the topic, quote, “VA Approaches to the Management of Chronic Multisymptom Illness in Gulf War I Veterans,” unquote.

The slide you presented to the committee shows that some VA doctors think Gulf War Illness is, quote, “mostly a physical disorder,” unquote, and some think it is, quote, “mostly a mental disorder,” unquote. However, this information is from an 11-year-old paper.

The current VA treatment guidelines revised in 2011 state, quote, that “chronic multisymptom illness is real and cannot be reliably ascribed to any known psychiatric disorder,” unquote.

I understand that you served on the committee that wrote the new guidelines, Dr. Hunt, but you didn’t present the new guidelines to the committee.

In speaking on VA Approaches to the Management of Chronic Multisymptom Illness in Gulf War I Veterans, why did you tell the committee the 11-year-old information that it might be physical or it might be mental, but didn’t tell the committee VA’s current guideline that clearly states it is not mental?

Dr. HUNT. Actually, thank you, Mr. Chairman, and thanks for the opportunity to be here. And I want to also acknowledge the service of all of our veterans here, and particularly our Gulf War veterans.

This slide was used to illustrate when Gulf War veterans first started coming back. The psychologist and I who ended up starting the first Gulf War veterans clinic at VA Puget Sound were noticing that people were coming in with a lot of symptoms, a lot of physical symptoms of different sorts that we would do lots of tests for, and we couldn’t find a disease to link up to the symptom. And so we knew we were facing something that ultimately now we are calling Chronic Multisymptom Illness. At that time we were describing it as medically unexplained symptoms.

We knew that we needed a new model of care, and the way that we sort of established that was by doing a survey of providers at that time when people were early on in the process of coming back.

And so we asked the medical providers, do you think this Gulf War Illness is more of a physical condition or more of a mental health condition? The medical—and we asked mental health providers, do you think it is more of a physical condition or mental health condition? These are providers at VA Puget Sound, VA Portland and Walter Reed. These are good clinicians, smart clinicians that know what they are doing.

What this showed to me, and the point that I was trying to make was, our paradigm wasn’t working, because our medical provider said, gosh, I am doing these tests, and they are all negative, so I can’t find a disease here, so maybe we should have them checked out by behavioral health.



Behavioral health people would look at them and say, gosh, there is all these symptoms, you know, but they don't really meet criteria for any mental health diagnosis. I—they have some condition. I think we should send them back to their medical provider for more tests.

This is the dilemma of Chronic Multisymptom Illness, and this is why we really appreciate the work that IOM has done in framing this thing for us in a bigger way, because our old paradigm, is it physical or is it mental, does not work.

We needed a paradigm where we said, look, you have been off to war, your health has been changed in a number of ways, we appreciate your service, we are glad you are here, and the way that we are going to address this is by having a medical provider, a mental health provider, social worker kind of put your care together in a way that—

Mr. COFFMAN. Dr. Hunt, did you think it is a mental condition or a physical condition?

Dr. HUNT. I think it is a health condition, and I don't think in mental health, physical health—

Mr. COFFMAN. Is it mental, or is it physical?

Dr. HUNT. It is a physical condition, and it has—our minds and bodies can't be split up in that way. I certainly would not say it is a mental condition or a psychological condition for sure. It is a health condition that we need to be very circumspect in our way of evaluating and treating.

Mr. COFFMAN. Dr. Davey, the law required the VA's agreement with the Institute of Medicine was to, quote, "convene a group of medical professionals who are experienced in treating individuals who served," unquote, "in the southeast Asia theater of operations of the Persian or Gulf War during 1990 and 1991," unquote. But in looking at the statement of work, VA tasked IOM to, quote, "review, evaluate, and summarize the available scientific and medical literature regarding the best treatments for Chronic Multisymptom Illness among Gulf War veterans," unquote.

Why did VA change the methodology of the congressionally mandated study?

Ms. DAVEY. In our statement of work, we asked the IOM to convene a group of medical professions, that is absolutely right, and to do the work around the kernel of the existing research.

Inherent in that, certainly intended, was that those medical professionals would bring their clinical research expertise to the table. And, as we know, experience and clinical experience in particular is one form of knowledge that we know, as is knowledge from research studies. We expected that those professionals would have discussions based on their experience as well as the research.

Mr. COFFMAN. And why wasn't—why weren't the findings of this research published for peer review purposes?

Ms. DAVEY. You may be referring to Dr. Coughlin's comments about some of our research in the Office of Public Health, the large epidemiologic studies. When you do a study such as a survey with scores of questions, you collect much data, and you prioritize in an analysis plan which analyses are going to take place first. Those analyses do take place in order, and we do carry them out.

Mr. COFFMAN. Why does it appear that there has been a misappropriation of funds appropriated for the purpose of research for Gulf War Illness that seems to be diverted for other purposes?

Ms. DAVEY. Mr. Chairman, that is a question for my research colleagues, and I would like to take that one for the record. We were not prepared here to talk about research funding.

[THE ATTACHMENT APPEARS IN THE APPENDIX]

Mr. COFFMAN. Very well. Ranking Member Kirkpatrick.

Mrs. KIRKPATRICK. Dr. Davey, in your testimony you state that the VA is now in the process of developing additional innovative training resources, such as mobile devices and Internet applications. After 22 years this seems a bit late to just now be developing applications for the environmental exposure symptoms and conditions. So when did this process begin, and when do you think you will be able to roll it out to veterans so that it might be helpful?

Ms. DAVEY. Well, to speak to your larger question, the care and treatment that we have learned, and we are experts in the care of veterans, have taken place over the course of 22 years because that is what time it takes. We have to understand what we are dealing with, and it has taken that amount of time.

With regard to the specific innovative tools, obviously since the technology has been available, but let me refer to Dr. West, who is developing one of the Internet applications or the mobile app—

Mrs. KIRKPATRICK. Please, Dr. West.

Ms. DAVEY.—comment more.

Dr. WEST. Well, thank you so much. I am actually a primary care physician and a general internist by trade, and I am proud to say that every day I take care of Gulf War veterans and all veterans, and it is really my privilege.

To answer that question directly, we have already developed a lot of these tools. In fact, in your packet you have one of them, the pocket card—I don't know if you guys have looked at it—which has essentially a lot of what Dr. Steele was talking about, a lot of the exposure concerns, a lot of the public health Web sites, Webinars, and training modules that have been developed through Office of Public Health and through VHA, you know, as a whole.

As far as getting that onto a mobile app, that is in the process. Otherwise we have talked a little bit about the IOM pop-ups and clinical reminders for physicians, which is another computer-based application. We have already developed a type of pop-up called a clinical reminder that helps physicians, A, understand where their veterans are coming from, their service; second, actually goes through the chronic multisystem illness and lays that out in a way that they can kind of follow a simple screen, answer questions, and better adequately answer the veterans' questions.

I mean, that is a key. I mean, these tools are really important to train providers, to get them out on the frontlines. Again, I see patients every day in clinic.

Mrs. KIRKPATRICK. And let me just interrupt quickly. I understand that, but my concern is how do we communicate to veterans so that they may get the resources they need? And the mobile apps, I know, are in the process, but do you have a timeline for when

you are going to roll that out, when that is actually going to be available to veterans so they can learn about it?

Dr. WEST. I don't have an exact timeline for the veterans communication app, so I would have to take that back for the record.

[THE ATTACHMENT APPEARS IN THE APPENDIX]

Mrs. KIRKPATRICK. Okay. Could you get back to me on that. I think it is—

Dr. WEST. Absolutely.

Mrs. KIRKPATRICK.—essential.

One of the things that I realize, it seems like the VA is always a little behind on this, and it has been 22 years, and so, I really would like to have some benchmarks, some timetables so that we can report to our veterans that we are moving forward with this.

And, Mr. Chairman, in the interest of time, I am going to yield back. I know we are going to have votes here in just a second.

Mr. COFFMAN. Mr. Murphy, in a recent request for information, VA responded to this Committee that they could not provide the total number of Gulf War-era veterans who were in receipt of service-connected disability benefits for CMI, because VBA does not have a diagnostic code to identify only CMI-related claims, and it could not be separated from other undiagnosed illnesses.

Other than CMI, what other undiagnosed illnesses does VA award service-connected benefits for?

Mr. MURPHY. Mr. Chairman, I don't have the answer to that question, but I can tell you that they are covered under a group of undiagnosed illnesses, which makes it very difficult without literally sitting down and going through file page by page, veteran by veteran to come in.

Mr. COFFMAN. I think the question is, is what other undiagnosed illnesses are there that benefits are awarded for other than CMI?

Mr. MURPHY. That is one I have to take for the record. I don't have an answer for that.

Mr. COFFMAN. You don't know?

Mr. MURPHY. No, sir, I do not.

Mr. COFFMAN. Okay. I want that information.

Mr. MURPHY. Yes, sir.

[THE ATTACHMENT APPEARS IN THE APPENDIX]

Mr. COFFMAN. If you are awarded service—if you are awarding service-connection for other undiagnosed illnesses, then why does 38 CFR 3.317, referring to the statute or regulation, the only regulation which explicitly mentions undiagnosed illness in CMI, and it, in fact, is labeled, quote, “compensation for disability due to undiagnosed illness and medically unexplained Chronic Multisymptom Illness,” unquote, specifically state that it applies to Persian Gulf veterans, defining both that phrase and the phrase, quote, “Southwest Asia theater of operations,” unquote, within the regulation?

Mr. MURPHY. I don't understand the question, Mr. Chairman.

Mr. COFFMAN. Why don't we take that one for the record?

Mr. MURPHY. Okay.

[THE ATTACHMENT APPEARS IN THE APPENDIX]

Mr. COFFMAN. Why doesn't VA have a specific diagnostic code to evaluate CMI? Is this something that is being looked into as part of the current rating schedule revision that is taking place?

Mr. MURPHY. Yes, absolutely. Under the rewrite project, this is absolutely being considered as a change, because the entire volume, in its entirety, is under rewrite.

Dr. HUNT. Mr. Chairman, there has kind of been a shift because the IOM report really has characterized this thing using the term and a kind of the nomenclature "Chronic Multisymptom Illness." Up until this point we have been using different nomenclature, "medically unexplained or undiagnosed illnesses." It is the same symptoms, and it is almost any physical symptom a person can have that a person can get service-connected for, a Gulf War veteran.

It is just that now we are calling it Chronic Multisymptom Illness, and there is some debate about how do we create a case definition for exactly what that means. Originally we said fatigue, idiopathic pain, and cognitive disturbances. Those are the three main ones. But then we started seeing bowel symptoms, we started seeing other neurological symptoms. So then we said really any symptoms a person has, and now we are—it is a new kind of characterization of it. It is not a new term, but now we are saying, look, we are going to—this is Chronic Multisymptom Illness; this is the way we get our arms around it and really start treating it more effectively.

Mr. COFFMAN. Ranking Member Kirkpatrick, any final questions or comments?

Mrs. KIRKPATRICK. No.

Mr. COFFMAN. Thank you all. I want to thank you all for testifying, both panels for testifying today. I want to say as a Gulf War veteran, I find the conduct of the Veterans Administration embarrassing on this issue in terms of their treatment of veterans.

I have to ask you, is anybody a Gulf War veteran that is on this panel right now?

You know, I think if there were—if there was one or if there were Gulf War veterans in senior positions in the Veterans Administration, I don't think we would be here today.

[Whereupon, at 5:01 p.m., the Subcommittee was adjourned.]

## A P P E N D I X

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### Prepared Statement of Hon. Mike Coffman, Chairman

Good afternoon. I'd like to welcome everyone to today's hearing titled "Gulf War: What Kind of Care are Veterans Receiving 20 Years Later?"

Yes, it has been over 20 years since the Gulf War. I remember it very well, having been there myself as a Marine. Now, as Chairman of this subcommittee, I am asking the same questions many fellow Gulf War veterans have- namely, how is this unique set of veterans being treated by VA?

While it may be pretty easy to determine whether a veteran served in the Gulf War, it has been difficult for some time to accurately identify what constitutes "Gulf War Illness." However, a lot of people, both in the veteran community and the medical community, agree that it exists. In fact, VA's current Chief of Staff, John Gingrich, once made the following comment about Gulf War Illness:

"While commanding an artillery battalion during Gulf War I, one of my soldiers suddenly became quite ill. Despite the best efforts of our medical team, they could not diagnose what made him so sick. Out of 800 soldier is [sic] under my command, no one else was that sick. Now here we are, almost 20 years later and this Veteran is still suffering- and has been since the war. I have watched him when he could barely stand up, couldn't cross the room on his own, his legs were so weak. He has been in and out of hospitals many times, seen by some of the best doctors and yet there is still no explanation for his debilitating illness ... and this Veteran is not alone."

Chronic, multisymptom illness, or "CMI", is by its own definition not just one item that a VA physician can look for. However, there are certain things a VA physician can and should look for, and determining whether a veteran likely has CMI that can be attributed to service in the first Gulf War should be a straightforward process. However, I'm concerned that is not what is happening in practice.

This hearing today is not about whether Gulf War Illness exists; this hearing is about how it is identified, diagnosed, and treated, and how the tools put in place to aid these efforts have been used. For example, is the Gulf War Registry working as intended and being used properly? If not, what is VA doing to fix the problem, and what can this Committee do to help VA in that effort?

Are the findings of the Research Advisory Committee being put to use in identifying, diagnosing, and treating those veterans suffering from Gulf War Illness? If not, where is the disconnect? How can this Committee help VA better assist these veterans?

We have learned a lot in the last twenty years. Science and research has identified unique medical issues for the veterans of the Gulf War, and established baselines from which we can gain a better understanding of those unique issues. Gulf War Illness has significant physical effects on the lives and well-beings of those veterans, and we need to make sure that VA can and does make every effort to accurately identify, diagnose, and treat them in a timely fashion. To be sure, it should not take another 20 years for us all to get this right.

I look forward to hearing from today's witnesses on what is working in treating Gulf War Illness, where problems remain, and how the entire process can be improved.

With that, I yield to Ranking Member Kirkpatrick for a statement.

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### Prepared Statement of Hon. Ann Kirkpatrick

Thank you Mr. Chairman.

Because we know that the deployment experience of our veterans is especially important in the world of research, and the care and treatment of injuries and illnesses, I want to thank you for holding this hearing on Gulf War veterans and the

progress or not, of recognizing and treating these veterans, for ill defined and undiagnosed conditions.

It is estimated that up to 35 percent of veterans who have served in the Gulf War suffer from symptoms that are not readily identifiable or well understood.

In the Institute of Medicine's report released just this past January and on which this hearing is based, these conditions are called Chronic Multisymptom Illness or CMI.

Veterans from the 1991 Gulf War have struggled for more than two decades to dispel the all too often accusation that "it is all in your head".

Veterans of the Iraq and Afghanistan wars have recently presented to the Veterans Health Administration with similar symptoms and have joined their fellow veterans in the fight for effective treatments and legitimate recognition of CMI by providers.

Keeping the struggle of this generation of veterans in the forefront of this Subcommittee is not just important, but crucial for us, as a Nation, to finally look at service in combat not so narrowly as just that span of time served in combat, but to look at the whole experience of the servicemember from the perspective of pre deployment, deployment and post deployment as the sum total of the things that have happened to a servicemember.

Hopefully this hearing will provide us a better perspective and a more holistic approach in understanding their unique needs and the full toll that serving takes on everyone. In this way, we are better able to contribute to their healing and readjustment.

I think it is incumbent upon us to learn as much as we can about what our Nation is asking of our servicemembers and families when they volunteer to raise their right hand.

We must recognize and be prepared to address the consequences of that service and bring to bear our best efforts to ensure that they are thoroughly prepared to serve and when they return home we commit to making them whole again.

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#### **Prepared Statement of Lea Steele, Ph.D.**

Thank you for inviting my testimony today. My name is Dr. Lea Steele. I'm an epidemiologist and have been involved in research on the health of 1991 Gulf War veterans since 1998, when I directed a Gulf War research program sponsored by the State of Kansas. Since that time, I've also served on a number of federal committees charged with planning, reviewing, and advising government agencies on Gulf War research. This includes appointment to the Congressionally-mandated Research Advisory Committee on Gulf War Veterans' Illnesses (RAC), and the privilege of serving as the Committee's Scientific Director from 2003 – 2008. I am currently Research Professor of Biomedical Studies at Baylor University, where I direct a multifaceted research program on the health of Gulf War veterans, in collaboration with scientists across the United States.

I've been asked today to provide information on the effectiveness of federal agencies in addressing health issues that affect veterans of the 1990–1991 Gulf War. The most prominent and widespread health problem from that war, as you know, is the condition commonly known as Gulf War illness. There are also other health issues of concern, but due to time constraints, my comments today will focus on this signature health problem. We use the term Gulf War illness to refer to the serious, often disabling symptom complex associated with military service in the 1990–1991 Gulf War. I want to be clear: by Gulf War illness, we mean a characteristic profile of symptoms—persistent memory, cognitive, and other neurological problems, widespread pain, disabling fatigue, digestive abnormalities, respiratory difficulties—concurrent symptoms that are *not* explained by established medical or psychiatric diagnoses.

Now, 22 years after the war, this pattern of chronic symptoms has been well documented in 1991 veterans from across the U.S. and other Coalition countries. We also know, from consistent research findings, that Gulf War illness is not a stress-induced or psychiatric disorder. Rates of stress and trauma-induced disorders like PTSD were much lower in Gulf War veterans than in other wars, and studies consistently find no association between war trauma or serving in combat, and rates of Gulf War illness. But studies do identify links between Gulf War illness and a number of hazardous exposures encountered by military personnel in theater. I should point out that today, March 13, 2013, is 22 years, almost to the day, since U.S. ground troops were exposed to low levels of chemical nerve agents following demolitions at a massive Iraqi munitions depot near Khamisiyah, Iraq, in the weeks

after the February 28 cease fire. The Pentagon estimates that about 100,000 U.S. troops located downwind were potentially exposed to low levels of nerve agents—sarin and cyclosarin gas—as a result.

Nerve agents are just one of a number of Gulf War-related toxicants identified as potential causes or contributors to the Gulf War illness problem. Regardless of its cause, however, there is no disagreement among scientists who have studied this issue that Gulf War illness is a real and serious problem for the many thousands of affected veterans. How many? Studies indicate between one fourth and one third of the nearly 700,000 veterans who served in the 1991 Gulf War developed Gulf War illness. Studies also show that few veterans have recovered, or even substantially improved, in the 22 years since the war.

In recent years, the federal government has made important progress in improving our understanding of Gulf War illness. However, there remain serious problems on a number of fronts at VA—including providing adequate healthcare for Gulf War veterans, and sponsoring the type of research needed to tangibly improve veterans' health.

I regret to say that, in some sectors within VA, there appears to have been backward movement, with actions that seem intended to ignore the science and minimize the fact that there is a serious medical condition resulting from military service in the 1991 Gulf War. This is a throwback to early speculation from the 1990s that there was no problem, or that veterans just had random, disconnected symptoms—symptoms that invariably develop after any military deployment and are likely stress-induced. Such opinions were more common in the 1990s, when there was limited research in this area. But they are inexplicable today, in 2013, in the face of consistent scientific evidence to the contrary. Such portrayals are especially troubling when they come from sectors within the federal agency tasked with serving veterans, and when they negatively affect government policies, healthcare, and research.

This is an incredibly important time for Gulf War illness research. Scientific advances in the last decade have provided important insights into Gulf War illness—how many people are affected, which factors are most implicated as contributing to this problem, and the biological processes that drive veterans' symptoms. Multiple research groups have now identified a range of neurological differences in veterans with Gulf War illness—differences in brain structures, brain function, and autonomic regulation. Studies have also identified specific immune, endocrine, and hematological differences in veterans with Gulf War illness. At the same time, results are beginning to come in from treatment studies that show significant benefits for veterans with Gulf War illness, with more treatment research in the pipeline, and more results expected in the near term. After so many years of waiting, there is finally some hope for Gulf War veterans—hope that they will have answers that are long overdue and hope that treatments will be found that can meaningfully improve their health and their lives. Those of us most involved in this research believe, based on recent progress, that these successes are possible, and within sight.

