I - MEMORANDUM TO THE
PRESIDENT - 2/10/95

THE WHITE HOUSE

WASHINGTON

February 10, 1995

MEMORANDUM FOR THE PRESIDENT

FROM: THE FIRST LADY

You asked me to look into the issue of Gulf War illnesses as a result of the letters the White House has been receiving, as well as the concerns directly raised with you by citizens. Many Gulf War veterans, it seems, have been left with the terrible impression that their country has forgotten them. I wanted to let you know what I have learned in the last several weeks, as I have been consulting with key government officials, Gulf War veterans and their families, and outside advocates. What I have found is that this remains a complex and elusive problem, frustrating both to those who suffer from debilitating illnesses and to the government officials working to address their problems.

Background Information:

There were 697,000 U.S. troops that served in the Persian Gulf War in 1990-91. Many had flu-like symptoms when they were there and after they came home, but it wasn't until more than a year later that concerns were raised about chronic illnesses by hundreds, and then thousands of PGW veterans, some of whom are still on active duty. Of particular concern are a variety of unexplained symptoms that do not fit any neat diagnosis.

Symptoms of the undiagnosed or "mystery illnesses" are varied, including chronic fatigue, memory loss, rashes, difficulty with sleeping, gastrointestinal disorders, allergies, respiratory problems, recurrent infections, headaches, joint pain, nasal discharge, tumors, and unusual bleeding.

Nobody knows what has caused these symptoms and it is likely that there are several causes, some of which may interact with each other. For example, if exposure to a chemical agent lowered a soldier's immune response, he or she would be more susceptible to infectious agents. The list of possible causes includes exposures to: toxic by-products from oil fires or tent heaters; depleted uranium; unapproved vaccinations and anti-nerve gas compound (pyridostigmine); infectious agents (leishmaniasis, malaria, brucellosis, giardiasis); chemical and biological

warfare; pesticides; microwaves; and special paints and solvents. An alternative explanation is post-traumatic stress disorder or stress.

What is particularly unusual is the growing number of reports of spouses and children who also appear to be ill with similar symptoms, as well as reported miscarriages and birth defects. Thus far, no well designed studies have been conducted to determine whether Gulf War veterans are more likely to have family members with these problems than other veterans. However, the VA and CDC have examined this issue with the limited data that are currently available, and they believe that there is no evidence to support these complaints.

VA and DOD Registries

PL 102-585 directed VA to establish a Persian Gulf War Veterans' Health Registry that could easily be cross-referenced with a Department of Defense (DoD) registry that had been previously established under the National Defense Authorization Act for FY 1992-1993. The purpose of the Registries was to gather information about individuals that would be useful in determining whether certain exposures or experiences (especially oil fires) resulted in certain illnesses.

Unfortunately, according to a report issued on September 30, 1993 by the Office of Technology Assessment (OTA), the VA and DoD registries are not well coordinated. Additionally, OTA indicated that the registries cannot be used to determine cause-and-effect relationships between illnesses and exposures. Because the registries were constructed with emphasis on oil fire exposure, the registries are much less useful for examining other potential exposures. Similarly, the medical testing performed through the VA Registry were not relevant to the diagnosis of disorders that have now been associated with the mystery illnesses (i.e., immune dysfunction, neurologic disease, chemical sensitivities).

Of the 697,000 U.S. troops serving in the Persian Gulf war, more than 337,500 are now veterans. Approximately 40,000 veterans are currently enrolled in the VA Registry, and 85% of them are sick. Of those studied thus far, 17% complain of fatigue, 17% have rashes, 14% have unusual headaches, 14% have muscle or joint pain, and 11% have loss of memory, and 8% have shortness of breath. It is unknown how many of these have undiagnosed illnesses.

NIH Workshop on Persian Gulf War Illnesses

In April 1994, several Federal agencies co-sponsored a workshop at NIH, where a panel of experts listened to testimony from Government experts, veterans, and scientists.

They issued a report that concluded that Gulf War veterans were suffering from undiagnosed illnesses of unknown origins, but

that there was no single entity that could be reasonably called "Gulf War Syndrome." They recommended that more research be done.

Recent Reports

In June 1994, the Task Force on Persian Gulf War Health Effects of the Defense Science Board, chaired by Dr. Joshua Lederberg, issued its report on the possible exposure of US troops to chemical or biological weapons or other hazardous agents. The report concluded that there was no evidence that US troops were exposed to chemical or biological weapons, and that "the overall health experience of US troops in Operation Desert Storm was favorable beyond previous military precedent." The report also recommended "substantial improvements" in medical assessments of US troops before and after deployment, to enable DOD and VA to better assess the health effects of military service.

