VA'S HEALTH CARE TREATMENT FOR PERSIAN GULF WAR ILLNESSES

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON VETERANS' AFFAIRS
HOUSE OF REPRESENTATIVES

ONE HUNDRED FIFTH CONGRESS

FIRST SESSION

JUNE 19, 1997

Printed for the use of the Committee on Veterans' Affairs

Serial No. 105–13

U.S. GOVERNMENT PRINTING OFFICE

44–671 CC WASHINGTON : 1997

For sale by the U.S. Government Printing Office
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402
ISBN 0-16-055774-7

AUTHENTICATED
U.S. GOVERNMENT
INFORMATION
GPO

COMMITTEE ON VETERANS' AFFAIRS

BOB STUMP, Arizona, *Chairman*

CHRISTOPHER H. SMITH, New Jersey
MICHAEL BILIRAKIS, Florida
FLOYD SPENCE, South Carolina
TERRY EVERETT, Alabama
STEVE BUYER, Indiana
JACK QUINN, New York
SPENCER BACHUS, Alabama
CLIFF STEARNS, Florida
DAN SCHAEFER, Colorado
JERRY MORAN, Kansas
JOHN COOKSEY, Louisiana
ASA HUTCHINSON, Arkansas
J.D. HAYWORTH, Arizona
HELEN CHENOWETH, Idaho
RAY LAHOOD, ILLINOIS

LANE EVANS, Illinois
JOSEPH P. KENNEDY II, Massachusetts
BOB FILNER, California
LUIS V. GUTIERREZ, Illinois
JAMES E. CLYBURN, South Carolina
CORRINE BROWN, Florida
MICHAEL F. DOYLE, Pennsylvania
FRANK MASCARA, Pennsylvania
COLLIN C. PETERSON, Minnesota
JULIA CARSON, Indiana
SILVESTRE REYES, Texas
VIC SNYDER, Arkansas
CIRO D. RODRIGUEZ, Texas

CARL D. COMMENATOR, *Chief Counsel and Staff Director*

SUBCOMMITTEE ON HEALTH

CLIFF STEARNS, Florida, *Chairman*

CHRISTOPHER H. SMITH, New Jersey
MICHAEL BILIRAKIS, Florida
SPENCER BACHUS, Alabama
JERRY MORAN, Kansas
JOHN COOKSEY, Louisiana
ASA HUTCHINSON, Arkansas
HELEN CHENOWETH, Idaho

LUIS V. GUTIERREZ, Illinois
JOSEPH P. KENNEDY II, Massachusetts
CORRINE BROWN, Florida
MICHAEL F. DOYLE, Pennsylvania
COLLIN C. PETERSON, Minnesota
JULIA CARSON, Indiana

CONTENTS

Page

OPENING STATEMENTS

Chairman Stearns 1
Hon. Luis V. Gutierrez 2
Hon. Michael Bilirakis 3
Hon. Joseph P. Kennedy II 5
Hon. Collin C. Peterson 6
Hon. Corrine Brown 6
Hon. Helen Chenoweth 43

WITNESSES

Backhus, Stephen P., Director, Veterans' Affairs and Military Health Care Issues, U.S. General Accounting Office, accompanied by Henry Hinton, Assistant Comptroller General, National Security and International Affairs Division 8
Prepared statement of Mr. Backhus 44
Clauw, Daniel J., M.D., Associate Professor of Medicine, Chief of Rheumatology, Immunology, and Allergy, Georgetown University Medical Center 12
Prepared statement of Dr. Clauw 113
Engel, Jr., Maj. Charles C., M.D., M.P.H., Chief, Gulf War Health Center, Walter Reed Army Medical Center 15
Prepared statement of Major Engel 131
Ford, Jeffrey S., Executive Director, National Gulf War Resource Center 36
Prepared statement of Mr. Ford, with attachment 176
Kipen, Howard, M.D., M.P.H., Institute of Medicine, Director and Associate Professor, Occupational Health Division, Robert Wood Johnson Medical School 9
Prepared statement of Dr. Kipen, with attachment 49
Kizer, Kenneth, M.D., M.P.H., Under Secretary for Health, U.S. Department of Veterans Affairs, accompanied by: Fran Murphy, M.D., M.P.H., Director, Environmental Agents Service; and John R. Feussner, M.D., Chief Research and Development Officer 24
Prepared statement of Dr. Kizer 143
Myers, Sarah V., Vice President and Legislative Chairman, Nurses Organization of Veterans Affairs 34
Prepared statement of Ms. Myers 162
Puglisi, Matthew, Assistant Director for Gulf War Veterans, National Veterans Affairs and Rehabilitation Commission, The American Legion 32
Prepared statement of Mr. Puglisi 155
Violante, Joseph A., Deputy National Legislative Director, Disabled American Veterans 35
Prepared statement of Mr. Violante 170

MATERIAL SUBMITTED FOR THE RECORD

Report entitled, "Adequacy of the Comprehensive Clinical Evaluation Program: Nerve Agents," submitted by Dr. Kipen, Institute of Medicine 55
Statement of Janet Ott, Mother of Anthony Gene Ott who was a member of the Army National Guard 187

VA'S HEALTH CARE TREATMENT FOR PERSIAN GULF WAR ILLNESSES

THURSDAY, JUNE 19, 1997

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HEALTH,
COMMITTEE ON VETERANS' AFFAIRS,
Washington, DC.

The subcommittee met, pursuant to call, at 9:32 a.m., in room 334, Cannon House Office Building, Hon. Cliff Stearns (chairman of the subcommittee) presiding.

Present: Representatives Stearns, Smith, Bilirakis, Moran, Cooksey, Hutchinson, Gutierrez, Kennedy, Brown, Doyle, Peterson, and Carson.

Also present: Representatives Evans and Mascara.

OPENING STATEMENT OF CHAIRMAN STEARNS

Mr. STEARNS. Good morning, everybody. The Subcommittee on Health of Veterans' Affairs will open. I want to welcome you all to what I believe is a very important hearing.

In testifying before the Veterans' Affairs Committee in February, VA stated that the Department has a, quote, well designed and comprehensive, end quote, health care program for Persian Gulf veterans. We questioned that statement then, and we question it now. We ask again today whether the existence of a well designed, comprehensive VA health care program for Persian Gulf veterans is a matter of rhetoric or reality.

Certainly, most veterans medical centers are able to respond effectively to routine medical conditions presented by Persian Gulf veterans, but our focus is on how VA cares for the thousands of undiagnosed or ill-defined conditions.

We will hear today from scientists, Government auditors, clinic personnel who treat Persian Gulf veterans, and veterans. The veterans themselves, perhaps, tell it best. By way of example, let me quote from the testimony of the American Legion:

"There is little evidence that VA's overall approach provides effective medical treatment to Gulf War veterans with difficult-to-diagnose and ill-defined conditions. The structure of VA's medical system, a lack of treatment protocol to guide VA physicians in the treatment of these illnesses, the nature of these illnesses, and site visits suggests that, on the whole, VA does not effectively treat these illnesses. VA's policies convey a different picture. With respect to its diagnostic examinations, VA policy calls for counseling the veterans regarding their registry exam findings, and it calls for providing a continuum of care to those with multiple symptoms."

We will hear today, however, that veterans seldom receive any counseling to explain their health problems and that the continuum of care often breaks down.

Is the treatment of Persian Gulf veterans a VA priority? Much work has certainly been put into establishing a mechanism to establish veterans and attempt to diagnose their illnesses, but the question is, what happens when lab studies and examinations don't present a clear cut diagnosis? There seems no sure answer to that question and no system to monitor the effectiveness of the treatment these veterans receive.

After our February hearing, we asked the VA whether the Department had any specific treatment programs for these patients. VA said no unique treatments have been proven effective for Persian Gulf veterans' illnesses and therefore no specialized treatment programs have been established. Yet several witnesses this morning will testify that there are treatments which can help these veterans even where there is no clear diagnosis.

I am pleased that the VA's testimony acknowledges that there is much room for improvement and that it offers some specific proposals. I also appreciate the insights and many suggestions our witnesses have offered on this important subject. We hope to learn more about what additional steps the VA can take to make the treatment of Persian Gulf veterans the priority it should be.

With that, I call on the ranking member, Mr. Gutierrez, for his statement.

OPENING STATEMENT OF HON. LUIS V. GUTIERREZ

Mr. GUTIERREZ. Thank you very much, Chairman Stearns, for calling this important hearing to discuss the provision of health care to Persian Gulf War veterans.

Once again, recent news stories, based on a recently disclosed GAO report, have called into question our Government's efforts to discover the causes of various ailments afflicting Gulf War veterans.

I recognize that the Pentagon has redoubled its efforts. I know that $27 million has been allocated by the Defense Department this year to investigate the risk factors possibly associated with Gulf War illness. Nevertheless, despite better-late-than-never initiatives, I still believe that our Government is failing, failing those who served in the Gulf War, failing their families, and failing the American people who expect our Government to work honestly and diligently on their behalf.

The Pentagon has not been entirely honest about the Persian Gulf War. They have admitted this, and have pledged to change their ways. But what we have now is a situation that feeds the already growing uncertainty and mistrust surrounding our Government's mishandling of this sensitive issue.

The danger is this: The perception that this mishandling creates in the minds of the American people, and the perception that our Government is not disclosing all the pertinent facts regarding the situation. I feel strongly that it is our Government's duty to ease the minds of the brave men and women who served in the Gulf. It is our Government's duty to be forthright with any and all useful information, and to provide adequate care and just compensation

to the veterans who triumphed over tyranny more than 6 years ago. In this regard, we have failed.

Many veterans don't believe that the answers will be provided, and many veterans don't believe that they will get the health care compensation they need and deserve. In the absence of hard facts, we must try harder, and we must offer the veterans of Desert Storm the benefit of the doubt by ensuring they receive the benefits they require.

I believe the subcommittee should conduct hearings later this year to specifically address the issues raised by the GAO report. These hearings would offer the Pentagon and the Presidential Advisory Commission a chance to explain their positions and clear the air.

Today we discuss the provisions of health care to Persian Gulf veterans at VA facilities. I believe that this is truly one of the most critical matters we will examine on this subcommittee. While many uncertainties remain, we know that more than 70,000 veterans of the Gulf conflict have reported a variety of debilitating or recurrent illnesses, and they need health care and benefits to get their lives back on track.

We do know that 26 percent of the veterans who participate in the Gulf War Registry have undiagnosed conditions. We also know that our Government has the responsibility to do a better job of counseling, diagnosing, and following up on Persian Gulf veterans. Allow me to express my strong support for now departing Secretary Brown's expansion of the presumptive period of Gulf War illness from 2 years to 10 years. This is a positive first step towards assisting Gulf veterans.

I would like to thank once again Chairman Stearns, and I look forward to questioning our witnesses as time permits.

Mr. STEARNS. I thank my colleague.

Mr. Bilirakis, my colleague from Florida.

OPENING STATEMENT OF HON. MICHAEL BILIRAKIS

Mr. BILIRAKIS. Thank you very much, Mr. Chairman.

First let me take a moment to commend you for scheduling the hearing. The illnesses experienced by Persian Gulf veterans continue to be a major concern to this committee, and it is something our VA has got to realize.

Almost 1 million United States soldiers served in the Persian Gulf region from August of 1990 through 1995. Approximately 700,000 of them served during Operation Desert Shield/Desert Storm. Many of these veterans, Mr. Chairman, as you know, are now experiencing unexplained illnesses. There have also been reports of similar unexplained illnesses among spouses of the Persian Gulf veterans. In addition, concerns have been raised regarding health problems and birth defects among the children of some of these veterans.

Despite a broad range of research projects into Persian Gulf War illnesses, researchers have been unable, apparently, to identify a single illness, syndrome, or cause of the health problems experienced by many of these veterans, and this is a continuing source of frustration, as we might expect, for our veterans and their families.

Since the end of the war, our committee has initiated a number of laws to assist our Persian Gulf War veterans. Under these laws, the VA provides Gulf exams and counseling to them. The VA also provides priority health care services for any health problems which may have been due to exposure to toxic substances or environmental hazards in the Gulf.

The VA has testified that it has a well designed and comprehensive health care program for Persian Gulf veterans who suffer from undiagnosed illnesses, and Mr. Gutierrez referred to this. However, questions have been raised as to whether or not VA has made veterans' treatment truly a real priority.

I have reviewed the written testimony of today's witnesses, and they raise many disturbing issues. For example, GAO makes the following observations regarding the care provided to Persian Gulf veterans, and I quote them. There is an inconsistency in the conduct of registry examinations. Personal counseling seldom occurs. There is a lack of continuity between the registry exam and any treatment. There is a lack of post-examination treatment, there is a lack of empathy from health care providers, and there is a lack of a mechanism to monitor treatment outcomes.

In light of these observations, certainly, Mr. Chairman, it is easy to understand why veterans are so frustrated with the care that they are receiving through the VA, and I personally have always felt much of the problems we have had with our veterans health care centers because, in general, I consider them pretty darn good in terms of being well equipped, the quality, the medical personnel in general and what-not, but I think it is an attitude problem. We have heard an awful lot of stories on poor attitudes of a lot of the employees, and maybe that attitude problem stems not only at the lower levels but also at the top levels.

I know Dr. Kizer is in the audience. He is a veteran. He can certainly empathize better than many people in the administration or in Government in general with these problems. Certainly Secretary Brown is a disabled veteran. It seems to me we could certainly do something about this attitude problem, because practically everything always stems from people, what is inside, and maybe what is inside is not good enough.

Obviously, it is incumbent upon us to do all we can to find a solution to the health problems now being experienced by some of the veterans and some of the active-duty personnel who are still on active duty and their families. However, in the meantime, we must make certain our veterans are receiving the highest quality of care.

I am anxious to hear the testimony of our witnesses, Mr. Chairman, and, like you, I have another hearing on energy and power and deregulation of electricity, which is really very important, so I will be shuffling back and forth. But I look forward to working with you and other members of the committee to see if we can do anything at all to improve the situation.

Thank you, Mr. Chairman.

Mr. STEARNS. I thank my colleague. Mr. Moran.

Mr. MORAN. Mr. Chairman, thank you for scheduling this hearing. This is a very important topic, and I am anxious to hear what the witnesses have to say. I have no opening statement.

Mr. STEARNS. Mr. Hutchinson.

Mr. HUTCHINSON. Mr. Chairman, I look forward to the testimony of the witnesses. I think the issue is whether there is a difference in the policy that is being implemented and the actual practice that happens at the hospitals in rendering the service. So I look forward to the testimony of the witnesses and yield any further comments.

Mr. STEARNS. Mr. Kennedy.

OPENING STATEMENT OF HON. JOSEPH P. KENNEDY II

Mr. KENNEDY. Thank you, Mr. Chairman.

Mr. Chairman, first of all, I want to thank you for having this hearing, and I appreciate the renewed interest that this committee is showing in this issue under your leadership.

In addition to hearing the testimony which I think will be important in terms of the kinds of treatments that the VA and others are proposing, I think that it is important for us to deal with the real health effects that our veterans are facing. It is important for this committee to deal with, and to speak out on the whole issue of what appears now to be an additional almost cover-up of what has actually occurred in the Persian Gulf.

This committee held the first hearings going back over 5 years ago in terms of listening to veterans who came forward, claiming they had illnesses that were a direct result of their service in the Persian Gulf. They were told—and it is an old story, it has been heard over and over again—that they were malingerers; they were complainers, and there was nothing wrong with them, that they were, in fact, never exposed to any chemical or biological weapons that could have created these kinds of illnesses. It was all put on the soldiers themselves, and I have met with them individually.

It was very hard to get this committee to even take testimony directly from soldiers. We heard from so-called experts who were doing studies, that there was no direct linkage. And now, after a Presidential Commission and numerous studies by the Pentagon, and so many different people coming before us claiming that there was no linkage, we finally have a GAO study that comes back indicating there is linkage. We don't even get a copy of this study, but it appears to have been leaked to the newspapers.

I think it would be very helpful if we had this document, and I am glad that Mr. Backhus from the GAO is here today.

Maybe you can shed some light on this issue.

I don't know, Mr. Chairman, if that is going to be one of the issues we are going to be able to get into, or if Mr. Backhus has the authority to comment on the GAO report. Can I ask that question, briefly, Mr. Chairman?

Mr. STEARNS. Mr. Kennedy, you will certainly have an opportunity to ask him any question you like.

Mr. KENNEDY. And this is an issue that he is familiar with, is it, Mr. Chairman?

Mr. STEARNS. Well, I think at this point, let's just get to the opening statements and we will come back. But he has been apprised that we will be asking a broad range of questions.

Mr. KENNEDY. I appreciate that, Mr. Chairman.

I also want to, at some point, deal with the fact that several years ago, we did hear from a Dr. Hyman who was down from Louisiana. Dr. Hyman, I believe, claimed that this was as a result of

some kind of chemical exposure and that created, as I recall, some type of infection in the soldiers. Everybody sort of ran the guy down, and said he was some kind of faker and he was trying to rip off the VA and the like.

I know those of you on the committee at the time remember that he was roundly debunked by everyone. Nevertheless, it seems that some of the issues he brought up may, in fact, have more validity than was given to him at the time.

So I would like to come back, and at least get your sense of what he was talking about, and whether or not, given this new information that the GAO has provided, he was onto something that nobody else would listen to.

In any event, I do want to thank the chairman again for holding the hearing. I very much appreciate the fact that the GAO has come forward with this report in the hopes that this will be a major step forward in terms of giving the soldiers, who served our country, who have never asked for anything but acknowledgment that there was direct linkage between their service and the illnesses that they have encountered. I think if all we say to them is, there doesn't seem to be any link and you never were exposed to the chemicals it leaves them with the feeling that nobody is telling them the truth, and there has been some kind of cover-up.

I think it is important, if there is information to suggest linkage, that we have a complete, open-air discussion pertaining to that direct linkage, if nothing else, to just satisfy and honor the soldiers who served this country.

Thank you very much, Mr. Chairman.

Mr. STEARNS. I thank my colleague. Mr. Peterson.

OPENING STATEMENT OF HON. COLLIN C. PETERSON

Mr. PETERSON. Thank you, Mr. Chairman. I want to thank you for holding this hearing, and I look forward to getting into this issue.

I somewhat want to associate myself with the comments of Mr. Kennedy. I heard from a lot of Persian Gulf veterans in my State who are concerned about the way this has been handled, are frustrated with the response to their problems, and from what I have seen, have real problems that have been caused by something. I think we are starting to get some information that will allow us to get to the bottom of this, and I hope we continue to work on this until we get to the bottom of it.

Mr. STEARNS. I thank my colleague.

Ms. Brown, my colleague from Florida.

OPENING STATEMENT OF HON. CORRINE BROWN

Ms. BROWN. Thank you, Mr. Chairman, and thank you for holding this hearing.

We all know that the Gulf War illness has been a complex problem to solve. We wonder about chemicals and oil. We worry about how to treat the veterans who seem to get no relief from the medical community. All of us have heard from the veterans who are suffering.

The research into this illness takes time, and we may not ever get the answers as to why they are sick, but we owe it to them to

make sure they get the best possible care. To me, what is most important is that veterans can go to the VA and get good care. We have heard some praises, and we have heard complaints. As a Member of Congress having oversight of VA, I want to know that VA is doing its best in delivering health care services to the veterans with these problems.

Mr. STEARNS. I thank my colleague.

Ms. Carson, do you have an opening statement?

Ms. CARSON. No.

Mr. STEARNS. Mr. Mascara is visiting.

Would you like to have an opportunity to have an opening statement?

Mr. MASCARA. I do not, Mr. Chairman.

I thank you for holding this meeting. My interest, of course, is I serve on two other Subcommittees, one of which is Oversight, and I thought I would partake this morning in this meeting because I was directly affected, in my District, by two young ladies, both of whom have received 100 percent disability—I am sorry, one in my District and one in Karen Thurman's District in Florida. I did agree to go before the President's Commission on Persian Gulf Illnesses to introduce them. The young lady in my District took a direct hit from a SCUD on the barracks, and she survived and other members from her unit back in my District were killed. So my interest is sincere, and I am here just to listen.

Thank you.

Mr. STEARNS. We appreciate you listening and coming by.

Ms. CARSON. Mr. Chairman, I am sorry, though I don't know where the hearing is going, I want to mention the concern I have among veterans in Indianapolis, from which I was elected, is that with the wave of cost-effective medical treatment, veterans are getting the brunt of that in terms of not being able to access quality medical care.

Those who were affected by the Persian Gulf, as well as all the way back to the Vietnam era, are having a difficult time in accessing medical benefits through the Department of Veterans Affairs. I am hoping that this subcommittee will ultimately be able to resolve those concerns, notwithstanding the cost of it.

Mr. STEARNS. Well, I appreciate your comments.

At this point, we will have our first panel, which is Mr. Backhus, Dr. Kipen, Dr. Clauw, and Major Engel.

You are recognized for your opening statements, and it is customary to have a 5-minute opening. We will start with Mr. Backhus.

STATEMENTS OF STEPHEN P. BACKHUS, DIRECTOR, VETERANS' AFFAIRS AND MILITARY HEALTH CARE ISSUES, U.S. GENERAL ACCOUNTING OFFICE, ACCOMPANIED BY HENRY HINTON, ASSISTANT COMPTROLLER GENERAL, NATIONAL SECURITY AND INTERNATIONAL AFFAIRS DIVISION; HOWARD KIPEN, M.D., M.P.H., INSTITUTE OF MEDICINE, DIRECTOR AND ASSOCIATE PROFESSOR, OCCUPATIONAL HEALTH DIVISION, ROBERT WOOD JOHNSON MEDICAL SCHOOL; DANIEL J. CLAUW, M.D., ASSOCIATE PROFESSOR OF MEDICINE, CHIEF OF RHEUMATOLOGY, IMMUNOLOGY, AND ALLERGY, GEORGETOWN UNIVERSITY MEDICAL CENTER; AND MAJ. CHARLES C. ENGEL, JR., M.D., M.P.H., CHIEF, GULF WAR HEALTH CENTER, WALTER REED ARMY MEDICAL CENTER

STATEMENT OF STEPHEN P. BACKHUS

Mr. BACKHUS. Thank you, Mr. Chairman.

Mr. Chairman and members of the subcommittee, I am very pleased to be here today to discuss our ongoing evaluation of medical care that VA provides to Persian Gulf veterans. As you requested, my comments this morning will focus on three topics: First, Persian Gulf veteran satisfaction with VA care; second, the extent to which VA follows its own guidelines for evaluation and treatment; and, third, a model of care at one medical center that Persian Gulf veterans seem to find more responsive to their needs.

Our information is based on observations and opinions from officials at VA headquarters, three medical centers, veterans service organizations, and dozens of Persian Gulf veterans themselves. We have thus far reviewed the medical records of 20 veterans who have been examined and treated for their symptoms.

While the scope of our work at this early stage is not broad enough to generalize to the conditions throughout the entire VA, we believe that along with other previous studies on these issues, our work does serve as an indicator of the medical care that these veterans are receiving.

Regarding their satisfaction with the VA care, Persian Gulf veterans appear to be confused by, frustrated with, and mistrustful of VA and the care they receive for their illnesses. While they appreciate the efforts of individual staff, they cite delays of up to 6 months in receiving services, unsympathetic attitudes of some health care providers, some cursory initial exams, poor feedback from and communication with health care personnel, and a lack of post-examination treatment.

Regarding our evaluation of care VA provides to these veterans, VA's guidance regarding the evaluation and treatment does not appear to be consistently implemented in the field. For example, some physicians do not perform all of the symptom-specific tests recommended by VA's uniform case assessment protocol, which could result in some veterans not receiving a clearly defined diagnosis for their symptoms.

In some cases, physicians appear to stop following the protocol even though a clearly defined diagnosis has not been reached, and several of the records we reviewed indicated physicians' diagnosis was simply a restatement of the veteran's symptoms.

Furthermore, while VA has a quality assurance mechanism for evaluating the care it provides, the mechanism neither ensures continuity of care for these veterans nor does it provide for follow-up with veterans who need continued care. Moreover, personal counseling of veterans, which is required by VA guidance seldom occurs.

Registry medical staff and veterans we talked with stated that feedback on the examination results is typically provided through a form letter. The letters, however, do not always explain the test results nor the diagnosis, which leaves veterans obviously frustrated and angry.

Physicians' views are mixed regarding the appropriateness of VA guidance in the origin of symptoms experienced by the veterans. For example, some physicians indicated they believed the veterans' problems are all in their heads. However, other physicians do display open attitudes about treating physical symptoms in determining the origin of their illness.

Several of the physicians we interviewed believed they should have the flexibility to use their own clinical judgment in determining which tests are necessary to establish a diagnosis and treatment plan. One physician stated that in most cases veterans' symptoms can be diagnosed without using some of the complex tests mandated by the protocol.

Turning now to the third topic, in response to veterans' concerns, VA is trying to improve service. For example, at one medical center, veterans now have the option of receiving treatment in a Persian Gulf special program clinic. The clinic allows veterans to receive primary care from medical staff experienced in Gulf War veterans and their concerns.

The coordination of the patient's overall medical treatment is assigned to a case manager and, in this case, a registered nurse who serves as their advocate and facilitates communication among patients, their families, and the medical staff.

Veterans we spoke with were pleased with the clinic and supported its operation. They believe it reflects a VA commitment to take seriously the health complaints of Gulf War veterans and that the clinic gives them access to physicians who are sympathetic and understand their special needs. Additionally, VA has recently established a system-wide program to obtain feedback and track complaints of Persian Gulf veterans.

Mr. Chairman, this concludes my summary statement. We will continue to assess these issues over the next several months, which will include holding many more discussions with veterans and VA health care providers. We will report our findings and conclusions when this more detailed evaluation is completed. I will be happy to answer any questions you or any other members of the subcommittee may have.

[The prepared statement of Mr. Backhus appears at p. 44.]

Mr. STEARNS. Thank you. Dr. Howard Kipen, welcome.

STATEMENT OF HOWARD KIPEN, M.D., M.P.H.

Dr. KIPEN. Thank you. Mr. Chairman and members of the committee, I appreciate the opportunity to appear before this subcommittee to describe the work in progress at the Institute of Med-

icine regarding the adequacy of clinical programs designed by the Department of Defense and Department of Veterans Affairs to diagnose and treat Persian Gulf veterans.

The IOM has two Committees examining this area. The Committee of which I am a member is charged with assessing the adequacy of the Department of Defense Comprehensive Clinical Evaluation Program regarding three aspects of its operation.

The first is the assessment of health problems of those individuals who may have been exposed to low levels of nerve agents, and we have completed a report on that. The remaining two aspects are the diagnosis and treatment of stress, psychiatric disorders, and the relationship between stress, psychiatric disorders, and physical symptoms; and then finally, approaches to dealing with difficult-to-diagnose and ill-defined conditions, such as chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivity.

We held three workshops, one on each major area of our charge, in order to gather the latest information from researchers and clinicians in the areas. The Committee, as I said, has produced a report about exposures to low levels of nerve agent as it relates to health problems, but we haven't yet produced reports on the stress issue and the ill-defined conditions issue.

In the report on nerve agents, the Committee stated that no evidence available to the Committee clearly indicated the existence of long-term health effects of low-level exposure to nerve agent. However, information reviewed about the types of health effects that might possibly exist as the result of such exposure, include neurological problems, such as peripheral sensory neuropathies, and psychiatric problems, such as alterations in mood, thinking, or behavior.

The conclusions that we came to take into account reports suggesting possible toxic synergistic or combined effects after exposures to multiple agents known to influence nerve transmission or cholinesterase activity. The Committee concluded in its first report that the CCEP, the Defense Department's examination registry, continues to provide an appropriate screening approach to the diagnosis of disease in veterans.

However, in view of the potential exposure to low levels of nerve agents, which has been raised over the last year, we did recommend certain refinements of the CCEP to increase its value. Many of these refinements related to improved documentation to ensure consistency across facilities.

In addition, the Committee recommended that primary care physicians doing the phase one exams have access to a referral neurologist and a referral psychiatrist during this phase one screening. We have submitted a copy of the report entitled, "Adequacy of the Comprehensive Clinical Evaluation Program: Nerve Agents," to the subcommittee to provide more detailed information. The Committee report on the remaining two areas of its charge is now in the process of being developed.

Thus, I can't appear before you with specific recommendations from the Committee. I can, however, summarize for you some of the information that we were given in the first workshop on difficult-to-diagnose and ill-defined conditions. The major focus of this workshop was on three conditions, as I mentioned before, and their

possible overlap. The conditions are chronic fatigue syndrome, or CFS, fibromyalgia, and multiple chemical sensitivity, or MCS, my particular area of academic concentration. The information presented to the Committee was not based on studies conducted on veterans but, rather, on the research that has been conducted over the years in members of the general population with the same conditions.

First, chronic fatigue syndrome. In 1994, CDC convened an international study group to develop criteria for defining CFS. The major feature of CFS is the symptom of fatigue that is not due to exertion, is not relieved by rest, and results in substantial reduction in previous levels of occupational, educational, social, or personal activities—a fairly devastating symptom. In addition, the person must have four or more of the following additional symptoms, all of which have to have lasted for at least 6 months: Impaired memory or concentration, sore throat, tender lymph nodes in the neck or under the arms, muscle pain, pain in multiple joints without swelling or redness that would indicate arthritis, and headaches of a new type or increased severity, unrefreshing sleep, or malaise after exertion lasting more than 24 hours.

The second specific undefined condition is fibromyalgia, a disorder of widespread pain, tenderness, fatigue, sleep disturbance, and psychological distress. Other clinical features of fibromyalgia, as I think the next speaker will talk about, include irritable bowel syndrome, numbness and tingling of the extremities, frequency of urination, and social interaction problems.

Problems with classification and diagnosis of fibromyalgia led to the development of some criteria by the American College of Rheumatology on joint diseases. In a 1990 study of criteria for fibromyalgia classification, the American College of Rheumatology found 81 percent of fibromyalgia patients complained of fatigue and three-quarters complained of sleep disturbance. In addition, 60 percent of fibromyalgia patients had problems with depression.

I am trying to highlight the overlap between these putatively separate things. MCS, my particular area of expertise, is a diagnosis which is given to patients who show a variety of symptoms that they attribute to exposures to chemicals but for which no apparent organic cause or underlying physiological abnormality can be found. There is little agreement on what these symptoms represent, and no definition has been endorsed for use by a clinical body, in contrast to the previous two conditions. The most widely accepted definition is summarized for you in the testimony, and I think for time purposes I will just skip over that now.

Patients with CFS, fibromyalgia, and MCS, in the view of the Committee and in my own view, seem to have a lot of symptoms in common; the things they complain about have great overlap. According to some, the conditions may actually overlap and may not be completely distinct. Dedra Buchwald in Seattle did a study of patients with the three diagnoses and found that 70 percent of the patients with fibromyalgia and 30 percent of those with MCS met CFS criteria, and other studies have shown similar things as well.

There are other disorders which overlap with CFS and MCS probably. For patients with temporal mandibular joint disorder, CFS symptoms of fatigue for more than 6 months were very com-

mon and 30 percent have some kind of reduced activity characteristic of CFS.

An adequate work-up in diagnosis for patients who exhibit the signs and symptoms common to this spectrum of illness is very important. It is also important to acknowledge the reality of the patients suffering. Without doing that, even with a complete evaluation and work-up, even limited approaches to treatment aren't going to be successful, because the patient will frequently feel alienated. In fact, it has been shown patients with these overlapping syndromes often consult many physicians and practitioners including people such as acupuncturists, naturopaths, homeopaths, clinical ecologists, perhaps, in our view and the view of the Committee, in frustration with the medical system and what they feel is inadequate work up and diagnosis.

Dr. Buchwald showed in her study that the average number of visits to a provider in 1 year for patients with CFS, fibromyalgia, and MCS were 22, 39, and 33 respectively, a huge number of physician visits. Our Committee at the Institute of Medicine is now taking this information and trying to develop a final report.

I mentioned at the beginning of my testimony that IOM has one other Committee concerned with evaluating the protocols for care provided to Persian Gulf veterans. The second Committee is evaluating the adequacy.

Mr. STEARNS. We have a vote on the House floor. Could the gentleman conclude, and we are going to go and come back.

Is the gentleman almost finished?

Dr. KIPEN. I have one more page. I am almost finished.

There is another Committee looking at the adequacy of the VA registry, and that Committee, of which I am not a member, has not concluded—has just barely begun its evaluations and has made some visits to date but has no conclusions.

At this point, I think I can conclude my remarks, and I would be happy to answer any questions when the time is proper.

[The prepared statement of Dr. Kipen, with attachment, appears at p. 49.]

Mr. STEARNS. Thank you, Doctor.

With all respect to the remaining panelists, we have a vote. This subcommittee will recess, and I urge all members to come back. It is very timely to have this panel, including the GAO here, so I urge members to come back.

The subcommittee is recessed.

[Recess.]

Mr. STEARNS. The subcommittee will reconvene.

The third panelist, Dr. Daniel J. Clauw.

STATEMENT OF DANIEL J. CLAUW, M.D.

Dr. CLAUW. Thank you, Mr. Chairman.

I have been involved in both research and the clinical care of persons afflicted with a number of ill defined and poorly understood medical conditions, which include fibromyalgia and chronic fatigue syndrome. I have both an Army grant and an NIH grant to study these conditions.

My opinion, which is shared by many others in these fields, is that these illnesses, which have affected Persian Gulf veterans, are

not unique to persons deployed to the Persian Gulf but instead are the same as those which occur commonly in the population. Likewise, the problems which Persian Gulf veterans suffer in receiving treatment for their illnesses are very similar to the problems encountered by patients with these ill-defined illnesses in the general population. I will review the reasons for these opinions as well as suggestions for better dealing with patients who suffer from these disorders.

Fibromyalgia, as Dr. Kipen noted earlier, is a disorder defined by the presence of diffuse musculoskeletal pain and the finding of widespread tenderness on physical examination. As he noted, in addition to diffuse pain, individuals with fibromyalgia typically also suffer from a number of other symptoms, including fatigue, weakness, and memory problems.

Although fibromyalgia is the most common rheumatic disease affecting individuals below the age of 60, involving at least 2 percent of the population in the United States, I suspect that many of you have not even heard about this disorder. Yet I am certain that all of you know individuals who suffer from fibromyalgia, although many of these persons have not yet been appropriately diagnosed or treated.

Chronic fatigue syndrome is a syndrome characterized by the presence of severe, persistent fatigue as well as a number of other symptoms, including joint aches, memory problems, poor sleep, et cetera. Again, this illness probably affects about 1 percent of the population, but, again, you may be unfamiliar with this condition.

Although fibromyalgia and chronic fatigue syndrome are defined quite differently, most people who meet criteria for one of these illnesses will also meet criteria for the other, suggesting they represent different ends of the same spectrum rather than discrete illnesses.

"Somatoform disorder" is yet another term used to describe persons who display this constellation of symptoms. Although I dislike this label, it is a psychiatric term used to describe individuals who display multiple types of different symptoms but no "physical cause" can be found for these complaints, and, once again, many individuals who meet criteria for fibromyalgia or chronic fatigue syndrome will also meet criteria for somatoform disorders.

Thus, although the symptom complexes go by a variety of semantic terms, most involved in the study of these conditions feel these illnesses represent one large spectrum of illness.

The symptoms and findings in individuals with the Persian Gulf syndrome are generally the same as those of persons labeled with these other conditions, except the Persian Gulf syndrome is defined by these illnesses occurring in conjunction with being deployed to the Gulf War.

Why are these illnesses not recognized and difficult to diagnose? One of the reason for incomplete recognition is that this symptom complex is given many different names and many different attributions. Another reason is, there are no blood tests or other diagnostic tests which are predictably abnormal in persons with this illness. Because of this, these conditions are diagnosed on the basis of symptoms and by excluding other medical problems which can cause the same types of symptoms.

Another significant problem with the recognition and acceptance of fibromyalgia and related conditions is that these illnesses in general have been termed psychosomatic conditions. All of these conditions can either be triggered by or exacerbated by a variety of physical, immune, or emotional stressers, and there likely is a common underlying cause or causes for this entire spectrum of illness. Unfortunately, however, the root cause for this spectrum of illness is not presently known.

The link in some cases to emotional stress, and the fact that at present we have no blood test or any other objective test to verify the presence of these conditions, has led some to contend the conditions are "all in the head." Well, in fact, the most recent research into these conditions suggests they probably do begin in the head but that instead of these being primarily psychiatric conditions, these entities are all characterized by dysfunction of various components of the central nervous system.

Although our incomplete understanding of the precise mechanisms which lead to these symptoms should not lead to treating this group of patients differently than those of illnesses we understand better, this is commonly done. Furthermore, the fact that these conditions can be either initiated or exacerbated by stress should not be viewed by either patients or physicians as a negative factor, since we now know that nearly all illnesses, including cancer and coronary artery disease, can likewise be profoundly affected by stress.

Finally, the relationship between these disorders and psychiatric conditions needs to be clarified. Many individuals with fibromyalgia and related conditions will have concurrent psychiatric diagnoses. However, in most cases, the psychiatric diagnosis is not the primary problem. In most cases, the individual has developed a mood disorder, such as depression or anxiety, as a result of the physical symptoms that they experience and the problems with function that they experience.

In clinical practice, telling an individual with this type of illness that it is, "all in their head" or there is no "organic basis" for their symptoms will always lead to frustration and the sense of abandonment by that individual. It is not difficult to see why many of the veterans with these illnesses, as well as their families and advocates, have become so frustrated with the vicious cycle of no diagnosis, no effective treatment, and the psychiatric attribution of their symptoms.

It may be of little consolation to the Gulf War veterans, but millions of Americans are struggling with the same issues on a daily basis when they are seen with these same symptoms in the private sector. Thus, we should be careful not to place the blame regarding the inadequate treatment of these individuals solely on the VA or the DOD. This is actually a much larger problem with our entire medical system.

Once an individual develops fibromyalgia or a related disorder, it does not appear to matter what triggered the illness, the treatment remains the same. In fact, this focus on causation is not only unlikely to be a benefit but may actually be harmful. Instead, it is more important that patients, health care providers, and policymakers begin to focus on better understanding the entire spectrum

of illness and to use our existing knowledge regarding these entities to develop multidisciplinary treatment programs for individuals who are afflicted.

Types of therapies which have been demonstrated to be effective include low doses of tricyclic drugs, graduated low-impact aerobic exercise programs, and cognitive behavioral therapy. Cognitive behavioral therapy is an educational program that focuses on changing the individual's life-style and behavior so that they can better adapt to this type of illness. Other types of therapy may be very effective in treating the conditions but have not proven so in blinded placebo-controlled trials.

My personal experience is that the VA medical centers in some cases are not well versed in the treatment of these conditions, perhaps in part because the illnesses occur much more frequently in females and so few women are seen within the VA system, and perhaps because in the past there has been a cultural bias in the VA to refer the patients quickly to a psychiatrist. If a physician or health care provider does not believe that the patient is suffering from a "real disease," they will likely be ineffective in treating this group of patients.

I will end by giving some recommendations. Much more funding is needed for research into these conditions. Most of the research that has been done to date has been on what caused the Gulf War syndrome. Although this is needed, there needs to be a much greater focus on understanding the physiology of the illnesses, and developing more effective treatments.

Number two, most of the experts on these types of illnesses in this country are not in the VA or military systems. The VA and DOD have reached out to the private sector to ask the advice of individuals who have expertise in the disorders, and this needs to continue.

Number three, and finally, continue to take the veterans seriously. The physical and emotional toll of this type of illness is tremendous, and these individuals developed these problems while serving our country. View with skepticism anyone who might assert that because there are no abnormalities in blood tests, X-rays, or other diagnostic studies, that there is nothing wrong or the individual is suffering from a psychiatric problem. It is arrogant of us, as scientists, to feel that because we cannot precisely define a problem, that it does not exist.

Thank you.

[The prepared statement of Dr. Clauw appears at p. 113.]

Mr. STEARNS. I thank you.

Our next witness is Major Charles Engel, Junior, who is also an M.D. Welcome.

STATEMENT OF MAJ. CHARLES C. ENGEL, JR., M.D., M.P.H.

Major ENGEL. Mr. Chairman and members of the committee, I would like to thank you, as a Gulf War veteran, a member of the Armed Forces, and as a physician, for the opportunity to tell you about the treatment program that we run for Gulf War veterans at Walter Reed, the Army Medical Center here in Washington, DC.

I would also like to thank Lieutenant General Ron Blanck, the Surgeon General of the Army; Major General Leslie Burger, the

North Atlantic Regional Medical Commander; and regular General Michael Cusman, the hospital commander at Walter Reed, all people who have been instrumental in supporting our program as it has developed over the last couple of years. Mostly I would like to thank the veterans of the Gulf War for teaching us about their illnesses, about their sacrifices, and about their wartime experiences.

I would like for a minute, if you could indulge me, to have you think about what happens when you see the doctor. Typically, the first thing that happens is, the doctor asks you questions. Secondly, they may lay on hands, they do an examination. In some instances, perhaps the majority of instances, they do medical testing of various sorts. This whole exercise—history, exam and testing—is aimed at coming up with a diagnosis, and the reason that we, in the medical system, care, and the traditional medical model care, about a diagnosis is because we use it to derive treatment.

The most classic example of this is infections of various sorts. You have a sore throat; you see the doctor; they do a throat culture. If you have strep throat, you are given penicillin, and hopefully you get better.

There is a practical problem involving all of health care, not just DOD or the military, but definitely involving a subset of Gulf War veterans, in which, if you go through this motion several times in a row of examining and doing diagnostic tests and you don't come up with answers, within the business-as-usual, traditional medical model, there is nowhere left to go.

What we have attempted to do in the specialized care program, at Walter Reed, is to come up with, to some degree, or put into motion, an alternative approach for veterans with persistent physical symptoms after their service in the Gulf War.

I would underline that this represents a subset of Gulf War veterans with persistent symptoms and not all of them. The subset we are seeing specifically seems to be high utilizers of the health care system, which probably isn't surprising, given that they are not hearing occurring a diagnosis that can derive treatment, and they return for increasing evaluations. They have many physical symptoms. On average, we find patients report to us 10 bothersome symptoms in the last month, and they are distressed about their symptoms.

The goal of our treatment program, rather than to focus on a narrow symptom like a headache, in which maybe the neurologist might apply a treatment, or belly pain, for which, perhaps, an internist might apply treatment, is to focus on the overall quality of life of the veteran and their functional status, and we do that using an evidence based model of care, which has been implemented for many years in chronic pain clinics around the U.S. and in Europe.

Our treatment model is an intensive outpatient treatment. It is 3 weeks long. We have treated 84 patients using this model to date in cycles, about four to eight patients per cycle. The treatment consists of a medical, physical, and psychosocial component. The medical component involves a careful reassessment on the part of an internist and subsequent explanation of previous medical testing that has been done.

We found that, on average, the veterans who have gone through our program have undergone 60 or more different diagnostic tests

in the process of being evaluated for their Gulf War-related health concerns. So many explanations are in those tests.

The physical component involves musculoskeletal evaluation for unique limitations and then gradual implementation of an activation strategy, a physical activation strategy. And the psychosocial component involves education, involvement of family members, and really an attempt to shift the person from a passive thinking that the system is going to come in and make a diagnosis that is going to lead to a quick treatment to a more active way of thinking, that these are things that I can do for myself over the longer haul to get better.

So far, we found patients improve in their level of functioning in certain domains, there is diminished illness concern at the time they leave the program, diminished levels of distress, as well as an improved sense of psychosocial support. We are following them up at 1 month and 6 months, clinically, and then up to 2 years, using a computer-assisted telephone interview, in order to evaluate the effectiveness of our methods.

Our facility represents about one-third of a ward over at Walter Reed, although we also utilize occupational and physical therapies at Walter Reed and consultative services as needed. Our staffing involves about 15 to 17 different clinical and administrative staff, some shared and others full-time with us.

Our current challenges at this point really are identifying folks for early participation in the program prior to their involvement in retirement, medical retirement proceedings, so that, ideally, we have optimal opportunity to improve their work functioning in the future and to open the possibility of opening the program to others, from other deployments; and maybe, most of all, education for providers, as well as patients, about persistent symptoms and perhaps the maladaptive impact in many cases of business-as-usual medicine, the tendency for us to seek diagnosis and causes in the sense that those will lead to specific treatments, which does not seem to be the case for many patients.

Thank you.

[The prepared statement of Major Engel appears at p. 131.]

Mr. STEARNS. I thank you, Major.

Let me open up with questions, and of course I would like to start with Mr. Backhus.

We received a draft of the GAO report, I guess on the 17th, and looking through the results in the brief summary, there are pretty dramatic conclusions GAO has indicated here: One, that neither DOD nor the VA has systematically attempted to determine whether ill Gulf War veterans are better or worse today than they were when they first examined.

You say that the research is not precise and accurate. Then you go on to say evidence to support several conclusions under the Presidential Commission is questionable. These three are pretty dramatic conclusions by the GAO.

My question is, since the Presidential Commission was 18 months and the GAO was 6 months, are you standing by these conclusions? And if you are, aren't you, in a sense, saying that there is negligence on the part of DOD and the VA? I mean, that is the bottom line. You are saying there is negligence here. Is it

negligence, incompetence, malfeasance, nonfeasance, here by the DOD and VA is what you are saying in these rather dramatic conclusions?

Mr. BACKHUS. Mr. Chairman, with your permission, may I call in reinforcements here?

Mr. STEARNS. Yes.

And would you state your name.

Mr. HINTON. Mr. Stearns, my name is Henry Hinton. I am the assistant comptroller general for GAO's national security and international affairs work that we do.

Right now, what I would like to do in response to that is tell you where we stand on that report. You did accurately comment on the conclusions.

Mr. STEARNS. You are standing by those three recommendations, or three conclusions?

Mr. HINTON. At this point, they are accurate, and let me tell you where we are in the process, because we have not finalized our report, and I think that is very important. I owe it to—GAO owes it to this committee, the Congress as a whole, and particularly the constituencies out there to seek DOD, VA, the Presidential Commission's comments on this report. That is a part of the process that GAO goes through on every one of its reports.

Unfortunately, it got leaked. We have not concluded that. We have those comments right now. We were still getting comments from VA as of last night. We have not finalized that. I expect this report to be through and completed in the early part of next week, at which time we would be happy to come up and brief the members of this committee.

Mr. STEARNS. Are you saying at this point you don't want to talk about the report?

Mr. HINTON. Yes, sir.

Mr. STEARNS. Okay. Let me ask you this. We have seen some of the criticism from the DOD and the VA. Without talking about the report, would you like to comment on some of their criticisms, particularly what the Presidential Advisory Committee has said?

Mr. HINTON. We have those comments, Mr. Chairman. I take those comments very seriously, as we do on every report that we get and send over to the Department, whether it is DOD, VA, NASA, or others. That is a part of our process that we are required to go through, to factor that in. It is a very important part, and let me tell you why.

One, it gives the agencies an important opportunity to critique our work. It gives the agencies an important opportunity to bring new information to the table. It gives the agencies an important opportunity to say, GAO, you need to clarify some points. That is what we are going through right now. There were some criticisms in there. We have to work through those. When our final report comes out, it will address each and every one of those with our evaluation.

Mr. STEARNS. So if I understand what you are saying, you are not prepared to talk about the report, you are not prepared at this point to answer the criticisms from the DOD or the VA or the Presidential Advisory Commission, but you are standing by the conclu-

sions, and when the report comes out, at the latter part of this week—we thought it was going to come out Monday.

Mr. HINTON. It will be out the early part of next week, hopefully Monday.

Mr. STEARNS. But you are saying that these results that I have here, and that the *New York Times* had in their articles, you are standing by those three major conclusions.

Mr. HINTON. At this point, I think that is a fair characterization. I have to complete the process I just explained to you as we finalize that product.

Mr. STEARNS. Well, I know other members will want to ask you some questions, too, on that.

Let me move to the panel—I have some time left—to perhaps one of the physicians.

The VA, states, quote, there is no evidence of a single unifying illness to explain the health problems of Persian Gulf veterans. Do you agree, and does that make a difference in terms of trying to improve the care VA provides?

And maybe Dr. Clauw can answer.

Dr. CLAUW. Yes, I do agree, and, no, it doesn't make a difference in the care that the VA provides. As we explained, this group of illnesses probably has a number of different triggers or different things that can lead to this group of illnesses, and once someone has this spectrum of illness, it doesn't really matter what caused it, the treatment is the same. The kind of things I mentioned and the other things people have mentioned are the effective treatments for this group of disorders.

Mr. STEARNS. Dr. Kipen, would you want to add anything?

Dr. KIPEN. I would now speak for myself, and not for the IOM Committee. I would add, in general, I agree with what Dr. Clauw said, except for the caveat that I think the evidence showing that there are effective treatments for the variety of medically unexplained syndromes that we have discussed today is not of great weight, if it does exist. Designing realistic treatment programs for VA and DOD should probably be done in the context of research, not just giving protocols to physicians at various facilities and saying this is what we know works, go do it.

I think there is an opportunity here to really advance the science and care for medically unexplained symptoms and syndromes but that we probably have to be very careful before we go ahead and say it is treatment doctrine, just like penicillin for strep throat is.

Mr. STEARNS. Major Engel, is there anything you would like to add?

