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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. report	[Re: medical records] (19 pages)	ca. 1994	b(6)
002a. letter	To Vereran from Grace Ziem, M.D. re: medical diagnosis (1 page)	06/20/1994	b(6)
002b. report	[Re: medical records] (8 pages)	ca. 1994	b(6)

COLLECTION:
Clinton Presidential Records
First Lady's Office
Melanne Verveer
OA/Box Number: 20034

FOLDER TITLE:
Gulf War Syndrome II (More) - Gulf War Illness: Diagnosis/Letters/Medical Records from Private Physician

2013-0534-S
ry1564

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
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GRACE ZIEM, M.D., Dr.P.H.
Occupational and Environmental Health
Research Office
1722 Linden Ave., Baltimore MD 21217
(410) 462-4085, Fax: (410) 462-1039

21 February 1995

Ms. Hillary Rodham Clinton
Office of the First Lady
Old Executive Office Building
Washington DC 20500

Dear First Lady,

I deeply admire your role in trying to achieve better health care for our citizens. I am deeply concerned about our Persian Gulf Veterans, five of whom are my patients. All five have multiple chemical sensitivity accompanied by evidence of chemical injury to multiple body systems. None are receiving adequate care from Walter Reed or the VA system, in my view.

The vast majority of Persian Gulf Vets are not being evaluated for their reactions to environmental chemicals; if they can be given even a single other "recognized" diagnosis, their chemical problems remain unevaluated. The minority who are asked about symptoms do not appear to receive recognition when they do react to environmental chemicals. No recommendations are provided for them to reduce exposures and thus reduce reactions. The VA and DOD rely heavily on medications to "treat" symptoms, but this may be contraindicated in chemically sensitive vets may experience severe reactions to both active and inert ingredients in medications.

I am following over a hundred chemically sensitive civilians: Many of these get better with environmental controls which reduce further exposure. My patients who are vets, however, are not getting better. Lack of adequate environmental controls and inappropriate diagnosis and care are significant factors, I believe.

I and several other independent colleagues discussed these issues at a meeting on 12 May 1994 with top level DOD and VA officials in charge of Persian Gulf illness, arranged and attended by members of Congress led by the Honorable Lane Evans. Despite promises and repeated attempts to follow up on particular cases, little progress has been made.

I'd like to request a meeting with you at your convenience to discuss these issues more fully. I would be happy to put together a small group of independent physicians who have been caring for Persian Gulf vets so you can hear a range of views. I encourage you not to conclude your review prior to hearing from independent physicians.

Thank you again for your concern.

Sincerely,

Grace Ziem

Grace Ziem, M.D., Dr. P.H.

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Copy to George Vaughan

GRACE ZIEM, M.D., Dr.P.H.
Occupational and Environmental Health
77 Dundalk Avenue
Baltimore, MD 21222
(410) 633-6769

Bonnie L. Cook
Assistant

June 7, 1994

Major General Ronald R. Blanck
Commander
Command Suite/WRAMC
Washington, DC 20307-5001

Dear General Blanck:

Thank you for sharing the draft protocol with me and other physicians who have experienced an interest in Gulf War Syndrome and chemical sensitivity.

I have now seen four Gulf War veterans with chronic illness since their time in the Gulf. All have multiple chemical sensitivities as well as involvement of the neurologic, respiratory and immune systems. The majority have gastrointestinal involvement as well.

It is absolutely essential that all vets that are studied receive the chemical sensitivity questionnaire. This is because chemical sensitivity can, and often does, co-exist with other diagnoses. You would be missing many chemically sensitive patients, I believe, if you exclude all of those that you can diagnose any other disorder in. The comparison group should also receive a chemical sensitivity questionnaire so you can distinguish the difference in chemical sensitivity responses on the questionnaire between individuals with and without chronic illness.

Regarding laboratory testing, a number of the proposed laboratory tests such as rheumatoid factor, serum immunogoblins, and other conventional immune tests have been studied in chemically sensitive patients by Dr. Howard Kipen at the Robert Wood Johnson Medical School. I encourage you to obtain his results. You can contact him at 201-463-4773. Most are normal in chemical sensitivity.

The immune tests which are most specific to chemical sensitivity include increased TA1 or CD26 cells and autoantibodies, especially autoantibodies to smooth muscle and myelin. I strongly recommend that TA1 and autoantibodies be

(1)

included in the testing for persons with suspect chemical sensitivity. These abnormalities have been found in multiple laboratories by Dr. Gunnar Heuser, Dr. Gordon Baker, myself and others.

Some individuals with chemical sensitivity will have abnormal thyroid function tests and may also have antithyroglobulin and/or antimicrosomal antibodies to thyroid. Regarding consultation testing, you have listed neuropsychologic testing which can be useful to distinguish cognitive problems in chemically sensitive persons and other persons with central nervous system involvement. I would anticipate abnormal neuropsychological testing in half or more of the Gulf War vets with chemical sensitivity.