What is not acceptable, at this stage, is federal research that is poorly informed, based on notions developed in the early years after the Gulf War, rather than on the scientific evidence now available. Fundamentally, we have a situation wherein two federal agencies sponsor very different scientific research programs, both ostensibly to address health issues affecting Gulf War veterans. One program, the Department of Defense's Gulf War Illness Research Program (GWIRP) is managed by DOD's Office of Congressionally Directed Medical Research Programs (CDMRP), and has made great strides in a short time period, with about \$34 million in funding provided over just 5 years between FY2006 and FY2011 (the most recent year for which full information is available). When this program was developed in 2006, it began by defining a mission, by establishing priorities, and by enlisting the input and guidance of experts in the field and veteran stakeholders. This mission-oriented approach has yielded impressive progress, and the proof is in the results. The highest priority research for Gulf War illness are studies to identify effective treatments. Of the 50 separate projects approved for CDMRP funding between 2006 and 2011, 18 are treatment-related projects—11 clinical studies to assess treatments for Gulf War illness, and additional studies to evaluate treatments in animal models of Gulf War illness.

In contrast to DOD's mission-oriented approach, the Department of Veterans Affairs has not historically established a research vision or scientific plan, or managed a coordinated program to achieve targeted priorities for Gulf War veterans. Although long advised by a Congressionally-mandated independent panel of experts in Gulf War research (the RAC committee on which I serve), research programs and studies at VA often run counter to the advice of scientific experts. The proof, again, is in the results. VA has reported spending over \$120 million for "Gulf War re-

search” over the 10 years from 2002–2011. This includes a total of just 5 human and animal projects related to treatment for Gulf War illness—two focused on stress reduction. Overall, the many millions of research dollars identified by VA as supporting “Gulf War” research yielded a very limited pay-off for ill Gulf War veterans.

What happened? Although the devil is often in the details, there are two overarching themes.

**VA has been slow to clearly and accurately acknowledge the Gulf War illness problem.** VA continues to provide mixed signals and vague or inaccurate representations concerning the reality and nature of Gulf War Illness. This condition, initially called Gulf War Syndrome by the media, is now most commonly identified as “Gulf War illness”—by scientists, by the Department of Defense, and by veterans. The one exception is VA, where this illness is referred to in different ways in different places, often in vague terms, and suggesting that veterans have no specific or identifiable symptom complex resulting from the 1991 Gulf War.

This “generic” representation of the Gulf War illness problem, as a constellation of disparate symptoms that overlap considerably with psychiatric disorders, and are commonly found in all populations, provided the basis for the recent Institute of Medicine (IOM) report on treatments, commissioned by VA in response to a Congressional directive. As detailed elsewhere, VA’s charge to IOM differed from that directed by Congress. The resulting report usefully points out shortcomings in the health care provided to ill veterans. But the report also repeats and amplifies VA’s mischaracterization of the 1991 Gulf War illness problem. Regrettably, VA’s charge did not direct the IOM panel to consider the biological mechanisms of Gulf War illness that could be amenable to treatment. Nor did the IOM identify methods that experienced physicians have found to be beneficial for treating this condition. The report, then, not only failed to address the charge directed by Congress, it missed the opportunity to provide new and informed insights about treatments that might be brought to bear for veterans with Gulf War illness.

There are widespread examples, large and small, of VA “minimizing” the Gulf War illness problem. It is unthinkable, for example, that VA’s current national study of Gulf War veterans, conducted in 2013, does not assess Gulf War illness symptoms. This is the largest study of 1991 Gulf War veterans conducted in the U.S., targeting 30,000 veterans. It includes scores of questions in such areas as psychological stress, substance abuse, and alternative medicine. But it does not include the basic symptom data needed to define Gulf War illness, by any case definition. This is a wasteful and inexcusable missed opportunity at best, and something akin to scientific malpractice at worst.

**VA’s failure to establish an effective and strategic scientific research program to address priority Gulf War illness research questions.** This has been an ongoing and serious problem detailed by the RAC in major reports and annual evaluations. Among many possible examples, I will emphasize here two overarching problems: the lack of focus, expertise, and planning in VA’s Gulf War research program, and the lack of accountability in how funding is allocated for this research.

*Scientific ineffectiveness of VA’s Gulf War research program.* Despite strong urging from scientific experts, VA did not begin the process of developing a strategic plan for Gulf War research until 20 years after the war. A comprehensive process was finally undertaken in 2011 to develop such a plan, with nongovernment scientific experts and stakeholders from multiple institutions and offices within VA—nine groups of at least 6 members each—working over many months to craft and review the plan. The draft comprehensive plan was largely approved, by two expert committees, early in 2012. In the next several months, however, the plan was extensively changed by VA internal editors, who removed references to Gulf War illness and substantially altered the program developed to effectively define, study, and treat this problem. The federal Research Advisory Committee (RAC) on which I serve had long urged VA to develop a plan of this type, and some of its members assisted in developing the draft plan. But the Committee was extremely concerned about the extensive changes made internally by VA, which they believed to take the science and the teeth out of the plan. Last June, the RAC withdrew its support of the plan, and reported to the Secretary that, under current circumstances, the Committee had no confidence in VA’s ability to develop an effective Gulf War research program.

*Misallocated and misrepresented Gulf War research funding.* The Research Advisory Committee on Gulf War Veterans’ Illnesses (RAC) was charged by Congress to review and advise on all federal research programs that address Gulf War health issues. Our committee staff’s review of Gulf War research expenditures each year invariably finds that a large proportion of VA-identified “Gulf War” research studies would not be considered “Gulf War” research by any other government or nongovernment program. Many of the studies identified as Gulf War research at VA



have limited relevance, or no relevance at all, to the health of 1991 Gulf War veterans. This is not a trivial problem. In many years, 60 percent or more of the millions of dollars identified for “Gulf War” research is actually used for other types of research with no link, in any important respect, to Gulf War service. There are far too many examples to identify here. But they include notable high-dollar research items, like the \$10 million dollars used to fund a post mortem brain tissue bank identified as the “Gulf War Biorepository Trust.” In reality, this program is a brain bank for veterans with ALS, or Lou Gehrig’s disease. Most VA ALS patients are older veterans who served in earlier eras. As of 2010, only 1 of the 60 brains in this brain bank came from a Gulf War veteran, despite the use of \$10 million in Gulf War funding for this program that, despite its name, neither targets nor studies Gulf War veterans in any important way. In contrast to the millions in “Gulf War” funding used for non-Gulf War projects, VA has sponsored relatively few studies in high priority Gulf War research areas—for example, studies to advance improved diagnosis and treatments for Gulf War illness.

The proof, as always, is in the results. Together, VA’s poor representation of the Gulf War illness problem, and failure to apply current scientific knowledge to develop a focused, state-of-the-art research program, have led to relatively little in the way of tangible benefits for ill Gulf War veterans. From my perspective as a scientist who has worked in this area for many years, it is time to get this right. And certainly the many thousands of veterans who have suffered with Gulf War illness for more than 20 years would say it is long past time.

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#### **Prepared Statement of Steven S. Coughlin, Ph.D.**

Chairman Miller, and Members of the Subcommittee, thank you for the privilege of testifying today. I am Dr. Steven Coughlin, and I have worked as an epidemiologist for over twenty-five years, including positions as a senior cancer epidemiologist at the CDC and as Associate Professor of Epidemiology and Director of the Program in Public Health Ethics at Tulane University. I chaired the writing group that prepared the ethics guidelines for the American College of Epidemiology.

For the past 4 1/2 years, I was a senior epidemiologist in the Office of Public Health at the Department of Veterans Affairs. In December 2012, I resigned my position in the US Civil Service because of serious ethical concerns that I am here to testify about today.

The Office of Public Health conducts large studies of the health of American veterans. However, if the studies produce results that do not support OPH’s unwritten policy, they do not release them. This applies to data regarding adverse health consequences of environmental exposures, such as burn pits in Iraq and Afghanistan, and toxic exposures in the Gulf War. On the rare occasions when embarrassing study results are released, data are manipulated to make them unintelligible.

The 2009–2010 National Health Study of a New Generation of US Veterans targeted 60,000 OIF and OEF veterans and cost \$10 million plus the salaries of those of us who worked on it. Twenty to thirty percent of these veterans were also Gulf War veterans, and the study produced data regarding their exposures to pesticides, oil well fires, and pyridostigmine bromide pills. It also included meticulously coded data as to what medications they take. The Office of Public Health has not released these data, or even the fact that this important information on Gulf War veterans exists. Anything that supports the position that Gulf War illness is a neurological condition is unlikely to ever be published.

I coauthored a paper for publication on important research findings from the New Generation study on the relationship between exposures to burn pits and other inhalational hazards and asthma and bronchitis in OIF/OEF veterans. My supervisor, Dr. Aaron Schneiderman, told me not to look at data regarding hospitalizations and doctors’ visits. The tabulated findings obscure rather than highlight important associations. When I advised him I did not want to continue as a co-investigator under these circumstances, he threatened me. Speaking as a senior epidemiologist with almost 30 years of research experience, there is no reason to work night and day for years on a complex data collection effort (which cost US taxpayers millions of dollars) if you are not comfortable putting your name on publications stemming from the study or if no scientific publications are released.

Another example of important data that has never been released are the results of the Gulf War family registry mandated by Congress. These were physical examinations provided at no charge to Gulf War veterans’ family members. I have been advised that these results have been permanently lost.

The Office of Public Health has also manipulated information regarding veterans' health through the questions included in their surveys. During the preparation of a major survey of Gulf War era veterans of which I was principal investigator, the Follow-up Study of a National Cohort of Gulf War and Gulf War Era Veterans, the Research Advisory Committee on Gulf War Illness made extensive recommendations regarding changes to the survey. I considered these changes as constructive, and some were adopted.

The VA Chief of Staff (COS) directed my supervisors to send the Gulf War study scientific protocol and draft questionnaire out for additional, objective scientific peer review. The OPH Chief Science Officer, Dr. Michael Peterson, contacted a long-time friend of his who is Dean of a school of public health, who identified a faculty member at his school, although the individual had no background in Gulf War health research. My direct supervisor, Dr. Schneiderman, spoke with the peer reviewer and told him that the RAC's comments were politically motivated, i.e. not objective in nature. The reviewer responded that he would "certainly try to help out." Not surprisingly, the reviewer's comments were very favorable. The Chief of Staff was never informed that the outside reviewer worked for a friend of Dr. Peterson.

My supervisors also made false statements in writing to the Chief of Staff. For example, they falsely stated that putting the study on hold long enough to revise the questionnaire would cost the Government \$1,000,000, delay the study for a year or longer, and potentially result in contract default. None of this was true. But as a result, the Chief of Staff ordered the survey to proceed without the changes.

The Office of Public Health also handles VA's dealings with the Institute of Medicine, which is part of the National Academies of Science. Congress and VA leadership rely on the Institute of Medicine for authoritative, objective information on medical science.

Last year, VA contracted with the IOM for a Congressionally-mandated study of treatments for chronic multisymptom illness in Gulf War veterans. Many Gulf War veterans were distressed that five speakers selected to brief the IOM committee presented the view that the illness may be psychiatric, although science long ago discredited that position. My understanding is that Dr. Peterson, an OPH Chief Science Officer, identified the speakers the IOM should invite.

I wish to close with a subject of particular importance to me. Almost 2,000 research participants from the New Generation survey self-reported that they had thoughts in the previous two weeks that they would be better off dead. However, only a small percentage of those veterans ever received a call back from a mental health clinician. Some of those veterans are now homeless or deceased. I was unsuccessful in getting senior Office of Public Health officials to address this problem in the New Generation study.

I was successful in incorporating these call-backs in the Gulf War survey, and they have saved lives, but only after my supervisors threatened to remove me from the study and attempted disciplinary action against me when I appealed their refusal to provide for call backs to higher authority.

I urge this Committee to direct VA to immediately identify procedures to ensure that veterans who participate in VA large-scale epidemiologic studies received appropriate follow-up care so that this tragedy is not repeated.

I also urge you to initiate legislation to cure the epidemic of serious ethical problems in the Office of Public Health I have described to you today. In view of the pervasive pattern where these officials fail to tell the truth, even to VA leadership, VA cannot be expected to reform itself. These problems impact the balance of risks and benefits of federally funded human subjects research costing tens of millions of dollars and which fail to serve the interests of the veterans they are intended to benefit.

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Included below is additional written testimony regarding efforts to ensure that call-back services were available to Gulf War veterans expressing suicidal thoughts, and mechanisms to provide for the sharing of survey data to qualified researchers.

In the Spring of 2012, in the course of planning the follow study of Gulf War Veterans, I had discussions with my supervisors at VA and with the Chair of the Institutional Review Board (IRB) at the VA Medical Center in Washington, DC about the need to identify mental health professionals who could call-back research participants who were experiencing suicidal ideation and assist them with getting into VA health care. After my efforts to ensure that Veterans enrolled in the study were appropriately cared for were blocked by my supervisors, I contacted the IRB Chair and the VA Office of Inspector General. I was then openly threatened and retaliated against by my supervisors, who made false and misleading statements in writing

about my efforts to put the call-back procedures in place. I received a written admonition and was also told I might be replaced as Principal Investigator of the study. Over the course of a few months, I successfully appealed the admonition by telling the truth, with the assistance of a VHA Deputy Under-Secretary.

In August of 2012, I was finally allowed to engage VAMC mental health professionals as co investigators on the study. Between August 2, 2012, and January 1, 2013, a team of licensed clinical social workers and psychologists completed 1,331 calls to Veterans. As of January 31st VHA clinical personnel have been able to directly contact 984 of those Veterans. Of these, 48 Veterans were referred to the Veterans Crisis Line for immediate assistance. The majority of calls provided the Veteran with either the Veterans Crisis Line toll free number, information about local resources including Vet Centers (local VA mental health centers) or community based outpatient clinics, and information on how to enroll for VA health care. Veterans were also encouraged to talk with their primary care physician about depression if they were not already engaged in mental health treatment. The VA mental health professionals who made the call-backs saved lives and ameliorated human suffering, partly by helping vulnerable research participants get access to health care benefits to which they are entitled to. When you are suffering from a neurologic condition such as Gulf War Illness, or a psychiatric condition such as major depression, it can be quite difficult to navigate the procedures for gaining access to health care benefits.

As a further practical suggestion, the Office of Public Health should put data from their surveys into VINCI (the VA Office of Research and Development's national data sharing resource). There are a lot of qualified VA researchers around the country who would love to have access to New Gen Study data (e.g., the extensive coded data on prescription medications and doctors visits in the past year) that have never been published. VINCI provides requires IRB review and approval and strict confidentiality safeguards. OPH has lost some key data sets that were stored at the Austin automation center mainframe computer in Texas. A notable example is the national registry developed several years for family members of Gulf War Veterans. That registry database, which was mandated by Congress, is apparently lost forever. The use of the VINCI data repository and data sharing resource developed by the VA Office of Research and Development (ORD) would protect against future catastrophic loss of data.

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#### Prepared Statement of Bernard Rosof, M.D.

Mr. Chairman, Ranking Member Kirkpatrick, and Members of the Subcommittee, I am Bernard Rosof, Chairman of the Board of Directors at Huntington Hospital in Huntington, New York. I also served as Chair of the Institute of Medicine's Committee on Gulf War and Health: Treatment for Chronic Multisymptom Illness. The Institute of Medicine, or IOM, is the health arm of the National Academy of Sciences, an independent, nonprofit organization that provides unbiased and authoritative advice to decision makers and the public. Thank you for the opportunity to submit testimony for the record based on the IOM's report *Gulf War and Health: Treatment for Chronic Multisymptom Illness*.<sup>1</sup>

##### *Background*

Chronic multisymptom illness (CMI) is a serious condition that imposes an enormous burden of suffering on our nation's veterans. Veterans who have CMI often have physical symptoms (such as fatigue, joint and muscle pain, and gastrointestinal symptoms) and cognitive symptoms (such as memory difficulties) and may have shared symptoms with known syndromes (such as chronic-fatigue syndrome [CFS], fibromyalgia, and irritable-bowel syndrome [IBS]) and other clinical entities (such as depression and anxiety). In its report, the IOM committee defined CMI as the presence of a spectrum of chronic symptoms experienced for 6 months or longer in at least two of six categories—fatigue, mood and cognition, musculoskeletal, gastrointestinal, respiratory, and neurologic—that may overlap with but are not fully captured by known syndromes (such as CFS, fibromyalgia, and IBS) or other diagnoses.

Despite considerable efforts by researchers in the United States and elsewhere, there is no consensus among physicians, researchers, and others as to the cause of

<sup>1</sup>IOM. 2013. *Gulf War and Health: Treatment of Chronic Multisymptom Illness*. Washington, DC: The National Academies Press.

CMI. The constellation of unexplained symptoms experienced by people who have CMI could result from multiple factors, but the etiology remains unknown.

*The Charge to the Committee*

The IOM study was mandated by Congress in the Veterans Benefits Act of 2010 (Public Law 111–275, October 13, 2010). That law directs the secretary of veterans affairs “to enter into an agreement with the Institute of Medicine of the National Academies to carry out a comprehensive review of the best treatments for CMI in Persian Gulf War veterans and an evaluation of how such treatment approaches could best be disseminated throughout the Department of Veterans Affairs [VA] to improve the care and benefits provided to veterans.”

In August 2011, VA asked that IOM conduct a study to address that charge, and IOM appointed the Committee on Gulf War and Health: Treatment for Chronic Multisymptom Illness. The complete charge to the committee follows.

The IOM will convene a committee to comprehensively review, evaluate, and summarize the available scientific and medical literature regarding the best treatments for CMI among Gulf War veterans. In its evaluation, the committee will look broadly for relevant information. Information sources to pursue could include, but are not limited to:

- Published peer-reviewed literature concerning the treatment of multisymptom illness among the 1991 Gulf War veteran population;
- Published peer-reviewed literature concerning treatment of multisymptom illness among Operation Enduring Freedom, Operation Iraqi Freedom, and Operation New Dawn active duty service members and veterans;
- Published peer-reviewed literature concerning treatment of multisymptom illness among similar populations such as allied military personnel; and
- Published peer-reviewed literature concerning treatment of populations with a similar constellation of symptoms.

In addition to summarizing the available scientific and medical literature regarding the best treatments for CMI among Gulf War veterans, the IOM will:

- Recommend how best to disseminate this information throughout the VA to improve the care and benefits provided to veterans.
- Recommend additional scientific studies and research initiatives to resolve areas of continuing scientific uncertainty.
- Recommend such legislative or administrative action as the IOM deems appropriate in light of the results of its review.

*The IOM Committee’s Conclusions and Recommendations*

The committee’s conclusions and recommendations are in five major categories:

- Treatments for CMI.
- The VA health-care system as it is related to improving systems of care and the management of care for veterans who have CMI.
- Dissemination of information through the VA health-care system about caring for veterans who have CMI.
- Improving the collection and quality of data on outcomes and satisfaction of care for veterans who have CMI and are treated in VA health-care facilities.
- Research on diagnosing and treating CMI and on program evaluation.

**Treatments for CMI**

The committee conducted a de novo systematic assessment of the evidence on treatments for symptoms associated with CMI. The committee also identified evidence-based guidelines and systematic reviews on treatments for related and comorbid conditions (fibromyalgia, chronic pain, CFS, somatic symptom disorders, sleep disorders, IBS, functional dyspepsia, depression, anxiety, posttraumatic stress disorder, traumatic brain injury, substance-use and addictive disorders, and self-harm) to determine whether any treatments found to be effective for one of these conditions may be beneficial for CMI. On the basis of the extensive evidence reviewed, the committee cannot recommend any specific therapy as a set treatment for veterans who have CMI. The committee concluded that a “one size fits all” approach is not effective for managing veterans who have CMI and that individualized health-care management plans are necessary. Specifically, the committee recommends that VA implement a system-wide, integrated, multimodal, long-term management approach to manage veterans who have CMI.

