Research Advisory Committee on Gulf War Veterans' Illnesses

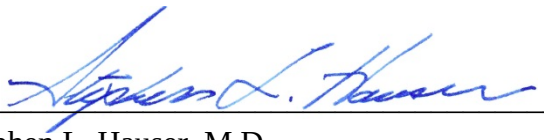
Committee Meeting Minutes
October 30, 2017

U.S. Department of Veterans Affairs
Washington, DC

Research Advisory Committee on Gulf War Veterans' Illnesses

Committee Meeting Minutes

I hereby certify the following minutes as being an accurate record of what transpired at the October 30, 2017, meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses.



Stephen L. Hauser, M.D.
Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

Attendance Record

Members of the Committee:

Dr. Stephen Hauser, Chair
Ms. Kimberly Adams
Mr. James Bunker
Dr. Fiona Crawford
Ms. Marilyn Harris
Dr. Stephen Hunt
Dr. Nancy Klimas
Dr. Katherine McGlynn
Mr. Jeffrey Nast
Dr. Stephen Ondra
Ms. Frances Perez-Wilhite
Dr. Scott Rauch
Dr. Caroline Tanner
Dr. Mitchell Wallin

Committee Staff:

Mr. Stanley Corpus
Mr. John Rukkila
Dr. Jon Van Leeuwen

Designated Federal Officer:

Dr. Victor Kalasinsky

Invited Speakers:

Dr. Douglas Drossman
Dr. Madhu Grover
Dr. Avindra Nath
Dr. Rachel Ramoni
Dr. Peter Rumm
Dr. Gary Wu

VA Personnel

Dr. Robert Jaeger, Office of Research and Development
Dr. Dawn Provenzale, Durham VAMC
Dr. Matthew Reinhard, DC WRIISC
Dr. Peter Rumm, Post-Deployment Health Services

Others in Attendance:

Mr. Brett Chaney, DoD CDMRP
Dr. Kristy Lidie, DoD CDMRP
Dr. Brian Walitt, NIH NINR

Veterans:

Ms. Kelly Degan
Mr. Hector Figueroa (telephone)
Mr. Chuck Gerard (telephone)
Mr. Paul Johnston
Mr. Kirt Love (telephone)
Mr. John Montecalvo (telephone)
Ms. Denise Nichols

Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses
Department of Veterans Affairs

LOCATION: Sonny Montgomery Room (Room 230)
810 Vermont Ave NW, Washington, DC 20420

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Agenda
Monday, October 30th, 2017

8:00 – 8:15	**Introductory Remarks**	**Dr. Stephen Hauser, Chairman** **Res Adv Cmte on GW Veterans' Illnesses**
8:15 – 8:45	**Discussion with VA Leadership**	**Senior Leadership** **Dept. of Veterans Affairs**
8:45 – 9:15	**Committee Discussion**	**Dr. Stephen Hauser, Chairman** **Res Adv Cmte on GW Veterans' Illnesses**
9:15 – 9:30	**Break**	
9:30 – 10:15	**The Gut Microbiome and its Metabalome in Health and Disease**	**Dr. Gary Wu** **University of Pennsylvania**
10:15 – 11:15	**IBS and FGIDs: A Conceptual Understanding and the Role of Infections and Microbiome**	**Drs. Douglas Drossman and Madhu Grover** **University of North Carolina at Chapel Hill** **Mayo Clinic**
11:15 – 11:40	**Gulf War Research Strategic Plan Update**	**Dr. Victor Kalasinsky** **VA Office of Research and Development**
11:40 – 12:40	**Lunch**	
12:40 – 1:25	**CFS & GWI Deep Phenotyping Study**	**Dr. Avindra Nath** **National Institutes of Health – NINDS**
1:25 – 2:00	**GWI & CFS Roundtable Discussion**	**Invited Guests and** **Res Adv Cmte on GW Veterans' Illnesses**
2:00 – 2:50	**Committee Updates and Discussion**	**Dr. Stephen Hauser, Chairman** **Res Adv Cmte on GW Veterans' Illnesses**
2:50 – 3:00	**Break**	
3:00 – 3:30	**Public Comment**	
3:30	**Adjourn**	

Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses
U.S. Department of Veterans Affairs

October 30, 2017
Washington, DC

Minutes

Introductory Remarks:

—Dr. Stephen Hauser, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

Dr. Hauser called the meeting to order at 8:18 am, introduced himself, and asked the committee members and other individuals to introduce themselves. Dr. Hauser described three major goals for the meeting: (1) diving deep into the topic of the gut microbiome and dysbiosis as well as understanding related best research practices in this area; (2) reviewing the details of the proposed study of chronic multi-system illness, or Gulf War illness, in collaboration with the NIH's deep phenotyping study for chronic fatigue syndrome; (3) finalizing the Committee's recommendations for 2017, which focus on two targeted and actionable areas: (i) pursuing a deep phenotyping study in partnership with NIH and (ii) further considerations for the coordinated system of centers concept the Committee recommended last year. Dr. Hauser then formally introduced Dr. Rachel Ramoni, Chief Research and Development Officer, CRADO, at the VA.

Discussion with VA Senior Leadership, Dept. of Veterans Affairs:

— Rachel B. Ramoni, D.M.D., Sc.D., Chief Research and Development Officer

Dr. Ramoni addressed the need for working together to characterize Gulf War illness, "in order to identify the cause, or causes, of this condition or some way to treat it or at least to diagnose it." She said the VA needs to, "do a very deep characterization of individuals with Gulf War illness," and make these data broadly available, in a de-identified manner, to researchers and as many people as possible not only to be transparent but also to have them look at these data, work on these data, and try to find solutions.

Dr. Ramoni emphasized the importance of coordination and to ensure that all the major tests to conduct are included because this is going to be a very intensive study. She said, "this far out from '91, we don't just want intriguing findings, we want conclusive findings for our Veterans."

Dr. Ramoni stressed the use of roadmaps in the VA Office of Research and Development (ORD). She said she strongly believes in investigator-initiated awards and that Gulf War illness may well benefit from having an intentional sequence of studies to get to a defined outcome. She suggested progressing to coordination of funding where a road mapping effort is especially useful to, "convene all of the groups together and decide who's best positioned to fund what study so that we're not duplicating each other's words or conducting two smaller studies when one would do."

Regarding Committee recommendations, Dr. Ramoni asked, "when you tell us what we should do, we'd also like to take the opportunity to tell you to talk about the how we should do it." She asked that, in making recommendations, the Committee consider not only the research component of the VA but also the operations side because they will be necessary partners. She stated that these partners are necessary to get not only the high-level recommendation, but also all the steps that would need to happen to allow that to occur. Dr. Ramoni concluded with the suggestion: "we should commit to some important

recommendations and then follow them through to their conclusion, rather than … constantly chasing new recommendations, unless something new should arise that would require that."

Mr. Bunker noted the lack of presumptive status for the many illnesses that Gulf War Veterans suffer from despite research showing high rates of incidence for some conditions. Mr. Bunker reviewed the continuing controversies about verification of exposures and undiagnosed status of illnesses complicated by scattered focus of research, lack of large-scale definitive studies, and frustrating inconsistent clinical care for Gulf War Veterans. He questioned why the VA has not recognized positive associations and asked Dr. Ramoni why the research evidence has not been acknowledged. Dr. Ramoni replied, "we don't view ourselves as being boxed in to research" and explained that she has spoken to the Secretary about this and plans to meet with the Veterans Benefits Administration "to talk to them about how our research should inform coverage specifically around Gulf War illness."

