

**Research Advisory Committee on Gulf War Veterans' Illnesses**

April 28-29, 2014 Committee Meeting Minutes

Department of Veterans' Affairs  
Washington, DC

**Research Advisory Committee on Gulf War Veterans' Illnesses**  
**Boston University School of Public Health**  
**715 Albany Street, T4W, Boston, MA 02118**  
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I hereby certify the following minutes as being an accurate record of what transpired at the April 28-29, 2014 meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses.

A handwritten signature in black ink, appearing to read "James H. Binns". The signature is written in a cursive style with a large initial "J" and "B".

James H. Binns  
Chairman  
Research Advisory Committee on Gulf War Veterans' Illnesses

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## **Attendance Record**

### **Members of the Committee**

James Binns, Chairman  
Roberta White, Scientific Director  
Joel Graves  
James Bunker  
Nancy Klimas  
Fiona Crawford  
James O'Callaghan  
Lea Steele  
Beatrice Golomb

### **Committee Staff**

Kimberly Sullivan, Associate Scientific Director  
Brittany Sutton

### **Designated Federal Officer**

Victor Kalasinsky

### **Guest Speakers**

Michelle Block  
Ashok Shetty

### **VA Office of Research and Development**

Robert Jaeger  
Victor Kalasinsky  
Timothy O'Leary  
Rebecca Schiller

### **VA Office of Public Health**

Victoria Davey  
Robert Bossarte  
Mitchell Wallin

### **VA Office of Public and Intergovernmental Affairs**

Robert Jesse, Principal Deputy Undersecretary for Health  
Madhulika Agarwal, Deputy Undersecretary for Health Policy and Services

## **Acronyms & Abbreviations**

AMVETS – American Veterans Organization  
ALS – Amyotrophic lateral sclerosis  
CDC – Center for Disease Control  
CDMRP – Congressionally Directed Medical Research Program  
CFS – Chronic fatigue syndrome  
CMI – Chronic multisymptom illness  
CNS – Central nervous system  
DEET - N,N-diethyl-m-toluamide  
DFP - diisopropylfluorophosphate  
DOD – Department of Defense  
GW – Gulf War  
FACA – Federal Advisory Committee Act  
GERD - gastroesophageal reflux disease  
GMPAC – Genomic Medicine Program Advisory Committee  
GWI – Gulf War illness  
GWV – Gulf War Veterans  
H.R. – House of Representatives  
IBS – Irritable Bowel Syndrome  
IOM – Institute of Medicine  
JAN – Job Accommodation Networks  
LED – Light-emitting diode  
LPS - lipopolysaccharide  
MD – Doctor of Medicine  
MRI – Magnetic Resonance Imaging  
MRT – Magnetic resonance therapy  
MS – Multiple sclerosis  
NF-kB – nuclear factor-kappaB  
NGWRC – National Gulf War Resource Center  
NOX2 – Nitrogen Oxide 2  
NRC – National Research Advisory Council  
OPH – Office of Public Health  
ORD – Office of Research and Development  
P50 – Protein pathway 50  
PB – Pyridostigmine bromide  
PCP – Primary care physician  
PTSD – Post-traumatic stress disorder  
RAC – Research Advisory Committee  
RFA – Request for application  
ROS – Reactive oxygen species  
rTMS – Repetitive transcranial magnetic stimulation  
TB - Tuberculosis  
VA – Veterans’ Administration  
VAMC – Veterans’ Administration Medical Centers

**Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses  
April 28-29, 2014**

**Department of Veteran Affairs, 810 Vermont Avenue, Room 230, Washington, DC**

***Agenda***  
**Monday, April 28, 2014**

- |                      |  |   |
|----------------------|--|---|
| <b>8:00 – 8:45</b>   | <b>Informal gathering, coffee</b>  |   |
| <b>8:45 – 9:00</b>   | <b>Welcome, introductory remarks</b>   | <b>Mr. Jim Binns, Chairman<br/>Res Adv Cmte Gulf War Illnesses</b>  |
| <b>9:00 – 10:15</b>  | <b>Update of VA OPH Gulf War research</b>  | <b>Dr. Victoria Davey<br/>VA Office of Public Health</b>  |
| <b>10:15 – 10:30</b> | <b>Break</b>   |   |
| <b>10:30 – 11:00</b> | <b>Presentation of Report to Principal<br/>Deputy Undersecretary for Health,<br/>Dr. Robert Jesse and<br/>Remarks of Dr. Jesse</b> | <b>Committee Members</b>  |
| <b>11:00 – 11:30</b> | <b>Remarks of Honored Guests</b>   | <b>Mr. Jim Binns, Chairman<br/>Res Adv Cmte Gulf War Illnesses</b>  |
| <b>11:30 – 12:30</b> | <b>2014 RAC Report</b>   | <b>Dr. Roberta White, Scientific Director<br/>Res. Adv Cmte Gulf War Illnesses</b>                              |
| <b>12:30 – 1:30</b>  | <b>Lunch</b>   |   |
| <b>1:30 – 2:30</b>   | <b>Update of VA ORD Gulf War research<br/>Portfolio</b>  | <b>Dr. Victor Kalasinsky<br/>Dr. Robert Jaeger<br/>VA Office of Research and development</b>                    |
| <b>2:30 – 3:15</b>   | <b>The role of protein radicals in<br/>neuroinflammation as a model of GWI<br/>and therapeutic strategies</b>                      | <b>Dr. Michelle Block<br/>Virginia Commonwealth University</b>  |
| <b>3:15 – 3:30</b>   | <b>Break</b>   |   |
| <b>3:30 – 4:15</b>   | <b>Efficacy of fluoxetine and resveratrol<br/>For easing memory and mood<br/>dysfunction in an animal model of GWI</b>             | <b>Dr. Ashok Shetty<br/>Central Texas Veterans Healthcare System</b>  |
| <b>4:15 – 4:45</b>   | <b>Committee and Panel Discussion: ‘how<br/>to discussion’ for GWI animal research</b>   | <b>Dr. Jim O’Callaghan<br/>Dr. Kimberly Sullivan, Assoc Scientific Dir<br/>Res. Adv Cmte Gulf War Illnesses</b> |
| <b>4:45 – 5:15</b>   | <b>Public comment</b>  |   |

**Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses  
April 28-29, 2014**

**Department of Veteran Affairs, 810 Vermont Avenue, Room 230, Washington, DC**

***Agenda***  
**Tuesday, April 29, 2014**

- |                      |  |  |
|----------------------|--|--|
| <b>8:00 – 8:30</b>   | <b>Informal gathering, coffee</b>  |  |
| <b>8:30 – 9:30</b>   | <b>'How to discussion:' GWI case-criteria and assessment of health outcomes in Gulf War veterans</b> | <b>Dr. Lea Steele<br/>Red Adv Cmte Gulf War Illnesses</b>  |
| <b>9:30 – 10:30</b>  | <b>'How to discussion:' GWI clinical treatments and study recruitment</b>                            | <b>Dr. Beatrice Golomb<br/>Res Adv Cmte Gulf War Illnesses</b>   |
| <b>10:30 – 10:45</b> | <b>Break</b>   |  |
| <b>10:45 – 12:00</b> | <b>'How to discussion:' GWI exposure assessment and biomarker development</b>                        | <b>Dr. Roberta White, Scientific Director<br/>Dr. Kimberly Sullivan, Assoc. Scientific Dir<br/>Res Adv Cmte Gulf War Illnesses</b> |
| <b>12:00 – 12:30</b> | <b>Public Comment</b>  |  |
| <b>12:30</b>         | <b>Adjourn</b>   |  |

**Honored  
Guests**

**Congressman Mike Coffman, Gulf War Veteran and chairman, House Veterans Affairs Committee  
Oversight and Investigations Subcommittee**

**Major (USMC ret.) Stewart Hickey,  
Gulf War veteran and National Executive Director, AMVETS**

**Former veteran members of the  
Research Advisory Committee on Gulf War Veterans' Illnesses:**

**Mr. Adrian Atizado  
Mr. Anthony Hardie**

## **DAY 1**

### **Welcome, introductory remarks**

#### **Mr. James Binns, Committee Chair**

Chairman Binns opened day 1 of the April 2014 Research Advisory Committee (RAC) meeting on Gulf War Veterans' Illnesses. He discussed that the release of the new Research Advisory Committee (herein known as the Committee) report would happen at this meeting. The report was an update on scientific findings and research since the Committee's last report that was released in 2008. He noted the discussions and presentations that would occur as well, along with updates from the Office of Public Health (OPH) and Office of Research and Development (ORD).

Chairman Binns offered prepared remarks urging all parties present to work toward ending the government's immoral and intellectually bankrupt Gulf War health policy. His remarks are attached as **Appendix A – Chairman's Presentation**.

Chairman Binns turned the program over to Dr. Sullivan, the associate scientific director, who introduced Dr. Victoria Davey and staff of the Office of Public Health.

### **Update of VA OPH Gulf War research**

#### **Dr. Victoria Davey, VA Office of Public Health**

Dr. Davey began the update of VA Office of Public Health (OPH) research by introducing Dr. Robert Bossarte, who discussed the follow-up studies that were being conducted, including the National Cohort of Gulf War and Gulf-Era Veterans and the National Health Study of a New Generation of Veterans. For the presentation covering all OPH discussion, please refer to **Appendix A – Presentation 1**. He covered the VA's initial national survey of Gulf War (GW) veterans, including timing and topic areas, and the three survey studies that have taken place since the Gulf War. The sample was of 15,000 GW deployed veterans and 15,000 GW non-deployed veterans. Studies results indicated that deployed veterans reported poorer health outcomes than their non-deployed counterparts. Study participants included individuals characterized by gender and deployment status. He stated that there have been a number of publications, in addition to numerous related studies, added policies, and findings by OPH studies that have informed presumptions for GW veterans. Causes of death for GW veterans were found to be different than the leading causes of death for the general population. The National Health Study for a New Generation of Veterans was covered briefly.

Dr. Mitchell Wallin called into the meeting, and thanked the Committee for the opportunity to speak. He briefly discussed the VA Multiple Sclerosis (MS) Cohort. Topics included the incidence and prevalence rates of MS in the Gulf War veterans' cohort. Additionally, relative

risks and rates of deployment were discussed. He stated that his research results suggested that deployment to the first Gulf War was not an increased risk factor for MS.

Dr. Victoria Davey concluded the presentation. She stated that OPH planned to characterize the full scope of health issues being experienced by Gulf War veterans in currently ongoing studies. She stated that through work with the VA Office of Research and Development as well as the RAC, these findings would be used to inform future research.