Major ENGEL. I would agree with what Dr. Kipen just said, that the strength in the evidence of applying this model of care is sort of mild to moderate in terms of its validity and it needs to be developed. It is an evidence-based model for the treatment of chronic pain.

Certainly, there is a body of evidence that suggests that chronic pain patients respond with diminished pain, improved return-to-work rates, and improved levels of morale in response to multidisciplinary treatments similar to the one we are offering symptomatic patients at the Gulf War Health Center. However, its utility specifically for symptomatic patients needs to be demonstrated.

Mr. STEARNS. Thank you. My time has expired.

The Ranking Member, Mr. Gutierrez.

Mr. GUTIERREZ. Thank you very much, Chairman Stearns.

Well, since Mr. Hinton is not going to discuss the GAO report here today, I will certainly respect that as he wants to go back and get all of the pertinent information. But, we have the report, and obviously we have Mr. Backhus's report, and just a cursory review of either one of those two reports, the one we are supposed to be talking about or the one we are not supposed to be talking about today because it is not finalized, there are some very serious implications of what is going on at DOD and VA.

I was listening attentively to Dr. Engel. The major described to us the procedure after somebody shows up at the hospital. He also described how Walter Reed hospital is treating people.

Given the panel's explanation of what they are doing, and given the GAO report about what is happening within the VA system, it is clear VA is not engaging in these types of treatment. What you are doing sounds like you should send a memo to everybody else, call them all together, and tell them, at least I have a method to the madness; we don't know what Persian Gulf Syndrome is, but I have a method, and here is how the method is working, and here is the success rate, and let's have this, so that everybody is doing the same thing and gathering the same information so that we can finally get to the bottom of what is causing this, because treatment is kind of haphazard.

I mean, I look at this, and this thing about stress. Any human being, whether you are in the Armed Forces or you are civilian, if you repeatedly go to a doctor, and you have such trust and confidence in these people, and the doctor can't tell you specifically what is wrong with you, what is causing your illness you are going to have stress. People are used to getting strep throat and being given penicillin, we all know that—we start with our children with Amoxicillin—we all know, you get something, you get something to treat it.

So not getting treatment causes a lot of stress. But the stress, it isn't that they served in the Gulf War and came back with stress, I don't believe, as much as that they came back from the Gulf War, they were ill, and then you have the stress because nobody is listening, especially when people treat you, as we hear in the GAO reports, with sometimes a callousness—as if it is all in your head.

Who wants to hear that? That treatment will cause stress too, because now you have to go home and say, well, am I all here? I have these medical experts either directly or indirectly associating my illness with mental incapacity. I think it all helps to create one system. I would like to ask Dr. Engel: Do you think that the veterans whom you have seen, are they suffering from PTSD?

Major ENGEL. I think that there is a subset who have posttraumatic stress disorder.

You know, if one looks at the comprehensive clinical evaluation report, or the report on the comprehensive clinical evaluation, about 1 in 20 patients participating in the program receives a diagnosis of PTSD, so it is a relatively small subset.

However, I would also make the point that posttraumatic stress disorder is a disorder that pertains to catastrophic trauma, like

combat or abuse in childhood or motor vehicle accidents. And trauma comes in all shapes and sizes, and response to trauma comes in all shapes and sizes, so to say that the extent necessarily, of stress, is represented in that 5 percent figure, it is difficult to narrow it to that, but certainly, as it pertains to PTSD, it does seem to be, in our population, only about 1 in 20 patients receives that diagnosis.

Mr. GUTIERREZ. Mr. Backhus, what can we do, given the GAO—what can we do so that everybody is on the same page, so that we can get an answer, and at least get on the road to finding a solution?

Mr. BACKHUS. I think we observed one particular model in Birmingham that seems to have significant potential for improving the care that is provided, and certainly the views of the veterans. It essentially means assigning a case manager to each and every veteran who presents themselves as ill and needs treatment. Somebody needs to follow them through the system, somebody to arrange their care, somebody to coordinate it, somebody to tell them what it means, somebody who is available to them, a person to manage a multidisciplinary approach to treating someone's illness. It is not just a headache and it is not just fatigue, it is several things that are a bothering a lot of the people. So you need a team effort and somebody to manage that effort.

If that particular program in Birmingham turns out to be as good as the preliminary indications seem to be, then I think there is a lot of potential for expanding that around the system and we may get much better results.

Mr. GUTIERREZ. Are veterans feeling better in Birmingham? Are they getting better?

Mr. BACKHUS. This only started in February, so it is impossible to say at this point. They are certainly more positive about it, and their frame of mind is better, and that is an accomplishment in and of itself.

Mr. GUTIERREZ. Mr. Chairman, I want to ask unanimous consent so that members of the committee can hand written statements over to be included in the record.

Mr. STEARNS. So ordered.

Mr. GUTIERREZ. You know, we have been here. I looked forward to this. I have a markup in the Banking Committee. I am going to get to that and try to get back here as quickly as I can.

Mr. STEARNS. Fine.

Mr. GUTIERREZ. Thank you, gentlemen.

Mr. STEARNS. Mr. Bilirakis.

Mr. BILIRAKIS. Thank you, Mr. Chairman.

This is the beginning of my 15th year in the House, and all of that time I have served on the veterans committee, and of course we have had so many hours, so many hearings on Agent Orange, not that that problem is ever going away, nor should it go away, but now we have another, quote, Agent Orange type problem. I guess as long as we are going to have wars, we are going to continue to have these things.

Dr. Engel, are you an internist?

Major ENGEL. I am a psychiatrist and an epidemiologist.

Mr. BILIRAKIS. I see. Well, do you go along with the statement made by I think it was Dr. Clauw.

Is it Clauw?

Dr. CLAUW. Clauw.

Mr. BILIRAKIS. I believe Dr. Clauw made the statement that there has been a cultural bias in the VA to refer the patients quickly to a psychiatrist.

Major ENGEL. Well, I can't speak to the VA. I certainly can speak to health care in general. I think that this subset of patients with persistent, unexplained symptoms tend to be in "No Persons Land," that psychiatrists historically find them somewhat frustrating in that the patients don't want to talk about the emotional aspects of their difficulty, and internists find them difficult because they are trained to look at what is the right diagnostic test and what is the result, and they don't get satisfying results from the diagnostic test, and that is part of the problem.

I think sometimes physicians, out of frustration, as they attempt to define cause or diagnosis, will say things to patients that maybe even they don't really think, but they feel stymied in this attempt, just as the patient does, to come up with a cause or diagnosis.

Mr. BILIRAKIS. Dr. Clauw, you are at Georgetown. Have you had occasion to see many Gulf War veterans?

Dr. CLAUW. I have only seen about 15, and the ones I have seen have the same types of symptoms and problems as I see all the time with people with fibromyalgia and chronic fatigue syndrome.

Mr. BILIRAKIS. They tend to have the same kind of problem that non-Gulf War veterans have that you can see?

Dr. CLAUW. Yes.

Mr. BILIRAKIS. Mr. Backhus, I realize that the sensitivity here that both of you gentlemen brought up in the process of your report—and, by the way, I might add that in my 14-plus years, I have, frankly, been very, very impressed with the work of GAO, and I really want to compliment you on that and the tremendous knowledge you have and share with us.

Mr. BACKHUS. Thank you.

Mr. BILIRAKIS. But in the process of developing your report, hadn't you coordinated with and worked with the DOD and VA and what-not? I mean, they weren't completely out of the picture in the process, were they?

Mr. BACKHUS. Are you making reference to the report that has to do with the research?

Mr. BILIRAKIS. I am making reference to the report. I mean, you submitted your written testimony to this subcommittee in preparation for this hearing, but you also had this report, which apparently has been leaked, in which you say—and I am sure rightly so—that it is incomplete. But in the process of developing that report, you didn't do it unilaterally—right?—you coordinated with all these other groups.

Mr. HINTON. Yes, sir, we have done work at the agencies.

The real issue we are working with, Congressman, right now is, we go through comments and assessing. The comments we got from VA, DOD, and the Presidential Commission basically center on the level of support for the emphasis behind some of the research that

has been done, that has been done, has not been done, and we are having that debate.

Through that process, we looked at all the studies that have been out there, our teams are going through the comments right now as we finalize our report, and that is what we are doing.

Mr. BILIRAKIS. But your report will still ultimately be an independent report.

Mr. HINTON. Yes, sir. Yes, sir, and we stand behind it. We will be behind that report, and we will stand on its merits, and when we conclude that, that is a part of every GAO report that is done.

Mr. BILIRAKIS. Let me ask this question. In my opening statement, and I am not sure I did it as adequately as I could have, but I talked about attitude, and I used the word "attitude" and "attitude problems" and all that. And I have been on the veterans committee, and I have visited veteran centers around the country, and much of the concern always has been the fact that veterans are, to use quotes, treated like welfare and things of that attitude—people problems. There have been reports of deaths in veterans facilities and things of that nature. And I attribute much of that to just an attitude kind of thing, just people not treating veterans the way they deserve to be treated.

Would you say that much of what you have uncovered is consistent with that?

Mr. BACKHUS. Well, in this particular case, the issue of treatment, we have really only made what I will call initial inquiries. We have been to three medical centers. I can't speak to the entire VA on this matter. However, that is what we hear and have heard from everyone we have spoken to, or nearly everyone we have spoken to, up to this point.

Mr. BILIRAKIS. So it is consistent then with what—and if it is a people problem, and I realize you can't legislate people's minds and what-not, but it seems to me we ought to be able to solve that. I know there is civil service there and protection for employees and things of that nature, but somehow, you know, if we don't solve that problem, I don't care what else we do, we are never going to be able to take care of things like this.

Mr. BACKHUS. I agree.

Mr. BILIRAKIS. Okay.

Thank you, Mr. Chairman.

Mr. STEARNS. I thank my colleague. Mr. Doyle.

Mr. DOYLE. Thank you, Mr. Chairman.

Mr. Backhus, I was sorry I got here late and didn't hear your testimony, but I have been reading through your report, and I think we share some of the concerns of Mr. Gutierrez and Mr. Bilirakis about the perception of Persian Gulf veterans that somehow we are not taking their problems seriously. And I take it, in the part of your report here you talk about the Persian Gulf Special Program Clinic, this is the Birmingham clinic you are referring to.

Mr. BACKHUS. Yes, sir.

Mr. DOYLE. It just seems to me—just a comment—that this seems like a VA center that is on the right track in terms of making sure that our Persian Gulf veterans feel like this problem is being taken seriously, and that they are seeing people who are

trained and geared towards working on the problems the Persian Gulf veterans have.

I just wonder, what do you see as the role of a VA primary care physician in providing treatment to these Persian Gulf veterans who have the hard-to-diagnose cases? What do you think their role should be?

Mr. BACKHUS. They play a key role, in my opinion. These are the physicians who will coordinate, or potentially coordinate, anyway—all of the care the veterans will receive. That means any referrals to any specialty care, consulting with those specialists, receiving the results of the tests and other exams and work-ups that are done on the patient from wherever they come, and being the principal form of communication between the veteran and the medical staff. It is a key role to play, and it determines a lot about the success of the treatment and how the patient feels about it.

Mr. DOYLE. I agree with that. Thank you very much, Mr. Backhus.

Thank you, Mr. Chairman.

Mr. STEARNS. We want to thank the panelists for attending and their patience because of the vote on the floor, and we would now like to call up the next panel.

Any member who would like to ask additional questions, as Mr. Gutierrez indicated, may ask those questions for the record.

Mr. STEARNS. And now we will have Dr. Kenneth Kizer, Under Secretary for Health, Department of Veterans Affairs.

Dr. Kizer, thank you for waiting, and we welcome the opportunity to hear from you. And perhaps it might be appropriate for you to introduce the people that are with you.

STATEMENT OF KENNETH KIZER, M.D., M.P.H., UNDER SECRETARY FOR HEALTH, U.S. DEPARTMENT OF VETERANS AFFAIRS, ACCOMPANIED BY: FRAN MURPHY, M.D., M.P.H., DIRECTOR, ENVIRONMENTAL AGENTS SERVICE; AND JOHN R. FEUSSNER, M.D., CHIEF RESEARCH AND DEVELOPMENT OFFICER

Dr. KIZER. Certainly. Good morning.

Accompanying me this morning is Dr. Frances Murphy, Director of our Environmental Agents Program; and Dr. John Feussner, Chief Research and Development Officer.

In the interest of time and not to be duplicative of the written testimony, I am going to make some very brief comments.

We have talked at a number of other forums about the overall approach the VA has taken to addressing the illnesses and the concerns of our Persian Gulf War veterans, and I am not going to repeat what has been said before. I would just note that the majority of our Persian Gulf veterans have a wide spectrum of medical conditions. Most of these patients have had their conditions diagnosed and have been treated according to the best contemporary medical knowledge.

The overall frequency of the unexplained symptoms among Gulf War veterans appears to be about the same as in a general medical practice, although the testimony of the other witnesses this morning would suggest that the frequency of these types of conditions is actually higher in the general population than among Persian

Gulf veterans. Having said this, though, I would stress that this in no way diminishes the importance which we place on these symptoms and conditions.

The questions that you have posed as a precursor and during the hearing raise a number of questions on how these difficult-to-diagnose and ill-defined conditions are being managed.

The difficulty in managing these conditions been a source of frustration to many VA health care providers, as well as to me personally. We have heard testimony at hearings like this, we have listened to statements that have been made in veterans forums, we have talked to veterans one on one—I personally have attended numerous forums with Gulf War veterans—about the care they have received at VA, and while most Persian Gulf veterans have expressed satisfaction with the care that they received, we have also heard complaints and dissatisfaction from some.

Some patients have been dissatisfied with the availability or access to care, although these complaints seem to be lessening as we have done some things to address problems in this regard. Others have complained about the continuity of their health care, and we have initiated a number of efforts to deal with this problem, and not just for Persian Gulf veterans but for all of our patients. I want to come back to this in a moment. Others have complained about the reception they have received by VA staff; some patients have rated the individual clinicians they have seen very highly, but they have expressed a great deal of frustration that their symptoms may be due to an uncertain cause. And as has been commented on by other witnesses, as well as members of the committee this morning, it is understandable how this would lead to a great deal of frustration on the part of the patient and the health care provider.

We think that we can address these concerns through both research and providing more treatment options. And, again, I want to come back briefly to say a couple things about that.

I would also like to put some of this in context. As you know, the Veterans Health Administration is just about 2 years into a massive reorganization—a fundamental restructuring and rethinking of how the system is going to function in the future.

One of the things that has been done is putting in place primary care teams. We now have universal primary care in VA, although how that is being implemented is not entirely uniform. This is not altogether surprising, recognizing the incredible effort that has been under way in the last 2 years to put in place universal primary care.

On the one hand, while we have primary care teams available at all of our facilities, they have not in all cases, and in quite a number of cases, put in place case management. And I can tell you, though, that after yesterday's meeting with all of our network directors, a major emphasis is under way and will continue for the next year to markedly increasing the amount of case management that is part of primary care, as well as beyond primary care.

A number of other things are under way that also will address issues of continuity of care—things like putting in place multi-institutional service lines, which we are poised to implement. Some of the facility integrations that are under way are really aimed at increasing the continuity of care and the access to services. We are

about to launch a major effort in nurse managed care, and it will address some of the things that were talked about earlier. Likewise, we are moving to implement a health outcomes management approach to care that really will be on the cutting edge of what is being done in health care today.

All of these things, as well as others, are aimed at improving continuity of care. I also would note that we are just about 2 years out from putting in place customer service standards. For 50 years, the VA never had customer service standards. Those have been put in place. We are now routinely surveying our patients to see what they say about the care, and we are holding management accountable to improving that, and we can demonstrate that actually care is improving, although it is not yet at the level I would like to see it at throughout the system, nor where it will be as we move forward.

Recognizing that the orange light is on, let me just say a couple of additional things.

I think I have expressed my interest at a number of hearings in the past about providing a variety of treatments and approaches to treatment that VA has not historically done, although I would note there are quite a number of challenges inherent in doing that. Some of this was talked about already this morning by other witnesses, as far as some of the treatment approaches to the symptoms-based illnesses are not amenable to outcomes research, or some of the traditional approaches to care, because there is a lack of a clear definition of what is being treated, there is no clearly defined health outcome, there is no single treatment, and there are a number of other things that make assessing it technically very difficult.

I would also note as an echo to what other witnesses said this morning, that many clinicians, inside and outside the VA, don't necessarily endorse many of what would be considered unconventional treatments, where there is a relatively weak-to-moderate evidentiary base supporting the efficacy of the treatment. And while I would personally like to pursue many of the options, I think there are a number of folks who would criticize moving forward in these areas of unproven treatments.

Finally, as one of the other challenges I would note for the record is that in an era of funding cuts and all the resource constraints that the VA is confronted with, it certainly would be helpful for Congress to clearly state its support for the VA to engage in what would be considered unconventional or alternative treatments for these conditions which the scientist in me, at least, would suggest that in time and with further investigation, some of which will be shown to be of questionable effectiveness. If we are going to truly innovate and do other things, there needs to be a clear statement of understanding that not everything will turn out to be efficacious.

Let me just conclude the comments by echoing again what some of the other witnesses said this morning, and that is simply that many of the symptomatic conditions experienced by Persian Gulf veterans, and perhaps even more so in the general population, and some of the problems they have encountered in the medical management of these symptom-based conditions go well beyond VA or

DOD; they really are intrinsic problems to the state of science of medical care.

I think we can do a better job by our Persian Gulf veterans and I think we can contribute to the health care in general in the country if we had some greater flexibility in how we use our resources in some cases, as well as if there were a clear statement by Congress indicating their desire to pursue some innovative things for which the evidentiary base is, at this point, weak to mild, as was commented on by other witnesses.

With that, I will be happy to answer your questions.

[The prepared statement of Dr. Kizer appears at p. 143.]

Mr. STEARNS. Thank you, Dr. Kizer.

We have a vote on the floor, and we have about 12 minutes left. I am just going to ask you a few questions, and then I will come back, and I urge other members to come back.

In February, I believe, one of your deputies said you were setting up well designed and comprehensive health care programs. And in this evaluation of VA Persian Gulf care, you asked your network directors to assess, how well a job are we doing with comprehensive health care.

Have you received any feedback, any appraisals, on how you are doing with evaluation of VA, Persian Gulf care? I think that is pretty important to us.

Dr. KIZER. I believe what you are referring to is the SEAT (Service Evaluation and Action Team that tracks trends in customer concerns) program, and we are getting that feedback. The instructions to set that out went out in February. Programs have been implemented only in the last couple of months. The feedback, I would judge, at this point, is still preliminary as they work through that systemwide, but that is the sort of information we will be looking at—and I know you will be looking at as well—to see the actual response that the Persian Gulf veterans are giving to their care.

Mr. STEARNS. So you are getting definite information back—since February, have you gotten that back?

Dr. KIZER. We have what I would consider preliminary information at this point, given these programs have only been up for a couple months, and the results, at least informally, appear to be mixed. There have been some very positive things, but the nature of this structure is to deal with the folks who are unhappy. So I expect what we will be hearing through these SEAT teams will be mostly complaints. Indeed, that is what they are designed to do, i.e., to hear from people who are not satisfied with the care and how we can use that to improve the care that we provide.

Mr. STEARNS. Both law and VA policy require that veterans be counseled on the results of the registry exam.

What is your response to finding that veterans are seldom counseled and get form letters instead?

Dr. KIZER. Let me ask Dr. Murphy to comment, who is more directly involved with that. Overall, I think that is an area we would like to see some improvement in. At least that is my sense in that, but let me ask Dr. Murphy to comment.

Dr. MURPHY. I think that you have to refer back to the statements that the GAO made in reporting their very preliminary findings. They are at the beginning of their audit and have had very

little or at best anecdotal experience with VA medical center Persian Gulf programs or veterans in this regard.

VA Headquarters certainly have, on numerous occasions, given our registry personnel instructions about talking with veterans about the results of their evaluations and, in addition, sending a follow-up letter so they have a written record of the registry examination results.

But, again, we don't view that as the end of the process. The registry examination really is only the beginning of the continuum of care including primary care team assignment. We expect an ongoing communication as the veteran is followed up and provided both care and treatment.

Mr. STEARNS. Dr. Kizer, what is your reaction to the idea of competitively awarding some amount of funding to VA medical centers to develop innovative approaches to providing care to Persian Gulf veterans with unexplained health problems that is putting some competition in the wards to these VA hospitals to try to get some innovative techniques?

Dr. KIZER. I am very supportive of that. As you may know, we have internally been looking at trying to use some of the medical care funds this year to do that. And there are a couple of the areas that you could actually be helpful in that regard, although if you want to appropriate or allocate additional funds, I certainly would welcome that as well.

But one of the problems we have is moving medical care funds into what is, as other witnesses characterized this morning, really a research endeavor, although it is also treatment. So, it is kind of that in-between.

So if we had a clear statement that that was something Congress supported, so when the GAO and others come back and say we misspent treatment funds to do basically investigative work, that would be helpful.

Likewise, insofar as these sorts of things may carry over between fiscal years, so that we may well be able to identify projects with funds that might be available this year, but by the time they got implemented and carried forward, they might go across one, two, or three fiscal years, the ability to manage those funds across time, which currently is not allowed by law, would be helpful as well.

These are two things that would seem fairly straightforward and would help us a lot in doing some of this type of thing, which I think we are philosophically in sync with.

Mr. STEARNS. Do you have any reaction to the GAO report? I mean, you have heard the gentlemen talk about it, you heard their three major findings, and I know DOD and VA have reacted pretty strongly. Is there anything you would like to say in respect to that GAO report that you feel is pertinent?

Dr. KIZER. I am not sure which of the two reports you are referring to. On the one hand, their preliminary report this morning——

Mr. STEARNS. This is the one that hasn't been released, although many members have copies, and obviously the *New York Times* had a copy of it.

Dr. KIZER. Let me come back to that. Their comments this morning, I think, were based on 20 patients of the more than 200,000 that we have treated. While I will wait to see what they find as

they expand their universe of inquiry, but I think a sample of 20 is a small sample, to say the least.

As far as the other one, the Department has formally responded. We think there are some very legitimate questions that have to be raised about the adequacy of the study. And I will leave it at that.

Mr. STEARNS. Well, we have a vote, so I am going to recess the subcommittee, and we will come back.

Thank you.

[Recess.]

Mr. STEARNS. The subcommittee will reconvene.

And Mr. Doyle, if you are ready for questions.

Mr. DOYLE. Thank you, Mr. Chairman.

Dr. Kizer, welcome, and as always, thank you for your candid testimony. I want you to know that many of us on this committee appreciate that.

I wonder if you could just take a minute, and tell us a little bit about what research, if any, is going on to look at these health effects of low-level exposure to things like we have seen in the Persian Gulf. Are we currently at VA doing any types of research to look at that? Is that being planned? Do you have the money to fund such research?

Dr. KIZER. There are some studies underway. I am going to ask the experts on the side of me to comment. I would note, out of all the areas that are difficult, this is one of the most difficult because some of the most fundamental things you would like to have to conduct research as far as what actually happened to our Persian Gulf War veterans you don't have, things like actual exposure dosages, duration of exposure, a number of other things that go with that. So the research really is focused more on controlled laboratory models that you may be able to infer from that to the actual setting. But as far as research, to actually answer the questions about what may have caused things among the veterans, that is probably never going to be productive because you don't have the basic information that you need to answer the question.

Let me ask Dr. Murphy and Dr. Feussner to comment on specific projects. Dr. Feussner.

Dr. FEUSSNER. Dr. Kizer pointed out some of the problems with low-level chemical exposures. What we did to try to get a sharper handle on this problem is convened an international conference in Cincinnati in March in conjunction with the Society of Toxicology and asked investigators from the United States, as well as from multiple European countries and the Japanese, who investigated the sarin subway incident in Japan, to come and help us with some issues and ideas about how to approach this research agenda.

Now, creating that research agenda is still in process; however, two of the three recent broad area announcements that have come out from DOD and have gone through the Persian Gulf research working groups specifically solicit applications that deal with low-level chemical exposures, mostly, as Dr. Kizer indicated, in animal models, looking at toxicology, looking at genetic variation and some of the enzyme systems that are affected by these compounds.

When the issue—when this issue broke last summer, there were three research projects from Europe that were part of the previous review but had not been funded, which were then considered and

funded. If I recall, those three projects alone cost about $2.5 million.

The review for the first two broad area announcements by DOD—that DOD has done with the input from the Persian Gulf research working group, are completed, and we should be announcing in the very near future funding some additional research projects in this area. And then as we develop our research strategy, we also intend to publish the proceedings from the international symposium, and hopefully that will also inform the process.

Dr. KIZER. If I might just interject one thing that I think it is important to at least put on the record that while the research is absolutely critical to furthering our understand of this, and hopefully better dealing with problems in the future, it is going to take time. This is a long-term strategy, and in the short term I agree with, I think, some of the other witnesses this morning that research is not going to provide answers to them because it is a long-term effort; and we really need to be looking at some alternative treatment modes that might be useful now even if we don't know whether exposures to given toxins or other environmental agents caused it or not. These veterans have problems now, and we need to be looking at more effective ways of dealing with them—and research isn't going to give us that answer right now.

Mr. DOYLE. Doctor Kizer, Mr. Backhus in the earlier panel referred to a medical center in Birmingham that has put together a special Persian Gulf clinic. Do you think that is a good thing, and something VA is going to model some more?

Dr. KIZER. Yes, it is, and I would comment a number of ways. One is if that turns out it is as effective as the preliminary results look, it should be promulgated further, and I agree with that. But I think it is important to note that he did qualify his statement by saying that the jury is still out on that.

I am very encouraged by it, and it does appear to have a lot of promise, just as there are other models around the system that are promising. One of the structural models we have put in place to deal with things like that is a lessons learned center where we have people specifically focusing on things like that. Historically, VA facilities operated kind of independently, but when someone is doing something good like that, or if they handled a particular problem particularly well, we want to generalize that and get that information out to all of our centers so it can be implemented much more quickly than has historically been the case. This is a good case study to actually use that approach with.

Mr. DOYLE. Thank you, Dr. Kizer.

Thank you, Mr. Chairman.

Mr. STEARNS. I thank my colleague.

Before I let you go, Dr. Kizer, here is an overall question that I would like to ask you: Would you discuss the feasibility of doing outcome research, actually what works on any aspects of treating the symptom of syndromes in these veterans; in other words, are you at the point now you can say this is what works, and we can now do outcome research to develop the effective models for treating Gulf War syndrome?

Dr. KIZER. I want to be a little pedantic just to make sure I am correct. Most of the conditions that people have are well-defined

conditions, e.g. diabetes or whatever. So I think what you are really asking her to do with the ill-defined conditions, the fibromyalgias, the chronic fatigue syndromes, the multiple chemical sensitivity syndromes, and those things there is some question about.

I have real questions in my mind whether you can do outcomes research these conditions at this time for some of the reasons I noted before, as far as not having a clearly defined condition, a clearly defined treatment and some other things that you need. But that in and of itself doesn't mean you can't put in place treatments that seem to work, and then you may be able to make some qualitative judgment about whether they are working or not. But to do at least what I am used to thinking about as far as outcomes research, which does have some specific criteria and parameters around it, it would still be very hard to do that with these sorts of ill-defined conditions, but I also don't think that mitigates against putting in place treatment programs and trying to get some assessment about what you are doing and how that works over time, even though it may not meet the rigorous definitions that a basic scientist would put around it. I would certainly defer, though.

Mr. STEARNS. Dr. Feussner, would you like to comment on that?

Dr. FEUSSNER. Well, if you are talking about undiagnosed illness, it presents a whole host of problems that Dr. Kizer enumerated, the definition of the disease, the definition of the intervention.

Mr. STEARNS. Well, I think we are saying, like Dr. Kizer said, we have had all this experience now with Gulf War syndrome. Are we at the point now we can actually come up with models of research?

Dr. FEUSSNER. Well, in some situations I think the answer to that question is yes. Perhaps the situation we are struggling with right now is the diagnosis of posttraumatic stress disorder, and last fall we funded a multisite national VA trial of Vietnam-era veterans, combat-related PTSD, looking at competing psychiatric interventions, trauma-focused group therapy versus usual counseling. That is a difficult and complex trial, but we have embarked on that.

In this particular area, we will be releasing a program announcement seeking additional ideas about treatment focusing on posttraumatic stress disorder. That program announcement will come out later in the summer.

In the area of fibromyalgia, chronic fatigue syndrome, there are a series of treatment strategies that have been proposed that involve combinations of exercise, psychiatric therapy and the like. The sample size in the preliminary research has been low. It might be possible to design some larger studies to look at these issues, but with mixed treatment results, it is not clear where that will take us.

Mr. STEARNS. Well, I think at this point, I appreciate your patience in waiting while we went to the vote, and I think we will call up panel number three. Thank you, Dr. Kizer.

And, again, if any Members would like to insert questions for the record to panel number two, it is so ordered they be able to do that.

Our third panel is Dr. Sarah Myers, of the Nurses Organization of Veterans Affairs; Matthew Puglisi, Assistant Director of Gulf War Veterans, the American Legion; Joseph Violante, Disabled

American Veterans; and Jeffrey Ford, Executive Director of the National Gulf War Resource Center.

Gentlemen and ladies—I guess Sarah is not here. Well, we want to thank you for your patience in waiting, and we will take your testimony. Welcome.

Mr. STEARNS. We will take Matthew Puglisi first.

STATEMENTS OF MATTHEW PUGLISI, ASSISTANT DIRECTOR FOR GULF WAR VETERANS, NATIONAL VETERANS AFFAIRS AND REHABILITATION COMMISSION, THE AMERICAN LEGION; SARAH V. MYERS, Ph.D, RNC, VICE PRESIDENT AND LEGISLATIVE CHAIRMAN, NURSES ORGANIZATION OF VETERANS AFFAIRS; JOSEPH A. VIOLANTE, DEPUTY NATIONAL LEGISLATIVE DIRECTOR, DISABLED AMERICAN VETERANS; AND JEFFREY S. FORD, EXECUTIVE DIRECTOR, NATIONAL GULF WAR RESOURCE CENTER

STATEMENT OF MATTHEW PUGLISI

Mr. PUGLISI. Thank you, Mr. Chairman. It is a pleasure to be here today and present testimony on this very important topic. I would like to thank you for inviting the American Legion and also thank you for having your second hearing in this Congress on Gulf War veterans' health. Gulf War veterans and VA will benefit directly from this committee's ongoing oversight.

Gulf War illnesses, or Gulf War syndrome, describe the health complaints of thousands of Gulf War veterans. Today these complaints have defied a clear definition or diagnosis by the medical community. The Chairman's decision to investigate how VA approaches the undiagnosed health complaints is very wise because it gets at the heart of the Gulf War illnesses issue.

The essential question this hearing asks is how well does the VA treat veterans with Gulf War illnesses? There is little evidence that VA's overall approach provides effective medical treatment for Gulf War veterans with difficult-to-diagnose and ill-defined conditions. The structure of VA's medical system, the lack of treatment protocol to guide physicians in the treatment of illnesses, the nature of the illnesses and site visits conducted by the American Legion suggests that on the whole, VA does not effectively treat these illnesses. Outcome studies, once conducted, will show whether VA care is effective.

There are a number of recommendations that the American Legion has made concerning how VA approaches the illnesses, and I would like to talk about one specifically, and that is training. VA should immediately investigate Gulf War veterans' experiences and psychological consultations and evaluate the consistency of the initial psychological evaluation of patients during a registry examination. Veterans diagnosed with PTSD have consistently complained of being sent to a wing or ward, along with patients who suffer from severe mental illnesses. Some have reported they do not return for care and are therefore left feeling ill.

Should veterans diagnosed with PTSD or depression be sent to a separate waiting room or wing? VA should immediately investigate this question and make immediate adjustments if the answer is yes.

Is it reasonable to dismiss certain risk factors associated with Gulf War illnesses, given what is currently not known? Although there are sparse scientific data linking chronic illness with low-level chemical agent exposure, the peripheral nerve damage found in some Gulf War veterans is not explained by stress.

The relationship between many of the risk factors encountered in the Persian Gulf and Gulf War illnesses is currently being investigated by many scientific studies. Many Gulf War veterans complain when they offer possible explanations concerning why they are ill, many VA physicians dismiss the explanations by pointing either to negative lab results or lack of scientific data. This behavior is not exclusively found at VA, but at the Department of Defense in some cases and in the civilian medical community as well. This behavior undermines the doctor/patient relationship and does not encourage patients to return to VA for care.

Mr. Chairman, I would now like to take the opportunity to raise an issue that is of great concern to the American Legion. Over the strong objections of VA's Persian Gulf expert scientific committee, VA has decided to delay the completion of its National Persian Gulf Survey. This survey of 30,000 veterans will answer one of the most important research questions related to Gulf War illnesses, and that is, what is the prevalence of Gulf War illness in the Gulf War veterans population?

VA has explained to the American Legion that the benefits of delaying this project, namely improving the design of the final stage of the study, outweigh the costs which are delaying answers to Gulf War veterans. The American Legion remains unconvinced. We have strongly urged VA not to delay the study for the benefits we cannot measure, and we encourage the Chairman to address this issue at his earliest convenience with the VA.

In conclusion, there is little evidence VA effectively treats veterans who suffer from Gulf War illnesses. Formal and well-designed outcome studies provide evidence which reveal how effective medical treatments provided by VA are. VA should immediately initiate the studies while it determines which methods are most effective in treating Gulf War illnesses.

There are also a number of structural changes that the American Legion recommends VA investigate in order to improve the health and well-being of ill Gulf War veterans and to pick up on a theme that was apparent in the first panel when some of the medical professionals talked about randomized clinical trials or some formal way of assessing which treatments are most effective in treating veterans with these complaints. The American Legion strongly urges Congress and the VA to look at funding such studies that will help us figure out how to best approach the illnesses, and these approaches can be implemented across VA.

Mr. Chairman, this concludes my prepared testimony. I will be happy to answer any questions that you have after the panel has testified.

Mr. STEARNS. Thank you.

[The prepared statement of Mr. Puglisi appears on p. 155.]

Mr. STEARNS. We will take Dr. Sarah Myers next.

STATEMENT OF SARAH V. MYERS, Ph.D., RNC

Ms. MYERS. Mr. Chairman and members of the subcommittee, as a legislative chair for the Nurses Organization of Veterans Affairs and a veteran of Operation Desert Storm/Desert Shield, I am pleased to present this testimony on care and treatment of veterans with Persian Gulf War illnesses in the Department of Veterans Affairs. My written testimony includes both background data and recommendations on the care and treatment of Persian Gulf War veterans. For the next few minutes, I would like to spend my time addressing the recommendations in my report.

While much has been done to improve the care and treatment of veterans with Persian Gulf War illnesses, inconsistencies still remain. NOVA would like to make the following recommendations: One, appoint an interdisciplinary primary care team to identify, screen and treat veterans with Persian Gulf War illnesses. Members of this primary care team should have an express interest in working with Persian Gulf War veterans. This team would also include an advanced practice nurse, such as a nurse practitioner. The cost-effectiveness of nurse practitioners is well-documented in the literature. For example, outcomes such as increased productivity, less use of prescription drugs and shorter hospital days have been reported. The appointment of an interdisciplinary team would provide more holistic, nonjudgmental and comprehensive care without increasing costs.

The second recommendation is to assign a female provider with expertise in the assessment, care and treatment of victims of sexual assault and trauma to the primary care team.

My third recommendation relates to implementing one Persian Gulf War referral center within each Veterans Integrated Network or visit.

My fourth recommendation is to provide increased education about stress as a source of illness. The awareness of the relationship between stress and illness may encourage some veterans to seek assistance.

My fifth recommendation is to disseminate findings from VA-funded research on Gulf War illnesses. This education should be directed in the community to vet centers, veteran service groups, the lay public, and VA as well as DOD staff.

My sixth recommendation is to develop creative strategies to facilitate maximum return rates of the updated Persian Gulf registry questionnaire.

And my final recommendation relates to considering a mandate for all Persian Gulf War veterans who are in the National Guard or Reserves to complete the revised Persian Gulf registry questionnaire through their reserve unit.

We feel the recommendations are critical in facilitating the continuity of care in Persian Gulf War veterans. Thank you for allowing me the opportunity to present this testimony, and I will be happy to answer questions at the end of the panel.

Mr. STEARNS. Thank you, Doctor.

[The prepared statement of Ms. Myers appears on p. 162.]

Mr. STEARNS. Next is Joseph Violante.

STATEMENT OF JOSEPH A. VIOLANTE

Mr. VIOLANTE. Thank you, Mr. Chairman, members of the subcommittee.

Since 1920, Disabled American Veterans has been dedicated to one single purpose, building better lives for disabled veterans and their families. On behalf of the more than 1 million members of the DAV and its auxiliary, I wish to express our appreciation for this opportunity to provide our assessment of the medical treatment of Persian Gulf War veterans suffering from Gulf War illness.

It has now been more than 6 years since the fighting ceased in the Persian Gulf and the majority of U.S. veterans returned home. Yet there is no noticeable decrease in the number of new claims filed by Gulf War veterans as a result of illness believed to be associated with their service in that theatre. The fact there are still many unanswered questions and conflicting medical opinions surrounding Gulf War illness only serves to exacerbate the situation.

Although most experts concede these veterans were exposed to a wide range of environmental hazards, such as experimental drugs, high levels of toxicity and substances from oil field fires, radioactive residue, parasites, pesticides, lead paint and chemical agents, there is little consensus in the medical/scientific community, as to the residuals, if any, from these exposures. Due to the confusion surrounding Gulf War illness, we question whether the veterans are receiving adequate medical care from VA or DOD.

Mr. Chairman, the DAV is extremely concerned with the proposed funding levels for VA health care in fiscal year 1998 and beyond, with the outyears being the most devastating on VA's ability to provide adequate health care to America's sick and disabled veterans. If VA health care funding levels are not increased, all veterans, including Persian Gulf veterans, will see their ability to receive appropriate care diminished. While the lack of appropriate care will have a devastating effect on all veterans, it will seriously impact Gulf War veterans as they attempt to recover from the effects of Gulf War illness as they transition to civilian life.

A frustrating aspect of Gulf War illness is that many of the veterans are also underrated, and when they seek medical care, VA physicians or private physicians are unable to adequately treat them because of the unknown nature of their disabilities. In many cases, these brave young men and women are unemployed because of the debilitating illness, yet they are unable to receive adequate compensation or meaningful medical care because of the confusion surrounding their illness.

An additionally frustrating aspect of this illness is that 6 years after the end of the war, we are still unable to answer the question about what is causing these illnesses. Unfortunately, the report by the Presidential Advisory Committee on Gulf War Illnesses, does not provide any concrete answers to the question of what is causing this illness, and as we have heard today, there are additional criticisms of that Committee.

As scientific and medical researchers continue to search for the answers to the nagging question, our Nation must not forget these veterans and their families are suffering because of the veterans' deployment to the Persian Gulf. Accordingly, this Committee must continue to seek answers to help explain the mystery surrounding

these unexplained ailments and to ensure that these veterans receive adequate compensation and appropriate health care.

One of the items that the PAC report did note is that follow-up treatment is usually problematic. It is noted that staffing constraints often result in long delays in scheduling appointments, and psychiatric staffing is particularly overloaded at some facilities. Additionally, many veterans receive follow-up care from a number of physicians, both government and private sector, and no single case manager is responsible for their care.

In the past, DAV has noted that there is a lack of coordination within the VA. VA health care intervention was often organized to respond to symptoms, rather than focus on possible underlying ideology. No VA medical person has the big picture of a veteran's multiple symptoms. Coordination of care and disease tracking would facilitate the overall understanding of the episodic as well as interrelational aspects of the medical problems reported by these veterans. Accordingly, a single manager would not only benefit the veteran, but would also serve to provide necessary coordination of care and disease tracking. As the VA moves towards primary health care physicians, it would appear the lack of coordination will hopefully be resolved.

Before I close, Mr. Chairman, I would like to caution the members of this subcommittee as the House considers the legislation passed in the Senate yesterday that would bar benefits to veterans who commit capital crimes. We ask that you would consider all the ramifications of that law, and we are opposed to any amendment to deny veterans' benefits to persons convicted of capital offenses. While we understand and appreciate the likely unpopularity of awarding government benefits to perhaps some infamous criminals, we believe that veteran status, once earned, should, in all but an extreme limited number of circumstances, be irrevocable on the basis of subsequent acts and shielded from disturbance on the basis of popular inflamed passions of the moment.

Thank you, Mr. Chairman. That ends my statement.

Mr. STEARNS. Thank you.

[The prepared statement of Mr. Violante appears on p. 170.]

Mr. STEARNS. Jeffrey Ford, Executive Director, National Gulf War Resource Center.

STATEMENT OF JEFFREY S. FORD

Mr. FORD. Mr. Chairman, members of the committee, I am honored to appear here for you today for the third hearing in a row, especially pleased to discuss today the health status and treatment of Gulf War veterans. In written testimony today, I have provided information from 66 Gulf War veterans, their family members, DOD and civilian contractors. Information obtained in this self-selected, non-scientific study was gained via the National Gulf War Resource Center web site e-mail referral system. Since March of 1997, we received 256 referrals, for a total of 676, as of October 1st, 1991. In April alone, we received 105 requests for assistance.

Whether it is the DOD CCEP or the VA registry examinations, testing, treatment, misdiagnosis, indifference to suffering, a broken compensation and benefits program are the norm, rather than the exception. Using the survey below, we randomly selected from our

database comments from April, May and June and present them to you today, the veteran's voice, unsolicited, raw, and if you will notice, very consistent in their condemnations. This is their testimony and not mine.

We have listed here some of the questions that we ask, and I will read some of the responses: Do you feel you are ill as a result of the Persian Gulf War? Yes.

Are you a veteran of the Gulf War, contractor or civilian employee? Yes.

Have you registered with either of the Persian Gulf registries? No.

Have you filed a claim with the VA? No.

Please enter anything that may help the referring coordinator assist you. Need to find out where I need to register and get the physical.

Another one: My son passed away February 15, 1997, while working a temporary job in Michigan. Mike called to tell me he was sick and in the hospital. At 2:08 a.m., February 15, the doctor called to tell me Mike had passed away. He kept getting colds since coming back from the service in August of 1994. The coroner said he died of acute leukemia. He was 27.

Another one: During my initial Gulf War workup, I was essentially blown off. While it was not attributed to my diabetes, which I developed after the Gulf War, it was attributed to "somatizations." This was true of most of the personnel who were screened at Womack Army Medical Center. Should I go to the Fayetteville VA Med Center and have the workup done again?

I have registered with one registry, not sure which one or what good it does; how to help, get help or compensation.

I am a 27-year-old male that feels 45 since the Gulf War incident. Please help me or direct me to a resource that can best help me with treatment and compensation. I feel as though parts of me are dying. Currently I have an honorable discharge as of 1994. No ETS physical was given, nor am I receiving any compensation or treatment of any kind.

Here is an interesting dynamic we hadn't considered: My former spouse is a veteran of the Gulf War. He was stationed with the 82nd Airborne Division. Apparently he was at Khamisiyah. My son, now 5 years old, has been recently diagnosed with a neurobiological disorder. I am looking for information on how many others have children being diagnosed with similar disorders. If information is required from his father, it may be difficult for me to get, as he does not keep in regular contact with his children.

Another one: I am a nonsmoker. Before going to the Gulf, I had no breathing problems. I returned from the Gulf in May of 1991. I retired from the Army in October of 1993. In late 1994, I went to the Gulf War review at the VA and was told by the VA my lungs were working at 78 percent, but that there was no environmental cause for it. I was stationed with the First Infantry Division, which, of course, after the cease-fire, was camped south of Safwan in the oil field fires.

Another one: I am getting nonstop headaches that last 4 days. My stools have blood in them off and on. I forget names, phone numbers, addresses. I get fits of anxiety and have to take medica-

tion. I get rashes that look like clusters of mosquito bites. The rashes pop up in small patches. I have also had some of the common symptoms of diarrhea, achy joints, chest pains and headaches. He still is yet to have a physical.

Another one: Please help me find a support group or someone who can help me. I am on active duty at Fort Campbell, Kentucky. I don't know how to go about getting a medical discharge.

Unsure what a VSO is, but after 5 years of trying to deal with the VA on my own and finally receiving a whopping 10 percent rating, not to mention having to travel 4 hours to the nearest VA Hospital, I would be very appreciative of any help I could get.

Another one: I think I am dying from Persian Gulf War syndrome. I feel like I am dying slowly. My friends are scared I am dying. I used to be a semiprofessional soccer player. Now I can hardly run from my car to the front door. My lungs are bad to the point I almost suffocate and pass out. Blood sometimes when I go to the bathroom, number two. Diarrhea a lot, muscle twitches, achy joints like arthritis, tightness in my chest when breathing. I almost died in 1992 from my lungs. I went to the hospital back then, and they denied Gulf War syndrome existed. I am a fifth-generation combat soldier.

Apparently there are soldiers still on active duty in the First Armored Division in Bamberg, Germany. I could go on and on.

Here is another one who is still on active duty: Been sick for the last 5 years, memory loss, fatigue, sick feeling, hurting in joints, night sweats. I have to stay on active duty. I am in Croatia.

I have provided 66 more testimonials here, and one, especially, that I would also attach to my testimony today, from the parents of a young man I met about 6 months ago, and with the help of Dr. Murphy and the White House, we were able to get him to Birmingham to the referral center in time to save his life. Unfortunately, by that time, it was too late, and he is most likely terminal and will probably die within the year.

I think what the GAO reports are saying and will continue to say is that we have had enough of the rhetoric research studies, into more research. I believe we have enough data to proceed, to go ahead and begin treating these soldiers and not just their symptoms, but their ailments, as a cluster, and we will know when that is finished when we stop receiving reports such as this. Thank you.

[The prepared statement of Mr. Ford, with attachment, appears on p. 176.]

Mr. STEARNS. I want to thank all of you. I have a few brief questions, and since we don't have any Members, I think the Minority staff might have a few questions for you.

Dr. Myers, were you encouraged by Dr. Kizer's testimony regarding greater use of nurse practitioners treating Persian Gulf veterans perhaps? Did you hear him talk earlier?

Ms. MYERS. I did hear him, and I was very encouraged because through telephone interviews with some of the Persian Gulf coordinators regarding the primary care teams, I learned nurse practitioners were not on the teams. I strongly recommend they be part of an interdisciplinary team in the primary care clinic or a separate team which specifically deals with Persian Gulf War veterans, similar to the women that—coordinators throughout the VA Medi-

cal Center,, so I really advocate they be placed on those teams. I think they have more time to talk to patients, and in many instances I think that is what patients want. They want someone to listen to them so they can hear what they are saying and spend time in dialogue.

Mr. STEARNS. Mr. Ford, while you were giving your testimony, I looked through some of these summaries, I guess these e-mails that came in. Have you gone back to them and tried to respond and help them?

Mr. FORD. Unfortunately, due to the fact we are a small organization without much staff, it is a problem right now. We are trying to attain grants and funding so we can hire staff. As I said in the testimony, we have 676 as of 1995.

Frankly, sir, no, I have not been able to go back and contact each and every one; however, each and every one that I do contact, there has been more than one time I have gotten off the phone and had to cry, especially in dealing with this gentleman who lost his son to acute leukemia, and it hadn't occurred to him that it may have been service-connected. And I spoke with him last week and come to find out he had been coughing blood, and there were many, many signs that he hadn't recognized. He was a tough Marine, and he didn't want his parents to know he was sick.

We hope to have enough funding here shortly to hire masters' in social work to contact these people.

Mr. STEARNS. I have got a solution for you. Every one of those cases should be referred to their local Congressman or woman. People who had those similar problems who come in, each Congressman has 15 to 22 employees, and in the District they have anywhere from four to nine. For these type of things, the veteran should contact a local Member of Congress. You could do a great service if you somehow could automatically e-mail back to them or send them a letter and say, your Congressman is such and such. Here is a toll free number for DOD, the Department of Veterans Affairs. Please contact your Congressman. We don't have the resources to do it. And that Congressman can help.

And in certain cases we have been able to help in my District, and in certain cases the veteran died. A young man fresh out of high school went to the Gulf and died, but we brought that case forward, like other Members here on the Veterans' Committee can bring that case forward and bring to bear the publicity that is required to try to solve this problem. That is just a suggestion.

Mr. FORD. I know in the particular case of the young man that recently died, I did refer him to Senator Campbell. We also encourage every one of our veterans to continue to try to work with the VA. If they were not happy with their first exam, we recommend that they try to get another one. We encourage them to get a primary care physician. We encourage them to call the American Legion, the DAV, the VFW.

Mr. STEARNS. Or just the toll-free number.

Mr. FORD. Toll-free numbers. And we also encourage every one of one of them to contact Dr. Rostker's team, who is looking into incidents that may relate to possible health outcomes. And I tell my veterans everything we did and saw in Saudi Arabia could have potential for an answer to what may be making these people sick.

So we do make an effort, but to tell you the truth, sir, I get an average of about 15 to 20 cases a week.

Mr. STEARNS. I get over 300 e-mails a week of which maybe 15 are in the district. The rest are just around the United States and are on automatic pilot.

