In a large epidemiological study, researchers supported by both the Department of Veterans Affairs (VA) and the Department of Defense (DoD) have found preliminary evidence that veterans who served in Desert Shield-Desert Storm are nearly twice as likely as their non-deployed counterparts to develop amyotrophic lateral sclerosis (ALS), commonly called Lou Gehrig’s disease. VA, working with DoD, studied nearly 2.5 million veterans for this investigation.

“I am pleased that VA is once again making a major contribution that will benefit veterans and, in fact, all Americans,” said Secretary of Veterans Affairs Anthony J. Principi. “I am committed to doing research that provides a better understanding of diseases that affect veterans and providing disability compensation as early as possible.”

“This research is a product of a significant investment by DoD and VA over the past several years and reflects our commitment to investigate the medical problems and health concerns of Gulf War veterans,” said Dr. Bill Winkenwerder, Jr., the Assistant Secretary of Defense for Health Affairs. “Scientific research helps answer veterans’ questions and holds the promise for better protection of the health of our men and women during future deployments.”

Both VA and DoD fund and operate programs dedicated to studying Gulf War illnesses and the effect of continuing deployments on the health of the men and women who have served in the armed forces.

This study, begun in March 2000, involved nearly 700,000 service members deployed to Southwest Asia, and 1.8 million who were not deployed to the Gulf during the period August 2, 1990, to July 31, 1991.

The study found 40 cases of ALS among deployed veterans. Although the researchers found the risk of ALS to be twice as high for deployed veterans compared to non-deployed veterans, it is a rare disease and the number of affected individuals is small.

“These findings are of great concern and warrant further study,” Secretary Principi said. “I intend to make certain that VA’s medical resources and research capabilities are fully focused on this issue.” He said he would also explore VA’s options for compensating veterans who served in the Gulf and who subsequently develop ALS.

ALS is a fatal neurological disease that destroys the nerve cells that control muscle movement. Neither a cause nor an effective treatment for ALS is known. The investigation, jointly funded by DoD and VA for $1.3 million, included case reviews, examinations and at-home interviews of the participants.

As a result of the findings, the Veterans Benefits Administration, an agency of VA, is stepping up its efforts to assist veterans with ALS. VBA has centralized its rating of the claims of Gulf War veterans with this disease as well as the claims of their survivors. VBA regional offices have been encouraged to move quickly when they identify Gulf War veteran claims and to immediately encourage those veterans to file for service-connection for ALS.

The VBA Data Management Office has provided regional offices with a list of deployed Gulf War veterans that VBA records indicated a claim for ALS or an undiagnosed neurological condition to assist in getting benefits to the veterans.

Q’s and A’s About the ALS Study and What VA Will Do

Q. As a result of this study, will VA take steps to compensate Desert Shield-Desert Storm veterans who were deployed to the Gulf War theater of operations between August 2, 1990, and July 31, 1991, found to be suffering from ALS?

A. Yes. We will act in a way that will get the benefits to eligible veterans and their survivors in the shortest time possible. VA will immediately undertake extensive outreach to these veterans to assist them in filing new claims or reactivating existing claims for benefits.

Q. What geographical area of service would be covered in establishing eligibility for compensation for ALS?
A. Veterans who served from August 2, 1990, through
July 31, 1991, in the Southwest Asian theater of oper-
ations will be eligible. The theater of operations
included Iraq, Kuwait, Saudi Arabia, the neutral zone
between Iraq and Saudi Arabia, Bahrain, Qatar, the
United Arab Emirates, Oman, the Gulf of Aden, the
Gulf of Oman, the Persian Gulf, the Arabian Sea, the
Red Sea, and the airspace above these locations (38
C.F.R. § 3.317 (d)(2)).

Q. How and where are these claims going to be pro-
cessed?

A. Claims will be processed at VA headquarters in
Washington, DC.

Q. What about veterans deployed during this period that
were not identified through this study?

A. This was a large study that sought to cover all active-
duty military and mobilized reserves and National
Guard who served for at least one month in the Gulf
theater of operations during the relevant period, and had
a diagnosis of ALS. There were a small number of
potential claimants, however, who were contacted, but
chose not to participate in the study. To the extent that
we can identify them, we intend to engage in outreach
to these potential claimants as well and offer them assis-
tance in determining whether they might have a valid
claim for benefits.