Dr. Sullivan thanked the Office of Public Health officials for their presentation, noting the consistencies in the results that OPH reported with the data that the Committee had reported in their reviews, with about 26% of deployed veterans experiencing Gulf War illness in comparison to their nondeployed counterparts. She asked whether this data would be going to publication soon or was still to be analyzed. Dr. Davey said that it would be going to publication soon, there were some further analyses that needed to be done, variables to further account for, but they would be moving to publication as soon as the analyses were complete.

Dr. Sullivan noted the additional OPH informational handouts in the Committee members' binders to supplement the presentation (see **Appendix B**).

Dr. Steele asked Dr. Bossarte two questions. She thanked him for the presentation of the early results and she asked to confirm whether the MS prevalence rates came from the VA health system records or from the national survey. Dr. Bossarte confirmed that the MS rates came from the VA health system records. She then asked what the results were from the national survey. He stated that they would be happy to make those survey results available. Dr. Steele asked whether the mortality results could have showed more information. Dr. Bossarte replied that given time and information constraints, they wanted to show as much information as they could, given the time they had to prepare it. Dr. Steele asked whether the suicide rates and actual completed suicide number came from the total number of veterans or from the percent of veterans with suicidal ideation. Dr. Bossarte replied that these rates came from the total number of veterans that participated in the study.

Dr. Klimas asked whether they were only asking questions that identified Gulf War illness as chronic multisymptom illness (CMI) in the survey. Dr. Bossarte replied that the Institute of Medicine (IOM) recommendation that the illness be referred to as Gulf War illness came out after the survey was released so the participants were queried at CMI not GWI. Her second question was in regard to gender differences in multiple sclerosis and what the current hypothesis was regarding women as being more susceptible. Generally this trend finding has been consistently found in the studies that have been completed. Studies have examined therapies regarding sex hormones in animal models and she thought it was important to examine trends. Dr. Bossarte stated that his office will continue to examine the data to try and determine the cause.

Dr. White asked a question regarding the environmental drivers of these problems. She wondered if, when looking at specific groups of people and seeing differences in morbidity and mortality, there were plans to complete analyses in specific cohorts and subsets of these cohorts. Dr. Davey replied that these were analyses that OPH fully planned to do moving forward.

Dr. Sullivan noted the importance of separating exposures, such as brain cancer rates in veterans who were exposed at Khamasiyah, and asked whether there were plans to look specifically at this. Dr. Davey replied that there were plans to do so. Rev. Graves thanked Dr. Sullivan for asking this question, noting the clear results in those individuals deployed, the differences in those exposed troops were extremely clear and different from other individuals.

Dr. Steele asked whether the veterans included in the MS cohort were MS service-related specific or included anyone who applied to the MS studies. Dr. Wallin replied that these individuals are not necessarily all service connected, but they can be separated in the study by service connection or not. Dr. Steele clarified that people would be less likely to apply if they were out of service for seven years or more, who knew MS would not be service connected. Dr. Steele noted that the numbers may be undercounting MS cases in GW veterans for this reason. Dr. Wallin replied that there are data gathering difficulties, but that this was true. Dr. Steele noted that individuals may be underrepresented, given the connection of people that are less likely to apply because they've been out of service for longer than seven years. Dr. Wallin noted that they used the entire military; anyone could apply without deployed or nondeployed discrimination.

Dr. Sullivan thanked Dr. Wallin for separating Gulf War veterans out in his analyses, which had not been done previously. She asked why specifically the 'less than seven years out of service' requirement was in place to qualify for MS presumption for service through the VA. Dr. Wallin stated that it wasn't a 'magic number' based on data, but has been around since it began in WWII. In his opinion, it would be best if all service connected individuals were included, regardless of years out of service. He stated that the seven year rule had been challenged by individuals trying to eliminate this in Congress, but without success.

Dr. Golomb asked who the Gulf War veterans were compared to, whether it was later in time or those non-deployed during the same time period. Dr. Wallin affirmed that it was deployed compared to nondeployed. Dr. Golomb wanted to remind everyone of the differences in those deployed that were not who had received treatments such as the anthrax vaccine. Differences in comparability must lend to caution in making conclusions about deployment and MS until more information is available. She also underscored that in every group the odds ratio was less than one that Dr. Wallin presented and that one could draw the conclusion that all military personnel

were healthier prior to deployment. This was a comparison of groups with different risk characteristics to begin with.

Dr. Steele wanted to make one more observation, that Air Force veterans have seen more illness rates such as ALS diagnosis and more recently MS diagnoses than veterans from other service branches.

Dr. Jesse noted that this data was extremely encouraging including the work that was done to analyze the data within this short period of time. He asked at what point these studies would be analyzed to completion and when they would be published. Dr. Davey stated that OPH supports full data sharing and support. She stated that her local researcher group would spend one or two years with the data to complete their own analyses and submit publications for peer review, and then following that they would make the data available to other interested scientists. With regard to publications, Dr. Davey planned to peer-review and display the findings to the community. She stated that OPH would like to continue to provide the Committee with pre-publication findings moving forward. Dr. Jesse noted the real opportunity present to be taking advice from the Committee on the front end, which will make published data more robust.

Dr. Sullivan asked Dr. Davey about previous national survey treatment questions that GW veterans had answered and that Dr. Davey had provided the Committee members with in their Committee binders (see **Appendix B**). She thanked Dr. Davey for the information on those treatments that had been shown to be beneficial to Gulf War veterans and she pointed out that past findings had shown that veterans had found strenuous exercise to be troublesome and cause them to feel worse rather than better.

### **Presentation of Report Committee Members**

Chairman Binns called on the longest serving Gulf War veteran Committee member, Reverend Joel Graves, to present the report on behalf of the Committee.

Rev. Graves thanked Chairman Binns for the opportunity to present the report and stated that he was honored to be there. He noted his presence on the Committee since its inception 12 years prior, and that he was presenting the report to Undersecretary for Health, Dr. Robert Jesse, although he had hoped that he would be presenting it to Secretary Shinseki. He felt that Secretary Shinseki's absence from the meeting perpetuated the idea that he did not support the veterans of the Gulf War living with Gulf War illness (GWI) who suffer from it every day.

From the beginning, the VA has pushed back against Gulf War illness, pushing psychological issues as the cause. He was an officer for ten years before Desert Storm. His unit was exposed to toxins, and a nerve agent that caused chemical alarms to go off. Afterwards, memory loss,

chronic pain, and illnesses began to plague him and his men. Upon his return home, he experienced many problems. He did not realize that he had Gulf War illness until he joined the Committee. He was told by his VA physician that he [the physician] did not believe in Gulf War illness, and that his injuries related to the war were documented as the result of post-traumatic stress disorder (PTSD). Rev. Graves no longer goes to the VA for treatment. However, he has seen Dr. Golomb's work from the VA, and others that do show promise. There are many others, however, that resist change for the better. The Committee has shown the causal relationship between service in the Gulf War and the illness they suffer. His service on the Committee has been one of the most frustrating experiences that he can recall. The VA has blocked the Committee at every opportunity. Even when things seemed to get better, something would happen to block and diminish positive efforts.

He stated that he and other Committee members had warned against using veterans' data including individuals post-Gulf War. They would produce results that would skew the data to make the results look less severe than they actually were. He hoped that the VA would change this. He was nervous that after the September meeting when members are rotated off, the VA will appoint members that have stress experience, and will try to bring the view back of GWI as a stress-related illness once again. He stated that veterans deserve the right to treatment after serving for their country. He felt that it had become clear that Gulf War veterans have not received this right, even after holding up their end of the bargain. He felt that the root of the VA pushing back so hard against Gulf War illness had come down to the costs involved. Reverend Graves concluded his comments by asking for the Secretary and the VA staff to work with the Committee as they seek to help Gulf War veterans.

Dr. Robert Jesse accepted the report on behalf of the VA. He thanked the Committee for the hard work in producing the report. He echoed Chairman Binns' sentiments that the 2008 Committee report truly changed the public's view of Gulf War illness, and he hoped that the current report would continue to do the same. He stated that the VA would review all recommendations, and try to work with the Committee on them. Dr. Jesse noted the goal of providing certainty to veterans regarding why they were becoming sick and how they could become better and the work the Committee had done continued to work fundamentally toward this goal. He thanked the veterans who spend their time and effort to attend the meetings, which he acknowledged was not easy. He thanked the Committee for the report on behalf of Secretary Shinseki, and stated that they would try their hardest to do it justice.

The Committee is federally mandated, and is in place to ensure that the government stay advised. The key to moving forward would be to continue to push forward the research agenda. He noted Dr. Golomb's work, and put forward the goal to design a study that furthers her research and other promising studies like it. He thought that it should be the goal of the VA to push promising research forward. He noted biomarkers being of importance to help provide certainty to studies.

The more that everyone can work to take uncertainty out of the equation, the better off Gulf War veterans will be. He stated that the VA believed that toxic exposure is a real threat, and that it must be studied continuously moving forward. He believed that the submission of higher quality proposals is of utmost importance. Budgets have become increasingly tight, but finding the right ways to approach all of these areas are key. The more certain the research for veterans that the Committee provides, the better positioned the VA will be to help. He stated that there was no intention by VA to avoid providing benefits to Gulf War veterans (GWV).

Dr. Jesse thanked the Committee for their extraordinary work. He stated that the VA would reply as quickly as possible to any report recommendations that they might have real problems with, and will move forward as quickly as they can with the others.

Chairman Binns noted the urgency for the VA to act now. He then stated that the next speakers would be the honored guests. The first speaker was Congressman Mike Coffman, a Gulf War veteran himself, and chairman of the House Veterans Affairs Committee subcommittee on Oversight and Investigations.

## **Remarks of Honored Guests**

### **Rep. Mike Coffman, United States Congress**

Congressman Coffman thanked the Committee for the opportunity to speak. He introduced himself as a Gulf War veteran. About 20 years prior to this meeting, he fought in the Gulf War. From the beginning of the Gulf War until its conclusion, many things were accomplished. Many of the men and women who returned from the war, however, still await service for their health issues. These issues were not related to battlefield stress, but as a result of the toxic environment. Research has always been the key, but the government spent much of its research money trying to prove that this problem was mental health related. VA's reported Gulf War research spending has declined considerably, and even fewer of those studies are directly related to Gulf War illness itself.

The VA had been charged with pushing forward research to provide treatments for Gulf War veterans, and has in large part failed. Only about 20,000 Gulf War veterans, of the 250,000 in need of health care, have been approved to receive such care at the VA. VA has failed to include questions key to identifying Gulf War illness in their ten-year survey. Congressman Coffman stated that for those reasons that he introduced the bipartisan bill H.R. 4261 to ensure the independence of the Committee. Gulf War veterans gave all of themselves in fighting for their country, they are asking for help for their health that is failing as a result of this service. Veterans deserve nothing less from their country, and from the Department of Veterans Affairs.

