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TO: Attendees at LENS September 12, 1997 conference on Gulf War Syndrome

FROM: Robinson O. Everett

February 20, 1998

When the conference was held on September 12, 1997, we anticipated that we would have a report distributed shortly thereafter. Due to a variety of delays – for which I take full responsibility – we only recently completed the report. Unfortunately, parts of the videotape of the conference were too inaudible to be transcribed; and therefore some items that were discussed may have been omitted from the report. As to the transcript of the conference, even though there are various omissions, I shall be happy to send any of you a copy if you so request.

Events subsequent to the conference lead me to believe that we were on the cutting edge when we met in Washington in September, and hopefully our conference and ensuing discussions added momentum to the effort to assure that all causes of the syndrome will be examined to the extent feasible. Two weeks ago the House Committee on Veterans Affairs conducted a hearing on the Gulf War Syndrome; and fortunately, I was able to hear two of the three panels of witnesses at that hearing. Apparently, this congressional committee and others are conducting some of the inquiries that those present at our conference believed to be necessary. However, there may still be a role for our LENS Center to play in the overall effort to determine why some of our veterans returned with disabilities from the Gulf War and what remedial actions should now be taken. We would welcome your suggestions.

I am sincerely,



Robinson O. Everett

**Discussions on the Gulf War Syndrome
Conference Report
Washington, D.C.**

September 12, 1997

On September 12, 1997, the Center on Law, Ethics and National Security conducted a “scoping conference” to determine whether the Center could play a helpful role in (a) finding answers to some of the troubling issues concerning the causes of the Gulf War Syndrome, (b) alleviating some of the needs and concerns of those now suffering from the syndrome and those who fear onslaught of the Syndrome in the future, and (c) developing recommendations for changes in laws and policy to deal more adequately with the Gulf War Syndrome and avoid future repetition of mistakes that may have occurred in dealing with the Syndrome.

The Conference took place in the Conference Room of the U.S. Court of Appeals for the Armed Forces; and in addition to the Center’s Founder, Robinson O. Everett, and its Executive Director Scott Silliman, there were present:

Admiral Elmo “Bud” Zumwalt

Dr. Hugh Fudenberg

Judge Eugene Sullivan

Dr. Mohammed Abou-Donia

Ms. Sarah Brau

Col. Bill McCarty

Mr. Bob McCarthy

Ms. Mia Zur

Dr. Kwai-Cheung Chan

Dr. Marguerite Knox

Dr. Allan Levin

In opening the Conference, Judge Everett described the events that had inspired the Center's awareness of and interest in the Gulf War Syndrome. These events began late in 1996 with a call to him from Robert McCarthy, who recounted that he had been an Army Reserve officer performing active duty at Fort McPherson during the Gulf War crisis, had been inoculated by Army medical personnel in preparation for his anticipated departure for the Persian Gulf, had unexpectedly been kept at Fort McPherson, but had developed the symptoms of Gulf War Syndrome without ever leaving Georgia. This anecdotal evidence that the Syndrome was not necessarily the result of exposure to poison gas led Judge Everett to inquire as to other possible causes.

Fortunately some evidence in this regard had been provided by the published research of Dr. Abou-Donia, which indicated that medications administered to military personnel in order to protect them against possible use of nerve gas by the Iraqis might have caused symptoms associated with Gulf War Syndrome. Moreover, the presence of the Syndrome among British and Israeli troops who had received the same medications administered to American troops and the absence of the Syndrome from French troops, who had not received the inoculations and bromides, corroborated the theory that such medications gave rise to the Syndrome. Two

prominent immunologists – Dr. Hugh Fudenberg and Dr. Allan Levin – expressed to Judge Everett their view that the “protective” medications might have caused or contributed to causing many of the cases of Gulf War Syndrome. Dr. Fudenberg also believed that if the cause of the Syndrome were determined, a cure might be developed – as he had done in the past for other diseases under somewhat similar circumstances.

To obtain additional insight into the issues involved, Judge Everett conferred with Dr. Marguerite Knox, a member of the Committee appointed by President Clinton to report on the existence and causes of the Gulf War Syndrome. Along with Robert McCarthy, Everett also met with Congressman Walter Jones of the House National Security Committee. On another occasion, he attended a hearing of a subcommittee of the House Committee on Government Reform and Oversight which was concerned with the handling of the Gulf War Syndrome. Subsequently he met with Dr. Chan of the Government Accounting Office, who testified at the hearing. Also, Everett read a relevant GAO report, which Dr. Chan helped prepare, and the initial Report submitted to President Clinton in January 1997 by Dr. Knox’s Committee.