**The VA health-care system as it is related to improving systems of care and the management of care for veterans who have CMI**

To identify veterans who have CMI and bring them into the VA health-care system, VA should commit the necessary resources to ensure that veterans complete a comprehensive health examination immediately upon separation from active duty. The results should become part of a veteran's health record and should be made available to every clinician caring for the veteran, whether in or outside the VA health-care system. Coordination of care, focused on transition in care, is essential for all veterans to ensure quality, patient safety, and the best health outcomes. Additionally, VA should include in its electronic health record a "pop-up" screen to prompt clinicians to ask questions about whether a patient has symptoms consistent with the committee's definition of CMI.

Once a veteran has been identified as having CMI and has entered the VA health-care system, the next step is to provide comprehensive care for the veteran, not only for CMI but also for any comorbid conditions. Existing VA programs, such as postdeployment patient-aligned care teams (PACTs), could be adapted to best serve veterans who have CMI. VA should develop PACTs specifically for veterans who have CMI (that is, CMI-PACTs) or CMI clinic days in existing PACTs at larger facilities, such as VA medical centers. A needs assessment should be conducted to determine what expertise is necessary to include in a CMI-PACT. Furthermore, VA should commit the resources needed to ensure that PACTs have the time and skills required to meet the needs of veterans who have CMI as specified in the veterans' integrated personal-care plans, that the adequacy of time for clinical encounters is measured routinely, and that clinical case loads are adjusted in response to the data generated by measurements. VA should use PACTs that have been demonstrated to be centers of excellence as examples so that other PACTs can build on their experiences. VA should develop a process for evaluating awareness among teams of professionals and veterans of its programs for managing veterans who have CMI, including PACTs, specialty care access networks (SCANs), and war-related illness and injury study centers (WRIISCs); for providing education where necessary; and for measuring outcomes to determine whether the programs have been successfully implemented and are improving care. Finally, VA should take steps to improve coordination of care among PACTs, SCANs, and WRIISCs so that veterans can transition smoothly across these programs.

**Dissemination of information through the VA health-care system about caring for veterans who have CMI**

A major determinant of VA's ability to manage veterans who have CMI is the training of clinicians and teams of professionals in providing care for these patients. To disseminate information about CMI to clinicians, VA should provide resources for and designate "CMI champions" at each VA medical center. The champions should be integrated into the care system (for example, PACTs) to ensure clear communication and coordination among clinicians. VA also should develop learning, or peer, networks to introduce new information, norms, and skills related to managing veterans who have CMI. Because many veterans receive care outside the VA health-care system, clinicians in private practice should be offered the opportunity to be included in the learning networks and VA should have a specific focus on community outreach. Another dissemination opportunity is for VA to provide required education and training for its clinicians in communicating effectively with and coordinating the care of veterans who have unexplained conditions, such as CMI.

**Improving the collection and quality of data on outcomes and satisfaction of care for veterans who have CMI and are treated in VA health-care facilities**

To improve outcomes and ultimately to improve the quality of care that the VA health-care system delivers, VA should provide the resources needed to expand its data collection efforts to include a national system for the robust capture, aggregation, and analysis of data on the structures, processes, and outcomes of care delivery and on the satisfaction with care among patients who have CMI so that gaps in clinical care can be evaluated, strategies for improvement can be planned, long-term outcomes of treatment can be assessed, and this information can be disseminated to VA health-care facilities.

**Research on diagnosing and treating CMI and on program evaluation**

Many studies on treatments for CMI reviewed by the committee have methodological flaws. Therefore, future studies funded and conducted by the VA to assess treatments for CMI should adhere to the methodologic and reporting guidelines for clinical trials, including appropriate elements (problem-patient-population, inter-

vention, comparison, and outcome of interest) to frame the research question, extended follow up, active comparators (such as standard of care therapies), and consistent, standardized, validated instruments for measuring outcomes. VA should fund and conduct studies of interventions that evidence suggests may hold promise for treatment of CMI.

The committee did not find comprehensive evaluations of VA programs, such as the PACTs, SCAN-ECHO programs, and WRIISCs. Program evaluation—including assessments of structures, processes, and outcomes—is essential if VA is to continually improve its services and research. Therefore, the VA should apply principles of quality and performance improvement to internally evaluate VA programs and research related to treatments for CMI and overall management of veterans who have CMI. This task can be accomplished using such methods as comparative-effectiveness research, translational research, implementation-science methods, and health-systems research.

#### *Summary*

As detailed above, numerous opportunities exist for VA to improve and expand its health-care services for veterans who have CMI. The IOM committee encourages VA to apply the principles set forth in its report, including at a minimum adequate resources to ensure early entry into the VA health-care system and adherence to the principles of patient-centered and compassionate care, shared decision-making, and regular clinical follow up as necessary. Our veterans deserve the very best health care.

Thank you, again. I would be happy to answer any questions the Subcommittee might have.

#### **Executive Summary**

##### **Gulf War and Health: Treatment for Chronic Multisymptom Illness**

On January 23, 2013, the Institute of Medicine (IOM) released its report, *Gulf War and Health: Treatment for Chronic Multisymptom Illness*.<sup>1</sup> IOM is the health arm of the National Academy of Sciences, an independent, nonprofit organization that provides unbiased and authoritative advice to decision makers and the public.

Chronic multisymptom illness (CMI) is a serious condition that imposes an enormous burden of suffering on our nation's veterans. Veterans who have CMI often have physical symptoms (such as fatigue, joint and muscle pain, and gastrointestinal symptoms) and cognitive symptoms (such as memory difficulties) and may have shared symptoms with known syndromes (such as chronic-fatigue syndrome, fibromyalgia, and irritable-bowel syndrome) and other clinical entities (such as depression and anxiety). Despite considerable efforts by researchers in the United States and elsewhere, there is no consensus among physicians, researchers, and others as to the cause of CMI.

The Department of Veterans Affairs (VA) asked that IOM conduct a study to evaluate treatments for CMI among Gulf War veterans to determine how to best manage care for veterans who have this condition. IOM assembled an expert committee to address this task.

The committee conducted an extensive systematic assessment of the evidence on treatments for CMI. It also assessed treatments for a number of related and comorbid conditions to determine whether any of them may be beneficial for CMI. On the basis of its assessment, the committee cannot recommend any specific therapy as a set treatment for veterans who have CMI. The committee concluded that a “one size fits all” approach is not effective for managing these veterans and that individualized health-care management plans are necessary. Specifically, the committee recommends that VA implement a system-wide, integrated, multimodal, long-term management approach to manage veterans who have CMI.

In its report, the committee makes 13 additional recommendations aimed at identifying veterans who have CMI, bringing them into the VA health-care system, and improving the quality of their care. VA should provide comprehensive care for the entire constellation of symptoms experienced by the veteran—including CMI as well as other health conditions. A health-care team-based approach is essential to provide this type of comprehensive care. Existing VA programs, such as postdeployment patient-aligned care teams, could be adapted to best serve veterans who have CMI.

Numerous opportunities exist for VA to improve and expand its health-care services for veterans who have CMI. Our veterans deserve the very best health care.

<sup>1</sup>IOM. 2013. *Gulf War and Health: Treatment of Chronic Multisymptom Illness*. Washington, DC: The National Academies Press.

### Prepared Statement of Anthony Hardie

Thank you, Chairman Coffman, Ranking Member Kirkpatrick and Members of the Veterans' Affairs Subcommittee on Oversight and Investigations for today's hearing.

Special thanks also to full committee Chairman Miller, Ranking Member Michaud, and Dr. Roe, whose leadership is helping fund the Gulf War Illness Congressionally Directed Medical Research Program – the only federal program in the 22 years since the 1991 Gulf War effectively working to improve the health and lives of ill Gulf War veterans.

Thank you also to the Gulf War veterans who traveled to attend this hearing, and to all the affected veterans watching from home.

#### BACKGROUND

As several Members already know, I'm a veteran of more than seven years active duty Army Special Operations service that included the 1991 Gulf War, Somalia, and four additional, non-combat overseas deployments. As I've provided in previous testimony, I developed health issues that commenced in the Gulf and have plagued me ever since, including a chronic cough that has never subsided, and other chronic health issues including chronic sinusitis, fatigue, irritable bowel, widespread pain, neurological, and other health issues.

As I have testified previously, many of us Gulf War veterans' chronic health issues began while still in the Gulf, in the prime of our young adulthood and at the peak of our health and physical fitness. Twenty-two years later, for many of us, our health issues have only worsened since first onset. In 2009, my own health worsened to the point where I was no longer able to continue working.

I wish that it was only me who was affected, but my experience is far from unique. A 2010 Institute of Medicine report summarized a large body of existing research and showed that Gulf War chronic multi-symptom issues continue to afflict roughly one in three of us Gulf War veterans.

Like nearly all other service-injured veterans I've encountered, the quest remains the same: effective treatments, and justice. As such, I'm honored to serve on the Congressionally chartered Research Advisory Committee on Gulf War Veterans' Illnesses (RAC), and the integration panel of the treatment-focused Gulf War Illness Congressionally Directed Medical Research Program (CDMRP) that sets the direction of the program and makes final recommendations on which research proposals to fund. I've also been honored to serve on the VA's Gulf War Research Steering Committee.

#### WHAT'S NOT WORKING

In 2009, I noted in testimony that Gulf War veterans looked to the new VA leadership, "with hopeful anticipation and continue to wish for their encouragement in achieving so many long-overdue and deeply needed goals on our behalf." Despite an initially strong restart, disappointingly, Gulf War veterans again seem to have been lost in the shuffle.

In 2009, I also testified that VA's own Gulf War research advisory "committees were not only not consulted; they still haven't even been informed of . . . decisions made without their input on issues directly within their purview." *These problems are now much worse. VA staff routinely ignore Congress, the law, expert advisors, basic democratic principles, and common decency.*

The real proof for Gulf War veterans is one of outcomes: VA still has no proven effective treatments for Gulf War Illness patients at VA medical centers, where they are often still thought to be psychosomatic. No VA newsletters to keep Gulf War veterans informed. No implementation of expert advisors' strategic plans and recommendations. No consistent, reliable medical surveillance of Gulf War veterans, including data on the prevalence of MS, cancers, or other serious health outcomes among Gulf War veterans.

VA's research focus over the last two decades has been largely related to stress, psychological issues, other diseases that affect veterans of all eras, and what has in the end amounted to trying to disprove there's anything wrong with the estimated one-third of Gulf War veterans suffering from Gulf War Illness. Instead of being aimed squarely at treatments and improving ill veterans' health and lives, many of these misguided efforts have continued through to the present. In VA's most recent annual national research review publication, VA's Gulf War research focus is characterized as, "investigating whether service in the Gulf War is linked to illnesses Gulf War veterans have experienced". [emphasis added]

*These failures are no accident.*

**IOM Treatments Committee.** A landmark 2010 report by the Institute of Medicine (IOM) confirmed successive research findings that the chronic multi-symptom illness we call Gulf War Illness is a unique diagnosis, that it is physical (not psychiatric) in nature, that it likely involves the interplay between environmental agents and individual genetics, that it affects more than 250,000 veterans of the 1991 Gulf War and other U.S. forces, and that treatments can likely be found. This IOM report confirmed similar 2008 RAC findings. IOM urged “a renewed research effort with substantial commitment to well-organized efforts,” to diagnose and treat GWI. Congress quickly followed with additional mandates to launch research, followed by a new VA contract with IOM related to treatments.

At its first meeting, presenters before a new IOM “treatments” panel diverged radically from both the Congressional authorizing language and established science. The panel was charged by VA to conduct a literature review rather than to consult with knowledgeable medical practitioners experienced in treating ill Gulf war veterans. And nearly all of the first presenters focused on “stress-as-cause”, psychol-ogical, and psychosomatic issues – all debunked years ago.

For example, one of the stress-as-cause presenters to the IOM “treatments” committee said, “Stress has been indicated as a factor in Gulf War Illness,”<sup>i</sup> citing three studies as reference. I immediately recognized one of cited studies, as its principal investigator had presented her findings to the RAC on which I serve, noting that what she found in ill Gulf War veterans was *distinct from and not* PTSD. The researcher’s actual conclusions were: “Despite the overlap of chronic unexplained health symptoms and PTSD in GWV, these symptom constellations appear to be biologically distinct.”<sup>ii</sup> This blatant mischaracterization of the research conclusions was not unique. And similar to other presenters that day, this presenter focused the second half of his talk on “stress management via relaxation-response (RR) therapies” – a mere band-aid for suffering veterans. The ill Gulf War veterans who called in to listen to the panel’s two public meetings were of course outraged.

Furthermore, the statutory mandate was for IOM to, “convene a group of medical professionals,” “experienced in treating,” 1990–91 Gulf War veterans. Instead, VA created a charge to the committee that it was to conduct a highly restricted literature review of published studies – which missed the entire statutory intent of eliciting potentially effective treatment modalities from experienced practitioners already caring for ill Gulf War veterans.

Additionally, the panel was led to lump together all sorts of chronic multisymptom issues, (“pick any two of six”) including in the general population, defined so broadly as to include nearly any human health condition.

In July 2009, a former IOM Gulf War and Health committee chair testified as to the unbiased and independent nature of such IOM committees: “The reports are developed through an established study process designed to ensure committees and the reports they produce are free from actual or potential conflicts of interests, are balanced for any biases, and are independent of oversight from the sponsoring agency.”<sup>iii</sup> However, in the case of this IOM treatments committee, the sponsoring agency – VA – not only issued the contract, but also presented its charge to the committee, shifted and limited the scope of what the committee could consider from the statutory authorizing language, and included multiple presenters to the committee – a far different reality from the unbiased 2009 expert witness testimony portrait.

A written request by three of us veterans to the IOM President for a copy of the VA–IOM contract and the presenter selection criteria was minimized and never fulfilled. A request to the VA Secretary’s office for the contract and appendant documents was similarly never fulfilled; the same goes for a FOIA request to VA. However, what is clear is the statutory language directing the formation of the committee, the VA’s charge to the committee that it of course followed, and the dramatic divergence between the two.

Thus, the process was fatally flawed through the actions of VA and likely other staff. The result was the well-intentioned, veteran-focused panel members almost entirely failed to meet the committee’s statutory mandate requiring a focus on consultation with medical practitioners experienced in treating ill Gulf War veterans, which could have gleaned important, beneficial insights. Furthermore, the final report included nearly 50 pages of recommended psychological treatment for a condition that is not psychiatric in nature. Finally, the report missed the main point emphasized by the 2010 IOM panel: effective treatments for GWI do not yet exist, but likely can be found, and a renewed national effort is recommended to develop treatments and preventions.

**Strategic Plan.** After being publicly criticized for not having a strategic plan to solve Gulf War Illness treatment, VA staff tasked its new, non-public Gulf War Steering Committee (on which I was appointed to serve as the sole Gulf War vet-



eran representative) to begin work to create such a plan. The Steering Committee, the RAC, and the VA's National Research Advisory Council (NRAC), and a myriad of drafting subcommittees that included VA and non-VA researchers and Gulf War veterans spent a year and a half in a model process finally developing a strategic plan.

The plan was a comprehensive, outcome-oriented, consensus-based. It was developed with the expertise of a substantial number of scientists and affected Gulf War veterans serving on a myriad of engaged, all-volunteer drafting subcommittees. It was aimed squarely at improving the health and lives of veterans suffering from Gulf War Illness. It met the approval of the Steering Committee, RAC, and NRAC.

However, after the report had been completed, VA staff quietly and unilaterally gutted and whitewashed the plan. Despite having been active participants in every step of the process, VA staff even went so far as to remove "Gulf War Illness" from the title. The end result was that it was no longer a plan to execute the IOM's call for a "renewed research effort . . . to better identify and treat multisymptom illness in Gulf War veterans." Instead, it had become a renewed license for VA staff to do pursue whatever research whims might next tickle their fancy, which to date has largely included research irrelevant or even inimical to Gulf War veterans' treatment needs – in other words, more of the same. One leading NRAC participant described feeling, "betrayed", and having "wasted" a year-and-a-half – sentiments I echoed then and today.

When the RAC met to discuss the whitewashed report, the Gulf War veteran members of the RAC were so angry at the wasted efforts of more than a year, the other Gulf War veteran on the panel stormed out in protest, and I discussed resignation with the committee chair. *Our panel responded by a unanimous decision to reject and return the plan to VA as unacceptable, and to declare "No Confidence" in VA's handling of Gulf War Illness research.*

It continues to get worse. VA staff have initiated sole-source contracting with IOM for a "literature review" to develop a new Gulf War Illness case definition. In addition to this process being in complete contravention to the thorough, careful process to develop a new case definition laid out in the draft Strategic Plan, I'm also told that this process is unprecedented and likely to harm Gulf War veterans. And, VA staff not only didn't inform the RAC of this initiative (the legal announcement was discovered online by another Gulf War veteran) but have refused to provide any details to the RAC. Why is VA allowed to continue unchecked?

**Multiple VA Failures.** The ensuing June 19, 2012 RAC report found that, "those responsible for VA [Gulf War] research fail to mount even a minimally effective program, while promoting the scientifically discredited view that 1991 Gulf War veterans have no special health problem as a result of their service."

The RAC report goes on to detail serious new grievances against VA, which in addition to gutting the proposed Gulf War Illness Research Strategic Plan, include secret cuts to the Gulf War Illness research budget, misrepresentation to VA leadership and Congress, blatant misdirection from statutory mandates, law violations, and citing as its research priority efforts to determine "whether" Gulf War veterans' illnesses are in fact linked to their Gulf War service rather than treatments to improve their health and lives.

**No Meetings.** VA staff have for one reason or another not allowed the RAC to hold a public meeting since that June 19th meeting. Public meetings scheduled for November/December and February in Washington, DC had to be cancelled.

In more recent times, the VA Secretary's office has remained largely and disappointingly silent and disengaged. Unlike his predecessors, and despite the Congressional language charging the RAC to advise the Secretary, Secretary Shinseki has never once personally come to a RAC meeting.

**OPH Survey.** Among the issues identified in the June 19th RAC report is regarding a follow-up survey by the VA's Office of Public Health (OPH) of a national cohort of Gulf War and Gulf War Era Veterans (earlier studies were conducted in 1995 and 2005; the health surveys are done to understand possible health effects of service and guide health care delivery).

This survey was heavily critiqued by the RAC on which I serve for failing to include expert recommendations related to Gulf War Illness, the overarching concern of the largest number of Gulf War veterans. Not only did the responsible VA staff stonewall our panel during a public meeting, entrenched VA bureaucrats ultimately convinced VA leadership to ignore the RAC's sound recommendations.

**MS Law.** Another of the issues identified in the RAC report is that VA continues to violate the law that requires VA to contract with IOM for a large-scale study to determine how prevalent Multiple Sclerosis is among veterans of the 1990–91 Gulf War and the Iraq and Afghanistan Wars.

The 2008 law directs VA to contract with IOM to conduct the prevalence study with a specific deadline. That deadline has long past, but VA continues to violate the law. It is my understanding that VA–OPH is the entity responsible for VA contracts with IOM.

It's more than a little ironic that while VA continues to ignore this law mandating MS prevalence research, an August 7, 2012 VA press release touted MS research as among VA accomplishments for Gulf War veterans.

**GWVI Task Force.** VA's Gulf War Task Force initially seemed to get off to a good start. However, VA leadership chose to not follow recommendations to involve affected stakeholders on the Task Force. As a closed group composed solely of internal VA staff, it has been prone to "groupthink", to repeating the same old problems, and to being entirely closed to and seemingly unresponsive to the Gulf War veteran public it was intended to serve. It operates in secret. Its meetings are not open to veterans or the public, the minutes of its monthly meetings are not made public, it has no website, and it has publicized only two reports in its multi-year existence. This secrecy is a far cry from the openness and transparency promised by our President and expected by affected veterans.

To its credit, the Task Force has fostered substantial written input from Gulf War veterans on its draft reports. However, most of that input has not appeared to impact the Task Force's final reports.