Q. Will VA issue a regulation to implement a presump-
tion of service connection as a result of this study?

A. Because we do not want to delay providing benefits
in these cases, and because the law permits us to adju-
dicate the claims on the basis of this evidence now, we
will not wait for a regulation.

Q. But what will happen when a Desert Shield-Desert
Storm veteran develops ALS in the future?

A. In the future, veterans with ALS who served in the
Gulf area during this period may be able to establish
direct service-connection with the evidence provided by
this study.

Q. This study covers a very narrow period of time,
only a one-year period from the summer of 1990 to
the summer of 1991. What if a veteran who served in
the Gulf outside of that period of time were to develop
ALS? Could such a veteran receive service
connection?

A. Currently, we have no evidence to support service con-
nection based on such deployment. Because of the unique
environmental exposures that occurred during this time, the
Desert Shield and Desert Storm periods were studied and
the results relate only to those periods.

About the “Review”

The “Gulf War Review” is written by VA’s Envi-
ronmental Agents Service (EAS). The “Review”
is published to provide information about the con-
cerns of Gulf War veterans, their families, and
others interested in possible long-term health conse-
quences of military service in the Gulf War. The
“Review” describes actions by VA and others to
respond to these concerns. For past and current
issues of the “Review” and additional information,
see our Web site at www.va.gov/gulfwar.

The most recent, prior to this, issues of the news-
letter are dated August 2001 and November 2001.
Additional issues will be prepared when warranted
by significant developments. EAS anticipates publi-
cation of the “Review” three or four times annually.
Four were issued in Calendar Year 2001. This issue
was completed in late-February 2002 and does not
include developments that occurred after that time.

Comments or questions concerning the content
of the “Review” are encouraged. Suggestions and
ideas for future issues of the newsletter should
be sent to Donald J. Rosenblum, Deputy Director,
Environmental Agents Service (131), VA Central
Office, 810 Vermont Avenue, N.W., Washington, DC
20420.

Requests for additional copies of this and/or
future issues should also be sent to Mr. Rosenblum.
A limited supply of the prior issues is available.
Please specify the quantity and issue date requested.

Questions about the Gulf War Registry examina-
tion should be directed to the Registry Coordinator
or Registry Physician at the nearest VA medical
facility. The telephone number can be found in the
local telephone directory under the “U.S. Govern-
ment” listings. Assistance is also available from the
toll-free VA Gulf War Helpline: 1-800-749-8387.
Q. Why did it take VA so long to study the ALS rate among Desert Shield-Desert Storm veterans? Reports of ALS among Gulf War veterans have been circulating for a long time.

A. VA takes very seriously everything that veterans have to say about their medical problems. ALS is an extremely rare disease, and consequently there have been very few cases to study. The initial reports about ALS often depended upon anecdotes about cases of ALS among Desert Shield-Desert Storm veterans without numbers of cases that were medically verified. Two previous mortality and hospitalization studies failed to show a connection between ALS and service in the Gulf region. Nevertheless, VA researchers became convinced the issue merited a special review. However, the study does not address the cause(s) of ALS, and, in general, the medical community does not understand the etiology of this disease. VA will continue to sponsor research into this subject.

Q. What caused the ALS among Desert Shield-Desert Storm veterans?

A. We don’t know. The cause of this disease is unknown in the general population. In a small proportion of cases, there is a family history of ALS. Some studies have evaluated whether occupational exposures could contribute to ALS, but the results have not been conclusive. The next stage in this Gulf War study will be to analyze the family and occupational history of the study participants.

Q. What are the chances of an individual Desert Shield-Desert Storm veteran developing ALS?

A. Despite the increased risk identified in this study, the number of veterans, likely to develop ALS is very small. This study suggests that fewer than 7 individuals per million per year are expected to be at risk for developing the disease.

Q. What can VA do, right now, to help Desert Shield-Desert Storm veterans with ALS?

A. VA can provide medical care and compensation. VA has the legal authority already to provide disability compensation for these veterans and medical care. Although VA will make every effort to contact ALS victims who took part in the recent study, veterans or family members who believe they qualify should contact the nearest VA medical center, or regional benefits office.