Although some of its findings received wide support, the report was criticized by veterans and Congress because some of its information was based on DoD reports that were not considered credible. For example the report stated that less than one tenth of one percent of the Gulf War troops have reported undiagnosed illnesses. Although the exact number is unknown, this number is considered by many to be unrealistically low and contributed to the perception of the report as a "DOD cover-up." Dr. Lederberg is a very well respected Nobel Laureate, but his selection was criticized because he has financial ties to DOD.

PL 102-585 also required VA and DoD to contract with the Institute of Medicine's Medical Follow-up Agency (MFUA) to review existing scientific, medical, and other information on the health consequences of military service in the Persian Gulf theater of operations.

The Institute of Medicine issued an interim report in January 1995. They concluded that research was needed to determine the prevalence and likely causes of Gulf War illnesses. They criticized the VA and DOD research that was underway as not adequately peer reviewed and concluded that the quality of the data was questionable.

The Senate Veterans Affairs Committee, chaired by Sen. Jay Rockefeller, issued a staff report in December 1994 that concluded that investigational drugs and vaccines were inappropriately distributed to US troops during the Persian Gulf War. Prior to the war, DOD obtained permission from FDA to use pills (pyridostigmine) in a way that was not proven safe or effective and a botulism vaccine that was not proven safe or effective. The report concluded that U.S. troops were not adequately informed of the possible risks of the drugs or

vaccines (as required by law), and that the vaccines and drugs were used in such a way that they probably would not have provided adequate protection against biological or chemical weapons.

The Senate report expressed strong concern that the pyridostigmine, which was intended to protect against chemical weapons, may have caused adverse reactions in some individuals, or may have enhanced the toxic effects of insecticides or other chemicals that were widely used in the Gulf.

Sen. Donald Riegle, Jr. issued two reports claiming that allied troops were exposed to chemical warfare, resulting from scud missile attacks or U.S. military bombing of Iraq's chemical warfare plants at a time when down-winds were unfavorable.

My meetings with DOD, VA and HHS

In January, I met with key officials from the DoD, VA, and HHS to discuss how best the Administration can respond to the concerns that have been raised. The agencies have been very engaged in addressing this issue. They are trying to improve medical evaluations and services for Gulf War veterans, conduct research that will enable them to better understand the causes of the illnesses, and provide compensation to veterans who are disabled. I received assurances that the departments are moving quickly to implement legislative provisions that you signed into law in October and November.

However, in the course of these meetings, I also learned that some of the research that the law requires to be conducted by independent researchers (such as university scientists) under grants from DoD was mistakenly being conducted by DoD. Deputy Secretary John Deutch assured me that this could be corrected, and suggested that he might ask NIH to assist DoD with a peer review system for these grants. I raised this issue with Dr. Phil Lee, the Assistant Secretary of Health at HHS, who agreed that PHS has much more expertise with peer review of grants than DOD.

Agency officials report that they are doing their best under difficult circumstances and feel besieged by Congress and the media. They claim that anecdotes, while compelling, do not constitute scientific evidence, and that Congress and the media are taking these anecdotes too seriously. In contrast, well respected scientists have testified before Congress that these "anecdotes" should be considered case studies, and point out that they may well be the first sign of significant health problems that will become obvious when research is finally conducted.

Meeting with Veterans' Service Organization Representatives

I also have had meetings with officials from the American Legion and the Veterans of Foreign Wars. Both of these meetings have been extremely helpful in helping me understand how the veterans view our Administration's role in helping Gulf War veterans. For example, I met with Steve Robertson, who is Legislative Director of the American Legion, and is himself a Gulf War veteran with multiple undiagnosed illnesses. One of his concerns was the DoD and VA view that stress was the main cause of these symptoms. He made it clear that he had experienced extreme stress in previous deployments (he gave the example of the possibility that he would have to "push the button" to launch nuclear weapons at the Soviet Union) and made it clear that his Persian Gulf experience was not at all stressful in comparison. He recited a long list of potential toxic exposures that were common in the Gulf; for example, pesticides that were sprayed everywhere, including on cooking utensils. He is very concerned that the combination of these exposures could have been much more toxic than any would have been individually. The Executive Director of the Legion, John Sommer, was clearly supportive of Steve's views.

In talking to the Commander of the Veterans of Foreign Wars (Gunner Kent) and their staff, I was assured that the VFW appreciates the legislative efforts that you and the VA have made to provide medical care and compensation to Gulf War veterans. He praised this Administration's quick response, especially compared to the "15 years it took to get anything for Agent Orange." However, the VFW has conducted a survey of more than 2,000 Gulf War veterans, which found that most have undiagnosed illnesses that are not being successfully treated. (This is not a random sample, but it is worrisome nevertheless.) The VFW does not blame the VA, but they do believe that the DOD is not providing VA with the information it needs to help determine the causes of these illnesses.

Veterans and Their Family Members

I have received many letters from Gulf War veterans and their spouses, and have had the opportunity to speak to some of these individuals on the telephone as well. They express great frustration with VA and DOD, and they clearly feel that the government has not done enough to address this health problem and that the government has not taken their concerns seriously enough. The specter of the government cover-up of the dangers of Agent Orange for Vietnam veterans is frequently mentioned.