The Task Force reports have also included a number of initiatives. As one example, VA outlined a new clinical care initiative in its 2011 GWVI Task Force Report. Since information about it is neither public nor has been shared with the federal panel charged by Congress with overseeing Gulf War health research, we can only guess at how the clinical care model project might be going. In any case, it's hard to imagine how helpful a mere model of healthcare delivery will be to ill veterans when VA has not yet developed even a single proven effective GWI treatment.

**Discontinuation of "Gulf War Review".** In my 2007 testimony, I noted that VA's "Gulf War Review" newsletter – VA's quarterly direct-mail publication to Gulf War veterans – had apparently been discontinued. VA OPH staff testified at that hearing that a new issue would be forthcoming soon. Instead, no issues were published that year at all.

Now, the Gulf War and OIF/OEF newsletters have not been published since 2010. Ironically, the last Gulf War issue included a feature article: "Secretary Shinseki Marks 20th Anniversary of Gulf War with Renewed Pledge to Improve Care and Services to Gulf War Veterans." Congress should pass legislation mandating the continuation in perpetuity of this and related quarterly veteran-oriented publications, which should include ongoing, clear, spin-free updates on every federally funded research study and benefits change relevant to the target population.

**Consequences of "Psychiatrization" of Physical Illness.** Many of us heard recently of an American Legion Iraq War veteran whose longstanding symptoms were found to be caused by Q-Fever. After appropriate treatment, he was essentially cured.

It is unconscionable that DoD and VA do not perform comprehensive infectious disease and immunological testing in veterans returning from overseas areas where such diseases are endemic. IOM's 2012 "treatments" report noted that Iraq and Afghanistan War veterans are symptomatic of the committee's loosely defined, "chronic multisymptom illness".

Congress should pass legislation requiring such testing identify, treat, or definitively rule out a clear list of at least nine debilitating, chronic infectious diseases endemic to southwest Asia deployments.

**Claims.** After a complete overhaul, VA has now apparently ceased publishing its data report on Gulf War veterans. The report was formerly published quarterly; VA has failed to publish any further reports since February 2011. These reports are important for identifying approval rates of VA claims, among other issues.

In 2010, VA issued a new FAST letter clarifying "medically unexplained chronic multisymptom illness" claims. However, any aggregate effect of this effort remains unclear due to VA's discontinued publication of its quarterly Gulf War/Era/OIF/OEF data report. Congress should pass legislation to fix this problem.

I believe VA's new efforts to create Disability Benefits Questionnaires (DBQ's) are steps in the right direction. However, the fact that there is not one for "medically unexplained chronic multisymptom illness" claims diminishes the weight of the related 2010 FAST letter. Nothing will help change the VA culture of deferring, delaying, and denying these claims than creating a clear DBQ in black and white and ensuring its full implementation in the claims approval process. Congress should hold VA accountable until VA fixes this problem.

VA has made no apparent effort to correct flaws in the rating schedule for Fibromyalgia and Chronic Fatigue Syndrome (CFS/ME), as I noted in my 2009 testi-

mony, which continue to authorize 100 percent ratings for veterans with CFS alone but unjustly limit ratings to 40 percent for veterans with both CFS and fibromyalgia. Congress should pass legislation to fix this longstanding problem that VA continues to ignore but which affects many Gulf War veterans.

However, VA continues to publish an annual report on Gulf War research, in accordance with Section 707 of Public Law 102-585, as amended by section 104 of Public Law 105-368 and section 502 of Public Law 111-163, which require that an annual report be submitted to the Senate and House Veterans' Affairs Committees on the results, status, and priorities of research activities related to the health consequences of military service in the Gulf War (GW) in Operations Desert Shield and Desert Storm; August 2, 1990 – July 31, 1991.

Congress should pass similar legislation requiring VA to submit to Congress quarterly reports regarding 1991 Gulf War, OIF, OEF, and Gulf War Era veterans, providing aggregate data of claims filed, pending, approved, and denied, health care enrollment, and other benefits usage, similar to the former Gulf War Veterans Information System (GWVIS) and Gulf War Era Veterans Reports.

**VA Still Excludes Some Gulf War Veterans.** VA continues to unjustly exclude some Gulf War veterans from Gulf War-specific benefits, including those whose Gulf War service was in Turkey or Israel. And, Gulf War chronic multisymptom illness presumptives extend to Iraq War, but not Afghanistan War (OEF) veterans. Congress should pass legislation to fix these problems.

**Cabal.** To date, VA has no proven effective treatments, not because such treatments are impossible to find, but because a small cabal of federal bureaucrats and contractors work at every step to delay, defer, and deny, and even so far as to obfuscate and refuse to implement laws, policies, and expert recommendations.

These issues are not just limited to affecting veterans of the 1991 Gulf War. DoD's "Force Health Protection" and VA's Office of Public Health (OPH) continue to find "no evidence" of the very real health issues affecting countless thousands of additional veterans caused by their exposure to burn pits, chemical solvents in drinking water, contaminated and questionable anthrax and other vaccinations, inhaled or ingested Depleted Uranium (DU) particulates. These misguided people also continue to minimize and spin the all to real health effects of blast waves, concussions and other brain injuries, combat psychological traumas, and more.

These are not abstract forces or nameless, faceless bureaucrats. They are people like Kelley Ann Brix from the Defense Department's misleadingly named "Force Health Protection" office and psychiatrist Charles Engel, people who have seemed at every step of the way for most of the last two decades to have fought against the legitimate health interests of Gulf War veterans.

If these bureaucrats and contractors somehow believe they're helping, one need only evaluate the outcomes. Look only to what VA has to offer ill veterans coming to VA for help: band aids for symptoms and psychological counseling to at best help cope with enduring physical ailments.

Much of the propaganda that has come out of "Force Health Protection" does not foster servicemembers' health, it denies that health hazards are hazardous, that war has health consequences, that the health conditions afflicting troops are even real. They construct studies that look in the wrong direction, then finding nothing as would reasonably be expected they use these flawed findings to justify stopping looking.

It is possible this cabal, which for all intents and purposes appears to be working against veterans' legitimate health interests, is taking its direction from the 1998 Presidential Review Directive 5, which was developed as a result of emerging Gulf War health issues and included extensive recommendations on "strategic health communications". Perhaps some have construed these extensive recommendations as a directive to coordinate national public relations efforts to minimize deployment health issues. But "spin" is no substitute for epidemiology to identify deployment injury and illness with the end goals of treatment and prevention. Congress should carefully review, repeal, and replace PRD-5 and regulations and programs subsequent to PRD-5.

For example, the RAND study on Gulf War vaccinations has been suppressed for more than a decade. Taxpayers paid for that study, and Congress should order it released.

As Administrations come and go, these heretofore unaccountable staff and contractors must be held accountable. When VA appointees are misled and misdirected and VA appointees fail to fix longstanding problems, then perhaps only Congress can create the statutory conditions to ensure desired outcomes.

Divergence from the letter and spirit of the law should be criminalized, with violators sentenced to prison.

And until these changes can be made, these wayward entities, including FHP and VA-OPH should be substantially defunded, their employees permanently laid off, their contractors cut loose, and their funding redirected to entities like the CDMRP and DARPA that continue to prove they can achieve outcome-oriented results.

In short, *despite all the best promises and intentions, actions speak louder than words: VA has again broken Gulf War veterans' trust.*

#### WHAT IS WORKING

However, there are two bright spots for the treatment of ill Gulf War veterans. **The GWI CDMRP.** As an ill and affected Gulf War veteran, I am strongly supportive of the work being done by the Gulf War Illness Congressionally Directed Medical Research Program (CDMRP). It is very much unlike other VA and DoD efforts, which have been consistently criticized over the last two decades.

People suffering from the health condition under review, called “consumers,” are fully integrated into the entire CDMRP research proposal review process – a key feature of all of the CDMRP’s. Consumer reviewers are placed on par with the scientist reviewers as equally respected, personally affected advisors, helping to enhance the program’s focus, ensure appropriate impact of funded proposals, and impart the sense of urgency felt by fellow afflicted patients.

Since the program began with Fiscal Year 2006 funding, I’ve had the honor of serving as a consumer reviewer for the Gulf War Illness CDMRP. I’ve found the program efficient, agile, carefully focused by the Congressional authorizing language, and fully engaged in finding and successfully funding the best, most responsive research proposals aimed at improving the health and lives of veterans afflicted by Gulf War Illness. And I’ve found the staff and contractors to be consistently capable and competent, responsive to the review panel, and integral to the success of the programs.

It is my understanding from other consumer reviewers that the same holds true for other CDMRP research programs.

And, as a consumer reviewer since the program began, I’ve also had the privilege of reviewing virtually all of the hundreds of pre- and full proposals in the history of the program, which has imparted a unique perspective.

As previously described, the collective efforts of this small cabal of DoD and VA (and perhaps also IOM) staff have produced a dearth of tangible results, no proven treatments, and have served only to disenfranchise, anger, and unite ill Gulf War veterans. However, in stark contrast to the national disgrace of that failed cabal, there are literally hundreds of highly capable scientists and medical practitioners who are ready, willing, able, and actively working to help solve Gulf War Illness. Many are at top research institutions. They spend countless hours compiling detailed research proposals, often as long as a hundred or more pages, carefully articulating how and why they believe they can help ill Gulf War veterans. For those who are ultimately funded, they appear to be truly making a difference.

One of the earliest successes of the GWI CDMRP is the discovery that a particular anti-oxidant can help reduce some Gulf War Illness symptoms. Another, studying the sarin nerve agent to which hundreds of thousands of Gulf War troops were exposed, may have important implications for future military or civilian populations in a homeland security situation since the research findings suggest low-dose, non-symptomatic exposure to sarin may result in long-lasting cardiac and neurological dysfunction. Another is that chronic inflammation may underlie many Gulf War Illness symptoms, and if so, effective treatments may already exist. Still another is taking an animal model of Gulf War Illness chemical exposures, which has effectively reproduced GWI symptoms, and testing an already available drug to treat pain and memory deficits common in GWI.

It is also clear that many researchers are making great strides towards unraveling and treating Gulf War Illness *without the need to know the specific substance(s) of causation*. Unraveling the specifics of *what is happening now* in the brains and bodies of ill Gulf War veterans appears to be at least as relevant to the identification and development of effective treatments.

The 2010 IOM committee wrote that effective treatments for Gulf War Illness can likely be found and suggested a path forward, “to speed the development of effective treatments, cures, and, it is hoped, preventions.” To date, only the Gulf War Illness CDMRP has been fully engaged in this effort, though still inadequately funded. Most importantly, these CDMRP efforts are producing real results.

Meanwhile, VA staff have wasted more precious years, squandered myriad experts’ time, energy, and hard work, and further alienated not just their most engaged advisors but also the very Gulf War veterans they are supposed to be helping. And though VA research staff have told us they are now funding treatment studies,

the RAC on which I serve has not been provided specific information on these new efforts.

**VA's WRIISC's.** In addition to the GWI CDMRP, I hear almost exclusively praise from ill Gulf War and other veterans who have participated in the VA's three regional War Related Illness and Injury Study Centers (WRIISC's). The centers take veterans on referral from local VA healthcare providers and ensure a comprehensive workup to identify any diagnosable health conditions. I also hear from some veterans that they've been able to use WRIISC evaluations to support their VA claims, an important piece of justice while proven effective treatments remain to be found. And, WRIISC clinicians are thereby regularly exposed to a constant inflow of patients whose collective experiences could help solve Gulf War Illness, another potential benefit.

However, as word regarding these important clinical resources has spread among veterans, there are now apparently long waits to participate. I've been told by some veterans the waiting list is now many months long, perhaps even as long as a year. Congress can help ailing veterans by allocating additional authorization and funding to these two areas that are indeed helping.

#### **NEXT STEPS**

We Gulf War veterans have been fighting the federal bureaucracy for much of the last 22 long years. We've seen laws passed only to seem them circumvented or not implemented with impunity. The independent expert panel created by Congress in 1998 was supposed to end gridlock at VA. The release of the RAC's 2008 report, and the IOM's 2010 study showed not only that GWI is real—what Gulf War veterans had been saying all along—but that effective treatments could be found, bringing much hope to many distraught service-disabled veterans. However, it is now clear that VA staff have continued are presumably will continue to betray Gulf War veterans for the reasons described above.

We have had countless Congressional hearings on Gulf War veterans' health and benefits. Time after time, researchers, advocates, veterans, and family members have told Congressional committees about the ongoing, serious problems they're experiencing and recommendations to fix them. Time after time, the Congressional committee members ask VA pointed questions about the VA's many missteps, and VA staff make more on-the-spot promises, which almost always turn out to be empty. Then a year or two later, and it's yet another round of the same.

I hope today's hearing will be different. I hope that Committee members, and perhaps finally even VA's present leadership, will see that that Gulf War veterans have been right all along – again: that VA and DoD staff, including in VA's Office of Public Health and DoD's Force Health Protection and possibly with cooperation from one or more IOM staff, have been circumventing and flouting the law, Congress, and the needs of veterans; that on occasion after occasion they have been obfuscating, manipulating, and even lying. The end result is that while we're closer today to finding effective treatments for the one-third of Gulf War veterans who, like me, remain ill and disabled more than two decades later, any progress is in spite of and not because of this cabal's efforts.

Today's hearing will not uncover every serious misdeed and transgression coming out of the longtime staff and contractors at VA or in DoD's Force Health Protection. In the strongest possible terms, I encourage the Members of this body to take further steps necessary to right these ongoing wrongs, including reallocation of funding from these non-performing entities, legislation to provide criminal sanctions for such behavior, and comprehensive legislation to right these many wrongs.

And despite all the best promises and intentions, actions speak louder than words: *VA continues unabated in its long tradition of violating Gulf War veterans' trust.*

#### **RECOMMENDED LEGISLATION**

VA staff must be forced by law to seek out, foster, and find the best Gulf War Illness treatment research aimed at improving the health and lives of those whose health has been impacted by their wartime exposures. To that and related ends, Congress should develop and pass legislation that includes:

- 1) A provision making it a crime punishable by federal imprisonment for a government employee or contractor to attempt to manipulate an IOM report ordered by a government agency, or for an IOM employee or member to conspire with a government employee or contractor for the purpose of manipulating a report.

- 2) A provision directing VA to immediately contract with the IOM for a study to determine the prevalence of multiple sclerosis in Gulf War and later veterans, as directed by P.L. 110–389, Section 804, and to provide criminal penalties for failure to comply.

3) A provision directing VA to immediately terminate the IOM case definition contract and contract instead with the DoD Congressionally Directed Medical Research Programs (CDMRP) Gulf War Illness program to develop a case definition that is linked to Gulf War service and excludes mental conditions, and that follows customary case definition practices (including assembling a committee of experts in the illness, who can consult original data sources).

4) Provisions to defund mis-performing VA–OPH and DOD FHP functions.

5) A provision requiring VA to make the data obtained from its surveys available to qualified researchers subject to reasonable restrictions, similar to other agencies.

6) A provision requiring an addendum to the national Follow-Up Survey of Gulf War and Gulf War Era Veterans be sent immediately to the full survey cohort that asks the RAC’s recommended symptom inventory.

7) A provision requiring VA medical staff be trained in the new 2011 standards, which show Gulf War Illness is not psychiatric.

8) A provision mandating future VA Gulf War research be focused on developing effective treatments to improve the health and lives of ill Gulf War veterans.

9) A provision amending the statute requiring the reports (Section 707 of Public Law 102–585, as amended by section 104 of Public Law 105–368 and section 502 of Public Law 111–163), to provide that these annual VA research summary reports to Congress should include only those human studies in which 1990–1991 GW veterans represent at least a majority of the cases (vs. controls), and only those animal studies addressing exposures pertinent to the 1990–1991 Gulf War.

10) A provision requiring VA to contract with the DoD CDMRP Gulf War Illness research program, to conduct the review of best treatments for chronic multisymptom illness in Persian Gulf War veterans specified in Sec. 805(a) of PL 111–275, which VA staff manipulated into an inconsequential literature review.

11) Provisions providing adequate funding for Gulf War Illness research to identify effective treatments, including:

a) Provisions in the FY14 and subsequent DoD authorization and appropriations bills that allocate at least \$25 million in annual DoD funding to the CDMRP Gulf War Illness research program;

b) Provisions in the FY14 and subsequent VA authorization and appropriations bills, requiring that VA spend at least \$25 million annually on GWI research AND directing VA to contract with DoD CDMRP to conduct at least \$20 million of VA-funded research as part of the CDMRP Gulf War Illness research program, as the CDMRP determines in its sole discretion.

c) Adequately funding research to identify treatments for Gulf War Illness is imperative now to make up for the twenty-two years lost while the federal government has obstructed this research.

12) Provisions in the FY14 and subsequent VA authorization and appropriations bills directing to expand the number, scope, reach, and funding for VA’s War Related Illness and Injury Study Centers (WRIISC’s).

13) A provision directing VA to implement the February 1, 2012 published RAC recommendations for the New Gulf War-Era Data Report.

14) A provision directing VA to implement the consensus Gulf War Illness Research Strategic Plan recommended by the RAC and NRAC, prior to unilateral VA staff revisions.

15) A provision mandating the continuation in perpetuity of the “Gulf War Review” and related quarterly veteran-oriented publications for veterans of other eras, which should include ongoing, clear updates free of “strategic health risk communication” minimization, on each newly concluding federally funded research study, and each benefits change relevant to the target population.

16) Provisions to correct injustices in the ratings for fibromyalgia and chronic fatigue.

17) Provisions strengthening the authority of the present Research Advisory Committee on Gulf War Veterans’ Illnesses.

18) Provisions that repeal and replace portions of Presidential Review Directive-5/National Science and Technology Council (PRD–5/NSTC), and subsequent programs and governing regulations, including:

- a) Provisions related to the use of investigational drugs and products on military service members.
- b) Provisions related to health risk communication.
- c) Provisions related to interagency applied research program on health risk communication for military members, veterans, and their families.
- d) Provisions related to electronic communications with state and community public health departments to disseminate health risk information to veterans and their families through local public health infrastructure.
- e) Provisions related to training local public health officials on the use of essential information technologies to disseminate and receive health risk information from veterans and their families.
- f) Repeal and replace the Military and Veterans Health Coordinating Board (MVHCB).

19) A provision requiring the consistent federal government use of a term for "Gulf War Illness".

B. Finally, as a group of 14 Gulf War veteran advocates has previously recommended, Congress should immediately develop and ensure the enactment of legislation to:

1) Reauthorize the expired provisions of the Gulf War Acts of 1998 [Persian Gulf War Veterans Act of 1998 (Title XVI, PL 105-277); Title I of the Veterans Programs Enhancement Act of 1998 (PL 105-368)]

2) Provisions that explicitly and directly grant exposure-based service-connection presumptions to known, suspected, or plausible Gulf War exposures including:

- a. Sarin (GB)
- b. Cyclosarin (GF)
- c. Sulfur Mustard (HD)
- d. Tabun (GA)
- e. Lewisite (L)
- f. Soman (GD)
- g. VX nerve agent
- h. Particulates (PM2.5: sub-2.5 micrometer in size, which are respirable and too small to be removed by the lungs' natural exfoliating processes)
- i. Pyridostigmine Bromide (PB) nerve agent protective pills (NAPP)
- j. Anthrax vaccine
- k. Multiple vaccinations
- l. Depleted Uranium (DU)
- m. Chemical pesticides

3) A provision that grants exposure-based service-connection presumptions for exposures in (2) above for all U.S. servicemembers who served anywhere in the Southwest Asia theater of operations (38 CFR 3.317) or were awarded the Southwest Asia Service Medal (32 CFR 578.27) for service between January 16, 1991 and the end of 1991. [Note: last oil well fire put out "by November" 1991].

