Annual Report Research Advisory Committee on Gulf War Veterans' Illnesses December, 2012

1. Origin and Membership

The Research Advisory Committee on Gulf War Veterans' Illnesses was established pursuant to Public Law 105-368. Members are appointed by the Secretary of Veterans Affairs. Committee members who served in 2012 are listed in Appendix A.

2. <u>Committee Activities</u>

The Committee held two meetings in 2012: January 30-31 in Washington, DC and June 18-19 in Boston, MA. A third meeting scheduled for November was deferred because of new VA rules regarding meetings and travel.

The year began with high hopes. After six months of members participating in working groups with members of VA staff and members of the VA National Research Advisory Council, the Committee met in January to review and discuss the Gulf War Illness strategic research plan prepared by the working groups under the leadership of Dr. Maximillian Buja. Members of the National Research Advisory Council also attended and participated in the meeting.

Overall the draft was well received, and there was enthusiastic participation by all who attended. The Committee commended VA staff for the collaborative process through which the plan was developed, involving both internal staff and outside advisors working together. It appeared that VA would at long last soon have a strategic plan to guide its Gulf War illness research program, that the plan would be a good one, and that a collaborative process had been created for guiding the program in the future. The creation of an effective strategic plan looked to be the next important step in the progress made over the previous two years since Secretary Shinseki announced his intent to change VA culture, and the treatment of Gulf War veterans in particular.

The following four months, however, saw a broad rollback of progress, both in the strategic plan and elsewhere. Although the VA staff members most directly involved in Gulf War research had participated fully in the working group process, the strategic plan was effectively gutted during the Department's coordination process, eliminating its focus and urgency. Research funding was reduced from \$15 to \$4.9 million in the VA FY13 budget.

Of even greater concern, discredited government positions from the 1990's and early 2000's appeared in the plan and in other VA pronouncements, notwithstanding the fact that they are now contrary to well-established science:

- The fiction that the multisymptom illness suffered by Gulf War veterans is not a diagnostic entity (as concluded by the IOM in 2010) but rather an assortment of "medically unexplained chronic multisymptom illnesses," (according to VA's Gulf War website), implying that these veterans have no common health problem.
 - The fiction that it is unknown "whether service in the Gulf War is linked to illnesses Gulf War veterans have experienced" (as VA's Gulf War website and 2012 annual research report stated), when the IOM has found that multisymptom illness is associated with Gulf War service.

The fiction that it is unknown if the illness is physiological or psychiatric (as VA's representative informed an IOM committee preparing a report on treatments), when VA's 2011 training guidance for physicians states that "we . . . know that chronic multisymptom illness is real and cannot be reliably ascribed to any known psychiatric disorder," as the 2010 IOM report also concluded, and when research based on the erroneous stress hypothesis has been banned at VA since 2004.

A major survey of Gulf War veterans configured to understate the incidence of multisymptom illness and overstate the incidence of psychiatric illness was allowed to proceed, based on false representations by Office of Public Health staff to the Secretary's Office.

The Committee reviewed these developments with disappointment and alarm at its meeting in June. Of particular concern is that these actions not only affect VA research, but also threaten to mislead research throughout the scientific community and thus undermine the entire foundation on which hopes of finding treatments are based.

The Committee provided detailed findings and recommendations to the Secretary. Many VA staff clearly do not believe these fictions, and the fictions assuredly do not represent the policy of the Secretary. Thus, they appear to be the work of a number of individuals wedded to the past, who have somehow imposed their will on the Department. Accordingly, the Committee recommended that these actions be investigated and that the individuals responsible be removed from positions of authority over Gulf War research.

As of the end of the year, however, these actions remain the policy of the Department of Veterans Affairs, with the exception that the statement that it is unknown if Gulf War service is related to illness has been removed from the Gulf War website. Indeed, in October the Office of Research and Development announced its intention to enter into a sole source contract with the IOM for the development of a case definition of chronic multisymptom illness in Gulf War veterans through a literature review by a committee unfamiliar with Gulf War research, when the Gulf War strategic plan (even after VA's revision) provided for a case definition by a committee of scientists with special expertise in the subject, as is commonly done in other illnesses. The unorthodox assignment of the critical task of defining the illness to an unfamiliar IOM literature review panel, a process which history has repeatedly shown to be subject to inappropriate influence by VA staff, is a clear indication that the campaign to erase a decade of scientific knowledge continues apace. (The 2010 IOM report escaped this fate due to the

intervention of the Secretary, who requested that the IOM invite the Research Advisory Committee to address that committee.)