One recurring theme is that doctors at the individual VA facilities minimize the seriousness of the patients' symptoms, are not particularly well informed about Gulf War illnesses, and sometimes even ignore the law that requires VA to provide free medical care to these veterans. For example, the President of the Gulf War Veterans of Massachusetts wrote on February 9, 1995:

"Veterans are bitter, and many of the ones I speak to have concluded that they are never going to get any help from the VA system. Why? First, despite the laws which have been passed, and despite Secretary Brown's convictions, Gulf veterans are still frequently refused service in VA hospitals. The VA claims system is a disaster...(my own claim was lost for over a year, and 30 months have passed since I initially filed it.) One of the biggest problems which I have been trying to work with on a local basis is simple ignorance of the situation by many of the VA physicians who are treating us. During my Persian Gulf Registry exam in January 1994, the doctor who examined me had never heard of depleted uranium and did not believe me when I told him of the exposure."

I have also heard from veterans who have cancer or who report that an usually high number of young Gulf War veterans have died of cancers or heart conditions. There is great fear that these fatal diseases were caused by service in the Gulf. Many veterans believe that the VA and DOD have not provided full and accurate information about deaths and diagnoses, and some staff from the agencies concur (off the record) with that assessment. I don't think that anyone knows whether there is statistical evidence of an abnormally high number of cancers or heart disease among Gulf War veterans, but it seems to me the thing to do is make sure that kind of information is available to the public, and properly analyzed by CDC. According to reports I have heard, several FOIA requests for such information have gone unanswered, or have been answered with information that is perceived to be inaccurate.

Lack of Effective Treatment

One of the major problems is that many of the undiagnosed illnesses do not respond to treatment. For example, some veterans complain of having diarrhea for 3 years, rashes that come and go but do not respond to treatment, or sensitivities to chemicals that make it impossible to go to gas stations or sit in hospital waiting rooms. Women who are married to Gulf War veterans report constant vaginal infections and pain related to sexual intercourse; neither the cause nor an effective treatment has been determined. VA does not provide medical care to spouses, so many of these women do not have access to medical tests or treatment. This is especially true if the veteran is too ill to work. This lack of health care makes it especially difficult to determine whether these illnesses are unusual or whether the major problem is lack of appropriate medical care.

In cases where VA and DOD medical facilities have been unable to effectively treat Gulf War veterans, many veterans have sought care in the private sector. Some Gulf War veterans have complained that the VA and DOD facilities are too conservative in their treatments. The countervailing point of view is that

private sector doctors are taking advantage of the desperation of Gulf War veterans, by selling useless or even dangerous diagnostic tests or treatment.

My staff has called scientists from across the country to learn more about the controversial treatments that Gulf War veterans are receiving in the private sector. Thus far, the experts suggest that there are no good diagnostic tools for determining chemical exposures to the brain, and that such diagnostic tools as SPECT scan and brain mapping have limited usefulness. One of the veterans who is very ill is currently going to a private facility for plasma pharesis at a cost of $15,000/month. Several experts have claimed that such a painful, dangerous, and expensive treatment would be difficult to justify except on an experimental basis. So, thus far the academic experts have made statements that are consistent with VA decisions not to use those tests and treatment. However, the usefulness of treatments that have been devised for multiple chemical sensitivity and other controversial diagnoses are more debatable.

Compensation

Veterans who have disabilities that are associated with military service are entitled to monthly benefits from the VA. The maximum benefit is approximately $23,000/year for a veteran who is considered 100% disabled.

As of ____ 1994 there were approximately ____ claims filed by PGW veterans or their survivors for general VA benefits. Approximately 10% were from veterans claiming disabilities from exposure to environmental hazards, but very few of those claims were granted. This is partly a function of the lack of diagnosis for these symptoms, and partly because it is more difficult to prove that an illness is service-connected if it is not reported until after a person leaves the military (battle wounds are obviously much easier to prove when filing a claim).

Thanks to the law that you signed in November (PL 103-), veterans whose illnesses are not diagnosed will, for the first time, be eligible to receive compensation if they can prove that they are disabled as a result of military service. The first compensation checks resulting from this law should be distributed in March. However, proving disability may still be difficult, and it will be essential to monitor this program to make sure that veterans receive the compensation that they deserve.

Working as a Team With VA, DOD and HHS

Among the VA, DOD, and HHS officials and the Gulf War veterans there is wide agreement that more targeted and coordinated research is needed. The Defense Reauthorization and the Veterans' Persian Gulf War Benefits Act that you signed in October and November include some important new research efforts, including research on the possibility that the veterans's health problems are transmissible to spouses and offspring. It is important that these efforts go forward expeditiously.