The case by case examinations for vertigo/tinnitus on your list includes the ENG, which is very useful to detect problems with balance in persons with chemical injury/sensitivity. The BAER appears to be abnormal in about half of the chemically sensitive patients I have tested. The MRI is not sensitive for chemical sensitivity in general. I strongly recommend that any individuals with history of memory loss, difficulty thinking or concentrating, should have neuropsychologic testing.

SPECT scan testing is also recommended in this group, as it is one of the most sensitive tests we have for chemical sensitivity. I do not feel the argument of lack of normalized or standardized readings for SPECT is an adequate argument to not do SPECT scans. You are readily able to compare SPECT scan results in persons claiming sensitivity to chemicals with healthy persons and with other persons in the VA system who have other neurologic diseases. These are the only two comparison groups that you need to be able to standardize your own interpretations of SPECT abnormalities with chemical sensitivity. There are also physicians such as Dr. Mena, and Dr. Theodore Simon of Texas, Dr. Peter Bernad of Virginia, and others who would be happy to show you SPECT scans in civilian chemically sensitive patients. This is another useful comparison group. Since the VA has many facilities with SPECT scans, this very sensitive and useful test method should definitely be used on persons suspected of having chemical sensitivity. Reduced blood flow is a common finding on SPECT.

Regarding evaluation of individuals with chest pain or palpitations, you should know that the Holter monitor may show tachycardia and/or periodic ectopic beats in persons with chemical sensitivity if they are having reactions or have had recent exposures. Thus, you would not want to exclude all abnormal Holters from consideration of chemical sensitivity.

Finally, regarding testing, I need to warn you that methacholine challenge is rather dangerous in persons with chemical sensitivity. I strongly recommend cold air challenge as a substitute for persons who appear to have chemical sensitivity from their questionnaire. Severe breathing difficulty can occur and periods of prolonged illness over several weeks can result from methacholine challenge in the chemically sensitive patient.

I feel your MCS questionnaire includes the basic exposures that exacerbate illness in chemical sensitivity. It would be nice to have an index of severity, such as how frequently the reactions occur or how severe they are, but even as is, this is a useful initial screening questionnaire for MCS. Since there are differences regarding chemical alarms for chemical weapon use, you may wish to include a date or approximate date(s) when alarms were heard by vets evaluated. This may help you verify the occurrences, since more than one vet may list a single point in time.

Finally, on the exposure history questionnaire, I feel you have included most of the important exposures. In taking histories from these vets, there are two important exposures that have been omitted, however. These include smoke from burning waste and from generators and exposure to pesticides sprayed regularly in the tent. Exposure to pesticides sprayed regularly in or near the tent or camp grounds.

Again, thank you for the opportunity to contribute to helping to resolve the problems of our young soldiers.

Sincerely,

Grace Ziem, MD, Dr.P.H.

Grace Ziem, M.D., Dr.P.H.

GZ:blc

cc: Jeanne Fites
Department of Defense

GRACE ZIEM, M.D., Dr.P.H.
Occupational and Environmental Health
77 Dundalk Avenue
Baltimore, MD 21222

(410) 633-6769

Bonnie L. Cook
Assistant

June 8, 1994

The Honorable Donald Reigle
Committee Chairman
Senate Banking Committee
U.S. Senate
Washington, DC

Dear Senator Reigle:

I am an occupational and environmental medicine physician and I specialize in the evaluation and care of patients who have been exposed to, and injured by, chemicals. I am now caring for several Gulf War vets.

Yesterday, I saw a vet with problems that raise serious issues in my mind. This vet was cared for at the Walter Reed Medical Facility at Fort Meade, Maryland. I have grave concern that this patient has not been treated with candor and honesty by his care providers. He had multiple tumors that he was told were normal and medical care for these was delayed because he was told to simply not worry about them. He had abnormalities on nerve conduction pointed out by one doctor only to be told that they were actually normal by another. They do not appear normal by my review.

He had a biopsy done that yielded insufficient tissue for analysis. However, for several months he was told that this test result was normal when there seems to be no report indicating that. He has lost all confidence in health care through the V.A. and military hospital system. He now comes for civilian care because he is frightened that doctors may misrepresent his condition to him. This has caused considerable expense and economic hardship for his family.

In addition to abnormalities in multiple organ systems, this vet has a serious sensitivity to many petrochemicals and combustion products. Commonly occurring exposure levels to a variety of chemical substances severely aggravate his illness. No physician caring for him until now has asked him about sensitivity to chemicals. This has delayed the recognition of a serious aggravating factor to his current condition. It has also delayed the introduction of necessary environmental controls.

01

I and my Gulf War patients feel that the medical care available to them has not been competent and candid, despite the public attention given to the Gulf War Syndrome. Urgent measures are needed to address the deficiencies in this health care system. Until these are adequately addressed, Gulf War vets should have a right to receive reimbursement through the civilian health care system.