4) Require VA to contract with the Institute of Medicine of the National Academy of Sciences to identify a comprehensive listing of health conditions and symptoms, including chronic and delayed onset, which are associated in humans or animals with exposure to acute, subacute, and low levels for each of the named exposures in (2) above and explicitly and directly require VA to include each of these conditions as presumptives for Gulf War veterans as described in (3) above. The review should be explicitly required to include data from a comprehensive review of the medical literature, and to also include:

- a. 1993 IOM report on WWII veteran Mustard/Lewisite experimentation survivors;
- b. Medical literature assessing long-term health effects of the cohort of Iranian mustard-exposed veterans of the 1980-88 Iran-Iraq War;

c. Classified and unclassified published and unpublished research by the federal government, federal contractors, and federally funded entities into acute and long-term health effects of even low levels of the above named exposures;

d. Animal studies.

5) Ensure the perpetuity, without expiration, of adding new presumptive conditions as described in (4) above as they become identified by medical research.

6) Expand the definition of the Southwest Asia theater of operations, for purposes of all VA benefits including healthcare, to include service qualifying for the award of the Southwest Asia Service Medal.

7) Establish permanent eligibility by law for Priority Group 6 VA healthcare for veterans who have been awarded the Southwest Asia Service Medal.

8) Require DOD to monitor, develop and retain accurate and detailed records regarding future troop hazardous exposures.

i p. 14, *Dusek, Jeffery, PowerPoint presentation: "Chronic Stress and Its Role in Emotional, Somatic, and Cognitive Symptoms"; Presented at Meeting 2: Institute of Medicine Committee on Gulf War and Health: Treatment of Chronic Multisymptom Illness, Feb. 29, 2012.*

ii *Golier, JA et al, "Twenty-four hour plasma cortisol and adrenocorticotropic hormone in Gulf War veterans: relationships to posttraumatic stress disorder and health symptoms. Biol Psychiatry 2007 Nov 15; 62(10):117t-8. Epub 2007 Jul 5.*

iii *Walters, Terry, Office of Public Health, U.S. Department of Veterans Affairs: "Institute of Medicine Committee on Gulf War and Health: Treatments for Multi-Symptom Illness," a PowerPoint presentation before the Institute of Medicine, Committee on Gulf War and Health: Treatment of Chronic Multisymptom Illness, Dec. 12, 2011, pp. 37-40. Retrieved from the Internet 3/10/13: <http://www.iom.edu/Activities/Veterans/GulfWarMultisymptom/2011-DEC-12.aspx>*

#### Prepared Statement of Victoria J. Davey, Ph.D., MPH, RN

Good morning, Mr. Chairman, Madam Ranking Member, and Members of the Subcommittee. Thank you for the opportunity to discuss the Department of Veterans Affairs' (VA) efforts to identify, diagnose, and treat Gulf War-era Veterans. I am accompanied today by Dr. Maureen McCarthy, Deputy Chief Patient Care Services Office, Dr. Stephen Hunt, Persian Gulf Registry Physician, and Dr. Gavin West, Physician, Salt Lake City VA medical center (VAMC).

VA focuses on all eras of Veterans and recognizes unique aspects of service associated with each era. In 2009, Secretary Shinseki established a Gulf War Veterans Illnesses Task Force (Task Force), headed by VA's Chief of Staff (COS), a Gulf War Veteran. The Task Force's mission is to ensure that VA maintains a focus on the unique needs of Gulf War Veterans. It was chartered to conduct a comprehensive review of VA's programs to support this population of Veterans; develop an overarching action plan to advance service to them; and ultimately to improve their satisfaction with the quality of services and support VA provides. The Task Force has prepared three annual reports detailing concrete steps VA has taken, and continues to take, to improve care and services to Gulf War Veterans. The Secretary and COS believe that ultimately, the Task Force's efforts must become a part of the culture and ongoing operations of VA and not simply the purview of a special Task Force.

At this time, Mr. Chairman, I would like to focus on the efforts the Veterans Health Administration has made in response to both the guidance of the Task Force and the needs of Gulf War Veterans, to improve their health and well-being.

VA is proud to offer continuing treatment as well as evaluation of the nearly 700,000 men and women who served in Operations Desert Shield and Desert Storm. My purpose today is to communicate the personalized and compassionate care that VA strives to deliver to fulfill the unique needs of the men and women who served in these Operations.

Many Gulf War Veterans are affected by a debilitating cluster of medically unexplained chronic symptoms that can include fatigue, headaches, joint pain, indigestion, insomnia, dizziness, respiratory disorders, and memory problems.

These symptoms can wax and wane, and may have lasted since deployment in some Veterans. Unfortunately, we yet do not know the cause, but a complex combination of environmental hazards, exposures, and individual genetic characteristics may be behind these symptoms. We refer to the illness that these Veterans describe as chronic multisymptom illness or 'CMI'.



Terminology like 'CMI' helps us define the populations of concern, plan treatments, and drive research. However, VA's fundamental approach to health care has evolved over the first decade of the 21st century. We believe the person, not the disease or the terminology, is the center of importance in the health care relationship. We want to meet the patient where he or she is in life, and develop with the patient a health plan of care that returns the patient to his or her highest possible level of health and enjoyment of life. As with every other Veteran, VA seeks to provide Veterans with CMI personalized, proactive, patient-driven care. As part of our services to Gulf War Veterans, VA offers a number of programs and services that are uniquely designed to meet their needs.

VA facilities throughout the Nation are working on bold, innovative programs that combine primary care and specialty care services. One such program links primary care services with specialty medical treatment models specific to Gulf War Veterans, in order to produce a seamless, patient-centric model that will improve patient care, safety, and satisfaction, as well as provider knowledge. This program is creating a system of care, which leverages VA's Patient-Aligned Care Team (PACT) concept. Through PACT, providers and staff members from multiple disciplines, outlooks, and experiences work together to provide the best possible care. Patients and family members are considered part of their own PACT.

VA has linked PACT teams working with Gulf War Veterans with a specialty care capability that focuses on treating the unique health care requirements of Gulf War Veterans. The program includes teaching aids, referral networks, and other types of collaboration. Front-line clinicians have been educated through monthly community of practices conference calls, informational meetings, pocket cards, and Web sites. The meetings are led by clinicians trained in issues specifically related to the integration of primary and specialty care.

Facilities involved in the program have seen improvement in their recent customer service scores; an improvement that has been corroborated in VA-led focus groups. VA is currently preparing a social media campaign to improve feedback on the program from Veterans, to keep Veterans involved in the progress of the program, and to allow Gulf War Veterans served by the program to communicate more easily.

VA providers being trained in clinical issues related to the Gulf War include family medicine and internal medicine doctors in training, nurse practitioner students, and those intending to become physician assistants. Many practitioners at participating VA hospitals and Community-Based Outpatient Clinics (CBOC) have noted a substantial increase in their knowledge about Gulf War Veterans issues, and have found it significantly easier to find information they require about the subject. Veterans have also noted that clinicians involved in the program are now more knowledgeable about their issues.

Another program specifically for Gulf War Veterans is our registry program, begun by VA in August 1992. The program offers a health examination at any of our health care facilities to any Veteran with Gulf War service. To date, about 130,000 Gulf War Veterans have undergone a registry exam, allowing their health concerns to be evaluated by VA physicians, and enabling them to be referred for additional care when needed. The comprehensive health exam includes an exposure and medical history, laboratory tests, and a physical exam. VA health professionals discuss the results face-to-face with Veterans and in a follow-up letter.

Since 2001, the War Related Illness and Injury Study Centers (WRIISC) have supported specialized care for Gulf War Veterans, and conducted cutting-edge research, clinician education, and a Veteran referral program. VA's three WRIISC locations have teams of clinicians ready to evaluate Gulf War Veterans with deployment-related concerns. Based on a comprehensive evaluation, the WRIISC team develops an individual, holistic treatment plan for Veterans with CMI or other ill-defined conditions, through a referral process based on geographic location.

Primary care physicians throughout VHA contact the WRIISC to refer Veterans to one of the three regional centers, using the consult process in VA's computerized patient record system. VA recently developed this streamlined specific interfacility consult for the Veteran's integrated team to use to seek help from the WRIISC for consultation and development of a coordinated treatment plan.

The WRIISC is not the only way in which the special needs of Gulf War Veterans are met throughout VA's health care system. VA conducts special educational programs for health care providers, Veterans, and their families. These include in-person training sessions, webinars, Web sites, and publications for both patients and providers on topics including assessments of environmental exposure and difficult-to-diagnose conditions.

VHA's Office of Public Health (OPH) holds quarterly conference calls with Environmental Health coordinators and clinicians located at every VA hospital. These

coordinators and clinicians are subject matter experts for Veterans and VA staff, offering advice on environmental exposure experience during military service. The conference calls provide coordinators and clinicians with ongoing training, allowing them to share patient care questions, challenges, administrative issues, and solutions that have come up at their facilities and provide an opportunity to discuss the latest information on environmental health.

Recently, OPH developed an Environmental Exposure pocket card that includes questions for practitioners to ask Veterans about their health concerns, including those related to Gulf War deployments. It also provides contacts Veterans can use to obtain information about additional VA resources and benefits to which they may be entitled. The card is available at <http://www.publichealth.va.gov/docs/exposures/environmental-exposure-pocket-card.pdf>.

VA now is in the process of developing additional innovative training resources, such as a mobile device and internet application that will provide real-time information on environmental exposures, associated symptoms and conditions, and potential treatments beneficial for clinicians in treating these Veterans.

Mr. Chairman, in accordance with Public Law 105–277, VA contracts with the National Academy of Sciences to independently examine and evaluate the medical and scientific literature regarding illnesses and deployment in support of the Gulf War. Since 2000, the Academy's Institute of Medicine (IOM) has provided its scientific conclusions on the strength of the evidence for associations between such exposures and illness. VA uses IOM's reports to help inform policy decisions regarding whether certain diseases or illnesses, called presumptive diseases, are related to qualifying military service.

VA recently engaged IOM to convene a committee to comprehensively review, evaluate, and summarize the available scientific and medical literature regarding the best treatments for CMI among Gulf War Veterans.

On January 23, 2013, IOM released a study containing recommendations to VA on how to recognize and treat Gulf War Veterans with CMI. IOM based

its recommendations on a review of 47 existing studies. IOM provided a working definition of CMI, as “the presence of a spectrum of chronic symptoms” in at least two of six categories, including fatigue; mood and cognition (such as memory difficulties); musculoskeletal; gastrointestinal, respiratory, and neurologic issues. IOM indicated that the symptoms of conditions that are already defined, such as chronic fatigue syndrome; fibromyalgia; functional gastrointestinal disorders; In addition, co-morbid conditions, such as depression and anxiety, may overlap those of CMI.

IOM made recommendations to VA in five categories, including how to: treat CMI; improve systems of care and management of care for Veterans with CMI; provide information throughout VHA about care for Veterans with CMI; improve the collection and quality of data on care outcomes and satisfaction with care for Veterans who have CMI; and how to conduct future research on diagnosing and treating CMI and on evaluating programs to treat the illness.

VA welcomes this opportunity to address these recommendations in an effort to improve how we meet the clinical needs and expectations of Gulf War Veterans. VA shares IOM's concern that Veterans experiencing CMI be managed compassionately and that they experience personalized, proactive, patient-driven care specific to their needs. Actions that we already are taking include a pilot program to provide every Veteran with a full health assessment when he or she separates from service. This is a combined VA–DoD separation health assessment. The Secretaries of Defense and Veterans Affairs acknowledged their commitment to full implementation of a universal, standardized separation health assessment for all transitioning Servicemembers (SMs) was supported through the resources of both DoD and VA in December 2012. Currently, VA and DoD representatives are drafting the memorandum of agreement (MOA) which will be ready for coordination by end of March 2013. The MOA will formally establish roles, responsibilities, standard exam criteria, and monitoring requirements. DoD and VA staff have been meeting weekly to discuss implementation options along with the drafting of the MOA. A pilot is taking place at the Washington, DC VAMC to test the processes related to performing the standardized health assessment elements as part of a VA disability exam in support of a claim for benefits.;

Moreover, other actions include VA's addition of a clinical reminder to its computerized patient record system to prompt clinicians to ask all Gulf War separating Servicemembers whether they may have symptoms consistent with CMI; and the special PACT program for Gulf War Veterans described previously in this testimony. We are improving communication among VA health care providers and with patients; improving patient satisfaction measurement tools, and training our staff to better recognize CMI. We are also developing a champions program and additional

webinars, and taking steps to strengthen research protocols submitted for funding in complementary and alternative medicine.

IOM notes in its report that the impacts of CMI are wide-ranging, and extend far beyond the health of individual Veterans. CMI has personal, occupational, and social consequences that impact not only Veterans and their families but also their employers and the communities in which they live. VA understands this. We remain committed to providing evidence-based, compassionate care for these Veterans, and for all of the Veterans it is our privilege to serve. VA intends to continue our ongoing efforts to improve our abilities to provide health care for Gulf War Veterans; to better educate our health care providers; and to expand the evidence basis for the treatments we provide for Gulf War Veterans, and all Veterans.

Mr. Chairman, this concludes my testimony. We appreciate the opportunity to appear before you today to discuss this important issue. My colleagues and I are prepared to answer your questions.

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### Statement For The Record

#### **Statement by Melissa A. Forsythe, PhD, RN, Program Manager for Gulf War Illness Research Program, United States Army Medical Research and Materiel Command**

Chairman Coffman, Ranking Member Kirkpatrick, distinguished Members of the Subcommittee; I thank you for the opportunity to provide this testimony on behalf of the Department of Defense (DoD) Gulf War Illness Research Program. This program studies the multi-symptom cluster known as Gulf War Illness (GWI) that afflicts as many as 250,000 of the 750,000 service members and Veterans who served in the Persian Gulf War theatre of operations during 1990 and 1991.

#### **Overview of DoD GWI Research Funding**

DoD-funded GWI research began in 1994 with the establishment of a Gulf War Veterans' Illnesses Research Program (GWVIRP) to study the health effects on the service members deployed in the 1990–1991 Persian Gulf War. From Fiscal Year (FY) 1994 to FY 2005, the GWVIRP was managed by the US Army Medical Research and Materiel Command (USAMRMC) Military Operational Medicine Research Program (MOMRP). Research pertaining to GWI also has been funded intermittently through the Congressionally Directed Medical Research Programs' (CDMRP) Peer Reviewed Medical Research Program (PRMRP) that supports selected military health-related research topics each fiscal year.

The MOMRP shared management responsibility for the GWVIRP with the CDMRP in FY 06 with separate \$5 million (M) appropriations. Although the GWVIRP, renamed the Gulf War Illness Research Program (GWIRP), did not receive funding in FY 2007, a \$10M appropriation renewed the program in FY 2008 to be managed fully by the CDMRP. Since that time, the GWIRP has been maintained with \$8M appropriations in FY 2009, FY 2010, and FY 2011. The FY 2012 GWIRP appropriation was \$10M. The program's mission is to "Improve the health and lives of Veterans who have Gulf War Illness." Thus, the program supports innovative, competitive peer-reviewed research for treatments that address the complexity of symptoms comprising GWI, identify objective markers (biomarkers) for the disease, and understand the pathobiology underlying GWI.

#### **CDMRP GWIRP Processes**

As with all CDMRP-managed programs, the GWIRP program management cycle includes a two-tier review process for application evaluation recommended by the National Academy of Sciences' Institute of Medicine. The first tier of evaluation is an external scientific peer review of applications against established criteria for determining scientific merit. This review is conducted by scientific and clinician experts in Gulf War Illness with input from consumers - veterans suffering from GWI.

The second tier is a programmatic review conducted by an Integration Panel (IP) composed of program-specific researchers, clinicians, and consumers who evaluate applications on innovation, potential impact, programmatic priorities, and mechanism specific criteria. The IP is composed of prominent members of the GWI research community, including Gulf War consumers. The IP coordinates with the Office of Research and Development within the Department of Veterans Affairs (VA) to ensure there is no overlap of funding and that portfolios are complementary.

The IP recommends applications for funding that best fulfill the program's vision and mission while also demonstrating innovative science. The recommendations of

IP members enable the GWIRP to find and fund cutting-edge research and set important program priorities to benefit ill Gulf War Veterans. The Commanding General of USAMRMC issues final approval for funding prior to award negotiations and execution.

#### **The Role of Veterans as Consumers**

A unique aspect of the CDMRP is the active participation of consumer advocates throughout the program. Consumers for the GWIRP are Gulf War Veterans who are experiencing symptoms and illnesses related to their military service in the 1990–1991 Persian Gulf War theater. Consumer advocates are a vital part of all CDMRP programs in that they express the collective views of survivors, patients, family members, and those affected by the disease. They sit side by side with research professionals on both peer and programmatic review panels, they vote as equal members of these panels, and their voices play a pivotal role in maintaining an appropriate focus within the program.

#### **CDMRP GWIRP Portfolio**

The GWIRP has focused on the development of treatments to address the myriad of symptoms that plague ill Gulf War Veterans. To that end, the GWIRP has offered Clinical Trial Awards (CTAs), Innovative Treatment Evaluation Awards (ITEAs), and Investigator-Initiated Research Awards (IIRAs) that support pilot studies and larger, more definitive clinical trials to investigate potential treatments for GWI.

To date, the GWIRP has funded 3 CTAs (\$3.6M), 5 ITEAs (\$3.1M), and 39 IIRAs (\$29M). Of these, 13 awards are focused on developing treatments, 15 are pursuing biomarkers, 8 are examining symptoms, and 6 are investigating exposures, while others are conducting basic research related to Gulf War Illness. Examples of these funded awards include the following:

a. IIRAs: (1) Beatrice Golomb, M.D., Ph.D., University of California, San Diego recently completed a 3½-year study (FY 2006 IIRA) examining the benefits of daily coenzyme Q10 (Q10) in ill Gulf War Veterans. Q10 is naturally produced in the human body where it is involved in cellular energy production as a key antioxidant. But, levels of Q10 can be inadequate to meet needs when there is increased “oxidative stress” or impaired energy production. Dr. Golomb hypothesized that mitochondrial dysfunction, linked to cellular energy production, may contribute to symptoms of GWI and sought to assess whether Q10 conferred benefit to overall health and symptoms in GWI.

Initial analysis of the study results found that the 100 mg dose led to better self-rated health scores than the 300 mg treatment. More importantly, fatigue with exertion, which 54% (25) of subjects reported at baseline, demonstrated significant improvement with Q10 at 100 mg compared to placebo treatment. The benefit to fatigue with exertion is important because increased exercise tolerance is a bridge to many health benefits (e.g., mood, function, and cognitive performance) as well as quality of life benefits crucial to ill Gulf War Veterans.

These findings provide important preliminary information that could inform a larger trial of Q10 better powered to show benefit to global health in ill Gulf War Veterans.

(2) Dr. Ronald Bach at the VA Medical Center in Minneapolis (VAMC Minneapolis) is using a FY 2008 GWIRP IIRA to further develop findings from VA-funded studies that indicated that ill Gulf War Veterans may be in a hyper-coagulable state of unknown etiology<sup>1</sup>. Earlier work showed strong correlations between the plasma concentrations of inflammation-related proteins and symptoms of GWI. Thus, he hypothesized that chronic inflammation is part of GWI pathophysiology.

Analyses determined that C-reactive protein (CRP) levels, a marker of systemic inflammation, were significantly higher in Gulf War Veterans with three symptoms (as defined in health surveys) versus asymptomatic veterans. Dr. Bach subsequently observed statistically significant linear correlations between CRP and a group of 18 plasma proteins. This set of pro-inflammatory potential GWI biomarkers has been labeled “The Gulf War Proteome”, though more in-depth analysis is pending.

b. ITEAs: (1) Dr. Ashok Tuteja of the Western Institute for Biomedical Research, is using a FY 2009 ITEA to study irritable bowel syndrome (IBS) resulting from gastroenteritis commonly found in ill Gulf War Veterans. Dr. Tuteja is examining the potential of pro-biotic treatment (live bacteria that re-establish normal gut flora)

<sup>1</sup>Hannan KL, Berg DE, Baumzweiger W, Harrison HH, Berg LH, Ramirez R, Nichols D. Activation of the coagulation system in Gulf War Illness: a potential pathophysiologic link with chronic fatigue syndrome, a laboratory approach to diagnosis. *Blood Coagulation and Fibrinolysis*. 11(7): 673–678, 2000.

to improve GWI-associated IBS, fatigue, joint pain, and headaches in a clinical trial of 80 Gulf War Veterans. This study is on-going.