The agency officials expressed their desire to work together to ensure that the needs of Gulf War veterans are met. We agreed that we must convey to the American people that the Administration recognizes that there are serious questions that need to be resolved, and we are committed to working to address them. For example, Dr. Kizer, the VA Under Secretary for Health, admitted that some VA facilities are doing a better job than others, and indicated his strong commitment to improving that situation, so that all veterans receive the care they deserve. He also is planning a major new effort to examine whether birth defects and reproductive problems are unusually prevalent among Gulf War veterans.

As you said when you asked me to follow up on this issue, we must do our very best to guarantee that the concerns of our veterans who served our nation so nobly in the Gulf are addressed properly and honestly, with the compassion their cases merit. This must be our collective guiding principle.

I suggested to Secretary Perry and Secretary Brown that together we visit appropriate sites, such as hospitals or research centers, to demonstrate the concern of this Administration and our commitment to working together to get answers and provide assistance to those who are suffering health problems from their service during the Gulf War. My first such visit, at the VA Medical Center in Washington, DC, is scheduled for February 14.

I believe that the agencies involved are making great efforts to improve the research and services for Gulf War veterans, but that the statements made by Department officials are often perceived as defensive and less than candid. This may be partly because many of the career employees who are providing information to Department officials are themselves responsible for previous decisions. It is human nature to be reluctant to admit that mistakes might have been made; however, these mistakes were made during the previous Administrations, and we should be willing to admit that they occurred and that we must and will do better in the future. Given the enormous publicity and the increased concerns that the veterans are expressing about the

adequacy of the Administration response, I believe it is essential to be more open and let veterans and the American people know that we are not satisfied with the status quo.

I believe we can move ahead to immediately reassure the veterans and the public by moving quickly on some new initiatives, and making those initiatives public. We need to let the American people know that we are just as concerned as they are about the veterans whose illnesses are not responding to treatment. And of course, we need to move as quickly as possible to make progress on these issues.

I suggest that we consider two very public announcements in the coming weeks:

A. DoD Press Conference:

1. The message needs to be that DoD is concerned that the safety of the long-term use of pyridostigmine, alone and in combination with stress, pesticides, and other toxic chemicals, was not adequately studied under the Reagan/Bush Administration prior to the Persian Gulf War. That is why new research is now underway. DoD can announce that research is underway, and that most of it will be peer reviewed, independent research. This will have implications for future soldiers, in addition to Gulf War veterans who are ill. Of course, any future use of these agents will be reviewed in light of the results. Dr. Steven Joseph could be in charge of this effort.

2. Announce that DoD has developed new policies to make sure that all service members are adequately warned about any potential side effects from any vaccines, drugs, pesticides, decontamination agents, and other toxic chemicals that they will come in contact with. Dr. Susan Bailey is the person in charge of this effort.

3. I believe that DOD should announce that they have withdrawn a request for a permanent waiver of informed consent for the use of experimental drugs. [They may still request such waivers on a case by case basis]. This could be done by Executive Order, or Secretary Perry could make the decision.

B. President (and Secretary Brown) Announces:

1. You and/or Secretary Brown could request that the VA Inspector General investigate allegations that some VA facilities are not providing appropriate free medical care to Gulf War veterans as required by law. VA does not have enough investigative staff to do this, and anyway, the IG is preferable because it is independent of VA.

2. The VA PGW Hot Line will compile information about any reported problems regarding access to medical care or compensation, and Secretary Brown will ensure that information will be used by VA to improve those efforts.

3. The lack of mortality statistics has angered some veterans groups. The VA could announce that, in response to requests from veterans groups, the VA will analyze data from PGW veterans who have died, and CDC will work with them to evaluate whether the number of deaths or diagnoses are unusual.

4. The VA will include information about ill spouses and children, including miscarriages and stillbirths, on the PGW Health Registry starting [insert date]. VA is already including information about birth defects. This will help provide information about whether an unusually large number of these problems are occurring. Dr. Ken Kizer has also proposed an even more ambitious surveillance system for reproductive problems among veterans, which he should announce.

5. Announce that the first compensation checks for undiagnosed illnesses will be sent in March.

<u>Blue Ribbon Panel</u>

I also believe that we should consider a new "blue ribbon" panel to examine these issues. This panel should have a broader mandate than the Lederberg panel, and should not include members who have contracts or consulting relationships with DOD or VA, or the chemical industry. In order to have credibility with veterans and the public, we need to make sure that the panel includes scientific experts who have reputations as being consumer-oriented or absolutely objective. The panel should have an adequate staff that enables them to monitor the many activities of these three agencies for at least one year.