Q. How can Desert Shield-Desert Storm veterans with ALS contact VA?

A. For general information they can call VA’s toll free number at 1-800-827-1000. They also can call another toll-free number at 1-877-342-5257 for information specifically about the ALS national survey.

Q. ALS is a progressive, fatal disease. What about families of veterans with ALS?

A. VA is committed to caring for the survivors of any Desert Shield-Desert Storm veterans who die of this disease and will be working to develop eligibility criteria for Dependency and Indemnity Compensation (DIC), enrollment in VA’s health-care program for survivors (CHAMPVA), educational assistance, vocational assistance, and access to the GI Bill home loan program.

Q. Will benefits for ALS victims and family members be retroactive?

A. Federal law determines who receives VA benefits and how financial payments must be calculated. As a rule, when VA provides compensation to veterans or their survivors, the benefits only go back as far as the date of the claim for those benefits.

**VA Extends Disability Compensation for Undiagnosed Illnesses in Gulf War Veterans**

On November 9, 2001, the Department of Veterans Affairs (VA) amended its adjudication regulations to extend through December 31, 2006, disability compensation for conditions in Gulf War veterans resulting from undiagnosed illnesses. The regulation change was necessary because existing regulations covered only those undiagnosed disabilities that appeared on or before December 31, 2001.

The regulation change was published in the Federal Register as “interim final rule with request for comments.” It was effective on the date of publication (November 9, 2001) on an “emergency basis” due to the pending expiration of the current manifestation period. Public comments were requested, to be received by VA on or before January 8, 2002. On December 27, 2001, the President signed a law (passed by Congress) further extending the manifestation period to September 30, 2011.

**Background**

In response to the needs and concerns of Gulf War veterans Congress enacted the Persian Gulf War Veterans’ Benefits Act as Title I of the “Veterans’ Benefits Improvements Act of 1994,” Public Law 103-446. This law authorized the Secretary of Veterans Affairs to compensate Gulf War veterans suffering with chronic disabilities resulting from undiagnosed illness (or combination of undiagnosed...
illness (or combination of undiagnosed illnesses) that appeared during active duty in the Southwest Asia theater of operations during the Gulf War and to a degree of 10 percent or more disabled within a presumptive period, as determined by the Secretary, following service in the Southwest Asia theater of operations during the Gulf War.

This was the first time that VA was authorized to provide disability compensation to veterans without a diagnosis. The new law specified that, in establishing the presumptive period, the Secretary should review any credible scientific/medical evidence, the historical treatment afforded other diseases for which service connection is presumed, and other pertinent circumstances regarding the Gulf War experience. Initially, in February 1995, VA established a 2-year post Gulf War-service presumptive period.

However, concerns were expressed about the adequacy of the 2-year period. In 1997, Secretary Jesse Brown determined that the presumptive period should be extended to cover illnesses that become manifest through December 31, 2001. In April 1997, VA published a final rule in the Federal Register establishing the December 2001 deadline.

The National Academy of Sciences’ Institute of Medicine (IOM) is conducting a series of reviews of available scientific literature concerning associations between diseases and exposure in military service to selected risk factors encountered or experienced during the Gulf War. A number of scientific studies are ongoing, and the IOM has suggested additional areas of possible research.

VA continues to receive claims for undiagnosed illnesses from Gulf War veterans, and military operations in the Southwest Asia theater of operations are continuing. No end date for the Gulf War has been established by Congress or the President.

It is anticipated that service members will be serving in the Gulf region long after December 31, 2001. Thus, VA argued that unless the manifestation period is extended, these individuals might be unfairly deprived of the benefits mandated by Congress.

The presumptive period is based primarily on the need for completion of additional research, rather than evidence concerning the manifestation period of undiagnosed illnesses. Further extensions of the presumptive period are possible should they prove to be necessary for any group of veterans. Thus, this change does not disadvantage any Gulf War veterans.

New Law Modifies “Undiagnosed Illnesses” Definition, Preserves Service-Connection for Research Participants

Public Law 107-103, the “Veterans Education and Benefits Expansion Act of 2001,” signed by President Bush on December 27, 2001, includes several Gulf War-related provisions. Specifically, Sec. 202 authorizes VA, effective March 1, 2002, to pay compensation to any eligible Gulf War veteran chronically disabled by an “undiagnosed illness,” a “medically unexplained chronic multisymptom illness defined by a cluster of signs or symptoms,” or “any diagnosed illness that VA determines in regulations … warrants a presumption of service connection” or any combination of these.