### **Maj Stewart Hickey, AMVETS**

Major Hickey thanked the Committee for the invitation to speak. He learned a lot as a Gulf War veteran from his service, as well as from his fellow Gulf War veterans, all of whom say the same thing: Gulf War veterans are sick, people are dying. How much longer must veterans wait for the treatment they deserve? He wanted to discuss the perception that Gulf War veterans have. He noted Congressman Coffman's note of the 20,000 of 250,000 being granted presumptives for service. He is not aware of veterans in other wars experiencing similar issues, but he doubts it. Gulf War veterans feel as though they have been abandoned by their government and by the VA.

He wanted to give the VA credit with how they've worked with AMVETS. VA staff who worked with them provided real help. The assumption with veterans has been that claims are not paid out for Gulf War illness. The VA needs to change this perception; they should not behave like a corporate insurance company, trying to minimize claims paid.

The other area that is important to note is toxic wounds. Gulf War veterans felt they were abandoned by the denial of the Government that any chemical weapons were used in the Gulf War. In his service, they breached two mine fields between the oil well fires. Chemical detection alarms went off four or five times. The official word is that they were faulty alarms, but he did not believe this to be the case. In closing, he thanked VA for helping with veterans' claims, but much work still needs to be done. Gulf War veterans are aging, and many have already succumbed to their illnesses. Casualties in actual wartime may not have been substantial, but they've continued on since then.

### **Mr. Adrian Atizado, Disabled American Veterans, former veteran members of the Committee**

Mr. Atizado thanked the Committee for the invitation to speak at the release of the report. He was on the Committee from 2006-2007. He recalled feeling overwhelmed by the depth and breadth of discussion around research in Gulf War illness. The Committee represented the beginning of a real sense of fairness for these veterans who have been fighting an uphill battle since their return from the war. Mr. Atizado discussed the funds being allocated by the VA for Gulf War illness. Of the funds budgeted for Gulf War illness, very little is being spent, and this number continues to drop. The VA has many commitments and responsibilities, but this Committee has a lot of work ahead. He hoped that the new members of the Committee take the time to reflect where the Committee has been, and what it has accomplished, which is great. He thanked the Committee for their efforts.

Chairman Binns acknowledged and recognized the contributions of the scientists that have made the report possible. He introduced Drs. Jim O'Callaghan and Lea Steele to provide their thoughts on the report.

**Dr. James O'Callaghan, Committee member**

Dr. O'Callaghan introduced himself to the audience and began with his start on the Committee. He recalled his beginnings in animal research, and how his career has been influenced by being a part of a Committee working with scientists that work directly with patients. His work has changed from being almost exclusively in the lab with animal models, to seeing where his research translates into the human populations (in this case Gulf War veterans) outside of his scope of study. He is in direct contact with researchers outside of animal models, and felt tremendously grateful to be able to work with these people in different fields of research.

After the 2008 report, the VA agreed that there was in fact something going on with this group of veterans, and worked to contract a group of diverse clinical and nonclinical researchers at the University of Texas Southwestern Medical Center. This group worked together towards the Gulf War illness problem and made numerous contributions towards Gulf War illness.

Consortia have also been helpful in bringing diverse groups of researchers with unique perspectives together to focus on the problem. He mentioned Mr. Anthony Hardie, a former veteran member of the Committee, who has played a major role in a number of functions including the Congressionally Directed Medical Research Program (CDMRP), which has funded the consortia. He thanked all of those individuals that are part of the Committee, those that were past members of the Committee, and thanked everyone for the opportunity he had to be a part of the Committee.

Chairman Binns thanked him and noted the significance of animal research in furthering knowledge of Gulf War illness.

**Dr. Lea Steele, Committee member**

Dr. Steele thanked everyone for the opportunity to speak. She has been on the Committee for twelve years, since its start, and prior to that had worked on the Kansas state-sponsored program for Gulf War veterans with Mr. Jim Bunker. She expressed the privilege of working for the Committee as its scientific director, reviewing research from scientists around the world related to service in the Gulf War. The work and dedication of the Committee members, and most especially the veterans, are the reason she has been able to continue working so hard for this cause. Government officials as a result have had to broaden their assumptions about Gulf War health issues.

The report shows that research has made great strides, but veterans are still struggling to experience better health since their return from the Gulf War. The veterans still have to push so hard for the treatment they deserve. She saluted with gratitude the veterans and scientists who

have served on the Committee, and the researchers who have provided great progress and contributions toward solving Gulf War illness. She also saluted government officials that continue to push for progress to improve the health of Gulf War veterans. Twenty three years has been too long to wait, for acknowledgement of their illness and treatment.

Chairman Binns took this time to acknowledge Dr. Roberta White and her staff in Boston, as well as the Committee members who contributed to the report and everyone else who helped bring the report to fruition. He introduced Dr. White to present the content of the report.

## **2014 RAC Report**

### **Dr. Roberta White, Scientific Director**

Dr. White thanked everyone for being present at the meeting. She noted the report issued is a pre-print version and that the print version would be produced at a later date. She discussed the process of producing the report. The Committee periodically produces these reports; the last one was produced in 2008. The 2008 report had a tremendous impact on public opinion. Since 2008, research has greatly progressed and has become much more sophisticated.

The content of the report is the scientific literature published since the last report. The RAC scientific office in Boston gathered all scientific papers regarding Gulf War illness, drafted tables, and summarized the research. Members of the Committee and its staff drafted other sections of the report, including Lea Steele, Jim O'Callaghan, Kimberly Sullivan, and Chairman Binns. The first draft was reviewed by the Committee in January 2014, was followed by a teleconference review in March 2014, and the final report is now released at this April 2014 meeting.

Contributions were also made by past Committee members including Marguerite Knox and Anthony Hardie, current Committee members Jim Bunker, Nancy Klimas, Beatrice Golomb, Floyd Bloom, Fiona Crawford, Joel Graves, and Steve Ondra. Dr. White noted that it is a consensus report. All Committee members contributed to the report, and the report was agreed upon regarding content, though not every edit suggested by every member could be made. The executive summary summarizes the main ideas of the report, and the rest of the report goes into detail in epidemiologic research, health conditions, etiologic investigations, animal models research, chemical and other causes of Gulf War illness, pathobiology of the illness, and treatment research. The final section consolidates the research recommendations from each section.

She gave a brief summary of the report. For the summary information, please refer to Dr. White's slides, **Appendix A – Presentation 2**. All population based studies completed since the war have identified a markedly increased excess rate in chronic systematic illness in 1990-1991 Gulf War veterans, in the range of 22%-30% of Gulf War veterans. The case definitions are the

main reasons for the different percent ranges. Broad case definitions produce higher rates of the disorder, while narrower case definitions produce much narrower ones. The Committee believes a data-based case definition should be developed to be used universally. Studies have indicated that Gulf War veterans' health has not improved over time. There were ongoing studies that she hopes will better inform the prognosis. Gulf War veterans have continued to report poorer health and lower health status since their return from the war.

Epidemiological literature has shown additional conditions associated with Gulf War illness including cancers and neurological disorders. Since 2008, additional research regarding adverse reproductive health has been conducted although results remain uncertain. Chronic fatigue syndrome (CFS), fibromyalgia and chemical sensitivity have also been studied. The criteria for these conditions do overlap with some of those in Gulf War illness, but don't account for Gulf War illness in its entirety. Research has shown that Gulf War illness cannot be explained as having psychological roots such as stress disorders.

When looking at mortality rates in Gulf War veterans, deployed veterans see no significant difference in mortality rates than their nondeployed era veteran counterparts. When comparing brain cancer rates for those veterans exposed to nerve gas agents, veterans experienced a significantly higher mortality rate. Assessing mortality in veterans and other subgroups by location and grouping was very important. A primary issue of concern regarding mortality is the lack of information, which based on the presentation of the VA Office of Public Health (OPH) that morning hopefully will change.

The Committee agreed on a number of recommendations. First, the Committee believes in the development of an evidence-based case definition. They also believe that the VA should explicitly refer to this illness as 'Gulf War illness' moving forward. They believe that ongoing monitoring and surveillance is critical as veterans' age. Systematic assessment of overall and disease specific mortality of Gulf War veterans and subgroups is essential and should be completed in five-year intervals. Morbidity rates from the longitudinal survey should assess conditions of concern. Epidemiologic research should be improved, there should be systematic methods for assessing symptoms and health outcomes in subgroups of importance.

With regards to chemical and pharmaceutical exposures in the field that likely led to Gulf War illness, research supports that pesticides and pyridostigmine bromide (PB) are a cause of Gulf War illness and other health and functional disorders in Gulf War veterans. Other exposures that contributed include sarin, cyclosarin, and oil well fires. One new study examined vaccine exposure but found no significant association. Studies have looked at depleted uranium, but since 2008, none of the studies found a significant relationship between DU exposure and health outcomes. Dr. O'Callaghan has researched Gulf War illness using animal models, replicating

Gulf War exposures. This research has been critical in development of hypotheses for symptom discovery.

The third section of the report covers the pathobiology of Gulf War illness. Fifteen studies were published since 2008 on the nervous system with significant findings relating to abnormal neurologic function in Gulf War veterans. Neuroendocrine function has additionally been studied. Immunological function has been studied in eight papers since 2008, six of which have found significant findings. Based on findings, the Committee recommends clear, operational case definitions based on the research conducted. Gender differences should also be considered in research. Dr. White mentioned Dr. Jesse's interest in biomarkers, and she echoed this sentiment. Epigenetic and genetic approaches would be informative. Regulatory dynamics should be focused on.

The published and ongoing studies in treatment research were then covered. Few studies have been published to date as many studies were still ongoing. One study was conducted that found improvement in a number of outcomes. Ongoing treatments included treatments in exercise resistance training, mindfulness, antibiotics, probiotics, acupuncture, LED therapy, rTMS study, and more. Animal model treatments are being conducted using flupirtine, Alzheimer's disease medications, and others. Recommendations made finding effective treatments the highest research priority, and detailed best methods of research.

In summary, research continued to show the occurrence of poorer health and greater disability among Gulf War veterans. These health problems have affected approximately 25%-30% of Gulf War veterans. Gulf War illness should be the term used for this disorder. Gulf War illness and other sources of ill health among Gulf War veterans are related to exposure to chemicals and pharmaceuticals in theater. Gulf War illness is a complex disorder, but studies are beginning to identify the underlying pathobiology of Gulf War illness. Improved health for Gulf War veterans has been the ultimate goal and should be urgently pursued moving forward.