We may want to consider "reinventing" the concept of a blue ribbon panel to make it less reliant on the expertise of a large number of extremely busy scientists. Unfortunately, such experts are often perceived as relying too heavily on the information provided by the agencies. Perhaps the focus should be on a small top-notch, independent investigative staff that is advised by a small number of well-respected experts, such as Admiral Zumwaldt, a medical ethicist, and a small number of scientists.

cc: Leon Panetta

DRAFT

February 10, 1995

MEMORANDUM FOR THE PRESIDENT

FROM: THE FIRST LADY

You asked me to look into the issue of Gulf War illnesses as a result of the letters the White House has been receiving, as well as the concerns directly raised with you by citizens. Many Gulf War veterans, it seems, have been left with the terrible impression that their country has forgotten them. I wanted to let you know what I have learned in the last several weeks, as I have been consulting with key government officials, Gulf War veterans and their families, and outside advocates. What I have found is that this remains a complex and elusive problem, frustrating both to those who suffer from debilitating illnesses and to the government officials working to address their problems.

Background Information:

There were 697,000 U.S. troops that served in the Persian Gulf War in 1990-91. Many had flu-like symptoms when they were there and after they came home, but it wasn't until more than a year later that concerns were raised about chronic illnesses by hundreds, and then thousands of PGW veterans, some of whom are still on active duty. Of particular concern are a variety of unexplained symptoms that do not fit any neat diagnosis.

Symptoms of the undiagnosed or "mystery illnesses" are varied, including chronic fatigue, memory loss, rashes, difficulty with sleeping, gastrointestinal disorders, allergies, respiratory problems, recurrent infections, headaches, joint pain, nasal discharge, tumors, and unusual bleeding.

Nobody knows what has caused these symptoms and it is likely that there are several causes, some of which may interact with each other. For example, if exposure to a chemical agent lowered a soldier's immune response, he or she would be more susceptible to infectious agents. The list of possible causes includes exposures to: toxic by-products from oil fires or tent heaters; depleted uranium; unapproved vaccinations and anti-nerve gas compound (pyridostigmine); infectious agents (leishmaniasis, malaria, brucellosis, giardiasis); chemical and biological warfare; pesticides; microwaves; and special paints and solvents.

An alternative explanation is post-traumatic stress disorder or stress.

What is particularly unusual is the growing number of reports of spouses and children who also appear to be ill with similar symptoms, as well as reported miscarriages and birth defects. Thus far, no well designed studies have been conducted to determine whether Gulf War veterans are more likely to have family members with these problems than other veterans. However, the VA and CDC have examined this issue with the limited data that are currently available, and they believe that there is no evidence to support these complaints.

VA and DOD Registries

PL 102-585 directed VA to establish a Persian Gulf War Veterans' Health Registry that could easily be cross-referenced with a Department of Defense (DoD) registry that had been previously established under the National Defense Authorization Act for FY 1992-1993. The purpose of the Registries was to gather information about individuals that would be useful in determining whether certain exposures or experiences (especially oil fires) resulted in certain illnesses.

Unfortunately, according to a report issued on September 30, 1993 by the Office of Technology Assessment (OTA), the VA and DoD registries are not well coordinated. Additionally, OTA indicated that the registries cannot be used to determine cause-and-effect relationships between illnesses and exposures. Because the registries were constructed with emphasis on oil fire exposure, the registries are much less useful for examining other potential exposures. Similarly, the medical testing performed through the VA Registry were not relevant to the diagnosis of disorders that have now been associated with the mystery illnesses (i.e., immune dysfunction, neurologic disease, chemical sensitivities).

Of the 697,000 U.S. troops serving in the Persian Gulf war, more than 337,500 are now veterans. Approximately 40,000 veterans are currently enrolled in the VA Registry, and 85% of them are sick. Of those studied thus far, 17% complain of fatigue, 17% have rashes, 14% have unusual headaches, 14% have muscle or joint pain, and 11% have loss of memory, and 8% have shortness of breath. It is unknown how many of these have undiagnosed illnesses.

NIH Workshop on Persian Gulf War Illnesses

In April 1994, several Federal agencies co-sponsored a workshop at NIH, where a panel of experts listened to testimony from Government experts, veterans, and scientists.

They issued a report that concluded that Gulf War veterans were suffering from undiagnosed illnesses of unknown origins, but that there was no single entity that could be reasonably called "Gulf War Syndrome." They recommended that more research be done.

Recent Reports

In June 1994, the Task Force on Persian Gulf War Health Effects of the Defense Science Board, chaired by Dr. Joshua Lederberg, issued its report on the possible exposure of US troops to chemical or biological weapons or other hazardous agents. The report concluded that there was no evidence that US troops were exposed to chemical or biological weapons, and that "the overall health experience of US troops in Operation Desert Storm was favorable beyond previous military precedent." The report also recommended "substantial improvements" in medical assessments of US troops before and after deployment, to enable DOD and VA to better assess the health effects of military service.

Although some of its findings received wide support, the report was criticized by veterans and Congress because some of its information was based on DoD reports that were not considered credible. For example the report stated that less than one tenth of one percent of the Gulf War troops have reported undiagnosed illnesses. Although the exact number is unknown, this number is considered by many to be unrealistically low and contributed to the perception of the report as a "DOD cover-up." Dr. Lederberg is a very well respected Nobel Laureate, but his selection was criticized because he has financial ties to DOD.