Let me ask the other veterans' organizations, you were here patiently through some of the testimony of Dr. Kizer, and perhaps you heard the first panel, too. Is there anything that you want to comment particularly with Dr. Kizer? Is there anything he mentioned in terms of new ideas or something that you would want to put on the record that suggests that we should expand the role for physicians' education, or for research, or for case management, or, as we talked about just before they left, trying to develop a model based on what will work from the research studies? Let me start with any one of you.

Mr. VIOLANTE. I for one would like to certainly see the VA move forward on any one of those initiatives. I think right now we are not getting the type of results we would like to see. And I think some of those ideas that were mentioned would certainly help this issue to move forward a little quicker than it is right now. And, again, I stress the need for appropriate levels of appropriations for VA in order for them to carry out those missions because it is important, particularly to these Persian Gulf veterans.

Mr. PUGLISI. Dr. Kizer made a comment that looks like a positive step that VA is taking and letting the divisions, the 22 legions of the VA, evaluate those and approach Gulf War veterans and treatment issues and within divisions assess how they can do it better and measure how effective treatments are. That is the SEAT process, the Service Evaluation and Action Teams that have been created. And they have been meeting since February. That is a positive step and something that we have recommended in our testimony, and I was happy to hear that that is going to be happening.

Dr. Kizer also seemed reluctant, and he gave some pretty valid reasons why, he seemed reluctant to conduct outcome studies because he rightly pointed out the wide range of symptoms that veterans are reporting, and it probably wouldn't be effective if VA were forced to look at this in a very broad way, all the symptoms that go undiagnosed and all the various treatments. But he did leave the door open a little bit when he talked about being a bit more focused, and that would certainly be appropriate, and perhaps looking at a veteran who has particular complaints of fatigue, and then measuring how VA has been approaching that kind of fatigue. Is it muscle fatigue after you mow the lawn or take a walk, or is it being tired all day long? Those subtle differences will tell doctors what kind of complaint it is and how to approach it, so I did hear some positive things.

But I want to point out that VA has been pressured from the outside in trying to find the cause for Gulf War illnesses and a definition. And those are important things to do, but this hearing and other efforts by GAO and Congress are going to encourage VA, and the American Legion has encouraged the VA, to look at treatment, because while these basic research projects are ongoing, and while DOD conducts its investigation into chemical weapons and things like that, veterans are left remaining ill. And we are not going to

have all of these studies completed until well after the year 2000, and they are still going to remain ill, so now is the time for the VA to start measuring and assessing how effective its treatments are now and how it could get better.

Mr. STEARNS. Dr. Myers, you will close.

Ms. MYERS. I have three comments and maybe one relates to Dr. Kizer's comments relating to case-managed clinics, and I would strongly recommend that because one of the things that I hear from Persian Gulf War veterans is the insensitivity that they face when they come to VA hospitals, and this has also been reported to me by some of the Persian Gulf coordinators at some of the various VA medical centers, so I think implementation of that would help a great deal.

Somehow there needs to be a method for VA personnel to be more responsive and available to the Persian Gulf veterans' availability. In my testimony, I mentioned Saturday clinics. One of the VAs, particularly the Boston VA, addressed that, and that was very—that was found to be very effective. However, one of the problems they had was the coordination that that took as well as the human resources that were needed for that clinic.

And my third comment relates to the need for longitudinal studies, which are expensive, but I think they need to be implemented to follow veterans over a period of time to look at differences.

Mr. STEARNS. My time has expired. Anything that the staff would like to add or like me to add for you?

Ms. EDGERTON. Let me go ahead and just get your responses as a panel to one final question. We have heard today that many Persian Gulf veterans are experiencing multiple and perhaps compounding problems. Are there specific symptoms or syndromes that you all think merit our attention focusing on treatment protocols? I'm looking for you to respond with any of the—maybe even controversial constellations of symptoms—termed as multiple chemical sensitivity or fibromyalgia.

Mr. FORD. I know that in my research, and I do communicate with a number of veterans, and there seems to be a continuing pattern, and that is joint pain, peripheral neuropathy, tingling and a numbness, fatigue. Most of them are to the point where they cannot work a full-time job. Headaches, the night sweats and rashes. Now, every now and then you will get the MCS symptoms in there also, but I don't seem to see that in a great frequency.

And one other thing I would like to point out while I have the chance, on the first week of this month, Dr. Murphy and Dr. Mather from the VA held a conference in Long Beach where 600 health care providers from the VA system had a 2-day seminar, and I would like to thank them for putting that together, and I believe it was very productive in reaching out to referral coordinators, vet centers, Persian Gulf examination physicians. And hopefully, if we can somehow keep the VA budget from being cut by over $2.092 billion over the next 5 years, hopefully Dr. Murphy and Mather and Dr. Kizer can have some more of the resources that they need to continue to deal with this problem and the programs more effectively.

Mr. VIOLANTE. I would have to agree. I think the constellation of symptoms that we see the most are fatigue, chronic joint pain,

memory loss and headaches. And I would certainly like to see some studies looking at those.

I would even go further and say I would like to see something done with multiple chemical sensitivity. I know in the beginning there was much talk about that. It is an expensive proposition, but I believe it is one worth looking into and would like to see something done in that area.

Mr. PUGLISI. We heard this morning from medical doctors who talked about things like CFS, MCS and fibromyalgia, and I am sure that you are aware that multichemical sensitivity is not recognized by the American Medical Association as a diagnosis. It may be one day, as CFS was not for a long period of time and eventually was when CDC came up with a case definition in 1988. But looking at those kinds of illnesses, whether or not they are completely accepted by the medical community is important to do because there is so much overlap between those diseases or illnesses and what we are seeing in Gulf War veterans. And that is why it was very important, I think, to hear from Dr. Clauw and Dr. Kipen and Major Engel on the first panel, gentlemen who devote a lot of time and energy to trying to understand patients who have these things.

And if we are going to look to clinical trials to find an effective treatment, it would be appropriate to look at how civilian doctors approach these patients and how VA and DOD approaches Gulf War veterans with these illnesses. And, again, it is not labeling the patients with any of the other things that may be occurring at the same time, and there is a lot of comorbidity with these illnesses of various other illnesses. And at the same time it is not coming up with an etiology at all. We are not saying that you are sick because of chemical weapons or are definitely not sick because of chemical weapons. It is just an acknowledgment of an illness and that it looks like a lot of these other things, and we should approach it in the same way.

Ms. MYERS. I think that more studies need to be done, conducted, related to the issue of birth defects in children of veterans, and I would like to reemphasize the comment I made earlier on longitudinal studies.

Ms. EDGERTON. Thank you.

Mr. STEARNS. I want to thank staff, and I want to thank all of our witnesses for their patience and for their participation. I think we have learned a great deal today, and I hope that Dr. Kizer will take a lot back to the central office, some of the ideas that we have talked about, that you folks have talked about, what has been proposed, and perhaps we are not any closer to the question of the cause of the Gulf War syndrome. I think we have a better sense that improvements can be made to the system of care that is afforded to the veterans, and we have a little bit better, Mr. Ford, as a result of your listing of the different people—those are real people out there that are having real problems, and I think every one of us as an elected official has a responsibility to try to answer their questions. We will be following up on the VA's efforts here, and we continue to have more hearings, but again, I want to thank all of you, and with that the subcommittee is adjourned.

[Whereupon, at 1:02 p.m., the subcommittee was adjourned.]

APPENDIX

Statement of Representative Helen Chenoweth
June 19, 1997
Health Subcommittee Hearing on VA's Health Care Treatment of Persian Gulf War Illnesses

Mr. Chairman, I would like to express my gratitude to you for holding this hearing today, and to each of the panelists for lending their insights. While we have held several hearings concerning Persian Gulf War Syndrome, this is the first hearing to focus solely on the treatment Gulf War veterans are receiving. This is the most important aspect of our inquiry into the Syndrome.

I am interested in the cause of illnesses experienced by Gulf War veterans, but only inasmuch as that information is helpful in developing a treatment or cure, or in preventing similar illnesses in the future. The health of Gulf War veterans should be our priority.

Unfortunately, the Gulf War veterans I have spoken to seem almost universally discontent with the medical treatment they have received. It is unconscionable that Gulf War veterans are receiving form letters instead of individual counseling, and I am concerned that VA's guidance regarding evaluation and treatment is not being consistently implemented. The care and attention Gulf War veterans receive should reflect their honored service to this nation. No less than this high level of service should be our goal.

I believe that this hearing is a step in the right direction, and I look forward to working with this committee and with each of the panelists to improve the diagnosis and treatment (both physical and emotional) of our Gulf War veterans.

Statement of Stephen P. Backhus, Director, Veterans' Affairs and Military Health Care Issues, U.S. General Accounting Office

Mr. Chairman and Members of the Subcommittee:

We are pleased to be here today to discuss our ongoing evaluation of the medical care the Department of Veterans Affairs (VA) provides to veterans who are suffering from illnesses they attribute to their military service during the Persian Gulf war.

Persian Gulf veterans have reported an array of symptoms including fatigue, skin rashes, headaches, muscle and joint pain, memory loss, shortness of breath, sleep disturbances, gastrointestinal conditions, and chest pain. VA's program to serve Persian Gulf veterans is a four-pronged approach addressing medical care, research, compensation, and outreach and education. The medical care portion includes a medical examination,[1] inpatient and outpatient treatment, specialized evaluations at four referral centers, and readjustment and sexual trauma counseling. More than 65,000 Persian Gulf veterans have completed the medical examination, or "registry exam."

My comments this morning will focus on information we have gathered to date, at your request, on (1) veterans' satisfaction with VA care and (2) the extent to which veterans are diagnosed, counseled, treated, and monitored. We will also discuss a model of care at one medical center that Persian Gulf veterans seem to find more responsive to their needs.

Our information is based on observations and opinions from officials at VA headquarters; VA's Atlanta Veterans Integrated Services Network office; medical centers in Washington, D.C., Atlanta, and Birmingham; Referral Centers in Washington and Birmingham; and veterans' service organizations; and from dozens of Persian Gulf veterans, both individually and in group interviews. We also reviewed a sample of medical records for 20 veterans who had received the registry exam in two of the three medical centers we visited to evaluate the registry exam process. We did not attempt to determine whether the tests, evaluations, and treatment provided to these veterans were appropriate but rather the extent to which VA followed its guidelines for evaluation and treatment and whether Persian Gulf veterans were satisfied with the treatment received. While the scope of our work to date is not broad enough to generalize to conditions throughout VA, we believe that, along with previous studies of these issues, our work does serve as an indicator of the medical care that Persian Gulf veterans receive.

The Persian Gulf veterans that we have talked with and who wrote to us, along with the veterans' service organizations we talked with, appeared to be confused by, frustrated with, and mistrustful of VA and the care they received for their illnesses. While veterans appreciated the efforts of individual VA staff, they expressed dismay with the "system," which often extends beyond VA to other agencies and, for some, to the federal government in general. Specifically, veterans continued to cite delays in receiving services, the nonsympathetic attitudes of some health care providers, the sometimes cursory nature of the registry exam, poor feedback and communication with health care personnel, and a lack of postexamination treatment.

On the basis of our work to date, it does not appear that VA's guidance regarding the evaluation and treatment of Persian Gulf veterans is being consistently implemented in the field. We observed, for example, that some physicians did not perform all of the symptom-specific tests recommended by VA's Uniform Case Assessment Protocol, which could result in some veterans not receiving a clearly defined diagnosis for their symptoms. We also found that personal counseling of veterans seldom occurred. In addition, the form letters sent to veterans at the completion of the registry exam did not always sufficiently explain the test results or diagnosis, which leaves veterans frustrated. Physicians' views were mixed regarding the origin of the symptoms experienced by Persian Gulf veterans. We heard and read physician comments indicating that they

[1]The Persian Gulf Registry Exam consists of a medical history, physical examination, and laboratory tests. The results of the examination are entered into a database that contains information on all Persian Gulf veterans who have received the examination.

believe Persian Gulf veterans' problems are only "in their heads." However, other physicians displayed open attitudes about treating the veterans' symptoms and determining the origin of their illnesses.

Medical center personnel cited limited resources and increased workloads as reasons their efforts are not as timely and responsive as they and veterans would like. One medical center we visited had experienced delays of up to 6 months in scheduling registry exams. However, steps are being taken at certain VA facilities to improve service. For example, at one medical center we visited, veterans now have the option of receiving treatment in a Persian Gulf Special Program Clinic. The Clinic allows veterans to receive primary care from medical staff experienced with Gulf War veterans and their concerns and has established a focal point for providing clinical management of Persian Gulf veterans' care.

PERSIAN GULF VETERANS' EXPECTATIONS REMAIN UNFULFILLED

The Persian Gulf veterans we spoke with held several common expectations regarding VA health care. They expected to be scheduled for the registry exam and tested in a timely manner. They expected doctors to listen to their symptoms and to take the problems they experienced seriously by performing the necessary tests and evaluations in order to reach a diagnosis. The veterans expected to be told their test results and to receive counseling and consultation regarding the need for further testing or treatment.

Veterans' perceptions of what is provided, however, were considerably different. Some veterans said they experienced delays in receiving the registry exam and follow-up testing they requested. Once scheduled for care, veterans said that some VA doctors and health care professionals projected the attitude that the symptoms Persian Gulf veterans experience are "all in their heads." Some veterans commented that the exam they received seemed too superficial to fully evaluate the complex symptoms they were experiencing.

Veterans indicated that personal counseling is generally not provided on the results of the registry exam and that this is true for veterans with diagnoses as well as for those without. The form letter sent to veterans at the completion of the exam generated considerable anger among Persian Gulf veterans we talked with, who interpreted it to mean that since their test results came back normal, the VA physician believed there was nothing wrong with them. Even some veterans who received a diagnosis did not understand their diagnosis or believe that their treatment was effective. For example, several veterans believed their medications made them feel worse and discontinued them on their own.

EXTENT OF SERVICES PROVIDED TO PERSIAN GULF VETERANS

Many Persian Gulf veterans have received care from VA for what they believe are service-related illnesses. These illnesses are manifested in a wide range of symptoms in multiple diagnostic categories. Although VA has developed comprehensive guidance for physicians to use in diagnosing Persian Gulf veterans, it appears to be inconsistently followed.

Medical Services Provided to Persian Gulf Veterans

The medical care portion of VA's approach is provided in a variety of settings. Of the total 697,000 veterans who served in the Persian Gulf War, more than 65,000 have completed the registry exam, which is available in most of VA's 159 medical centers. More than 191,000 veterans have been seen in VA's outpatient care clinics; about 19,000 veterans have been admitted to inpatient care in VA medical centers. Approximately 390 veterans have received special evaluations in referral centers in Washington, D.C.,

Birmingham, Houston, and Los Angeles; and more than 79,000 have received readjustment counseling at VA's Vet Centers.[2]

The diagnoses recorded in the registry exam database for Persian Gulf veterans spanned a range of illnesses and diagnostic categories. About 25 percent of registry diagnoses were for musculoskeletal and connective tissue disorders, approximately 15 percent for respiratory problems, 12 percent for gastrointestinal conditions, 14 percent for skin disorders, 16 percent for psychiatric conditions, 7 percent for cardiovascular and circulatory problems, 7 percent for infectious diseases, and 5 percent for injury and poisoning. Twenty-six percent of registry participants did not have a definitive medical diagnosis, and 12 percent reported no health problem.[3] The latter group asked to participate in the examination because they were concerned that their future health might be affected as a consequence of their service in the Gulf War.

Evaluation and Treatment of Persian Gulf Veterans
Do Not Appear to Consistently Follow Guidelines

In 1995, VA implemented a Uniform Case Assessment Protocol designed in conjunction with the Department of Defense and the National Institutes of Health to provide guidance to the physicians responsible for administering the Persian Gulf Registry Exam. The protocol consists of two phases. Phase I requires registry physicians to (1) obtain a detailed medical history, which includes collecting information on exposure to environmental and biochemical hazards; (2) conduct a physical examination; and (3) order basic laboratory tests. Phase II, which is to be undertaken if veterans still have symptoms that are undiagnosed after phase I, includes additional laboratory tests, medical consultations, and symptom-specific tests. Veterans who do not receive a diagnosis after phase II may be sent to one of VA's four referral centers for additional testing and evaluation. At the completion of these examinations, veterans are to receive personal counseling about their test results. Once diagnosed, veterans are generally referred to primary care teams for treatment. VA has issued a contract to the Institute of Medicine to review the appropriateness of its Uniform Case Assessment Protocol. The Institute's findings are due by the end of 1997.

Presently, the protocol remains VA physicians' primary reference on how to evaluate Persian Gulf veterans' conditions and to obtain an accurate diagnosis of the symptoms they report. According to VA's guidance, the veterans registry physician or designee is responsible for clinical management of veterans on the registry and serves as their primary health care provider unless another physician has been assigned this responsibility. According to VA program guidance, the registry physician's essential responsibilities include counseling the veteran as to the purpose of the examination, conducting and documenting the physical examination, and personally discussing with each veteran the examination results and need for additional care. The registry physician is also to prepare and sign a follow-up letter explaining the results of the registry examination and may initiate, if necessary, the patient's further evaluation at one of VA's referral centers.

On the basis of our review of medical records and discussions with program officials, including physicians, it does not appear that VA's guidance is being consistently implemented in the field. For example, while the protocol mandates that veterans without a clearly defined diagnosis are to receive additional baseline laboratory tests and consultations, not all such veterans received the full battery of diagnostic procedures. In

---

[2]These numbers represent individual veterans provided service in each setting. The same veteran could be counted more than once if he or she was seen in more than one setting. Also, for outpatient visits, VA's data do not indicate whether the veterans were seen for Persian Gulf-related illnesses.

[3]Percentages total more than 100 percent because some veterans have multiple diagnoses.

some cases, physicians appeared to stop following the protocol even though a clearly defined diagnosis had not been reached. In addition, several of the records we reviewed indicated that the physician's diagnosis was simply a restatement of the veteran's symptoms. For example, a veteran who complained of major joint stiffness and sleep disturbances was diagnosed as having major joint stiffness and sleep disturbances. Furthermore, veterans suffering from undiagnosed illnesses were rarely evaluated at VA's referral centers; of the approximately 15,000 cases that VA reported as having undiagnosable illnesses, only 390 veterans had been evaluated at a referral center.

At two locations we visited, the registry physician was rarely involved in the phase I examination process, instead delegating this task to a physician's assistant or nurse. In several cases, medical records indicated that the registry physician did not even review the results of the examination. After the phase I examination, instead of receiving ongoing treatment managed by the registry physician, veterans were referred to one of the medical center's primary care teams for postexamination treatment. Here, Persian Gulf veterans are seen by other doctors who treat all veterans and do not concentrate on the specific needs of Persian Gulf veterans. Veterans who expect treatment designed for those suffering from Gulf War illnesses appeared more likely to express frustration and disappointment with the care they receive.

According to VA guidance, counseling the veteran about the examination results is one of the key responsibilities of the registry physician. However, our work to date suggests that personal counseling between veterans and their physicians rarely takes place. Registry medical staff, as well as veterans we talked with, stated that feedback on examination results is typically provided through a form letter to veterans. The letter generally states the results of laboratory tests and provides a diagnosis if one was reached. In some instances, when laboratory results were negative, the veteran perceived that VA does not believe there is a problem. Even when a diagnosis is reached, the letter does not explain the meaning of complex or uncommon medical terms.

We discussed these concerns with registry and other physicians as well as VA Persian Gulf program officials. Several of the physicians we interviewed believed they should have the flexibility to use their own clinical judgment in determining which tests are necessary to establish a diagnosis and treatment plan. One physician stated that a good physician should, in most cases, be able to diagnose a veteran's symptoms without using the more complex battery of tests mandated by the protocol. We were told that some of the phase II symptom-specific tests are invasive procedures that could have serious side effects, and unless the tests are specifically needed, they should not be given routinely just because a veteran has symptoms. Other physicians resisted prescribing some phase II tests because of the associated costs. Furthermore, some physicians told us that they believed there was no physical basis for the symptoms Persian Gulf veterans were experiencing and that these symptoms were often psychologically based and not very serious. This attitude may contribute to physicians' lack of enthusiasm for the protocol exams.

We also noted that VA has established no mechanism to monitor treatment outcomes for Persian Gulf veterans. The VA official responsible for the Persian Gulf program told us that if monitoring of treatment outcomes does occur, it will be initiated in primary care.

MEDICAL CENTERS' EFFORTS TO IMPROVE CARE FOR PERSIAN GULF VETERANS

Medical center personnel often cited limited resources and increased workloads as reasons their efforts were not as timely and responsive as they and veterans would like. Some facilities are taking steps to overcome the negative experiences of Persian Gulf veterans. For example, one of the three medical centers we visited uses a different model to provide care to these veterans. At this facility, veterans have the option of receiving treatment in a Persian Gulf Special Program Clinic. Although it operates only on

Tuesdays and Fridays, the Clinic allows veterans to receive primary care from medical staff experienced with Gulf War veterans and their concerns. Veterans are still referred to hospital specialists as necessary but, unlike the other two facilities we visited, responsibility for monitoring patients' overall medical treatment is assigned to the Persian Gulf Clinic's case manager. The case manager is a registered nurse who serves as an advocate for veterans and facilitates communications between patients, their families, and the medical staff. The specific steps that are to be used in monitoring patient care had not been developed at the time of our visit. The Clinic staff also interacts regularly with the Persian Gulf Advisory Board, a local group of Persian Gulf veterans who meet weekly in the VA medical center to discuss specific concerns.

Veterans we spoke with were pleased with the Clinic and supported its continued operation. They believed that it reflects a VA commitment to take seriously the health complaints of Gulf War veterans. They also believed that the Clinic gives veterans access to physicians who are sympathetic and understand the special needs of Persian Gulf veterans and their families. In addition, veterans we talked with who use this facility indicated a higher level of satisfaction with the care they receive than the veterans who use the two other medical centers.

- - - - -

Mr. Chairman, this concludes my prepared statement. We will continue to assess these issues and will report our findings and conclusions at a later date. I will be happy to answer any questions you or other members of the Subcommittee may have.

(101602)

Statement of
Howard M. Kipen, MD, MPH
National Academy of Sciences
Institute of Medicine
to the
House Committee on Veterans' Affairs
Subcommittee on Health
June 19, 1997

Mr. Chairman, I appreciate the opportunity to appear before this Subcommittee to describe the work in progress at the Institute of Medicine (IOM) regarding the adequacy of the clinical programs designed by the Department of Defense and the Department of Veterans Affairs to diagnose and treat Persian Gulf veterans. The IOM has two committees examining this area. The committee of which I am a member is charged with assessing the adequacy of the Department of Defense Comprehensive Clinical Evaluation Program (CCEP) in three areas:

1. the assessment of health problems of those who may have been exposed to low levels of nerve agents;

2. the diagnosis and treatment of stress and psychiatric disorders, and the relationship between stress, psychiatric disorders and physical symptoms; and

3. approaches to dealing with difficult-to-diagnose and ill-defined conditions, such as Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivity.

We held three workshops, one on each major area of our charge, in order to gather the latest information from leading researchers and clinicians in each of these three areas. The committee has produced a report on the adequacy of the CCEP as it relates to health problems which *might* be a result of exposure to low levels of nerve agents.

In its report the committee stated that no evidence available to the committee *clearly* indicated the existence of long-term health effects of low-level exposure to nerve agents. However, information reviewed about the types of health effects that *might* exist as a result of exposure include neurological problems such as peripheral sensory neuropathies and psychiatric problems such as alterations in mood, cognition, or behavior. These conclusions also take into account reports suggesting a possible toxic synergistic effect following exposure to multiple agents known to influence cholinesterase activity.

The committee concluded in its first report that the CCEP continues to provide an appropriate screening approach to the diagnosis of disease. However, in view of potential exposure to low levels of nerve agents, certain refinements in the CCEP would increase its value. Many of these refinements related to improved documentation to help insure consistency across facilities. In addition, the committee recommended that primary care physicians have access to a referral neurologist and a referral psychiatrist during Phase I screening. We have submitted a copy of the report, *Adequacy of the Comprehensive Clinical Evaluation Program: Nerve Agents,* to the subcommittee in order to provide more detailed information.

The committee report on the remaining two areas of its charge is now in the process of development. As a result, I am unable to appear before you with recommendations. I can, however, summarize for you the information we were given in the workshop on difficult-to-diagnose and ill-defined conditions. The major focus of this workshop was on three conditions and their possible overlap. Those conditions are Chronic Fatigue Syndrome (CFS), Fibromyalgia, and Multiple Chemical Sensitivity (MCS). The information presented to the committee was not based on studies conducted on Persian Gulf veterans, but rather on the research that has been conducted over the years on the general population.

In 1994, the Centers for Disease Control convened the International Chronic Fatigue Syndrome Study Group which developed the criteria for defining CFS. The major feature of CFS is fatigue that is not due to ongoing exertion, is not relieved by rest, and results in a substantial reduction in previous levels of occupational, educational, social or personal activities. In addition, the person must also have four or more of the following symptoms, all of which must have persisted or recurred for at least 6 months: impaired short-term memory or concentration; sore throat; tender cervical or axillary lymph nodes; muscle pain, multi-joint pain without swelling or redness; headaches of a new type or severity; unrefreshing sleep; or postexertional malaise lasting more than 24 hours.

Fibromyalgia is a disorder of widespread pain, tenderness, fatigue, sleep disturbance, and psychological distress. Additional clinical features may include irritable

bowel syndrome, paresthesias, headache, irritable bladder, and social dysfunction. Problems with classification and diagnosis of fibromyalgia led to the development of criteria by the American College of Rheumatology. In a 1990 American College of Rheumatology study of criteria for the classification of fibromyalgia, 81% of the patients complained of fatigue and 74% complained of sleep disturbance. In addition, 60% of patients with fibromyalgia report having had significant problems with depression.

Multiple chemical sensitivity (MCS) is a diagnosis given to patients who exhibit a variety of symptoms that are attributed to a chemical exposure but which have no apparent organic base. There is very little agreement on what the symptoms represent and no definition has yet been endorsed for clinical use by a body of physicians. The most widely accepted definition, primarily for research purposes, appears to be that by Mark Cullen. This definition has four characteristics:

1. MCS is *acquired* in relation to some documentable environmental exposure.
2. Symptoms involve more than one organ system, and recur and abate in response to *predictable* environmental stimuli.
3. Symptoms are elicited by exposures to chemicals that are *demonstrable* but very low.
4. The manifestations of MCS are *subjective*.

Patients with CFS, fibromyalgia and MCS seem to have many symptoms in common. According to some, these conditions may represent overlapping clinical syndromes. A study by Buchwald and Garrity found that 70% of patients with fibromyalgia and 30% of those with MCS met the criteria for CFS. A study by Hudson found that 42% of fibromyalgia patients have met the criteria for CFS, while a study by Goldenberg found that 70% of patients diagnosed as having CFS met the ACR criteria for fibromyalgia.

There are other disorders which overlap with CFS. For patients with TMD, or temporomandibular disorder, almost 60% have the CFS symptom of fatigue for more than 6 months and 30% have reduced activity. Another overlap syndrome is Sjogren's Syndrome, an autoimmune disorder that is characterized by dry eyes and dry mouth.

An adequate workup and diagnosis for patients who exhibit the signs and symptoms common to this spectrum of illness is very important. It is also very important to acknowledge that the patient's suffering is real. Without such acknowledgment, based upon complete and adequate workup and diagnosis, even the limited objectives of treatment in this area can not be achieved. In fact, it has been shown that patients with these overlapping syndromes consult many types of physicians and providers including acupuncturists, chiropractors, naturopaths/homeopaths, clinical ecologists, perhaps in frustration with the medical system and lack of what they feel is an adequate workup and diagnosis. In addition, patients with CFS, fibromyalgia and MCS use a great deal of resources with yearly visits to a medical provider averaging 22.1, 39.7 and 23.3 visits, respectively.

The Institute of Medicine Committee now has the task of taking the very detailed information provided during the workshop by leading researchers, clinicians and the DoD, and determining whether the CCEP does provide for adequate workup and diagnosis of Persian Gulf veterans who present with these symptoms and conditions. We take this charge very seriously and will be pleased to share with you our report with recommendations as soon as it is completed.

I mentioned at the beginning of my testimony that the IOM had two committees concerned with the care provided to Persian Gulf veterans. The second committee is evaluating the adequacy of the Department of Veterans Affairs Uniform Case Assessment Protocol. The charge to that committee is to answer three questions:

1. Is the protocol adequate to address the wide range of medical assessment needs of Persian Gulf veterans?

2. How has the protocol been implemented and administered by the VA?

3. What does the IOM committee feel could or should be done to (a) make veterans aware of what the Persian Registry can do, and (b) educate providers about Persian Gulf issues?

I am not a member of this second committee, however, I can briefly describe for you the activities in progress. As part of its information gathering phase, the committee conducted site visits to three VA facilities and met with Persian Gulf Registry providers,

specialists who would likely be called upon to see Persian Gulf veterans upon referral, primary care providers who are *not* part of the PG provider team, outreach personnel who are the first point of contact for the PG veteran, and Persian Gulf veterans who have received services at each of these facilities. In addition, the committee has sent a letter to veterans organizations and to all VA facilities inviting them to submit information about their experiences with and perspective on the Persian Gulf Registry and UCAP.

The VA has provided a tremendous amount of information to this IOM committee regarding protocol development, education of providers, and use of services. The task now is to carefully analyze the adequacy of the protocol and the implementation of the system, both in its theory and, to the extent possible, its practice. The IOM plans to complete this report by December of this year and will be happy to share it with your committee.

Mr. Chairman, again I thank you for the opportunity to provide you with information on the activities of the Institute of Medicine as they relate to evaluating the clinical services provided to Persian Gulf veterans. I will be happy to try to answer questions, if you wish.

Howard M. Kipen, MD, MPH
Associate Professor and
Director of Occupational Health
Department of Environmental and Community Medicine

Howard Kipen is associate professor and Chief of the Occupational Health Division of the Department of Environmental and Community Medicine at UMDNJ-Robert Wood Johnson Medical School in Piscataway, New Jersey. He is also Director of the Occupational Health Division at the Environmental and Occupational Health Sciences Institute, jointly sponsored by the medical school and Rutgers University, where he also holds graduate faculty appointments in public health, toxicology, and environmental science. He received his undergraduate and medical degrees at the University of California and his MPH from Columbia University School of Public Health. He had internal medicine residency training at Columbia Presbyterian Medical Center in New York, and occupational medicine training at Mount Sinai Medical Center in New York. He is board certified in internal medicine and occupational medicine and holds joint faculty appointments in the Departments of Internal Medicine and Family Medicine.

He is currently a recipient of a five year academic award in environmental and occupational medicine from the National Institute of Environmental Health Sciences (NIEHS). He chaired the ATSDR meeting on Immune Function Test Batteries for Use in Environmental Health Field Studies. He is a member of the Department of Veterans Affairs Persian Gulf Expert Scientific Committee. He has served on both Institute of Medicine CCEP committees, and recently chaired IOM's Committee on Increasing Health Professionals' Use of Toxicology and Environmental Health Databases. He chaired a workshop on Multiple Chemical Sensitivities in Berlin for the World Health Organization International Program on Chemical Safety.

He has published a number of papers on the effects of exposure to environmental agents including benzene, asbestos, and airway irritants. He recently published a chapter on the role of environmental factors in Human Cancer Causation and another on the role of environmental and occupation factors in causing lymphohematoipoietic malignancies. Recent publications include: Multiple Chemical Sensitivity: A Primer for Pulmonologists in Clinical Pulmonary Medicine, and editorship with Dr. Nancy Fiedler of Experimental Approaches to Chemical Sensitivity (a 1997 Supplement to Environmental Health Perspectives). For six years he collaborated on an NIH funded study with Nancy Fiedler, PhD, on the investigation of individuals who present with Multiple Chemical Sensitivities. As an extension of this work, he is Co-principal Investigator of New Jersey Center for Environmental Hazards Research, a Department of Veterans Affairs-funded research center (for 5 years at $2,600,000) devoted to research on the health problems of Persian Gulf veterans. The major goal of this project is to investigate the health status of veterans of the Persian Gulf War for which Dr. Kipen is PI for the Robert Wood Johnson Medical School and Rutgers, The State University of New Jersey portion of approximately $109,000 this current year.

The Institute of Medicine has received funding to investigate the health of Persian Gulf veterans as follows:

Health Consequences of Service in the Persian Gulf, September, 1993 through September, 1996, Department of Defense and Department of Veterans' Affairs, $1,500,000.

Evaluation of the Comprehensive Clinical Evaluation Program, Phase I, September, 1994, though September, 1995, Department of Defense, $192,000.

Evaluation of the Comprehensive Clinical Evaluation Program, Phase II, May, 1996 through September, 1997, Department of Defense, $475,000.

Evaluation of the Uniform Case Assessment Protocol, September, 1996 through December, 1997, $280,815.

Adequacy of the Comprehensive Clinical Evaluation Program

Nerve Agents

Committee on the Evaluation of the Department of Defense
Comprehensive Clinical Evaluation Program

Division of Health Promotion and
Disease Prevention

INSTITUTE OF MEDICINE

NATIONAL ACADEMY PRESS
Washington, D.C. 1997

NATIONAL ACADEMY PRESS • 2101 Constitution Avenue, N.W. • Washington, DC 20418

NOTICE: The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine. The members of the committee responsible for the report were chosen for their special competencies and with regard for appropriate balance.

This report has been reviewed by a group other than the authors according to procedures approved by the Report Review Committee consisting of members of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

The Institute of Medicine was chartered in 1970 by the National Academy of Sciences to enlist distinguished members of appropriate professions in the examination of policy matters pertaining to the health of the public. In this, the Institute acts under both the Academy's 1863 congressional charter responsibility to be an adviser to the federal government and its own initiative in identifying issues of medical care, research, and education. Dr. Kenneth I. Shine is the president of the Institute of Medicine.

This study was supported by the US Department of Defense under Contract Number DASW01-96-K-007. The views presented are those of the Institute of Medicine Committee on the Evalution of the Department of Defense Comprehensive Clinical Evaluation Program and are not necessarily those of the funding organization.

International Standard Book No. 0-309-05743-4

Additional copies of this report are available for sale from:

National Academy Press
2101 Constitution Avenue, N.W.
Box 285
Washington, DC 20055
Call (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area), or visit the NAP's on-line bookstore at **http://www.nap.edu.**

For more information about the Institute of Medicine, visit the IOM home page at **http://www2.nas.edu/iom.**

Copyright 1997 by the National Academy of Sciences. All rights reserved.

Printed in the United States.

The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The serpent adopted as a logotype by the Institute of Medicine is a relief carving from ancient Greece, now held by the Staatlichemuseen in Berlin.

COMMITTEE ON THE EVALUATION OF THE DoD COMPREHENSIVE CLINICAL EVALUATION PROGRAM

Dan G. Blazer,* *Chair*, Dean of Medical Education and Professor of Psychiatry, Duke University Medical Center, Durham, North Carolina

Margit L. Bleecker, Director of the Center for Occupational and Environmental Neurology, Baltimore, Maryland

Evelyn J. Bromet, Professor, Department of Psychiatry, State University of New York at Stony Brook, Stony Brook, New York

Gerard Burrow,* Dean, Yale University School of Medicine, New Haven, Connecticut

Howard Kipen, Associate Professor and Director, Occupational Health Division, Robert Wood Johnson Medical School, Piscataway, New Jersey

Adel A. Mahmoud,* Chairman, Department of Medicine, Case Western Reserve University and University Hospitals of Cleveland, Cleveland, Ohio

Robert S. Pynoos, Associate Professor of Psychiatry and Dean of the Trauma Psychiatry Service, University of California at Los Angeles, Los Angeles, California

Guthrie L. Turner, Chief Medical Consultant, Office of Disability Determination Services, State of Washington, Tummwater, Washington

Michael Weisman, Professor, Division of Rheumatology, University of California at San Diego Medical Center, San Diego, California

Staff

Lyla M. Hernandez, Study Director

Sanjay S. Baliga, Research Associate

David A. Butler, Program Officer

Donna M. Livingston, Project Assistant

James A. Bowers, Project Assistant

Kathleen R. Stratton, Director, Division of Health Promotion and Disease Prevention

Constance M. Pechura, Director, Division of Neuroscience and Behavioral Health

---

*Member, Institute of Medicine.

Contents

EXECUTIVE SUMMARY 1

INTRODUCTION 4

THE COMPREHENSIVE CLINICAL EVALUATION PROGRAM 6
Overview, 6
Implementation, 7
CCEP: The Initial IOM Report, 8
CCEP: IOM Review Continued, 9

TESTING FOR AND IDENTIFYING HEALTH EFFECTS OF EXPOSURE TO NERVE AGENTS 11

RECOMMENDATIONS 15

REFERENCES 21

APPENDIXES
A Recommendations of the Initial CCEP Committee, 25
B Outline of the CCEP Medical Protocol, 44
C Workshop on the Adequacy of the CCEP for Evaluating Individuals Potentially Exposed to Nerve Agents: Agenda and Speakers List, 48
D DoD Memorandum for Persian Gulf War Veterans Concerning Kamisiyah, Iraq, 52
E Persian Gulf War-Related Events: Timeline, 55

Executive Summary

On August 2, 1990, Iraq invaded Kuwait and the Persian Gulf War began. The United States deployed almost 700,000 military personnel to the Gulf in Operations Desert Shield and Desert Storm. Following a brief war, most troops returned home and resumed their normal activities. Some, however, began to report various health problems that they believed were related to their deployment in the Persian Gulf. As reports of a purported "Persian Gulf Illness" circulated, public concern grew. In response, the Department of Veterans Affairs (VA) and the Department of Defense (DoD) developed a registry and clinical programs to track the health of Persian Gulf veterans.

The Comprehensive Clinical Evaluation Program (CCEP) was developed by the DoD to provide a systematic clinical evaluation program for the diagnosis and treatment of active-duty military personnel who have medical complaints they believe could be related to their service in the Persian Gulf. Since the program began, about 28,600 active duty Persian Gulf veterans have requested clinical examinations. By December 31, 1996, 24,400 veterans had received completed evaluations; an additional 4,180 are currently involved in some phase of the examination process.

In 1994, the DoD asked the Institute of Medicine to convene a committee to evaluate the adequacy of the CCEP. This committee reached the conclusion that the CCEP is a comprehensive effort to address the clinical needs of the thousands of active-duty personnel who served in the Gulf War. In addition, the committee found that, although the CCEP is not appropriate as a research tool, the results could and should be used to: educate Persian Gulf veterans and the physicians caring for them; improve the medical protocol itself; and evaluate patient outcomes.

The DoD asked the Institute to continue its evaluation of the CCEP with special attention to three issues: (1) approaches to addressing difficult-to-diagnose individuals and those with ill-defined conditions; (2) the diagnosis and treatment of stress and psychiatric conditions; and (3) the assessment of health problems of those who may have been exposed to low levels of nerve agents. This new committee (CCEP 2) was also asked to consider whether there are medical tests or consultations that should be added to the CCEP to increase its diagnostic yield. The following diagram describes the output of the two CCEP committees.

CCEP 1 →	CCEP 1 →	CCEP 1 →	CCEP 2 →	CCEP 2
First Report Released December 1994	Second Report Released August 1995	Final Report Released January 1996	First Report Released April 1997	Final Report Anticipated October 1997

Because of growing concern about the health problems of those veterans who may have been exposed to low levels of nerve agents, the DoD asked the committee to address this issue first. A 1-day workshop was held during which leading researchers and clinicians presented the latest scientific and clinical information regarding possible health effects of low-level exposure to nerve agents and chemically related compounds, as well as the tests available to measure the potential health effects of such exposures. Because there is little available research documenting long-term health effects of low-level exposure to nerve agents, speakers were asked to address the kinds of effects that *might* exist. These potential effects included neurological problems such as peripheral sensory neuropathies and psychiatric effects such as alterations in mood, cognition, or behavior.

The committee concluded that, overall, the CCEP provides an appropriate screening approach to the diagnosis of a wide spectrum of neurological diseases and conditions. The issue of psychological and psychiatric problems will be addressed in greater detail in the upcoming workshops and the final committee report.

The committee agreed that, given the possibility of low-level exposure to nerve agents, certain refinements in the CCEP would enhance its value. Although these refinements need not be applied retrospectively, the committee hopes implementation will be rapid so that as many new enrollees as possible will benefit from the improved system. Refinements include:

- improved documentation of the screening used during Phase I for patients with psychological conditions such as depression and posttraumatic stress disorder (PTSD);
- improved documentation of neurological screening used during both Phase I and Phase II of the CCEP;

- ensuring that Phase I primary physicians have ready access to a referral neurologist and a referral psychiatrist;
- ensuring that more complete histories are taken, particularly regarding personal and family histories, the onset of health problems, and the occupational and environmental exposures for each patient;
- standardization—to the extent possible—of predeployment physical examinations given members of the armed forces across the services;
- increased uniformity of CCEP forms and reporting procedures across sites;
- for each patient, the physician should provide written evidence that all organ systems were evaluated; and
- DoD should offer group education and counseling to soldiers and their families concerned about exposure to toxic agents.

The committee emphasizes that the CCEP is *not* an appropriate vehicle for addressing questions about the possible long-term health effects of low-level exposure to nerve agents. Those questions must be addressed through rigorous scientific research. The CCEP is a treatment program. Therefore, it is important not to attempt to use the findings of the CCEP to answer research questions. The committee believes strongly that although data from the CCEP cannot be used to test for potential associations between exposures and health effects, it can, combined with other information, be used to identify promising directions for separate research studies.

Introduction

A large Iraqi force invaded the independent nation of Kuwait on August 2, 1990. Within 5 days, the United States began deploying troops to the Persian Gulf in Operation Desert Shield. On January 16, 1991, UN coalition forces began intense air attacks against the Iraqi forces (Operation Desert Storm). By February 1991, more than 500,000 US troops were present and ready to engage the Iraqi army. A ground attack was launched on February 24, and within 4 days Iraqi resistance crumbled. After the fighting, the number of US troops in the area began to decline rapidly. By June 1991, fewer than 50,000 US troops remained.

Almost 700,000 US troops participated in Operations Desert Shield and Desert Storm. The composition of these troops differed from any previous US armed force. Overall, they were older, a large proportion (about 17%) were from National Guard and Reserve units, and almost 7% of the total forces were women.

US casualties were low during the Persian Gulf War. There were 148 combat deaths, with an additional 145 deaths due to disease or accidents. Despite the low number of fatalities and injuries, service personnel in the Persian Gulf were exposed to a number of stresses. These included environmental factors such as pesticides, diesel fumes, microbes, and oil well fires; and psychosocial factors such as the sudden mobilization for military service (especially for military reserves), the different cultural traditions of the region, and the primitive living conditions into which some troops were placed.

Following the war, most troops returned home and resumed their normal activities. However, a number of active-duty military personnel and veterans have reported various health problems they believe are connected to their Persian Gulf deployment. Symptoms commonly described include fatigue, memory loss, severe headaches, muscle and joint pain, and rashes (Iowa Persian Gulf Study Group, 1997). As reports of a purported "Persian Gulf Illness"

circulated, public concern grew. Both the Department of Defense (DoD) and the Department of Veterans Affairs (VA) developed a registry to track the health of Persian Gulf veterans and clinical programs to diagnose and treat program participants. In June 1994, the DoD instituted the Comprehensive Clinical Evaluation Program (CCEP), the purpose of which is to diagnose and treat active-duty military personnel who have medical complaints they attribute to service in the Gulf.

In 1994, the DoD asked the Institute of Medicine (IOM) to assemble a group of medical and public health experts to evaluate the adequacy of the CCEP. This committee met four times and prepared three reports between October 1994 and January 1996 (IOM 1995, 1996a,b). A general discussion of this committee's findings appears in the section entitled, "CCEP: The Initial IOM Report" (page 8). A complete list of the first CCEP committee's recommendations appears in Appendix A. Given these recommendations and an analysis by the DoD of information derived from the CCEP, the IOM was asked to continue its review of the CCEP with special emphasis on three areas: (1) approaches to addressing individuals with difficult-to-diagnose or ill-defined conditions, (2) diagnosis and treatment of stress and psychological or psychiatric conditions, and (3) identifying health problems of those who may have been exposed to nerve agents.

Given the intense interest in and concern about the potential health effects of possible exposure to nerve agents, DoD asked the committee to focus first on addressing the health problems of those who may have been exposed to such agents. To do so, a 1-day workshop was held at which leading researchers and clinicians presented the latest scientific and clinical information regarding possible health effects of low-level exposure to nerve agents and chemically related compounds, as well as the tests available to measure the potential health effects of such exposures.

The Comprehensive Clinical Evaluation Program*

OVERVIEW

In June 1994 the DoD instituted the CCEP to provide a thorough systematic clinical evaluation program for the diagnosis and treatment of Persian Gulf veterans at military facilities in the US and overseas. Since then, more than 37,800 veterans (of whom about 13% are women) have enrolled in the CCEP registry. Of those, about 28,580 (about 12% of whom are women) have requested clinical examinations. By December 31, 1996, 24,400 veterans (or about 12% of those eligible) had received completed evaluations, while an additional 4,180 are currently involved in some phase of the examination process.

The CCEP was designed to: (1) strengthen the coordination between the DoD and the VA; (2) streamline patient access to medical care; (3) make clinical diagnoses in order to treat patients; (4) provide a standardized, staged evaluation and treatment program; and (5) assess possible Gulf War-related conditions. (Veterans who have left military service entirely are eligible for evaluations from the VA; personnel still on active duty, in the Reserves, or in the National Guard may request medical evaluations from DoD.) Phase I of the CCEP consists of a medical history, physical examinations, and laboratory tests. These are comparable in scope and thoroughness to an evaluation conducted during an inpatient internal medicine hospital admission (see Appendix B). All CCEP participants are evaluated by a primary care physician at their local medical treatment facility and receive specialty consultations if they are deemed

*Portions of this section are based upon workshop presentations by Anthony Amato, M.D.; Col. Ray Chung; Lt. Col. Tim Cooper; Capt. Andrew Dutka; Maj. Chuck Engel; Lt. Col. Robert Gum; and Col. Kurt Kroenke.

appropriate by their primary care physician. Evaluation at this phase includes a survey for nonspecific patient symptoms, including fatigue, joint pain, diarrhea, difficulty concentrating, memory and sleep disturbances, and rashes.

The primary care physician may refer patients to Phase II for further specialty consultations if he or she determines it is clinically indicated. These Phase II evaluations are conducted at a regional medical center and consist of targeted, symptom-specific examinations, lab tests, and consultations. During this phase potential causes of unexplained illnesses are assessed, including infectious agents, environmental exposures, social and psychological factors, and vaccines and other protective agents. Both Phase I and Phase II are intended to be thorough for each individual patient and to be consistent among patients.

Every medical treatment facility has a designated CCEP physician coordinator who is a board-certified family practitioner or internal medicine specialist. The coordinator is responsible for overseeing both the comprehensiveness and quality of Phase I exams. At regional medical centers CCEP activities are coordinated by board-certified internal medicine specialists who also oversee the program operations of the medical treatment facilities in their region.

In March 1995, the DoD established the Specialized Care Center at Walter Reed Army Medical Center to provide additional evaluation, treatment, and rehabilitation for patients who are suffering from chronic debilitating symptoms. A small select group of patients have been referred from regional medical centers to the Specialized Care Center for an intensive 3-week evaluation and treatment program designed to improve their health status.

IMPLEMENTATION

The DoD has summarized the information obtained through the CCEP in reports released to the public. In the most recent published report, which covered 18,598 participants seen through December 6, 1995, the most frequent primary diagnoses were psychological conditions (18.4%); musculoskeletal conditions and connective tissue diseases (18.3%); symptoms, signs, and ill-defined conditions (17.9%); respiratory diseases (6.8%); and digestive system diseases (6.3%). An additional 9.7% were found to be healthy.

When both primary and secondary diagnoses were considered, the most common diagnostic categories were musculoskeletal diseases (47.2%); symptoms, signs, and ill-defined conditions (43.1%); psychological conditions (36.0%); digestive diseases (17.5%); and nervous system diseases (17.8%) (CCEP report on 18,598 participants, April 2, 1996).

The most frequently recorded psychological diagnoses were tension headache, depression, anxiety disorders, adjustment reactions, and somatoform disorders. For participants with a primary diagnosis of symptoms, signs, and ill-

defined conditions, the most common conditions were malaise and fatigue (26.6%), sleep disturbance (17.7%), and/or headache (15.3%). More than 50% of the patients with a primary diagnosis of musculoskeletal and connective tissue conditions had pain in joints, osteoarthrosis, and backache.

Five percent of the participants in the CCEP had a primary diagnosis of a neurological disorder. In addition, 11.8% of all participants were diagnosed with at least one neurological condition. The most common primary neurological diagnosis was migraine headache (56%) followed by carpal tunnel syndrome (9.5%), other peripheral mononeuropathies (0.25%), and benign essential tremors (2.3%) (DoD, 1996: 68).

Major neuromuscular complaints recorded during Phase I included myalgias, fatigue and weakness. Patients who complained of severe muscle weakness, fatigue, or myalgias that lasted at least 6 months and interfered with normal functioning were referred to neuromuscular specialists for evaluation. At a minimum, these patients had median and sural sensory nerve action potentials recorded. Additional tests were ordered as deemed necessary by the neurologist. After extensive clinical, electrophysiological, and histological testing, no significant, objective neuromuscular pathology was identified that would suggest a possibly distinct neuromuscular disorder in these patients.