The Research Advisory Committee has continued to follow closely scientific developments of relevance to Gulf War veterans' health. Each meeting explored the latest scientific work by VA and other researchers. The January meeting addressed studies of the HPA axis and cerebrospinal fluid markers in Gulf War illness. The June meeting focused on new discoveries made through imaging (including diffusion tensor imaging, functional magnetic resonance imaging, and magnetoencephalography) and on recent insights regarding the effects of organophosphate exposures. Since the June meeting, the committee staff has been preparing a draft report to present and analyze relevant scientific developments over the past four years. This draft will be reviewed at the next meeting of the Committee in February, 2013.

Representatives from VA, DoD, and other federal agencies were invited to attend Committee meetings and to participate in discussions with presenting scientists along with Committee members. All meetings were open to the public. Time was reserved to allow members of the public to provide comments on the Committee's work and on matters related to the health of Gulf War veterans.

Committee members have been active participants in all aspects of the Committee's work. Meetings have been well-attended. Members have devoted substantial time outside of meetings.

The Committee has kept VA leadership and the Office of Research and Development (ORD) informed of its work and findings on an ongoing basis. This task has been accomplished through attendance and participation of ORD and OPH officials at Committee meetings, and ongoing communications between the Committee chairman, scientific director and associate scientific director, and the Secretary's Office and ORD.

3. <u>Support Activities</u>

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Responsibility for providing scientific and administrative support to the Committee was provided by the Boston University School of Public Health, Department of Environmental Health, through a contract with the Bedford, Massachusetts VAMC. Committee member Dr. Roberta White currently serves as Scientific Director, and Dr. Kimberly Sullivan serves as Associate Scientific Director. In addition to ongoing activities relating to monitoring research relating to Gulf War veterans health, preparation of Committee reports, development of Committee meetings, and preparation of meeting minutes, the staff has primary responsibility for Committee administrative activities and management of the Committee's website.

4. Designated Federal Officer

The Designated Federal Officer for the Committee is Dr. Victor Kalasinski, who also serves as manager for the Gulf War Health portfolio within the VA Office of Research and Development.

5. <u>Accomplishments</u>

Committee members began the year with the expectation that their work on the strategic plan in 2011, in partnership with VA staff and members of the National Research Advisory Council, was ushering in a new era of progress and collaboration. It appeared that the energies of all concerned would at last be focused on solving Gulf War multisymptom illness.

Instead, the Committee has regretfully found itself in the familiar role of delineating the unwillingness of VA to address straightforwardly the tragic health consequences of the 1991 Gulf War. The Committee has provided honest independent advice to the Secretary regarding the conduct of the research program.

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The Committee has brought to the attention of the Office of Research and Development and the Office of Public Health the latest science and most promising research opportunities, through its meetings, the strategic plan draft, and individual communications.

The Committee Charter requires that the Committee measure federal Gulf War research against the standard of whether this research has improved the health of Gulf War veterans. No improvement was made in 2012.

Appendix A

Research Advisory Committee on Gulf War Veterans' Illnesses 2011 Committee Members

<u>Chairman</u>

James H. Binns, former Chairman, Parallel Design, Inc.; former Principal Deputy Assistant Secretary of Defense; Phoenix, Arizona.

Committee Members

Carrolee Barlow, MD, PhD, Vice President Biology Research, Brain Cells, Inc., San Diego, California.

Floyd E. Bloom, MD, Professor Emeritus, Molecular and Integrative Neuroscience Department, The Scripps Research Institute, La Jolla, California.

Dedra S. Buchwald, MD, Professor of Medicine, University of Washington, Seattle, Washington.

Beatrice A. Golomb, MD, PhD, Associate Professor of Medicine and of Family Preventative Medicine, University of California at San Diego, La Jolla, California.

Joel C. Graves, Anglican priest and Captain, U.S. Army (Retired); 1990-1991 Gulf War veteran, Lacey, Washington.

Anthony Hardie; 1990-1991 Gulf War veteran, Madison, Wisconsin.

Marguerite L. Knox, MN, NP, LTC South Carolina National Guard Medical Command; 1990-1991 Gulf War veteran, Hopkins, South Carolina.

William J. Meggs, MD, PhD, Professor and Chief, Division of Toxicology, The Brody School of Medicine at East Carolina University, Greenville, North Carolina.

James P. O'Callaghan, PhD, Head of Molecular Neurotoxicology, Toxicology and Molecular Biology Branch, Health Effects Laboratory Division, Centers for Disease Control and Prevention-NIOSH, Morgantown, West Virginia.

Lea Steele, PhD, Associate Professor, Institute of Biomedical Studies, Baylor, University, Waco, Texas

Roberta White, PhD, Chair and Professor, Department of Environmental Health, Boston University School of Public Health; Scientific Director, Research Advisory Committee on Gulf War Veterans' Illnesses, Boston, Massachusetts.

Consultant to the Committee

Jack Melling, PhD, Consultant to the United States Government Accountability Office, Salisbury, United Kingdom.