Dr. White thanked the veterans for the time and tremendous effort they put into attending and listening in on these meetings, and expressed the Committee's sentiments that the veterans make all of their efforts worth it.

Mr. Jim Bunker made a comment. He noted that he did not see in the report the direct recommendation for some of the follow-on studies of those studies that show real promise. He handed out the details to all Committee members, and thought the Committee should consider adding them in an addendum.

Dr. White noted that the report was finalized and could not be added to at this point. She noted that there were a number of specific recommendations for follow-on studies in the report already.

Mr. Bunker noted that he did not think that those existing recommendations were detailed enough as they were written. Dr. White noted that she and the Committee believed that they addressed the questions he had. Chairman Binns noted that he took the time to compare the report with the recommendations that Mr. Bunker has suggested previously, and that most of those recommendations are in fact included in the report.

Dr. Klimas said that she thought that the theme of these recommendations Mr. Bunker discussed were in the way of finding methods to ensure that those small treatment studies that show promise and success are then further considered in validation studies. She agreed that this was an important point, and was an integral point made in the report recommendations where the VA ensures that they fund validation studies.

Dr. Sullivan also noted the opportunity to make these very specific recommendations happens after every meeting. It was very difficult to include every specific recommendation in a multi-year report. Mr. Bunker asked that his document be included in the minutes, and Chairman Binns replied that this document and the response would be included. Both documents can be seen in **Appendix C – Document 1 & 2**.

Chairman Binns thanked Drs. White, Steele, and Golomb for keeping the Committee on a narrow scientific track as they have done their work as the Committee's scientific directors over the years. None of the progress that has been made in getting an increased acceptance of the illness would have been possible if not based on sound, convincing, and overwhelming evidence. There is nothing included in the report that cannot be discussed at any meeting with any scientist. There is no question about what the science says about the illness.

### **Update of VA ORD Gulf War Research Portfolio Dr. Victor Kalasinsky, VA Office of Research and Development**

Dr. Robert Jaeger introduced Dr. Kalasinsky. He noted that Gulf War Research has been Dr. Kalasinsky's only task, and that he has done a significant amount of work in pushing forward the best research possible. He has made sure that all requests for applications (RFAs) are completed on time; he has improved the research panel, ensuring that the panel reviews this research on schedule. Dr. Kalasinsky has also reached out to any researcher that has not met review quality standards and has worked with and encouraged resubmission of their grant applications. The funding has gone up every year since Dr. Kalasinsky has been a part of the program. Dr. Jaeger was very thankful for having had the opportunity to work with him.

Dr. Kalasinsky presented a research program overview on behalf of the Office of Research and Development (ORD). For presentation slides, please refer to **Appendix A – Presentation 3**. The VA ORD research and development strategic plan for 2010-2015 was covered, including the mission and vision, the capacities in research, the volume of funded projects, and the research portfolio. The VA ORD funding information can be found in **Appendix D - Document 1**.

Dr. Kalasinsky described the model used to determine which research projects to fund, and the process of placing RFA's. There were a number of resources available to the public regarding information about VA-ORD funded research. These included sites that can be accessed by the general public, which include information on current and past trials, research projects, published studies, and the ORD office journal.

There were three ORD-based Federal Advisory Committee Act (FACA) committees discussed. In addition to the RAC, the National Research Advisory Council (NRAC) and the Genomic Medicine Program Advisory Committee (GMPAC) were discussed. The eight focus areas of the 2013-2017 Gulf War Research Strategic Plan were: symptomatic and specific treatments, databases and continued surveillance, establishing an evidence-based case definition of chronic multisymptom illness in Gulf War veterans, genetic genomic and systems biology, biomarkers, animal models, improving coordination and communication, and translating research findings into practice.

Dr. Kalasinsky followed up with a preview of the Gulf War research projects that were currently active in 2014, as well as the topics of those Gulf War research projects selected for funding. A number of research projects in Gulf War illness were concluded in 2013, and publications were set to follow in the near future. He provided a brief overview of the GW research biorepositories as well as other research activities. He concluded with the methods of continued coordination with the Committee and the Department of Defense (DOD).

Dr. Sullivan asked whether the Committee can get updated abstracts on the newly funded studies. Dr. Kalasinsky confirmed that he included them in the Committee handouts. Dr. Sullivan noted that she was glad to see that they had improved to about 20% funding from the 10% funding of submitted grants previously. She also noted that it was encouraging that Dr. Kalasinsky reached out to work through resubmissions with researchers, and thanked him for that.

Dr. Golomb asked about follow-up funding, as she has heard that it is not being utilized. Dr. Kalasinsky stated that he could not explicitly discuss follow-up funding for specific studies, but that any studies that show promise the VA will follow-up on. Dr. Golomb noted that distinguishing what constitute promising differs greatly across the VA. Dr. Kalasinsky agreed.

Rev. Graves asked whether there was a mechanism for informing medical centers when VA is looking for research in specific areas such as Gulf War illness or is it more generalized. Dr. Kalasinsky noted that it was a two-step process: individuals will express interest in research, and then will be directed to the strategic plan for specifics on research. It is not as specific as a specific drug for a specific condition, but rather "drug trials for these conditions".

Dr. Sullivan asked for the RFA's so that the Committee can see exactly what the VA is looking for. Dr. Kalasinsky stated that they were updated once a year. They are using the same RFA for the April deadline as they will be on the September deadline. He will send the new information to Dr. Sullivan.

Dr. Crawford asked if there were any plans for interagency plans for research in Gulf War illness. Dr. Kalasinsky stated that they would like to do this moving forward, but they are waiting for new CDMRP leadership to come onboard before they move forward with this.

Dr. Steele wondered whether there were efforts to recruit Gulf War researchers into working in the VA so that they can be funded for research through them. Dr. Kalasinsky said that he had suggested that to a few people, but that this is a more localized decision, this is not a standardized process. Dr. Golomb noted that the non- five-eighths employees (less than) have not historically been able to gain VA funding in Gulf War research. Drs. Kalasinsky and Davey noted that this has changed, that in certain cases there is more flexibility. Drs. Golomb and Klimas noted the inflexibility because having the MD credentials prohibit this, as they are clinically affiliated with the VA.

Dr. Ondra asked whether there was an overarching ORD environmental exposures group that the Committee would be a part of that could help to engage researchers. Dr. Davey noted that the research takes place at the actual VA centers across the country. There are no research centers of excellence specifically in environmental exposures. Dr. Ondra encouraged the development of something like this. He also noted that it seems as though people feel as though the VA is uninterested in Gulf War illness or research, and he wanted to make it clear that the fact that it has been twenty years and there is still not cured should not really come as a surprise. He noted that the people he knows at the VA are not only interested, but are fully invested in Gulf War illness and research.

Chairman Binns asked whether there was an RFA or an affiliated program with the Consortia. He wondered whether this had moved forward yet. Dr. Kalasinsky noted that this was not yet done, and that it is planned since the Consortia has gotten off the ground. Dr. Jesse noted the importance to engage patients throughout the whole process. He stated that this Committee does that, and they can help by being extremely direct in the types of research that they want the VA to fund. Dr. Jesse noted mitochondrial research, and that RFAs can be designed around this. The more direct the Committee is to address the research needs, the better the RFA designs will be from the VA.

## **The role of protein radicals in neuroinflammation as a model of GWI and therapeutic strategies**

**Dr. Michelle Block, Virginia Commonwealth University**

Dr. Block thanked the Committee for the invitation to present at the Committee meeting. She noted that she would be discussing the role of protein radicals in neuroinflammation as a model of Gulf War illness and therapeutic strategies. For presentation slides, please refer to **Appendix A – Presentation 4**. This model involves microglial activation and its interaction with pathogens, environment, and disease. She began with a brief snapshot of Gulf War illness. Gulf War illness was a devastating multisymptom illness, in which symptoms are delayed and persistent, and affect approximately one-third of the 1990-1991 Gulf War veterans.

What was not known were the exact specific causes, although there were very strong hypotheses; the pathobiology has been poorly understood, and markers and treatments have been elusive. Many GWI symptoms have been linked to peripheral and central inflammation, including headaches, pain, impaired learning, gastrointestinal dysfunction, memory deficits, behavioral impairments, and chronic fatigue. So she decided to ask why the immune perturbation was chronic. It is known that activated microglia are a source of chronic inflammation and oxidative stress. Environmental exposures and other physical stressors can cause inflammatory triggers with microglial activation and also direct neurotoxic insults resulting in neuronal death or damage. Both scenarios can cause a self-perpetuating cycle of reactive microgliosis and neurotoxicity.

Her prior work with Parkinson's disease showed that inflammation-mediated neuropathology was both delayed and progressive. With chronic microglial activation, a disrupted homeostatic balance was noticed. With a pro-inflammatory response, there was an increase in microglial activation, which was amplified and became chronic. Dr. Block then discussed that NOX2 was a common mechanism of microglia-mediated neurotoxicity in a number of studies with microglial activators or neurotoxins. Microglial reactive oxygen species (ROS) were found to be detrimental through two distinct mechanisms, the first mechanisms caused direct neuron damage or impaired function, and the second mechanism caused damage through the amplification of pro-inflammatory genes and chronic release of proinflammatory cytokines. In inflammation, nuclear factor-kappaB (NF-kB) in the p50 protein pathway had dual roles including initiating pro-inflammatory gene expression, and repressing the inflammatory suppressor mechanisms.

As a result, Dr. Block's work focuses on the multiple hit hypothesis of Gulf War illness, which was that many potential causes, exposures, and stressors may act in synergy for persistent impact and chronic health symptoms. These combined exposures (physical stressors, oil well fires, cholinergic and related neurotoxicants, depleted uranium, vaccines, sand and particulate exposures and infectious diseases) could have resulted in chronic peripheral immune perturbation and chronic central nervous system (CNS) microglial activation. The chronic

activation could also lead to priming of future immune responses which lead to the peripheral and CNS symptoms giving way to a therapeutic window with Nitrogen oxide-2 (NOX2) inhibition. Dr. Block hoped to eventually translate these findings into a treatment approach targeting NOX2 inhibition to un-perturb the peripheral immune response, reset the chronic neuroinflammation and get rid of the chronic microglial response. Dr. Block concluded her presentations and asked for questions.