CCEP: THE INITIAL IOM REPORT

In July 1994, Dr. Stephen Joseph, Assistant Secretary of Defense for Health Affairs, asked the IOM to convene a committee to evaluate the clinical assessments of the CCEP and to comment on the interpretation of its results to date. That committee was also asked to make recommendations regarding how the clinical assessments should be conducted in the future and on DoD's broader program of Persian Gulf health studies. Committee members included experts in general medicine, occupational and environmental medicine, rheumatology, infectious disease, psychiatry, psychology, and clinical neurotoxicology. The committee reached the following conclusions (for a complete set of recommendations of the first CCEP committee, as well as a list of committee members, see Appendix A):

- The CCEP is a comprehensive effort to address the clinical needs of thousands of active-duty personnel who served in the Gulf War. The CCEP leads to a specific medical diagnosis or diagnoses for most patients. The DoD has made conscientious efforts to build consistency and quality assurance into this program at the many medical treatment facilities and regional medical centers across the country.
- DoD efforts to compare the symptoms and diagnoses in the CCEP with those in several community-based and clinically based populations "should be

made with great caution and only with the explicit recognition of the limitations of the CCEP as a self-selected case series. The CCEP results do have considerable clinical utility, and they could be used to address many important questions from a descriptive perspective."

- "The results of the CCEP can and should be used for several purposes, including (1) educating Persian Gulf veterans and the physicians caring for them, (2) improving the medical protocol itself, and (3) evaluating patient outcomes. The medical findings of the CCEP should be distributed promptly to all CCEP primary care physicians." These findings would also be of "considerable value and interest to physicians in the VA system and in the community."
- "DoD should consider developing a comprehensive document for use in the CCEP that describes the potential physical, chemical, biological, and psychological stressors that were present in the Persian Gulf theater. If the CCEP physicians could obtain a clearer picture of the possible range of exposures, they might be able to counsel their patients more effectively."
- DoD has taken a serious approach to the treatment and rehabilitation of patients who have treatable, chronic diseases. If the Specialized Care Center "program is successful in improving the health and functional status of its patients, perhaps the elements that are most effective in enabling the patients to cope with their symptoms could be identified. It might then be possible to disseminate some of these elements to the DoD medical treatment facilities, which are close to where the CCEP patients live and work."

CCEP: IOM REVIEW CONTINUED

Late in 1995, the DoD asked the IOM to continue its evaluation of the CCEP with special attention to two issues: (1) difficult-to-diagnose individuals and those with ill-defined conditions; and (2) the diagnosis and treatment of patients with stress and psychiatric conditions. A new committee was convened to address these issues. Most members of the newly formed committee were also members of the first IOM CCEP committee.

With the disclosure in June of 1996 that some US ground troops may have been exposed to low levels of nerve agents following the destruction of the munitions dump at Khamisiyah, the DoD asked the IOM to add to its assessment whether the present CCEP protocol is adequate for evaluating the health of individuals who may have been exposed to low levels of nerve agents.

In defining the tasks included in Phase II, it is important to note what is *not* included in the committee's charge. It is *not* this committee's charge to determine whether or not there is such an entity (or entities) as "Persian Gulf Illness." It is *not* this committee's charge to determine whether or not there are

long-term health effects from low-level exposure to nerve agents. These questions are more properly the subject for extensive scientific research.

The committee charge, then, is threefold. It is to evaluate the adequacy of the DoD's Comprehensive Clinical Evaluation Program regarding:

- approaches to dealing with difficult-to-diagnose individuals and those with no diagnosis, as well as poorly defined conditions such as chronic fatigue syndrome, fibromyalgia, and multiple-chemical sensitivity;
- the diagnosis and treatment of stress and psychiatric conditions, the relationship between stress and psychiatric conditions and physical symptoms, and predeployment screening and mitigation of stressors in future deployments; and
- assessment of the health problems of those who may have been exposed to low levels of nerve agents.

The committee also will consider whether there are medical tests or consultations that should be systematically added to the CCEP to increase its diagnostic yield.

A series of workshops was planned to obtain information on these topics. Given the urgency surrounding the question of health problems of those who may have been exposed to low levels of nerve agents, DoD asked the Committee to address this topic first. A 1-day workshop was held on December 3, 1996, during which information was gathered from leading researchers and clinicians about effects of exposure to nerve agents and chemically related compounds, as well as about tests available to measure potential health effects of such exposures. (See Appendix C for the workshop agenda and list of speakers.) The committee spent the day following the workshop examining and analyzing this information in detail in order to develop its recommendations.

Testing for and Identifying Health Effects of Exposure to Nerve Agents*

Nerve agents are extremely toxic compounds that were designed specifically to kill or incapacitate. Sarin and cyclosarin (the agents of concern in the Persian Gulf) are organophosphates that permanently inhibit acetylcholinesterase. This results in an accumulation of acetycholine at the cholinergic synapses, causing continued stimulation of the affected organ. The toxic effects of poisoning depend largely on the intensity of exposure. The effects range from miosis, or pinpoint pupils, and blurred vision at lower concentrations, to involuntary defecation, nausea, vomiting, muscular twitching, weakness and convulsions, and death at somewhat higher concentrations.

Experimental studies on the long-term effects of sarin on animals and humans have produced inconclusive results. In 1982, the National Research Council conducted a study examining long-term or delayed adverse health effects of 15 anticholinesterases tested on about 1,400 military volunteers during the 1960s and 1970s. That panel concluded that "although no evidence has been developed (to date) that any of the anticholinesterase test compounds surveyed carries long-range adverse human health effects in the doses used, the panel is unable to rule out the possibility that some anti-ChE [cholinesterase] agents produced long-term adverse health effects in some individuals. Exposures to low doses of OP [organophosphate] compounds have been reported (but not confirmed) to produce subtle changes in EEG, sleep pattern, and behavior that lasts for at least a year." (NRC, 1982: 33).

---

* The material in this section is based, in part, upon presentations and discussion by Kent Anger, Ph.D.; Arthur Asbury, M.D.; David Cornblath, M.D.; Bhupendra Doctor, M.D.; Eva Feldman, M.D.; Lt. Col. Robert Gum, M.D.; David Janowsky, M.D.; Richard Johnson, M.D.; Robert MacPhail, Ph.D.; Peter Spencer, Ph.D.; and Roberta White, Ph.D.

Lack of knowledge regarding who might have been exposed to nerve agents and at what level is impeding researchers attempting to answer questions about health effects. The extent and frequency of exposure of troops to nerve agents in the Persian Gulf is still being investigated. Concerns about exposure were heightened by the announcement that troops in the vicinity of Khamisiyah on March 10, 1991, may have been exposed to sarin or cyclosarin when US military personnel destroyed a munitions dump. It is not known whether or to what extent personnel were exposed. In addition, the military is investigating other potential exposures to nerve agents in the Persian Gulf. Without definitive information on the intensity and frequency of exposures, interpretation of research results is problematic.

Research on exposure to organophosphate pesticides, some of the most acutely toxic and potentially lethal pesticides in use today, may provide information useful to those studying the effects of sarin and cyclosarin because these types of pesticides and nerve agents both inhibit cholinesterase. Acute symptoms of poisoning from these OP pesticides can be as severe as those found with any nerve agent, but the long-term neurobehavioral health effects in the absence of acute clinical effects at the time of exposure are still debated

A study of individuals occupationally exposed to organophosphate pesticides examined workers without acute, clinical symptoms, but with blood measurements that showed depressed cholinesterase levels. Neurobehavioral tests were used in the study but no residual neurologic health effects were documented in this population (Ames et al., 1995).

Detection, over time, of organophosphate nerve agents in the blood is impossible because such agents are completely detoxified by a set of enzymes in the body. Therefore, measuring the presence of nerve agents in the blood over time is not a practical approach for determining whether an exposure occurred. In addition, there is no surrogate marker of exposure.

Another important issue is the use of pyridostigmine bromide (PB) pills which were distributed to soldiers deployed to the Persian Gulf. Pyridostigmine bromide is a carbamate that also inhibits acetylcholinesterase. Unlike sarin and cyclosarin, however, PB binds *temporarily* with acetylcholinesterase. The DoD's intent, therefore, was for troops threatened with exposure to chemical warfare agents to take the pills so the PB could bind temporarily with their acetylcholinesterase, leaving little available for the nerve agents to act on. Any acute clinical response to PB would be short-lived, unlike responses to sarin and cyclosarin, thereby saving the life of the exposed victim. Acute, short-term effects of PB can include respiratory problems, nausea, and diarrhea. As is the case with sarin and cyclosarin, there has been little research into the long-term health effects of PB used in healthy individuals exposed to low levels of nerve agents.

Long-term health effects of low level nerve agent exposure have not been shown to exist. However, it might be hypothesized that such health effects, if they exist, might relate to inhibition of acetylcholinesterase and be manifested as

neurological problems (e.g., peripheral sensory neuropathies) and as psychiatric problems (e.g., alterations in mood, cognition or behavior). Persons who may have been exposed to nerve agents could, therefore, be examined for both junctional myopathies and peripheral neuropathies. Junctional myopathy is normally associated with life-threatening respiratory muscle damage, not with acute anticholinesterase effects. Organophosphate-induced junctional myopathies are thought to be caused by excessive acetylcholine activity at the neuromuscular junction, whereas peripheral neuropathies are thought to be caused by inhibition of an enzyme known as neuropathy target esterase.

Toxic insults can damage nerve axons, resulting in subsequent loss of nerve fiber and the development of neuropathy. Symptoms of neuropathy include numbness, tingling, and prickling sensations with differing degrees of intensity and duration. Signs of neuropathy include mild loss of vibration at toes, decreased ankle reflexes early on, and sensory loss later. A conventional neuropathy diagnosis begins with a careful patient history, followed by a characterization of the symptoms and electrophysiological tests. These tests traditionally involve nerve conduction studies and quantitative sensory testing. Severe neuropathy may extend to the central nervous system, leading to more critical problems.

An accurate, ètiologic diagnosis of a neuropathy cannot be based on symptoms alone. A simple, reliable neuropathy diagnosis requires a neurologist, a set of noninvasive diagnostic instruments including a thorough patient history questionnaire; clinical examination questions about sensory, motor, and autonomical functions; and simple nerve conduction and quantitative sensory tests. In addition, physicians must consider other possible etiologies of neuropathy in patients, including inherited problems, paraneoplastic syndromes, immune-mediated neuropathy, infectious vectors including HIV status, diabetes, alcohol use, and the use of therapeutic drugs.

In routine clinical practice, the first choice in diagnosing a neuropathy would be to perform a routine neurological examination. If the results were normal, one would end the investigation. If the results were abnormal, or if controlled scientific research was being conducted on a potential, undefined, subclinical, or preclinical-type syndrome, one would then perform quantitative sensory testing and nerve or skin biopsies.

Other important health effects that should be examined include psychological or psychiatric changes or problems. There are well-known, useful neurobehavioral tests for neurotoxicity that are reliable (i.e., the results are replicable), valid in the sense that they detect established effects seen at higher concentrations as well as at low concentration exposure, and are specific for certain chemical classes and not for others. These neurobehavioral tests for neurotoxicity are the same tests as are used in neurological evaluations of other conditions. Neuropsychological tests are generally classified into domains of function. The domains most commonly applied include motor skills, general

intelligence and academic abilities, attention, executive function, verbal and language abilities, visuospatial skills, memory (anterograde, retrograde), and personality and affect.

In order to apply neuropsychological tests to clinical assessment, the technique used must allow the clinician first to document brain damage attributable to neurotoxicant exposure (from subtle to severe) and second, to feel comfortable attributing any observed deficits to neurotoxicant exposure rather than some other cause. It is important to explicitly rule out other potential causes of impairment such as age, education, smoking, alcohol use, developmental disorders, psychiatric disorders, neurological disorders, and motivational states in which persons consciously or unconsciously sabotage their own test performance.

A recent study of Oregon veterans investigated psychosocial, neuropsychological, and neurobehavioral elements to determine objective memory and attention impairment. The population-based study used questionnaires as well as clinical examinations to identify behavioral, psychosocial, and performance disorders. Results indicate that neurobehavioral tests can identify veterans with objective deficits in attention or memory and cognitive processes (Anger, 1996, Unpublished presentation). Whether these objective deficits result in clinical impairments has not yet been documented. In addition, although neurotoxic chemical exposure is one possible explanation for these outcomes, other possibilities exist.

Recommendations

The charge to the committee was to determine whether the Comprehensive Clinical Evaluation Program could adequately diagnose and treat possible health problems among service personnel who may have been exposed to low levels of nerve agents. The committee reviewed extensive clinical and research results regarding the effects of nerve agents. No evidence available to the committee conclusively indicated the existence of long-term health effects of low-level exposure to nerve agents. Because firm conclusions about these effects remain elusive, the committee reviewed information about the types of health effects that *might* exist as a result of exposure. Leading scientists presented information suggesting that the possible effects *might* include neurological problems such as peripheral sensory neuropathies and psychiatric problems such as alterations in mood, cognition, or behavior.

Recent reports suggesting a possible toxic synergistic effect following exposure to multiple agents known to influence cholinesterase activity will require extensive research to determine their significance (Haley and Kurt, 1997; Haley et al., 1997a,b; Lottie et al., 1993). The results of the research to date, however, did not appear to indicate any additional possible health effects should be considered by the committee other than those already identified.

The committee concluded that the CCEP continues to provide an appropriate screening approach to the diagnosis of disease. Most CCEP patients receive a diagnosis and 80% of participants receive more than one diagnosis. Although the types of primary diagnoses commonly seen in the CCEP involve a variety of conditions, 65% of all primary diagnoses fall into three diagnostic groups (1) psychological conditions; (2) musculoskeletal diseases; and (3) symptoms, signs, ill-defined conditions or a fourth group designated as "healthy." **However, in view of potential exposure to low levels of nerve agents, certain refinements in the CCEP would increase its value.** These

refinements are viewed as part of a natural evolution and improvement process and, therefore, need not be applied retrospectively. The committee does encourage rapid implementation in order to provide the benefits of an improved system to new enrollees.

The committee recommends improved documentation of the screening used during Phase I for patients with psychological conditions such as depression and posttraumatic stress disorder (PTSD). The DoD (DoD, 1996) reported that depression and PTSD account for a substantial percentage of those receiving a diagnosis of a psychological condition. In addition, if there are long-term health effects of nerve agent exposure, it is possible that these effects could be manifested as changes in mood or behavior. The committee will be conducting an in-depth examination of the adequacy of the CCEP as it relates to stress and psychiatric disorders at a later time; however, because of the increased importance of ensuring that all possibilities are thoroughly checked, better documentation in this area is encouraged. Primary physicians could use any of a number of self-report screening scales, but consistent use of the same scale across facilities would ensure consistent results.

The committee recommends improved documentation of neurological screening done during both Phase I and Phase II of the CCEP. Concern about nerve agent exposure as well as the number of nonspecific, undiagnosed illnesses among CCEP patients makes documentation of neurological screening extremely important. CCEP patients are referred to neuromuscular specialists if they have complaints of severe muscle weakness, fatigue, or myalgias lasting for at least 6 months that significantly interfere with activities of daily living. These patients are evaluated by board-certified neurologists who have subspecialty training in neuromuscular disease. Based on the description of the tests administered and examinations conducted, the committee finds that the CCEP is sufficient to ensure that no chronic, well-established neurological problem is being overlooked. The documentation of the use of these tests and procedures, however, could and should be improved. Such improvements would engender confidence that neurological examinations and treatments across facilities are comparable.

Given the importance of thorough neurological and psychiatric screening, **the committee recommends that Phase I primary physicians have ready access to a referral neurologist and a referral psychiatrist.** As mentioned earlier, patients are referred to neuromuscular specialists if they have complaints of severe muscle weakness, fatigue, or myalgias lasting for at least 6 months that significantly interfere with activities of daily living. Appropriate psychiatric referrals could include those with chronic depression that is treatment resistant, an unexplained, persistent complaint of memory problems, or significant impairment secondary to behavioral difficulties, such as not being able to maintain productive work due to behavioral abnormalities. While patients referred for Phase II consultations with a neurologist or psychiatrist are cared for adequately, it is sometimes difficult for the primary physician to determine

whether or not a referral is appropriate. In such instances, the physician tends to refer more frequently than not. It may be that, if the primary care physician had neurological and psychiatric consultations readily available, referral decisions could be made more easily and appropriately.

The committee recommends that physicians take more complete patient histories, particularly regarding personal and family histories, the onset of health problems, and occupational and environmental exposures. While there currently is grave concern about exposure to nerve agents during deployment in the Persian Gulf, other factors affect on psychological and neurological disorders. Patients can perform below expectations on neuropsychological tests for a number of reasons. In clinical assessments, therefore, it is important to rule out alternative causes of impairment. In addition, current and past exposures to occupational and environmental toxicants are important. Detailed histories are a valuable tool in identifying the etiology of a patient's problems.

The committee recommends that, to the extent possible, predeployment physical examinations given to members of the armed forces should be standardized among the services. The lack of uniform baseline information about service members makes diagnosis and treatment of postdeployment problems more difficult. To the extent that adequate baseline information is unavailable, physicians must rely on self-reporting. Adequate predeployment physical examinations, standardized across services, could prove an important tool for both clinical assessment and structured research.

The committee recommends that DoD increase the uniformity of CCEP forms and reporting procedures across sites. The CCEP system would benefit from increased consistency and the knowledge that each service is collecting and using the same information. Currently, each branch of service and each facility use different forms to complete examinations, tests, and referrals. Increasing the consistency of such forms and procedures would provide a more reliable picture of the care given to patients in the CCEP. As was stated in the 1996 report on the Health Consequences of Service During the Persian Gulf War, it is extremely important to create a uniform, continuous, and retrievable medical record. In addition, the 1996 report stated that the information should be collected according to standardized procedures and maintained in a computer-accessible format. (IOM, 1996b) The committee concurs with those findings.

For each patient, the physician should provide written evidence that all organ systems were evaluated. The CCEP primary care physicians examine patients, and, if there are problems requiring additional expertise, the patients are referred to specialists. This is standard medical practice used across the United States. It would be appropriate, however, for the CCEP primary care physicians to document that their evaluations covered all organ systems. The committee is not recommending the use of new or sophisticated testing mechanisms. It is reinforcing the importance of the components of the basic medical examination.

This increased documentation could be completed by noting the organ systems evaluated and whether each was normal or abnormal. For those listed as abnormal, additional information could be provided.

The committee strongly urges the DoD to offer group education and counseling to soldiers and their families concerned about exposure to toxic agents. Following the revelation by the DoD of possible exposure to nerve agents due to the destruction of the munitions dump at Khamisiyah, approximately 20,000 service personnel received a letter from the DoD stating that their units were in the vicinity during the demolition. Each recipient was encouraged to contact an 800 number if he or she was experiencing health problems believed to be a result of service in the Persian Gulf. Given this revelation, there may be a heightened sense of insecurity and concern among Persian Gulf veterans and their families about possible exposure to nerve agents. Risk communication is an important clinical activity. Family and group counseling can address heightened concerns about exposure as well as other issues. Such an approach provides an appropriate public health mechanism for imparting information and addressing concerns and should be made available to all Persian Gulf veterans.

Although it is beyond the scope of the charge to this committee to determine whether low-level exposure to nerve agents causes long-term health effects, the committee believes strongly that this is an important research area that ought to be pursued. Most of the literature regarding health effects of exposure to nerve agents (i.e., sarin and cyclosarin) addresses exposures high enough to cause clinically observable effects. These clinical effects are well documented and include miosis, blurred vision, nausea, vomiting, muscular twitching, weakness, convulsions, and death. Little known research has been conducted regarding the long-term health effects of low levels of exposure to these nerve agents. The application of findings from research on organophosphate pesticide exposure to the area of nerve agent exposure has limitations. However, even in such pesticide studies, long-term health effects have been documented only for acutely poisoned individuals—that is, persons with immediate clinical symptoms.

The committee emphasizes that the CCEP is *not* an appropriate vehicle for scientifically assessing questions about long-term health effects of low levels of exposure to nerve agents. *The CCEP is a clinical treatment program, not a research protocol.* It is important, therefore, not to attempt to use the findings of the CCEP to answer research questions. Those questions must be addressed through rigorous scientific research.

The committee notes that the CCEP could be useful in identifying promising directions for separate research studies. Examinations of the health effects—if any—of various wartime exposures have been hampered by poor information about the level of exposure and an inability to identify the individuals who may have been exposed. It is often difficult to retrospectively estimate exposure levels. However, information about where individuals were and when they were there could be combined with data regarding the presence of an exposure to

develop surrogate measures. These surrogate measures could then be linked to health information and used to examine potential associations between exposures and health effects.

Although data from the CCEP can not be used to *test* for associations, it can be combined with other information to help identify areas for future research. For example, the DoD identified approximately 20,000 service people belonging to units that were within a 50-kilometer radius of Khamisiyah at the time of the munitions demolition. Examining the health records of these people may yield insights into whether those who participated in the CCEP (or a similar program administered by the VA) have different illnesses or patterns of illnesses than do CCEP participants outside the 50-kilometer radius. More detailed discrimination of proximity to Khamisiyah (e.g., within 20 kilometers or within the units directly responsible for the munitions destruction) may provide additional information.

It is important, however, to understand the limitations of such comparisons. The results cannot be taken as research findings and generalized to the entire population of those deployed to the Persian Gulf. Active-duty military personnel participating in the DoD health registry may be either more or less healthy than other nonparticipants on active duty. CCEP comparisons on this self-selected group of patients should not be used to draw conclusions about the entire population of Persian Gulf veterans.

More broadly, the committee notes that information that helps to identify where individuals were in the Persian Gulf and when they were there will also facilitate research into potential service-related health problems. This information is currently needed to address the question of who might have been exposed to nerve agents and who could be part of the (unexposed) comparison groups necessary for epidemiological studies. Such information could also be used to more quickly and easily identify the exposed and unexposed groups that would be required to assess any future concerns regarding this or other exposures.

Generating geographical and temporal information for all 700,000 people who served in the Persian Gulf would be an immense endeavor. It would not be prudent to undertake such a task without first thoroughly understanding the effort required to complete it. It would, however, be appropriate to take steps now to identify and preserve records that could assist in the generation of such a database in the future. Records-based information is intrinsically superior to personal recollections, especially several years after the fact.

References

Ames, RG., Steenland, K., Jenkins, B., et al. 1995. Chronic neurologic sequelae to cholinesterase inhibition among agricultural pesticide applicators. Arch Environ Health 50(6):440-444.

Anger, W.K., Letz, R., Chrislip, D.W., et al. 1994. Neurobehavioral test methods for environmental health studies of adults. Neurotoxicol Teratol 16(5):489–497.

Chaudhry, V., Eisenberger, M.A., Sinibaldi, V.J., et al. 1996. A prospective study of suramin-induced peripheral neuropathy. Brain 119:101–114.

Chaudhry, V., Rowinsky, E.K., Sartorius, S.E., et al. 1994. Peripheral neuropathy from Taxol and Cisplatin combination chemotherapy: Clinical and electrophysiological studies. Ann Neurol 35(3):303–311.

Davis, C.S. and Richardson, R.J. 1980. Organophosphorus compounds. Experimental and Clinical Neurotoxicology edited by Spencer, P.S. and Schaumburg, H.H. Baltmore: Williams & Wilkins. 527–544.

DoD. 1996. Comprehensive Clinical Evaluation Program for Persian Gulf Veterans—Report on 18,598 Participants (Draft). April 1996. Washington, D.C.

Dyck, P.J., Dyck, P.J.B., Grant, I.A., et al. 1996. Ten steps in characterizing and diagnosing patients with peripheral neuropathy. Neurology 47:10–17.

Feldman, R.G., and White, R.F. 1996. Role of the neurologist in hazard identification and risk assessment. Environ Health Perspect 104(2):227–237.

Haley, R.W., and Kurt, T.L. 1997. Self-reported exposure to neurotoxic chemical combinations in the Gulf War. A cross-sectional epidemiologic study. JAMA 277(3):231–237.

Haley, R.W., Hom, J., Roland, P.S., et al. 1997a. Evaluation of neurologic function in Gulf War Veterans. A blinded case-control study. JAMA 277(3):223–230.

Haley, R.W., Kurt, T.L., and Hom, J. 1997b. Is there a Gulf War syndrome? Searching for syndromes by factor analysis of symptoms. JAMA 277(3):215–222.

IOM (Institute of Medicine). 1994. Committee on the DoD Persian Gulf Syndrome Comprehensive Clinical Evaluation Program: First Report. Washington, D.C.: IOM.

IOM. 1995. Committee on the DoD Persian Gulf Syndrome Comprehensive Clinical Evaluation Program: Second Report. Washington, D.C.: IOM.

IOM. 1996a. Evaluation of the U.S. Department of Defense Persian Gulf Comprehensive Clinical Evaluation Program. Washington, D.C.: National Academy Press.

IOM 1996b. Health Consequences of Service During the Persian Gulf War: Recommendations for Research and Information Systems. Washington, D.C.: National Academy Press.

Iowa Persian Gulf Study Group. 1997. Self-reported illness and health status among Gulf War veterans: A population-based study. JAMA 277(3):238–245.

Lotti, M. Moretto, A., Capodicasa, E., et al. 1993. Interactions between neuropathy target esterase and its inhibitors and the development of polyneuropathy. Toxicol Appl Pharmacol 122:165–171.

Marrs, T.C., Maynard, R.L., and Sidell, F.R. 1996 A History of Human Studies with Nerve Agents by the UK and USA in Chemical Warfare Agents: Toxicology and Treatment. New York: John Wiley & Sons.

Morita, H., Yanagisawa, N., Nakajima, T., et. al. 1995. Sarin poisoning in Matsumoto, Japan. Lancet 346:290–293.

MRICD (Medical Research Institute of Chemical Defense). 1995. Medical Management of Chemical Casualties, Second Edition. Aberdeen Proving Ground, MD: MRICD.

NAS (National Academy of Sciences). 1982. Possible Long-Term Health Effects of Short-Term Exposure to Chemical Agents. Volume 1: Anticholinesterases and Anticholinergics. Washington, D.C.: National Academy Press.

Presidential Advisory Committee on Gulf War Veterans' Illnesses. 1996. Final Report. Washington, D.C.: U.S. Government Printing Office.

White, R.F., Gerr, F., Cohen, R.F., et al. 1994. Criteria for progressive modification of neurobehavioral batteries. Neurotoxicol Teratol 16(5):511–524.

White, R.F., and Proctor, S.P. 1992. Research and clinical criteria for development of neurobehavioral test batteries. J Occupat Med 34:140–148.

Xintaras, C., and Burg, J.A.R. 1980 Screening and prevention of human neurotoxic outbreaks: Issues and problems. Experimental and Clinical Neurotoxicology edited by Spencer, P.S. and Schaumburg, H.H. Baltimore: Williams & Wilkins. 663–674.

Appendixes

APPENDIX A

Recommendations of the Initial CCEP Committee

Evaluation of the U.S. Department of Defense Persian Gulf Comprehensive Clinical Evaluation Program: Overall Assessment and Recommendations

Committee on the DoD Persian Gulf Syndrome Comprehensive Clinical Evaluation Program

Division of Health Promotion and Disease Prevention

INSTITUTE OF MEDICINE
Washington, D.C. 1996

1.) OVERALL ASSESSMENT OF THE CCEP GOALS PROCEDURES:

The Comprehensive Clinical Evaluation Program (CCEP) clinical protocol is a thorough, systematic approach to the diagnosis of a wide spectrum of diseases. A specific medical diagnosis or diagnoses can be reached for most patients by using the CCEP protocol. The Department of Defense (DoD) has made conscientious efforts to build consistency and quality assurance into this program at the many medical treatment facilities (MTFs) and regional medical centers (RMCs) across the country.

The committee is impressed with the quality of the design and the efficiency of the implementation of the clinical protocol, the considerable devotion of resources to this program, and the remarkable amount of work that has been accomplished in a year. The high professional standards, commitment, and diligence of the physicians involved in the CCEP at the RMCs were readily apparent at the three committee meetings. The committee commends the DoD for its efforts to provide high-quality medical care in the CCEP and the success that it has achieved to date in developing the infrastructure necessary to efficiently contact, schedule, refer, and track thousands of patients through the system.

Overall, the systematic, comprehensive set of clinical practice guidelines set forth in the CCEP are appropriate, and they have assisted physicians in the determination of specific diagnoses for thousands of patients across the country.

2.) GENERAL RECOMMENDATIONS FOR THE IMPLEMENTATION OF THE CCEP:

2.1.) Referrals of Patients from Phase I to Phase II of the CCEP:

2.1.1.) Structure and revise the CCEP protocol and logistics to allow the majority of patients to receive a final diagnosis by Phase I:

Currently, the majority of patients do not receive a final diagnosis until Phase II, yet some of these patients have straightforward medical problems. The Committee recommends that final diagnoses could be reached in Phase I if more diagnostic resources are made available. This major change would require the availability of substantial numbers of internists or family practitioners at MTFs to perform comprehensive evaluations. It would also require better, more consistent explanations to MTF physicians about the purposes and procedures of the CCEP. It would require regional medical center physicians to provide adequate quality assurance of MTF work-ups and timely feedback to MTF providers.

On January 17, 1995, the DoD adopted these suggestions by setting goals that about 80% of patients would receive a definitive diagnosis at an MTF level. For some patients, this change has required specialty consultations at the MTF, as well as advice from an RMC physician. These changes necessitated an enhanced quality control role by the RMC physician and prompt, appropriate feedback to the MTF physician.

2.1.2.) Curtail diagnostic work-ups in patients not seriously disabled with minor complaints:

Initially, patients who do not accept their initial diagnosis could request a continued evaluation all the way through Phase II. The Committee recommends that diagnostic work-ups in patients not seriously disabled but with minor complaints should be curtailed. Alternatively, if a physician has made a definitive diagnosis and appropriate treatment has been given, the evaluation would be concluded.

On January 17, 1995, the DoD implemented the suggestions that referral to Phase II be made on the basis of the clinical judgment of the primary care physician, and patients were no longer permitted to self-refer to an RMC.

2.1.3.) Require additional efforts to provide more care at the primary care level:

The Committee encourages efforts to provide more care at the primary care level, because they will enhance the continuity of care and will foster the establishment of an ongoing therapeutic relationship.

2.1.4.) Continue referral of subgroups of patients whose illnesses are difficult to diagnose:

Patients whose illnesses are difficult to diagnose should continue to be referred to Phase II at an RMC. The decision to refer to Phase II should be based on the clinical judgment of the primary care physician, which, in turn, would be dependent on the clarity of the patient's diagnoses and the feasibility of the proposed treatment program at the MTF level. The DoD should continue its goal of enhanced accessibility of RMC physicians to allow regular consultations with MTF primary care physicians on patients with more complex diagnoses.

2.2.) Systematic Guidelines for Psychiatric Referrals and Adequacy of Psychiatric Resources:

2.2.1.) Develop explicit guidelines for the identification of Phase I patients who would benefit from a psychiatric evaluation:

CCEP physicians have noted the need for standardized guidelines for screening, assessing, evaluating, and treating patients. Such Phase I guidelines should be developed to help ensure adequate psychiatric resources for both the initial evaluation and long-term follow-up care.

2.2.2.) Alert primary care physicians about the high prevalence of psychiatric disorders:

Two methods that have been proposed by RMC physicians to expedite the scheduling of psychiatric evaluations would be (1) the more frequent use of civilian psychiatrists and (2) consideration of using Ph.D.-level psychologists, as well as psychiatrists, when necessary.

3.) SPECIFIC OBSERVATIONS OF AND RECOMMENDATIONS FOR THE IMPLEMENTATION OF THE CCEP:

3.1.) Analysis and interpretation of the CCEP results:

3.1.1.) Symptoms and Diagnoses in the CCEP Population:

3.1.1.1.) No evidence has been found that the DoD has been trying to avoid reaching a single unifying diagnosis:

The committee found no evidence that the DoD has been trying to avoid reaching a single "unifying" diagnosis when a plausible one was available. A "unifying" diagnosis is defined here as a single diagnosis that could explain most or all of a patient's symptoms.

3.1.1.2.) Signs and symptoms in many patients can be explained by well recognized conditions:

One interpretation of the CCEP results is that the signs and symptoms in many patients can be explained by well-recognized conditions that are readily diagnosable and treatable. The committee concludes that this is a more likely interpretation than the interpretation that a high proportion of the CCEP patients are suffering from a unique, previously unknown "mystery disease."

3.1.1.3.) Provide more detailed information on specific diagnoses in future reports:

By providing more detailed information on specific diagnoses in its future reports, the DoD might help correct the impressions among the general public that exist about the high degree of prevalence of a "mystery disease" or a new, unique "Persian Gulf Syndrome."

3.1.1.4.) Investigate the diagnosis in patients with disability processing actions:

Disability processing actions in the Services' Physical Disability Processing Systems have been completed for 246 of the 10,020 CCEP patients. The DoD has not provided any data about their diagnoses or their reasons for medical separation from the military. The committee recommends that the DoD investigate the diagnoses in this group of patients in future reports, as well as whether or not the disorders could have been caused or exacerbated by service in the Persian Gulf.

3.1.1.5.) Don't view CCEP results as estimates of the prevalence of disability related to Persian Gulf service:

Many other individuals who served in the Persian Gulf have left active service and, hence, are not eligible for the DoD's CCEP. Some of these veterans may have disabilities related or unrelated to their service in the Persian Gulf, and those with disabilities might be more likely to have left active service. For these reasons, the CCEP results should not be viewed as estimates of the prevalence of disability related to Persian Gulf service.

3.1.2.) Evidence of a New, Unique Persian Gulf Syndrome:

3.1.2.1.) There is a lack of clinical evidence of a unique Persian Gulf Syndrome:

The committee agrees with DoD that there is currently no clinical evidence in the CCEP of a previously unknown, serious illness among Persian Gulf veterans. If there were a new or unique illness or syndrome among Persian Gulf veterans that could cause serious impairment in a high proportion of veterans at risk, it would probably be detectable in the population of 10,020 CCEP patients. On the other hand, if an unknown illness were mild or affected only a small proportion of veterans at risk, it might not be detectable in a case series, no matter how large.

3.1.2.2.) Share the entire CCEP data set with qualified researchers outside of the DoD:

The committee encourages the DoD's plan to share the entire CCEP data set with qualified researchers outside of the DoD who might be able to undertake the kind of research with the methodological sophistication that the identification of a new syndrome would require.

3.1.3.) Potential Relationship of Illnesses in CCEP Patients to Service in the Persian Gulf:

3.1.3.1.) Discuss the issue of causality explicitly and unambiguously in its future reports:

Physicians involved with the development and the administration of the CCEP have, in various public presentations, acknowledged that some CCEP patients have developed illnesses that are directly related to their service in the Persian Gulf. The recent DoD report on 10,020 CCEP participants, however, only touches on this issue indirectly. The committee encourages the DoD to discuss the issue of causality explicitly and unambiguously in its future reports. Such a discussion might help to alleviate the current climate of confusion and mistrust that exists among some Persian Gulf veterans and the general public.

3.1.3.2.) Determine the timing of the onset of disease:

The committee recommends that the DoD attempt to determine the timing of the onset of disease, especially for patients who have significant impairments. Review of military or civilian medical records that predate enrollment in the CCEP may provide contemporaneous documentation of the onset of symptoms in some patients, especially if the symptoms are serious. In addition, it is important to determine whether service in the Persian Gulf has contributed to the exacerbation of preexisting diseases in some CCEP patients.

3.1.4.) Comparison of the CCEP Population with Other Populations:

3.1.4.1.) Be cautious about comparison with other populations:

In its most recent report, the DoD compares the symptoms and diagnoses in the CCEP population with the symptoms and diagnoses in several community-based and clinically based populations. In the committee's view, interpretations based on comparisons with other populations should be made with great caution and only with the

explicit recognition of the limitations of the CCEP as a self-selected case series. The CCEP was not designed to answer epidemiological questions, such as how the frequencies of certain diagnoses compare between the CCEP population and a control population. Instead, it was designed as a medical evaluation and treatment program. Indeed, the research aims of the CCEP do not appear to be stated explicitly, nor does there appear to be a concrete epidemiological study plan. Without research hypotheses, it is not possible to judge whether any particular comparison group is appropriate. Each individual population should be described to prevent confusion.

3.1.4.2.) It's Difficult to establish causal relationships by relying on CCEP data alone:

It would be extremely difficult to establish causal relationships or to identify and characterize a new "Persian Gulf Syndrome" definitively by relying on data from the CCEP alone. The latitude permitted in the clinical examination program conflicts with the rigor necessary to answer an epidemiological question.

3.1.4.3.) Consider the CCEP data to have high clinical utility:

The CCEP data do have considerable clinical utility, and they could be used to address many important questions from a descriptive perspective. Many case series could be derived from these data. In addition, the results of the clinical exams could provide guidance in the selection of research questions and in the design of future epidemiological research. The CCEP findings could be used to generate epidemiological questions on other types of diseases that are much more frequent in the CCEP population, such as musculoskeletal diseases.

3.2.) Specific Medical Diagnosis:

3.2.1.) Psychiatric Conditions:

3.2.1.1.) Make patients aware of psychiatric conditions and their prevalence and morbidity:

Patients need to understand that psychiatric conditions and disorders are real diseases that cause real symptoms and that diagnoses are made with objective criteria and are not merely "labels" applied because physical abnormalities were not found. The CCEP patients, as well as their primary care physicians, also need to understand the prevalence of and the concomitant morbidity that result from psychiatric disorders in the

general population (major depression, for example). Finally, the CCEP patients need to be aware that effective treatments that actually ameliorate symptoms exist for many of these disorders.

3.2.1.2.) Emphasize effects and diagnosis of psychosocial stressors:

In its future reports, the DoD is encouraged to emphasize that psychosocial stressors can produce physical and psychological effects that are as real and potentially devastating as physical, chemical, or biological stressors. The DoD should also emphasize that thorough efforts to diagnose psychiatric conditions in the CCEP population may lead to appropriate, successful treatments.

3.2.1.3.) Identify people with risk of developing depression or Post-Traumatic Stress Disorder (PTSD):

The committee is particularly concerned about the CCEP patients who have developed or who are at risk of developing major depression or PTSD. These people need to be identified and provided with some form of preventive intervention.

3.2.1.4.) Improve standardization of psychiatric evaluations:

The committee recommends that the DoD consider methods of improving the standardization of the psychiatric evaluations in the CCEP. The DoD should consider establishing detailed guidelines for the psychiatric evaluations and should attempt to obtain greater standardization of these evaluations among the various hospitals across the country. These guidelines could provide suggested procedures for the use of selected self-report instruments for the assessment of the most commonly diagnosed disorders, as well as procedures for more in-depth structured clinical interviews when indicated.

3.2.1.5.) Document and investigate the onset and course of symptoms and psychosocial stressors:

It would be especially important to document the onset and course of symptoms and to investigate their possible link with psychosocial stressors associated with mobilization and return home, as well as with service-related exposures in the Persian Gulf region. This assessment would require an additional set of questions to supplement the questionnaire currently used in Phase I of the CCEP. The thorough assessment of psychosocial stressors is essential information for treatment planning for patients with complex, chronic symptoms.

3.2.1.6.) Standardize neuropsychological evaluations:

Standardization of the neuropsychological evaluations is a related concern. The neuropsychological methods vary from pencil and paper testing at some sites to computer-administered testing at other sites. One method of achieving a better consensus is to convene a meeting attended by one psychiatrist and one neuropsychologist from each center to attempt to standardize their methods.

3.2.1.7.) Standardize classification and coding of diseases:

In addition to the standardization of psychiatric evaluations in the CCEP, the classification and coding of these diseases should also be standardized.

3.2.1.8.) Document headache categories differently:

The classification of different types of headaches into three separate categories may be consistent with ICD-9 coding rules, but the DoD should also report a special tabulation that combines all headaches into one group.

3.2.1.9.) Add explicit written instruction on medical record-keeping and coding:

More explicit written instructions could be added to the CCEP guidelines to help prevent the most frequent problems found in the medical record-keeping and coding. Committee comments about inconsistencies are mainly aimed at the quality control necessary for accurate reporting of summary data rather than at the quality of the medical care itself.

3.2.1.10.) Expand discussion of psychological stressors:

DoD should consider expanding discussion of the psychological stressors that were present during the Persian Gulf War.

3.2.1.11.) Utilize results of on-going studies to revise CCEP:

It is possible that the DoD will be able to use the results of on-going epidemiologic studies on psychiatric conditions to revise the CCEP, that is, to revise the standardized questionnaires or to add or delete targeted lab tests or specialty consultations. In addition, the CCEP clinicians may be able to utilize these results in the counseling and treatment of their

patients. These results may also be useful for the DoD in its planning to minimize the effects of psychosocial stressors in future deployments through the use of preventive medicine interventions.

3.2.2.) Musculoskeletal Conditions:

3.2.2.1.) Provide more details of diagnostic categorization of musculoskeletal conditions:

The draft and final DoD reports on 10,020 CCEP patients do not provide adequate details for the IOM committee to make a thorough evaluation of the diagnostic categorization of musculoskeletal conditions. More explanation about the diagnostic aspects of these musculoskeletal conditions would be useful, for example, information on single-joint involvement versus multijoint conditions or articular versus non-articular conditions. In addition, details on disease severity and disease activity would be useful.

3.2.2.2.) Place more emphasis on musculoskeletal conditions:

The DoD and the DVA should consider placing more emphasis on research on musculoskeletal conditions, since these are the most prevalent disorders among the CCEP populations.

3.2.3.) Signs, Symptoms and Ill-Defined Conditions:

3.2.3.1.) Clarify types of disorders included in the ICD-9 category:

The committee recommends that in future reports the DoD attempt to clarify the types of disorders that are included in the ICD-9 category of signs, symptoms, and ill-defined conditions (SSIDC). Individuals with these signs, symptoms, and ill-defined conditions should be evaluated in a rigorous manner, just as individuals with any other symptoms are evaluated.

3.2.4.) Infectious Diseases:

3.2.4.1.) Infectious disease is not a frequent cause of serious illness:

The IOM committee concludes that infectious diseases are not a frequent cause of serious illness in the CCEP population.

3.2.4.2.) Veterans are not likely afflicted with some previously unknown pathogen:

On the basis of the current evidence, it is unlikely that a significant proportion of Persian Gulf veterans are afflicted with some previously unknown pathogen that is evading the current diagnostic efforts.

3.2.5.) Chronic Fatigue Syndrome, Fibromyalgia, and Multiple Chemical Sensitivity:

3.2.5.1.) Estimating prevalence of chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivity is difficult:

The IOM committee's review of the CCEP protocol suggests that data on chronic fatigue syndrome (CFS), fibromyalgia (FM), and multiple chemical sensitivity (MCS) may have been collected by various diagnostic methods. For this reason, it is not possible to estimate the prevalence of these conditions from the CCEP data.

3.2.5.2.) Collect data using established diagnostic criteria for CFS and FM:

In the clinical evaluations, data should be collected by using established diagnostic criteria for CFS and FM.

3.2.5.3.) Established diagnostic criteria does not exist for MCS:

A widely accepted set of diagnostic criteria does not exist for MCS. Consequently, the medical evaluation in CCEP cannot be expected to diagnose the clinical syndrome of MCS.

3.2.5.4.) Include CFS, FM, and MCS in on-going and future epidemiological research studies:

If more is to be learned about the relationship between these disorders (CFS, FM, and MCS) and Persian Gulf service, they should be included among the epidemiological research studies that are ongoing or planned for the future.

3.2.5.5.) Continue thorough workup to diagnose sleep disturbances and fatigue:

Because of the thorough, systematic workup mandated in the CCEP, many disorders that could contribute to sleep disturbance and fatigue have been diagnosed. These diligent efforts to unmask occult medical problems that could substantially contribute to fatigue have been productive and should continue.

3.3.) Use of the CCEP results for education improvements in the medical protocol, and outcome evaluations:

3.3.1.) Use of the CCEP Results for Education:

3.3.1.1.) Continue public release of analysis results of the CCEP on an on-going, periodic basis:

The IOM committee encourages the DoD to continue to release its analysis of the results of the CCEP on an ongoing, periodic basis. Several audiences that would be interested in these results include active-duty members of the service, veterans, members of the U.S. Congress, the lay media, as well as military, DVA, and civilian medical and public health professionals. The CCEP medical findings would also be of interest to physicians in the DVA system and in the general community.

3.3.1.2.) Distribute CCEP findings to all primary care physicians at MTFs and RMCs:

The medical findings of the CCEP should be distributed promptly to all primary care physicians at the MTFs and RMCs. This would provide feedback on their diagnostic decision-making. Information on the frequencies of particular symptoms and their specific diagnoses made in the CCEP population could be useful, for instance, in developing a differential diagnosis for individual patients.

3.3.1.3.) Develop a more concise version of the DoD report for active-duty service personnel and veterans:

A more concise version of the DoD report on 10,020 patients, written in nontechnical language and with clearly stated conclusions, should be developed for a target audience of active-duty service personnel and veterans. If the DoD developed and distributed a fact sheet or newsletter aimed at Persian Gulf veterans, the information on the CCEP would be

more accurate and more comprehensive than most reports in the general news media. This would also provide an additional opportunity to notify the readers about the availability of the medical exam in the CCEP, the hotline number, and the eligibility criteria.

3.3.1.4.) Develop a more comprehensive document describing potential exposures in more detail:

The DoD should also consider developing for clinical use in the CCEP a more comprehensive document that describes the many potential exposures in more detail. Any document that is prepared, however, must make clear what is known and what is unknown about the relationship between these stressors and the physical or psychological consequences.

3.3.2.) Use of the CCEP Results to Improve the Medical Protocol:

3.3.2.1.) Use CCEP examination results to improve standardization practices:

The DoD now has results on the examinations of more than 10,000 CCEP patients, which could be used to improve the standardized questionnaires, lab tests, and specialty consultations.

3.3.2.2.) Refine questions related to potential psychological stressors:

More refined questions related to potential psychological stressors could be added systematically to the Phase I medical history. The CCEP physicians might find this information useful in diagnosing and counseling their patients. In addition, it may be possible to identify patients who are at increased risk of psychological problems on the basis of their experiences in the war. Perhaps explicit questions on death exposure and other known risk factors could be added to the Phase I questionnaire.

3.3.2.3.) Determine if lab tests or specialty consultations should be added to Phase I:

The CCEP results should be analyzed to determine whether there are lab tests or specialty consultations that should be added systematically to Phase I to increase its diagnostic yield. Diseases that are diagnosed relatively frequently in Phase II may often be overlooked in Phase I. If

such diseases could be identified, perhaps appropriate screening instruments could be added to Phase I.

3.3.2.4.) Compare and coordinate methods and clinical results of the CCEP and UCAP:

The DVA uses a protocol similar to that used in the CCEP called the Uniform Case Assessment Protocol (UCAP). The methods and clinical results of the CCEP and UCAP should be compared to coordinate and improve the two programs.

3.3.3.) Use of the CCEP Results for Patient Outcome:

3.3.3.1.) Perform targeted patient evaluations:

On the basis of more than 10,000 patient evaluations to date, RMC physicians could begin to perform a series of targeted patient evaluations. The most common diseases in the CCEP could be identified, and suggested approaches to patient treatment could be developed. Consensus guidelines for the treatment and counseling of CCEP patients who have the most common disorders could be useful for primary care physicians.

3.3.3.2.) Communicate successful treatment methods between RMCs:

If one RMC has had a lot of experience with a particular disease category and some measure of success in its treatment, the DoD could ensure that a description of their successful methods is communicated to the other MTFs and RMCs across the country.

3.3.3.3.) Review disorders among CCEP patients who have applied for disability payments of for medical discharge from the service:

The DoD could perform a review of the types and severities of the disorders among CCEP patients who have applied for disability payments or for medical discharge from the service. In addition, the final disposition of these cases could be evaluated, including the potential relationship between particular diseases and Persian Gulf service. The DoD could use the results of these disability determinations to predict which diseases are likely to be associated with the most impairment among CCEP patients in the future. The DoD could also use these results to develop rehabilitation and early intervention methods for impaired Persian Gulf veterans, such as the

Specialized Care Centers (SCC). Another reason to analyze these disability claims would be to investigate possible preexisting risk factors for the development of the impairment. If such risk factors are identifiable, then targeted preventive medicine interventions could be planned for individuals participating in future overseas deployments.

3.3.4.) Specialized Care Center (SCC):

3.3.4.1.) The DoD has made serious efforts to develop an SCC program that has ambitious goals:

The IOM committee concludes that the DoD has made serious efforts to develop an SCC program with ambitious goals for a select group of seriously impaired military personnel. The committee's review should be considered preliminary, however, because it is based on one visit and it is still early in the development of the program.

3.3.4.2.) Provide multidisciplinary treatment modalities:

The SCC currently performs a thorough reevaluation of each patient's medical problems. SCC physicians should consider limiting the diagnostic role that they play to focusing on the incoming patients who have been very difficult to diagnose at the RMC level. Instead, the SCC should focus on providing multidisciplinary treatment modalities that are not readily available at the RMC level.