On the basis of the information he was assembling, Everett brought to the attention to the LENS Board of Directors some of the unanswered issues concerning Gulf War Syndrome and recommended that the Center consider an examination of these issues and possible sponsorship of conferences on the Syndrome. The Board approved further inquiry by the Center in this area. Moreover, Admiral Horace B. Robertson, USN (Ret.), one of the Center’s Directors, noted the parallel between the controversy that arose after Vietnam concerning the effects of Agent Orange and the currently developing controversy about a possible Gulf War Syndrome. Admiral Robertson also mentioned that Admiral Zumwalt, CNO during the Vietnam War, had organized

a foundation to consider effects of Agent Orange; and subsequently Robertson put the Center in touch with Admiral Zumwalt.

After this introduction by Judge Everett, Marguerite Knox described her own experience as a member of the National Guard who was called to active duty for Desert Storm and deployed for five months in the Persian Gulf only a few weeks after giving birth to her second child. She then discussed the membership and work of the President's Committee to which she had been appointed and noted that its final report was due by the end of October 1997. She could not predict what the Committee's recommendations would be in its report, but she was confident that President Clinton was concerned about the Syndrome.

Admiral Zumwalt then discussed some relevant lessons that had been learned in the process of identifying Agent Orange as a cause of some illnesses experienced by Vietnam veterans – illnesses that in some instances had been disabling or even fatal. One such lesson was that, for various reasons, persons with possible knowledge about the causes of an illness affecting veterans might be reluctant to provide it. Admiral Zumwalt made clear his hope that everything feasible would be done to assure that veterans of the Gulf War receive adequate care for any illness that they may have contracted in the course of their service.

Dr. Abou-Donia described the research he had performed at Duke which supported the hypothesis that servicemembers who served during the Gulf War might have contracted illnesses because of inoculations and medications they had been administered for the supposed purpose of protecting them when deployed to the Persian Gulf. As a result of such illnesses, some veterans might be infectious and therefore capable of transmitting diseases to spouses or children. Thus, an additional need exists for research into causes of Gulf War Syndrome and possible cures in

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order to protect some possibly exposed non-veterans.

Dr. Fudenberg then discussed some of the research he had performed as an immunologist and explained why his research and experience led him to believe that inoculations intended to immunize American servicemembers against certain chemical and bacteriological weapons had actually caused effects similar to those they were intended to prevent. Some corroboration of this view is supplied by the numerous complaints of Gulf War Syndrome among American, British and Israeli servicemembers, who had received these inoculations, and the absence of any such complaints among the French and Moroccan troops, which had not received them. Dr. Fudenberg noted that pyridostagmine bromide (PB), which is used for treatment of *myasthenia gravis*, had not been approved by the Food and Drug Administration (FDA) prior to the Gulf War; but that the Department of Defense had obtained an approval from the FDA for administering the drug to servicemembers. No servicemember had been asked to give informed consent to the administration of PB; but it had not been administered to all American troops that deployed to the Gulf. Apparently the decision to administer PB depended on various unit commanders; and it is unclear by what process or under what circumstances unit commanders decided to have PB administered.

Because some American servicemembers were administered PB and others were not, a determination whether servicemembers' complaints of Gulf War Syndrome correlated with their having been administered PB would assist greatly in determining to what extent PB caused – or helped to cause – the Syndrome. Unfortunately this correlation is hard to establish. The record keeping as to inoculations of servicemembers relied heavily on the “shot records” which servicemembers carried with them. These records often were misplaced by servicemembers or

discarded after their tour of duty in the Persian Gulf. Apparently, centralized record keeping as to the inoculations administered to individual servicemembers was inadequate or non-existent. Moreover, apart from the “shot records,” servicemembers typically had no knowledge of the inoculations they were being administered – often all at one time.

Dr. Fudenberg then posed questions to Robert McCarthy about the nature of his symptoms and the time that had elapsed between his inoculations at Fort McPherson and the appearance of the symptoms. According to Dr. Fudenberg, the answers he received from McCarthy supported the hypothesis that McCarthy’s symptoms – which match those of the Gulf War Syndrome – were caused in part by PB.

Dr. Fudenberg pointed out that DoD’s initial denial that Gulf War Syndrome existed and then its position that any syndrome resulted only from stress had caused great delay in considering the possibility that the preventive inoculations might have produced illnesses. During this period of delay, doctors treating servicemembers or veterans for complaints would have had no occasion to ask their patients about the inoculations they had received. Moreover, some career servicemembers may never have reported their complaints to military doctors for fear that they would be separated by reason of disability.

Despite these difficulties, Dr. Fudenberg believed that an effort should be made to assemble information as to any relation between a servicemember’s current complaints and his or her having been administered PB during Desert Shield or Desert Storm. For example, civilian or military physicians treating persons who had served during the Gulf War should be encouraged to ask their patients if they recalled being vaccinated and, if so, whether they had retained any shot records; and to what unit they had been assigned while in the Gulf. Dr. Fudenberg indicated

that he and Dr. Levin could develop a questionnaire for use in acquiring relevant information from Gulf War veterans; and this questionnaire could be administered by various means. For example, VA or other doctors treating patients for Gulf War Syndrome could use the questionnaire. Also, it could be disseminated by veterans organizations, placed on a Web site by the LENS Center, or used in connection with an 800-number and recorded questions to be asked of persons calling in.