Dr. Klimas asked whether the in-vitro model could be used to test potential treatments. Dr. Block stated absolutely, and that they are already doing so. Dr. Steele asked for clarification on whether the NOX2 inhibitors are actually establishing a treatment for persistent inflammation or if they are preventing it. Dr. Block replied that she had seen both. They were working to try and modulate a response where the inflammation was stopped; she wants to be able to reset this. Dr. Steele noted that some of these veterans had seen these symptoms for twenty years. Dr. Block replied that these chronic reactions can be stopped, where the trigger of inflammation can be turned off.

Dr. Sullivan asked whether they had any specific pharmacological agents they planned to use. Dr. Block replied that they had been working with one with some individuals and were looking for other inhibitors that were more effective. She noted that she could not state explicitly those agents they had been considering.

Dr. Block noted that for the reactive oxygen species (ROS) to have an effect, it has to be extremely close to whatever it would be affecting. When it did have an effect, it was next to an extremely sensitive cell. Dr. Jesse thanked Dr. Block for her exciting presentation. He noted the extreme reactions that people with these cell sensitivities see, and noted that this was key in her presentation. Dr. Steele asked what else might be used to trigger a response as Gulf War veterans had multiple exposures. Dr. Block noted that it wasn't the trigger that they were using that was the focus, but the activation of a response, which was often a more distinct response than normal in GWI, and seeing where this response was coming from.

Chairman Binns asked whether mast cells were involved. Dr. Block stated that they could be, many cells were ignored in the study. The group just pulled out as much noise as they could in the reactions and started from there. Dr. Sullivan asked whether they were looking at other pesticides besides chlorpyrifos. Dr. Block noted that they had considered them, but that they were trying to stay out of other research groups' territories, but that they would love to collaborate. Dr. Golomb asked whether they would consider using an inhalational exposure. Dr. Block replied that they had looked at inhaled toxicants, they just had not in the funded study presented.

## **Efficacy of fluoxetine and resveratrol for easing memory and mood dysfunction in an animal model of GWI**

**Dr. Ashok Shetty, Central Texas Veterans Healthcare System**

Dr. Shetty thanked the RAC Committee for inviting him to present at the meeting. He presented his findings on the efficacy of fluoxetine and resveratrol for easing memory and mood dysfunction in an animal model of Gulf War illness (GWI). For presentation slides, please refer to **Appendix A – Presentation 5**. He began with a brief synopsis of GWI, including the affected population, symptoms, potential causes, and multiple chemical exposure hypothesis. Through his research, he worked to generate a rat model of GWI. This was done by exposing rats to low doses of pyridostigmine bromide (PB), N,N-diethyl-m-toluamide (DEET), and permethrin with or without five minutes of restraint stress for four weeks.

The pathophysiology included cognitive and mood dysfunction associated with hippocampus pathology, decreased levels of hippocampal neurogenesis (birth of new neurons), partial loss of hippocampal principal neurons, mild inflammation, and oxidative stress. The therapeutic strategies examined included administration of the antidepressant fluoxetine or the anti-inflammatory and antioxidant compound resveratrol.

Dr. Shetty assessed behavioral impairments in the rat model of Gulf War illness, which included swim speed, learning, swim path efficiency, and memory retrieval on the Water Maze Test. Rats modeled with Gulf War illness performed poorly on most tests compared to their non-GWI modeled counterparts. In the additional behavioral impairment tests, including object location and novel object recognition tasks, similar results were seen with the exposed animals performing more poorly than the unexposed animals. Additionally, mood impairments showed decreased mood in GWI rat models. In the GWI rat model, hippocampal neurogenesis impairments, stem cell proliferation impairments, and hippocampal neuron loss were found.

With regards to the fluoxetine treatment, the research design centered on adult rats about four months old, chemical exposure was provided, followed by either the fluoxetine or vehicle (placebo) treatment, with a month waiting period before behavioral tests and euthanasia/histological analyses. Results suggested that fluoxetine improved spatial learning and memory function in a rat modeled with Gulf War illness. Additionally, it normalized object location memory function, novel object recognition memory function, reduced depressive-like behavior, improved net hippocampal neurogenesis, and enhanced generation of new dentate granule cells in the hippocampus. Dr. Shetty discussed that increased neurogenesis in the hippocampus at least partially underlies the beneficial effects mediated by fluoxetine. He stressed the need for further studies, however, because other mechanisms that may also be involved.

With regards to the resveratrol treatment, research design centered on adult rats about three months old. They were exposed to chemicals, given a month's waiting period, dosed either with the resveratrol or the placebo, waited two months, and were given behavioral tests followed by euthanasia and histological analyses. Dr. Shetty found that resveratrol treatment to rats exposed to Gulf War related chemicals and stress improved hippocampus-dependent spatial learning and memory function. It relieved hippocampus-dependent object location memory dysfunction. It normalized novel object recognition memory function. The treatment also reversed mood dysfunction, and increased neurogenesis, suppressed inflammation, and modulated oxidative stress in the hippocampus. As a result, it was likely that the resveratrol treatment contributed to the beneficial effects seen in the study. He gave thanks to the Committee, and asked for questions.

Dr. Klimas noted that it seemed like the treatment dosing was very high, and asked how Dr. Shetty developed his study parameters. He stated that they had been working on this group for a long time, starting with significantly lower doses and increasing incrementally for resveratrol. If dosing subcutaneously, the dose presented was most effective. Dr. Crawford asked about the significantly enhanced differences noted when stress was added to the chemically exposed group of animals. Dr. Shetty stated that he had published a paper with regard to stress, which showed that increasing stress increased the rate of symptoms in his animal models. Dr. Crawford asked for how long these results lasted. Dr. Shetty noted that they had not gone extended periods of time, but had seen similar results at six months post-exposure in his rat model.

Dr. Jesse asked Dr. Shetty whether he understood or could explain why the mechanism of stem cells being present, but not activating, existed. Dr. Shetty noted that it was the added stressor that they believed altered the hippocampal cell neurogenesis resulting in none of the stem cells being destroyed but resulting in them just not becoming activated. Dr. Golomb asked that they be cautious of interpreting animals moving less or moving slowly as being depressed, because this is indicative of other causes as well. She wanted hesitation on this classification because it could potentially add to the stigma of Gulf War illness being psychologically based. Dr. Shetty confirmed that these were absolutely valid concerns and were important to watch for.

### **Public Comment**

Chairman Binns asked for public comments, asking that those on the phone speak first, with those present at the meeting to follow.

Dr. Borchund spoke first for public comment. He served for the U.S. Army from 1991-1993, as the medical consultant for nerve agent exposure. He was witness to the demyelination and multiple sclerosis that was seen from exposure to the nerve agent sarin. During his service, he was not deployed to Iraq, was not given PB, and was never given the anthrax vaccination. He

stated there was data on the organophosphates and the nerve agent drops, but this information was not readily available. After inspections of these toxins, he developed total paralysis in his leg and lower back. He was sent to rehab, where he was injected with steroids, and recovered over time. After treatment, he experienced bladder difficulties and leg weakness. Treatments did not work. The only thing that seemed to work was steroids. After his service, he never had pesticide exposure or the like to explain symptoms. He has witnessed much of the VA trying to push stress as the major component. Stress should not be thought of as the reason for Gulf War illness. He was close to bedridden. He had two spinal taps. He suffered from demyelination, and has had relapses since treatment. The steroids were the only thing that seem to work. He wanted to know what happened to the environmental data. Anyone deployed had the potential to develop neurological disease; he believed this should be a presumption.

Jack Halcom followed with his public comment. He was diagnosed with multiple psychiatric conditions as a result of his service from 1990-1995 in the Persian Gulf. He was also diagnosed with degenerative disc disease, digestive disorders, and upper GI issues. These diagnoses came much later than they should have. He received all three anthrax shots, but this was not noted in his medical record anywhere. He took the Gulf War registry exam in 2012, but had yet to hear from the VA regarding it.

William Foosie followed with public comment. He had a document that was unclassified regarding the first surveillance; document 12 over sequence 18. This documented the need for soldiers to take ciprofloxacin (cipro) and pyridostigmine bromide pills (PB). There was a short time later the order to halt this treatment for soldiers. They had 42 days of cipro. He had just come across this documentation, which he had been trying to prove since 1991.

Daryl Uring spoke next for public comment. He served from 1982-2003 and was a part of the Gulf War. He had Gulf War illness, and served in the Gulf numerous times over the course of active duty. After leaving the Gulf, he broke out in rashes over his shins. He along with his crew members experienced sick flu-like symptoms and meningitis. Since his return from the Gulf, he has experienced unrelenting pain in joints and memory loss. VA said they would help with his issues related to service, but provided extremely poor care on countless occasions. Veterans should not have to fight for these treatments like they have to. He has been called a liar on many occasions, and thought that this was unacceptable.

The next caller was Marsha Young who served in Desert Storm as a nurse. She sat on the Board of Advisors on the Kansas City VA. She found that the lack of communication at the VA is a substantial problem. Research is not being filtered down to the front workers at VA. Ms. Young suffered from severe headaches, seizures, joint disorders, cognitive impairment, gastroesophageal reflux disease (GERD) issues, night sweats. Her issue was that too many VA people do not know what is going on. She would like for the Committee to be given the chance to do the work they were set up in order to do.

Dr. Golomb at this time asked the veterans who spoke over the phone to send their contact information or email to the RAC office at [rac@bu.edu](mailto:rac@bu.edu), and she would contact them.

Mr. Foosie asked to comment one more time. He would like to see cipro on the list of toxic exposures, because the Marines and Army were instructed to take this. Dr. Golomb noted at this time that the only study she knows of with regards to looking at cipro as a risk factor did show a statistically significant relationship even in a fully adjusted model. A number of individuals have contacted Dr. Golomb who have taken cipro and present with very similar symptoms, although not identical.

Chairman Binns at this point moved to the audience members of the public who wanted the opportunity to speak.

Steve Hohman was the first to speak; he was a Gulf War veteran. He was deployed in August as a part of the 82<sup>nd</sup> airborne in Desert Shield. He was exposed to pyridostigmine bromide pills, and a shot which he cannot recall and never went into the record. He was exposed to sand storms, oil well fires, mustard gas, sarin, and sand fleas. He did not feel prepared for all of this. Upon his return from the war, he tested positive for tuberculosis (TB) and was subsequently treated. He ran a high temp of unknown origin twice, gained weight, experienced chronic fatigue, rashes, and heavy dandruff-like symptoms. He suffered from neurological problems, including seizure-like symptoms; no one could figure the source out. He suffered from anxiety related to uncertainty and not knowing how or if he would get better. He found out a few years prior that he was no longer on the Gulf War registry, despite the fact that he had been after his return from the war. Mr. Hohman noted the difficulty veterans have finding out which research is going on and where. There is a need for a more cohesive database for Gulf War research. He was told there was a lot of VA incompatibility; records at one VA medical center may not necessarily be transferred to another medical center within the VA.