Dr. Ondra discussed how the application of research findings to presumptives differed for Gulf War Veterans compared to Vietnam-era Veterans who were granted presumptive status for Agent Orange exposure based on review of the single toxic agent dioxin. In reviewing Agent Orange exposure to get to studies that had enough scientific rigor for a decision on a presumptive, he explained that a lot of studies were found to be scattered and without focus and were thrown out as unusable because they were not connected. For Gulf War illness research, he stated, "I think the path that you're going on, you don't want to rule out innovation, but you also want to have some sort of focus and direction; otherwise you get nowhere."

Mr. Bunker pointed out for Gulf War research the difficulty of pinpointing one among over 30 different toxic exposures as well as the lack of confirmation of toxic exposures, incomplete diagnoses, and inconsistency in clinical care follow-up. He added that the problem with Gulf War research is the great number of animal and pilot studies with scattered results but only a couple of large-scale studies with focused results. Gulf War researchers he emphasized, "…need to come together and finally set a goal and get there together."

Dr. Klimas pointed out that the Congressionally Directed Medical Research Program (CDMRP) rely on the VA to be the space for the validation studies and coordinating CDMRP and VA portfolios works in a roadmap kind of way already. She added, the "Committee…has been trying to be responsive and find that space where the research committee can interface with the clinical side, the benefits side, and so on and help inform their process. But the truth is the VA needs a task force, working group, whatever, in that space to implement that."

In a later comment about funding of studies for CDMRP, Dr. Crawford stated: "The bulk of the funding is going towards clinical translation, and that's really how it should be. If we're really serious about trying to get something that gets into the clinic and actually has value for our Veterans, that's where the bulk of the funding has to be. We have to make it so that that's the only way you do get funded is if you actually have something that's on track and you understand translational research, you're not just using it as a buzz word to get funded."

In response to comments, Dr. Ramoni confirmed in seeding the endpoints for the roadmaps that one big target would be presumptives in Gulf War illness, which in addition to previous massive literature reviews needs an analysis of our electronic health record to see what associations can be found and where there are gaps to be filled in active communication with the benefits administration. She confirmed a second target would be "consistency of care for those with Gulf War illness, which would be along the lines…of health services research." Dr. Ramoni suggested, "I would like the group [RAC] to say what

ought to be end points for roadmaps that we might…for instance, in the presumptives area, …work with the DoD, NIH, to convene a group to come up [with] what is the roadmap for that."

Committee Discussion:

—Dr. Stephen Hauser, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

Committee Discussion overlapped and blended in with Dr. Ramoni's continuing discussion. Dr. Hauser indicated that he and the Committee have been trying to simplify its recommendations and narrow in on a few key issues, with the current focus on two priorities: First, the development of a comprehensive deep phenotyping study of Gulf War illness in partnership with the NIH; Second, creating a coordinated system of centers that uses a hub-and-spoke network to provide a model that integrates research with stepped-clinical care for complex chronic conditions of post-deployment. He stated, "it's been fantastic that we can get this NIH alliance deep phenotyping study started, but we are also so hopeful that we can create this center of excellence concept."

Dr. Ramoni emphasized the need to "get in the nitty gritty of the 'how'" and perhaps have meetings outside of the Advisory Committee to talk with the people on the operations side. She stated, "on the research side, we need to be bringing together the DoD, the VA, the NIH, to talk about our research portfolios and who does what." She suggested, "if DoD funds early pilot studies, …then perhaps it's the de facto job of the VA and the NIH to conduct validation on those that seem promising, and on the other side, speaking to VHA and VBA about practical implementation of findings from the research side."

Dr. Rauch observed that in the case of Gulf War illness, weigh the price of action versus inaction. He stated in the typical long-term trajectory for discovery of what an illness is and what is a viable treatment, it really has to be different for these disorders where there is a finite cohort. He noted: "A perfect solution to this 75 years from now is worthless. Conclusions 15 and 20 years from now are largely going to be worthless to this cohort of people who served and have been suffering." Dr. Rauch emphasized, "it would be really important to think about … what should guide our action…."