The term “undiagnosed illness” has been interpreted previously by VA to preclude from eligibility under the law spelled out in 38 USC Sections 1117 or 1118, any veteran who has received a diagnosis, even if the diagnosis is merely a descriptive label for a collection of unexplained symptoms. This new statute expands VA’s authority. It is the intent of this legislation to ensure eligibility for chronically disabled Gulf War veterans even without diagnostic label by a clinician because of the absence of conclusive pathophysiology or etiology.

The definition of undiagnosed illness encompasses a variety of unexplained clinical conditions, characterized by overlapping symptoms and signs, which share features such as fatigue, pain, disabilities out of proportion to physical findings, and inconsistent demonstrations of laboratory abnormalities. Although chronic fatigue syndrome, fibromyalgia, and irritable bowel syndrome are the most common diagnoses under this definition, other conditions that may be characterized similarly include other chronic musculoskeletal pain disorders and chronic headache disorders.

The legislation also modified existing law by substituting a specific date (October 1, 2010) - for “10 years after the last day of the fiscal year in which the National Academy of Sciences (NAS) submits the first report” under Sec. 1603(j) of the “Persian Gulf War Veterans Act of 1998.” That provision also requires VA to contract with the NAS for a series of literature reviews.

The legislation also amends 38 USC 1117 and 1118 to extend VA authority to determine that a disease warrants presumptive service-connection based on these NAS reports through September 30, 2011. (In November 2001, VA had extended this period by regulation to December 31, 2006. See article above).
Preservation of Service-Connection for Research Subjects

Section 203 of the new law protects veterans participating in medical research sponsored by VA from the loss of service-connection granted under 38 USC 1117 or 1118, if VA determines that such protection is necessary for the conduct of the research. VA is required to publish in the Federal Register a list of medical research projects sponsored by VA for which service-connection is protected by this section.

Law Extends Gulf War Heath Care Eligibility

On January 23, 2002, President Bush signed Public Law 107-135, the Department of Veterans Affairs Health Care Programs Enhancement Act of 2001. This legislation includes a provision (Section 211) that authorizes a one-year extension of eligibility for health care services for veterans who served in Southwest Asia during the Gulf War. The additional year expires on December 31, 2002.

Depleted Uranium Update

In December 2001, the *Journal of Occupational Environmental Medicine* published an article updating the findings of a team of investigators, led by Melissa A. McDiarmid, M.D., M.P.H., University of Maryland Department of Medicine and the VA Medical Center, Baltimore, MD, exploring the long-term health effects of depleted uranium exposure in Gulf War veterans.

DU was first used in combat by the U.S. and allied forces during the Gulf War. It was used in major weapons systems because of its density, availability, and relative low cost. DU is estimated to contain about 50-60 percent of the radioactivity of natural uranium.

(For information about DU, its use in the Gulf War, and the VA-sponsored and funded DU follow-up program, see the September 1999, June 2000, and May 2001 issues of the “Gulf War Review” newsletter.)

Dr. McDiarmid and her colleagues are performing periodic medical surveillance examinations to determine the possible long-term clinical health effects in a group of 50 Gulf War veterans. Uranium’s chemical toxicity is a major concern in Gulf War veterans, with particular focus on the kidneys.

Dr. McDiarmid and the other authors reported that 8 years after their initial exposure, Gulf War veterans with retained DU fragments continue to have elevated levels of uranium in their urine. The high correlations over the three surveillance periods (1994, 1997, and 1999) suggest that the uranium concentration is in a steady state.

So far, few health effects have been found. Soldiers who still have DU shrapnel fragments have a higher than expected urine uranium level. In 1997, there were some subtle changes in neuropsychological test results. These changes are evident only at the group level. That is, the authors only see these differences when they compare the group with a higher than normal urine uranium value to the group with a lower urine uranium value. In 1999, these differences between groups were no longer there.