Dr. Klimas noted that these records have made strides in transferability, and are actually very easy to transfer now.

Mr. Hohman noted again the difficulty in accessing research. He only heard of the Committee through Facebook. As he is on the registry, he should not have had to hear about it this way. He struggles in working through his multiple ailments, and has difficulty because he cannot contribute to society as a working citizen as the rest of the public can. He recommended having a veteran representative per state, so that the various inputs are accounted for. This information needs to be disseminated in a better way. Mr. Hohman was from Fayetteville, North Carolina.

Mike Jerrett, a retired US army Gulf War veteran spoke next. He was Army transportation. After the war, he was back about a year or so, when began experiencing symptoms. He had some sort of trigger, and that was when everything started. He experienced chest pains, severe diarrhea, panic attacks, and headaches. His physicians could not find anything wrong, and recommended that he see a psychiatrist. He suffered from irritable bowel syndrome (IBS), and severe stomach problems. He got to a point where he could no longer be a member of the Army. He requested early retirement after that. He tried to keep a positive attitude, is not trying to be negative. Being present at the meeting and hearing what has been discussed has given him hope. Upon his first treatment at the VA, he worked with a very good physician. Still, they didn't know what he was dealing with. The physicians were frustrated, and did not know how to deal with Mr. Jerrett's ailments. He was told bottom line that he has an unknown disease process. He had been going for magnetic resonance images (MRI) every few years, but results have not been helpful in diagnosis or treatment. In February of this year, he received another MRI, and he was told this screening could not be compared to the previous one. This scan revealed frontal lobe atrophy; reports suggest a congenital issue, or neurodegenerative changes. His primary care physician (PCP) is trying to refer him to studies, but is having substantial difficulties. Mr. Jerrett asked to provide a few recommendations. First is for better communication within the VA. Second was asking for each state to have at least one physician well trained in GWI. Third was in traveling to receive treatment research, he thought that travel and lodging for these necessary costs should be covered. Mr. Jerrett is from Virginia.

Mr. Binns asked that, if any remaining individuals had unique aspects and recommendations, to share those, because of given time constraints for the first day's meeting.

Mr. Glenn Stewart spoke next, he is a veteran advocate who served in Desert Storm/Desert Shield. His symptoms included IBS, fibromyalgia, chronic fatigue syndrome (CFS), neurocognitive dysfunction and sleep apnea. He submitted multiple claims for these ailments, all of which are considered presumptive for GWI. He has been denied time after time. He has been working on appeals since 2012, none of which have been resolved. While the VA central office may have issued these as presumptives for GWI, they are still not considered as such at the local VA level. This was a failure of the local VA to be educated on these presumptives. He was able right after the war to make copies of his personal medical records, because he felt something was off. He submitted all of the records to benefits, provided pictures as evidence to prove that his symptoms were not normal. All of these submissions found no success in reversing the denial of claims. He has placed all of his communications and evidence on a site on the internet so that the public can see the troubles faced by Gulf War veterans.

Mr. Stewart has gone back to testimonies over the years since the Gulf War, and the same thing is being said year after year. From 1996-2012, he saw nothing, but in 2012 he finally began to see some progress. He spoke of Timothy Gabriel, an honorable veteran that suffered horribly

from GWI, and faced adversity from the VA until the day of his passing in May of 2013. He left a wife, and young daughter, and many brothers behind. In closing, he is new to advocating. He recommended a few changes. First, the Committee should not report to the VA nor should the Committee members be appointed by the VA. The VA has the power to ignore the Committee with these powers in place. Second, the Committee needs to be given more power to do their job. They should report directly to the House on their budget, make recommendations to the House, which will be then passed onto the VA. Third, research needs to be made easily available online, so that veterans can put in personal requests to participate in the current Gulf War research being conducted. Fourth, the local VA physicians need to be educated more properly on current Gulf War illness treatments. Lastly, the push of the use of the term “chronic multisymptom illness” (CMI) must be stopped. “Gulf War illness” needs to be used. Mr. Stewart came from Oklahoma.

Former Committee member Mr. Steve Robinson spoke next. He thanked the Committee and veterans first. He’s seen some good and some bad; he believed that some battles were still being fought to that day that were being fought in 2002. Mr. Robinson mentioned the recent Agent Orange presumption notice, noting that it was almost 40 years after exposure. Veterans were skeptical because the VA seems to have pushed back on every piece of progress that veterans have made. No one can be blamed for being skeptical of the VA. The Committee existed to evaluate and detect performance and behavior on behalf of the VA. The Committee is supposed to be able to protect veterans’ rights, and to inform research, science, and policy with the veterans’ interest in Gulf War illness. He hoped that the RAC can reestablish and maintain their abilities to do what they are supposed to be able to do. He hoped that with the same goal in mind, everyone can work together to ensure that everything that can be done for the veterans is in fact being done.

Former Committee member Mr. Anthony Hardie spoke last for public comment. He thanked the Committee and veterans who traveled and called in to the meeting. He reminded his fellow veterans that they should keep fighting, keep putting one foot in front of the other. The Committee has been committed to exceptional work, publishing several reviews, a number of reports, and multiple appearances in front of Congress. The work that has been done has profoundly influenced the understanding of Gulf War illness, but more importantly has also influenced scientific understanding and progress. The development of the Strategic Plan was a sound map by which science and research can be developed, with the VA, the Committee, and other outside scientists working together. It was disappointing for him to see the Committee stripped of their abilities to make progress. He extended his immense gratitude to the Committee in their unwavering effort to help Gulf War veterans. Research has shown that treatment can be developed and those suffering from Gulf War illness can be helped. Two decades after the Gulf War, the VA continues to provide little meaningful or measureable action to veterans. The VA’s failure to implement their part of the strategic roadmap strengthens the belief that any solution to be found in Gulf War illness will be done without any help from the VA. If the VA’s leaders are

serious about helping Gulf War veterans, providing everyone with clear evidence of the implementation that has been planned, is necessary. Until then, Mr. Hardie stated that the VA needs to show it is serious with actions, because words are not enough.

Mr. Binns thanked the veterans for their comments, thanked all of the individuals present at the meeting, including especially those veterans that traveled on their own dollar to be present. The meeting would reconvene the following morning.

## **DAY 2**

Chairman Binns called to order the second day of the Committee meeting, opening the floor to Dr. O'Callaghan, to begin the 'how to discussion' for GWI animal research.

### **Committee and Panel Discussion: 'how to discussion' for GWI animal research**

**Dr. James O'Callaghan, Committee member**

**Dr. Kimberly Sullivan, Associate Scientific Director**

Dr. O'Callaghan made a brief presentation. He noted that the direct examination of tissues, especially in the brains of animals tested, has been a key advantage of animal models in research of Gulf War illness. For slides, please refer to **Appendix A – Presentation 6**. Using animals, the persistent molecular, cellular and functional effects associated with individual and combined exposures and outcomes encountered in the Gulf War can be evaluated in a number of different ways. Based on this research, specific hypotheses can be tested, in addition to the fact that therapeutic interventions can be evaluated.

He noted some "how to" uses of animal models of Gulf War illness. In toxicology, for example, research can show how the dose 'X' hazard can equal risk, as researchers have not become fully informed on dose or hazard for Gulf War illness. In research, exposures should mirror the potential culprits of GWI. These should not be done just alone but also in combination, as this was likely to have been the case in the Gulf War, for example sarin, PB, permethrin, DEET, chlorpyrifos, dichlorvos, etc. Additionally, contributing factors should be considered, for example, gender, physiological, and environmental variables.

Gulf War illness has been persistent over decades up until the current day. In testing animal models, they should reflect this persistence, and not just the effects of acute exposures. Dr. O'Callaghan noted that while this sounds challenging, it is important to consider persistent effects research has accepted and studied, including learning and memory, drug tolerance, addiction, seizure, susceptibility, or sensitization to drugs. Animal models should also be used to consider the testing of potential therapies of Gulf War illness. Before turning to open discussion, he noted with the translational value, regardless of the endpoints examined in a given Gulf War illness animal model, consideration should be given to sample blood with the aim of biomarker development for comparison to blood data from ill veterans.

Dr. Steele asked Dr. O’Callaghan whether he could clarify on behavior in animal models, because the translational value is much more difficult than in humans. Dr. Shetty answered that the animal behavioral models were the gold standard. There were ways to measure behaviors, while there are differences because animal cannot vocalize their pain, which animal models present in different ways than just vocally. It is important, given limitations, to use several tests to try and gain the most specific and accurate insights into behavioral changes. Dr. Steele asked whether other systems were affected that they could see. Dr. Shetty noted that his treatment rats experienced bad skin rashes post-exposures. Dr. O’Callaghan noted that there were multiple ways to test for multiple modalities in animal models. Dr. Klimas asked how fatigue was measured. Dr. Shetty replied that they had not specifically measured for fatigue. Dr. Golomb noted that some of those measures that indicated depression may also be used to measure fatigue.

Dr. Klimas noted that there are certainly individuals that are too depressed or fatigued to eat, but that the measures used in the eating test to measure depression rather than fatigue were extremely different, and may get confused. Dr. Shetty noted that the rats were fasted for 24 hours and were at peak hunger levels, which given the small area and direct route to food helped to divide between depression and fatigue. Dr. Crawford noted the need to be hesitant in the interpretation especially in animal modeling, where symptoms may be confused, and interpreting the results with regards to the fact that they were rats, is important. Dr. White echoed these sentiments, especially noting that behavioral effects of brain damages were often confused with psychogenic causes. The terminology thrown around has not been carefully considered, and affects the animal side of the research field in a large way. Imaging may also be a good consideration in animal models.

Dr. Sullivan asked Dr. O’Callaghan the exposure models used. Dr. O’Callaghan noted the model is diisopropylfluorophosphate (DFP), which was a surrogate substitute for sarin. They did not use sarin, because it cost about \$50,000 for a 20 mice dosage. This has been combined with PB and DEET. They’ve used lipopolysaccharide (LPS) as the positive control for the animals. They also use exogenous corticosterone as a substitute for high physiological stress. This exacerbates the effects of using DFP alone.

### **‘How to discussion’: GWI case-criteria and assessment of health outcomes in Gulf War veterans**

**Dr. Lea Steele, Committee member**

Dr. Steele began her ‘how to discussion’ by providing a brief background on Gulf War illness research. For presentation slides, please refer to **Appendix A – Presentation 7**. She highlighted the needs for an evidence-based case definition, and optimized, consistent health measures and methods. She highlighted the efforts to research health measures and outcomes over the years, in studies and workshops starting in 1994 until the present day. The presentation covered case

definitions for GWI, symptom assessment in Gulf War veterans, and other health measures of importance.