Please let me know if I can be of assistance to you in any way in this effort. I would also be happy to meet and/or discuss these issues with you and your staff.

Sincerely,

Grace Ziem, M.D., Dr.P.H.

GZ:vs

cc: The Honorable Robert Dole, U.S. Senate

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MCS Referral & Resources
professional outreach, patient support and public advocacy
devoted to the diagnosis, treatment, accommodation and prevention
of Multiple Chemical Sensitivity Disorders

GULF WAR SYNDROME -- A SYMPOSIUM

Boston, 5 November 1994

PRESENTATION BY ALBERT DONNAY, MHS

ON PROBLEMS IDENTIFIED IN DOD AND VA RESPONSE TO PERSIAN GULF SYNDROME

Mr. Donnay is the executive director of MCS Referral & Resources, a Baltimore-based organization engaged in professional outreach, patient support and public advocacy on issues related to the diagnosis, treatment, accommodation, and prevention of Multiple Chemical Sensitivity disorders.

He co-founded this organization with Dr. Grace Ziem, an occupational medicine physician who has specialized in working with MCS patients since the mid-1980s.

Mr. Donnay earned his masters' degree in environmental health engineering from the Johns Hopkins School of Hygiene and Public Health in 1982 and has worked since then as a grassroots organizer and researcher on various nuclear and environmental issues.

He will speak today about some of the problems identified in the Department of Veterans' Affairs and the Department of Defense response to Persian Gulf Syndrome.

2326 Pickwick Road, Baltimore MD 21207, 410-448-3319, Fax 448-3317

PRESENTATION BY ALBERT DONNAY, MHS
ON PROBLEMS IDENTIFIED IN DOD AND VA RESPONSE
TO PERSIAN GULF ILLNESS, 5 November 1994

Thank you Dr. Atwood for inviting me to speak at this important conference. I'm glad to be here and especially glad to have heard the presentations of the VA researchers this morning. I wish all the VA and Department of Defense (what I will call DOD) officials with whom I've been dealing in Washington were as candid and forthcoming about their work.

Before I discuss the problems I've identified in the VA and DOD response to Persian Gulf Syndrome -- what they call "unexplained illness"-- let me tell you how Dr. Grace Ziem and I came to be involved in this issue.

Dr. Ziem was invited last fall by Major Richard Haines to join in a presentation on Multiple Chemical Sensitivity (MCS) being given to DOD doctors involved in the treatment of Persian Gulf veterans at the Walter Reed Army Medical Center. Also through Richard's efforts, she began seeing some Gulf Veterans as patients and started talking with other independent doctors who were doing the same.

It was immediately apparent to her that these veterans exhibited the classic symptoms of multiple chemical sensitivity--specifically they complained (when asked) of newly developed sensitivities to a multitude of different chemicals (such as gasoline vapors, alcohol, perfume, cleaning products, etc.) at levels previously well tolerated.

To demonstrate just how widespread this symptom is, I would like to ask all those in the audience who believe they are suffering from Persian Gulf Syndrome to raise their hands. And now I would like to ask all of you who have developed new sensitivities to chemical odors to put <u>down</u> your hands. You are the ones with MCS. As you can see, there are not many Persian Gulf veterans left who <u>don't</u> have MCS. (When I asked this at the NIH Symposium in April of this year there was only one hand left raised.)

It was also evident from Dr. Ziem's visit to Walter Reed that government physicians there knew little about multiple chemical sensitivity. Given the potential scope of the problem (we'd heard at that time that over 20,000 vets might be ill), Dr. Ziem and I promptly decided to try to reach out to key VA and DOD officials to inform them about the diagnosis and treatment of MCS.

In January of this year I began trying to identify all of the federal government committees and research programs involved in the Persian Gulf issue, many of which were just getting underway and/or being organized, so that we could create a database of their members for further contact.

[FIRST OVERHEAD PLEASE -- P1]

In attempting to compile this list, it quickly became apparent that the federal effort was widely scattered and poorly coordinated. Despite a lot of talk about interagency cooperation, for example, no one even had a list of all the committees involved, never mind their members.

This should have been available from the lead committee, of course, the Persian Gulf Coordinating Board (the Board), which President Clinton created to provide "continuing interagency coordination and communication among the DOD, VA and HHS on all matters related to Persian Gulf Illness." In reality, this office is usually staffed by an answering machine, and most of the written and telephone requests we've made for information have gone unanswered.

Next on this list is the Persian Gulf Interagency Research Coordinating Council, also known as the Research Working Group of the Board, which is supposed to coordinate all medical research activities related to Persian Gulf Illness undertaken by the VA, DOD, HHS and EPA.. Numerous press releases issued by the DOD and VA have touted some 23 to 30 research projects underway, but we have been unable to obtain their protocols (the head of the Board told me that the investigators wouldn't want to release them because the field is so competitive!).