Soldiers with injuries and those who still have shrapnel have symptoms associated with their injuries. Otherwise, the health measures of the Baltimore participants is no different from the health measures of soldiers who were in the Gulf War but not exposed to DU. This comparison group of soldiers who were not exposed to DU was examined in 1997.

One other blood measure of a neuroendocrine hormone (prolactin) was also elevated at the group level in 1997 in the high uranium group. This did not appear to be of clinical significance or to have caused a change in sexual function. In the 1999 evaluation, this finding was no longer present.


VA Secretary Principi Orders Study of Death Rates for Khamisiyah Veterans

In mid-February 2002, the VA’s Veterans Benefits Administration released preliminary data on death rates and benefit claims that seems to suggest that some soldiers who may have been exposed to chemical weapons during the demolition of munitions in Khamisiyah, Iraq in March 1991 are dying at a greater rate than soldiers not near Khamisiyah in March 1991.

Earlier published scientific studies by the VA’s Environmental Epidemiology Service found no differences in death rates of veterans near Khamisiyah compared with other Gulf War veterans. (Continued on page 7)
Although the panel will not conduct research, its charter instructs the committee to review “all relevant research, investigations, and processes” done in the past to assess methods, results and implications for future research. The committee will also review proposed federal research plans, initiatives, procurements, grant programs, and other activities regarding Gulf War-associated illnesses.

The committee will be chaired by James H. Binns Jr., a Vietnam veteran, former Principal Deputy Assistant Secretary of Defense, and Chairman of the Board of Parallel Design, Inc., of Tempe, Arizona, acquired by General Electric in December 2000.

The advisory committee will be assisted by an expert panel of scientists and subject matter authorities who will add additional expertise, functioning as an auxiliary that reviews committee findings and provides expert guidance to the committee and the Secretary. Members of the advisory committee and the expert panel are identified below. An initial meeting date has not yet been announced; however, it is anticipated that the committee will meet later this year.

VA Creates Gulf War Research Advisory Committee

On January 23, 2002, Secretary of Veterans Affairs Anthony J. Principi announced the establishment of a new advisory committee that will help the Department of Veterans Affairs (VA) oversee its research into the medical problems of Gulf War veterans.

“Gulf War veterans have waited too long for answers to many of their questions,” Principi said. “This committee, composed of medical experts and veterans, will focus on the research that we hope will improve the health of ill Gulf War veterans.”

The 12-member Research Advisory Committee on Gulf War Veterans’ Illnesses was established by Congress to advise the VA Secretary on proposed research studies. The panel must submit an annual report on the status and results of government research during the previous year and on research priorities identified by the committee.

Section 104 of Public Law 105-368, which was signed by President Clinton on November 11, 1998, says the Committee shall provide advice and make recommendations to the Secretary of Veterans Affairs on “proposed research studies, research plans and research strategies relating to the health consequences of military service in the Southwest Asia theater of operations during the Persian Gulf War.”

Although the panel will not conduct research, its charter instructs the committee to review “all relevant research, investigations, and processes” done in the past to assess methods, results and implications for future research. The committee will also review proposed federal research plans, initiatives, procurements, grant programs, and other activities regarding Gulf War-associated illnesses.

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Research Advisory Committee on Gulf War Veterans’ Illnesses and Expert Panel

Advisory Committee:

• James H. Binns Jr., Chairman,

• Dr. Nicola Cherry, Professor of Public Health Sciences at the University of Alberta, Canada,

• Dr. Beatrice Golomb, Assistant Professor of Medicine at the University of California at San Diego, CA,

• Dr. Robert Haley, Chief of the Epidemiology Division of the University of Texas Southwestern Medical Center in Dallas, TX,

• Marguerite Knox, nurse practitioner, Hopkins, SC,

• Dr. William J. Meggs, Chief of the Division of Toxicology of the East Carolina University School of Medicine,

• Jack Melling, Ph.D., Director of the Karl Landsteiner Institute for Vaccine Development in Vienna, Austria,

• Dr. Pierre Pellier, Vice President, Neurosciences, Global Medical Affairs, with GlaxoSmithKline Inc.,
Two Congressional Panels Hold Hearing on Gulf War Veterans’ Issues on January 24, 2002

In the morning of January 24, 2002, two Congressional subcommittees held separate hearings in Washington, DC, regarding Gulf War veterans’ health issues.