3.3.4.3.) Need for individualized follow-up and therapeutic regimens:

The need for individualized follow-up is crucial for the types of difficult patients who are likely to be treated at the SCC. Medical staff at the SCC will need to know whether a particular therapeutic plan is feasible at the patient's nearest MTF and whether long-term follow-up care can be performed. The primary care physician at the MTF needs to encourage continuous patient compliance with the carefully designed, individualized therapeutic regimens.

3.3.4.4.) Develop objective measure of functional status for follow-up evaluation:

The SCC physicians should develop a set of relatively objective measures of functional status for the follow-up evaluation. These could include (1) appropriate utilization of medical care, (2) appropriate use of medications or other methods to cope with symptoms, (3) general

level of activities of daily living, (4) employment status, and (5) status of interpersonal relationships.

3.3.4.5.) Evaluate the SCC program itself:

The SCC program itself needs an evaluation component after several of its graduates have returned for their 6-month reevaluations. Several issues will need to be evaluated in light of the successes and barriers that the program has experienced, including eligibility criteria for patients; roles of the SCC in a diagnostic reevaluation of patients; successful continuity of care of patients, with shared responsibility by the SCC and MTFs; and the unique need for the SCC, beyond the usual standard of a tertiary care medical center.

3.3.4.6.) DoD has taken a serious approach to the treatment and rehabilitation of these patients in the SCC:

The committee believes that the DoD has taken a serious approach to the treatment and rehabilitation of these impaired patients who have treatable, chronic diseases.

3.3.4.7.) Investigate costs and benefits of the SCC program:

Because this program is very labor intensive, it is probably very expensive on a per-patient basis. At the same time, the potential benefits for each patient could be high, if successful rehabilitation of serious, long-term impairment can be achieved. Subsequent evaluations of the SCC program should investigate its costs and benefits, if possible.

3.3.4.8.) Identify the most effective elements of the SCC program:

If the SCC program is successful in improving the health and functional status of its patients, perhaps the elements that are most effective in enabling the patients to cope with their symptoms could be identified. Perhaps some of these elements could be disseminated and integrated into existing MTF programs that are close to where CCEP patients live and work.

3.4.) Research Relevant to the CCEP:

3.4.1.) Epidemiological Research Relevant to the CCEP:

3.4.1.1.) Utilize on-going epidemiological studies for revising or improving the CCEP:

The results of on-going epidemiological studies may be useful for making revisions or improvements in the CCEP medical protocol itself, for example, to revise the standardized questionnaires or to add or delete targeted lab tests. The study results may also be useful in the counseling and treatment of CCEP patients.

3.4.1.2.) Acknowledge the serious limitations of the CCEP data for epidemiological purposes:

Data from individuals in the CCEP are also being used in some of these epidemiological studies. In these studies, the serious limitations of the CCEP data for epidemiological purposes that were previously identified must be kept in mind.

3.4.2.) Exposure Assessment Research Relevant to the CCEP:

3.4.2.1.) Investigate experiences of individuals in UICs with higher rates of CCEP participation:

The IOM committee encourages DoD to perform further investigations on the war and postwar experiences of individuals in the Unit of Assignment Codes (UICs) with higher rates of CCEP participation.

3.4.2.2.) Investigate exposures restricted to particular locations or special occupational groups:

The committee encourages the DoD to investigate exposures that were restricted to particular locations or special occupational groups, such as troops who had direct combat exposure. The types of symptoms and diseases in CCEP participants in these special groups and UICs could be analyzed and contrasted with the symptoms and diagnoses of CCEP participants in other units.

COMMITTEE ON THE DOD PERSIAN GULF SYNDROME COMPREHENSIVE CLINICAL EVALUATION PROGRAM

Gerard Burrow,* *Chair*, Dean, Yale University School of Medicine, New Haven, Connecticut

Dan Blazer,* Dean of Medical Education and Professor of Psychiatry, Duke University Medical Center, Durham, North Carolina

Margit Bleecker, Director, Center for Occupational and Environmental Nuerology, Baltimore, Maryland

Ralph Horwitz, Chairman, Department of Internal Medicine, Yale University School of Medicine, New Haven, Connecticut

Howard Kipen, Associate Professor and Director, Occupational Health Division, Robert Wood Johnson Medical School, Piscataway, New Jersey

Adel Mahmoud,* Chairman, Department of Medicine, Case Western Reserve University and University Hospitals of Cleveland, Cleveland, Ohio

Michael Osterholm, State Epidemiologist, Minnesota Department of Health, Minneapolis, Minnesota

Robert Pynoos, Professor of Psychiatry, University of California at Los Angeles, Los Angeles, California

Anthony Scialli, Associate Professor, Department of Obstetrics and Gynecology, Georgetown University Medical Center, Washington, D.C.

Rosemary Sokas, Associate Professor of Medicine, Division of Occupational and Environmental Medicine, George Washington University School of Medicine, Washington, D.C.

Guthrie Turner, Chief Medical Consultant, Division of Disability Determination Services, State of Washington, Tummwater, Washington

Michael Weisman, Professor, Division of Rheumatology, University of California at San Diego Medical Center, San Diego, California

Staff

Michael A. Stoto, Director, Division of Health Promotion and Disease Prevention

Kelley A. Brix, Study Director

Deborah Katz, Research Assistant

Amy Noel O'Hara, Project Assistant

Donna D. Thompson, Division Assistant

Mona Brinegar, Financial Associate

---

*Member, Insititute of Medicine.

APPENDIX B

Outline of the CCEP Medical Protocol

FORM REQUIREMENTS

At the MTF level, the CCEP record should include all CCEP forms and relevant medical data to the program.

Blank forms included with this guide supersede previous editions of these forms and are intended to be used with the new CCEP.

All individual forms will be complete and legible.

Forms forwarded to NMIMC and maintained in the participant record shall be in the following order:

Phase I completed:

MTF Phase I Diagnosis Form
Patient Questionnaire
Provider-Administered Symptom Questionnaire
Information Release Form
Declination/Completion Form

Phase II completed:

RMC Phase II Diagnosis Form
Declination/Completion Form

MEDICAL PROTOCOLS

The CCEP is based upon a thorough clinical evaluation which emphasizes comprehensive and continuous primary care. The local MTF primary care provider maintains responsibility for patient evaluation and care throughout the CCEP process.

Medical Treatment Facility (Phase I)

Phase I will consist of a comprehensive history and medical evaluation with completion of Phase I questionnaires and related forms. The examination, both in content and quality, should parallel an in-patient admission work-up. The Phase I examination will include a complete medical history including: family, occupation, social (including tobacco, alcohol, and drug use), exposure to possible toxic agents, psychosocial condition and review of symptoms. The provider will specifically inquire about the symptoms listed on the CCEP Provider-Administered Patient Questionnaire. A comprehensive medical evaluation, with focused attention to the patients symptoms and health concerns, should be conducted.

Individuals who, after completing MTF Phase I evaluations do not have a clearly defined diagnosis which explains their symptoms should be reviewed by the CCEP designated physician for further evaluation and consultations needed and/or for referral to the RMC.

Phase II Level Evaluations are performed only after complete clinically indicated evaluations (including appropriate specialty consultations) are conducted at the MTF and the RMC.

Phase I Laboratory Tests

CBC
U/A
SMA-12

Regional Medical Center (Phase II)

Phase II evaluations consist of the following laboratory tests, consultations and as necessary, symptom-specific examinations. J Elements of the Phase II evaluation may be accomplished by the local MTF as needed in the comprehensive evaluation of the Phase I patient in order to obtain a definitive diagnosis.

Phase II Laboratory Tests

CBC
Sedimentation rate (ESR)
C-Reactive protein
Rheumatoid factor
ANA
Liver function
CPK
Urinalysis
TB skin test (PPD) with controls
Chest X-ray
Hepatitis serology
HIV testing
VDRL
B12 and folate
Thyroid function tests

Phase II Consults

(if not accomplished at MTF level)
Dental: Dental only if participant's annual screening not done
Infectious disease
Psychiatry: With physician-administered instruments:
Structured Clinical Interview for DSMIII-Rcm
(SCID) (delete modules for mania and psychosis)
Clinician-Administered PTSD Scale (CAPS)

Neuropsychological Testing: Only as indicated by psychiatry consult

SYMPTOM-SPECIFIC EXAMINATIONS

The RMC CCEP Physician ensures that Phase II patients with the following undiagnosed symptoms receive the tests and consultations listed below.

Diarrhea
GI consult
Stool for O and P
Stool Leukocytes
Stool culture
Stool volume
Colonscopy with biopsies
EGD with biopsies and aspiration

Abdominal
GI consult
EGD with biopsy/ aspiration
Colonscopy with biopsy
Abdominal ultrasound
UGI series with small bowel FT
Abdominal CT scan

Headache
MRI—head
LP (glucose protein, cell count, VDRL, oligoclonal myelin, basic protein, pressure)
Neuro consult

Muscle Aches/
Numbness
EMG/NCV

Chronic Fatigue
Polysomnography
and MSLT

Chronic Cough/SOB
Pulmonary consult
Pulmonary function
Tests with exercise
and ABG
Methacholine
challenge
If PFTs are normal,
consider broncho-
scopy with biopsy/
lavage

Memory Loss
(Only if verified by
psych evaluation)
MRI—head
Lumbar puncture
Neuro consult
Neuro psych testing

Chest Pain/
Palpitations
ECG
Exercise stress test
Holter monitor

Reproductive
Concerns
Urology consult
GYN consult

Vertigo/Tinnitus
Audiogram
ENG
BAER

Skin Rash
Dermatology consult
Consider biopsy

APPENDIX C

Workshop on the Adequacy of the CCEP for Evaluating Individuals Potentially Exposed to Nerve Agents: Agenda and Speakers List

NATIONAL ACADEMY OF SCIENCES
INSTITUTE OF MEDICINE

December 3, 1996
Foundry Building FO-2004, Georgetown

AGENDA

10:00–10:15	Welcome/Purpose and Conduct of the Workshop Dr. Dan Blazer, Chair, Committee on the Evaluationt of the DoD Comprehensive Clinical Evaluation Program for Persian Gulf Veterans
10:15–12:00	Workshop Session I—Issues regarding the CCEP Dr. Raymond Chung, *Origins/Background* Dr. Charles Engel, *Mental Health* Dr. Andrew Dutka, *Neurologic Conditions* Dr. Timothy Cooper, *Pain* Dr. Anthony Amato, *Neuromuscular Symptoms* Dr. Kurt Kroenke, *Diagnostic Approach/ Generalized Symptoms*
12:00–1:00	Lunch in meeting room
1:00–2:45	Workshop Session II—Issues regarding organophosphates, anticholinesterases and nerve agents Dr. Peter Spencer, *Neurotoxicology of organophosphates* Dr. Robert MacPhail, *Behavioral toxicology of organophosphates and pyridostigmine*

Dr. Robert Gum, *Possible health effects in humans from low level exposure to nerve agents*
Dr. Bhupendra P. Doctor, *Endogenous detoxification of sarin*

2:45–3:00	Break
3:00–4:45	Workshop Session III—Issues regarding neurological testing protocols Neurophysiological testing Dr. Eva Feldman Dr. David Cornblath Neurobehavioral and neurocognitive testing Dr. Kent Anger Dr. Roberta White
4:45–5:00	Break
5:00–6:30	Workshop Session IV—Moderated Discussion Dr. Dan Blazer, *Moderator* Dr. Richard Johnson Dr. Arthur Asbury Dr. David Janowsky
6:30	Workshop adjourns

SPEAKERS LIST

December 3, 1996
Foundry Building, Georgetown

Anthony A. Amato, M.D.
University of Texas San Antonio
Department of Neurology and Medicine

W. Kent Anger, Ph.D.
Associate Director for Occupational Research and Health Promotion
Oregon Health Sciences University
Portland

Arthur Asbury, M.D.
Van Meter Professor of Neurology
Hospital of the University of Pennsylvania
Philadelphia

Col. Raymond Chung
Gulf War Health Center
Walter Reed Army Medical Center
Washington, DC

Lt. Col. Timothy W. Cooper, M.D.
Infectious Disease Service
74th Medical Group Hospital
Wright Patterson AFB, OH

David Cornblath, M.D.
Pathology Department
Johns Hopkins Hospital
Baltimore, MD

Bhupendra Doctor, M.D.
Director, Division of Biochemistry
Walter Reed Institute of Research
Washington, DC

Capt. Andrew J. Dutka, M.D.
Neurology Service
National Naval Medical Center
Bethesda, MD

Maj. Charles C. Engel, Jr., M.D.
Chief, Gulf War Health Center
Walter Reed Army Medical Center
Washington, DC

Eva Feldman, M.D., Ph.D.
Associate Professor
Department of Neurology
University of Michigan
Ann Arbor

Lt. Col. Robert Gum, M.D.
Chief, Chemical Casualty Care Office
U.S. Army Medical Research Institute of Chemical Defense
Aberdeen Proving Ground, MD

David Janowsky, M.D.
Department of Psychiatry
University of North Carolina Neurosciences Hospital
Chapel Hill

Richard Johnson, M.D.
Director
Department of Neurology
Johns Hopkins University
School of Medicine
Baltimore, MD

Col. Kurt Kroenke, M.D.
General Internist
Uniformed Services University
of Health Sciences
Bethesda, MD

Robert C. MacPhail, Ph.D.
Neurotoxicology Division
Environmental Protection
Agency
Research Triangle Park, NC

Peter S. Spencer, Ph.D.
Director
Center for Research on
Occupational and
Environmental Toxicology
Oregon Health Sciences
University
Portland

Roberta White, Ph.D.
Environmental Hazards Center
Department of Veterans Affairs
Medical Center
Boston

APPENDIX D

DoD Memorandum for Persian Gulf War Veterans Concerning Khamisiyah, Iraq

DEPUTY SECRETARY OF DEFENSE

1010 DEFENSE PENTAGON
WASHINGTON, DC 20301-1010

October 1996

MEMORANDUM FOR PERSIAN GULF WAR VETERANS CONCERNING KHAMISIYAH, IRAQ

The Department of Defense is continuing its wide-ranging investigation of incidents that might be related to Persian Gulf veterans' illnesses. We are asking for your help in providing us with important information.

Evidence from an ongoing investigation indicates that chemical weapons were present when U.S. forces destroyed a series of ammunition storage bunkers and crated munitions in an open pit area at a complex called "Khamisiyah" or "Tal al-Lahm," about 15 miles southeast of "An Nasiriyah" in southern Iraq. Our records show that your unit participated in the demolition operations at Khamisiyah in March 1991.

To our knowledge, service members at that time did not report the symptoms associated with acute exposure to chemical agents (nerve gas), but our search for information continues. Since you may have been part of the demolition operations, we need to hear from you, not only about your experience at or near the site but also any health problems you think may be a result of your service during Operation Desert Storm/Operation Desert Shield.

We urge you to call our PERSIAN GULF INCIDENT HOTLINE at 1-800-472-6719. When you call please indicate you were a member of the Khamisiyah demolition team. The person answering the telephone will ask you a few simple questions and then, if you desire, refer you to an appropriate medical facility for medical evaluation and care. We want to be sure you receive any health care you may need for health problems related to your service in the Gulf War.

Be assured, the Departments of Defense and Veterans Affairs are working together to bring all necessary resources to bear on this issue. But we can not do it alone. To understand the events at Khamisiyah and to address the concerns of our Gulf War veterans, we need your help in this effort.

We are indebted to each one of you for your service to our country during the Persian Gulf War.

John P. White

Enclosure: Frequently Asked Questions and Answers

Frequently Asked Questions and Answers About Khamisiyah

Here are the answers to several frequently asked questions relating to the events at Khamisiyah.

Q: What kinds of weapons were destroyed by U.S. forces at Khamisiyah?

A: Khamisiyah was a large Iraqi ammunition storage site. Of the approximately 100 bunkers destroyed in March 1991, one has been assessed by UNSCOM (United Nations Special Commission) to have held 122mm rockets containing chemical agents (the nerve agents sarin and cyclosarin). In addition, rockets containing these nerve agents were found by UNSCOM inspectors in an open pit near the bunker complex, where U.S. forces also conducted demolition operations in March, 1991.

Q: What are the effects of these chemical weapons?

A: As you may recall from your training, chemical weapons create serious immediate symptoms (blurred vision, tightness in the chest, runny nose, dizziness) and, if immediate treatment is not provided, can incapacitate or kill troops on the battlefield. While research continues, the best current medical evidence indicates you should not experience long-term health problems from low level exposure to chemical nerve agents.

Q: Were any such symptoms experienced by our troops during the Gulf War?

A: To our knowledge, service members neither died or reported such immediate symptoms in connection with Khamisiyah. Soldiers reported possible chemical events during the war, but we have been unable to confirm any nerve agent exposure from these reports.

Q: What are the long-term health effects of non-lethal exposure to nerve agent?

A: Although they are limited in number, studies of human exposure to nerve agent suggest that no long-term health effects from low level, short-term exposure to nerve agent are likely, even when doses are large enough to produce some immediate symptoms. We are stepping up the research directed toward finding a more definitive answer to this question.

Q: If I, as a Gulf War veteran, experienced no symptoms at the time and studies indicate there are no long-term health effects, why am I receiving this letter and being asked to call the hotlines?

A: First, we are asking your help in our understanding of the events surrounding Khamisiyah. Second, we want to be sure you receive any health care you may need for health problems related to your service in the Gulf War.

APPENDIX E

Persian Gulf War-Related Events: Timeline

Date			Significant Event
1990	August	2	Iraq invades Kuwait
1990	August	8	U.S. Air Force arrives in Saudi Arabia
1990	August	9	U.S. ground forces arrive in Saudi Arabia
1990	November	29	UN Security Council authorizes use of force to eject Iraq from Kuwait
1991	January	12	Congress authorizes use of force to eject Iraq from Kuwait
1991	January	16	Operation Desert Storm commences as U.S. warplanes attack military targets in Iraq and Kuwait
1991	January	17	First hostile fire
1991	January	20	First oil well fires started in Kuwait
1991	January	27	Coalition forces declare air supremacy
1991	February	19	Majority of oil well fires ignited
1991	February	24	Ground war begins
1991	February	25	SCUD attack in Dhahran killing U.S. troops
1991	February	28	Cease-fire takes effect and offensive operations end
1991	March	10	U.S. troops destroy munitions dump at Khamisiyah
1991	June	13	Last U.S. ground troops return to the United States
1992	August		Expert Panel on Petroleum Toxicity established
1993	July		Office of Technology Assessment Workshop on Persian Gulf Health held
1993	October		Start of IOM Committee to Review the Health Consequences of Service During the Persian Gulf War
1993	December		Defense Science Board established
1994	January		Persian Gulf Veterans Coordinating Board established
1994	April		National Institutes of Health Technology Assessment Workshop Panel held
1994	May		Independent Council Harrison Spencer (dean, Tulane University School of Public Health) appointed
1994	June		IOM Committee to Review DoD's Comprehensive Clinical Evaluation Program established
1994	December	2	IOM Committee on the Comprehensive Clinical Evaluation Program's first report submitted to DoD
1995	March		Senior-Level Oversight Panel, Persian Gulf Investigation Team, and Declassification Program established
1995	March		Task Force on Analysis and Declassification of Intelligence Records established
1995	May	26	Presidential Advisory Committee of Gulf War Veteran's Illnesses established
1995	August	7	IOM Committee on the Comprehensive Clinical Evaluation Program's second report submitted to DoD

Date			Significant Event
1996	January		IOM Committee on the Comprehensive Clinical Evaluation Program's final report submitted to DoD
1996	March		DoD releases report, "The Possible Role of Vaccine Adjuvants in Persian Gulf War Veterans Illness"
1996	March	11	Congressional hearings held on "Status of Efforts to Identify Persian Gulf War Syndrome Part I"
1996	March	28	Congressional hearings held on "Status of Efforts to Identify Persian Gulf War Syndrome Part II"
1996	June	21	DoD announces that suspected chemical weapons might have been at the Khamisiyah Ammunition Storage Depot (300-400 U.S. troop potentially exposed to nerve agents)
1996	June	25	Congressional hearings held on "Status of Efforts to Identify Persian Gulf War Syndrome Part III"
1996	August	2	CIA releases report on Intelligence Related to Gulf War Illness
1996	August	4	DoD releases report on "Coalition Chemical Detectons and Health of Coalition Troops in Dectection Area"
1996	August	8	DoD releases "Report on Possible Effects of Oganophosphate 'Low-Level' Nerve Agent Exposure"
1996	September	4	DoD releases CCEP Database for Independent Scientific Investigation
1996	September	19	Congressional hearings held on "Status of Efforts to Identify Persian Gulf War Syndrome Part IV"
1996	September	19	DoD revises estimate of number of troops potentially exposed to nerve agents to 5,000
1996	October	2	DoD revises estimate of number of troops potentially exposed to nerve agents to 15,000
1996	October	22	DoD revises estimate of number of troops potentially exposed to nerve agents to 21,000
1996	November		Special Assistant to Gulf War Veterans Illnesses appointed
1996	November		Special Assistant to the President for Gulf War Veterans Illnesses appointed
1996	December		Second IOM Committee to Review DoD's Comprehensive Clinical Evaluation Program established
1996	December	10	Congressional Hearings held on "Status of Efforts to Identify Persian Gulf War Syndrome Part V"
1996	December	31	Presidential Advisory Committee submits its final report
1997	January	9	Senate hearings held on "Persian Gulf War Illnesses"
1997	January	21	Congressional hearings held on "Status of Efforts to Identify Persian Gulf War Syndrome Part VI"

Statement of Daniel J. Clauw, M.D., Associate Professor of Medicine, Chief of Reheumatology, Immunology and Allergy, Georgetown University Medical Center

BACKGROUND. My name is Daniel Clauw. I am an Associate Professor of Medicine and Orthopedics, and the Chief of Rheumatology, Immunology, and Allergy, at Georgetown University Medical Center. I have been involved in both research and the clinical care of persons afflicted with a number of ill-defined and poorly understood medical conditions, which include fibromyalgia and chronic fatigue syndrome. I have both an Army grant and an NIH grant to study these conditions. My opinion, which is shared by many others in these fields, is that the illnesses which have affected Persian Gulf veterans are not unique to persons deployed to the Persian Gulf, but instead are the same as those which occur commonly in the population. I will review the reasons for these opinions, as well as suggestions for better dealing with patients who suffer from these disorders.

DEFINITION OF FIBROMYALGIA AND CHRONIC FATIGUE SYNDROME. Fibromyalgia is a disorder defined by the presence of diffuse musculoskeletal pain, and by the finding of widespread tenderness on physical examination. In addition to diffuse pain, individuals with fibromyalgia typically also suffer a number of other symptoms including fatigue, weakness, and memory problems. Although fibromyalgia is the most common rheumatic disease in individuals below the age of 60, affecting at least 2% of the population, I suspect many of you have not even heard of this disorder. Yet, I am certain that all of you know individuals who suffer from this condition, although many of these persons have not yet been appropriately diagnosed or treated.

Chronic Fatigue Syndrome is a syndrome characterized by the presence of severe, persistent fatigue, as well as a number of other symptoms such as muscle and joint aches, memory problems, poor sleep, etc. Again, this illness probably affects about 1% of the population, but you also may be unfamiliar with this condition.

Although fibromyalgia and Chronic Fatigue Syndrome are defined quite differently, it turns out that most people who meet criteria for one of these illnesses also meet criteria for the other, suggesting that these disorders represent different ends of the same spectrum, rather than discrete illnesses.

Somatoform disorder is yet another term used to describe persons who display this constellation of symptoms. Although I dislike this label, this is a psychiatric term

that has been used to describe individuals who display multiple different types of symptoms, but no "physical" cause can be found for these complaints. And once again, many individuals who meet criteria for fibromyalgia or Chronic Fatigue Syndrome will also meet criteria for somatoform disorders, and vice-versa.

The Venn diagram below displays the overlap between fibromyalgia, Chronic Fatigue Syndrome, and somatoform disorders, and also shows that most individuals who returned from the Gulf War with unexplained symptoms will also meet criteria for one or more of these other disorders.

Thus, although these symptom complexes go by a variety of semantic terms, most involved in the study of these conditions feel that these conditions are one large spectrum of illness. The symptoms and findings in individuals with the Persian Gulf Syndrome are the same as those of persons labeled with these other conditions, except that the Persian Gulf Syndrome patients developed these problems during or after to deployment to the Gulf War.

WHY ARE THESE ILLNESSES NOT RECOGNIZED, AND DIFFICULT TO DIAGNOSE? One of the reasons for incomplete recognition of these conditions is that this symptom complex is given many different names, and many different attributions. Another reason is that there are no blood tests or other diagnostic studies which are predictably abnormal in persons with this illness. Because of this, these conditions are diagnosed on the basis of symptoms, and by excluding other medical problems which can cause the same types of symptoms.

Another significant problem with the recognition and acceptance of fibromyalgia and related conditions is that these illnesses in general have become known as "psychosomatic" conditions. *All of these conditions are either triggered or exacerbated by a variety of physical, immune, or emotional stressors, and there is likely a common underlying cause or causes for this entire spectrum of illness. Unfortunately, the root causes for this spectrum of illness are not presently known.*

The link to emotional stress, and the fact that at present we have no blood test or other objective diagnostic tests that can verify the presence of these conditions, has led some to contend that these illnesses "are all in the head." Well, in fact, the most

recent research into these conditions suggests that these illnesses really do begin in the head, but that instead of these being primary psychiatric conditions, these entities are characterized by dysfunction of various components of the central nervous system.

Although our incomplete understanding of the precise mechanisms which lead to symptoms in these disorders *should not* lead to treating this group of patients differently than those with illnesses we understand better, this is commonly done. Furthermore, the fact that these conditions can be either initiated or exacerbated by stress should not be viewed by either patients or physicians as a negative factor, since we now know that nearly all illnesses, including cancer and coronary artery disease, can likewise be profoundly affected by stress.

Finally, the relationship between these disorders, and psychiatric conditions, needs to be clarified. Many individuals with fibromyalgia and related conditions will have also have concurrent psychiatric diagnoses. However, in most cases, the psychiatric diagnosis is not the primary problem. In most cases, the individual has developed a mood disorder such as depression or anxiety disorders *as a result of* the physical symptoms.

THE PROBLEM WITH CONSIDERING THESES ILLNESSES AS PSYCHIATRIC CONDITIONS. In clinical practice, telling an individual with this type of illness that it is "all in their head," or that there is no "organic" basis for their symptoms, will always lead to frustration and a sense of abandonment by that individual. It is not difficult to see why many of the veterans with these illnesses, as well as their families and advocates, have become so frustrated with this vicious cycle of no diagnoses, no effective treatment, and psychiatric attribution of symptoms.

This may be of little consolation to the Gulf War veterans, but millions of Americans are struggling with all of these same issues on a daily basis when they are seen with these same syndromes in the private sector. Thus, we should be careful not to place the blame regarding the inadequate treatment of these individuals solely on the VA or military hospitals. It is actually a much larger problem with our entire medical system.

WHY WOULD GULF WAR VETERANS DEVELOP FIBROMYALGIA AND RELATED CONDITIONS? Why and how could this happen? There seem to be a variety of physical, immune, and emotional stressors that are capable of triggering or exacerbating this entire spectrum of illness. Physical trauma such as motor vehicle accidents, immune stressors such as infections, and emotional stressors of virtually any type are the best described triggers of this fibromyalgia and related illnesses. Individuals deployed to the Persian Gulf may have been exposed to any or all of these types of stressors. I am aware that there is an ongoing debate regarding the potential role of biological, chemical, or toxins in the development of these symptoms. I feel that these questions remain unanswered at present, so I will not offer opinions about whether these types of environmental exposure may have played a role in causing symptoms in some of the veterans. However, from a biological standpoint *it is quite plausible that these illnesses could have been triggered without any of these types of environmental exposures. Also, studies suggest that the risk of developing these symptoms had little to do with where in the Persian Gulf an individual was deployed. And this same set of symptoms has occurred after nearly every conflict that the U.S. has been involved in, although different names have been used to describe the symptoms. Thus, if specific environmental exposures are involved in the development of these illnesses, they probably play a minor role.*

IF THESE INDIVIDUALS SUFFER FROM FIBROMYALGIA AND CHRONIC FATIGUE SYNDROME, WHAT SHOULD WE DO NOW? Once an individual develops fibromyalgia or a related disorder, it does not appear to matter what triggered the illness; the treatment remains the same. In fact, this focus on causation is not only unlikely to be of benefit, but may actually be harmful. Instead, it is more important that patients, health care providers, and policy makers begin to focus on better understanding this entire spectrum of illnesses, and to use our existing knowledge regarding these entities to develop multi disciplinary treatment programs for afflicted persons.

Types of therapy which have been demonstrated to be effective include low doses of tricyclic drugs, graduated low-impact aerobic exercise programs, and

cognitive-behavioral therapy. Cognitive behavioral therapy is an educational program that focuses on changing the individual's lifestyle and behaviors to better adapt to this illness. Other types of therapy may be effective but have yet to be proven so in double-blind, placebo-controlled trials.

My personal experience is that in some cases the VA Medical Centers are not well-versed in the treatment of these conditions, perhaps in part because these illnesses occur more frequently in females (and so few women are seen within the VA system), and perhaps because there is a cultural bias within the VA system to quickly refer these patients to psychiatrists. If a physician or other health care provider does not believe that these individuals are suffering from a real disease, they will likely be ineffective in treating this group of patients.

I will end by giving a few discrete recommendations:

- Much more funding is needed for research into these conditions. The problems regarding the diagnosis and treatment of Persian Gulf veterans are a symptom of a much larger problem in this country. Amazingly enough, despite the very high prevalence of these illnesses in the population, the aggregate amount of yearly funding for these conditions through all institutes at the NIH, and through other sources such as DOD, may perhaps reach 20 million dollars. This spectrum of illness costs the government alone billions of dollars in lost productivity, disability, and health care costs. The costs to the private sector are much larger.

Most of the research to date has focused on what *caused* the Persian Gulf Syndrome. Although this is needed, there needs to be a greater focus on understanding the physiology of these types of illnesses, and developing more effective treatments.

- Most of the experts on these types of illnesses in this country are not in the VA or military systems. The VA and DOD have reached out into the private sector to ask the advice of individuals who have expertise in these disorders, and this needs to continue.

- Continue to take these veterans seriously. The physical and emotional toll of

this type of illness is great, and these individuals developed these problems while serving our country. View with skepticism anyone who might assert that because there are no abnormalities on these individuals' blood tests, x-rays, or other diagnostic studies, that there is nothing wrong, or that the individual is suffering from a psychiatric condition. It is arrogant of us as scientists to feel that because we cannot precisely define a problem, it doesn't exist.

CURRICULUM VITAE

DANIEL JOSEPH CLAUW M.D.

3800 Reservoir Road, NW
Washington, D.C. 20007
O (202) 687-8233

Place of Birth Detroit, Michigan 9/25/58

Education

1981 - 1985 University of Michigan Medical School
Ann Arbor
Graduated with Honors M.D.

1976 - 1981 Undergraduate, University of Michigan
Ann Arbor

Post-Graduate Training

1988 - 1990 Rheumatology Fellowship
Georgetown University Medical Center
Division of Rheumatology, Immunology
and Allergy

1985 - 1988 Internal Medicine Residency, Department of Medicine
Georgetown University Medical Center

Current Position

1991 - 1997 Assistant Professor

1997 Associate Professor of Medicine
Acting Chief, Division of Rheumatology, Immunology, and Allergy
Georgetown University Medical Center

Board Certification, Licenses

1991 Board Certification in Rheumatology

1990 - present District of Columbia Medical License

1988 Board Certification in Internal Medicine

1987 - present State of Virginia Medical License

Honors/Awards

1990	Senior Fellow Award, American College of Rheumatology, Southeast Regional Meeting
1987	Hussey Teaching Award, given to the Internal Medicine Resident who is most influential in their medical education, by the Senior Class of Georgetown medical students
1986	Intern of the Year Award, Georgetown University Hospital

Professional Societies

1997 - present	International Association for the Study of Pain
1992 - present	American Federation for Medical Research
1991 - present	American College of Physicians
1990 - present	American College of Rheumatology
1988 - 1990	American Medical Association

Committees / Service

Study Sections: Ad Hoc Reviewer, NIH Study Section, National Institute of Dental Research, 1996; Ad Hoc Reviewer, NIAMS Special Emphasis Panel 1996; Ad Hoc Reviewer, Chronic Fatigue Syndrome Special Emphasis Panel, 1997

Other Extramural Grant reviews: Arthritis Foundation (1994); Canadian Arthritis Federation, (1995, 1996); American College of Rheumatology abstracts (1994, 1995, 1996)

Journal Reviews: (1990 - present) Annals of Internal Medicine, JAMA, Pediatrics, Journal of Rheumatology, Arthritis and Rheumatism, Journal of Clinical Endocrinology and Metabolism, Journal of Clinical Rheumatology, Journal of Musculoskeletal Pain, New York State Medical Journal

Extramural Committees:

1991 - present	Consultant, Food and Drug Administration Devices Panel
1994 - present	Chair, American College of Rheumatology Study Group on Environmentally Associated Connective Tissue Diseases
1995 - present	Counselor, Southeast Region, American College of Rheumatology
1993 - present	GUMC Representative, American Federation for Medical Research

1992	Consultant, World Health Organization Workshop on EMS / Toxic Oil Syndrome
1991 - present	Chairman, Research Advisory Council, Showa Denko Corporation
1990 - 1993	Public Health Foundation EMS Study Group

Intramural committees:

1996 - present	Clinical Research Center Committee
1996 - present	Research Space Committee, Department of Medicine
1997	Faculty Composition Task Force, Department Of Medicine
1994 - 1996	Clinical Competency Committee

Publications:

1. Wheeler RH, Clauw DJ, et al. Cytokinetic evaluation of the four drug combination of bleomycin, vincristine, mitomycin C, and methotrexate in cultured Burkitt's lymphoma cells and human bone marrow. Cancer 1982;15(10):1993-99.

2. Wheeler RH, Clauw DJ, Natale RB, Ruddon RW. The cytokinetic and cytotoxic effects of ICRF-159 and ICRF-187 in vitro and in human bone marrow in vivo. Investigational New Drugs 1983;1:283-95.

3. Clauw DJ, Katz P. Treatment of the eosinophilia myalgia syndrome. New Eng J Med. 1990;323(6):417.

4. Clauw DJ, Nashel DJ, Umhau A, Katz P. Tryptophan associated eosinophilic connective tissue disease; a new clinical entity? JAMA 1990;263:1502-6.

5. Ahmad SR, Clauw DJ. USA: EMS and L-tryptophan. Lancet 1991;338:1512.

6. Read CA, Clauw DJ, Wier C, DaSilva A, Katz P. Dyspnea and pulmonary function in the L-tryptophan-associated Eosinophilia Myalgia Syndrome. Chest 1992;101:1282-86.

7. Clauw DJ, Siegel LB, Katz P. Serum cytokines and the eosinophilia myalgia syndrome. Ann Int Med 1992;117(4):344-5.

8. Clauw DJ, Siegel LB, Whalen G, Katz P. Serum aldolase and lactate dehydrogenase levels in the Eosinophilia Myalgia Syndrome. Clin Exp Rheum 1993;11(1):97-8.

9. Clauw DJ, Alloway J, Katz P. The Use of Cyclosporin A in the eosinophilia myalgia syndrome. Annals of Rheumatic Disease 1993;52(1):81-2.

10. Clauw DJ, Beary JF. "Low Back Pain," in Manual of Rheumatology and Outpatient Orthopedic Disorders. Little, Brown and Co., 1993.

11. Clauw DJ, Hewes B, Nelson M, Katz P, Rajan S. 31-P Magnetic resonance spectroscopy

of skeletal muscle in the Eosinophilia Myalgia Syndrome. J Rheumatol, 1994;21(4)654-7.

12. Flockhart DA, Clauw DJ, Sale EB, Hewett J, Woosley RL. Pharmacogenetic characteristics of the eosinophilia myalgia syndrome. Clin Pharm Ther, 1994;56(4):398-405.

13. Clauw DJ, Ward K, Wilson B, Katz P, Rajan SS. Magnesium deficiency in the eosinophilia myalgia syndrome: report of clinical and biochemical improvement with repletion. Arthritis Rheum, 1994;37(9):1331-4.

14. Clauw DJ, Flockhart DA, Rajan S, Katz P, Medsger TA Jr. Eosinophilia Myalgia Syndrome not associated with the ingestion of nutritional supplements. J Rheumatol, 1994;21:2385-7.

15. Waller PA, Clauw DJ, Cupps T, Silver RM, LeRoy EC. Fasciitis (not scleroderma) following prolonged exposure to organic solvents (trichloroethylene). J Rheumatol, 1994;21:1567-70.

16. Epstein SA, Krahn L, Clauw DJ, Gomes AP, Weigert S, Goldberg RL. Psychiatric aspects of the eosinophilia myalgia syndrome. Psychosomatics, 1995; 36:22-5.

17. Hertzman PA, Kaufman LD, Love LA, Mease PJ, Philen R, Pincus T, Rosenberg NL, Silver R, Varga J, Clauw DJ. The eosinophilia myalgia syndrome - guidelines for patient care. J Rheum, 1995; 22(1):161-3.

18. Crofford L, Clauw DJ. Eosinophilic Rheumatic Disorders. Rheum Dis Clin N Amer, 1995; 21(1):231-246.

19. Clauw DJ. Fibromyalgia: more than just a musculoskeletal disease. Am Fam Phys, 1995; 52(3): 843-51.

20. Hertzman PA, Clauw DJ, Kaufman L, Varga J, Silver RM, Thacker HL, Mease P, Espinosa L, Pincus T. Eosinophilia myalgia syndrome: status of 205 patients and results of treatment two years after onset. Ann Intern Med, 1995;122:851-5.

21. Clauw DJ. The pathogenesis of chronic pain and fatigue syndromes, with special reference to fibromyalgia. Med Hypothesis; 1995;44(5):369-78.

22. Clauw DJ, Katz P. The overlap between fibromyalgia and inflammatory rheumatic diseases: when and why does it occur? J Clin Rheumatol, 1995;1:335-41.

23. Clauw DJ. Review of research conference in CFS - physiology. Journal of Chronic Fatigue Syndrome, 1995;1(3/4):185-90.

24. Clauw DJ, Hewett J, Blank CA, Katz P, Flockhart DA. P450 metabolism in fibromyalgia. J Musculoskeletal Pain, 1995;3(4):25-32.

25. Clauw DJ. Eosinophilic fasciitis and eosinophilia myalgia syndrome. In *Therapy of Systemic Rheumatic Diseases,* edited by Van de Putte, Williams, Van Riel, and Furst; Marcel Dekker, in press.

26. Clauw DJ. Ankylosing spondylitis. In *Current therapy in Allergy, Immunology, and Rheumatology*, eds. Lichtenstein and Fauci, Mosby, pp 212-14, 1996.

27. Clauw DJ. Animal models of eosinophilia myalgia syndrome. J Rheumatol, 1996;46S(23):93-97.

28. Clauw DJ, Pincus T. The eosinophilia myalgia syndrome (EMS): What we know, what we think we know, and what we need to know. J Rheumatol, 1996;46S(23):2-6.

29. Ward KM, Rajan SS, Wysong M, Radulovic D, Clauw DJ. Phosphorus nuclear magnetic resonance spectroscopy: *in vivo* magnesium measurements in skeletal muscle of normal subjects. Magnetic Resonance in Medicine, 1996;36:475-80.

30. Clauw DJ. Chronic fatigue syndrome. In: *Internal Medicine*, Stein editor, in press.

31. Clauw DJ. Ankylosing spondylitis. In: *Current Therapy in Internal Medicine*, Kassirer and Green, eds., in press.

32. Clauw, DJ. Non-musculoskeletal features of fibromyalgia. Lyon Mediterranee Medical, in press.

33. Clauw DJ, Schmidt M, Radulovic D, Singer A, Katz P, Bresette J. The relationship between fibromyalgia and interstitial cystitis. J Psychiatric Research, in press.

34. Slotkoff A, Clauw DJ. Fibromyalgia: When thinking is impaired. J Musculoskel Med, 1996; 13(9):32-6.

35. Clauw DJ. Environmentally associated rheumatic diseases. In: *Rheumatology*, Klippel and Dieppe eds., in press.

36. Clauw DJ. Fibromyalgia: more than just a musculoskeletal disease. In: *Year Book of Family Practice*, Mosby, 1997.

37. Clauw DJ. Clinical features of EMS and related disorders. Adv Exp Med Biol, 1996; 398:331-338.

38. Slotkoff-Marx, A, Radulovic D, Clauw DJ. The relationship between fibromyalgia and multiple chemical sensitivity syndrome. Scand J Rheumatol, in press.

Abstracts (those indicated by astericks were selected for podium presentations):

1. *Clauw DJ, Nashel DJ, Umhau A, Katz P. Tryptophan associated connective tissue disease. Arthritis Rheum 1990;33(5S).

2. *Clauw DJ, Nashel DJ, Katz P. Clinical, laboratory and histologic features of the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1990;33(9S):50.

3. Clauw DJ, Scott LF, Morris TA, VandeVort KA, Katz P. The effect of abnormal tryptophan metabolism on the development of connective tissue disease in the rat. Arthritis Rheum 1991;34(5S):27S.

4. Clauw DJ, Alloway JA, Read CA, Katz P. The use of cyclosporin A in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1991;34(5S):26S.

5. Clauw DJ, Siegel LB, Whalen G, Oliver SJ, Katz P. Laboratory abnormalities in the Eosinophilia Myalgia Syndrome: correlation with disease activity. Arthritis Rheum 1991;34(5S):25S.

6. Clauw DJ, Read CA, Wier C, DaSilva A, Katz P. Pulmonary abnormalities in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1991;34(9S):D182.

7. Clauw DJ, Alloway JA, Read C, Katz P. The use of cyclosporin A in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1991;34(9S):D181.

8. Siegel LB, Clauw DJ, Rajan S, Nelson M, Katz P. Evaluation of muscle disease in Eosinophilia Myalgia Syndrome by Phosphorus magnetic resonance spectroscopy. Arthritis Rheum 1991;34(9S):D164.

9. Oliver S, Clauw DJ. A Reversible Cause of Myopathy in Rheumatoid Arthritis. American College of Physicians District of Columbia Meeting, 1/11/92.

10. Zackrison L, Whalen G, Katz P, Clauw DJ. Lack of correlation between serum cytokines and disease activity in eosinophilia myalgia syndrome. Arthritis Rheum 1992;35(5S).

11. Clauw DJ, Scott L, Manz H, Kagan E, Katz P. A rat feeding study using tryptophan implicated as causal in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1992;35(S).

12. Hoogland Y, Katz P, Clauw DJ. Retrospective comparison of male and female fibromyalgia patients. Arthritis Rheum 1992;35(5S).

13. Clauw DJ, Wetter N, Katz P, Cupps TR. Site specific T-cell immune function in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1992;35(5S).

14. Epstein SA, Krahn L, Clauw DJ, Gomes M, Weigert S, Goldgerg RL, Katz P. Psychiatric Aspects of the Eosinophilia Myalgia Syndrome. Presented, Academy of Psychosomatic Medicine, San Diego, October 31, 1992.

15. Clauw DJ, Epstein SA, Krahn L, Gomes AP, Weigart S, Goldgerg RL, Katz P. Psychiatric Aspects of the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1992;(supp)35(9):S67.

16. Zackrison LH, Katz P, Clauw DJ. Fibromyalgia as a late complication of the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1992;(supp)35(9):S345.

17. Read CA, Clauw DJ, DaSilva AMT, Katz P. Persistent pulmonary function test abnormalities in L-tryptophan associated Eosinophilia Myalgia Syndrome. Presented at the May

1993 American Thoracic Society Meeting.

18. Zackrison LH, Blank CA, Katz P, Clauw DJ. Fibromyalgia and the Eosinophilia Myalgia Syndrome. Clin Res 1993;41(2):375A.

19. Flockhart DA, Buchert EJ, Clauw DJ, Woosley RL. Pharmacogenetic characteristics of the Eosinophilia Myalgia Syndrome. Clin Res 1993;41(2):243A.

20. Hertzman P, Clauw DJ, Kaufman L, Silver R, Varga J, Callahan L, Pincus T. 18-24 month follow-up of 210 patients with Eosinophilia Myalgia Syndrome. Arthritis Rheum 1993;36(5S):R26.

21. Zackrison LH, blank CA, Katz P, Clauw DJ. Fibromyalgia and the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1993;36(5S):R27.

22. Clauw DJ, Mullins W, Blank C, Rajan S, Flockhart D, Katz P, Medsger TA. Eosinophilia Myalgia Syndrome not associated with the ingestion of nutritional supplements. Arthritis Rheum 1993;36(5S):R26.

23. DeGuzman D, Cupps TR, Katz P, Clauw DJ. T-Cell proliferative responses of putative contaminants in Eosinophilia Myalgia Syndrome (EMS). Arthritis Rheum 1993;36(5S):R26.

24. Clauw DJ, Blair SD, Blank CA, Ziavras E. Ocular manifestations of the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1993;36(5S):R26.

25. Pincus T, Clauw DJ, Hertzman P, Kaufman L, Silver R, Varga J, Callahan LF. 18-24 month follow-up of 210 patients with eosinophilia myalgia syndrome in 12 states. Arthritis Rheum 1993;36(9S):A196.

26. Clauw DJ, Flockhart DA, Buchert E, Harris J, Blank CA, Katz P, Woosley RL. Xenobiotic metabolism in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1993;36(5S):R15.

27. *Clauw DJ, Hewes B, Blank CA, Nelson M, Katz P, Rajan S. P-31 Magnetic resonance spectroscopy in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1993;36(5S):R16.

28. Flockhart DA, Buchert E, Harris J, Clauw DJ, Woosley RL. Pharmacogenetic characteristics of the Eosinophilia Myalgia Syndrome. Clin Pharmacol Ther 1993;53:121.

29. Clauw DJ, Flockhart DA, Buchert E, Harris J, Blank CA, Katz P, Woosley RL. Xenobiotic metabolism in the eosinophilia myalgia syndrome. Arthritis Rheum 1993;36(9S):A98.

30. Clauw DJ, Hewes B, Blank CA, Nelson M, Katz P, Rajan S. P-31 magnetic resonance spectroscopy in the eosinophilia myalgia syndrome. Arthritis Rheum 1993;36(9S):A98.

31. Ling SM, Blank C, Hewett-Meulman J, Katz P, Clauw DJ. Demonstration of low tissue levels of magnesium in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1993;36(9S):313.

32. Clauw DJ, Krahn L, Goldgerg R, Katz P, Epstein S. Psychiatric symptomatology and the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1993;36(9S):A102.

33. Clauw DJ, DaSilva AT, Katz P, Read CA. Pulmonary function abnormalities in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1993;36(9S):A99.

34. Clauw DJ, Morris S, Starbuch V, Epstein S, Kay G. Neuropsychological function in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1993;36(9S):A101.

35. Clauw DJ, Hewes B, Blank CA, Nelson M, Katz P, Rajan S. P-31 magnetic resonance spectroscopy in the Eosinophilia Myalgia Syndrome. Arthritis Rheum 1993;36(9S):A98.

36. Hiltz RE, Gupta PK, Maher KA, Blank CA, Benjamin SB, Katz P, Clauw DJ. Low threshold of visceral nociception and significant objective gastrointestinal pathology in patients with fibromyalgia syndrome. Arthritis Rheum 1993;36(9S):C93.

37. Clauw DJ, Blank C, Hewett-Meulman J, Katz P. Low tissue levels of magnesium in fibromyalgia. Arthritis Rheum 1993;36(9S):B118.

38. Clauw DJ, Blank C, Tefft M, Sears R, Moscowitz L, Marenco J, Katz P, Manz H. Features of the Eosinophilia Myalgia Syndrome in mouse model. Arthritis Rheum 1993;36(9S):A100.

39. Clauw DJ, Hewett J, Blank CA, Katz P, Woosley RL, Flockhart DA. Xenobiotic metabolism in fibromyalgia. Arthritis Rheum 1994;37(6S):R28.

40. *Clauw DJ, Blank C, Hiltz R, Katz P, Potolicchio S. Polysomnography in fibromyalgia patients. Arthritis Rheum 1994;37(6S):R19.

41. Clauw DJ, Wilson B, Phadia S, Radulovic D, Katz P. Low tissue levels of magnesium in fibromyalgia. Arthritis Rheum 1994;37(6S):R29.

42. Clauw DJ, Morris S, Starbuck V, Blank C, Kay G. Impairment in cognitive function in individuals with fibromyalgia. Arthritis Rheum 1993;37(6S):R29.

43. Clauw DJ, Williams D, Hiltz R, Blank CA, Katz P, Epstein SA. The effect of psychological status on pain in fibromyalgia. Arthritis Rheum 1994;37(6S):R29.

44. Clauw DJ, Kay G, Potolicchio S, Starbuck V. Abnormal auditory evoked potentials in fibromyalgia. Arthritis Rheum 1994;37(6S):R29.

45. *Clauw DJ, Ward K, Katz P, Rajan S. Muscle intracellular magnesium levels correlate with pain tolerance in fibromyalgia. Arthritis Rheum 1994;37(6S):R29.