(2) Dr. David Rabago of the University of Wisconsin, Madison, is using a FY 2010 ITEA to examine the effectiveness of routine nasal care plus saline or xylitol nasal irrigation compared to routine care alone as therapy for chronic rhino sinusitis and fatigue in 75 ill Gulf War Veterans. Study outcomes will gauge responses to surveys and assess the cost-effectiveness of the treatment. Dr. Rabago will also examine pro-inflammatory cytokine markers and cell types in the mucosal profile to elucidate biomarkers of the condition. This study is on-going.

### **The Way Forward**

Since its inception at CDMRP in FY 2006, the GWIRP has served as a springboard for GWI Research, identifying and developing a community of researchers and clinicians dedicated to pursuing robust research. The quality of applications submitted to the GWIRP has increased from overall scientific merit scores averaging 3.0 (on a scale of 1.0 to 5.0, with 1.0 representing a 'perfect' application) in FY 2006, to scores of 1.9 on average in FY 12. While quality has improved significantly, the quantity of awards made has not, given the available appropriations. In FY 2012, the GWIRP funded 13% of applications.

In FY 2010, the GWIRP took a bold step by offering a Consortium Development Award (CDA). This award provided \$200,000 over one year for researchers to create a Coordinating Center and to establish the necessary collaborations at potential research sites to develop a multi-institutional GWI research effort.

The CDA supported experts from differing fields of GWI, and helped to bring their consolidated efforts to bear toward moving research forward, finding new treatments, developing biomarkers, and improving our understanding of GWI. Three CDAs were awarded, all of which scored very high on scientific merit, and also addressed a different focus of GWI.

In FY 2012, these three CDA awardees competed for a full Consortium Award. Two of the three were selected for initial funding (\$2.5M each), with the additional funds (again, \$2.5M each) to be awarded as an option from FY 2014 funds, depending on the availability of funds and the progress of each consortium toward accomplishing its specific goals. While both of these awards are under negotiations, they are poised to propel the field of GWI research beyond what could be accomplished by individual researchers' efforts.

In addition to the Consortium Award, in FY 2012 the GWIRP again offered the Investigator-Initiated Research Award, Clinical Trial Award, and the Innovative Treatment Evaluation Award established in FY 2009. These awards will add to the growing portfolio of GWIRP-funded, high-impact research designed to help our ill Gulf War Veterans.

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**From David K. Winnett, Jr.**

Dear Chairman Miller and Distinguished Members of the Committee,

Today, almost twenty-two years after the 1991 Persian Gulf War (PGW) more than 250,000 Veterans of that war continue to suffer from very debilitating medical symptoms directly related to their wartime service.

As a four-time "Consumer Reviewer" panelist on the "Congressionally Directed Medical Research Programs" (CDMRP) for Gulf War Illness Research, the consensus among the scientific and medical communities now points to the strong likelihood that PGW Veterans sustained neurological damage to the part of the brain that regulates the autonomic nervous system. This seems a quite viable explanation given the myriad of symptoms that have destroyed the quality of life for so many PGW Veterans and their families. Unfortunately, researchers who for years have valiantly searched for effective treatments for the numerous symptoms associated with Gulf War Illness have been greatly handicapped by not knowing precisely what caused these illnesses.

Today there are many thousands of documents that remain classified concerning events that occurred before, during, and after the PGW. Former Senator Donald Riegle's 1994 report on Gulf War Illness made public a number of disturbing revelations concerning weapons technologies that were authorized for sale by the United States government to the Iraqis during the late 1980's. The Senator's report inferred that some of those same weapons technologies, chemical and biological weapons among them, may have been the cause of Gulf War Illness. His report also recommended a Justice Department investigation into these questionable weapons

sales to Iraq; an investigation that the Justice Department has never deemed important enough to pursue.

Not surprisingly, compelling evidence to explain Gulf War Illness now points to confirmed widespread battlefield exposures to chemical warfare agents, including *Sarin Gas* that were inadvertently released into the atmosphere by pre-ground war American/Allied aerial bombing of Iraqi ammo storage areas within the theater of operations, and/or administration of medicines (i.e., *Pyridostigmine Bromide* pills) that were prescribed to all ground forces, despite the fact that at the time they were not yet FDA approved, and/or tainted vaccinations - i.e., excessive *Squalene* utilized in the adjuvant (booster) of mandatory vaccines administered to our troops *without their informed consent*.

Also suspect as a possible cause of Gulf War Illness, now referred to as "*Chronic Multisymptom Illness*" was widespread ingestion of micro-particulates of post-impact *Depleted Uranium* (DU), a heavy weapons technology first used on a large scale during the 1991 PGW. Despite the fact that DU has been proven by DOD and others to cause extremely long-term environmental damage as well as posing considerable health risks to anyone exposed to it, DU is still in use in America's arsenal today. Perhaps that might explain why many of today's Warriors are coming home with symptoms eerily similar to Gulf War Illness?

There is little dispute now that Gulf War Illnesses are real, but for reasons that continue to confound the Veteran community, the *majority* of Persian Gulf War Veterans who have submitted claims for Veterans disability compensation related to their wartime service have had their claims *denied*. This prevents the chronically ill Veteran from receiving financial compensation that would help to offset their loss of earning capacity and denies them the priority medical care status that the VA extends to Veterans with service-connected disabilities.

The disenfranchisement of the over 250,000 men and women who carried out one of the most effective military operations in our country's history is a tragedy of the highest order. These are American heroes whose life-altering chronic medical problems have been largely ignored by their fellow countrymen for over twenty years, a human tragedy far beyond anything that I am aware of in our country's history where American War Veterans are concerned.

Despite numerous setbacks that our Persian Gulf War Veteran community has experienced over the last two decades, I remain extremely confident that sooner or later, the truth will be known. The question I have for the Chairman, and for the Honorable Members of your Committee is - which side of history will you be on? Will you choose the side that the vast majority of our Colonels, Generals, and the Politicians who presided over the Persian Gulf War have chosen? Like them, will you remain loyally silent to your last breath - will you sleep soundly at night under the morally misguided perception that "matters of national security" or the release of "sensitive information" trumps the health and welfare of America's sick Gulf War Veterans? Like them will you be deafened to the cries for help that continue to echo from the battlefield - pleas for help from the same brave and selfless Warriors who did the dirty work that made so many of our Generals overnight celebrities? Like them, will you continue to turn your back on this magnificent group of American heroes who carried out one of the most resounding wartime victories in our country's history? Or, will you be on the side of moral justice - the side that advocates for complete truth and transparency, no matter its cost, when it comes to once and for all declassifying and disclosing the precise reason(s) why so many Persian Gulf War Veterans fell ill after the war, no matter whose military or political legacies may suffer, and no matter the potential for embarrassment and/or civil liability that certain defense contractors may face?

I am very close to completing a book that describes what I believe to be the largest disenfranchisement of American military personnel in the history of this country. The working title of the book is "To Fight for Right and Freedom" (A Marine Corps "Mustangs" battle with Gulf War Illness, and the War Machine that created it). The book, now over 400 pages in length does not paint a kind picture of those within our government and defense establishment whom I believe to be complicit in this unconscionable act of betrayal against our troops. I've paid an enormous personal price as a direct result of my public outspokenness over this often controversial issue, the details of which are explicitly outlined in my book. But there is no penalty that anyone can possibly levy on me that will succeed in deterring me from continuing to exercise the moral leadership that I was so blessed to assimilate as a United States Marine. This mission will be accomplished, and I plan to be around when that day comes. I very much hope to see you all there.

And so, in closing I would respectfully ask only two things from each of you when it comes to making decisions about how best to deal with the issue of Gulf War Illnesses - and they are, BE HONEST and DO THE HONORABLE THING. Do what

you were elected to do - represent the interests of the American citizens; the citizen Warriors who put their lives on the line twenty-two years ago, serving you, so that you could one day have the privilege of serving them. So please, serve them. They may not have paid for your political campaigns, but they have paid dearly for your freedoms. It is up to each of you to decide which holds the most value.

It's been twenty-two years. That's quite long enough. Too many have died, too many have suffered with constant pain, profound fatigue, and other debilitating symptoms too numerous to list. More importantly, far too many continue to have their *disability claims denied by the Department of Veterans Affairs, despite voluminous regulations that your honorable body created*; laws that were supposed to give the *benefit of the doubt* ("*Presumption of service connection*") to the symptomatic Persian Gulf War Veteran. With great respect, please trust me; by in large the very laws (the *Direct Orders!*) that you issued to the VA to take care of these Veterans are being summarily *ignored at the vast majority of VA Regional Offices* across this country. *That* is beyond unconscionable.

History is watching.

Very Respectfully,  
David K. Winnett, Jr.  
Captain, United States Marine Corps (Retired)  
100% Disabled Persian Gulf War Veteran

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#### **Chris Thomas, Summary of My Case History with the Veteran's Administration**

- In 1991 and 1993, I served with the 3rd Armored Cavalry Regiment in the Persian Gulf region. Between May and December of 1993 he was gassed and shelled in combat with my regiment. Military records support this point and have been undisputed in claims made to the VARO.
- I was discharged from active duty service in 1996. I began service in the reserves from 1996 to 2000. I suffered chronic kidney problems (stones, other) during the years leading up to my discharge from the reserves.
- October 13, 2008 I suffered an episode of anaphylaxis resulting severe respiratory distress. I had to be rushed by ambulance to the Skyline Medical Center where I was intubated. This experience is consistent with my claim that symptoms of Parasympathetic Autonomic Dysfunction (PAD) began in 2008.
- I was diagnosed on December 4, 2008 by Dr. Zia, a private practice neurologist in Bowling Green, with Parasympathetic Autonomic Dysfunction (ANS/ALS & neuro condition) by my neurologist and began losing feeling in my feet and legs. DRO Chuck Tate dismissed this diagnosis because he thinks Zia practices in a rural market and doesn't have the skills of physicians in a university setting. Zia is a Boston University and Harvard Medical School graduate. Dr. Zia performs over 300 tilt table tests annually to determine Parasympathetic Autonomic Dysfunction. Dr. Smith (VA neurologist) also rejected Zia's diagnosis.
- November, 2008 I was hospitalized for migraine and tremor.
- December, 2008 I was hospitalized for chest pain.
- April, 2009 I required surgical removal of grossly enlarged axillary lymph nodes.
- May, 2009 Dr. Diana Cavanaugh, Allergist with Graves-Gilbert Clinic writes a letter opining that the anaphylactic episodes, joint pain, migraines, tremor, lymphadenopathy and chest pain symptoms must have some underlying cause which can link all of these symptoms together.
- June 6, 2009 I took the Gulf War Registry exam which was not a complete physical. Examiner didn't review my registry paperwork. My claim was denied.
- August 15, 2009 I was diagnosed by (Dr. Dewey Dunn) VAMC Nashville as having (a) mild restrictive lung disease; (b) migrane headache disorder; (c) multiple arthralgias of unknown etiology and (d) irritable bowel syndrome. Yet the DRO said I did not have lung disease and IBS in his denial of my claims for assistance.
- March 3, 2010 was the first scheduled appointment with Dr. DeMuth as the primary care physician.
- April 21, 2010 While an inpatient at VAMC, Dr. Hatfield (VA Gastroenterologist) indicated to me that Irritable Bowel Syndrome (IBS) is secondary to PAD.
- May, 2010 After losing nutrition and fluid and experiencing vomiting for several over two weeks, I was admitted as an inpatient at VAMC. I went through

multisystem failure and was on the verge of coding and was transferred to Jewish Hospital from May 14–18, 2011. Medical staff at Jewish said my bowels were dying. Dr. Hatfield explained to me that Gulf War Syndrome degrades your bowels/stomach because they are part of your auto immune system. He said serin attacks every phase of your auto immune system.

- June 3, 2010 Dr. Ron Stattenberg, VA Radiologist conducted a MRI of my brain and reported evidence of chronic small vessel ischemic change. Small vessel ischemic change is consistent with stroke, hypertension, migraines or other medical conditions. I have a history of these symptoms.
- July 6th, 2010 Dr. Ramirez, Infections Disease physician with VAMC Louisville diagnosed me with radiation poisoning. Dr. Smith, Neurologist stopped the proposed medications to treat the radiation poisoning so Ginko Balboa or fish oil was proposed as an over the counter medication. This treatment was discontinued shortly due to adverse gastrointestinal side effects. Smith's nurse told me 'Nothing is wrong with you.' Again Dr. Smith rejects another physician's diagnosis as he did with when he rejected Dr. Zia's diagnosis of Parasympathetic Autonomic Dysfunction.
- June through late 2010, I was treated at Southern Kentucky Rehab Hospital where I was treated for physical therapy, speech therapy and occupational therapy. My inability to perform basic exercises is well documented by qualified therapists. My musculoskeletal functions progressively worsened and pain increased over those months. Rehab care was discontinued the hospital for fear that lack of progress would threaten the reimbursement of costs for such care.
- Early 2011, My condition worsened. I frequently experienced swelling and inability to urinate. Weakness in the left side of his body worsened and I experienced tremors frequently. No cohesive plan of care was established so I reached out to Congressman Guthrie to do something to get the VAMC to take me seriously and develop a cohesive plan of care to make me better.
- In late Spring 2011, Mark Lord from Guthrie's staff secured a meeting with Louisville VAMC leadership including Director Pfeffer, Chief of Staff Marylee Rothschild, VAMC legal counsel and risk management staff. Rothschild debated my claims about a lack of diligent care and the risk management person pressed that I was not compliant with efforts to seek PTSD treatment. Mr. Lord made the point that his anxiety will be dramatically reduced if his medical needs will be treated diligently. Director Pfeffer brought up the prospect of sending Ito the War Related Injury and Illness Center because he said they are the specialists for these types of cases.
- August 2011, I went to the WRIISC in Washington, DC. It was a major disappointment. What was described as a specialty center to treat war related injuries of an obscure nature like GWI turned out to be a research facility with very little treatment capacity. The bottom line was I came home with a diagnosis of low testosterone and a big bag of vitamins. I also came home very sick and hurting from the MRI's which heated up the shrapnel in my body.
- Six weeks passed and no one from WRIISC and the VAMC nor primary care were talking with each other. So I got Congressman Guthrie's staff to press them to take action. Congressman Guthrie got wrote a letter on my behalf complaining about the poor continuity of care associated with my case.
- In November of 2011, my health is worsening under the care of the VA. Dr. Ramirez and Dr. Peyrani, Infectious Disease physicians in the VA described me as having progressive neurological symptoms and multiorgan dysfunction affecting the heart, brain, kidneys, bone marrow, peripheral nerves and the immune system.
- As my condition worsened under the VA, the care providers did not demonstrate appropriate diligence in carrying out a treatment plan for me. My first appointment to discuss the recommendations from the WRIISC did not going to happen until February of 2012 which would have been six months from my discharge from the WRIISC. Fortunately, with Congressman Guthrie's help it was moved up to November.
- The continuity of care with my case was very poor given the acuity of my symptoms. My primary care physician, Dr. DeMuth, was not communicating well with specialists involved in my care. Other than one consultation with WRIISC physician, Dr. Li, DeMuth did not have consultations with the specialists involved in my care. He relied only on case notes. Given my involved and worsening condition, more diligence should reasonably be expected.
- DeMuth did not communicate adequately with me. DeMuth told me that he would complete the referral for me to see a cardiologist and an urologist for the severe symptoms that I was experiencing. Instead of completing the referral he put in for tests to take place weeks later that would qualify me to see the spe-



cialists. DeMuth also prescribed tests that would expose me to high levels of radiation that could be potentially harmful to a patient with probable radiation poisoning, yet did not consult with me and did not take my phone calls about the matter days before the procedure was to be done. In late 2011, DeMuth began sending vitamins and drugs to me without consultation about the purpose of them. DeMuth even went so far as to demand that I sign a contract with him limiting the number of medical concerns that I can talk to him about at two concerns per visit. The contract also limited the amount of his time that I could have in a patient visit.

- Through late 2011, VAMC leadership was not advocating any material change in the way I was treated. Upon my desperate request for help Congressman Guthrie's, sent a letter to Director Pfeffer and Chief of Staff Rothschild outlining these concerns. The response from Chief Rothschild was that the care I was receiving was completely within their standard of care and that this office "should let doctors be doctors." Her only recommendation was to designate a nurse on DeMuth's staff as a case manager and encourage DeMuth to spend 30 minute visits with me rather than the customary 15 minutes typically provided. This seems ironic that she advocated letting the doctors be doctors yet nine months ago their plan was to get me into the care of the WRIISC because the appropriate expertise was not sufficient in this VA region to care for me adequately.
- There is apparently no defined protocol to treat veterans with symptoms of radiation poisoning or biological/chemical combat exposures.
- Meanwhile, I pleaded desperately for the opportunity to see a specialist for the symptoms that I was experiencing. I have grown increasingly angry at the VA system for not treating my combat injuries and for treating me as though my symptoms are fiction. I acknowledged that I am 100% PTSD disabled and I am willing to get treatment. But I want my physical symptoms to be taken credibly so I can get care that is consistent with private health care providers outside the VA system.
- In late 2011, I felt that I didn't not have long to live. As a former critical care nurse at the Vanderbilt Hospital, I know that untreated atrial fibrillation of the heart, the chronic kidney dysfunction and weakened immune system can easily lead to death rapidly. This and numerous other symptoms combined to degrade my quality of life.
- In early 2012, we seemed to have exhausted all options at the Louisville VAMC level with no good reason to expect improvement in my care. So Congressman Guthrie's staff escalated my complaint to VISN 9 Director Dandridge conceded to move my care outside the VA to private physicians.
- Currently, I am making some progress now but my physicians have almost no experience treating the patients with exposures to bio/chem agents or radiation poisoning. Reimbursements from the VA are chronically slow pay which makes them want to drop me as a patient. Likewise, there have been frequent battles with the VA pharmacy to get the meds filled the way the doctors want them filled.

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**From Kirk P. Love**

Dear OI subcommittee

My name is Kirt P. Love. I served in the 1990 Persian Gulf War as a generator mechanic with 141 Single Battalion attached to VII Corp. Our unit deployed from Germany in November 1990 and left in April 1991.

I got deathly ill in 1993 and the system failed me. Filed for VA benefits in 1994 that turned into a nightmare battle heading to my 2002 meeting with Sec Principi's staff after my BVA hearing. Have been 60% rated since 2002. It should not have taken a meeting with the VA Secretaries staff after 8 years of fighting with VA to make it happen.

Since 1997 I've run a survey and website advocating Gulf War veterans. By 1999 I attended regular meetings with the Pentagon with 33 other advocacy groups over our concerns. By 2002 the Pentagon shut down outreach with the GWI community and put the whole show in VA's hands. The Research Advisory Committee was formed about that time but only specialized in research.

By 2005 healthcare and benefits issues were moot as only the RAC had any Congressional mandate or interest. The Gulf War Registry as well as any other GW Programs had floundered badly. The only venue for us to replace the defunct Gulf War Referral centers was the War Related Illness and Injury Study Centers. There how-

ever were one time visits provided you could get a referral from your primary care physician. My own health struggled as I kept defying the system such as getting multiple referrals to the WRIISC that did not allow it. No matter what I did from the days of the Gulf War Illness referral centers, to the WRIISC, and so on – I could not get answers or long term help.

Conditions that were acute in the 90's have progressed to chronic in the present while VA's answer to me is "we don't know" or worse.