Dr. Fudenberg also said that the possibility should not be totally discounted of finding some relevant military records. For example, if it were determined that particular unit commanders had decided not to administer PB to the members of their units, locating these members and determining if they had experienced Gulf War Syndrome could provide valuable leads. Likewise, commanders of the medical units which handled the inoculations could help identify servicemembers who had not been inoculated. (One such commander – a doctor in Durham, N.C. who had commanded an Army medical unit deployed from Fort Bragg to the Persian Gulf – has already been contacted by Judge Everett).

Based on his prior experience, Dr. Fudenberg was optimistic that if it were established that PB and similar medications had caused Gulf War Syndrome, a cure could be developed. This would benefit not only the diseased veteran but also would reduce the risk that the veteran would transmit that disease to a spouse or child.

Dr. Levin pointed out that during Vietnam inoculations were administered at intervals – rather than all at one time; but it appeared that many servicemembers deploying to the Persian Gulf received all their protective inoculations at one time. Whether such a practice might produce undesirable synergistic effects should be considered.

Dr. Chan provided some background as to GAO's study of DoD's handling of Gulf War Syndrome complaints. In this connection, he noted that in 1992 he had first become aware of these complaints, and that subsequently he had followed developments concerning the Syndrome.

Mia Zur, who was present from the staff of Congressman Walter Jones, emphasized the Congressman's desire to facilitate any project that the LENS Center might undertake in this field and to determine what remedial legislation might be necessary.

Colonel McCarty pointed out that DoD was in the process of contracting for a more effective system for maintaining medical records. Thus, if similar issues arose in connection with future military operations, it would be more feasible to assemble information necessary to discover causes of a syndrome and develop cures. McCarty also emphasized his view that this Conference and any future study of the Gulf War Syndrome by the Center should be forward-looking – rather than focused on assigning blame for any past failures in discovering the existence and causes of the Syndrome.

Judge Sullivan pledged his assistance if the Center decided to sponsor a televised discussion of issues concerning the Syndrome. Federal Bar Association President-Elect Robert Mueller appeared briefly to inform the conferees that the FBA might be interested in co-sponsoring with the Center some type of public forum on the Gulf War Syndrome. On the basis of her recent White House experience, Sarah Brau expressed her view that the Clinton Administration is genuinely interested in assisting those who have the Syndrome.

As the Conference concluded, there seemed to be a consensus on certain matters. First and foremost was the conclusion that many issues concerning the causes of the Gulf War

Syndrome have not yet been resolved. Moreover, the belief was shared that the Center might be able to assist in studying these issues. To do so would require that it seek and obtain grants from private foundations and possibly some grants from governmental agencies. Fortunately, the Center is well-situated to seek grants because of its established reputation for objectivity and impartiality; its presence at Duke University, where some relevant medical research has been recently conducted; and its location in a State with two major military institutions from which many servicemembers deployed to the Persian Gulf during Desert Shield and Desert Storm.

The Center should consider means to increase awareness of some of the issues concerning the causes and treatment of the Gulf War Syndrome and prevention of a similar illness in the event of a future armed conflict. Sponsorship or co-sponsorship of future conferences, television forums, and debate might be a means of accomplishing this objective. Of special importance is the providing of information to members of Congress, who may wish to adopt legislation relevant to the Gulf War Syndrome, and to doctors at VA hospitals and elsewhere who are treating veterans of the Gulf War – or perhaps their spouses or children.

Without engaging in recrimination, the Center should make proposals for legislation to (a) provide funding for impartial efforts by medical researchers to determine causes of the Gulf War Syndrome – with special focus on the role of PB and other protective medical treatments as a cause; (b) provide funding to develop a cure for the Syndrome and relief for its symptoms until there can be a complete cure; (c) require better keeping of inoculation records by the Department of Defense; and (d) assure clearer accountability for decisions concerning preventive measures to be taken against bacteriological or chemical warfare threats.

In undertaking further study, the Center should consider carefully the creation of a Task

Force on the Gulf War Syndrome, which hopefully would be headed by some well-recognized leader, such as Admiral Zumwalt. This Task Force would have a separate Web sit to be used for assembling information concerning the Gulf War Syndrome and identifying persons who suffer from that Syndrome. Moreover, efforts would be made to inform the public about the Task Force, and to this end programs and conferences would be encouraged.

Finally, when the Conference Report is prepared a draft should be circulated to the conference participants and a suitable press release distributed to the media.