Dr. Steele described post war illness in 1990-1991 Gulf War veterans, how it was first an unknown illness referred to in multiple ways. Over time, the problem persisted, that there was still no generally accepted case definition for GWI. Research has been conducted, millions of dollars spent on research, much of which uses no or differing case definitions. The studies, however, were able to identify a consistent set of symptom domains, which fit in to six different categories: pain symptoms, neurological symptoms, fatigue symptoms, gastrointestinal symptoms, respiratory symptoms, and skin problems. At the point of the meeting, there were eight different GWI case definitions, and four other methods used to classify GWI “cases”.

Dr. Steele discussed that which made a good GWI case definition. She discussed the need for a good case definition to have both specificity and sensitivity. Lacking either or both can undermine any study designed to identify effective treatments or determine biological differences between GWI and health controls. In the best case scenario it would interfere with study results, in the worst case scenario it would yield erroneous results. A good case definition should distinguish individuals with the condition from those who don't have it. The case definition identification was in the VA Gulf War Research Strategic Plan of 2013-2017. The process includes a review of the literature, a comprehensive analytic effort, and an expert consensus process. There are a number of major considerations in optimizing research case definitions. The Committee made a number of recommendations regarding the GWI case definition in their 2014 RAC Report, reiterating the importance of using the process outlined in the strategic plan in its development. It additionally called for the recommendation that VA use the term Gulf War illness for this condition. In 2014 the IOM released a Chronic Multisymptom Illness (CMI) case definition report. The recommendations by the IOM included that the VA use the Center for Disease Control (CDC) and Kansas case definitions because they capture the most commonly reported symptoms. They recommended the VA systematically assess existing data to identify additional features of chronic multisymptom illness to produce a more robust case definition, and recommended that the VA use the term Gulf War illness rather than chronic multisymptom illness. Dr. Steele raised the issues with specificity that could arise, and that the consideration of exclusionary criteria in defining Gulf War illness is very important.

The impact of using different Gulf War illness case definitions on research results could have a large impact on the research comparability. Research would be evaluated analytically in multiple ways, when broader or narrower GWI case definitions are used on different studies. Additional health measures of importance included symptom assessment in Gulf War veterans, and the health measures used in health studies of Gulf War veterans. These included the high priority of identification of objective measures with sufficient sensitivity and specificity to use to diagnostic purposes, and the use of objective biomarkers. Dr. Steele examined a key question, which was

how to best measure treatment response and outcomes. The optimal treatment outcome measure would be the change in biomarker pre-vs. post-treatment.

In summary, accelerated progress in Gulf War health research requires the use of better, more consistent methods and measures. Until diagnostic biomarkers are available, advances in GWI research would be greatly facilitated by establishing an evidence-based, widely accepted case definition for Gulf War Illness. It has been important to assess symptoms systematically, and to use standardized instruments to assess functional status, symptom domains of interest for the particular study question. Overall, the Gulf War research effort would benefit from testing and validation of particular instruments and measures for purposes of studying Gulf War illness. She thanked everyone for the opportunity to present.

### **Public Comment**

Chairman Binns opened up the floor for public comment during the remainder of the Committee meeting. He asked that veterans take care to ensure they discuss symptoms at the onset of the illness because it would be very important to the Committee. He held the floor for a quick comment by Dr. White.

Dr. White wanted to say two quick things. First, she discussed the enormity of effort that went into the work. She noted that it was the veterans that kept her going the nights and weekends that it took working on the report. She thanked them for making the huge effort to be present for the report presentation earlier that morning. She also received some good news that morning from an important journal asking for her to summarize the paper for the journal, which will be a peer reviewed journal.

The first speaker was Mr. David LaShell, who was with the United States Air Force during the Gulf War. He thanked everyone that was present in the audience and everyone on the Committee. He stated that he was a very energetic, non-smoking, fit person prior to the Gulf War. After returning from the Gulf War, he experienced fatigue, muscle tone loss, and pain. The harder he worked to turn this around, the worse the pain got. Mr. LaShell began working upon his return, but the pain and muscle deterioration became worse. The headaches became very frequent. He was losing the ability to keep communication up with his family. He then decided to get help for this. In 2004, he went to the Dayton VA, was seen by a social worker nurse, who sat and listened to him. He kept working through the pain, and learned about Gulf War syndrome in 2006. He submitted his claim in 2009, received most of it in 2011. He was at that point unemployable, which he does not like. He told veterans that this could be overcome.

The Committee is the biggest help the veterans have. He has had great experiences with his VA healthcare. He wished it could be used as a model for other veterans. His PCP was very interested in his illness, and helped in every way that he could. From 2009-2012, using Dr.

Golomb's report one page at a time, the PCP worked out a prescription level that Mr. LaShell could work with, that keeps him much more comfortable, cognitive, and functioning. He recalled an anecdote about a patient presenting with symptoms and going through treatment in very much a similar way that Gulf War veterans had. He has begun counting more good days than bad days. The PCPs were willing to learn, but were also limited in their resources. If there was a communication set up from the VA medical centers to the central office, a whole lot would get done with regards to Gulf War treatment. He stated that it was time for the VA to put everything behind them and start working with the Committee and with the veterans, and this would help progress. He thanked everyone for their effort and their time.

Dr. Klimas thanked Mr. LaShell for his statement. She mentioned a study of where they were trying to find these "gold star" PCP providers, and asked that he please send their information to Dr. Klimas, so that they can look to see the work that they are doing and their successes.

Ms. Consuelo "Connie" Gonzalez spoke next for public comment. She served in the Gulf War. She did not receive any pre-deployment physicals, but was pregnant and unaware of this. She received a number of vaccinations prior to deployment. She also took the PB pill, and within a few days, she was experiencing stomach issues and severe cramping. It was after a hospital trip due to this that she found out about her pregnancy. She was being shipped back to Germany when she was present for the incoming Scud missiles. She did not have her gas mask on. After her return to Germany, she experienced extreme fatigue and hair loss. After her son was born, the symptoms presented more obviously. She had nausea, facial rash, dermatitis, bronchitis, diarrhea, body pains, and depression.

Between 1991 and the present, she has been diagnosed with fibromyalgia, chronic pancreatitis, chronic gastritis, gastro inflammation, neuralgia, major depression, panic and anxiety attacks, IBS, gastro-reflux disease, and migraines. What has not been diagnosed is the hip and buttocks pain, tingles in the tips of her fingers and feet, jaw pain, and Epstein bar virus. Body jerks in her hands, arms and legs, muscle twitching, vision problems, eye socket pain, shortness of breath, chest pain, and rapid heartbeat have been constant. Treatment that has helped includes massages and water pressure on the body. She had extreme difficulty getting an excuse letter for work declaring that she has disabilities. She would also have liked memory loss medication, because she has become increasingly forgetful since her return from the Gulf War. She also noted that for the Job Accommodation Networks (JAN), Gulf War illness needs to be in there, because it is not, and she needs accommodations for the workplace. Some of her disability claims were service connected partially at 30%. Because of the Gulf War illness, she has experienced extreme difficulty with work harassment because she has not been able to file disability successfully. She was retaliated against in the workplace for her disability claims. She wanted to thank the Committee for all of their hard work; she appreciates it.

Mr. Keith Nording spoke next. He served in the Gulf War. He went to sleep one night while deployed, woke up with limited vision and painful headaches, which went on for three days. These were a result of chemical bombs. During one evening, chemical alarms went off, but they were told they were faulty. They realized some years later that chemical bombs did in fact go off near them. Since his return from the war, he experienced ongoing health issues. He experienced knee deterioration, joint problems, severe stomach problems, severe gastritis, cannot walk very far without pain, burning and tingling in arms and legs, and diastolic dysfunction. He was told he had to break all of his health problems down and apply piece by piece for claims. He received disability for some, but did not for many other health problems. The VA has got some great people, but a lot that are not so great. There are a lot of discrepancies from location to location. There needs to be information dissemination in a more meaningful way. Some physicians he had gone to had never ordered or never even heard of the 'pocket card' on Gulf War illness that the VA had. Mr. Nording has tried to be a patient advocate for those who are having difficulty with treatment. He has stood up for himself, and will continue to do so as long as he can.

The next speaker for public comment was Mr. Richard Murphy. He was in his early 20s during the Gulf War. He was not thinking about the onset of symptoms while deployed or immediately post deployment. He did try to look back to his records while deployed, but came across a memo stating that the records would be destroyed because there was no way to return the records to the United States. What he did access were his records upon returning from the Gulf War. He also held a diary while deployed and wrote some of his symptoms down. He experienced severe diarrhea, insomnia, hot and cold flashes, fatigue, small infections that took weeks or months to heal, weakness, headaches, and bladder issues. Was exposed to all exposures mentioned. Upon his return home, he experienced all of the mentioned issues plus acidic semen, uncontrollable rage, cognitive dysfunction, hypervigilance, PTSD, fatigue, nightmares, isolation, aversion to light/sound, risk-seeking behavior, depression, and rashes. The rash appears as tough water blisters that are very itchy, almost intolerably itchy. Many of these symptoms still occur presently to varying degrees. His last point, his youngest daughter was born without her 22q11 chromosome. He isn't aware of whether this is because of his exposures during the Gulf War; he hopes not. Dr. Lea Steele asked what year his daughter was born, to which he replied 1999.

Mr. Peter Greene spoke next for public comment. He served in the Gulf War and thanked everyone for the opportunity to speak. He is also a CDMRP consumer reporter. He was a part of the 101<sup>st</sup> airborne division at the Gulf War. They made excursions deep into Iraq two weeks prior to the beginning of the ground war. His migraine headaches began almost immediately following these flights, after taking PB pills and being exposed to gas fires. A little later, the bowel issues began, and his IBS started. He came to this meeting from Portland, Oregon. When he started getting very sick, he reached out to the VA for his care. He was met with ridicule, resistance, and dismissive physicians. At the mention of GWI, he was basically turned away. He dug deeper into this VA dysfunction, and realized that the problem was from the top of the VA, all the way

down. He was hoping to address Dr. Jesse at the meeting; unfortunately he could not be present. The veterans like himself attended the meeting to lobby Congress in addition to attending this meeting. Mr. Greene found out that Dr. Jesse had already been to Congress lobbying against the law helping out Gulf War veterans. He asked that if the Secretary cannot come down to talk with them, please find another position. He thanked everyone again.