46. Clauw DJ, Schmidt M, Radulovic D, Slotkoff A, Singer A, Bresette J. The relationship between fibromyalgia and interstitial cystitis. Arthritis Rheum 1994; 37(9S):S347.

47. Slotkoff AT, Clauw DJ, Nashel DJ. The effect of soft tissue corticosteroid injection on glucose control in diabetics. Arthritis Rheum 1994; 37(9S):S347.

48. Slotkoff A, Radulovic D, Clauw DJ. The relationship between multiple chemical sensitivity and fibromyalgia. Arthritis Rheum 1994; 37(9S):S347.

49. *Radulovic D, Barbey JT, Katz P, Baraniuk J, Clauw DJ. Tilt table testing as a measure of dysautonomia in fibromyalgia. Arthritis Rheum, 1995; 38(6S):R25.

50. Ali M, Clauw DJ, Whalen G, Katz P, Baraniuk J. Prolactin receptor mRNA is present in natural killer cells. Arthritis Rheum, 1995; 38(6S):R29.

51. Clauw DJ, Sabol M, Radulovic D, Wilson B, Katz P, Baraniuk J. Serum neuropeptides in patients with both fibromyalgia and chronic fatigue syndrome. Arthritis Rheum, 1995; 38(6S):R28.

52. Clauw DJ, Radulovic D, Heshmat Y, Barbey JT. Heart rate variability as a measure of autonomic function in patients with fibromyalgia and chronic fatigue syndrome. Arthritis Rheum, 1995; 38(6S):R25.

53. Gaumond E, Baraniuk J, Wethington S, Clauw DJ. Allergic symptoms in individuals with chronic fatigue syndrome and fibromyalgia. Arthritis Rheum, 1995; 38(6S):R27.

54. Ward KM, Rajan S, Clauw DJ. 31P NMR spectroscopic Magnesium measurements in normal controls and fibromyalgia. Proc Soc Exp Biol Med 1995; 209(3):300.

55. Clauw DJ, Woodward M, Manz H. Spinal cord involvement in the eosinophilia myalgia syndrome (EMS). Arthritis Rheum, 1996; 39(6S):R21.

56. *Clauw DJ, Keefe B, Maher K, Benjamin S. Comparison of esophageal manometry and results of visceral nociceptive testing in individuals with fibromyalgia and noncardiac chest pain (NCCP). Arthritis Rheum 1996; 39(6S):R17.

57. Clauw DJ, Gaumond E, Radulovic D, Pandiri P, Ali M, Foong S, Baraniuk JN. The role of true IgE mediated allergic mechanisms in the allergic symptoms of fibromyalgia (FM). Arthritis Rheum 1996; 39(6S):R20.

58. Clauw DJ, Radulovic D, Antonetti D, Bagati R, Baraniuk J, Barbey JT. Tilt table testing in fibromyalgia. Arthritis Rheum 1996; 39(6S):R20.

Selected Invited Presentations (in addition to those abstracts indicated by astericks above):

5/97	Invited speaker, Medical Grand Rounds, National Naval Medical Center, "Update on our understanding of chronic pain and fatigue syndromes"
4/97	Invited speaker, Annual Conference on Disability for the Long Term Provider "Fibromyalgia"
4/97	Invited speaker, NIH conference on Vulvodynia, "Associated Conditions"
3/97	Keynote speaker, Connecticut CFIDS Group, "Fibromyalgia," Yale University

3/97	Invited speaker, Institute of Medicine, "Difficult to Diagnose and Ill-Defined Conditions"
1/97	Conference Organizer, "Meeting of Federal Researchers on Persian Gulf Veteran's Illnesses, Ft. Detrick, MD; invited presentation, "Overview of Chronic Pain and Fatigue Syndromes"
10/96	Moderator, Annual American College of Rheumatology meeting, symposium on Fibromyalgia
10/96	Moderator and organizer, Annual American College of Rheumatology meeting, Study Section on Environmentally Associated Connective Tissue Diseases, "Is scleroderma an Environmentally Associated Connective Tissue Disease?"
10/96	Invited presentation: "Silicone breast implants and immunologic disorders: An ongoing controversy," American Association of Chronic Fatigue Syndrome, Annual meeting, San Francisco.
9/96	Invited presentation: "Symptom-based treatment of fibromyalgia," Mid-Atlantic Conference on the Treatment of Fibromyalgia
7/96	Invited participant, NIH Workshop on Scientific Advances in Fibromyalgia
6/96	Invited presentation, "Fibromyalgia and its association with chronic pain syndromes," presented at The Fourth Annual Congress on Women's Health, Washington, D.C.
5/96	Invited presentation, Massachusetts CFIDS Association, "Update on chronic pain and fatigue syndromes"
3/96	Invited testimony before U.S. Congress; House of Representatives Committee on Government Reform Oversight regarding "Fibromyalgia: relationship with unexplained illnesses associated with deployment to the Persian Gulf
2/96	Invited presentation, "Fibromyalgia," Presidential Advisory Committee on Gulf War Veterans Illnesses, San Antonio
10/95	Moderator, American College of Rheumatology Study Section on Environmentally Associated Connective Tissue Diseases
10/95	Moderator, American College of Rheumatology Meeting, "Fibromyalgia and soft tissue rheumatism"
10/95	Invited speaker, National Vulvodynia Association
9/95	Invited Speaker, University of Virginia Rheumatology Grand Rounds,

Update on the Pathogenesis and Treatment of Fibromyalgia"

6/95 Invited Speaker, Persian Gulf Veterans Coordinating Board Clinical Group, "Update on Chronic Fatigue Syndrome and Fibromyalgia"

6/95 Invited Speaker, National Institutes of Health Arthritis Branch Grand Rounds, "Update on the Pathogenesis and Treatment of Fibromyalgia"

5/95 Invited Speaker, University of Virginia Women's Center, "Update on the Pathogenesis and Treatment of Chronic Pain and Fatigue Syndromes"

5/95 Grand Rounds, Martinsburg City Hospital, Martinsburg, W.V., "Update on the Pathogenesis and Treatment of Chronic Pain and Fatigue Syndromes"

4/95 "Meet the Professor" talk, American College of Rheumatology meeting Philadelphia, "Update on the Pathogenesis and Treatment of Fibromyalgia"

4/95 Invited participant, NIH Workshop, "Developing Outcome Measures for Clinical Trials in Chronic Fatigue Syndrome"

1/95 Invited speaker, Children's National Medical Center, "Chronic Pain and Fatigue Syndromes"

12/94 Invited consultant, FDA Advisory Panel, "FDA Alternatives to Silicone Breast Implants Workshop"

9/94 Invited speaker, "Cognitive dysfunction in fibromyalgia patients", ACR Behavioral Rheumatology Study Group, Minneapolis

6/94 Invited speaker, "Chronic pain syndromes", Second Annual World Women's Health Congress, Washington, D.C.

4/94 Invited participant, NIH/ICA workshop on Interstitial Cystitis

10/93 "Overview of the Eosinophilia Myalgia Syndrome", Medical University of South Carolina

5/93 Participant, NIH Workshop, "Future Directions in Fibromyalgia Research"

3/93 Co-Moderator, "Environmentally Associated Connective Tissue Diseases" Southeast Regional Meeting of the American College of Rheumatology

3/93 "Update on the Eosinophilia Myalgia Syndrome" Food and Drug Administration Pilot Drug Division

1/93 "Update on the Eosinophilia Myalgia Syndrome" Food and Drug Administration Endocrinology and Metabolism Division

9/92 "Update on the Eosinophilia Myalgia Syndrome" Vanderbilt University

6/90 "Treatment of the Eosinophilia Myalgia Syndrome" Los Alamos Conference

5/90 "Eosinophilia Myalgia Syndrome" NIH Arthritis Branch, Rheumatology Grand Rounds

Funding:

Past:

Role: P.I. Title: Animal Model of EMS Source: Showa Denko
Direct costs: $24,950 Total: $31,188 Dates: 1/24/90 - 1/23/91

Role: P.I. Title: Cyclosporin in the Treatment of EMS Source: Showa Denko
Direct costs: $181,169 Total: $226,461 Dates: 7/1/90 - 7/1/92

Role: P.I. Title: Development of an Animal Model of EMS Source: Showa Denko
Direct costs: $236,311 Total: $295,393 Dates: 7/1/91 - 7/1/93

Role: P.I. Title: Center Grant for the Study of EMS Source: Showa Denko
Direct costs: $294,828 Total: $368,535 Dates: 3/1/92 - 7/1/94

Role: P.I. Title: Magnesium deficiency in EMS Source: Showa Denko
Direct costs: $99,494 Total: $124,368 Dates: 7/1/93 - 3/1/95

Role: P.I. Title: Autonomic function in fibromyalgia Source: American Fibromyalgia Syndrome Association Total and Direct costs: $29,650 Dates: 7/1/95 - 6/30/96

Role: P.I. Title: Physiologic pathogenesis of EMS Source: Showa Denko
Direct costs: $82,025 Total: $90,227 Dates: 6/1/94 - 12/32/95

Active:

Role: P.I. Title: Central Nervous System Dysregulation in Interstitial Cystitis
Source: NIH RO1 Direct costs: $385,050 Total costs: $618,526
Dates: 9/1/94 - 8/31/97

Role: P.I. Title: Dysregulation of the Stress Response in Persian Gulf Syndrome
Source: Department of Defense Direct costs: $616,673 Total: $970,578
Dates: 5/1/96 - 4/32/99

RECORD VERSION

STATEMENT BY

MAJOR CHARLES C. ENGEL, JR., M.D., M.P.H., MEDICAL CORPS
UNITED STATES ARMY
CHIEF, GULF WAR HEALTH CENTER,
WALTER REED ARMY MEDICAL CENTER
ASSISTANT PROFESSOR OF PSYCHIATRY,
UNIFORMED SERVICES UNIVERSITY

BEFORE THE

COMMITTEE ON VETERANS' AFFAIRS
SUBCOMMITTEE ON HEALTH
UNITED STATES HOUSE OF REPRESENTATIVES

ON THE
MULTIDISCIPLINARY MEDICAL TREATMENT OF
PERSISTENT PHYSICAL SYMPTOMS AFTER GULF WAR SERVICE

19 JUNE 1997

NOT FOR PUBLICATION
UNTIL RELEASE BY THE
COMMITTEE ON VETERANS'
AFFAIRS UNITED STATES
HOUSE OF REPRESENTATIVES

Mr Chairman and Members of the Committee:

Thank you for this opportunity to speak to you about the Gulf War Health Center. We at the Gulf War Health Center are honored and appreciative that you have asked to hear about the treatment we use to help veterans experiencing persistent physical symptoms after their service in the Persian Gulf. I am a veteran of the Gulf War, having served as the Division Psychiatrist in the Army's First Cavalry Division, and I have research and clinical expertise in the treatment of persistent, unexplained physical symptoms. If I may, I would like to thank LTG Ronald Blanck, The Surgeon General, Army, for endorsing the Gulf War Health Center's initial charter in early 1995 when he was the Commanding General of Walter Reed Army Medical Center and MG Leslie Burger, the current Commanding General at Walter Reed Army Medical Center, for their continued support of the center. Indeed, all of us who work at the Gulf War Health Center are thankful to the entire Army Medical Department for the opportunity to provide this unique health service for veterans of the Gulf War. Mostly, we thank the veterans themselves for their service to the country.

The purpose of my testimony today is to: 1) to present the history of the Gulf War Health Center, Walter Reed Army Medical Center's program for evaluating and treating Gulf War related health concerns; and 2) to describe the Gulf War Health Center's Specialized Care Program, a partial hospital program providing intensive treatment to individuals with persistent, disabling Gulf War related physical symptoms that employs methods used in chronic pain centers internationally.

Brief History of the Gulf War Health Center's Specialized Care Program.

On August 2, 1990, Iraq launched a surprise invasion of the oil rich neighboring nation of Kuwait. This marked the beginning of a rapid overseas deployment of US and other armed forces. Eventually nearly 697,000 U.S. troops served in the Persian Gulf. Six weeks of US and coalition bombing of Iraq commenced on January 16, 1991 and was followed by a 4-day ground war. Troops faced a range of environmental exposures during the conflict and its aftermath, including smoke from burned excrement, oil well fires, diesel

exhaust, toxic paints, pesticides, sand and other particulates, depleted uranium, infectious agents, chemoprophylactic agents, immunizations, and chemical/biological warfare agents.

Subsequent reports suggested that some veterans and their families were experiencing persistent symptoms since returning from the Persian Gulf. Some suggested the emergence of a specific syndrome involving fatigue, aches, pains, rashes, headaches, dizziness, and concerns were raised regarding congenital anomalies among family members. To investigate further, Department of Defense (DoD) and the Department of Veterans Affairs (DVA) initiated registries of symptomatic Gulf War veterans. In June, 1994 DoD initiated the Comprehensive Clinical Evaluation Program (CCEP), a centrally coordinated and DoD-wide health care program designed to provide rapid, accessible, and expedited clinical assessments for Gulf War veterans with Gulf War related health concerns. The Gulf War Health Center was initiated at Walter Reed Army Medical Center to coordinate CCEP activities among the 23 Army, Navy, and Air Force medical facilities in the Northeast portion of the U.S., to perform tertiary care CCEP evaluations for the region, and to complete primary CCEP assessments for those in the immediate Walter Reed vacinity.

CCEP findings were subsequently presented to the Institute of Medicine in a series of reports. Particular attention focused on a subset of about 10-15% (the fraction has fallen over time) of CCEP patients with incompletely explained physical symptoms. In December of 1994, DoD decided that a multidisciplinary treatment program was needed to help Gulf War veterans with persistent physical symptoms, and in March of 1995 the Specialized Care Program treated its first patients at the Gulf War Health Center. In May, 1995 a panel of experts on the multidisciplinary treatment of individuals with chronic pain was convened, and the Specialized Care Center methods were reviewed and refined. Currently, the Specialized Care Program is the only treatment program offering this multidisciplinary chronic pain treatment approach tailored to the needs of those with persistent Gulf War related physical symptoms.

Mission, Objectives, and Description of the Specialized Care Program.

The mission of the Specialized Care Program is to provide a multidisciplinary treatment program, the Specialized Care Program, for people with persistent Gulf War related physical symptoms. The broad objectives of the Specialized Care Program are to help those with persistent Gulf War related physical symptoms reduce those symptoms and improve their quality of life, functional status, and occupational performance. More specifically, the Specialized Care Program works with each individual to:

1) maximize control over symptoms through the formulation and initiation of an individualized wellness plan;

2) significantly reduce overall symptomatology;

3) improve morale and mood;

4) maximize active coping with persistent and disabling physical symptoms;

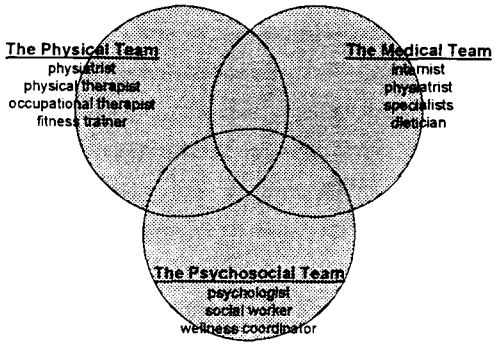
5) develop a consistent, primary care-based follow-up plan;

6) address psychosocial contributors to symptom-based disability;

7) improve relationships with health care providers and significant others; and

8) reduce excessive and potentially harmful use of the health care system.

Figure 1. The Specialized Care Program is organized around 3 conceptual rehabilitative teams with overlapping objectives and staffing.



The Specialized Care Program emphasizes comprehensive, multidisciplinary collaboration aimed at reducing persistent symptoms and associated functional impairment. Family involvement is extremely important, and extra efforts are taken to maximize their collaboration with the health care team (e.g., paid travel, long distance telephone assessment). Specialized Care Program patients work closely with an internist and a health psychologist. Other members of the health care team include a physiatrist, occupational therapist, physical therapist, fitness trainer, wellness coordinator, clinical social worker, and a nutritionist. A range of medical specialists such as occupational medicine, preventive medicine, infectious disease, and others are available for consultation depending on a given patient's estimated medical needs.

The Specialized Care Program staff can be divided conceptually into three overlapping teams, each oriented to an aspect of the patient's health and rehabilitation needs: the medical team, the physical team, and the psychosocial team. (figure 1) *The medical team* is primarily concerned with evaluating each patient for the presence and severity of diseases and to make certain that patients' are medically appropriate for the Specialized Care Program. Given the Specialized Care Program emphasis on chronic

symptoms, it is imperative to make sure that patients are not suffering from acute or unstable illnesses. The medical staff also thoroughly explain patients' medical status and review completed medical testing with them. *The physical team* helps patients initiate an exercise program individualized to their unique musculoskeletal and medical limitations and exercise history. Exercise is the cornerstone of treatment for many patients. It allows them to develop stamina and control over their health concerns and to minimize the impact of symptoms on their functioning. *The psychosocial team* offers various kinds of support during the treatment process. Typically, bothersome symptoms wear patients down, reduce the quality of their relationships, and diminish morale and mood. Similarly, depressed patients may dwell more on their symptoms, experience more symptoms, and lack energy to function through their symptoms. Psychosocial team staff offer various types of support, therapy, and counseling as patients request and need it. The psychosocial team is also responsible for coordinating the educational portion of the Specialized Care Program. Participatory seminars (see table 1) encourage education and discussion designed to help patients improve their use of the health care and disability compensation systems, communications with providers, their understanding of persistent symptoms, and their knowledge of what is currently known about Gulf War health issues. Anticipating obstacles to aftercare is also an important task of the psychosocial team.

Table 1. Common seminar topics given for participants in the Specialized Care Program.

- Orientation & overview
- Illness series
  - Disease and illness
  - Acute and chronic illness
  - Illness, beliefs, & behavior
  - Illness, mood, & anxiety
- Users' Guide to:
  - Your doctor
  - Prescription meds
  - Disability compensation
  - Medical labs & tests
- Learning about your body
  - Activity and morale
- Learning about body (cont'd):
  - The nervous system
  - Impact of diet on symptoms
  - Review of common symptoms
  - Gulf War exposures & health
- Strategies for coping with illness
  - Overcome illness flares
  - Pacing yourself
  - Sleep hygiene
  - Setting realistic goals
  - overcoming inactivity
  - Relaxation techniques
  - Problem-solving
  - Communication skills

Bringing The Parts Together.

Each week of the Specialized Care Program has a slightly different emphasis. The first week emphasizes medical reassessment and trust and rapport-building between staff and patients. Many patients enter the program concerned that there is a conspiracy to invalidate the physical reality of their health concerns. Other patients simply feel that previous providers have minimized their concerns, blamed them for their problems, or suggested their symptoms are psychological. Because of this, substantial effort is taken to listen to the patients' concerns and reassure them that we know that their symptoms are real. By week two, patients are feeling more comfortable discussing the ways their physical symptoms limit their lives and cause them emotional discomfort. Week three emphasizes behavioral coping, goal setting, and discharge planning.

Table 2. An example of patients' daily schedule for patients during the Specialized Care Program.

0600	Individualized Fitness Training
0700	Hygiene and Breakfast
0800	Participatory Seminar
0900	Occupational Therapy
	Individual Therapy
to	Physical Therapy
	Physician
1130	Team Rounds
1200	Lunch
1300	Wellness Activities
	Medical Tests PRN
to	Physical Therapy
	Nutrition Therapy
1500	Medical System Review Group

Table 2 displays the patient schedule for a typical Specialized Care Program day. The day begins with individualized physical training followed by shower and breakfast. After breakfast, patients meet together with one or more of the staff for the morning meeting and participatory seminar. Patients can use this forum to address any pressing issues. The rest of the morning and the early part of the afternoon is scheduled with various providers according to each patient's treatment needs. The afternoon session closes with Medical Systems Review group followed by an hour with the wellness coordinator for practicing wellness strategies such as relaxation techniques.

Morning and afternoon is broken by rounds and lunch. The basic purpose of rounds is to develop patients' treatment plans, to track patient progress, and to keep the multidisciplinary staff in tune with what one another are doing for each patients. A multidisciplinary program can undermine itself if providers from different disciplines do not respect each others' clinical input. Most days, rounds last 30 minutes and entail brief 'housekeeping' visits between staff and patients, followed by staff treatment planning and coordination. Once weekly, rounds last for an hour without patient participation.

Table 3. Demographic Characteristics of Specialized Care Program participants compared with characteristics of Comprehensive Clinical Evaluation Program participants and all military personnel deployed to the Gulf War.

	Specialized Care Program [Mean (±sd) or N (%)]	CCEP Participants[1] [Mean or %]	All Gulf War Veterans[1] [Mean or %]
Age at the Gulf War	33.3 (±8.3)	26	26
% Female	20 (27%)	12%	7%
Ethnicity			
White	42 (57%)	57%	70%
Black	24 (32%)	32%	23%
Other	8 (11%)	11%	7%
Rank			
Junior Enlisted	15 (20%)	---	---
Non-Commissioned Officer	36 (49%)	---	---
Senior Non-Commissioned Officer	20 (25%)	---	---
Commissioned Officer	7 (10%)	11%	10%
Service Branch			
Army	54 (73%)	81%	50%
Navy	8 (11%)	4%	23%
Air Force	3 (4%)	10%	12%
Marine	8 (11%)	4%	15%
Service Status			
Active	55 (74%)	83%	83%
Reserve/Guard	13 (18%)	13%	17%
Other	6 (8%)	4%	---

Preliminary Data on Health Outcomes.

Since August, 1996, an aggressive outcomes evaluation program has been developed and piloted. Available medical records were abstracted from past participants and a computer assisted telephone interview has been developed to obtain longitudinal data. To date, 84 patients have completed SCP treatment. Once started, only one patient failed to complete the 3-week program. Table 3 shows demographic data from SCP patients, comparing them to Comprehensive Clinical Evaluation Program participants and to the entire group of military personnel deployed to the Gulf War. Compared to these other groups, SCP patients were older at the time of the Gulf War, and a larger proportion of SCP patients are female. SCP patients are comparable in ethnic mix to CCEP participants, but a larger proportion of both SCP and CCEP patients are from various ethnic minority groups than was the case for all Gulf War veterans. The proportion of commissioned officers is similar among SCP patients, CCEP patients, and all Gulf War veterans. Compared to CCEP participants, Air Force personnel are under-represented among SCP patients, and Navy and Marine Corps personnel are over-represented.

Table 4. Baseline health status and health care use among Specialized Care Program participants. (data are for the last 19 SCP patients unless otherwise noted)

	Mean (±SD)
Serious Undiagnosed Illness Concerns	15/19 (79%)
Number of Diagnoses	5.9 (± 2.3)
Bothersome Symptoms (# in Past Month)	10.3 (± 3.2)
CCEP Utilization:	
Ambulatory Visits	16.9 (± 8.2)
Laboratory Tests	55.6 (±28.6)
Radiographic Tests	2.2 (± 2.1)
Other Tests	4.2 (± 3.8)
PRIME-MD Screens:	
Anxiety Disorder	17 (90%)
Depressive Disorder	13 (68%)
Eating Disorder	6 (32%)
CAGE Criteria	0 (0%)
Reported Service Use (Past 6-Months)	
General Medical Care	12.5 (±25.2)
Mental Health Care	1.6 (± 3.7)
Alternative Health Care	1.1 (± 3.9)
Reported Medication Fills (Past 6-Months)	
Any Prescription Medication	13.1 (±10.9)
Pain Medications	2.9 (± 2.7)
Psychoactive Medications	2.8 (± 4.0)

Baseline health status of SCP participants can be found in tables 4 and 5. Even though patients were selected on the basis of having an inadequate or incomplete physical explanation for their symptoms, they have still been given nearly 6 ICD-9 diagnoses on average and as many as 13. Nearly 80% of patients describe concern that they might have a serious undiagnosed medical condition. Data abstracted from available CCEP records as well as self-report data regarding recent health care utilization suggests that SCP patients are high service utilizers, especially when one considers that the average patient is only 38 years old. We find clinically that many patients are distressed about their physical symptoms. Indeed, our research indicators also suggest that many of our SCP patients are psychosocially distressed. Data from mental illness screening suggests that SCP patients are often psychosocially distressed. Data from the Brief Symptom Index (BSI) (table 5) suggests that specific areas of distress are obsessive worry and physical symptom concerns (obsessive-compulsive and somatization subscales respectively). Patients describe generally poor functioning at baseline. The SF-36 summary scales of physical and mental health functioning have been standardized against population norms. For both of these

scales, population mean scores are 50 and the standard deviation is 10. SCP patients report levels of physical health functioning nearly 2 standard deviations and mental health functioning nearly 1 standard deviation lower than population norms.

Table 5. Indicators of health outcome: Comparison of participant status at exit from versus at entry to the Specialized Care Program.

	SCP Entry	SCP Exit	Mean Δ	Effect Size	Significance
Functional Status (SF-36)					
General Health	31	33	2.7	0.2	
Physical	49	48	- 1.8	-0.1	
Social	53	61	6.2	0.3	
Role, Physical	26	33	6.6	0.1	
Role, Emotional	48	70	22.2	0.4	
Pain	42	45	3.7	0.2	
Mental Health	58	68	9.3	0.6	*
Vitality	30	37	6.7	0.3	
SF-36 Summary Scales					
Physical Health Functioning	32	30	- 0.9	-0.2	
Mental Health Functioning	41	48	6.5	0.9	***
Physical Health Concerns (Whitely Index)	60	53	- 6.7	0.3	
Social Support Rating (SSS)	66	74	8.1	0.5	
Distress Ratings (BSI)					
Global Severity Index	21	17	- 3.3	0.6	**
Somatization	30	28	- 1.2	0.1	
Obsessive-Compulsive	39	34	- 3.0	0.2	
Interpersonal Sensitivity	15	11	- 3.1	0.3	
Depression	17	13	- 3.7	0.4	
Anxiety	19	15	- 3.7	0.6	*
Hostility	17	11	- 5.8	0.6	*
Phobic Anxiety	11	9	- 2.2	0.3	
Paranoia	18	15	-2.2	0.2	
Psychoticism	12	8	- 3.8	0.8	***

Data on early SCP outcomes suggest that patients' status improves compared with status at entry to SCP. Table 5 expresses the mean change from baseline as an effect size for each outcome measure. Since outcome measures have differing variability, each measure is adjusted for its degree of variability so as to allow comparisons across different measures. Effect size is calculated as the mean change from program entry to exit divided by the standard deviation of the change. If the change is in the direction of improvement, the effect size is positive. Effect sizes of 0.20, 0.50, and 0.80 are considered small, moderate, and large, respectively. Of the 22 outcomes measured in table 5, 18 (82%) suggested at least a small change in the direction of improvement. 2 outcomes showed large improvements, the summary mental health functioning score of the SF-36 and the psychoticism scale of the BSI. Indeed, the summary mental health functioning score approached population norms. Improvements in unusual health beliefs may account for the

improvement observed in the psychoticism domain. Another 5 outcomes suggest improvements in the moderate range, the BSI anxiety, hostility, and global severity (a measure of overall psychosocial distress) scales, the global social support scale from the SSQ, and the mental health scale of the SF-36.

It is noteworthy that physical functioning seems the most refractory to change during SCP. Small negative changes in the SF-36 physical functioning and summary physical functioning scales suggest minor decrements may occur in these areas during SCP treatment. Similarly, only minimal improvement is observed in the SF-36 role functioning-physical scale (i.e., the extent that physical health problems impaired one's ability to perform in various social and occupational roles). Individualized and gradual physical conditioning is a cornerstone of SCP treatment. During the 3-week program, patients are equipped with a conditioning plan. If the plan is too aggressive, patients become more symptomatic and do not adhere to the plan. Goals must be set and gains consistently realized over a long period, 6 months to a year, before meaningful change in physical functioning parameters can be realized. We are currently collecting follow-up data every 3 months for 2 years to determine the time-course of treatment response.

These pilot data suggest that there is sound basis to suspect that a multidisciplinary multifaceted intensive outpatient treatment like SCP can and is benefiting individuals with persistent post-deployment physical symptoms. The data presented, however, have important limitations. Findings may be confounded by the passage of time (i.e., patients may simply improve over time). Similarly, nonspecific elements of the intervention, such as performing long outcome assessments, may impact on findings. Therefore, we have proposed to evaluate the medical and cost effectiveness of this treatment using a randomized design comparing SCP to usual medical care. This grant proposal was submitted to the US Army Medical Acquisition Activity on April 30, 1997. If the project is found to be designed well and is funded, the money is expected to be available in the first quarter of fiscal year 1998.

Statement on the
Medical Evaluation and Treatment of Persian Gulf War
Veterans Having Difficult to Diagnose or Ill Defined Conditions

Kenneth W. Kizer, M.D., M.P.H.
Under Secretary for Health
Department of Veterans Affairs

Before the
House Veterans Affairs' Committee
Subcommittee on Health
Hearing on
Persian Gulf War Veterans' Illnesses

June 19, 1997

****

Mr. Chairman and Members of the Subcommittee:

I welcome this opportunity to discuss VA's medical management of Persian Gulf War veterans having difficult to diagnose or ill-defined conditions.

Before commenting on the specific subject of today's hearing, I will take this opportunity to refresh your memory about VA's overall response to Gulf War veterans' healthcare needs, describing specific elements of our approach to the diagnosis and treatment, as well as research, of the illnesses of these veterans.

BACKGROUND

On August 2, 1990, Saddam Hussein invaded Kuwait, and American military personnel were deployed to Southwest Asia soon thereafter. Ultimately, nearly 700,000 U.S. troops were deployed to the Persian Gulf in Operations Desert Shield and Desert Storm.

It was clear to the military leaders planning this action that military personnel engaged in these actions would be exposed to a variety of risks. A number of preventive measures were taken for the purpose of protecting them from biological and chemical weapons; these measures included the administration of pyridostigmine bromide and special vaccinations. After months of tense military build-up in a stark and hostile desert

environment, coalition military forces fought a successful air war, followed by a four-day ground war.

For some Gulf War military personnel, however, the trauma and pain of war did not end with the ceasefire. Veterans returned home, and began to come to VA for help with a variety of symptoms and illnesses. They reported a long list of environmental exposures which occurred during their service in the Gulf War. We listened to the veterans' concerns and utilized the increasing knowledge gained to design and implement special healthcare programs to serve their needs. These special Persian Gulf War programs are a supplement to the comprehensive healthcare services VA provides for the nation's veterans of other conflicts.

VA's Persian Gulf Registry health examination program was the first component of VA's comprehensive Gulf War response. VA developed the Registry in 1991, and implemented it in 1992. Persian Gulf War health programs in the days soon after the war were given high priority. Of note, the Persian Gulf Registry was not intended or designed to be a scientific research study. Neither was it designed to be a "stand-alone" healthcare program, nor to provide longitudinal follow-up to Gulf War veterans. It was never envisioned to be a mechanism to monitor health outcomes. Instead, the Registry was established primarily to assist Gulf War veterans gain entry into the continuum of VA care and to act as a health screening database. As such, VA staff are instructed to encourage all Gulf War veterans, symptomatic or not, to get a Registry examination.

VA's Persian Gulf War Registry serves a valuable function, but it also has significant limitations, including providing information only on a self-selected population and being a single evaluation of veterans examined over a variable time period since their Gulf War service.

Since the Registry examination program was initiated, VHA's Gulf War programs have grown to encompass a comprehensive approach to health services, addressing relevant medical care, research, and educational issues. In 1993, at the request of VA, Congress passed legislation later enacted as Public Law 103-210, giving Persian Gulf War veterans special eligibility (priority care) for VA healthcare. This law gave VA the authority it requested to treat Gulf War veterans who have health problems which may have resulted from an environmental or hazardous exposure during Gulf War service. VA now provides Gulf War Registry health examinations and hospital and outpatient follow-up care at its medical facilities nationwide, specialized evaluations at four regional Referral Centers, and readjustment and sexual trauma counseling to Gulf War veterans. To date, more than 66,000 Gulf War veterans have completed Registry examinations; more than 1.8 million ambulatory care visits have been provided to 191,000 veterans; more than 19,000 veterans have been hospitalized at VA medical facilities; nearly 400 veterans have received specialized Referral Center evaluations; and more than 74,000 Gulf War veterans have been counseled at VA's Vet Centers.

REGISTRY EXAMINATIONS

Gulf War veterans participating in the Registry examination program have commonly reported that they suffer from a diverse array of symptoms, including fatigue, skin rash, headache, muscle and joint pain, memory problems, shortness of breath, sleep disturbances, gastrointestinal symptoms, and chest pain. These multisystem symptoms have been treated seriously, and veteran patients have received medical evaluations, as appropriate. Of particular note, 12 percent of the VA Registry examination participants have had no specific health complaints but, have wished to participate in the examination because they were concerned that their future health might be affected as a consequence of their service in the Persian Gulf War. Overall, while 26 percent of the Registry participants rated their health as poor, 73 percent receiving this examination reported their health as all right to good. To date, the diagnoses received by Registry participants do not

cluster in one organ system or disease category. Instead, the diagnoses span a wide range of illnesses and diagnostic categories. This data has been provided to the Subcommittee on a number of occasions.

Only a minority of symptomatic Gulf War veterans who have been evaluated in the VA Registry have unexplained illnesses. Depending on the particular nomenclature used, between 10-25 percent of veterans from the Registry who have been examined have been found to have unexplained illnesses. While some symptoms of Gulf War veterans are difficult to diagnose and remain unexplained, there is consensus among government and non-government physicians and scientists alike that current evidence does not support the commonly held lay impression that these illnesses represent a single, unique illness that can explain *every* Gulf War veterans symptoms. As such, the unexplained illnesses of Gulf War veterans do not meet the clinical definition of a medical syndrome, per se.

As previously stated, the majority of Gulf War veterans have a wide spectrum of diagnosed medical conditions. The overall frequency of unexplained symptoms among Gulf War veterans appears to be about the same as in a general medical practice (i.e., a non-VA or non-military general medical practice). I should stress, however, that this in no way diminishes the importance of these health problems or the intensity or type of evaluation the symptomatic person receives at VA facilities. Also, does this mean that care for Gulf War veterans with diagnosed or undiagnosed illnesses has been ignored by VA? The answer is absolutely no.

We recognize that the wide variety of medical conditions diagnosed in Gulf War veterans, and the lack of a unique Gulf War Syndrome per se has created a significant set of challenges for VA clinicians. We believe that Gulf War veterans who seek care from VA are suffering from genuine illnesses and, as indicated already, we are providing a substantial amount of healthcare and treatment for these veterans.

TREATING AND MANAGING PERSIAN GULF WAR VETERANS' ILLNESSES

This Subcommittee has asked that I address the Department's efforts to treat and manage the relatively small group of veterans having ill-defined health problems, as well as VA's evaluative findings regarding the treatments provided.

The difficulty VA has with monitoring and evaluating the results of treatment and precisely determining the outcomes of our healthcare efforts are directly related to the lack of a single consistent, definable medical condition in Gulf War veterans. Approximately 75 percent of symptomatic Gulf War veterans in our Registry who have been examined have had their condition definitely diagnosed and treated. Treatments are based on the best contemporary medical knowledge and are tailored to the individual veteran's complaints and symptoms. There is no cookbook or formula approach to treatment that will give relief to every Gulf War veteran who is treated. We must rely on the clinical skills and best medical judgment of VA's physicians and other practitioners. VA clinicians must also carefully evaluate the latest and best available therapies for "symptom syndromes" such as chronic fatigue syndrome and fibromyalgia that are seen in a number of Gulf War veterans. We encourage the use of innovative and non-traditional forms of therapy, although specific treatments employed remain the prerogative of the treating clinician. We use both monitored clinical and research approaches to obtain the maximum information from our efforts. These ill-defined symptoms provide equal challenges to VA and non-government healthcare providers alike. Treatments provided by VA healthcare providers meet the high standards that we set for VA healthcare in general. The quality of care for veterans, including Gulf War veterans is subject to continuous external and internal peer-review and scrutiny.

Your questions do raise some significant issues that have been a source of frustration to VA healthcare providers and to me personally. We have heard testimony, listened to statements made in veterans forums, and heard from veterans one-on-one in our

examination rooms around the nation. Some Gulf War veterans are dissatisfied with the availability of or access to VA care. Others complain about the continuity of their healthcare. Still others rate individual clinicians highly, but are very frustrated that they have symptoms from an uncertain cause. We share these frustrations and have tried to restructure services to deal with these issues.

As you know, the Veterans Health Administration is undergoing a massive reorganization. We are in the process of transitioning from a predominantly inpatient system to an outpatient-based healthcare delivery system. We are implementing primary care teams nationwide for every veteran, including Gulf War veterans. It has been our judgment that primary care would be helpful in providing both better access to and continuity of healthcare. On the other hand, primary care teams have not always provided an acceptable solution for some veterans with complex medical problems. Many of these veterans, and certainly the most complex Gulf War cases, need a system of care which utilizes case management. This is one of the reason that increased case management will be targeted in our VISN Director performance contracts. We believe that case managed care should be an integral part of VA's healthcare delivery system, if not the foundation of the system since VA treats so many patients with complex medical and socioeconomic conditions. As we move forward in these areas, we will keep the Committee informed of our progress.

While VA has been a leader in the development of veterans healthcare programs, improvement of understanding concerning PGW health issues and dissemination of knowledge on Gulf War-related health issues, and while we believe that our programs have been well designed, we also know that they are neither uniformly delivered nor perfect. We also recognize that some veterans have not received the kind of reception or care at VA medical facilities that we can be proud of. To both you and those veterans I pledge that the Veterans Health Administration (VHA) is working diligently to improve their satisfaction with our services.

In this regard, VHA has established quality monitors and performance standards for the Registry program. In February, I established Service Evaluation and Action Teams (SEATs) within the Veterans Integrated Service Networks to evaluate and improve healthcare delivery and customer satisfaction. The SEATs are envisioned to first address Gulf War veterans and, if successful, later be used for other programs. VHA has also developed a new customer satisfaction survey which over-samples Gulf War veterans. This survey will, for the first time, provide us the opinions of Gulf War veterans. The survey will produce adequate statistical power from which to draw valid conclusions about these data. These programs will allow us to collect data for quality improvement of VA programs and support our goal of providing the highest quality care to veterans.

EDUCATION

In order to keep our healthcare providers well informed about the latest developments related to Gulf War veterans, VA has utilized a wide array of communication vehicles, including periodic nationwide conference calls, mailings, satellite video-teleconferences and annual on-site continuing medical education (CME) conferences. In 1995 and 1996, we broadcast teleconferences on undiagnosed illnesses and on the evaluation and management of chronic fatigue syndrome. A 1996 CME conference was comprised of workshops focused on evaluation and management of common symptoms and medical conditions identified in Gulf War veterans. The latest national Persian Gulf War CME conference was held on June 3-4, 1997, in Long Beach, California; it was judged by participants as being highly informative and useful.

VA's past internal educational efforts have been primarily aimed at developing a dedicated cadre of well-informed Registry physicians and staff, who in turn provide a source of education and consultation to other healthcare providers at their facilities. However, with the advent of primary care and the growing recognition that the health problems of Gulf War veterans span all medical subspecialties, we believe VA needs to expand its

educational programs. We see an opportunity to improve the understanding of Gulf War-related health issues by other medical personnel. Our goal is that all VA healthcare providers will have a working understanding of Gulf War exposures and health issues and will be able to discuss with their Gulf War patients how these issues could impact on their current or future health status. In order to meet this challenge and continue to improve our programs, the Veterans Health Administration has developed and will publish a self-study Persian Gulf CME program for every VA physician this year. We will make this available to non-VA physicians, at cost, as well. The Presidential Advisory Committee found that our Registry and Referral Center personnel were indeed knowledgeable and well-informed about all aspects of Persian Gulf War veterans' health issues. However, they opined that education of healthcare providers not directly involved in the Registry program and VA's risk communication efforts should be enhanced and augmented. VA agrees, and efforts to accomplish this are already underway.

RESEARCH

In order to get the best assessment of the health status of Gulf War veterans, a carefully designed and well executed research program is necessary. VA, as lead agent for federally- sponsored Persian Gulf War research programs, has laid the foundation for such a research plan. Under the auspices of the Persian Gulf Veterans Coordinating Board's Research Working Group, VA has developed a structured research portfolio to address the currently recognized, highest priority medical and scientific issues. More than 90 research projects are in progress and or have been completed. We continue to search for answers and to expand our understanding of the complex array of issues related to Gulf War veterans' illnesses.

VA's own research programs related to Gulf veterans' illnesses include more than 30 individual projects being carried out nationwide by VA and University-affiliated investigators.

After initiating a nationwide competition in 1993 VA established three Environmental Hazards Research Centers in 1994. All three Centers are carrying out projects which address aspects of the potential adverse health outcomes of exposure to a wide variety of hazards, including chemical warfare neurotoxins. In 1996, we established a fourth center at the Louisville VAMC for investigation of adverse reproductive outcomes. In addition, VA's Environmental Epidemiology Service has completed an initial Persian Gulf Veterans Mortality Study and has begun a long-term mortality study. The VA National Health Survey of Persian Gulf Veterans and Their Families is being carried out by the VA's Environmental Epidemiology Service. Phase I, a postal survey of 15,000 Gulf War veterans and a comparison group of 15,000 Gulf era veterans, was completed in August 1996. The questions on this survey asked veterans to report health complaints, medical conditions, and possible exposures to a wide variety of possible environmental agents, including potential nerve gas or mustard gas exposure. Phase II will consist of 8,000 telephone interviews and a review of 4,000 medical records. Phase II will address the potential for non-response bias, provide a more stable estimate of prevalence rates for various health outcomes, and verify self-reported health outcomes in medical records. The Phase III examination protocol for the examinations of veterans and their family members is in final planning stages. Details of these and other government-sponsored research studies are included in the report Federally Sponsored Research on Persian Gulf Veterans Illnesses for 1995. Copies of this report and its update have been previously provided to the Subcommittee.

Lastly, you asked that I discuss current or planned VA research regarding health outcomes associated with particular approaches to treatment or management of the health problems of Gulf War veterans. Research on Gulf War health issues has proceeded according to an orderly and coordinated strategic plan. It has progressed from initial descriptions of individual veterans' health problems, to cluster investigations, to descriptive epidemiology studies and basic science investigations of the potential adverse health effects of specific exposures which occurred during Gulf War service. While these efforts represent a

reasonable approach and a good beginning, I have asked VA's Research Service to take a completely fresh and comprehensive look at these issues in light of the growing realization of the complexity of the medical issues involved. This new effort will be fully coordinated with the Persian Gulf Veterans Coordinating Board.

Specifically, first I have asked them to develop a research strategy for studying the health effects of low-level exposure to chemical warfare nerve agents. During March of this year, VA sponsored an international conference on the health effects of low-level exposure to chemical warfare nerve agents. The findings and conclusions of this conference will play a key role in the development of our research strategy. Low-level chemical exposure issues are of great importance to veterans of the Gulf War, as well as to the entire U.S. population. I also believe it is essential to bring together a multi-disciplinary interagency group of experts to focus on finding innovative solutions to these perplexing issues. Further, I agree that it is now appropriate for research to look at treatments for those conditions that occur in Gulf War veterans for which a case definition exists and which, therefore, lend themselves to prospective research studies (for example chronic fatigue syndrome and fibromyalgia), even though the occurrence of such conditions may not be widely supported by medical scientists. Finally, I have asked the Office of Research and Development to provide increased focus on outcomes research for Gulf War and other veterans.

A question that naturally arises is whether there are effective ways of treating undiagnosed, symptom-based illnesses which may not have measurable physiologic findings. In the traditional view of treatment outcomes research such undifferentiated, symptom-based illnesses are not amenable to outcomes research because one or all of the following requirements for a treatment trial are lacking: a clearly defined definition of the disease, a clearly defined health outcome, and a single treatment aimed at a biologically plausible etiology. Treatment trials are the foundation of evidence-based medicine, which is changing the way clinicians carry out their mission by informing them of the best, most effective approaches to treatment and care.

The VA Office of Research and Development has a long tradition of supporting outcomes research and devotes over $40 million per year in this area. As an example of the type of studies it supports, VA has recently launched a new cooperative (multi-center) trial on treatment for PTSD. This study expands traditional pharmacological approaches to PTSD to include more complex non-pharmacological treatment approaches. The primary objective of this trial is to evaluate the efficacy of trauma-focused group therapy for treating PTSD symptoms. VA is also interested in additional ideas for treatment of patients with PTSD, and will shortly circulate a program announcement for additional VA cooperative studies. We will be specifically soliciting trials of non-pharmacological and innovative treatments of PTSD; trials for treatment of PTSD in special subpopulations such as women, Gulf War veterans, the Vietnam veterans, the so-called "atomic veterans" and others; studies of treatments aimed primarily at comorbid disorders prevalent among PTSD patients; and studies of the effects of treatments on "preclinical" markers that might be used as screens for treatment strategies which would then be subject to additional scientific testing. The findings of such research, along with the development of novel methodological approaches to outcomes research on non-pharmacological and non-conventional treatments of PTSD, should have multiplicative benefits for research and treatment for undiagnosed illnesses.

Research related to the illnesses of Gulf War veterans is highly complex, and this is equally true of outcomes research. VA is committed to meeting these challenges and providing quality healthcare and the most effective treatments to Gulf War veterans. We will continue to solicit the advice of scientific experts, oversight groups and this Sub-committee to improve our programs for veterans. VA healthcare providers are dedicated to providing compassionate care and answering important medical questions. President Clinton has made it clear that no effort should be spared in this regard.

Although both the treatment and research for Persian Gulf veterans have been strong, we have proactively taken steps to improve the program when weaknesses have been identified. We believe the approaches being pioneered for these veterans will benefit

others in the future. We welcome your specific suggestions for how VA care can be improved and how VA can be more responsive to those who it serves.

That concludes my statement. I will be happy to answer your questions.

MATTHEW L. PUGLISI
ASSISTANT DIRECTOR FOR GULF WAR VETERANS
VETERANS AFFAIRS AND REHABILITATION COMMISSION
THE AMERICAN LEGION
BEFORE THE
VETERANS' AFFAIRS SUBCOMMITTEE ON HEALTH
UNITED STATES HOUSE OF REPRESENTATIVES
ON
MEDICAL TREATMENT PROVIDED TO GULF WAR VETERANS WITH DIFFICULT TO DIAGNOSE AND ILL-DEFINED CONDITIONS

JUNE 19, 1997

Mr. Chairman and distinguished members of the committee:

Thank you for inviting The American Legion to provide testimony concerning medical treatment offered by the Department of Veterans Affairs (VA) to Gulf War veterans with difficult to diagnose and ill-defined conditions. The American Legion would like to take this opportunity to commend the Chairman for convening a second hearing devoted to Gulf War veterans' health so early in this Congress. Gulf War veterans, and VA, will benefit from the Committee's ongoing oversight.

Gulf War Illnesses (GWI), or Gulf War Syndrome, describe the health complaints of thousands of Gulf War veterans. To date, these complaints have defied a clear definition or diagnosis by the medical community. The Chairman's decision to investigate how VA approaches these undiagnosed health complaints is very wise because it gets at the heart of the GWI issue. The essential question that this hearing asks is: how well does VA treat veterans with GWI?

There is little evidence that VA's overall approach provides effective medical treatment to Gulf War veterans with difficult to diagnose and ill-defined conditions. The structure of VA's medical system, the lack of a treatment protocol to guide VA physicians in the treatment of these illnesses, the nature of these illnesses, and site visits conducted by The American Legion suggest that, on the whole, VA does not effectively treat these illnesses. Outcome studies, once conducted, will show whether or not VA care is effective.

Background
Public Law 102-585 mandated VA's Persian Gulf Health Registry (the Registry) in August 1992. The Registry was created in the wake of Congressional concerns over the short and long term health effects of veterans' exposure to the oil well fire smoke in the Persian Gulf. Any Gulf War veteran is eligible for a free, complete physical examination with basic lab studies, whether or not the veteran is ill. The examination protocol has been revised and improved over the life of the Registry, and as of today over 65,000 Gulf War veterans have taken advantage of this health examination. VA has designated a physician at every VA Medical Center (VAMC) to coordinate this program.

Gulf War veterans are eligible for medical treatment from VA where an illness possibly related to exposure to an environmental hazard or toxic substance is detected during a Registry exam. Follow-up care is provided on a higher-eligibility basis than most nonservice-connected care. This follow-up care is the key in returning sick veterans to good health.

An expert committee convened by the Institute of Medicine (IOM) is currently evaluating the Registry, but another IOM committee judged the Department of Defense's (DoD) Comprehensive Clinical Evaluation Program (CCEP) "excellent" for the diagnosis of illnesses (IOM, 1996). DoD's CCEP and the Registry share identical protocols, and the Presidential Advisory Committee on Gulf War

Veterans' Illnesses (PAC) therefore assumed that VA's Registry would be similarly judged by IOM. The American Legion, however, has found that in practice the Registry may not be as excellent as the PAC assumes, and I will discuss why later in my testimony.

The PAC found that VA provides "high-quality health care" to Gulf War veterans (PAC, 1996). This finding was based on several site visits to VAMCs by PAC staff, and the public comment received by the PAC at its meetings. This sparse data hardly supports such a definitive finding concerning VA health care.

In the last fifteen years, outcomes research has examined the subjective experience of patients under real-world conditions. The goal has generally been not merely to test the efficacy of interventions ("can drug treatment for a particular disease make patients feel better") but whether a given group of patients actually feels better after specific forms of treatment.