By 2008 I managed to get a VA Gulf War Illness Advisory Committee through the system with Rep. Chet Edwards help. But, VA sabotaged the committee with ringers since it wasn't a chartered Congressional committee and the chairman pushed hard to wrap it up early even if the final report was thin. In the end the committee did not do the job it should have and I disputed the final report as putting Dr. Stephen Hunt in charge of the show. The visit in Seattle had shown me he was running a psyche clinic railroading vets through that did not want to return. They called it the PDICI and over time shifted the focus to a different term to the PACT but same focus. Mental health rather than physical evidence.

VA snowballed our committee and did not want to provide any hard line information during our tenure. The only statistical reporting system at that time was the GWVIS which had become more and more erratic. I discovered a variance in the data in which they had been showing a 10% drop in the overall numbers of those filing for benefits. This led to a subcommittee to look into the numerical error, and led to the change to the GWVIS into the pre911 report. However, VA decided to do one report and then mothball it since it wasn't under any mandate.

Our committee was made promises by VA of such things as the Gulf War Review being published 2 to 3 times a year. They published only one in July 2010 following our disbanding and produced none since then.

They followed our committee up with the Gulf War Illness Task Force. Complete with annual reports and a public comments website. The first year they completely left out the public comments and the second year they edited them for content rather than included verbatim. Only to find later the committee was deaf to input, and operated in secret with no public meetings or even basics like blog or website to show there meetings. In effect this private internal committee became the end all be all that did not have to interact with the public or actually acknowledge outside interest in our own plight.

VA tried to parade its newest incarnation the Gulf War Veterans' Illnesses Biorepository in January as if it was a positive thing. Except, I was there in 2006 when we pushed for the Gulf War Brain Bank as a tissue repository to replace the defunct AFIP that did not cooperate with researchers as it should have. The brain bank languished from lack of support. It changed hands, became the ALS repository in Tucson AZ. Then changed hands again under Dr. Neil Kowall, M.D who later confirmed in 2010 before the RAC they had not collected one sample. In 2012 he confided with the RAC the GWVIB only has 2 years of funding. They gave no reference in 2012 of collected samples. So far to date all they have is the brain of Wade George.

I can go into much greater detail with 17 years of email and correspondence with a large plethora of folks all around all this. But, long story short at each stage that I try to get my own answers I find more and more bureaucracy that thwarts my attempts to find answers to my question of what went wrong 22 years ago in the Gulf War. From the reclassification of 6 million records from the war to the continued efforts of VA to push GW vets into psychiatry rather than cutting edge research. Now we have the most resent insult wherein the IOM's volume 9 report on Multisymptom Illness takes a total departure from the content of its former Volume 8 report which had been more realistic. Why? The results might have been coached by VA for a less happy agenda?

A current realistic attempt would be the effort to have 100 GW veterans genomes sequenced and look at the total genome for answer as to any defective gaps that might answer current medical myths on cause. The "Gulf War Genome Project" would finally put to bed the debate over physical cause if it finds anomalies that surface in regularity outside the general population.

But, having done this type of work for 17 years now I've learned its better to be brief with Congressional committees or risk being ignored. In short, if we financed a genomic study we can put all this to rest and head towards "diagnoses/treatment" with real possible results. All else is treacle as the genome is the final answer in medical research circles. A tangible goal with a real future. Granted long term.

Astoria the rest, VA has for 22 years mishandled Gulf War Medical Research and any possible treatment trials of value. It cannot govern itself and should be stripped of any authoritative position concerning Gulf War vets. They should no longer receive funding for GW IOM projects as neither the IOM nor VA can be objective of such. There should be PERMANENT oversight in place with VA over any future

Gulf War Illness concerns as veterans have suffered long enough at their hands. The GWVITF should be disbanded since it only serves VA internally as a tool of elderly agendas that do not fit current medical theology. In short, you can't leave the child in charge of the cookie jar.

Sincerely  
 Kirt P. Love  
 Director, DSB  
 Former member VA ACGWV

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**From Beatrice A. Golomb, MD, Ph.D.**

**I. It is a mistake to group together GWI with other chronic multisymptom conditions.**

Multiple chronic symptoms can be seen in numerous conditions, from hypothyroidism to vitamin D deficiency to mitochondriopathy. For each of these, the constellation of symptoms might be viewed as not "distinct." The same symptoms commonly reported *at elevated rates* in each such condition are also present *at lower levels* in people without these conditions (and also at elevated levels, in people with the *others* of these conditions), and no specific symptom is either required or pathognomonic.

In these cases, the conditions are potentially distinguishable because ultimately the mechanism involved was ascertained and tests became available. (Moreover, it is the case that some of these "chronic" conditions can cease to be chronic when the cause is identified and leads to a definitive treatment.) However, this has not always been the case, and indeed, it has not been the case for all that long historically.

The constellation of symptoms in GWI may be seen in many other conditions – such as the conditions cited, hypothyroidism to vitamin D deficiency to mitochondriopathy. For each of these (as for GWI), the constellation of symptoms might also be viewed as not "distinct." The same symptoms commonly reported *at elevated rates* in each such condition are also present *at lower levels* in people without these conditions (and also at elevated levels, in people with the *others* of these conditions), and no specific symptom is either required or pathognomonic. In these cases, the conditions are potentially distinguishable because ultimately the mechanism involved was ascertained and tests are available; however, this has not always been the case, and indeed, it has not been the case for all that long historically.

There are specific environmentally induced versions of these conditions: radioactivity induced hypothyroidism; bariatric surgery induced vitamin D deficiency; medication-induced mitochondriopathy. If tests were not yet available, there would have remained strong utility in grouping persons with these elevated multisymptom health problems in the context of their common exposure setting, in order to facilitate research to enable these distinct conditions and their foundations to be ultimately elucidated and understood.

It is true that some treatments may provide some benefit, taking the edge of the impact of chronic multiple symptoms (and for that matter, many diagnosed conditions), irrespective of the mechanism that produced the chronic symptoms – coping mechanisms, gentle exercise, addressing the anxiety that may arise from health problems. But grouping GWI together with other chronic multisymptom conditions has potential to do a terrible disservice to those affected. It may retard or extinguish prospects for identifying mechanisms and providing treatments that are so urgently needed by these veterans. Many who served in the Persian Gulf are affected by disabling symptoms, and these problems arose as a consequence of service to their nation. It is possible that their conditions need not remain chronic, if the mechanism is identified and addressed. That should be the goal in GWI.

**II. It is a mistake to group these with war-related multisymptom conditions**

While unquestionably, health conditions have arisen in association with many prior conflicts, it should be recognized that a range of factors, differing in profile, will have contributed in different conflicts: malnutrition, dehydration and electrolyte imbalance (from diarrheal illness), trenchfoot, malaria, brucellosis, parasitic illness, etc have all affected health of military personnel in different deployments. Many of these (and many other conditions) can produce fatigue and CNS symptoms, and some can engender a broader set of symptoms, commonly in the short term, providing a reminder that common symptoms can arise in different conflicts from dif-

ferent causes with different optimal treatments. More relevant than the existence of symptoms that are features of many conditions, and that have therefore not surprisingly occurred also with prior wartime conditions, is that GWI embodies characteristics that *distinguish* it from other post-war conflicts. In any case, the existence of features common to many health conditions does not imply the health conditions are the same or are optimally managed in the same fashion.

Conditions that are prominent in veterans of recent conflicts are PTSD, TBI, and GWV: These can be conceptualized as resulting from psychic stress, mechanical brain injury, and environmental/chemical injury respectively. While some symptoms (and even *some* downstream pathways) may be in common, separate means for protection from these conditions, and separate study to understand mechanisms are in order – and separate or minimally, stratified treatment trials. Treatment with thyroid hormone – though a definitive treatment for hypothyroidism – may not show up as conferring significantly beneficial, if persons with hypothyroidism are combined with persons with numerous other causes of multisymptom illness, diluting the effect. Equally troubling, a treatment may be effective due to benefit in a subgroup, and demonstration of effectiveness, if the groups are conceptualized as one entity, may lead a treatment effective in one group to be inflicted on another group in which it is ineffective or harmful.

For these reasons, it remains desirable to retain conditions with distinct proximal causes, nonidentical mechanisms, and possibly very distinct optimal treatments as distinct, even if some mitigating treatments test as being helpful for several or all of them.

It may ultimately prove to be the case that common causes and mechanisms are involved in some instances of chronic multisymptom health problems in veterans of subsequent deployments, in nondeployed veterans, and in civilians. But it is preserving the group with a common corpus of exposures that provides the greatest chances of ultimately identifying the foundations of this condition, and helping not only Gulf War veterans, but others who have developed similar problems from related exposures.

### III. GWV are disadvantaged in screening and referrals

Presently, veterans with GWI seen at the VA are the forgotten stepsisters among veterans with chronic problems. While there are mechanisms in place for screening and referral for TBI and PTSD, no such approaches are in place for GWI. Many VA physicians, nurses, and scientists are not even aware that GWI differs from PTSD, because no formal training occurs about GWI for those who join the VA. Physicians who have been at the VA for a long time received mandated training about GWI that implied they were not ill or it was basically all in their heads. (This was not a conclusion that could be drawn from evidence even at the time; and copious subsequent evidence has refuted this position.)

Physicians that have been at the VA for a shorter time have had no formal required training on GWI, so have no reason to be aware of a difference from PTSD. This is compounded by the fact that the VA has chosen to define and label as Gulf War veterans not only those deployed in 1990–1, but all deployed to the region from 1990 onward. This also precludes meaningful use of VA databases to track health problems and outcomes separately in Gulf War veterans.

GWV with chronic multisymptom problems are often not treated with compassion they deserve. Physicians unfamiliar with their issues, and with limited time, may have little patience for their multiple problems, not understanding that these arose from military exposures. One Gulf War veteran in a high paying job requiring excellent skills who developed new onset weakness with no known cause, read the RAC report and became familiar with evidence on Gulf War illness. He reasonably was concerned that his Gulf War experience might relate to his problems. He presumed that VA physicians would be knowledgeable and went to the local VA. He was seen by a neurologist there who told him categorically that he did not believe in Gulf War illness. (The patient shared with me that he cried.) The neurologist told him he only believed in real diagnoses, and so labeled him with a different diagnosis, despite acknowledging that the test results were not consistent with that diagnosis. In frustration, that veteran actually chose to fly to another city to get primary care from a physician who had some knowledge about GWI.

### IV. Outside referrals

In principle there are referral approaches for veterans with Gulf War illness that can allow them to undergo more comprehensive evaluation and management at a war related illness center. In practice, there are no meaningful (controlled or randomized) data to say if these centers provide benefit (though, at least patients may feel their problems are receiving attention). Additionally, many VA physicians are

not aware that there is an option to refer to these centers, and this option may in practice be limited both by restricted capacity of these centers (there are just a few, not geographically distributed) and the requirement that the local VA cover any costs to fly the patient to the center, which the VA may decline due to fiscal considerations (providing selective access to those who are geographically close).

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**Questions For The Record**

**Letter From: Hon. Michael H. Michaud, Minority Ranking Member, Committee on Veterans' Affairs, To: The Hon. Eric K. Shinseki, Secretary, U.S. Department of Veterans Affairs**

March 20, 2013

The Honorable Eric K. Shinseki  
Secretary  
U.S. Department of Veterans Affairs  
810 Vermont Avenue, NW  
Washington, DC 20420

Dear Mr. Secretary:

In reference to our Full Committee hearing entitled, *Gulf War: What Kind of Care are Veterans Receiving 20 Years Later?* that took place on March 13, 2013, I would appreciate it if you would answer the enclosed hearing questions by the close of business on May 1, 2013.

In preparing your answers to these questions, please provide your answers consecutively and single-spaced and include the full text of the question you are addressing in bold font. To facilitate the printing of the hearing record, please e-mail your response in a Word Document, to Carol Murray at [Carol.Murray@mail.house.gov](mailto:Carol.Murray@mail.house.gov) by the close of business on *May 1, 2013*. If you have any questions please contact her at 202-225-9756.

Sincerely,

MICHAEL H. MICHAUD  
Ranking Member

CW:cm

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**Questions From: Committee on Veterans' Affairs, To: U.S. Department of Veterans Affairs**

**Submitted by Ranking Member Kirkpatrick**

1. The War Related Illness and Injury Study Centers, or WRIISCs seem to be popular among the Gulf War veterans and receive high marks. We have heard from the first panel that there is a waiting list to get in to the centers.

a. Is there a waiting list and if there is how long is it?

b. What process does VA have in place to get data from the WRIISCs and other programs to measure outcomes to determine whether the programs have been successfully implemented and is improving care?

c. Should we expand access to the WRIISCs?

2. Please tell the Committee about the National Health Study of a New Generation of US Veterans.

a. How many veterans were involved?

b. How much did VA spend on the study?

c. Have the results been released? If they have, what did they tell us? If they have not, when will they be released?

d. How is VA going to use the findings of the study?

3. According to your testimony VA seeks to provide veterans with CMI, personalized, proactive, patient-driven care.

a. What challenges has VA faced in implementing this care?

b. Are the Patient-Aligned Care Teams staffed and if not when do you think they will be?

c. How long has VA been linking PACT teams working with Gulf War veterans with a specialty care capability?

4. Please elaborate on the social media campaign VA is engaging in to improve feedback on the program to veterans?

a. How is VA ensuring that Gulf War veterans served by the program can communicate more easily?

5. I understand that about 130,000 Gulf War veterans have undergone a registry exam. However, the IOM has reported that VA does a poor job of gathering data.

a. How is VA gathering and aggregating data, so that it is useful, in the bigger picture to the treatment and care of Gulf War veterans?

6. We all know how important research is. In April 2012 the Committee received the Annual Report to Congress on Federally Sponsored Research on Gulf War Veterans' Illnesses for 2011 mandated by Congress. According to the report this is the eighteenth report on Federal research and research activities. There are many projects listed in the report. The report is 112 pages long. The report talks about VA creating a Gulf War Research Strategic Plan to map the direction of research for the next five years.

a. Where is VA in reaching that goal? Do you have a timeline?

b. Have stakeholders, like the first panel, been brought in to help VA with the strategic plan? If not, why not?

7. The IOM had 14 recommendations, yet, reading your testimony VA seems to have all the bases covered and everything is fine. I think the first panel may disagree. Please elaborate on the Office of Public Health and the quarterly conference calls with Environmental health coordinators and clinicians located at every VA hospital.

a. How long have the quarterly calls been going on?

b. Are there minutes kept of the calls that are shared with interested parties and stakeholders? If not, why not?

c. What kind of policy and procedures actually are products of these calls that benefit veterans?

8. In testimony you state that VA is now in the process of developing additional innovative training resources such as a mobile device and internet applications. After 22 years, this seems a bit late to just now be developing applications for the environmental exposures, symptoms and conditions.

a. When did the process begin? When do you think it will be rolled out to veterans who may find it helpful?

9. I find it hard to believe and disappointing that VA is testifying that they are just now adding a clinical reminder to the computerized patient record system to prompt clinicians to ask all Gulf War separating servicemembers whether they may have symptoms consistent with CMI. I am sure you would agree this is long overdue and is a disservice to the men and women who have served in the Gulf.

a. How are you improving communication among VA health care providers and with patients concerning CMI?

b. What do you mean when you say you are improving training to staff to better recognize CMI?

c. How are you measuring whether this training is effective or not?

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**Questions and Responses From: U.S. Department of Veterans Affairs, To: Committee on Veterans' Affairs**

**Submitted by Ranking Member Kirkpatrick**

**1. The War Related Illness and Injury Study Centers, or WRIISCs seem to be popular among the Gulf War veterans and receive high marks. We have heard from the first panel that there is a waiting list to get in to the centers.**

**a. Is there a waiting list and if there is how long is it?**

**Response:** Each War Related Illness and Injury Study Center (WRIISC) site offers a suite of clinical services based on the complexity of the medical needs of the individual Veteran. These range from a comprehensive, in-person multi-day evaluation to more focused evaluations. Multi-day evaluations may take up to five days and involve as many as ten clinicians. Each site manages referrals made through the electronic medical record independently. The amount of time between the consult request and the determination of eligibility and appropriateness varies on a case-by-case basis due to Veteran and referring provider responsiveness to requests for essential information and completion of preliminary tests at the referring site. The WRIISCs proactively communicate with both referred Veterans and their providers to ensure questions are resolved as quickly as possible. Each WRIISC may have approximately six Veterans who are awaiting an appointment as the details of their referral are refined and timing of the appointment is agreed upon with the Veteran. Once eligibility and appropriateness for comprehensive WRIISC examinations are determined, the average wait is four months to obtain a comprehensive inpatient evaluation. Urgent cases are evaluated sooner. Waiting times are less for Veterans seen on an outpatient basis. While there is currently a waiting list for appointments, the length of these waits is decreasing due to filling staff vacancies at the WRIISCs, streamlining the intake process, and working more closely with referring providers to ensure the completeness and appropriateness of each consult. We anticipate that these wait times will continue to decrease through these efforts and through additional ongoing efforts to provide referring clinicians with the information they need to handle more of these cases such as a train the trainer pilot for post deployment health champions.

**b. What process does VA have in place to get data from the WRIISCs and other programs to measure outcomes to determine whether the programs have been successfully implemented and is improving care?**

**Response:** Each WRIISC site engages in ongoing quality improvement processes, including evaluation of clinical services and patient and provider feedback. WRIISCs systematically collect patient satisfaction data at the completion of the in-person comprehensive evaluation and elicit referring provider feedback. Results of these surveys consistently indicate overall patient satisfaction with their visit at over 95 percent. In addition, WRIISCs conduct follow-up calls with Veterans after their in-person evaluation to assess implementation of the recommendations and to problem solve barriers to that implementation. The WRIISCs are currently developing a strategic plan that will incorporate objective measures of outcomes. OPH is establishing a formal and regular review process of the WRIISC activities to provide oversight and guidance of WRIISC performance.

WRIISC personnel regularly use their clinical experience and research findings to educate VA, DoD, and other providers as well as the Veteran community. The WRIISCs regularly host conferences, webinars, and other opportunities for continuing education. WRIISC Veteran and provider educational activities promote greater appreciation of the impact of deployment on health and greater knowledge on how best to address and manage deployment health concerns (e.g., CA WRIISC sponsored a conference in July 2012 entitled “Gulf War Illnesses: What Providers Need to Know”).

Finally, WRIISCs have a track record of publishing research based on the clinical experience in peer-reviewed journals (e.g., the *Journal of Occupational and Environmental Medicine's* special issue on Health Hazards of deployment to Iraq and Afghanistan published in 2012). These publications provide information about WRIISC evaluations and Veterans seen, and provide evidence that the data collected and the results obtained regarding symptoms and exposure concerns stand up to the scrutiny of review by other medical and scientific experts.

**c. Should we expand access to the WRIISCs?**

**Response:** The best way to expand access to high quality of care modeled by the WRIISCs is to take what the WRIISCs have learned from providing clinical care to Veterans with the most serious and debilitating deployment health concerns, especially First Gulf War Veterans, and disseminating it to other VA providers through clinical consultation and educational activities. The WRIISCs already partner with colleagues from VHA (including Patient Aligned Care Teams (PACT), Veteran Service Organizations (VSO), Veterans Benefit Administration, (VBA), academia, and DoD) to expand the reach of educational and clinical care activities nationally. Strategic expansion that leverages these existing collaborations is an appropriate ap-

proach towards expanding Veterans access to high quality post-deployment health care.

The three parts of the WRIISC mission: clinical care, research, and education, interact to allow the advancement of the knowledge and expertise necessary to improve the lives of Veterans. For example, Veterans are invited to participate in research protocols, and, in return, Veterans benefit from the application of innovative approaches to diagnosis and treatment (e.g., all three sites have programs and research activities promoting and evaluating Complementary and Alternative Medicine (CAM) practices to aid in the management of chronic symptoms). Similarly, the WRIISC clinical experience is leveraged to create educational products and training events to disseminate knowledge and best practices to providers in the field. This experience and knowledge is translated into educational products for Veterans and their families.