PL 102-585 also required VA and DoD to contract with the Institute of Medicine's Medical Follow-up Agency (MFUA) to review existing scientific, medical, and other information on the health consequences of military service in the Persian Gulf theater of operations.

The Institute of Medicine issued an interim report in January 1995. They concluded that research was needed to determine the prevalence and likely causes of Gulf War illnesses. They criticized the VA and DOD research that was underway as not adequately peer reviewed and concluded that the quality of the data was questionable.

The Senate Veterans Affairs Committee, chaired by Sen. Jay Rockefeller, issued a staff report in December 1994 that concluded that investigational drugs and vaccines were inappropriately distributed to US troops during the Persian Gulf War. Prior to the war, DOD obtained permission from FDA to use pills (pyridostigmine) in a way that was not proven safe or effective and a botulism vaccine that was not proven safe or

effective. The report concluded that U.S. troops were not adequately informed of the possible risks of the drugs or vaccines (as required by law), and that the vaccines and drugs were used in such a way that they probably would not have provided adequate protection against biological or chemical weapons.

The Senate report expressed strong concern that the pyridostigmine, which was intended to protect against chemical weapons, may have caused adverse reactions in some individuals, or may have enhanced the toxic effects of insecticides or other chemicals that were widely used in the Gulf.

Sen. Donald Riegle, Jr. issued two reports claiming that allied troops were exposed to chemical warfare, resulting from scud missile attacks or U.S. military bombing of Iraq's chemical warfare plants at a time when down-winds were unfavorable.

My meetings with DOD, VA and HHS

In January, I met with key officials from the DoD, VA, and HHS to discuss how best the Administration can respond to the concerns that have been raised. The agencies have been very engaged in addressing this issue. They are trying to improve medical evaluations and services for Gulf War veterans, conduct research that will enable them to better understand the causes of the illnesses, and provide compensation to veterans who are disabled. I received assurances that the departments are moving quickly to implement legislative provisions that you signed into law in October and November.

However, in the course of these meetings, I also learned that some of the research that the law requires to be conducted by independent researchers (such as university scientists) under grants from DoD was mistakenly being conducted by DoD. Deputy Secretary John Deutch assured me that this could be corrected, and suggested that he might ask NIH to assist DoD with a peer review system for these grants. I raised this issue with Dr. Phil Lee, the Assistant Secretary of Health at HHS, who agreed that PHS has much more expertise with peer review of grants than DOD.

Agency officials report that they are doing their best under difficult circumstances and feel besieged by Congress and the media. They claim that anecdotes, while compelling, do not constitute scientific evidence, and that Congress and the media are taking these anecdotes too seriously. In contrast, well respected scientists have testified before Congress that these "anecdotes" should be considered case studies, and point out that they may well be the first sign of significant health problems that will become obvious when research is finally conducted.

Meeting with Veterans' Service Organization Representatives

I also have had meetings with officials from the American Legion and the Veterans of Foreign Wars. Both of these meetings have been extremely helpful in helping me understand how the veterans view our Administration's role in helping Gulf War veterans. For example, I met with Steve Robertson, who is Legislative Director of the American Legion, and is himself a Gulf War veteran with multiple undiagnosed illnesses. One of his concerns was the DoD and VA view that stress was the main cause of these symptoms. He made it clear that he had experienced extreme stress in previous deployments (he gave the example of the possibility that he would have to "push the button" to launch nuclear weapons at the Soviet Union) and made it clear that his Persian Gulf experience was not at all stressful in comparison. He recited a long list of potential toxic exposures that were common in the Gulf; for example, pesticides that were sprayed everywhere, including on cooking utensils. He is very concerned that the combination of these exposures could have been much more toxic than any would have been individually. The Executive Director of the Legion, John Sommer, was clearly supportive of Steve's views.

In talking to the Commander of the Veterans of Foreign Wars (Gunner Kent) and their staff, I was assured that the VFW appreciates the legislative efforts that you and the VA have made to provide medical care and compensation to Gulf War veterans. He praised this Administration's quick response, especially compared to the "15 years it took to get anything for Agent Orange." However, the VFW has conducted a survey of more than 2,000 Gulf War veterans, which found that most have undiagnosed illnesses that are not being successfully treated. (This is not a random sample, but it is worrisome nevertheless.) The VFW does not blame the VA, but they do believe that the DOD is not providing VA with the information it needs to help determine the causes of these illnesses.

Veterans and Their Family Members

I have received many letters from Gulf War veterans and their spouses, and have had the opportunity to speak to some of these individuals on the telephone as well. They express great frustration with VA and DOD, and they clearly feel that the government has not done enough to address this health problem and that the government has not taken their concerns seriously enough. The specter of the government cover-up of the dangers of Agent Orange for Vietnam veterans is frequently mentioned.