Do Gulf War veterans *feel* better after they receive treatment from VA? VA has not formally measured health outcomes for Gulf War veterans after they are provided health care. The American Legion, short of providing data collected from an outcome study, will present the evidence that it has collected to date that suggests the aforementioned question would be answered in the negative.

VA's Persian Gulf Registry

The American Legion has evaluated the Registry through: site visits; the observations of a medical expert; and through experiences reported by Gulf War veterans and local American Legion officials throughout the country.

The American Legion maintains a Field Service division at its Washington Office. The mission of the Field Service is to conduct site visits to Veterans Health Administration (VHA) healthcare facilities to examine specific aspects of VA's delivery of services. Four Field Representatives are assigned specific geographic areas to conduct visits, and the division visits 50-60 facilities per year. The division has visited 25 sites so far this year.

The American Legion also enjoys the services of a medical consultant, Dr. Michael Hodgson, M.D., M.P.H., an associate professor of medicine at the University of Connecticut Medical School. Dr. Hodgson has evaluated the Registry through a review of VA's Uniform Case Assessment Protocol (the Registry's protocol), U.S. General Accounting Office (GAO) and Legion reports, site visits to a VAMC, interviews with VA physicians, and the available medical and scientific literature concerning the treatment of fatigue and other ill defined illnesses.

Although The American Legion has not conducted a formal survey of Gulf War veterans, it has provided tens of thousands of Gulf War veterans with assistance in seeking VA benefits. These veterans share their experiences with Legionnaires and this provides local, state and national Legion officials with a vast collective knowledge of veterans' experiences at VA.

Field Service Methodology

Field Service Representatives review designated topics during their site visits. For example, many site visits in 1997 have focused on the changes involved with establishing the Veterans Integrated Service Networks (VISN) system and the development of a primary care approach at VHA. Topics for the site visits are determined through evaluating: VA reports; GAO reports; responses to briefing questions by VA staff; interviews with VA personnel and patients (as available); and, input from state or local American Legion officials.

Strengths

The American Legion's Field Service provides first-hand observation and advocacy regarding local concerns. It is able to discuss the Registry with various

administrative coordinators and some clinical providers. The division also conducted site visits to three of the National Referral Centers (NRC) so far this year, and the fourth NRC will be paid a visit before the end of the Summer.

Limitations
Site visits are not an audit or scientific review, and personal contact with Gulf War veterans is often difficult to arrange while they are visiting a VAMC.

Observations

VA's Persian Gulf Registry

Strengths
Registry providers on the whole appear concerned and dedicated. The Registry examination is widely available, and it has been improved since its inception. Many physicians at VAMCs have become familiar with the protocol, and over 65,000 exams have been conducted. Site visits, reports from local Legion officials and comments from Gulf War veterans suggest the Registry is developing into an appropriate introduction for veterans to VHA.

Limitations
First year residents in primary care teams are very likely to conduct Registry examinations at a number of VAMCs. These residents have little experience in undiagnosed illnesses and symptoms, and are in many cases confronted with patients who are extremely challenging to manage for even experienced physicians.

Fatigue is the most common complaint of Gulf War veterans who report poor health during a Registry examination, yet the Registry's protocol does not direct physicians to conduct standard clinical testing under current diagnostic strategies in primary care for fatigue. Veterans are not likely to be treated appropriately for fatigue, and are therefore likely to continue to feel ill.

Gulf War veterans' most consistent complaints concerning the medical treatment provided at VA are: the care's ineffectiveness; "insensitive" physicians who are quick to dismiss patients' concerns and ideas regarding their illness; and the sometimes disorganized and haphazard follow-on care process after a Registry examination. Many complain that they "slip through the cracks" after the Registry examination. Those who do not seek the assistance of the patient representative or a veterans service organization may become "lost" to VA and not provided medical treatment at all. This is a great concern of The American Legion.

The anger Gulf War veterans express concerning psychological diagnoses and psychological consultations during and after the Registry process is well known, and likely the most widely reported aspect of GWI by the media with the exception of chemical warfare agents exposures. The American Legion recognizes the general stigma attached to mental illness throughout our society, and earlier battles over the recognition of Posttraumatic Stress Disorder (PTSD) have displayed that veterans view mental illness no differently than the society in which they live. Available data clearly shows that although there are Gulf War veterans who suffer from PTSD, PTSD is not an explanation for GWI. However, a veteran can be ill from chemical weapons exposures *and* clinical depression at the same time. One would expect that chronic poor health that goes undiagnosed would lead to poor mental health in some veterans. The pressures of chronic poor health, lack of answers, unemployment or underemployment and maddening government bureaucracies is a cruel fate faced by many who served their country so well in the deserts of Southwest Asia. Yet, if this is the case for some Gulf War veterans, the illnesses that the medical community, and VA, are most able to treat effectively (psychological illnesses) are the diagnoses associated with the worst experiences veterans have had with VA. If some Gulf War veterans suffer

from nerve damage due to chemical warfare agent exposures, that nerve damage cannot be effectively treated by any known method today.

It is not known if this nerve damage can eventually lead to death. Yet studies suggest that men who suffer from depression, and who do not seek treatment, are at greatly increased risk to commit suicide. The statistically significant rise in single vehicle auto accidents in deployed Gulf War veterans suggests that suicides may already occur at a greater rate in this population. This behavior was observed in Pittsburgh with unemployed steel workers in the early 1980s. They chose to take their lives in such a way so as not to prevent insurance companies from paying their survivors benefits.

Given the negative experiences of many Gulf War veterans at VA, are some Gulf War veterans going untreated for mental illness? If so, this predominately male population is being put at a greater risk for suicide and deteriorating health.

After the Registry Exam: Treatment

Specialty Consultations
Information from subsequent specialty consultations do not get back to the physician who conducted the Registry examination in all cases. At many VAMCs there is no one individual who is tracking or managing a Gulf War veterans' follow-up treatment after the initial exam. The primary care model, which VHA is moving towards, addresses this shortfall. VHA is not, however, moving to designate primary care physicians, but primary care teams. It is likely that these teams will be more effective than the current model at VHA in caring for veterans with GWI. Primary care teams, however, will likely not offer veterans as high quality care as a primary physician would.

National Referral Centers (NRC)
VA advertises the NRCs as the place where veterans are sent if they do not receive a diagnosis after a Registry examination in which they have a health complaint. Phase II of the Case Assessment Protocol guides physicians through this in-depth examination process. The goal of Phase II is to absolutely get to the bottom of what ails the patients. VA reports that most patients, after completing Phase II, do indeed receive a diagnosis. VA has designated four VAMCs as NRCs: Washington, DC; Birmingham, Alabama; Houston, Texas; and, West Los Angeles, California. In practice, however, this is not the role of the NRCs.

Strengths
The NRCs provide a level and sophistication of intervention that should address difficult to diagnose patients. They also have the resources to admit patients for an extended period, and they provide continuity of care and control of the patient as the examination process evolves.

Limitations
Less than 1,000 veterans have been referred to the NRCs, yet approximately 13,000 have not received a diagnosis during a Registry examination. Why have so few veterans been referred when so many do not receive a diagnosis?

Some veterans have expressed that they have no desire or ability to travel such a great distance and for such a long period of time as is required to attend an NRC. Some VAMCs can provide the wide range of diagnostic workups required in the Phase II examination offered at the NRCs and therefore do not refer patients. During site visits several VA physicians admitted that they refer "problem" patients to NRCs, those patients who "make a lot of noise" concerning their care at VA. These physicians refer the patients in order to convince the patients that VA is doing all it can to diagnose their illness, not because of any particular merit in the NRC system.

Another limitation is that the NRCs visited to date (Birmingham has not been visited) do not always have assigned teams who administer Phase II examinations. Patients see the specialist on call, and this has prevented any growth in the collective knowledge at the NRC concerning Phase II examinations and the nature of GWI.

Recommendations

Treatment
VA should conduct formal outcome studies to measure the effectiveness of the medical treatment provided to veterans suffering from GWI, and to measure these patients' subjective experience at VA. The findings of such studies will aid VA in either validating its current health care approach, or offering it clues as to how to improve this approach.

In other diseases without a known "cure," the U.S. health care model has evolved an approach over the last 30 years, namely randomized clinical trials of various possibly effective treatments in an attempt to weigh the benefits and costs. The logical approach to GWI is then to conduct randomized controlled trials comparing various treatment approaches. Congress should investigate funding this proposal in the budget currently under consideration.

Process
VA should immediately reevaluate the merits of the NRC system, and investigate the merits of creating VISN level referral centers. Each VISN, theoretically, is self-sufficient. Each should be able to offer a Phase II examination without referring a patient outside the VISN. The ongoing Service Evaluation and Action Team (SEAT) process at the VISNs offers a vehicle to evaluate this recommendation.

VA should also investigate the assignment of GWI patients to one primary care provider. This would provide continuity and coordination of care that is not currently evident at many VAMCs. This may address the lack of coordination and focus that many veterans confront after they undergo a Registry examination, and it should lead to more effective care offered by VA. It should also lead to healthier veterans, the outcome we all are seeking.

Training
VA should immediately investigate Gulf War veterans' experiences at psychological consultations, and evaluate the consistency of the initial psychological evaluation of patients during a Registry examination. Veterans diagnosed with PTSD have consistently complained of being sent to a wing or ward along with patients who suffer from severe mental illnesses. Some have reported that they do not return for care, and are therefore left feeling ill. Should veterans diagnosed with PTSD or depression be sent to a separate waiting room or wing? VA should immediately investigate this question and make immediate adjustments if the answer is "yes."

Is it reasonable to dismiss certain risk factors' association with GWI given what's currently not known? Although there is sparse scientific data linking chronic illness with low level chemical agent exposure, the peripheral nerve damage found in some Gulf War veterans is not explained by stress. The relationship between many of the risk factors encountered in the Persian Gulf and GWI is currently being investigated by many scientific studies. Many Gulf War veterans complain that when they offer possible explanations concerning why they are ill, many VA physicians dismiss these explanations by pointing either to negative lab results or lack of scientific data. This behavior is not exclusively found at VA, but at the Department of Defense and in the civilian medical community as well. This behavior undermines the doctor-patient relationship, and does not encourage patients to return to VA for care.

Conclusion

There is little evidence that VA effectively treats veterans who suffer from GWI. Formal and well designed outcome studies will provide evidence that will reveal how effective medical treatments provided by VA are. VA should immediately initiate such studies, while it also determines which methods are most effective in treating GWI. There are also a number of structural changes that The American Legion recommends VA investigate in order to improve the health and well being of ill Gulf War veterans.

Mr. Chairman, this concludes my testimony. I will be happy to answer any questions.

References

Bou-Holaigah, I., Kan, J., Rowe, P.C., Calkins, H., *The Relationship Between Neurally Mediated Hypotension and the Chronic Fatigue Syndrome.* JAMA. 1995;274:961-7

Chalder, T., Wessely, S., Deale, A., Marks, I., *Cognitive Behavior Therapy for Chronic Fatigue Syndrome.* American Journal of Medicine. 1995;98:419-20

Friedman, M.J., presentation to the Department of Veterans Affairs Persian Gulf Expert Scientific Committee, January, 1997.

Hyams, K.C., Wignall, F.S., and Roswell, R., *War Syndromes and Their Evaluation: From the U.S. Civil War to the Persian Gulf War.* Annals of Internal Medicine 125(5):398-405, 1996.

Institute of Medicine, *Evaluation of the Department of Defense Persian Gulf Comprehensive Clinical Evaluation Program* (Washington, DC: National Academy Press, 1996).

Institute of Medicine, *Evaluation of the Comprehensive Clinical Evaluation Program: Nerve Agents* (Washington, DC: National Academy Press, 1997)

Kizer, K.W., *Veterans Health Administration Directive 97-008* (Washington, DC, February 1997)

Persian Gulf Veterans Coordinating Board, *Unexplained Illnesses Among Desert Storm Veterans. A Search for Causes, Treatment, and Cooperation.* Archive of Internal Medicine. 1995;155:262-8

Persian Gulf Veterans Coordinating Board, *A Working Plan For Research on Persian Gulf Veterans' Illnesses: First Revision* (Washington, DC: Department of Veterans Affairs, November, 1996)

Presidential Advisory Committee on Gulf War Veterans Illnesses: Final Report (Washington, DC: U.S. Government Printing Office, December 1996).

Reeves, W., Chief, Division of Viral Exanthems and Herpes Virus Branch, National Center for Infectious Diseases, Centers for Disease Control and Prevention, presentation to the Department of Veterans Affairs Persian Gulf Expert Scientific Committee, November, 1996.

Schwartz, D.A., et al., *Self-Reported Illness and Health Status Among Gulf War Veterans.* The Journal of the American Medical Association 277:238-244, 1997.

Stretch, R.H., Bliese, P.D., Marlowe, D.H., Wright, K.M., Knudson, K.H., Hoover, C.H., *Physical Health Symptomatology of Gulf War-Era Service Personnel from the States of Pennsylvania and Hawaii.* Military Medicine. 1995;160:131-6

Sutker, P.B., Uddo, M., Brailey, K., Vasterling, J.J., Errera, P., *Psychopathology in War-Zone Deployed and Nondeployed Operation Desert Storm Troops Assigned Graves Registration Duties.* Journal of Abnormal Psychology. 1994;103:383-90

Takla, N.K., Koffman, R., Bailey, D.A., *Combat Stress, Combat Fatigue, and Psychiatric Disability in Aircrew.* Aviation Space Environmental Medicine. 1994;65:858-65

Viola, J.M., McCarthy, D.A., *An Eclectic Inpatient Treatment Model for Vietnam and Desert Storm Veterans Suffering from Posttraumatic Stress Disorder.* Military Medicine. 1994;159:217-20

Ware, N.C., *Society, Mind and Body in Chronic Fatigue Syndrome: An Anthropological View.* CIBA Foundation Symposium. 1993;173:62-73; discussion 73-82, 1993.

Wessely, S., *Cognitive Behavioral Therapy in the Chronic Fatigue Syndrome.* American Journal of Psychiatry. 1996.

NOVA NURSES ORGANIZATION OF VETERANS AFFAIRS
1726 M Street, N.W., Suite 1101
Washington, D.C. 20036
Phone (202) 296-0888
Fax (202) 833-1577

STATEMENT OF

THE NURSES ORGANIZATION OF VETERANS AFFAIRS
(NOVA)

Before the United States House of Representatives
Committee on Veterans Affairs Subcommittee on Health

On Care and Treatment of Persian Gulf War Veterans in the
Department of Veterans Affairs

By
Sarah V. Myers, Ph.D, RNC

June 19, 1997

Mr. Chairman and members of the Subcommittee, I am Dr. Sarah V. Myers, Ph.D., RNC, Supervisor and Gerontological Clinical Nurse Specialist at the Veterans Affairs Medical Center, Atlanta, Georgia. As Legislative Chair for the Nurses Organization of Veterans Affairs (NOVA) and a veteran of Operation Desert Storm Desert Shield, I am pleased to present this written testimony on Care and Treatment of Veterans with Persian Gulf War Illnesses in the Department of Veterans Affairs (DVA) on behalf of NOVA. I speak for our membership and the more than 40,000 professional nurses employed by the DVA.

INTRODUCTION

NOVA is a professional organization and our mission is: Shaping and Influencing Professional Nursing Practice within the DVA Health Care System. NOVA is very interested in assuring that all Persian Gulf War veterans receive comprehensive, accessible, and cost effective health care within the DVA. As outlined bye Secretary Jesse Brown in his testimony to you earlier this year, Persian Gulf War veterans are being treated based on identified symptoms and problems. More than 62,000 veterans have completed the Persian Gulf War Registry examinations. Recently, the DVA mailed out it's revised Persian Gulf War Registry Questionnaire to Persian Gulf veterans who were participants in the initial voluntary registry examinations. The symptoms reported by Persian Gulf War veterans are treated seriously during 19,000 hospital stays, 187,000 primary health care clinic visits and 74,000 Vet Center visits.

Care and Treatment of Veterans with Persian Gulf War Illnesses.

Since the DVA is the Nation's largest employer of nurses, especially advanced practice nurses, these nurses could be utilized in key positions to affect education of and positive health outcomes for Persian Gulf War veterans. These positions could include assignment in Compensation and Pension exams and in primary care clinics with a focus on health promotion. The literature cites countless examples of cost effectiveness of nurse practitioners. For example, outcomes such as shorter hospital stays, increased productivity, less use of prescription drugs, decreased use of the emergency room by patients, improved clinical outcomes and fewer hospital admissions have been reported (Buppert, 1995; Brown, 1995). Nurse practitioners positively impact access and quality of care, patient satisfaction and patient functional status. Nurse practitioners could potentially have a significant impact on Persian Gulf War veterans and quality care.

Persian Gulf War veterans are currently being compensated in a timely manner with the assistance of veteran service organizations. More than 44,000 letters have been mailed to veterans announcing new entitlements. Approximately 11,000 cases are being reviewed for claims and 27,000 service-connected veterans are receiving benefits.

The clinical assessment protocol addresses a broad range of needs of Persian Gulf War Veterans. Health care providers in the field reported that the Persian Gulf Registry (PGR) clinical protocol is appropriate for the scope of medical assessments needed by this veteran population. The knowledge base of health care providers has increased markedly, and the protocol has been expanded to include additional elements for evaluation. The protocol also serves as a guide for specific procedures to be followed for the twelve most commonly reported Gulf symptoms. Additionally, data is now collected on reproductive problems. The expertise of DVA practitioners, advances in computerized technology including electronic consults, electronic health care summaries, electronic records and patient care encounter forms has resulted in effective and efficient care for these veterans as well as more efficient data tracking.

While there has been some improvement in the protocol there are also some perceived limitations. One weakness of the protocol is it's inability to identify health problems resulting from service in certain areas of Southwest Asia. The majority of Gulf War veterans received their clinical protocol exams during the early implementation phase of the Registry program.

These veterans were not assessed for the additional elements related to reproductive health problems. Another weakness of the protocol is related to the process of data collection. Veterans occasionally identify problems after the assessment data has been completed and submitted. Although veterans receive treatment for these problems, it is not submitted as part of the Persian Gulf War Registry data and findings from the examination to the health care providers.

IMPLEMENTATION OF CLINICAL ASSESSMENT PROTOCOL

One of the major problems in implementation of the PGR clinical protocol is related to educating the veterans about the program. Many Persian Gulf War veterans failed to seek medical care at the VA medical centers because of a lack of knowledge. This lack of knowledge of the examination and how to access the system resulted in an inadequate understanding of veterans' expectation of the system as well as the examination. Mistrust of federal agencies continues. Mistrust toward the VA system is also reported as an obstacle in seeking health care services. However, placing advanced practice nurses in key positions, as mentioned earlier, could reduce

this barrier. A final concern reported by Persian Gulf War veterans is the different methodologies used in implementing the protocol within the VA network. Again, educating advanced practice nurses in a standardized training program would ensure consistent implementation throughout the DVA.

OUTREACH PROGRAMS

Telephone interviews with Persian Gulf Coordinators revealed that a variety of approaches have been utilized in an effort to reach Persian Gulf veterans. One approach included a large mail campaign informing veterans of the PGR program and inviting these veterans to come to VA medical centers for free examinations. Outreach efforts to educate both the public and veterans of services available to Persian Gulf War veterans have utilized both local and national coverage. Evaluation of this program reflected that Persian Gulf War veterans did not seek health care from the VA medical centers nor receive their registry examination.

A major concern voiced by Persian Gulf War veterans is the unexpected waiting time experienced at VA medical centers. Creative programs such as the Persian Gulf Saturday Clinics at Boston, Massachusetts VA Medical Center have been very effective. These Saturday clinics not only provided registry examinations but also provided a comprehensive approach to their health care. The Boston clinic used an interdisciplinary approach. Saturday clinics can serve as a model for delivering health care to Persian Gulf War veterans. Saturday clinics such as those held at the Boston VA have also proven to be effective in meeting the needs of veterans who are employed in settings where granting time off for any reason is a major issue. These clinics were very successful in screening more than 1,098 Persian Gulf War veterans and enrolling 460 of these veterans into primary care clinics.

READJUSTMENT COUNSELING CENTERS

Vet Centers across the country provided a full range of services for Persian Gulf War veterans. After an initial intake assessment, the veteran is referred to an interdisciplinary team and appropriate individuals and agencies for specialized assistance. Currently, Vet Centers offer services such as counseling for Post Traumatic Stress Disorder, marital and family counseling, psychological and sexual trauma counseling, depression and substance abuse counseling and assistance for other expressed health care issues and social problems. Employment assistance and career planning are provided through working agreements with state job services and state colleges.

Community education and post hospital follow-up for veterans suffering from war traumas also provide psychological support with referral to community and federal agencies.

RECOMMENDATIONS

While much has been done to improve the care and treatment of veterans with Persian Gulf War illnesses inconsistencies still remain. NOVA would like to make the following recommendations:

1. Appoint one interdisciplinary primary care team to identify, screen, and treat veterans with Persian Gulf War illnesses. Members of this primary care team should have an expressed interest in working with Persian Gulf War veterans. This team should also include an advanced practice nurse.

   Rationale: Primary care providers with expertise in screening for Gulf War Illnesses (GWI) will over time develop expertise in the identification of the constellation of symptoms and available treatment, provide emotional support and validate the symptoms experienced by veterans with GWI, and provide more holistic, nonjudgemental, comprehensive care without increasing costs.

2. Assign a female provider with expertise in the assessment, care, and treatment of victims of sexual assault and trauma to the Persian Gulf primary care team.

   Rationale: The number of female veterans with GWI associated with service in the Persian Gulf War has increased.

3. Implement one Persian GWI Referral Center located within each Veterans Integrated Service Network (VISN).

   Rationale: The center would decrease travel and waiting time and provide continuity for determination of service connection.

4. Provide increased education about stress as a source of illness.

   Rationale: The stigma of mental illness continues to be prevalent within our society. Many veterans may be reluctant to admit they are experiencing psychiatric problems as a consequence of the Persian Gulf War. Awareness of the relationship between stress and illness may encourage veterans to seek assistance.

5. Disseminate findings from VA funded research on Gulf War Illnesses.

   Rationale: Providing up-to-date information can reduce anxiety and reduce paranoia. The VA should expand educational and support programs to include education of veterans in

community settings, Vet Centers, veterans services groups, lay public and all VA and Department of Defense staff regarding the following topics: GWI status, outcomes of research projects in the past seven years, and alternative treatments available such as the non medical model research projects being funded by the National Institute of Health.

6. Develop creative strategies to facilitate maximum return rates of the updated Persian Gulf Registry Questionnaire.

   Rationale: Data gathered from the revised Persian Gulf Registry will add to the existing knowledge base for use in planning effective and efficient clinical programs, and identifying areas for further study.

7. Consider a mandate for all Persian Gulf War veterans who are in the National Guard or reserves to complete the revised Persian Gulf Registry through their reserve unit.

   Rationale: Persian Gulf Registry data will add to the existing profile of Persian Gulf War veterans.

SUMMARY

It is extremely important to educate VA staff and veterans about the Persian Gulf Clinical Program. Medical staff and all other professionals should be informed about current issues of Persian Gulf War Veterans. Relevant research findings by investigators should also be shared. For example, health care providers should be familiar with the new diagnostic criteria related to multiple chemical sensitivity and chronic fatigue. Staff also need to be aware of the Persian Gulf War Services offered throughout the VA and other federal agencies. All current research committees such as the Presidential Advisory Committee's recommendation, government response should be widely publicized.

This information should also be made available to the team working with this group of veterans at each VA Medical Center and Outreach Center. Gulf War Veterans is a special group of veterans who actively seek out information. They are very critical when they encounter medical staff and other professional staff who are not well informed on subjects of interest to Persian Gulf Veterans. Education sessions which assist health care providers who are working with Persian Gulf Veterans to understand the nature of the complaints of these individuals is extremely important. Veterans have also reported that these sessions are beneficial and they feel that their issues are taken seriously when they can provide input.

I would like to thank NOVA's President, Dr. Maura Farrell Miller, Ph.D, ARNP, CS, Legislative Co-Chair Barbara Zicafoose, MSN, RNCS, ANP, Jacqueline C. Hall, MSN, RNCS, NOVA members, and the Persian Gulf War Coordinators who participated in the telephone interviews for their assistance in the preparation of this testimony.

REFERENCES

Brown, S.A., & Grimes, D.E. (1995). A Metaanalysis of Nurse Practitioners and Nurse Midwives in Primary Care, Nursing Research, 44, 332, 339.

Buppert, C.K., (1995) Justifying Nurse Practitioner Existence: Hard Facts to Hard Figures. Nurse Practitioner, 20, 43-48.

Hyams, K.C., Wignall, S., & Roswell, (1996). War Syndromes and Their Evaluation from the U.S. Civil War to the Persian Gulf War. Annals of Internal Medicine, 125 (5), 398-404.

Mezy, M.D. & McGivendo, E.D.(1993). Nurses, Nurse Practitioners: Evaluation to Advanced Practice, New York: Springer Publishing Co.

National Institute of Medicine (1995). Health Consequences of Service During the Persian Gulf War: Recommendations for Research and Information Systems. Washington, D.C.: National Academy Press.

STATEMENT OF
JOSEPH A. VIOLANTE
DEPUTY NATIONAL LEGISLATIVE DIRECTOR
OF THE
DISABLED AMERICAN VETERANS
BEFORE THE
HOUSE VETERANS' AFFAIRS COMMITTEE
SUBCOMMITTEE ON HEALTH
JUNE 19, 1997

MISTER CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE:

Since 1920, the Disabled American Veterans (DAV) has been dedicated to one single purpose: building better lives for disabled veterans and their families. On behalf of the more than one million members of the DAV and its Auxiliary, I wish to express our deep appreciation for this opportunity to provide the Subcommittee with the DAV's assessment of the medical treatment of Persian Gulf War veterans suffering from Gulf War illness.

The issue of Persian Gulf War illness is a serious problem made more difficult because of its complexity, the lack of scientific/medical evidence, the failure to maintain complete military and medical records, the failure of the Department of Defense (DoD) to come forward with critical evidence establishing the possible exposure to chemical agents by U.S. troops, and the conflicting reports and conclusions being reached by various scientific/medical commissions and individuals. These are not new dynamics for veterans. Veterans returning from all our Nation's wars and military conflicts have been faced with similar problems in attempting to establish the foundation for recognizing the onset of certain conditions as service-connected; however, Persian Gulf War veterans, as a group, appear to be sicker and more severely disabled as a result of their service in the Persian Gulf than their predecessors. It has now been more than six years since the fighting ceased in the Persian Gulf theater and the majority of U.S. veterans returned home, yet there has been no noticeable decrease in the number of new claims filed by Gulf War veterans as a result of illness believed to be associated with their service in that theater. The fact that there are still many unanswered questions and conflicting medical opinions surrounding Persian Gulf illness only serves to exacerbate the situation.

Mr. Chairman, the plight of Persian Gulf War veterans suffering from undiagnosed illnesses continues to be one of our foremost concerns. In addition to not receiving adequate compensation for their disabilities or illnesses, Persian Gulf veterans face many other dilemmas. Although most experts concede that these veterans were exposed to a wide range of environmental hazards, such as experimental drugs, high levels of toxicity in substances from oil field fires, radioactive residue, parasites, pesticides, lead paint, and chemical agents, there is little consensus in the medical/scientific community as to the residuals, if any, from these exposures. Due to the confusion surrounding Persian Gulf illness, we question whether these veterans are receiving adequate medical care from the VA or DoD.

In general, Persian Gulf War veterans face the same difficulties as other veterans in receiving adequate health care from the Department of Veterans Affairs (VA). While some of the inefficient and inflexible aspects of the health care delivery system have been eradicated by the reorganization of the Veterans Health Administration (VHA) into 22 Veterans' Integrated Service Networks (VISNs), a number of veterans still feel that they are not being provided with adequate health care services. However, these complaints are not very numerous and are scattered throughout the country and, therefore, there does not appear to be a system-wide deficiency in the care provided to Persian Gulf veterans. The change instituted under Secretary of Veterans Affairs Jesse Brown and Under Secretary for Health Kenneth Kizer have increased customer satisfaction.

Mr. Chairman, the DAV is extremely concerned with the proposed funding levels for VA health care in fiscal year 1998 and beyond, with the outyears being the most devastating on the VA's ability to provide adequate health care to America's sick and disabled veterans. If VA health care funding levels are not increased, all veterans, including Persian Gulf veterans, will see their ability to receive appropriate care diminished. While the lack of appropriate care will have a devastating effect on all veterans, it will seriously impact Persian Gulf veterans as they attempt to recover from the effects of Gulf War illness as they try to make a transition to civilian life.

One of the most frustrating aspects of dealing with Gulf War illness is the medical community's desire to provide a diagnosis for these veterans' illnesses. Physicians are trained to provide a diagnosis, in other words, to "pigeonhole" the problem with their best guess. There appears to be some inconsistency in whether a veteran is provided with a diagnosis for his illness or whether the illness goes undiagnosed. In other words, two veterans with similar symptoms may find themselves treated very differently by the VA if one is provided with a diagnosis, and the other is determined to be suffering from an undiagnosed illness.

Another frustrating aspect of Persian Gulf illness is that many of these veterans are not only underrated but, when they seek medical care, VA physicians or private physicians are unable to adequately treat them because of the unknown nature of their disabilities. In many cases, these brave young men and women are unemployed because of their debilitating illness, yet they are unable to receive adequate compensation or meaningful medical care because of the confusion surrounding their illness.

An additionally frustrating aspect of Persian Gulf illness is that, six years after the end of the Persian Gulf War, we are still unable to answer the question about what is causing these undiagnosed illnesses. Unfortunately, the report by the Presidential Advisory Committee on Gulf War Veterans' Illnesses (PAC) does not provide any concrete answers to the question of what is causing Persian Gulf illness. While the PAC has stated that "veterans clearly have service-connected illnesses," they conclude that the current scientific evidence does not demonstrate a causal connection between so-called Persian Gulf illnesses and the environmental risk factors that veterans were exposed to in the Persian Gulf. These environmental risk factors include: pesticides, chemical and biological warfare agents, vaccines, pyridostigmine bromide, infectious diseases, depleted uranium, oil well fires and smoke, and petroleum products.

The PAC does note, however, that further investigation is required to determine the long-term effects of exposure to low-level chemical warfare agents and the synergistic affects of exposure to pyridostigmine bromide and other risk factors. The PAC also cautioned that some of the environmental risk factors were potential carcinogens and that there was a possibility of an increase in the risk for cancers after decades following the end of the war. It is our sincere hope that DoD and VA will continue to track these veterans and monitor them for any increased cancer risks.

The PAC report focuses on stress as a likely contributing factor to the broad range of physiological and psychological illnesses currently being reported by Persian Gulf veterans. It is noted that currently, scientists are beginning to "unravel the psychological connection between the brain and various other parts of the human body" (p. 124). Additionally, it was noted that, based on decades of clinical observations, physicians recognize that many physical and psychological diagnoses are the consequence of stress. This led the PAC to conclude that "stress can contribute to a broad range of physiological and psychological illnesses. Stress is likely to be an important contributing factor to the broad range of illnesses currently being reported by Gulf War veterans" (p. 125).

We note with great interest the PAC's statement that decades of clinical observations demonstrate a causal connection between stress and many physical and psychological diagnoses. For decades, the VA has denied any connection between service-connected Post Traumatic Stress Disorder (PTSD) and most physical or psychological disabilities. Veterans have routinely been unsuccessful in attempts to obtain service connection for mental and physical disabilities as secondary to PTSD. Why are these claims being denied if decades of clinical observations show a causal connection between stress and physical ailments? Congressional oversight in this area would clearly be appropriate and we urge this Committee to exercise that authority.

As scientific/medical researchers continue to search for the answer to the nagging question of Persian Gulf illness, our Nation must not forget that these veterans and their families are suffering because of the veteran's deployment to the Persian Gulf. Accordingly, this Committee must continue to seek answers to help explain the mystery surrounding these unexplained ailments and to ensure that these veterans receive adequate compensation and appropriate medical care.

With respect to follow-up treatment, the PAC notes that follow-up treatment is usually problematic. It is noted that staffing constraints often result in long delays in scheduling appointments and that psychiatric staffing is particularly overloaded at some facilities. Additionally, many veterans receive follow-up care from a number of physicians, both government and private sector, and no single case manager is responsible for their care.

In the past, DAV has noted that there is a lack of coordination within the VA. VA health care interventions were organized to respond to symptoms rather than focus on possible underlying etiology. No single VA medical person had the "big picture" of a veteran's multiple symptoms. We have found that if a veteran presents him or herself to a VA medical clinic with a

number of different symptoms, he or she is referred to each clinic that handles the specific symptom. In other words, a veteran suffering from headaches, rashes and a gastrointestinal disorder is sent to three different clinics. Sometimes, by the time the veteran is seen, the symptoms have disappeared, only to return at a later date. Coordination of care and disease tracking would facilitate the overall understanding of the episodic, as well as interrelational aspects of the medical problems reported by Persian Gulf veterans. Accordingly, a single case manager would not only benefit the veteran, but would also serve to provide necessary coordination of care and disease tracking.

As the entire VA health care system moves toward primary care physicians, it would appear that the lack of coordination of care will be resolved.

This concludes my statement. I would be pleased to answer any questions you or members of the Subcommittee may have.

Motto: "If I cannot speak good of my comrade, I will not speak ill of him."

DISABLED AMERICAN VETERANS

NATIONAL SERVICE and LEGISLATIVE HEADQUARTERS
807 MAINE AVENUE, S.W.
WASHINGTON, D.C. 20024
(202) 554-3501

DISCLOSURE OF FEDERAL GRANTS OR CONTRACTS

The Disabled American Veterans (DAV) does not currently receive any money from any federal grant or contract.

During fiscal year (FY) 1995, DAV received $55,252.56 from Court of Veterans Appeals appropriated funds provided to the Legal Service Corporation for services provided by DAV to the Veterans Consortium Pro Bono Program. In FY 1996, DAV received $8,448.12 for services provided to the Consortium. Since June 1996, DAV has provided its services to the Consortium at no cost to the Consortium.

Joseph A. Violante, Esq.
DISABLED AMERICAN VETERANS
Deputy National Legislative Director

807 Maine Ave. SW
Washington, D.C. 20024

Phone (202) 554-3501
Fax (202) 554-3581

EDUCATION:

1981	Juris Doctorate, University of La Verne, College of Law
1975	Bachelor of Arts, History and Political Science, University of New Mexico

MILITARY SERVICE

1969-1972	*United States Marine Corps, separated as Sergeant, E-5*

EMPLOYMENT:

1996-Current	***Deputy National Legislative Director, Disabled American Veterans (DAV)***
1992-1996	***Legislative Counsel, DAV***
1990-1992	***Staff Counsel, DAV***
1985-1990	***Attorney, Department of Veterans Affairs, Board of Veterans' Appeals***
1981-1985	***Attorney, Sole Practitioner***

ORGANIZATIONS AND AFFILIATIONS:

Member, State of California and District of Columbia Bars
Member, Presidential Delegation (POW/MIA's) to Southeast Asia, March, 1996
Co-chair, Veterans' Appeals Committee, Federal Circuit Bar Assoc., 1992-1996
Co-chair, Legislative Committee, Federal Circuit Bar Assoc., 1996-present
Vice chair, Veterans' Benefits Committee, American Bar Association, 1991-present
At-large board member, Veterans' Law Section, Federal Bar Association, 1991-1992
Life member, Disabled American Veterans, Chapter Commander, 1990-1991
Life member, Veterans of Foreign Wars, Post Commander, 1984-1985
Life member, 3d Marine Division Association, Chapter Secretary, 1986-1987
Member, American Legion, Marine Corps League, and 2nd Bn, 4th Marines Assoc.
Member, Knights of Columbus, Fourth degree
Member, National Italian-American Foundation, Council of 1000
Member, National Italian-American Bar Association
Member, Geriatrics and Gerontology Advisory Committee, Dept. of Veterans Affairs
Board of Directors, Bowie Cable TV, 1992-1994
Member, Bowie Cable TV City Council Advisory Committee, 1989-1991
Co-host, *Veteran's Forum*, Bowie Cable TV, 1991-1994

The National Gulf War Resource Center, Inc.
P. O. Box 10402
Kansas City, Mo. 64171
(816) 960-0991 voice (816) 960-0993 fax
Office Address: 3100 Main St. Suite 207
Kansas City, Mo. 64111
e-mail to: ngwrc@gulfwar.org

Executive Director
Jeffrey S. Ford

President
Chris Kerekes

Vice President
Erika Landholm

Secretary
Kevin Knight

Treasurer
Duane Meverer

Board of Directors

Don Fahey

Hilary Jones

Debbie Judd, R.N.

Paul Lyons

Jackie Olson

Paul Sullivan

James J. Tuka, III

Alternate
Jim Brown

Testimony

of

Jeffrey S. Ford
Persian Gulf War veteran
and
Executive Director, NGWRC

before
U. S. House of Representatives Committee on Veterans Affairs,
Subcommittee on Health
June 19, 1997

Mr. Chairman, Members of the Committee,

I am honored to appear before you today for the third hearing in a row, and especially pleased to discuss today the health status and treatment of Gulf War veterans. In written testimony today I have provided information from 66 Persian Gulf veterans, their family members, DOD and civilian contractors. Information obtained in this self-selected non-scientific study was gained via the NGWRC web-site e-mail referral system. Since March 13, 1997 we have received 256 referrals for a total of 676 as of Oct 1, 1995. For the month of April, 1997, we received 105 requests for assistance. For May, 79 and so far in the month of June, 33 Gulf War veterans or their families have contacted NGWRC for assistance. Problems they have are across the board and wide ranged. Whether it is the DOD CCEP or the VA registry examinations; testing, treatment, misdiagnoses, indifference to suffering and a broken compensation and benefits program are the norm rather than the exception. Using the survey below we randomly selected from our database comments from April, May and June, 1997 and present them to you today, the veterans voice, unsolicited, raw and if you will notice, very consistent in their condemnations. This is their testimony, not mine.
Questions asked on our electronic survey located at http:\\www.gulfweb.org

- Name, Phone or, e-mail, Mailing Address, City, State, Country, Postal Code,
- Do you feel that you are ill as a result of the Persian Gulf war?
- Are you a veteran of the Gulf War (includes contractors, civilian employees, etc.)?
- If No, are you related to a Gulf War veteran?
- If Yes, what is your relation?
- Have you registered with either of the Persian Gulf Registries?
- Have you filed a claim with the VA, or are you being/have you been processed for a medical discharge by the Military?
- Please enter anything that may help the referral coordinator assist you:

- - Do you feel that you are ill as a result of the Persian Gulf war?

Yes

- Are you a veteran of the Gulf War (includes contractors, civilian employees, etc.)?

Yes

- Have you registered with either of the Persian Gulf Registrics?

No

- Have you filed a claim with the VA, or are you being/have you been processed for a medical discharge by the Military?

No

- Please enter anything that may help the referral coordinator assist you:

Need to find out where I need to register or get the physical.

- My bosses at my work are partially aware of my illnesses, they would be fully aware, but I can not think of all of the problems that I have. One illness seems to lead to another. I would be glad to get together some of my VA history for you and let you look over it. I am not really worried about the information being used to help other veterans, but I don't really want my name to be published. If someone was to need to contact me then they could contact you. I had a Persian Gulf exam in August of 1994. I was retested about a week later for blood in my urine. I was told that I had a hernia and I needed to take a couple of days off and rest. Next I got three small red patches. The next day the patch on my chest was the size of a quarter and burned, I went to the VA and they said that it was a bug bite. The next day it was the size of my fist and the skin was peeling off of my body. I went to the emergency room and the doctor said that it had already been diagnosed as a bug bite and I was wasting his time. I returned two days later and was treated for a chemical burn. The doctor said how could any of those other doctors diagnose that as a bug bite. I kept getting sicker and I gained 27 pounds in three days. I returned to the emergency room and found the same doctor that had hassled me before. He said that I had eaten too much Thanksgiving dinner and I was just wasting his time and I wanted some free disability money. I complained about the doctor and never seen him again. I was put in the VA hospital for about four days. I was released for two days and then placed in the VA hospital in Jackson MS and they took a kidney sample and sent it to the University MS lab. I was diagnosed with Chronic Idiopathic Glomeral Nephritis and told that I would probably die in two years. I do not remember most of the details, but my mother talked to the doctor quite frequently and has most of the details about my case for that time. I suffer memory lapses and I can not remember most of the last two or three years. I remember the birth of my son, getting ill and being diagnosed with the disease and being told that it is incurable, the day I was finally able to go back to work, and the day that I realized that there are more important things to live for and not feel sorry for myself. I have been treated with chemo therapy for six months, and steroids for one year. I completed the treatments July 96 and Jan 97 respectively.

- Thanks for contacting me. I have unexplained rashes and dark spots appearing all over my body. I did not have any of this things prior to going to the Gulf. My first child was born with a ptosis of his eye. Please contact me.

- One of the things that has happened to me is I got these " mysterious infections". My civilian doctor called them staff infections. They were located on my spine (approx. 5 over a one year period), and one on my stomach. They would lay me up for a few days and I generally had to take four days off of work. The other symptoms I have had was: tiredness in the middle of the day, weight gain loss(but not dramatic), and some PTSD with some nightmares to the point that my neighbors wake up. I have not been to the VA or am sure at times if I want to go because I have heard some " stories" about them from my uncle, who is a 'Nam vet.

- I was a Naval Reservist activated from 15Feb91 to 10Apr91. During this short amount of time I was in Daharan for app. 4 days before being transported to my ship the USS MT. HOOD AE-29 were I spent the duration of my service in the Persian gulf. We were not issued gas masks during my few days in Daharan and we did witness oil refineries blown up and had daily air raids. I do not remember any smells but I do remember the haze that was usually in the air. Also my wife and I had a son in Aug of 92 and he had some fused fingers and toes and a heart murmur. Surgery corrected the web fingers. He has also recently been diagnosed Attention Deficit. Other than these symptoms he is a bright healthy boy.

- I have registered with one registry.. not sure which one.. or what good it does, how to get help or compensation. I am a 27 year old male that feels 45 since the Golf War incident. Please help me or direct me to a resource that can best help me with treatment, and compensation... I feel as though parts of me are dying. Currently I have an honorable discharge as of April 1994. No ETS physical was given, nor am I receiving any compensation or treatment of any kind. Please contact me as soon as possible.

- My former spouse is a veteran of the Gulf War. He was stationed with 3/504 PIR, 82nd Airborne Div. He remembers hearing the explosion and seeing the smoke rise at Khamisiyah. My son (now 5 yrs old), was conceived within 2 1/2 mos. of his fathers' return from the war. He was recently diagnosed with a neurobiological disorder. I'm looking for information on how many others have children being diagnosed with similar disorders. It is not usually a detectable syndrome until the child is of school age. I just happen to work with children and was able to see the problem and push for an early diagnosis.
If information is required from his father, it may be difficult for me to get. He does not keep in contact with his children on a regular basis.

- I was a contractor supporting the troops on the Abrams/Bradley vehicles from 1 Feb- 15 May 1991. I was laid off the day of the Iraqi invasion of Kuwait under the employment of Chrysler in 1990. I was part of the on going downsizing of the military complex. In Nov of 90 they called me back off lay off to support their financial gains as they could not find anyone else within the company to support the test equipment, the troops or the FREEDOM we all enjoy in this country. If I had not accepted the offer my bridging benefits to the next job would have been stop. At that time Chrysler designed and manufactured the automatic test equipment that tests and repairs the electronic assemblies inside the M1 Abrams battle tank and M2 Bradley fighting vehicle for over 15 years in times of peace. As I continue to work in the same field of tanks and visit numerous sites all over the world and talk with veterans , it appears I could be developing the same profiles as discussed in my reading on GWS. In January of 1997 Chrysler decided to sell this division to private investors and the medical benefits I had earned ceased. Since Desert Storm I have been requiring various drugs to relieve chronic and at times acute respiratory and muscular / skeletal problems. I did not need or use this type of medication prior to that time.
I am looking for legal assistance in drafting a letter to my former employer Chrysler about the situation before the statute of limitations runs out to protect my family . I am not looking to jump on the train of possible entitlements of the active/reserve troops who served in the Gulf.
I am a Vietnam vet and still believe oppression of the freedoms we enjoy is worth fighting for.

- I am a non-smoker. Before going to the gulf, I had no breathing problems. I returned from the gulf in May 91. I retired from the army in Oct 93. In late winter 94 I went through the gulf war review at the VA. I was told by the VA that my lungs were working at 78%, But that there was no environmental cause for it. I was stationed with the First Infantry Division, (THE BIG RED ONE), after the cease fire, we were camped south of the Iraqi city of Safwan, between the Raumhatain and Sabriyah oil fields.

- I'm getting none stop headaches that last for days. My stools have blood in them off and on. I forget names, phone numbers and addresses. I get fits of anxiety and have to take medication.

- I get these rashes that look like a cluster of big mosquito bites. These rashes pop up in small patches of a dozen or more on different parts of my body and then itch. After a while they just go away. I also have flaky skin on my head , behind my ears and for awhile on my face. I've also have had some of the common symptoms of diaherra, achy joints, chest pains, headaches. The symptoms come and go but when they come I usually deal with them for about a month or two and then they go away. I have not had a check up since being released from active duty in 1994 but I'm definitely going to arrange one soon.

- Since return from Gulf in 1991, I have experienced a number of recurrent symptoms including:
  - alcohol addiction
  - extreme fatigue
  - muscle/joint aches and stiffness
  - an undiagnosed lump underneath chin area
  - headaches
  - sleep disorder
  - need for isolation/non-communication

To date, I have been unable to receive adequate attention for these problems.

- Please help me find a local support or someone who can help me. I am on active duty at fort Campbell, Kentucky. I don't know how to go about, getting a medical discharge.

- diagnosed with testicular carcinoma 12 months after being discharged from the Navy. had cancer of the lymphnodes and had a skin cancer on my left shoulder. Was assigned to the USS Saratoga (CV-60) during Dessert Storm.

- When the so-called Gulf War Syndrome was first announced. I suspected that there was a lot of Vet's trying to take the government for a ride!! Since that time I have suffered from Headaches in different severity's and Knee problems and a virtue of pain in the joints in the lower extremities of my body. I have also recently undergone back surgery. While in the hospital I read an article in the November 96 issue of news week. This article is the only one in which was able to tell me exactly where chemical weapons where destroyed and where the poison went. I was in that area at that time (Log base Ecco and KKMC)and am extremely concerned about the issue. I would like as much information mailed to me as soon as possible. Thank you for any and all the help. PS I have registered in the Gulf War Registry but have never been contacted by them. How do I find out if I'm registered??

- Unsure what a VSO is but after 5 years of trying to deal with VA on my own and finally receiving a whopping 10% rating not to mention having to travel 4 hours to nearest VA hospital despite having a VA clinic here in Redding, Calif. I would be very appreciative of any help I could get. Thank you for your time and all the efforts you have made. Your Mailing list has been my only real touch with other veterans in my position and has on more than one occasion kept me from going crazy and doing something stupid.

- VA is helpful but slow and indecisive - I am no longer able to work like I did I have become a semi cripple with fatigue is there anyone out there with a cure? I think I am dying from Persian Gulf War syndrome feel like I am dying, slowly. My friends are scared I am dying. I used to be a semi-professional soccer player, now I can hardly run from my car to the front door. Night sweats, disorientation (sometimes), distinct memory loss. My lungs are bad to the point where I almost suffocate and pass out. Blood sometimes when I go to the bathroom, #2. Diarrhea alot. Muscular twitches, achy joints like arthritis. Tightness in my chest

when breathing(every day). I almost died in '92 from my lungs, I went to the hospital back then and they denied Gulf War Syndrome existed. I am a fifth generation combat soldier. None in my family is sick like me.

My personal opinion about my illness: A mixture of "Oil well smoke, oil rain(black rain), the destruction of the chemical weapons plant up towards Baghdad, chemical weapons in the ammo bunkers; I myself have personally destroyed one in Southern Iraq. Possible germ warfare, little plastic vials found outside and around our perimeter before the ground war started, possibly dropped by the white four-wheel drive trucks that kept driving by our perimeter. The pills I(we) took to boost our immune level against chemical weapons." My company was attached to the 470th tanker unit..

First Armor Division,
Bamberg, Germany

• PLEASE ADVISE ME HOW TO PROCEED AFTER BEING DENIED DISABILITY AND COMPENSATION FOR AILMENTS I BELIEVE WERE RELATED TO GULF WAR PARTICIPATION. THANK YOU!