Specifically, the House Government Reform Committee, Subcommittee on National Security, Veterans Affairs and International Relations held a hearing entitled “Gulf War Veterans’ Illnesses: Health of Coalition Forces.” Secretary of Veterans Affairs Anthony J. Principi testified.

Simultaneously, the House Veterans’ Affairs Committee, Subcommittee on Health, held a hearing on Gulf War veterans’ issues, focusing on lessons learned in the 10 years since Desert Shield/Desert Storm. Dr. Frances M. Murphy, Deputy Under Secretary for Health, testified.

Q’s & A’s

We have received many inquiries from Gulf War era veterans who served in Europe, the Continental United States, or elsewhere other than the Gulf War Theater of Operations. They have complained that while they had exposure to some of the same risk factors encountered by the Theater veterans (for example, vaccinations, pesticides, depleted uranium), they have been denied certain benefits and services accorded these veterans, including the Gulf War Registry health examination.

We understand and sympathize with these non-theater deployed veterans. However, the law - not the Department of Veterans Affairs (VA) - defines who is eligible for the benefits and services administered by VA.

We have also received many letters and calls from individuals who served as civilians in Southwest Asia during the Gulf War and from the spouses of Gulf War veterans who have reported that they are experiencing some of the same health problems as Gulf War veterans.

We are not authorized to provide medical examinations to those who served as civilians. VA can examine but not treat the spouse and children of Gulf War veterans who are in the Gulf War Registry. The spouses can make arrangements by calling our Helpline at 1-800-PGW-VETS (1-800-749-8387).

VA Secretary Principi Orders Study of Death Rates for Khamisiyah Veterans

(Continued from page 5)

VA Secretary Anthony J. Principi responded to the new data by ordering immediate follow-up research to ensure that we fully understand the issue. He indicated that since we do not understand these new data, we have an obligation to veterans to fully investigate this matter.
Where to Get Help

Active duty military personnel with questions or concerns about their service in the Persian Gulf region - contact your commanding officer or call the Department of Defense (DoD) Gulf War Veterans’ Hotline (1-800-796-9699) for an examination.

Gulf War veterans with concerns about their health - contact the nearest VA medical center. The telephone number can be found in the local telephone directory under Department of Veterans Affairs in the “U.S. Government” listings. A Gulf War Registry examination will be offered. Treatment will be provided to eligible veterans. The VA Gulf War Information Helpline can also provide the latest information and assistance. The toll-free telephone number is 1-800-PGW-VETS (1-800-749-8387). Our website is http://www.va.gov/gulfwar.

Gulf War veterans in need of marital/family counseling - contact the nearest VA medical center or VA vet center. For additional information, call the Gulf War Information Helpline at 1-800-PGW-VETS (1-800-749-8387).

Gulf War veterans seeking disability compensation for illnesses incurred in or aggravated by military service - contact a Veterans Benefits Counselor at the nearest VA regional office or health care facility at 1-800-827-1000, or call the VA Gulf War Information Helpline at 1-800-PGW-VETS (1-800-749-8387).

Gulf War veterans seeking participation for their spouses or children in the VA-funded health examination program for spouses and children - call the VA Gulf War Information Helpline at 1-800-PGW-VETS (1-800-749-8387). Veterans interested in the alternative self-funded examination for spouses or children - contact the Gulf War Registry Coordinator at the nearest VA medical center for forms and information.

Gulf War veterans interested in learning about the wide range of benefit programs administered by VA - contact a Veterans Benefits Counselor at the nearest VA regional office or health care facility at 1-800-827-1000, or call the VA Gulf War Information Helpline at 1-800-PGW-VETS (1-800-749-8387).

DoD has changed its “Incidents Hotline” to the “Direct Veterans Hotline” to more accurately reflect the work done by the Hotline’s contact managers. The new toll-free number is 1-800-497-6261.

Veterans who have been diagnosed with a motor neuron disease (including amyotrophic lateral sclerosis or Lou Gehrig’s disease) and who were on active duty between August 2, 1990, and July 31, 1991, regardless of whether they actually served in the Gulf War theater of operations (or family/friends of veterans who are deceased or otherwise unable to contact VA) - call 1-877-DIAL-ALS (1-877-342-5257) to participate in a national survey.