

Submission from Brian Sell, June 8, 2016

In response to IOM, Gulf War and Health: Volume 10: Update of Health Effects of Serving in the Gulf War, page 9: Other Health Conditions:

Recommendation: Further studies to assess the incidence and prevalence of circulatory, hematologic, respiratory, musculoskeletal, structural gastrointestinal, genitourinary, reproductive, endocrine and metabolic, chronic skin, and mental health conditions due to deployment in the Gulf War should not be undertaken. Rather, future research related to these conditions should focus on ensuring that Gulf War veterans with them receive timely and effective treatment.

I argue three topics.

1) Not all conditions are cancer! Pulmonary fibrosis, Sarcoidosis and other respiratory conditions are not compensated nor recognized as Gulf War Illness.

2) Correspondence with IOM Robbie Wedge, Study Director admits to three colossal incompetencies: did not explore, did not review, and never had evidence. Three main quotes from this email. "The IOM committee did not actually review the medical records of Gulf War veterans and thus we had to rely of published Studies", "*The 2016 and earlier committees did not explore the cause of Sarcoidosis particularly potential exposures during deployment to the Persian Gulf*" and "*The IOM has never had evidence on the prevalence of Sarcoidosis so we have been unable to make such an association*".

3) Freedom Of Information Act (FOIA) request number 16-06232-F.: will very limited research I was able obtain that Sarcoidosis has respectful number of Gulf War Veterans with diagnosis. Respectful enough to look at presumptive condition acknowledgment. The cause of Sarcoidosis is not known and it should fall under undiagnosed conditions because of its prevalence.

I am asking that you intervene on my behalf with the VA as it relates to Gulf War Illness. General population and media alike are being misled about the thoroughness of research about Gulf War illnesses. IOM (Institute of Medicine) which changed their name to Health and Medical Division along the VA want to cut funding for Gulf War Syndrome research. This must not happen! Even after 20 years since the Gulf War ended the current research is not adequate.

The Health and Medicine Division (HMD) is a division of the National Academies of Sciences, Engineering, and Medicine (the Academies). The Academies are private, nonprofit institutions that provide independent, objective analysis and advice to the nation and conduct other activities to solve complex problems and inform public policy decisions related to science, technology, and medicine. The Academies operate under an 1863

congressional charter to the National Academy of Sciences, signed by President Lincoln. I remind you that the IOM or HMD makes recommendation to the VA as it pertains to research, care and presumptive conditions as to veterans.

As a Sarcoidosis patient in both lungs and now in bones I have been denied compensation coverage by the VA for reasons that they believe I did not develop sarcoidosis from the gulf war. I also have been diagnosed with Fybromyalgia and Chronic Fatigue syndrome in which they agree that I received this from the Gulf War. So how do I have two conditions that by description or cause could be from environmental exposures yet one that has same possible cause not be covered? I posed this question to IOM.

After reading the reply for IOM I then thought that it was very evident that no research had been done on Sarcoidosis in Gulf War Vets. Now I hear about how much the VA has done for us and how dedicated they are to veterans, so I thought “how many vets have been diagnosed with the presumptive conditions compared to Sarcoidosis in Gulf War Vets.” I have attached the VA reply to my Freedom Of Information Act (FOIA) request number 16-06232-F.:

VHA Gulf War Veterans* by Diagnosis Category** FY 2000 to FYTD 2016 (5/2/2016)	
Diagnosis Category	Gulf War Veteran Uniques
Campylobacter jejuni	46
Burcellosis	12
Coxiella burnetii (Q Fever)	48
Mycobacterium tuberculosis	1,465
Nontyphoid Salmonella	79
Visceral leishmaniasis	9
West Nile Virus	8
Malaria	1
Sarcoidosis	2,048
Shigella	23
Uniques may appear in multiple Diagnosis Categories. The summation of the above data results in 3,739 figure, but the actual number of Unique Veterans represented in the data is 3,696	

Data source: VSSC Diagnosis Cube tables

Data accessed: 5/6/2016 via SQL

*Gulf War Veterans ideintification specifics described on Cover Sheet

**Diagnosis Category description and specific ICD codes described on Cover Sheet

jf (dx & report) jw (Gulf War Identification)

I am asking that you use the information from the FOIA data I supplied and the response from IOM, admitting the lack of research on Sarcoidosis to or pursue on your own and gather your own facts. Here are my contentions:

- **The current process for establishing presumptive disability decisions involves four major entities: Congress, the VA, the Institute of Medicine (IOM), and other stakeholders**
- **The IOM want to cut funding for further research into the cause of Gulf War Veterans. This must not happen.**
- **On their own admittance, email from Robbie Wedge the IOM has not thoroughly investigated Sarcoidosis in Gulf War Vets.**
- **Based on my FOIA request, presumptive conditions for Gulf War Illness is ALL smoke and mirrors! The numbers don't justify some presumptive illness coverage yet does not recognize Sarcoidosis even with very strong numbers.**
- **VA compensation claims with Sarcoidosis continually get denied. VA raters are not aware of Sarcoidosis as it relates to cause, one of them being environmental conditions.**
- **VA states respiratory conditions in Gulf War Vets are to be compensated. That is not the case, only certain cancers are covered. Sarcoidosis is not cancer but is just a chronic, disabling and does cause death in the victims for sarcoidosis.**
- **The rating schedule for this disease is not enough to help or support a veteran. 0% if you even have it in your lungs. By the time this disease is at an appropriate financial level it is too late you are dead or going to die. The treatment for Sarcoidosis is large volume of steroids which equally have chronic outcomes. So you suffer while trying to work to support a family and any help you may get financially only comes to the veteran at the end stages of this chronic disease.**
- **Congress has already acknowledged toxic exposure via Public Law 103-446 Title 1. Sec.102 Findings (1)**

I quote from Public Law 103-446-Nov.2, 1994

SEC. 103. PURPOSES.

The purposes of this title are—

(1) to provide compensation to Persian Gulf War veterans who suffer disabilities resulting from illnesses that cannot now be diagnosed or defined, and for which other causes cannot be identified;

The cause of Sarcoidosis cannot be identified!!!!!!!!!!!!!!!!!!!!!!

I ask that you add Sarcoidosis to your list of presumptive list for Persian Gulf Veterans, that you adjust schedule for compensation for sarcoidosis to improve financial outcome for veteran. Veterans must wait and suffer from not only the chronic disease but also the mental stress this causes is unreal! The fight for compensation time frame and care is disgraceful. We suffer, our family suffers all while we assume the VA, Congress and IOM are doing a thorough job and eventually compensation and care is coming: WE HAVE TO WAIT! It's been 20 plus years since the end of the Gulf War. Did we not learn anything from the lack of attention to Agent Orange?

Respectfully,

Brian Sell