• I HAVE SUFFERED FROM IDIOPATHIC GLOUMERAL NEPHRITIS FOR A COUPLE OF YEARS. I HAD FAILURE OF BOTH KIDNEYS IN DECEMBER 1995. I HAD A BIOPSY. MY SERVICE CONNECTION DISABILITY CLAIM NUMBER IS [ ]. YOU CAN OBTAIN MY RECORDS FROM THE REDDING CA VA CLINIC, THE MARTINEZ CA VA CLINIC, OR THE RENO NV VA HOSPITAL. I AM STILL WAITING TO HEAR BACK FROM THE VETERAN'S ORAL HEARING BOARD THAT I WENT TO LAST SEPTEMBER 1996. I TOOK TWO PILLS AND TWO SHOTS BEFORE ENTERING THE PERSIAN GULF THEATRE OR OPERATIONS IN SEPTEMBER 1990. I FIND NO RECORD OF THE PILLS THAT I TOOK. I AM CURIOUS WHY MY KIDNEYS FAILED AND WHY I HAVE THE SYMPTOMS OF THE PB PILLS IF "I WAS NEVER GIVEN THEM". I WAS PLACED ON CHEMO-THERAPY FOR SIX MONTHS AND ON STEROID TREATMENTS FOR ONE YEAR. I HAVE BEEN TOLD THAT I STILL COULD DIE OR LOSE BOTH OF MY KIDNEYS WITHIN TWO TO TEN YEARS. IT HAS BEEN ABOUT ALMOST TWO YEARS SINCE I FIRST BEGAN TO REALIZE THAT I WAS ILL.

• Migraine headaches, some memory loss, weight loss, fatigue

• I am in the process of filing a claim with the VA. I am certain that my wife and kids have been effected. I am really concerned about the long term effects to me and my family

• I AM DIVORCED FROM MY GULF WAR SPOUSE AND DO NOT KEEP IN CONTACT WITH HIM. BEFORE OUR SEPARATION HE WAS DISPLAYING GWS SYMPTOMS WHICH WAS A CONTRIBUTOR TO OUR DIVORCE. I HAVE SINCE REMARRIED AND AM ALSO EXPERIENCING CERTAIN SYMPTOMS AS DESCRIBED BY MY EX-HUSBAND AND OTHERS VIA THE WEB. MY CURRENT HUUSBAND IS VERY CONCERNED FOR MY HEALTH AS WELL AS MYSELF AND OTHER FAMILY MEMBERS. MY DOCTOR'S MASK MY PROBLEMS WITH MEDS OR TELL ME THERE IS NOTHING WRONG. I FEEL AT A LOSS AS TO WHAT I SHOULD DO. I IT IS NOT IMPOSSIBLE FOR ME TO CONTACT MY EX-HUSBAND AND WILL DO SO IF IT WILL HELP ME FIND AN ANSWER TO MY PROBLEMS. I JUST DON'T KNOW ENOUGH ABOUT GWS AND IF IT TRULY IS CONTAGIOUS...IS IT ME OR IS IT GWS??? ANY HELP WOULD TRULY BE APPRECIATED.

• I am the ex-wife of an army sergeant, after his return from the war, him my daughter and now myself have fallen ill. All the symptoms seem to be the same. And we have reason to believe it is from the same source. We

have had no support from the government, of course and have little recourse at this time. Is there anything we can do to get aid of any kind or at least some answers.

- I am still on active duty. I have been sick for the last five years. Memory loss, fatigue, sick feeling, hurting in joints, night sweats, etc. I have to stay on active duty, am currently downrange in Slavonski Brod, Croatia.

- I don't really think I am suffering the usual symptoms, however, the more I read about them the more I wonder if I'm not suffering at least a few, but they could very well be non-GW related. There is one area in which I do feel may be related to the GW. Since my return from the Gulf, my wife has had 3 miscarriages. We have a 5 1/2 year old son who is perfectly normal. Her doctor feels that the problems we are having now may be a genetically incompatibility, the question is, if we have a child already, how is that possible? Since we have no genetic sample from before I left, we obviously cannot compare with my genetics now. Should I register with the VA? I really don't know what to do at this point. I was stationed on the USS Nimitz, and others who were there with me have had successful child births, so we really just don't know. I was in the Gulf from Apr to June I believe, if that helps any.

- since my return from the Persian gulf war in 1991, i have experienced some medical problems that neither my doctor or myself can fully explain. I have watched alot of programs on CNN/extra, and various other talk shows and feel that I need some medical attention that I am not getting with my personal private doctor. I wish that somebody would come up with a solid and final answer why so many of us vets who went to fight for the freedom of others under our glorious flag, are being told that what we have is not related to the Persian gulf war. how can so many soldiers and countries have the same or similar type of illnesses, if according to bureaucrats say that we are not ill. thank you for listening to me.

- For the past year and a half I have had night sweats, vomiting, and diarrhea. My bowls seem to do as they please. I have put my self on all registrics. I got a letter from the Army stating my Unit was in a 10 mile radius of the bunker explosion in Khamisiyah,Iraq. All I would like is to get a physical. I have been trying for the past six months. Thank you.

- Just trying to get some answers. I have been though all the medical exams at Fitzsimons Army Medical Center. This was in 1994. I was given all the medical records and was told to file a claim. I did but my claim was declined, Because my Military Medical Records were lost. Is there something I can do or is this a lost cause.

We have taken to a family of a gulf war veteran, Donald. He is married and the father of 3 children. Our relationship started 2 years ago when my husband and I bought an earthquake damaged mobile home, fixed it up and put an add in the local paper hoping to sell it and make enough of a profit so that I could stay home with my children. The first couple and their two children were the [ ]. I immediately liked them, but because of the relationship kept my distance. For the next year or so, this couple struggled with his declining health, lack of income, a sense of hopelessness. All the while no one would confirm Mr. [ ] illness, how frustrating! They tried desperately to meet all their obligations, but where let with their rent to the park several times, and missed their payment to us for the mobile home. Never were they over 30 days late. Last November we stepped in to help them. First for our own selfish reasons, but then because we began to care for this family. In exchange for Nita coning in to our home and watching our children(my children adore her and her very well behaved children) we would not expect payment and help them in whatever way would could without giving them charity. Don became more ill and finally his illness was validated and he was put on disability and treated. He is now trying to work as a security officer where their is little physical labor involved,

but he gets very tired. Yesterday the VA doctors told him he had Hepatitis C. In all this the mobile home park has decided to evict them. We have tried everything and they will not allow them to stay. Where can we go for help so that this family does not loose to home that they sincerely love. Your help is appreciated. Thank you, just a friend.

- They say I had a stroke at 29. I have intense migraines, face numbness, lesions on my brain that might be MS, always tired, leg and arm on left side feel heavy and hard to use, a rash on my hands and feet that no one knows what it is. The doctors NEVER listen and offer the same meds over and over. I was medically discharged, there was no tax on the severance they SAID, did not write, that my illness was somehow war related. I also have degenerative disk and spinal arthritis. Pretty sad for only being now the very old age of 32. I feel like I should be at least 60.

- Once in the enviable position of having perfect health prior to enlisting in the service, I now am suffering from chronic fatigue, unexplained rashes, muscle pain and cramping, and hyperthyroidism. My husband, also a Gulf War veteran, now has recurrent kidney stones and chronic fatigue. We have both filed disability claims regarding these "unexplained" symptoms. However, the claims boards only recognize my unexplainable rashes and his kidney stones. It has become difficult to maintain acceptable attendance at work. Every attempt to readjust claims has failed.

- I am engaged to marry a man who served in the Marines for 8 yrs. he was in the gulf war. His job was a sniper/ infantry. My concern is for his health. so far he is O.K. the only problems have been nightmares, but they have stopped considerably in the past yr. I am mainly concerned about the problems the vets. are having with children being born unhealthy. my main question is this, is there any way of knowing if the chances of having an unhealthy child exists? He is very confidant that everything is fine, but I worry that alot of that is denial. I would appreciate any information you could send me about this matter. Thank you.

- I get the shanks for no reason. I am not a drinker or drug taker. My body functions are not as good, before the War. And I do thing its because I am older now. Am just 36 now. We had a people that went with us get medical discharge and he was with me and our unit during Desert Storm. Our camp also got the shits do too bad water. I also have my orders of this time.

- I may be interested in filing a claim based on my medical condition, but I am also concerned about the potential impact upon my military reserve career (I am currently an Army Reserve Captain). Do I run the risk of filing a claim, and then being discharged as unfit for duty? I was in Kamislyah with 2/4 Cavalry (24th Infantry Division) during the time of the ammunition depot explosions - I know that my unit is considered a "key unit" for the Persian Gulf Registry. I would appreciate any help you can give me.

- I was one of the troops sent on the advance party to the khamislyah site.

Currently have often muscle spasming and joint pain, lack of all appetite, memory problems. Major concerns are why after I have contacted all the stupid 1-800-help us help you numbers, no information of any kind has been sent to me. Specifically if the syndrome can be passed on to my family. Also have several pictures with soldiers and myself holding tank rounds on our shoulders in front of bunkers we destroyed. would greatly appreciate an answer or reply

- My original claim, approximately two years ago, resulted in the Cincinnati Veterans Hospital dismissing my complaints as "non desert storm related." Since that time I have experienced continued chronic migraine headaches, tooth and gum disorders not explained nor aided by dental treatment, continued depression medication, continuous sleeping disorder, and several other difficulties resulting in absence of

work. Please advise on my next step to obtain recognition or help.

- I am suffering from muscle pains, dizzincss and

problems with my neck and throat.
I arrive at Saudi Arabia with the 311 qm.grv.reg Co.and was attached to Co. A 101st.support group.(Big Red One).I spent 11 days doing search and recovery operations for decease personnel in and around the Kuwaiti oil fields.

- Randy has unexplained lesions on his brain, fatigue, numbness in his face, weakness in his arm and leg. the list is long and we don't know what else to do.

- I was an Md. working on a contract basis at camp pendelton.i gave exams to returning gulf vets and have been ill ever since. would appreciate local legal referral and orgs.

- I've been diagnosed with; (by the va)
  chronic fatigue syndrome
  brain atrophy
  abnormal bone scan
  fibromyalgia
  dry eyes & dry mouth
  memory loss
  mental confusion
  hepatitis B

I need help ! I'm currently filing papers with social security. They turned me down once already.

- I'm concerned about the lack of attention to support personnel. I personally was in a transportation company and moved around alot. I was at so many places and for various times and supported to many units to remember .I have been denied benefits due to the fact that I did not report any problems when they started. I come from a very small town and was at least a 150 miles from a VA hospital, and was not financially able to see a private physician. These things I feel were not taken into consideration and I am very concerned about some people I served with having severe problems with sterility and births. They have received compensation for that. Do I need to go through that to receive compensation? How can I find out if I'm going to have those problems and what I can do? Any input or redirection would be appreciated very much, not knowing and feeling like I'm being called a liar is not enjoyable

- Three wives have had total of 6 miscarriages....2girlfriends one each...Hairloss....Major deterioration of teeth and gums..

- I was told it is no longer possible to be put on the registry. is this true? if not, how do I register? I have a great deal of minor, chronic problems and I believe the gulf war may be cause. I am still active duty and the military medicine at fort hood treats soldiers like they are on an assembly line. chronic joint pain is treated with motrin repeatedly. Then when you take so much motrin your stomach starts to give you problems, you are given tagamet. please send me information on the registry, how it works and how to get on it.

- My daughter is sick all the time. The military doctors seem to just ignore her and gave her prozac. Am very upset about this. She lives in Herrington, KS. She was in the Gulf War. I believe she was there for 6 months. Any information would help us. The doctors just think she is making everything up. Civilian doctors don't know a thing. She has rashes all the time. Her joints ache. Her stomach is a mess. Her hair is falling out. She is sure she is loosing her mind most of the time! Everything I have read in this area is describing her problems.

- I was on the staff of Third U.S. Army (rank Major) and was scheduled to deploy to SWA in Feb 91. I had not been on AD since 1985 and had no meds since 1984. I received all deployment meds and PB at Ft. McPherson Clinic. I was diverted at the last moment and did not deploy with the rest of the reservists that had been mobilized to fill out the TUSA HQ in SWA. I became violently ill with all the symptoms of a Nerve Agent attack at my residence. I was told I likely had the flu. Over the next 18 months the Army admitted that all my various

illnesses occurred in the line of duty. I have been unemployed and very ill since 1992. The local paper (The State) recently did an article on my efforts to address PB as a cause of Desert Illness. Retired Chief Judge of the Court of Military Appeals, The Honorable [R. E.] is acting as my legal counsel. Please contact me as I believe that we will be able to help many people.

• After leaving USAF in Dec.93 and moving to the UK I have suffered from severe headaches and about 35lbs weight loss and suffer from unexplained extremely hi fever and flu like symptoms about 2 or 3 times a year. The local doctors have done numerous test with inconclusive results and finally a young Canadian doctor pointed me in your direction I served in the UAE prior to airwar and then we were sent to KKMC I was an F16 crewchief

• I am still on active duty, USN, and 3 weeks ago I was Dx with PTSD, I have had some pulmonary problems and enlarged lymph lodes.

• I have gotten respiratory problems, such as bronchitis and asthma, in which I never had this prior to going to the Persian Gulf. I did receive medications while there, and I did take them. I have had problems with fatigue since leaving from the Persian Gulf also. This fatigue has had my nights interrupted several times in the middle of the nights(restlessness). I have had the breaking out on my elbows and knees with little tiny white pusety clustered bumps. Over the years they have become excessively dry and peeling areas on my body. Although, I may have been to the Veterans Hospital only on one occasion. I also informed the doctor of the stiffness I had in my joints. I had experienced this only after coming back from the Persian Gulf War. I haven't received any response on the out come of my Veteran's Preference yet, My appointment was February of '96. I do understand that this department(Veteran's Affairs Department) handles several cases; I'd like to know of any additional information that could be given to me for me to contact them, or have them contact me. I have been discharged from active duty since February 14, 1994. At the present time I don't have any medical coverage and neither does my spouse. My children are now covered by a private charity, other than that I have no medical coverage for myself. I hope to receive at a medical card for myself, so that my wife could possibly get her own coverage. I ask that someone check into this matter as soon as possible it would be greatly appreciated for and please feel free to contact me personally. All your help will be greatly acknowledged...Thank You

• Myself, along with others who feel we are suffering memory loss and other symptoms due to the Gulf War, are apprehensive about registering with DOD or VA. Friends of mine who I was stationed with at Doha, Qatar know of individuals who have been medically discharged after they complained of Gulf War Syndrome. We don't know who to turn to!

• I'm having a lot of medical problems since returning from the Gulf war. Some of the problems were identified to me by the wife. I'm currently experiencing several problems. Joint pain, lose of memory, chronic fatigue, sleep disorder, lose of interest in hobbies and other things, lose of appetite(sp), a lot of pain in the knees, legs, feet, headaches. As well as confusion, and, depression. I went to the doctors at Ft.Rucker today and they believe I might have a severe case of depression (desert Storm Syndrome)? While station in Hawaii, I believe I was registered at Trippler Army Hospital. the doctors name is [ ], he works with internal Medicine. I don't know what you can do for me, but have no where to turn to. Any information would be greatly appreciated.
CW3 , Ft.Rucker, Al.

• FREQUENT COLDS, PERIODS OF DEPRESSION, PERIODS OF LACK OF ENERGY, OCCASIONAL BLOODY NOSE (NO RECOLECTION OF PAST EXPERIENCES)

• I have been diagnosed with having asthma, severe migraine headaches, and gastrointestinal disorders

- Please note, the e-mail address is for his brother in California. We have been searching for a source to help get medical attention for this veteran and get some financial benefits that he is entitled to. If for some reason you are unable to contact him, please reach [Jim] at the e-mail address. His condition is quite bad and his Mother, who is 75 years old has to attend him. Thanks for any help or assistance you can render.

- I need to contact anyone that was out west with 18th Airborne corp and the French Foreign Legion. I was attached to an MRLS unit to provide short range air defense as a Stinger missile operator. I am have had serious problems from neurotic problems, psychological break-downs, and physical problems even slipping into a coma. Anyone that was there as we went north to objective Rochambeau and objective White. Then since we were an Arcent asset we went hundreds of miles east to BASRA. Anyone from the MLRS unit that was from Fort Sill or from Alpha Battery 5/62 Air Defense Artillery write me. Or anyone that traveled the same path as me during the war. Here is why: I can deal with my pain but Monday, March 24th MY 4 YEAR OLD SON WAS ADMITTED TO THE HOSPITAL here in Maryland and he has a fever (105 degrees), a rash on his entire body, severe body pain, severe headache, and stomach pain. He has spent three days in the hospital and no doctor has a clue what is wrong with him. They have taken blood from his poor arm 8 times and he is on an iv. I told them about the Gulf and they are testing for Mycoplasma. They think he might have viral syndrome. It is very scary for our family. Please write if you or your family has gone through this. I just went for the registry and gave my blood for tests and I have a physical on April 29th.

- I was put on the TRDL by the USMC may, 96 from Camp Lejeune, NC I sent all my paperwork, i.e. medical record, forms for disability rating from the VA However the last step was to give them a copy of my DD214. The VA rep at Camp Lejeune told me not to submit this because I was relocating to my current address. I have been going to the Westhaven branch of the VA in CT. I enrolled in the va and was given a service connected disability card and have been seen several times and received medication. Now the are sending me bills because I am not in there system. I could use some advice on how to expedite getting my records sent to CT.

- I was a Dept. of the Army Civilian assigned to Khobar/Daheran KSA during June 91 to Dec 91 In the fall we were exposed to dense smoke cloud for almost three weeks. As a Civilian, what recourse do I have for reparation. I am a military veteran also. I have been initially screened at Wright Patterson Air Force Base Medical Center in 1995. Undetermined causes were stated for my declining health since my return. Please advise. Is there an ongoing study? Have any other civilians been evaluated. Is there a follow-up process from phase I, II? It's really stressing me out after being both active and a drilling Reservist for twenty-eight years, and now I can't even feel good in the morning. My previous symptoms have not gone away, and seem to be getting more pronounced. Please help.

- Claim came back denied by the VA because I didn't complain about any of the symptoms while I was still on active duty. I retired four months after returning from the Gulf. I recently got this computer and was glad when I got on the net and found others seemed to be as frustrated about the VA as I am. I have several of the symptoms but was told that it was either genetic or because my body is getting older. I could really tell some horror stories about the way I have been treated by the VA .

- **How do I register with the Persian Gulf registries? Is there still an 800 number for the VA concerning Persian Gulf illnesses?**

- I was stationed in Manama,Bahrain during the Gulf War. About a year after my release I started experiencing neck and back pains, but now it's gone as far as numbness in my arms and legs, excessive fatigue, among other things. I was diagnosed today as having chronic degenerative bone disease in my neck but the doctor has no idea what may have caused it. I'm not sure

exactly what the Gulf War syndrome symptoms are but I do know I have a problem and don't know what to do. Any help you can give would be much appreciated.

- My son passed away February 15, 1997 while working at a temporary job at Farmington Hills Michigan. AT 10:05 p.m. Feb. 14, Mike called to tell me he was sick and in the hospital. At 2:08 a.m. Feb. 15 the Doctor called to tell me Mike had passed away. He kept getting "colds" since coming back from the service Aug. 1994. The coroner said he died of acute leukemia. He was 27. His name was [ ]. We want to find out if his death was connected to his service in Kuwait, Saudi Arabia, Somalia. Please help if you can. We could have understood losing him in battle, but this is very difficult. He was very proud of being a Marine and he considered it an absolute honor to serve his country.
Thank you.

- During my initial "Gulf War workup" I was essentially blown off. What was not attributed to my diabetes, which I developed after the Gulf War, was attributed to "somatizations". This was true of most of the personnel who were screened at Womack Army Medical Center. Should I go in the Fayetteville VA Med Cen and have the work up done again?

- As a quality assurance inspector I performed iso dock inspections on just about every c-5 aircraft that went to and came back from the Persian gulf. I was called up as an air reserve technician to active duty during desert shield and storm. Although I didn't deploy to the gulf I am still sick with fibromyalgia, chronic fatigue and pain. I also had a brain tumor removed in Sept 1996. Judging from the size of the tumor and average growth rate, it originated right after the gulf war. I was in excellent health before the war and now I am not. How can this be explained? I am presently in p4 status and as soon as the gulf war clinical evaluation program is finished testing me I will go before a reserve medical evaluation board. I am faced with loosing both my military reserve and my civil service career. Can anyone help? Need some good advice!!!!

- He is not getting counseling - The charges were upgraded to Capital Murder. The state of Virginia does not have a diminished capacity defense, so he is either guilty or insane - insanity is impossible to prove in this state, so he will either get 68 years minimum or the death penalty. Right now he is so tired, after coming back from the war, then 4 years of constant turmoil with his ex-wife, he just wants peace.
He has decided that if the doctors don't find any thing wrong with him, to plead guilty to Capital Murder so that they will sentence him to die. He doesn't want to put his family through any more pain. The lawyers know about gulf war syndrome, but feel it is a "physical" problem, not mental. Isn't that ironic, since everyone who manifests physical symptoms are being told it is mental not physical. All I can do is wait, and watch a good & decent man die. His lawyers are doing everything they can, and there could be some change down the road, but as of this moment, that is how it stands.

- Could you please tell me whether there has been a marked increase noted among the Gulf War vets in liver and/or pancreatic cancer? A close friend died of this recently and was a gulf war vet. His widow is wondering if there would be any evidence that this may have been caused by this syndrome.

- Attempted to obtain my medical records from the USAF after my retirement to continue the treatment that I was receiving after my return from Desert Storm/Shield. The USAF stated that my Medical records were lost and could not be located. I have copies but not the official ones from USAF. After my return from the Gulf I unable to run and was taking motrin by the hand full to rid myself of the joint pain. Only by using motrin was I able to walk and work but had to retire in 1994 because I could not make the required Physical training Standards as an Explosive Ordnance Disposal Technician. Prior to Gulf I ran 6 miles a day with an average 7 minute miles. Due to inactivity I have gained over 60 pounds and can't exercise and sleep almost 12 hours a day. What do I do ?

Testimony

of

Janet Ott
Mother of Anthony Gene Ott

Before

U.S. House of Representatives,

Subcommittee on Health

June 19, 1997

as
attachment to testimony by

Jeffrey Ford

National Gulf War Resource Center

Our son Anthony Gene Ott was a member of the Army National Guard 142nd Field Artillery from Rogers, Arkansas. The Unit was called to active duty in November 1990. They were sent to the Persian Gulf in January 1991 being assigned to the 7th Corp. While in the Persian Gulf this unit traveled extensively and were very near the oil well fires in Kuwait. I remember Tony calling us from a pay phone in Kuwait and we talked about the fact that it was noon there and very dark due to smoke from the fires. The 142nd returned to the U.S. in mid May 1991. Tony was then discharged on June 8, 1991. His original discharge date would have been earlier had he not been called to active duty.

Two weeks following his return Tony went back to work at All States Credit in Springfield, Mo. At this time we live on Grand Lake near Grove, Ok. About 6 months after Tony returned from the Persian Gulf we began to notice that he had developed what appeared to be "allergies". Since he had never been allergic we thought perhaps he had been away from all of the trees and grasses and was having to readjust to them. Tony always said oh Mom it is just a cold or sinus. After many months if not a year of sneezing, running nose and watering eyes he developed a chronic type cough and began having headaches. Please understand the Tony has always been into a healthy lifestyle. He has worked out 6 days a week since before he graduated from college in 1981. He has always watched his diet and maintained a low fat to lean ratio.

As time progressed Tony went to various health care professionals and while several gave him antibiotics the cough always returned and progressively worsened. At the time we moved to Mo. in late 1995 it was very evident whatever Tony has was progressively debilitating him. By early 1996 he literally could not cough because doing so caused excruciating pain in his neck that radiated through his head. He went to a Internal Medicine Physician (Dr.Pennington) at the Ferrell Duncan Clinic who ordered CAT scans of the neck which did not show anything conclusive. By this time he was missing work frequently and had ceased all workouts at the gym.

In early March 1996 Tony went to the Veterans Administration Clinic in Mt.Vernon, Mo. for a Gulf War physical. Lab work was drawn and he got his Identification Card. He returned to V.A. Clinic on March 21, 1996 and was seen by a Dr. Kime who scheduled a follow up visit in 90 days. On

June 19, 1996 Dr. Kime ordered x-rays of the neck looking for the cause of the severe head and neck pain. On July 19th Dr. Kime referred Tony to a V.A. Neurology Service at the Harry S. Truman Veterans Administration Hospital in Columbia, Mo. An appointment was made for August 20, 1996.

On August 13, 1996 the pain became so severe Tony was taken to the Emergency Dept. at Cox Medical Center in Springfield, Mo. He was basicly knocked out with pain medicine and given pain pills. It is difficult to describe the kind of pain he was in. The best I can do is that it is like having an explosion in your neck that hurts beyond description and radiates into the head. There were times when a spasm of pain would drop him in his tracks, grabbing his head and writhing in pain.. On August 14th my brother went to Springfield and took Tony back to the E. R. at Cox. They suggested he go to the V.A. Emergency Room in Columbia, Mo. On August 15th my brother took Tony to the Emergency Room at the HST V.A. Hospital in Columbia, Mo. He was seen be a physician named Geeta Katwa (White Team). Dr. Katwa treated Tony as if he were a drug addict. After a brief neurological type exam she stated that there was nothing wrong with him and that he

needed to learn to relax. She prescribed Motrin and told him to cancel his neurology appointment scheduled for the next week. Tony was brought back to our home in horrible condition. The next morning I took him to our family physician Dennis Younker, M.D. Dr. Younker told us he had worked at the V.A. hospital when he was in Med school and that we should ignore their diagnosis as they were presuming that everyone who comes to the E.R. is seeking "drugs". He felt we should keep the V.A. Neurology appointment and he also referred us to Jeffrey Greenberg, M.D. who is a Neurosurgeon. Dr. Younker said he would take care of the pain medicine until we could get the situation under control.

August 20,1996 HST V.A. Hospital, Columbia, Mo. saw Dr. Ben Moore in Neurology Clinic. He was surprised that Dr. Katwa had not called in the Neurologist on call when Tony presented at the E.R. on the 13th. Dr. Moore stated he needed an MRI as soon as possible. If it were up to him it would be done that day but since it was the V.A. all he could do was order the MRI and the V.A. would send us an appointment for it. He ordered a cervical collar.

August 22, 1996 Tony saw Dr. Jeffrey Greenberg, Neurologist our family physician referred us to. An MRI was ordered and performed on August 27, 1996. The MRI confirmed three lesions in the brain. Dr. Greenberg advised the situation is very serious and explains the terrible pain. He then ordered full body CAT scans to see if these were lesions secondary to some other primary site. Steroids were ordered to reduce the inflammation and prepare Tony for possible neurosurgery. CAT scans performed on August 28th. We reviewed all results with Dr. Greenberg on the 20th. All tests were negative except for the MRIs.

Tony entered the hospital on Sept. 5, 1996 for a CT localization of mass and was scheduled for surgery the next morning. When they were unable to locate the masses on the CT with double dose of contrast a spinal tap was performed immediately. At this point Dr. Greenberg began to question if Tony had been out of the country or had ever been exposed to any chemicals. We explained the Persian Gulf was the only time he has ever been out of the United States and that he works in a business office environment which should preclude any exposure to chemicals. Since the brain lesions were steroid responsive the exploratory surgery was cancelled.

Sept. 10, 1996 we met with Dr. Greenberg. All test results were negative. A repeat MRI was ordered for a month later and Tony was instructed to continue decreasing steroids until he was off of them. By Sept.19th he was off of them. Within 48 hours he was again in terrible pain, and was barely able to swallow. He was again unable to drive or work and was put back on steroids.

October 8, 1996 repeat MRIs showed changes in lesions, some lessened and some expanded. Dr. Greenberg advised this would be a very complex case as he had never observed this kind of extensive demylinization in a patient. He again questioned the exposure issue and advised us to keep our V.A. appointment stating they should have the research facilities to handle this kind of complicated case.

October 9,1996 I called Shirley Sapp, Patient Representative at HST V.A. Medical Center to question why we never heard from the MRI ordered by the V.A. Neurologist on August 20,1996. Shirley called back to say Tony's only diagnosis was neck pain and that the MRI was scheduled for October 17th. I then faxed her copies of the Freeman Hospital MRI reports. She had a Dr. Harry White call me back. Dr. White advised us to keep the MRI appointment (which we only

found out about thru a phone call) and an appointment the same day with Dr. Katwa. Dr. White said to have Dr. Katwa call the neurologist on call.

October 15, 1996 Tony and I met with Chris Andrew, M.D. who reviewed his case for Dr. Greenberg and suggested we continue with the V. A. as they should have the resources and the medical history as to any injections or pesticides Tony was given. He too stated it is a very unusual and complex case especially in light of his age. (37 yrs. old)

October 20, 1996 MRI performed at M.U. then we went for scheduled appointment with Dr.Katwa. She did call in Dr. Kahn, neurologist and she also ordered an HIV test. She seemed to be in shock when she read the MRI reports we had faxed them - as in how could I make such a error. We entered the exam room that day at 4:00 p.m. and were there until 9:00 p.m. Dr. Kahn after an extensive examination called Dr. Eric Nottmeier, a neurosurgeon , over from M.U. who then repeated the neurology examination. Dr. Nottmeier said he would get the new MRI's,(we gave him all of the Joplin MRI films) and confer with Dr. Sundroni. He was supposed to contact us back on the 21st or 22nd. When we called back on the 23rd to see why we did'nt hear from him he said he had given all of the information to the V.A. doctor who was to call us. I really broke down when explaining Tonys worsening condition and pain level. Dr. Nottmeier called right back and said that a Dr. Callipinto and neuroradiologist Dr. Rodriquez agree that there is not an immediate need for surgery. The demylinization appears to be a condition for Dr. White or Dr.Batchu to work-up and develope a treatment plan. Dr. Callipinto said not to get a Resident but to insist that Dr. White or Dr. Batchu handle this case as a MS case.

October 25, 1996 Dr. White called back and said he would admit Tony on 10/28/96 for testing. I spoke with Shirley Sapp on this day because when I called Linda Duffen she insisted we needed to schedule Tony for a Gulf War exam which I told her he had in March 1996. Shirley called back and said their records did show he had already had his Gulf War phase I exam in March. These people don't seem to have a clue as to what they have or have not done.

Oct. 28th (Mon)Tony was admitted to HST V.A.M.C. Steve Williams and Rowena Tabamo began his testing with a spinal tap. Since it was Dr. Williams first spinal tap it took a very long time, like about 10 times as long as it took Dr. Greenberg to do his first spinal tap. Another Resident, Frank Edelman joined the Williams-Tabamo team the next day. Tony was moved to lodger status on Tuesday. On Thursday Dr. Hennesy from Washington University examined Tony. Friday Nov. 1,1996 a case review was held at M.U. with numerous neurologists present. Dr. Horawitz from Washington University could produce some strange reflexes - two other doctors also participated in the examination and many other observed. Following the case review Tony went to a scheduled pulmonary function test. We were dismissed at 2:00 p.m. on 11/1/96 with instructions to cut down on the steroids and they would schedule a follow-up visit to go over all test results with us.

Nov.1st Tony again began decreasing the dosage on the steroids. By November 12th he was no longer able to work or drive due to the neck and head pain. By the 15th he was brought to our home in Joplin. My husband was in very serious condition in the hospital at this time. Our family went back and forth to check on Tony as I was spending all nights at the hospital with Gene.

Nov. 18, 1996 Tony's coworker Russ Bingman took him to Columbia. He saw Dr. Tabamo in Clinic 1 which I believe is the Emergency Room. She said she plans to refer him to several other

doctors. He was given Percocet and Midrin for pain - returning home at 9:00 pm. It is a 5 hour drive each way to Columbia, Missouri. The Midrin did nothing and the Percocet barely helped. Nov. 20,1996 Pain level continues to build again. Tony seems in deep pain and barely able to function, also appears to be exhausted.

Nov. 21, 1996 I called Dr. Tabamo and she said to go to the nearest Emergency Room and have them call her. We went to Freeman Hospital and Dr. Donald Cotton called Dr. Tabamo. Tony was given Tordol which had no effect at all. Then he was given a Demerol and Vistaril injection. This injection made him sleepy but you could still see the spasms in is head by the grimaces as he dozed. His chin was by this time drawn as far down on the sternum as possible. He was barely able to swallow the Percocet which truly did no good anyway. I called Dr. Tabamo and she said to get him to the V.A. for admission. My sister and her husband drove us on to Columbia from the edge of Kansas City. They agreed they had never seen or heard of anyone in this type of pain. Dr. Kahn, Neurologist saw Tony in the E.R. and admitted him. Since he was on the seriously ill list.we were able to stay with him around the clock the first 6 days. Tony has no memory of the first three days for which I am very thankful. I asked Dr. Kahn in the E. R. if he had ever observed a MS patient in this kind of pain and he said he had never seen this kind of pain in anyone. To be truthful it is inhuman to let anyone (an animal much less a person) get in this condition. Tonys jaws were locked in a grimace, his mouth and lips were caked with crud. He was no longer drooling because he was so dehydrated. CAT scans were performed on admission and again the next morning. I will not bore you with the details of the 13 day stay except to say that the nursing staff did everything they possibly could to help my son. There are serious flaws in the V.A. system by which physicians write orders for medications that are not in the formulary at V.A. and the nurses must then run the doctor down and get a different order. In getting Tony on a pain management program until the steroids could reduce the inflammation we had numerous problems with medication orders. Tony was admitted Thursday Oct.21,1996. His attending physician Dr. White left on Friday for 9 days. When he returned we found out he was no longer going to be Tony's attending physician. On Friday Nov. 29th while Tony was out of the room for a Barium Swallow test I talked with Dr. Tabamo about his case and she indicated that they would begin to look at the more exotic possible causes as this does not fit any MS. In fact she said it may still be a Vasculitis. She seemed very interested in the case. On Sunday evening Dr. Tabamo came by at 10:30 p.m. to say she had been rotated off the case and a different Resident would be assigned the next day. Dr. Sophia Ahmed was the new Resident.

On Friday Nov. 29th when I asked Shirly Sapp about the Phase II exam she made it very clear that only Linda Duffen knew anything about that and Linda should be back on Monday. Mrs. Sapp also stated that when Jim Byer the VSO told Tony he did'nt need to send the Army a medical records request he was all wrong. So we filled it out ourself and sent it off. As of this date Jan. 14, 1997 we still have not heard any response from the Army.

Monday Dec. 2nd Tonys 12th day at the hospital I met with Linda Duffen at 2:00 p.m. She advised a Dr. Carlos Sanchez is the Environmental Physician at HST VAMC and he alone could make any referral in Tony's case. She had a "there can't possibly be anything wrong with these guys attitude" and made sure that I understood that if they did refer Tony it would be their first in over 200 Gulf War examinations. When I questioned her about the Oct.21st VAMC Video Conference on the Gulf War Veterans programs she became very vague and said Dr. Sanchez was the only physician there who would have seen it and he was not

available that day. I offered her a copy of the tape but she said she thought they had it somewhere. What this lady does not understand is that I do not care if my son is one in a million who needs a referral I expect it to be done as soon as humanly possible.

Tues. December 2nd Tony was dismissed to return on Friday for the MRI that was ordered shortly after he was admitted 13 days ago. He was told it would be a couple of weeks before all of the blood cultures and spinal fluid exam cultures were in. Dr. Burger said if they were not conclusive he would then do a referral.

Friday Dec. 6, 1996 we went for the MRI at the Med Center and picked up the Joplin films from the V.A. as we no longer felt they were safe there. To be truthful when we started to the car with them we noticed they not only gave us the Freeman Hospital Joplin films but also had given us many other X-ray films on Tony that belonged to the V.A. I read the reports on the outside of the jackets and took them immediately back to the Radiology department. In both interactions with radiology we were not asked for identification. I hope it was because they recognized my son as the patient.

On 12/12/96 when I called to see when the follow up visit was scheduled we were told the first time we could see Dr. Burger is March 1997. Once again I hung up and called Shirley Sapp who had the Neurology secretary call me back and we scheduled the appointment for Dec. 31, 1996. As always the most simple interaction is complicated.

Dec.31, 1996 we met with Dr. Burger and Dr. Ahmed. Physical exam is basicly unchanged. They have all test results back and do not have any diagnosis. MS tests are negative. They will be making a referral to Birmingham, Al. Dr. Burger said to schedule a follow-up visit in 4 weeks and reduce steroids by 5mg. at a time until he gets to 20mg then reduce by 2.5 mg. At least this time the clerk scheduled the return visit in 4 wocks. The clerk for Clinic 2, James Clasby is positivly the most hateful obnoxious person I have ever seen in a position that meets the public. I am not concerned at how he treats my son, we can ignore his behavior, but to see him be so rude to the line of elderly veterans each day is pathetic to say the least.

Jan. 8, 1997 Tony continued decreasing steroids. When he got to 30mg per day the pain level was already increasing. He called Dr. Ahmed for pain medicine which arrived on Jan. 13th. I called on the 9th to see where the referral process is and was told Dr. Burger will return on the 13th. I then asked for Dr. Ahmed who said she would check things out and get back with me. As usual we not heard another word. I also called Dr. Sanchez who said Dr. Burger is handling everything so who knows. These physicians all seem oblivious to time and quality of life considerations.

MY SON HAS BEEN GOING TO THE V.A. FOR 10 MONTHS NOW AND WE TRULY HAVE NO MORE INFORMATION THAN THE PRIVATE NEUROLOGIST GAVE US WITHIN A WEEK OF MEETING OUR SON. WE FIND HIS TREATMENT (lack of) NOT ONLY TO BE INADEQUATE, WE ARE SINCERELY ASHAMED THAT ANYONE IN THIS NATION COULD RECEIVE THIS TYPE OF TREATMENT. THERE ARE MANY PEOPLE WHO ARE WILLING TO TESTIFY TO MY SONS TREATMENT. WE HAVE BEEN RELUCTANT TO DESTROY OUR PRIVACY BY GOING PUBLIC, HOWEVER

IT APPEARS THAT IS OUR ONLY ALTERNATIVE AVAILABLE. I AM THANKFUL THAT WE HAVE DOCUMENTED AS MUCH AS WE HAVE. ALL OUR SON WANTS IS TO HAVE HIS LIFE BACK AND IF THAT IS NOT POSSIBLE TO UNDERSTAND WHAT IS WRONG AND WHY. WE SUPPORT HIM IN THIS EXPECTATION.

Note:
All information above this line was faxed to the White House Liaison Officer on Jan 14, 1997

Upon speaking with the Liaison Officer she immediately asked for a referral from a physician so she could speak with Dr. Mark Hallett. Dr. Jeffrey Greenberg made this referral. Shortly after the release was sent to the White House we began to get calls from V. A. personnel who wanted to help us. I believe they reviewed the manner in which our son had been shifted from doctor to doctor with no real treatment plan and decided to handle the case differently. Linda Duffen the Persian Gulf Coordinator for the VAMC in Columbia, MO processed the referral to Birmingham. Linda also took care of our travel arrangements to fly to Birmingham and while there were several hitches like our tickets had been cancelled when we arrived at the Kansas City airport. Linda corrected the problems as quickly. This was the only travel that has connected to our son's illness that has been paid for by the V.A. During this time we received several calls from Dr. John Bauer the Chief of Staff at the Columbia, MO VAMC. He was most helpful and seemed to be truly concerned regarding Tony's care.

The Birmingham VAMC Persian Gulf Coordinator, Ms. Windia Wilbert met us at the airport and was a tremendous help during our stay . We arrived there on Wed. Jan29th and they began running tests on Thursday the 30th. Many physicians saw our son but his primary care was coordinated by Dr. James Geyer a Neurologist and Dr. Christopher Cai a Neurosurgeon. Dr. Geyer had a Dr. Whittaker a specialist in Multiple Sclerosis review Tony's case and he said this is not MS of any kind. After the reviews the doctors felt a Stereotactic Biopsy was the only was to get answers to the puzzle so one was performed at UAB on 2/6/97 by Dr. Cai and Dr. Guthrie. Tony was taken to UAB by wheelchair which caused pain beyond my ability to describe. He was moved back to the V.A. Intensive Care Unit by ambulance. While at UAB I had to explain where the referral form and lab reports were in the chart that Ms Wilbert had so carefully prepared for them. The day of Tony's biopsy was like nothing I have ever encountered and I sincerely believe the most wretched awful people on earth should not be treated as we were that day. The day after the biopsy my son was dismissed with the results to be forwarded to his VA physicians in Columbia, MO. With the exception of the day at UAB the Birmingham staff were concerned and seemed to be interested in finding out what is wrong with Tony. The Persian Gulf group meetings I attended both weeks were helpful in dealing with this nightmare. My personal cost was well over $1,000. for the 10 days we were there and while I do not expect anyone to pay for that I mention it because many families would not have the resources available to go with their veteran. It was and still is a necessity that someone be with my son as he gets lost and confused very easily. His sense of reality at times is very poor. I do not know the outcomes of the psychological tests that were performed in Birmingham but they could not possibly have been normal by any standard. Unlike private medicine the V.A. does not follow up on

results with the patients. While I have met many people who are somewhat paranoid about this I believe with all sincerity that it is simply just a matter of too many patalents and not enough resources to adequately respond to their needs.

On February 14, 1997 we went to the VAMC in Columbia to have the stitches from the brain biopsy. Tony was assigned to a treatment team and a primary care physician Dr. William Patterson. Dr. Bauer the Chief of Staff had told us this would happen and we are certainly forever grateful for this change in how Tony's care is handled. There were many changes evident when we made the February visit to Columbia. First the rude man in Clinic 2 is no longer at the receptionist desk. He is still in the facility but does not interact one on one with patients and families. The whole treatment team concept works very well and provides for continuity of care that had been lacking to this point. Dr. Patterson treats Tony as person not a "case". While I know he must have endless duties as Medical Director he does follow up on things and has called to check on Tony several times. We saw a pain management doctor on 2/24 and Dr. Patterson on the 28th. Tony tried taking Cyclosporin to lessen the inflammation but the side effects were such that he had to stop the treatment. Dr. Harry White the Chief of Neurology at Columbia called at this time to advise that the preliminary biopsy results ruled out several things but once again they have no idea what is wrong or how to treat it. By this time Tony was having difficulty controlling his blood pressure so additional lab tests were performed and he was started on another medication. The side effects from the steroids are such that people who saw Tony during the holidays are not able to recognize him. In his phone call Dr. White stated "I just do not know what the future holds for Mr. Ott". While I appreciate Dr. White's honesty I cannot accept that every possible avenue has been investigated. Dr. Patterson ordered an MRI on April 11th to check on the lesions in the brain and spine. While there were not any changes in the brain lesions there appears to be changes in other parts of the spine as his condition continues tso decline. By this time his thumbs are drawing into his palms involuntarily and the tremors in his arms and legs are worse. At this time Dr. Patterson made a referral to a team of Neurologist at the Oklahoma City VAMC.

During the time all of this has been going on we have continued to exchange letters with the Adjudication officer in St. Louis. I have promptly responded to their every request even when the requests make no sense at all. For instance we were sent to the VAMC in Fayetteville, Arkansas on March 11, 1997 for a disability physical. The physician assigned to the examination had never seen Tony before, and they do not have any neurology services at the VAMC were he is a contract physician. Tragicly on that day we saw several other Persian Gulf Veterans who were also there for physicals. The one I will always remember was much like my son in gait and orientation only he appeared to be at least ten years younger than Tony. The Fayetteville physician said if all these Neurologists cannot diagnose this case what would a peon like me be able to add. He was truly concerned and said our son was the 4th Persian Gulf Veteran he had seen that day with neurological damage. I wrote to the Adjudication Officer and asked why our son was sent to Fayetteville for this exam but as usual there is no response to date. I have made

a concious effort to focus only on medical care for our son. There will be a time in the future to deal with the adjudication issues. One thing for certain I will never ever call that Department again without recording the conversation. The one call I made to them is still like something out of a bizarre novel. I try to forget it ever happened. Tony has not had a cent of income in over seven months and we are told they have no idea when this might be resolved. I guess this explains all of the Veterans in the Homeless Shelters. Most families do not have the financial resources to deal with this kind of situation and many Veterans do not have families to fall back on.

On May 20, 1997 my son was examined by three Neurologist's in Oklahoma City. They will report back to Dr. Patterson with recommendations. The last time we saw Dr. Patterson on June 5th he had still not been able to reach the Oklahoma City physician's. During our trip to Oklahoma City Tony picked up a shoulder bag that weighed less than my purse. When we were walking out of the hotel it fell off his shoulder causing what we thought was a pulled muscle. Over the next few days the pain worsened to where I called Dr. Patterson the day after Memorial Day. In his usual kind manner he said to bring him in the next day at noon. I am certain he saw Tony on his lunch hour. He ordered x-rays which showed a compression fracture in Tony's back. The steroids that keep the swelling down in Tony's brain have thinned his bones to where the slightest strain causes severe damage. I so wish anyone who reads this could observe what the first two weeks of recovery from the stress fracture have been like. One thing about it he no longer argues about the need to ride in a wheel chair. We returned to Columbia a week later for follow-up care after stopping by the V.A.Clinic in Mt. Vernon to deal with another one of the demands by the Fayettoville VAMC. I explained this to Linda Duffen the Persian Gulf Coordinator at Columbia who has attempted several times to help resolve the neurological referral, adjudication and social security issues. Linda celebrated her 25th anniversary with the V.A. on June 6th so she is not a novice in dealing with complex cases such as our sons. Only the other parents I have met can understand the frustration in dealing with this system. I thank God every day that my son is still a positive caring person. While his health has been totally destroyed he is always appreciative of the many efforts of others on his behalf. I lack both the wisdom and courage he has because he still believes in his country.

Any parent who has seen their child suffer like this and live day to day on all kinds of drugs will know where I am coming from. Tony starts each morning with an injection of Miacalon, then he takes Dexamethasone (steroid), Verapamil, HCTZ and Clonidine for blood pressure, Potassium Chloride, Calcium, Amitriptyline for sleep and the only thing that helps with the neck and now back pain is Vicodin. I understand this is a narcotic but frankly at this point my son becoming addicted to something is the least of my concerns. I wonder if he would be able to get any medicine at all if we were unable to pay his copay on the medications for him? I kept hoping that Tony would get strong enough that I could get the local DAV to take him to the VAMC for his appointments but I now must face the reality that his condition only worsens. I am taking a leave of absence from my job because it is not the kind of position you can leave the amount of time I have been out in the last year.

IN CLOSING MY MOST SINCERE AND OBJECTIVE OPINION IS THAT THE SYSTEM CURRENTLY IN PLACE DOES NOT WORK. THAT IS NOT TO TAKE ANYTHING AWAY FROM THE VERY CARING COMPASSIONATE EFFORTS OF PROFESSIONALS LIKE DR. BAUER, DR. PATTERSON, LINDA DUFFEN, WINDIA WILBERT AND THE HUNDREDS OF OTHERS WE HAVED MET WITHIN THE V.A. SYSTEM. I ONLY HEAR OF FUNDING CUTS AND DENIALS THAT ANYTHING EVEN HAPPENED TO THE PERSIAN GULF VETERANS. IF THE MEMBERS OF THE COMMITTEES THAT OVERSEE THE FUNDING OF THESE PROGRAMS COULD PUT ASIDE POLITICS AND DEAL WITH THE VERY REAL ISSUES OF ADEQUATE CARE FOR AMERICA'S VETERANS IT WOULD BE A GREAT FIRST STEP. WHEN I HEAR THAT A CONSPIRACY EXISTS TO COVER UP WHAT HAPPENDED TO VETERANS IN THE PERSIAN GULF I FIND IT HUMEROUS. I HONESTLY BELIEVE WE LACK THE ABILITY FOR A CONSPIRACY AND THAT THE MILITARY BUNGLED THE MEDICAL INFORMATION SO BADLY THAT THEY TRULY DO NOT HAVE ANY RECORDS OF WHAT MEDICATIONS THEY GAVE TO WHO IN PREPARATION DEPLOYMENT TO THE PERSIAN GULF. THEY MAY WELL HAVE CAUSED MY SON AND THOUSANDS OF OTHERS A HORRIBLE DEATH IN THE PROCESS, BUT AS ALWAYS IN AMERICA WITH MALICE TOWARD NONE. I DO NOT OFFER ANY APOLOGY FOR THE ANGER I FEEL. AS AN AMERICAN I AM SHOCKED AND DEEPLY ASHAMED OF THE WAY THE VETERANS ADMINISTRATION AND THE PATIENTS THEY SERVE ARE TREATED. SHRINKING RESOURCES AND INCREASING DEMANDS CAN ONLY LEAD TO DISASTER. IT IS TIME FOR THOSE IN AUTHORITY TO ACCEPT RESPONSIBILITY FOR WHATEVER HAPPENED TO OUR VETERANS AND SEE TO IT THAT THEY GET THE BEST IN MEDICAL CARE IMMEDIATELY. I KNOW THAT THE V.A. IS TRYING TO IMPROVE BUT THEY CANNOT PROGRESS WHILE BE SHREDDED IN THE BUDGET EACH YEAR.

I WILL CERTAINLY DO ANYTHING I CAN TO ASSIST ON BEHALF OF ALL THE AMERICAN VETERANS. MY SON IS IN DESPERATE NEED OF VERY COMPLEX, EXPENSIVE MEDICAL CARE. HE AND MANY OTHERS DO NOT HAVE TIME TO "WAIT" WHILE CHANGES ARE IMPLEMENTED SO I BEG YOU TO ACT NOW.

Janet R. Ott - Mother of Anthony Gene Ott 486-70-5628
130 Gum Road
Carl Juntion, Mo. 64834

Home phone 417-781-8349
Office 417-626-3030

○

ISBN 0-16-055774-7

90000

9 780160 557743