It took 9 months of badgering just to get the Board and Council to release the names of the VA's principal investigators. Information from the other agencies is still unavailable. Just two months ago, in September, the coordinating council published an update on its Persian Gulf research that says "a common database of these activities is desirable" and "efforts are underway to develop an interagency database listing research and research-related activities."

The Persian Gulf Expert Scientific Committee is a purely advisory group of 18 government and non-government experts who meet every several months to hear presentations on the VA's research agenda.

The Defense Science Board Task Force was appointed by the DOD to investigate reports of biological and chemical weapons use and other potential causes of "unexplained illnesses." It held several hearings and issued a report this summer saying no such weapons were used and no diagnoses or risk factors could be identified from available data.

The Committee to Review the Health Consequences of Serving During the Persian Gulf War was formed by the National Academy of Sciences, Medical Follow-up Agency at the request of Congress. It has held several hearings and is to remain active for three years overseeing all government research on this issue.

Even though this committee was supposed to oversee all government research, the DOD has asked for its own NAS Committee (from the Institute of Medicine) to review its new Comprehensive Clinical Evaluation Program. The DOD's program was designed and has been running for months, however, without any oversight.

The NIH Workshop on Persian Gulf Experience and Health consisted of an "expert" panel, appointed by an EPA-led planning committee, which heard presentations by other "experts" (also picked by the planning committee) on possible exposures and diagnoses. They met for two days in April of this year and then wrote a report overnight (issued on the third day of the conference), which said there was insufficient data to come up with a case definition or diagnosis or to identify risk factors of Persian Gulf Syndrome.

[NEXT OVERHEAD PLEASE -- P2]

One other problem we identified in compiling this database is the lack of MCS expertise among the 80 or so people on all these committees and boards. Only 3--all members of the Expert Scientific Committee--had any direct experience with MCS patients, and only one of these is regularly consulted by one of the VA's referral centers. In addition, the VA has only one staff physician with acknowledged MCS expertise--Dr. Myra Shayevitz-- who fortunately is here with us today--but her counsel has not been sought by policy makers and her proposal for an MCS-based treatment plan has been "under review" for one and a half years!

Neither the VA or DOD are willing to consult regularly with outside MCS physicians, despite offers from Dr. Ziem and others, and so consequently patients get shuffled from one "specialist" to another who treat them symptomatically, usually with prescription medications that only aggravate their MCS. One vet who came to Dr. Ziem recently had been given over 200 prescriptions.

The first specific research effort we investigated (back in March) was the DOD's attempt to develop a case definition, a project assigned by Gen. Blanck of WRAMC to Dr. Jay Sanford, a retired specialist in infectious disease and a past president of the Uniformed Services Health Services University. The Sanford case definition, critiqued in detail by Dr. Ziem for General Blanck, fails to mention MCS as either a symptom or diagnosis. Numerous recommendations made for improving the Sanford definition were ignored by General Blanck in subsequent revisions, and the entire effort has since been abandoned. The Research Council's latest report, released this September, says "it has not been possible to develop a case definition."

[NEXT OVERHEAD PLEASE -- P3]

The patient history questionnaire developed by the VA for its Persian Gulf Registry examinations also fails to ask about the symptom of newly-developed sensitivities to chemicals. This across-the-board refusal to record or report sensitivity to chemicals as a symptom is probably the most fundamental problem with the government's approach to studying Persian Gulf illness.

By focusing only the vague and non-specific symptoms recorded by the VA, it is easy for federal officials to say that no clear-cut diagnosis is evident. If, however, the symptom of multiple chemical sensitivity is put at the top of this list where it belongs--as we saw from the earlier show of hands--it would immediately focus attention on the very few medical conditions known to include this symptom, namely MCS itself, occupational asthma, sick building syndrome, and porphyria, a relatively rare enzyme-deficiency disease that is nevertheless well documented in the medical literature. Vets seen by Dr. Ziem confirm that none of the VA and DOD doctors they've seen ever asked them about chemical sensitivity symptoms. Had they done so, they quickly would have been able to focus their attention on these four diagnoses, only two of which--MCS and porphyria--can account for most if not all of the other symptoms being seen as well. (Sensitivity to light, also not recorded by the VA, is a hallmark symptom of many types of porphyria and also seen in some cases of MCS.)

It is not clear that any of the more comprehensive epidemiological investigations that the VA and DOD have planned in conjunction with the CDC and other agencies will ask about chemical sensitivity as a

(3)

symptom, although we have repeatedly urged that they do so. [Glad to learn this morning that some VA researchers are now asking this...]