Ms. Angela McLamb spoke next for public comment. She has discussed her illness since the Gulf War at other meetings. She has been ill since being exposed during the Gulf War to the anthrax vaccine and other toxic exposures in the environment. She spoke for all Gulf War veterans that suffered. All of these people need to be seen. All of these people are ill as a result of their service in the Gulf War. Ms. McLamb noted her mysterious illness since her return from the Gulf War. She feared being around young children and elderly for fear of making them sick. Her husband came down with rash, cognitive issues, weight loss, pain, diarrhea, communication skills; she was nervous that she made him sick. Her husband passed away January 2014. The doctors found out eventually that he had progressive cerebral degeneration, which was at the root of his problems, in addition to cardiac arrest. She participated in the Georgetown University Gulf War study, noting brain atrophy as being a common symptom. She has trouble operating things from day to day. She asked the VA to step up. They need to address the problems present, to be there for the veterans as they suffer through Gulf War illness. She asked whether decisions will be made that help veterans, or hurt veterans, as they have been in the past. She asked the VA to do the right thing. Everyone should work together, because otherwise it will only continue to get worse. No one should be left behind.

Ms. McLamb also noted a few points regarding the prior day's meeting. Dr. Victoria Davey noted her utilization of ill Gulf War veterans' medical records to inform reports. This is not true; physicians don't have this information. There needs to be more research regarding the issues females have come across as a result of their service in the Gulf War. There was some discussion of the Committee meetings becoming closed door; this cannot happen. For veterans with skin issues, she found that gold bond lotion and porter's salve helped the most for cracked skin. She recommended that VA make appointments for next visits in person if possible. She was diagnosed at one VA by a nurse practitioner, but told at her new VA that the old diagnosis was incorrect, and is going through a new series of tests. With regards to alternative treatment options, she would like to see Dr. Weil connected with her old physician that helped her out very much. She thanked everyone.

Dr. Klimas noted quickly to all those who recalled physicians who were very helpful in treating them. She asked that they go to the site "Patients Like Me" where individuals can write down what they are taking, and what has helped. There were only seven veterans from the Gulf War on the site at that point in time, but this would be very helpful for veterans to reference.

Mr. Sean McKnight spoke next, a Gulf War veteran and the legislative representative of the National Gulf War Resource Center (NGWRC). He noted he would be speaking on the presumptives that they would be trying to add including brain cancer, lung cancer, and migraine to Gulf War illness. He spoke of the many sick veterans that are a part of the NGWRC. Mr. McKnight would like an update on those conditions that scientific evidence has indicated as part of Gulf War illness. The request was a personal matter to him. His comrades never had the ability to seek treatment or benefits they should have earned fighting in the Gulf War. The demolition of the chemical depot Khamisiyah exposed many individuals to toxic chemical agents. Evidence shows that many of these exposures have led to increased rates of brain and lung cancers in veterans.

He also wanted to speak on a new treatment he participated in a few weeks prior to the meeting in California. The Brain treatment center out of Newport, CA asked a number of veterans to participate in this study. The treatment was in magnetic resonance therapy (MRT)/repetitive transcranial magnetic stimulation (rTMS). He spoke regarding his own experience with the treatment. As a result of the Gulf War, he had seventeen disabilities including chemical burns on the arms, joint issues, fibromyalgia, chronic fatigue syndrome, and loss of sleep. For the past twelve years he had been taking Ambien to get to sleep. After the first treatment, he had a full night's sleep. After the two more treatments, he could go to sleep and stay sleeping for the full night without taking Ambien. In the three weeks since the treatment, he has not needed to use Ambien. His anxieties and secondary conditions he felt had disappeared. This research changed his life. His relationship with his family and significant others are stronger. The treatment was a must for funding, he feels almost completely healed. People should pay attention to this. He felt wonderful. Mr. McKnight wanted to advocate this treatment for his brothers and sisters.

In his closing, he would have liked to see RAC meetings provide better online documentation for those members of the public, so that they have time to better understand and disseminate the research. David LaShell brought up the point that the VA stated that no new presumptives would be added to Gulf War illness. Mr. McKnight stated that as advocates, they needed to continue to present the evidence and research that these presumptives need to be added; advocates cannot stop trying to get around that. Mr. Bunker added that the NGWRC had gone to Congress already, and shown research to them, with which Congress agreed. The Secretary needs to keep being told by Congress. Chairman Binns also added that these recommendations have been sent by Congressmen specifically, and the Committee supported this recommendation.

Dr. Jesse and Chairman Binns were very interested to hear about this treatment, and very much look forward to following up on the treatment. Mr. Bunker noted that another Gulf War veteran who had been in treatment for a year was still experiencing the extremely positive "cure" like results. Veterans who had participated were from other wars and environments as well. Mr. McKnight looked forward to putting the Committee in touch with the center in California. Dr.

Sullivan asked that he keep the Committee updated on his treatment and his health. Mr. McKnight stated that he would do so.

At this point those who called in but did not have the opportunity to speak the day before were given the chance to do so.

Mr. Jason Blackwood spoke for public comment. He served in the Gulf War in the oil fields. He became sick after the Gulf War. He stated that he was not as optimistic as some of the other veterans. He did not trust the IOM, the Committee, or the VA. His question was, how was all of the information being talked about going to get down to the local physician and VA clinics, because that was where the problems start for the veterans. He experienced a number of instances where he was met with complete resistance.

Mr. Jose Valasquez spoke next; he was a Gulf War veteran. He pointed out the PB pills that he had taken, and the anthrax shots. His problems began when he received the second shots in the Gulf War. His injection site swelled up very painfully. His record had been missing since the Gulf War, but he did remember that.

Dr. Golomb asked to make sure that all veterans calling in please leave their contact information at the Committee email, [rac@bu.edu](mailto:rac@bu.edu).

Mr. Kip Schultz spoke next, called from Oklahoma and was a Gulf War veteran. He has seen a lot of the research dollars have not been spent for long-term cipro dosage from 42-50 days, which only the Marines were given. He asked to be corrected if he was wrong about this. Dr. Golomb noted that this is correct, but she had been contacted by individuals heading a research study looking at these symptoms and comparing them to symptoms in Gulf War veterans.

Mr. Darryl Gaines, a Gulf War veteran out of St. Louis spoke next. He spoke to his issues regarding the difficulty in getting treatment from his primary care physicians. He had been listed as having Gulf War illness, but his physician only asks him what he needs and wants, but is not prepared with the treatment he needs.

Mr. Dean Lumbe out of California spoke next. He had two brain lesions upon his return from the war, which had since increased to ten. He has been diagnosed with MS, fibromyalgia, and IBS. He wanted to reiterate the need for better treatment when they go into their primary care physicians. PTSD remains the primary focus of treatment when they seek care. He has found a lot of frustration from this, and seeing PTSD being pushed over some of the more serious issues veterans' experience.

Maj. Denise Nichols spoke next. She thanked the Committee researchers for all of the work they have done. She wanted to speak directly to the VA representatives present. She has attended the meetings regularly and advocates as much as she has been able to. Veterans attend these meetings out of their own pockets. She asked that the VA stop doing what they were doing to the Committee, trying to remove it of its significance. Maj. Nichols spoke to the trust and faith that have been broken by the VA. The Committee was making great headway, but over the past two years this has been halted at every turn. She's heard that claims are not going through day after day. The veterans need to be able to watch these meetings on the internet; they need to see the slides ahead of time; the VA just doesn't seem to understand what they should be doing. They need to be concerned about communicating the results of these studies, and cooperating with the veterans and the Committee when they can. The VA should stop being concerned with removing the independence of the RAC, and start being concerned with making sure that the veterans are getting the care and information they need. Maj. Nichols asked for a local meeting at Veterans Administration Medical Centers (VAMC) once a month, where veterans could speak to physicians about their health concerns. These types of things need to happen. Physicians needed to be trained better. The news features the VA has on their website really never are about the Gulf War.

Mr. Paul Sullivan spoke last for public comment. He worked on the legislation that created the Committee, and thanked them for all of the work they have been doing for veterans over the course of the last twelve years. He mentioned a book regarding the veterans exposed to Agent Orange, and discussed the similarities with Allison Hickey's statement that she can meet President Obama's desire to end the medical backlog as long as they add no new presumptives. The VA policy remains to be deny and delay. He has seen a lot of the Phoenix VA issues going on recently, and spoke to the issues of VA blocking efforts in research and progress. People still die because they are being denied care and being made to wait for what they deserve. VA does not have the money to give what is due to veterans. Veterans have been supporting the bill H.R. 4261, which calls for the Committee's charge and powers to be restored. He also recommended that the VA put a halt to actively blocking research efforts for Gulf War veterans. Until an illness becomes a presumptive, veterans do not receive free VA care. VA needs to become more proactive, by doing better research.

Mr. Sullivan walked into a VA facility a few months ago, tried to speak to a physician about Gulf War illness, and was recommended mental health care. He believed Secretary Shinseki had failed the veterans; he had abandoned Gulf War veterans. Physicians in the VA treating veterans still very much believe that GWI is a mental health problem. Mr. Sullivan asked the VA to train their physicians in Gulf War illness. He asked for the VA to stop interfering with the CDMRP. He thanked Chairman Binns for the amazing work he has done over the years. He has stood with the veterans in every way since the start of the Committee. Mr. Sullivan thanked the rest of the Committee for their work as well. He closed with the following: he has received credible

information that the VA is denying four out of every five Gulf War illness claims. This is unacceptable, and Secretary Shinseki and Dr. Jesse are responsible for this. The VA has sought to silence credible and honorable individuals. These people will not back away, despite the VA attempts to stop progress.

Major Nichols spoke to the studies running in New Jersey that veterans would like to participate in, but the VA will not support travel funding for these veterans. Research can go on more quickly if veterans are given the opportunity to travel to the research studies that are occurring around the United States. She also noted that those studies that have promising results, in addition to providing data, it would be helpful to repeat studies that need to see larger sample sizes.

Chairman Binns closed the meeting. He noted the fact that while the Committee allowed more time than normal for public comment, the Committee meetings are the only forum for these people to say what they need to say. He thought that there were many themes that came across that should be worked upon.

Mr. Robert Bossarte of the VA thanked the Committee and the veterans for their continued efforts, and wanted to express the VA commitment to rededicate efforts to research that provides scientific evidence that will help improve treatments to help veterans. They were grateful for the veterans and Committee for aiding them in showing the directions they should go in.

Mr. Ronald Brown asked where the funding dollars go that have not been spent. Dr. Kalasinsky noted that the dollars are all spent on research. ORD covers all of the projects and programs in that office. The entire amount of appropriations spent, are spent on research, whether it is Gulf War or not.

Chairman Binns adjourned the meeting.