One recurring theme is that doctors at the individual VA facilities minimize the seriousness of the patients' symptoms, are not particularly well informed about Gulf War illnesses, and sometimes even ignore the law that requires VA to provide free

medical care to these veterans. For example, the President of the Gulf War Veterans of Massachusetts wrote on February 9, 1995: "Veterans are bitter, and many of the ones I speak to have concluded that they are never going to get any help from the VA system. Why? First, despite the laws which have been passed, and despite Secretary Brown's convictions, Gulf veterans are still frequently refused service in VA hospitals. The VA claims system is a disaster...(my own claim was lost for over a year, and 30 months have passed since I initially filed it.) One of the biggest problems which I have been trying to work with on a local basis is simple ignorance of the situation by many of the VA physicians who are treating us. During my Persian Gulf Registry exam in January 1994, the doctor who examined me had never heard of depleted uranium and did not believe me when I told him of the exposure."

I have also heard from veterans who have cancer or who report that an usually high number of young Gulf War veterans have died of cancers or heart conditions. There is great fear that these fatal diseases were caused by service in the Gulf. Many veterans believe that the VA and DOD have not provided full and accurate information about deaths and diagnoses, and some staff from the agencies concur (off the record) with that assessment. I don't think that anyone knows whether there is statistical evidence of an abnormally high number of cancers or heart disease among Gulf War veterans, but it seems to me the thing to do is make sure that kind of information is available to the public, and properly analyzed by CDC. According to reports I have heard, several FOIA requests for such information have gone unanswered, or have been answered with information that is perceived to be inaccurate.

Lack of Effective Treatment

One of the major problems is that many of the undiagnosed illnesses do not respond to treatment. For example, some veterans complain of having diarrhea for 3 years, rashes that come and go but do not respond to treatment, or sensitivities to chemicals that make it impossible to go to gas stations or sit in hospital waiting rooms. Women who are married to Gulf War veterans report constant vaginal infections and pain related to sexual intercourse; neither the cause nor an effective treatment has been determined. VA does not provide medical care to spouses, so many of these women do not have access to medical tests or treatment. This is especially true if the veteran is too ill to work. This lack of health care makes it especially difficult to determine whether these illnesses are unusual or whether the major problem is lack of appropriate medical care.

In cases where VA and DOD medical facilities have been unable to effectively treat Gulf War veterans, many veterans have sought care in the private sector. Some Gulf War veterans have

complained that the VA and DOD facilities are too conservative in their treatments. The countervailing point of view is that private sector doctors are taking advantage of the desperation of Gulf War veterans, by selling useless or even dangerous diagnostic tests or treatment.

My staff has called scientists from across the country to learn more about the controversial treatments that Gulf War veterans are receiving in the private sector. Thus far, the experts suggest that there are no good diagnostic tools for determining chemical exposures to the brain, and that such diagnostic tools as SPECT scan and brain mapping have limited usefulness. One of the veterans who is very ill is currently going to a private facility for plasma pharesis at a cost of $15,000/month. Several experts have claimed that such a painful, dangerous, and expensive treatment would be difficult to justify except on an experimental basis. So, thus far the academic experts have made statements that are consistent with VA decisions not to use those tests and treatment. However, the usefulness of treatments that have been devised for multiple chemical sensitivity and other controversial diagnoses are more debatable.

Compensation

Veterans who have disabilities that are associated with military service are entitled to monthly benefits from the VA. The maximum benefit is approximately $23,000/year for a veteran who is considered 100% disabled.

As of ____ 1994 there were approximately ____ claims filed by PGW veterans or their survivors for general VA benefits. Approximately 10% were from veterans claiming disabilities from exposure to environmental hazards, but very few of those claims were granted. This is partly a function of the lack of diagnosis for these symptoms, and partly because it is more difficult to prove that an illness is service-connected if it is not reported until after a person leaves the military (battle wounds are obviously much easier to prove when filing a claim).

Thanks to the law that you signed in November (PL 103-), veterans whose illnesses are not diagnosed will, for the first time, be eligible to receive compensation if they can prove that they are disabled as a result of military service. The first compensation checks resulting from this law should be distributed in March. However, proving disability may still be difficult, and it will be essential to monitor this program to make sure that veterans receive the compensation that they deserve.

Working as a Team With VA, DOD and HHS

Among the VA, DOD, and HHS officials and the Gulf War veterans there is wide agreement that more targeted and coordinated research is needed. The Defense Reauthorization and the Veterans' Persian Gulf War Benefits Act that you signed in October and November include some important new research efforts, including research on the possibility that the veterans's health problems are transmissible to spouses and offspring. It is important that these efforts go forward expeditiously.