[NEXT OVERHEAD PLEASE -- P4]

The VA Persian Gulf Registry examinations and those of the DOD's recently developed Comprehensive Clinical Evaluation Plan also fail to include any of the diagnostic tests reported elsewhere to be associated with symptoms of chemical sensitivity.
These include:

- SPECT scans of the brain
- PET scans of the brain
- Quantitative EEG
- Rhinolaryngoscopy
- Balance testing
- Autoimmune antibodies to myelin and smooth muscle
- Other immune activation markers such as Ta1/CD26
- 24-hour urine and stool sample analysis for excretion of porphyrins

(Note that a diagnosis of porphyria also requires blood tests to detect the specific enzyme deficiencies associated with excess excretion of porphyrins. Two classic symptoms of porphyria that can be confirmed without any special tests are photosensitivity and dark or red urine.)

[NEXT OVERHEAD PLEASE -- P5]

Despite these shortcomings, some VA physicians like Dr. Shayevitz are diagnosing MCS in their Gulf Vet patients. Without an official diagnostic code for MCS in the International Classification of Diseases, however, and without any guidance from the VA's central office on how to code or track the diagnosis, VA officials have no way of knowing how many cases of MCS have been diagnosed by their own physicians.

Most vets in the Persian Gulf Registry are given numerous symptomatic diagnoses (such as intrinsic asthma, sinusitis, dermatitis, depression or restrictive airway disease), all of which may be seen in MCS patients, but only the primary diagnosis is counted in the Registry's virtually meaningless ranking of these diagnoses.

[NEXT OVERHEAD PLEASE -- P6]

Another problem is that the VA has provided no training or written guidance on MCS treatment to its physicians or patients, even though Dr. Ziem and others have provided this. And even though MCS is known to be made worse by medications, the VA provides no warnings about this to its staff. The only information it has provided is an anti-MCS article by Dr. Abba Terr, a notoriously unqualified critic who believes MCS is completely psychological.

I should point out that, despite Dr. Terr's documented bias and lack of qualifications, he was invited to give an anti-MCS presentation at the NIH Workshop, appointed to the Defense Science Board, and appointed to the VA's Persian Gulf Grant Review Committee. An ethics complaint that Dr. Ziem and I filed concerning his role in the latter is currently under investigation by a Congressional Oversight Committee and the VA's Inspector General.

To try to address these various problems, Dr. Ziem and I enlisted the aide of several congressmen, including Joe Kennedy Jr., Lane Evans, and Bernie Sanders, who arranged a private meeting with several high level officials responsible for the DOD and VA's response to Persian Gulf Illness. At this meeting, held in May, Dr. Ziem and a small group of other independent physicians presented their case for appropriate diagnosis and treatment of MCS. We also presented these officials with a carefully selected bibliography on MCS evaluation, treatment, accommodation and research (the bibliography is listed on the back of our resource list which is on the literature table out front).

While we were told at the time that the VA's environmental referral centers would consider distributing some of this information, such as Dr. Ziem's environmental control plan for MCS patients, they have never done so. We were also promised an opportunity to provide input into the design of the DOD's new Comprehensive Clinical Evaluation Plan, but the comments subsequently provided by Dr. Ziem and her colleagues concerning appropriate history questions and diagnostic tests for MCS were rejected.

[NEXT OVERHEAD PLEASE -- P7].

They also rejected our suggestion that the VA conduct follow-up studies to compare the health outcomes of Persian Gulf vets treated symptomatically at their special environmental referral centers with those treated for MCS by Dr. Shayevitz, in whom significant improvements have been seen.

They have refused, in fact, to conduct any followup studies that could evaluate the efficacy of their treatment plans, which they obviously should know are not working.

[NEXT OVERHEAD PLEASE -- P8]

One of the worst problems from the veterans' perspective is the Catch-22 that restricts their access to non-government medical care. The VA and DOD refuse to pay for consults with independent MCS physicians, which leaves veterans at the mercy of their private health insurance (assuming they have any). Since private insurance companies rightly consider the veterans' medical problems to be military-related, they are excluded from commercial coverage. When we brought this to the attention of VA and DOD officials in May, they denied any awareness of the problem and nothing has been done since to fix it. Worse, even when vets pay their own way to see experts like Dr. Ziem, their VA doctors often refuse to accept the diagnosis and treatment they receive.

[NEXT OVERHEAD PLEASE -- P9]

Finally, a most pernicious problem is that potentially valuable independent research into the causes of Persian Gulf Syndrome is often ignored by the VA and DOD. Dr. Ziem and I are not the only ones who have been so ignored, as you can see from this list:

- Results from AAEM Study of MCS Symptoms and Diagnostic Tests in 39 Gulf War Veterans, offered by Dr. Charlie Hinshaw, the study's coordinator
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The VA and DOD are now looking at some of these issues, but not with the data of the researchers who brought it to their attention.

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In conclusion, we must remember that VA officials waited 20 years before agreeing to compensate Vietnam veterans for a rare type of chemically-induced porphyria (PCT) linked to Agent Orange exposure--doing so only at the urging of the National Institute of Medicine in July of this year.

Will it take another 20 years for the VA to recognize the porphyria/MCS connection in Persian Gulf veterans? There are a lot of sick veterans, spouses and children who may not be around long enough to find out.

