THE DEPUTY SECRETARY OF VETERANS AFFAIRS
WASHINGTON

March 14, 2005

The Honorable Lane Evans
Ranking Democratic Member
Committee on Veterans' Affairs
U.S. House of Representatives
Washington, DC 20515

MAR 18 2005

Dear Congressman Evans:

Thank you for your follow-up letter of December 16, 2004, in which you inquired about the intentions of the Department of Veterans Affairs (VA) to act on the results of the Department of Navy follow-up study on sarcoidosis. This was discussed previously in a letter to you dated December 9, 2004. VA and the Navy are coordinating their actions. I apologize for this delayed response.

Enclosed is a fact sheet on sarcoidosis and other lung diseases in Navy personnel. The global recommendations made by the Public Policy Advisory Committee are not appropriate for the following reasons:

- The Navy has informed VA that it does not consider individual notifications appropriate because of the serious difficulties in identifying and locating individual veterans, many of whom left active duty several decades ago, but views some form of group notification both adequate and sufficient.

- VA has no statutory authority to offer free medical evaluations for a poorly-defined group for which screening of asymptomatic individuals is not clinically recommended.

VA will work with veterans' service organizations and the Navy to disseminate the results and interpretation of the study. The Navy and VA have discussed the notification needs for Navy active duty service men and women and veterans. The agencies agree that the most effective notification should occur through newsletters and other existing routes, but not take the form of individually mailed letters The agencies will work together to achieve the goals of notification.

VA will soon publish a continuing medical education program on military occupational lung disease in the Veterans Health Initiative series with specific chapters on sarcoidosis and silicosis with continuing medical education credits, and will issue an information letter to clinicians when that document has been published. These approaches are very similar to those pursued by the Navy.

The Honorable Lane Evans

Thank you very much for the important inquiry. Should you have further questions, please have a member of your staff contact Doug Dembling, in the Office of Congressional Liaison Affairs, at (202) 273-5615.

Sincerely yours,

Gordon H. Mansfield

Enclosure

Department of Veterans Affairs (VA)
Veterans Health Administration (VHA)

Sarcoidosis and Other Lung Diseases in Navy Personnel

Fact Sheet

The Department of Veterans Affairs recently had a chance to review the Navy Report "Navy Lung Disease Assessment Program, Special Project # 60208", also recently published as *Gorham ED, Garland CF, Garland FC, Kaiser K, Travis WD, Centeno JA. Trends and occupational associations in incidence of hospitalized pulmonary sarcoidosis and other lung diseases in navy personnel: a 27-year historical prospective study, 1975-2001. Chest. 2004 Nov;126(5):1431-8.* in the peer-reviewed literature. That study was conducted in follow-up to prior similarly designed epidemiological work. A major addition was the inclusion of pathological tissue evaluations. The results do differ dramatically from the prior studies on deck grinders.

After lengthy review and discussions, VHA was specifically concerned about four aspects of the study.

- The original group at risk, "deck grinders," no longer appeared to be at risk in follow-up study.
- Under the microscope, sarcoid granulomas look dramatically different from silica granulomas. Silica deposition is commonly found in the lungs, without the presence of silicosis.
- One of the veteran members of the Public Policy Advisory Committee discussed the presence of beryllium exposure from a variety of uses for the same groups, a far more likely cause of that histological picture than silica.
- Finally, elemental analysis, a marker of "deposition," doesn't necessarily demonstrate causal relationships without careful definition of case/control groups and detailed understanding of the non-response issues. A pathology study relied on lung tissue, collected on only 2.3 percent of the requested samples, analyzed at the Armed Forces Institute of Pathology (AFIP) and the State University of New York at Syracuse (SUNY). The AFIP results showed no association between dusts and sarcoidosis, although SUNY found some mild increase. SUNY found a mild increase in birefringent particles, i.e., silica, in personnel assigned to aircraft carriers, analyses not done by AFIP. Both found increases in metals associated with granulomatous disease, including titanium and cobalt. The latter, though, is associated with a form of granulomatous lung disease involving prominent Giant Cells.

An earlier follow-up clinical project failed to identify silicosis and sarcoidosis misdiagnosis among currently treated veteran patients.

At present, service men and women who receive a diagnosis of sarcoidosis during service may receive service-connected benefits. Veterans who develop disease after separation from service may file claims for compensation. Identifying an exposure associated with the development of sarcoidosis does not lead to different treatment. Subsequent peer-reviewed publications suggest that silica exposure represents a very low risk for sarcoidosis and that sailors are as likely at high risk from moisture and mold as from silica. VA is working with National Institute for Occupational Safety and Health-funded scientists to understand the potential relative contribution of moisture and silica to sarcoidosis. The scientific advisory committee made recommendations for further Navy research. The Public Policy Committee made recommendations on notification of Navy personnel and enlisted men with sarcoidosis for follow-up. VA has considered the recommendations of the committees but do not find them to be based on scientific data.

In the view of VA health professionals and scientists, there are no consequences from this work for medical treatment. The scientific work presented in the current project does not justify laboratory analyses for clinical purposes. Once exposure has ceased, the clinical treatment remains the same, irrespective of the etiology in sarcoidosis. Therefore, there is little VA clinicians have to offer. There are interesting research questions, warranting follow-up on dust levels for research purposes in the broader context of causation, but these do not at present affect either compensation decisions or clinical treatment.

VA does have records of 5,079 veteran patients with sarcoidosis who have received treatment between 1990 and 2003 and will ensure that clinicians caring for these are able to answer appropriate questions. VA will publish an information letter on sarcoidosis directed at its clinicians, the techniques of occupational history taking, the limitations of lung tissue analysis for particle concentrations, and the implications for health care. VA will also publish a continuing education module on military occupational lung disease and occupational history taking that has specific chapters on silicosis and sarcoidosis. No modifications to those chapters were suggested by the scientists accessible to VA. VA suggested that one of the clinicians on the scientific advisory committee, considered a patient advocate by the veterans' representative of the committee, be given those same chapters.

Three scientific questions have been raised:

1. Are subjects aware of the results of their tissue analyses?
VA is under the impression that the US Navy is moving forward on notification of the study subjects.

2. Are medical evaluations appropriate to clarify whether sarcoidosis is related to exposure?
At present, this is under discussion, but the information on exposure remains quite uncertain, and further research is warranted to determine whether there are ways of making such determinations. Authors of subsequent studies are conducting further analyses to help guide such assessment.

3. Should potentially exposed Navy personnel be notified?
This suggestion requires the notification of all Navy personnel on the hazards and potential risk for disease and offering Compensation and Pension examinations to a large group of veterans. Given the open research questions listed above, the unknown population attributable risk, and the diagnostic criteria to be used, VA and the Navy considers that individual notification to have no beneficial consequences. VA will work with the U.S. Navy and veterans' service organizations to disseminate knowledge of the study, its results, and its consequences through existing routes including VA newsletters.

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