The agency officials expressed their desire to work together to ensure that the needs of Gulf War veterans are met. We agreed that we must convey to the American people that the Administration recognizes that there are serious questions that need to be resolved, and we are committed to working to address them. For example, Dr. Kizer, the VA Under Secretary for Health, admitted that some VA facilities are doing a better job than others, and indicated his strong commitment to improving that situation, so that all veterans receive the care they deserve. He also is planning a major new effort to examine whether birth defects and reproductive problems are unusually prevalent among Gulf War veterans.

As you said when you asked me to follow up on this issue, we must do our very best to guarantee that the concerns of our veterans who served our nation so nobly in the Gulf are addressed properly and honestly, with the compassion their cases merit. This must be our collective guiding principle.

I suggested to Secretary Perry and Secretary Brown that together we visit appropriate sites, such as hospitals or research centers, to demonstrate the concern of this Administration and our commitment to working together to get answers and provide assistance to those who are suffering health problems from their service during the Gulf War. My first such visit, at the VA Medical Center in Washington, DC, is scheduled for February 14.

I believe that the agencies involved are making great efforts to improve the research and services for Gulf War veterans, but that the statements made by Department officials are often perceived as defensive and less than candid. This may be partly because many of the career employees who are providing information to Department officials are themselves responsible for previous decisions. It is human nature to be reluctant to admit that mistakes might have been made; however, these mistakes were made during the previous Administrations, and we should be willing to admit that they occurred and that we must and will do better in the future. Given the enormous publicity and the increased concerns that the veterans are expressing about the

adequacy of the Administration response, I believe it is essential to be more open and let veterans and the American people know that we are not satisfied with the status quo.

I believe we can move ahead to immediately reassure the veterans and the public by moving quickly on some new initiatives, and making those initiatives public. We need to let the American people know that we are just as concerned as they are about the veterans whose illnesses are not responding to treatment. And of course, we need to move as quickly as possible to make progress on these issues.

I suggest that we consider two very public announcements in the coming weeks:

A. DoD Press Conference:

1. The message needs to be that DoD is concerned that the safety of the long-term use of pyridostigmine, alone and in combination with stress, pesticides, and other toxic chemicals, was not adequately studied under the Reagan/Bush Administration prior to the Persian Gulf War. That is why new research is now underway. DoD can announce that research is underway, and that most of it will be peer reviewed, independent research. This will have implications for future soldiers, in addition to Gulf War veterans who are ill. Of course, any future use of these agents will be reviewed in light of the results. Dr. Steven Joseph could be in charge of this effort.

2. Announce that DoD has developed new policies to make sure that all service members are adequately warned about any potential side effects from any vaccines, drugs, pesticides, decontamination agents, and other toxic chemicals that they will come in contact with. Dr. Susan Bailey is the person in charge of this effort.

3. I believe that DOD should announce that they have withdrawn a request for a permanent waiver of informed consent for the use of experimental drugs. [They may still request such waivers on a case by case basis]. This could be done by Executive Order, or Secretary Perry could make the decision.

B. President (and Secretary Brown) Announces:

1. You and/or Secretary Brown could request that the VA Inspector General investigate allegations that some VA facilities are not providing appropriate free medical care to Gulf War veterans as required by law. VA does not have enough investigative staff to do this, and anyway, the IG is preferable because it is independent of VA.

2. The VA PGW Hot Line will compile information about any reported problems regarding access to medical care or compensation, and Secretary Brown will ensure that information will be used by VA to improve those efforts.

3. The lack of mortality statistics has angered some veterans groups. The VA could announce that, in response to requests from veterans groups, the VA will analyze data from PGW veterans who have died, and CDC will work with them to evaluate whether the number of deaths or diagnoses are unusual.

4. The VA will include information about ill spouses and children, including miscarriages and stillbirths, on the PGW Health Registry starting [insert date]. VA is already including information about birth defects. This will help provide information about whether an unusually large number of these problems are occurring. Dr. Ken Kizer has also proposed an even more ambitious surveillance system for reproductive problems among veterans, which he should announce.

5. Announce that the first compensation checks for undiagnosed illnesses will be sent in March.

Blue Ribbon Panel

I also believe that we should consider a new "blue ribbon" panel to examine these issues. This panel should have a broader mandate than the Lederberg panel, and should not include members who have contracts or consulting relationships with DOD or VA, or the chemical industry. In order to have credibility with veterans and the public, we need to make sure that the panel includes scientific experts who have reputations as being consumer-oriented or absolutely objective. The panel should have an adequate staff that enables them to monitor the many activities of these three agencies for at least one year.

We may want to consider "reinventing" the concept of a blue ribbon panel to make it less reliant on the expertise of a large number of extremely busy scientists. Unfortunately, such experts are often perceived as relying too heavily on the information provided by the agencies. Perhaps the focus should be on a small top-notch, independent investigative staff that is advised by a small number of well-respected experts, such as Admiral Zumwaldt, a medical ethicist, and a small number of scientists.

cc: Leon Panetta