Thank you.

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  —> 23+ Medical Research Projects Underway
  (investigating such things as chronic fatigue syndrome, PTSD, health effects in children, psychological assessments, depleted uranium exposure, gastroenteritis virus, intracellular parasites, Botulinum toxoid, etc. etc. – but none on MCS)

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- VA and DOD do not seek out or promote internal MCS expertise.

- VA and DOD do not seek out external MCS expertise.

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- Veterans are seen by numerous specialists, ending up with numerous symptomatic diagnoses

- Veterans end up with dozens and sometimes hundreds of prescription medications for various symptoms.

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•Patient History Questionnaire (and database) used by VA's Persian Gulf Registry does not ask about or record Sensitivity to Chemicals as a symptom

In decreasing order of frequency, VA reports:

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(Media coverage also fails to identify chemical sensitivity as a symptom)

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VA and DOD examination protocols do not include diagnostic tests used elsewhere to show abnormalities in MCS patients:

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(Protocols do include numerous tests repeatedly shown to be normal in MCS patients and Gulf veterans.)

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•VA gives most vets multiple symptomatic diagnoses, such as depression, chronic sinusitis, dermatitis, peripheral neuropathy, and occupational asthma.

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MCS Referral & Resources
professional outreach, patient support and public advocacy
devoted to the diagnosis, treatment, accommodation and prevention
of Multiple Chemical Sensitivity Disorders

GULF WAR SYNDROME -- A SYMPOSIUM

Boston, 5 November 1994

PRESENTATION BY ALBERT DONNAY, MHS

ON PROBLEMS IDENTIFIED IN DOD AND VA RESPONSE TO PERSIAN GULF SYNDROME

Mr. Donnay is the executive director of MCS Referral & Resources, a Baltimore-based organization engaged in professional outreach, patient support and public advocacy on issues related to the diagnosis, treatment, accommodation, and prevention of Multiple Chemical Sensitivity disorders.

He co-founded this organization with Dr. Grace Ziem, an occupational medicine physician who has specialized in working with MCS patients since the mid-1980s.

Mr. Donnay earned his masters' degree in environmental health engineering from the Johns Hopkins School of Hygiene and Public Health in 1982 and has worked since then as a grassroots organizer and researcher on various nuclear and environmental issues.

He will speak today about some of the problems identified in the Department of Veterans' Affairs and the Department of Defense response to Persian Gulf Syndrome.

2326 Pickwick Road, Baltimore MD 21207, 410-448-3319, Fax 448-3317

PRESENTATION BY ALBERT DONNAY, MHS
ON PROBLEMS IDENTIFIED IN DOD AND VA RESPONSE
TO PERSIAN GULF ILLNESS, 5 November 1994

Thank you Dr. Atwood for inviting me to speak at this important conference. I'm glad to be here and especially glad to have heard the presentations of the VA researchers this morning. I wish all the VA and Department of Defense (what I will call DOD) officials with whom I've been dealing in Washington were as candid and forthcoming about their work.

Before I discuss the problems I've identified in the VA and DOD response to Persian Gulf Syndrome -- what they call "unexplained illness"-- let me tell you how Dr. Grace Ziem and I came to be involved in this issue.

Dr. Ziem was invited last fall by Major Richard Haines to join in a presentation on Multiple Chemical Sensitivity (MCS) being given to DOD doctors involved in the treatment of Persian Gulf veterans at the Walter Reed Army Medical Center. Also through Richard's efforts, she began seeing some Gulf Veterans as patients and started talking with other independent doctors who were doing the same.

It was immediately apparent to her that these veterans exhibited the classic symptoms of multiple chemical sensitivity--specifically they complained (when asked) of newly developed sensitivities to a multitude of different chemicals (such as gasoline vapors, alcohol, perfume, cleaning products, etc.) at levels previously well tolerated.

To demonstrate just how widespread this symptom is, I would like to ask all those in the audience who believe they are suffering from Persian Gulf Syndrome to raise their hands. And now I would like to ask all of you who have developed new sensitivities to chemical odors to put down your hands. You are the ones with MCS. As you can see, there are not many Persian Gulf veterans left who don't have MCS. (When I asked this at the NIH Symposium in April of this year there was only one hand left raised.)

It was also evident from Dr. Ziem's visit to Walter Reed that government physicians there knew little about multiple chemical sensitivity. Given the potential scope of the problem (we'd heard at that time that over 20,000 vets might be ill), Dr. Ziem and I promptly decided to try to reach out to key VA and DOD officials to inform them about the diagnosis and treatment of MCS.

In January of this year I began trying to identify all of the federal government committees and research programs involved in the Persian Gulf issue, many of which were just getting underway and/or being organized, so that we could create a database of their members for further contact.