**2. Please tell the Committee about the National Health Study of a New Generation of US Veterans.**

**a. How many veterans were involved?**

**Response:** The VA Post-Deployment Health Epidemiology Program (EP) conducted the “National Health Study for a New Generation of U.S. Veterans.” Thirty thousand Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF) Veterans and thirty thousand Veterans who served elsewhere during the same time period were invited to participate. Surveys were sent to 60,000 Veterans. In total, 20,563 Veterans provided complete surveys (11,337 OEF/OIF Veterans and 9,226 Veterans who served elsewhere during the same period). The participants for the health survey were selected from Veterans who served in each of these cohorts from the onset of the conflict in October 2001 through June 2008, and the survey was conducted from August 2009 to January 2011. The survey used postal, Web-based, and telephone administered surveys to collect self-reported health information from deployed and non-deployed Veterans concerning their chronic medical conditions, history of traumatic brain injury (TBI), Post-traumatic Stress Disorder (PTSD) and other psychological conditions, general health perceptions, reproductive health, pregnancy outcomes, functional status, health care utilization, and behavioral risk factors. Results from the study will be prepared for publication in the peer-reviewed scientific literature. The response to 2.c. below provides additional detail about topics that will be examined over the next 12 months. Five papers from the Study have been submitted to peer reviewed journals; data for an additional three papers are being analyzed; and an additional six studies are being planned.

**b. How much did VA spend on the study?**

**Response:** VA contracted the logistical support and implementation of the survey to a Service Disabled Veteran Owned Small Business. The value of the contract was just under \$5 million.

**c. Have the results been released? If they have, what did they tell us? If they have not, when will they be released?**

**Response:** The study is still ongoing. There are a number of planned studies as well as an initial pilot to test incentives to improve overall response rate.

Articles on the following topics are in preparation for submission to peer-reviewed journals or have been submitted:

Goals for the next five months:

- The National Health Study for a New Generation of United States Veterans: Methods for a Large-Scale Study on the Health of Recent Veterans – in preparation
- Adjustments for Temporal Misclassification of Exposure Status in Surveys of Health Outcomes - submitted
- Prevalence of Respiratory Diseases among Veterans of OEF and OIF: Results from the National Health Study for a New Generation of U.S. Veterans – submitted

Goals greater than 5 months:

- History of infertility among men and women Veterans: underlying causes, medical evaluation, and outcomes – in preparation
- Population Prevalence Estimates of Screening Positive for TBI and PTSD: Results from the “National Health Study for a New Generation of U.S. Veterans” – in preparation



- Prevalence of functional health measures, illness, and military exposures – in preparation
- Respiratory disease and associated risk factors – in preparation
- The relationship of TBI/PTSD to self report of suicidal ideation – in preparation
- Use of Complementary and Alternative Medicine (CAM) modalities – in preparation
- Self reported birth defects among OEF/OIF era Veterans – in preparation
- Health risk behaviors: Smoking and alcohol rates – in preparation
- HIV risk taking behaviors among OIF/OIF Veterans – in preparation
- Self reported risky driving behaviors and health behavior correlates – in preparation

The initial pilot (noted above) included a test on the use of incentives to encourage greater response rate because previous VA studies have suffered from low response rates, raising concerns about the generalizability of the findings. This test was recommended by the Office of Management and Budget to assess the effect of small monetary incentives in improving response and decreasing non-response bias. The results showed that a small pre-paid monetary incentive significantly increased participation rates. This was important to test as no data were available regarding the acceptability and success of using incentives in research with Veterans, and these results have been published in the journal, *Survey Practice* (2011).

One study assessed the prevalence estimates of TBI and PTSD. The results were presented in a poster presentation at the 2012 National Meeting of the International Society for Traumatic Stress Studies, November 2, 2012, in Los Angeles, CA.

Main findings:

Population prevalence estimates (screening):

- possible TBI among deployed =15.7% vs. possible TBI among non-deployed = 8.9%.
- possible PTSD among deployed =15.7% vs. possible PTSD among non-deployed = 10.9%.
- possible TBI & PTSD among deployed =7.7% vs. possible TBI & PTSD among non-deployed = 3.1%.

These figures are based on self-reports of illness based on clinical visits. The positive TBI screening would suggest a referral to second level TBI evaluation.

#### **d. How is VA going to use the findings of the study?**

**Response:** Results from the study will be used to inform VA leadership, Congress, Veterans, healthcare providers, the public and other stakeholders about the health and illness experience of the OEF/OIF Veteran population. The information will be used by VA leadership in the development of policy and provision of care.

### **3. According to your testimony VA seeks to provide veterans with CMI, personalized, proactive, patient-driven care.**

#### **a. What challenges has VA faced in implementing this care?**

**Response:** Effectively assessing and managing Chronic Multi-Symptom Illness (CMI) is a challenge in any medical setting. The process of ruling out the broad range of diagnosable diseases or specific conditions that might be causing any particular symptom or cluster of symptoms is the first step in the assessment and management of CMI. Health care in the Veterans Health Administration (VHA) is widely acknowledged to meet the highest standards in terms of disease diagnosis and management. If a specific diagnosis cannot be established to account for a symptom or cluster of symptoms, then a symptom-based syndrome such as CMI must be considered. Avoiding redundancy in repeated testing, assessments and empirical interventions, while being ever vigilant for emerging diagnosable conditions that may be contributing to the symptoms, requires a critical balance that is best served by team-based care with continuity over time. The PACT model is specifically designed to provide the type of patient centered, team based, continuous, health oriented care recommended by the Institute of Medicine (IOM) report and by the best practices described in the literature for assessing and managing CMI. The challenges in implementing personalized, proactive, patient driven care for Gulf War (GW) Veterans with CMI are in many ways the same challenges involved in the transformation to the PACT model: integrating services at all levels within the VHA; creating high-functioning interdisciplinary teams within our medical centers and clinics; educating and training teams consistent with the new paradigm of care generally as well as with respect to unique needs of specific cohorts of Veterans such as GW Veterans

with CMI; and monitoring care to ensure progress and fidelity to the standards and practices established for PACT.

**b. Are the Patient-Aligned Care Teams staffed and if not when do you think they will be?**

**Response:** National standards for staffing PACT have been developed. Nationally staffing of PACTs meets the recommended levels. There is local variation however, and not all teams currently have all the support staff that is recommended. Overall staffing continues to improve, and we are working with those sites that are lagging to determine the barriers they are facing and how they can be alleviated. Many aspects of PACT can be fully implemented regardless of staffing and all sites that provide Primary Care in VHA are expected to use the PACT model of care.

**c. How long has VA been linking PACT teams working with Gulf War veterans with a specialty care capability?**

**Response:** Many of the principles and practices recommended by IOM as well as by the clinical medical literature for optimally addressing the concerns of individuals with CMI were in motion prior to the implementation of PACT. The WRIISCs, the Gulf War Registry program, and the Gulf War Veterans Health Initiative (VHI) were oriented toward assessing the unique concerns of GW Veterans with undiagnosed symptoms. The VBA Program establishing presumptive service connection for undiagnosed conditions allowed for additional benefits and services for GW Veterans with CMI. The importance of comprehensive assessments of these, and of all, Veterans was served by the implementation of the Primary Care-Mental Health Integration Program throughout VA beginning in 2007, and the Post-Deployment Integrated Care Initiative (PDICI) in 2008. The latter built upon the work of the OEF/OIF/Operation New Dawn (OND) Program and supported the development of the type of integrated post-deployment care specifically mentioned in the IOM Report as the recommended approach to caring for individuals with CMI. These efforts served to strengthen the subsequent implementation of PACT, as these approaches are all derived from a common set of clinical principles: Veteran-centered, team-delivered, evidence-based, and health-oriented care. The alignment of PDICI teams with PACT resulted in Post-Deployment PACTs in many Centers, as well as an overall increased emphasis on enhancing the quality of “deployment health care” in all VHA facilities. This is being accomplished by broad based education of VHA staff on issues such as Military Culture, Deployment Health concerns (including CMI in GW Veterans), Military Service-related environmental exposures, and Compensation and Pension/Benefits-related to specific cohorts of Veterans (such as GW Veterans with CMI). The evolution of this heightened awareness of deployment related health concerns has components that relate to GWI Veterans specifically. These enhancements of post-deployment care and the emphasis on “PACT based post-deployment care” will serve not only our GW Veterans with CMI, but all Veterans with deployment related health issues, as it is important to remember that while CMI is much more common in GW Veterans than in other combat Veteran cohorts, it is a phenomenon we see in combat Veterans after all wars.

**4. Please elaborate on the social media campaign VA is engaging in to improve feedback on the program to veterans?**

**a. How is VA ensuring that Gulf War veterans served by the program can communicate more easily?**

**Response:** A multifaceted combination of traditional and new methods enhance communication with VA and Gulf War Veterans. Over the last 22 years, VA produced 41 editions of its Gulf War Newsletter.

A new “Gulf War Update” format is being developed for wide mailing and web posting. Examples of other communications include the following:

- Three versions of a Gulf War “VA Cares” poster to alert GW Veterans to health care, benefits, and the registry program
- A registry brochure in a print and online format
- A comprehensive web page at <http://www.publichealth.va.gov/exposures>, with substantial Gulf War-related health information at <http://www.publichealth.va.gov/exposures/gulfwar/index.asp>. This site has been improved by Veteran feedback.
- Active updating of the web pages with findings and reports, along with email subscriptions for web page updates as content changes are made
- Announcements via email and social media (Facebook and Twitter) on content updates that include both news (such as the posting of a report) and reminders about VA care (such as the availability of the Gulf War Registry program or

of certain resumptions). VA monitors social media for comments and questions when Gulf War topics are posted

- Solicitation of comments via the online tool UserVoice on the annual VA's *Gulf War Veterans' Illnesses Task Force Report*. VA reviews these comments for follow up and incorporates samples into the final report
- Interactive briefings at regular meetings VHA holds with Veterans Service Groups
- Response to media interviews and queries
- A variety of clinical education materials and tools that are made publicly available to Gulf War Veterans, including those that will be usable on smartphones and tablets

As more Gulf War Veteran care is provided by patient-centered care teams, there will be an emphasis on personalized and proactive care, with attention to rapport between the Veteran and an identified, interdisciplinary team of professionals. Care continuity will include of routine outgoing communications and outreach to the Veteran, including medication reconciliation and test notification, post-discharge telephone follow-up, and care management and telehealth around specific symptoms or clinical conditions. In addition, communication will improve via self-help resources on MyHealtheVet and other online platforms, secure messaging directly to each Veteran's PACT team, and telephone service capabilities with a variety of clinical resources. PACT based post-deployment care continues to enhance communication with Gulf War Veterans in a number of ways. First, the emphasis on personalized and proactive care in PACT is critical for Veterans with CMI, and establishes rapport between the Veteran and an identified, interdisciplinary team of professionals. The identification of a specific team of individuals serving each Veteran within PACT cannot be overestimated in promoting a smooth process of communication and any necessary dialogue to ensure understanding of the information by both patient and providers. Second, the overall goal of excellent continuity in care for Veterans is further advanced by a variety of routine outgoing communications and outreach to the Veteran, including medication reconciliation and test notification, post-discharge telephone follow-up, and care management and telehealth around specific symptoms or clinical conditions. Finally, VHA has established and is continuously improving multiple modalities of communication to better serve the Veteran, including self-help resources on MyHealtheVet and other online platforms, secure messaging directly to each Veteran's PACT team, and telephone service capabilities with a variety of clinical resources.

**5. I understand that about 130,000 Gulf War veterans have undergone a registry exam. However, the IOM has reported that VA does a poor job of gathering data.**

**a. How is VA gathering and aggregating data, so that it is useful, in the bigger picture to the treatment and care of Gulf War veterans?**

**Response:** The Gulf War Registry Examination is an important part of VA's commitment to the health care of Gulf War Veterans with environmental health concerns. VA uses the registry program, in effect since 1992, and data from other programs to obtain a comprehensive view of Veterans' health. The registry examinations capture self-reported symptoms and exposures and are used by VA researchers. In addition, to ensure VA obtains a full representative estimate of health effects in those who served in the Gulf War, VA continues to support and conduct well-planned research studies, such as the Office of Public Health Gulf War Veteran surveys.

VA realizes the importance of improving our health care system through monitoring performance of new and existing efforts that address the health care needs of Gulf War Veterans. VA agrees with IOM's recommendations 8 through 11 on "Improving Data Quality and Collection" in its "Treatment for Chronic Multisymptom Illness" report, and is developing plans to use all health care encounters, not just registry data, in our process metrics. As most primary care providers do not have extensive knowledge of the long-term health effects of environmental toxins, VA is improving coordination between PACT and the registry program Environmental Health Clinicians to ensure Veterans have these concerns appropriately addressed in their overall care plan.

**6. We all know how important research is. In April 2012 the Committee received the Annual Report to Congress on Federally Sponsored Research on Gulf War Veterans' Illnesses for 2011 mandated by Congress. According to the report this is the eighteenth report on Federal research and research activities. There are many projects listed in the report. The report**

**is 112 pages long. The report talks about VA creating a Gulf War Research Strategic Plan to map the direction of research for the next five years.**

**a. Where is VA in reaching that goal? Do you have a timeline?**

**Response:** The “Gulf War Research Strategic Plan – 2013–2017” was approved in February 2013. It will be available on the VA Office of Research and Development Web site very soon.

**b. Have stakeholders, like the first panel, been brought in to help VA with the strategic plan? If not, why not?**

**Response:** The draft Gulf War Research Strategic Plan was discussed in January 2012 at a meeting of the Research Advisory Committee on Gulf War Veterans’ Illnesses (RACGWVI). The RACGWVI and the National Research Advisory Council (NRAC), who are stakeholders in the Gulf War research program, provided recommendations which were incorporated into the draft Strategic Plan. As discussed at the January 2012 meeting, some sections were re-worded during VA review and concurrence to be consistent with VA policy and statutory requirements.

**7. The IOM had 14 recommendations, yet, reading your testimony VA seems to have all the bases covered and everything is fine. I think the first panel may disagree. Please elaborate on the Office of Public Health and the quarterly conference calls with Environmental health coordinators and clinicians located at every VA hospital.**

**a. How long have the quarterly calls been going on?**

**Response:** They began about 1980 with discussions about environmental exposure issues that predated the Gulf War.

**b. Are there minutes kept of the calls that are shared with interested parties and stakeholders? If not, why not?**

**Response:** Minutes are kept for each quarterly Environmental Health Quarterly Conference Call. Written transcripts of the quarterly calls are kept on a SharePoint site that is available for all Environmental Health providers. This allows information sharing, collaboration, reference material for those providers. Each call typically covers a wide variety of topics that span across multiple eras of Veterans with many different communication needs. VA analyzes these needs by topic and develops focused external outreach products based on these needs.

**c. What kind of policy and procedures actually are products of these calls that benefit veterans?**

**Response:** Each environmental health registry program, such as the Gulf War Registry, is documented in a VHA handbook to provide guidance for field staff. The quarterly calls provide an opportunity for dissemination of new policies and procedures to the field and to receive questions and comments from the field. Comments and suggestions from field staff are considered during handbook revisions and development of education products supported by the Office of Public Health. Through these processes, field staff has access to up-to-date and relevant information to care for Veterans with environmental health concerns. As an example, the recommendations in the 2013 IOM report were discussed in detail during the March 2013 call. One hundred and twenty-five call-in lines were required to support a large audience of field staff. Briefly, the agenda included a welcome to new staff and discussion of the IOM January 2013 report, Camp Lejeune health care law and ATSDR studies, Agent Orange reports, the Shipboard Hazard and Defense (SHAD) IOM study (currently in data collection phase), planning for the Open Burn Pit Registry, and planning for a train-the-trainer initiative.

**8. In testimony you state that VA is now in the process of developing additional innovative training resources such as a mobile device and internet applications. After 22 years, this seems a bit late to just now be developing applications for the environmental exposures, symptoms and conditions.**

**a. When did the process begin? When do you think it will be rolled out to veterans who may find it helpful?**

**Response:** VA continues to maximize all available modes of training to ensure staff is prepared to assist Veterans with GW health concerns. Over the last 22 years, VA Office of Public Health products have included face-to-face workshops and seminars, Veterans Health Initiative (VHI) study guides, and VHA training letters. VA produced 41 editions of its Gulf War Newsletter, three versions of a Gulf War “VA CARES” poster, including a 20th anniversary edition, VHI topics include a

“Guide to Infectious Diseases of Southwest Asia” and “Guide to Gulf War Veterans’ Health.” Information on depleted uranium includes a fact sheet and pocket card. In recent years, as technology has evolved, we have focused our efforts on more Web-based products, such as our comprehensive Webpage, <http://www.publichealth.va.gov/exposures>, to allow for ease of access to pertinent information as it becomes available. Currently, we are developing a Web and mobile application that providers can use to access exposure-related information during patient visits. Our concept is to offer the application on multiple platforms, including smartphones, tablets, and desktop computers, and although providers are our target audience, it will be made publicly available for download so that the information is available to anyone who might find it useful, such as Veterans, family members of Veterans, and VSOs. We started this effort in January 2012 and expect that the application will be available for providers in the field in calendar year 2014.

**9. I find it hard to believe and disappointing that VA is testifying that they are just now adding a clinical reminder to the computerized patient record system to prompt clinicians to ask all Gulf War separating service members whether they may have symptoms consistent with CMI. I am sure you would agree this is long overdue and is a disservice to the men and women who have served in the Gulf.**

**a. How are you improving communication among VA health care providers and with patients concerning CMI?**

**Response:** VA understands the critical importance of communication between patients and their care teams to achieve positive health outcomes. VA developed and provided specialized training on military culture and the events related to the Gulf War to provide VHA staff a common awareness of what Veterans have experienced to foster a shared understanding. VHA has also provided seminars for field staff through its WRIISC on chronic multisymptom illness, health risk communication, and other deployment health related issues. In the last two years, the WRIISCs have offered more than six nationally broadcasted webinars or satellite broadcasts per year.

**b. What do you mean when you say you are improving training to staff to better recognize CMI?**

**Response:** In some cases, a Veteran may be seen multiple times before the entire constellation of symptoms develops to qualify as a multisymptom illness. While a clinical reminder provides an additional tool to prompt a screening evaluation, it is not clear how often this screening should occur to ensure this illness is recognized. Therefore, regardless of a clinical reminder, staff must be able to recognize Veterans who develop chronic multisymptom illness each time a Veteran presents for care. Recognizing CMI in the clinical environment is challenging because the clinical presentation of CMI varies considerably between patients. Many CMI symptoms are non-specific and could be secondary to other common medical conditions. A lack of a consensus definition of CMI and validated screening tools further adds to the diagnostic difficulties in diagnosing CMI. Clinically this means that providers must determine if a Veteran has CMI on a case-by-case basis. VA’s Post-Deployment Integrated Care Initiative and WRIISCs continue to educate providers on these complex issues through webinars, consultations, and seminars. A WRIISC webinar originally broadcast in March 2012 remains available through the VA Talent Management System. In addition, a pocket card with resource links was distributed to over 23,000 VA staff.

**c. How are you measuring whether this training is effective or not?**

**Response:** Process and outcome measures are used to determine training effectiveness. As with all continuing medical education, participants are required to complete program evaluations to receive credit for their attendance. This evaluates if the training was perceived by each provider to be effective and the potential impact on the participant’s practice. VA is working to incorporate more direct measures of effectiveness such as a pre and post test evaluation system. Measures of patient satisfaction for VA’s Salt Lake City Gulf War Clinic Pilot program were collected and these data are currently being evaluated. Family medicine doctors in training, nurse practitioner students, physicians’ assistant students, and internal medicine doctors in training have all noted significant improvement in comfort with knowledge-base and ease in providing referrals to GW Veterans. These results are part of an ongoing study which uses focus groups and patient surveys. Through focus groups and surveys, staff in outlying clinics have also noted an increase in knowledge and ease of access of information regarding Gulf War clinical issues. Further efforts to im-

prove training for primary care providers include two planned conferences designed to provide education for local trainers. The planned Environmental Health train-the-trainer course will include measures of pre-intervention knowledge and post-intervention knowledge.

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