[FIRST OVERHEAD PLEASE -- P1]

In attempting to compile this list, it quickly became apparent that the federal effort was widely scattered and poorly coordinated. Despite a lot of talk about interagency cooperation, for example, no one even had a list of all the committees involved, never mind their members.

This should have been available from the lead committee, of course, the Persian Gulf Coordinating Board (the Board), which President Clinton created to provide "continuing interagency coordination and communication among the DOD, VA and HHS on all matters related to Persian Gulf Illness." In reality, this office is usually staffed by an answering machine, and most of the written and telephone requests we've made for information have gone unanswered.

Next on this list is the Persian Gulf Interagency Research Coordinating Council, also known as the Research Working Group of the Board, which is supposed to coordinate all medical research activities related to Persian Gulf Illness undertaken by the VA, DOD, HHS and EPA.. Numerous press releases issued by the DOD and VA have touted some 23 to 30 research projects underway, but we have been unable to obtain their protocols (the head of the Board told me that the investigators wouldn't want to release them because the field is so competitive!).

It took 9 months of badgering just to get the Board and Council to release the names of the VA's principal investigators. Information from the other agencies is still unavailable. Just two months ago, in September, the coordinating council published an update on its Persian Gulf research that says "a common database of these activities is desirable" and "efforts are underway to develop an interagency database listing research and research-related activities."

The Persian Gulf Expert Scientific Committee is a purely advisory group of 18 government and non-government experts who meet every several months to hear presentations on the VA's research agenda.

(2)

The Defense Science Board Task Force was appointed by the DOD to investigate reports of biological and chemical weapons use and other potential causes of "unexplained illnesses." It held several hearings and issued a report this summer saying no such weapons were used and no diagnoses or risk factors could be identified from available data.

The Committee to Review the Health Consequences of Serving During the Persian Gulf War was formed by the National Academy of Sciences, Medical Follow-up Agency at the request of Congress. It has held several hearings and is to remain active for three years overseeing all government research on this issue.

Even though this committee was supposed to oversee all government research, the DOD has asked for its own NAS Committee (from the Institute of Medicine) to review its new Comprehensive Clinical Evaluation Program. The DOD's program was designed and has been running for months, however, without any oversight.

The NIH Workshop on Persian Gulf Experience and Health consisted of an "expert" panel, appointed by an EPA-led planning committee, which heard presentations by other "experts" (also picked by the planning committee) on possible exposures and diagnoses. They met for two days in April of this year and then wrote a report overnight (issued on the third day of the conference), which said there was insufficient data to come up with a case definition or diagnosis or to identify risk factors of Persian Gulf Syndrome.

[NEXT OVERHEAD PLEASE -- P2]

One other problem we identified in compiling this database is the lack of MCS expertise among the 80 or so people on all these committees and boards. Only 3--all members of the Expert Scientific Committee--had any direct experience with MCS patients, and only one of these is regularly consulted by one of the VA's referral centers. In addition, the VA has only one staff physician with acknowledged MCS expertise--Dr. Myra Shayevitz-- who fortunately is here with us today--but her counsel has not been sought by policy makers and her proposal for an MCS-based treatment plan has been "under review" for one and a half years!

Neither the VA or DOD are willing to consult regularly with outside MCS physicians, despite offers from Dr. Ziem and others, and so consequently patients get shuffled from one "specialist" to another who treat them symptomatically, usually with prescription medications that only aggravate their MCS. One vet who came to Dr. Ziem recently had been given over 200 prescriptions.

The first specific research effort we investigated (back in March) was the DOD's attempt to develop a case definition, a project assigned by Gen. Blanck of WRAMC to Dr. Jay Sanford, a retired specialist in infectious disease and a past president of the Uniformed Services Health Services University. The Sanford case definition, critiqued in detail by Dr. Ziem for General Blanck, fails to mention MCS as either a symptom or diagnosis. Numerous recommendations made for improving the Sanford definition were ignored by General Blanck in subsequent revisions, and the entire effort has since been abandoned. The Research Council's latest report, released this September, says "it has not been possible to develop a case definition."

[NEXT OVERHEAD PLEASE -- P3]

The patient history questionnaire developed by the VA for its Persian Gulf Registry examinations also fails to ask about the symptom of newly-developed sensitivities to chemicals. This across-the-board refusal to record or report sensitivity to chemicals as a symptom is probably the most fundamental problem with the government's approach to studying Persian Gulf illness.

By focusing only the vague and non-specific symptoms recorded by the VA, it is easy for federal officials to say that no clear-cut diagnosis is evident. If, however, the symptom of multiple chemical sensitivity is put at the top of this list where it belongs--as we saw from the earlier show of hands--it would immediately focus attention on the very few medical conditions known to include this symptom, namely MCS itself, occupational asthma, sick building syndrome, and porphyria, a relatively rare enzyme-deficiency disease that is nevertheless well documented in the medical literature. Vets seen by Dr. Ziem confirm that none of the VA and DOD doctors they've seen ever asked them about chemical sensitivity symptoms. Had they done so, they quickly would have been able to focus their attention on these four diagnoses, only two of which--MCS and porphyria--can account for most if not all of the other symptoms being seen as well. (Sensitivity to light, also not recorded by the VA, is a hallmark symptom of many types of porphyria and also seen in some cases of MCS.)

It is not clear that any of the more comprehensive epidemiological investigations that the VA and DOD have planned in conjunction with the CDC and other agencies will ask about chemical sensitivity as a

(3)

symptom, although we have repeatedly urged that they do so. [Glad to learn this morning that some VA researchers are now asking this...]

[NEXT OVERHEAD PLEASE -- P4]

The VA Persian Gulf Registry examinations and those of the DOD's recently developed Comprehensive Clinical Evaluation Plan also fail to include any of the diagnostic tests reported elsewhere to be associated with symptoms of chemical sensitivity.
These include:

- SPECT scans of the brain
- PET scans of the brain
- Quantitative EEG
- Rhinolaryngoscopy
- Balance testing
- Autoimmune antibodies to myelin and smooth muscle
- Other immune activation markers such as Ta1/CD26
- 24-hour urine and stool sample analysis for excretion of porphyrins

(Note that a diagnosis of porphyria also requires blood tests to detect the specific enzyme deficiencies associated with excess excretion of porphyrins. Two classic symptoms of porphyria that can be confirmed without any special tests are photosensitivity and dark or red urine.)

[NEXT OVERHEAD PLEASE -- P5]

Despite these shortcomings, some VA physicians like Dr. Shayevitz are diagnosing MCS in their Gulf Vet patients. Without an official diagnostic code for MCS in the International Classification of Diseases, however, and without any guidance from the VA's central office on how to code or track the diagnosis, VA officials have no way of knowing how many cases of MCS have been diagnosed by their own physicians.

Most vets in the Persian Gulf Registry are given numerous symptomatic diagnoses (such as intrinsic asthma, sinusitis, dermatitis, depression or restrictive airway disease), all of which may be seen in MCS patients, but only the primary diagnosis is counted in the Registry's virtually meaningless ranking of these diagnoses.

[NEXT OVERHEAD PLEASE -- P6]

Another problem is that the VA has provided no training or written guidance on MCS treatment to its physicians or patients, even though Dr. Ziem and others have provided this. And even though MCS is known to be made worse by medications, the VA provides no warnings about this to its staff. The only information it has provided is an anti-MCS article by Dr. Abba Terr, a notoriously unqualified critic who believes MCS is completely psychological.

I should point out that, despite Dr. Terr's documented bias and lack of qualifications, he was invited to give an anti-MCS presentation at the NIH Workshop, appointed to the Defense Science Board, and appointed to the VA's Persian Gulf Grant Review Committee. An ethics complaint that Dr. Ziem and I filed concerning his role in the latter is currently under investigation by a Congressional Oversight Committee and the VA's Inspector General.

To try to address these various problems, Dr. Ziem and I enlisted the aide of several congressmen, including Joe Kennedy Jr., Lane Evans, and Bernie Sanders, who arranged a private meeting with several high level officials responsible for the DOD and VA's response to Persian Gulf Illness. At this meeting, held in May, Dr. Ziem and a small group of other independent physicians presented their case for appropriate diagnosis and treatment of MCS. We also presented these officials with a carefully selected bibliography on MCS evaluation, treatment, accommodation and research (the bibliography is listed on the back of our resource list which is on the literature table out front).

While we were told at the time that the VA's environmental referral centers would consider distributing some of this information, such as Dr. Ziem's environmental control plan for MCS patients, they have never done so. We were also promised an opportunity to provide input into the design of the DOD's new Comprehensive Clinical Evaluation Plan, but the comments subsequently provided by Dr. Ziem and her colleagues concerning appropriate history questions and diagnostic tests for MCS were rejected.

[NEXT OVERHEAD PLEASE -- P7].

They also rejected our suggestion that the VA conduct follow-up studies to compare the health outcomes of Persian Gulf vets treated symptomatically at their special environmental referral centers with those treated for MCS by Dr. Shayevitz, in whom significant improvements have been seen.

They have refused, in fact, to conduct any followup studies that could evaluate the efficacy of their treatment plans, which they obviously should know are not working.

[NEXT OVERHEAD PLEASE -- P8]

One of the worst problems from the veterans' perspective is the Catch-22 that restricts their access to non-government medical care. The VA and DOD refuse to pay for consults with independent MCS physicians, which leaves veterans at the mercy of their private health insurance (assuming they have any). Since private insurance companies rightly consider the veterans' medical problems to be military-related, they are excluded from commercial coverage. When we brought this to the attention of VA and DOD officials in May, they denied any awareness of the problem and nothing has been done since to fix it. Worse, even when vets pay their own way to see experts like Dr. Ziem, their VA doctors often refuse to accept the diagnosis and treatment they receive.

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