In response to Dr. Rauch, Dr. Ramoni replied, "What are the target questions?" Regarding treatments, she said that answering the right questions "will direct us to what information do we have now," and to whether it is "sufficient to make decisions" or "are there ways to rapidly get that information to be sufficient."

Dr. Ramoni further stated regarding the deep phenotyping study: "I'm hoping that it doesn't take 15 years. My suggestion would be that it would be better for us to focus our funds to rapidly—complete a phenotyping study as rapidly as possible given the throughput available at the NIH, rather than drawing it out for many years so that we could fund other things at the same level."

Related to the issue of having limited information in advocating for Veterans' health, Dr. Hauser stated: "one of the most vexing challenges for this committee in its past was how can we be forthright, as we have to be, regarding what is known for sure and what is associated but not known for sure while at the same advocating for veterans who are... suffering from problems that are in this gray zone scientifically," and he went on to reiterate Dr. Rauch's point by saying, "we often need to act with the best data that we have and not wait for the data that may never come." Dr. Rauch followed-up by commenting that organizational coordination may accelerate progress and, alluding to the 2016 RAC-GWVI recommendations, stated that the Committee, "made a fairly compelling case for aligning better the care and the research so that what's going on in care can inform the research and then communicate back out as things are learned."

Dr. Van Leeuwen asked Dr. Ramoni whether from her experiences with leading the Undiagnosed Diseases Network, were there ways in which she was able to effectively bring together scientific research and clinical care? Dr. Ramoni replied, "There was no secret sauce other than actually bringing people together and developing relationships across the silos." She suggested, "This Advisory Committee can really start to serve as a nexus point for research in clinical care and that we just have to build in consistent structures." Dr. Ramoni said about engaging with the operations side to just begin "with meaningful engagement and a sense of shared responsibility for the outcome rather than just saying now you do this."

Session 1: The Gut Microbiome and its Metabalome in Health and Disease

—Dr. Gary Wu, University of Pennsylvania

Dr. Wu began with a discussion of the intestinal microbiome, specifically the environment of the gut and its role in early life events and association with disease. He described that the human microbiota consists of a very distinct, densely populated, and complex microbial community of bacteria, viruses, fungi, yeasts, and archaea. The microbiome in the lumen of the gut is separated from the external environment by the single-cell layer of the intestinal epithelium. He noted the microbiota is shaped by diet, plays a role in the incidence of many diseases, and has associations with inflammation. He added that failure to establish a normal microbiome may play a role in the pathogenesis of and predisposition to immune-mediated chronic disease.

Dr. Wu continued with a review of how diet and the gut microbiome—and related metabolome of small-molecules—could have an effect on other organs, even those distant from the gut, to influence health and disease. He said, "diet not only shapes the composition of the microbiota, but it's used as a substrate to produce all these small molecules." The environment of the gut, he pointed out, is a factor contributing to pathogenesis of chronic inflammatory processes such as inflammatory bowel disease (IBD). He said, as an additional example, a very large metabolomic screen of individuals at risk for coronary vascular disease found "small molecules that strongly were associated with coronary vascular disease." Dr. Wu noted, "one of those molecules actually comes from the gut microbiota largely" and the gut microbiota's interaction with dietary fat affects production of the molecule.

He went on to discuss how innovative strategies to prevent and treat disease may include use of drugs to inhibit activity of gut bacteria or diets that reduce bacterial production of undesirable molecules. In summary, Dr. Wu stated: "It's a new sort of paradigm to think about drug delivery and drug mechanisms for the treatment of disease focused on more of the [microbiome] environment than on the host."

Dr. Wu's final presentation topic was on the gut microbiome in chronic IBD and engineering the environment of the gut. He stated, "that environmental factors are the largest contributor to pathogenesis for inflammatory bowel disease, yet our current strategies do not focus on the environment of the gut." He noted, "over the past several decades, there's a skyrocketing increase in the development and incidence of inflammatory bowel disease worldwide." Dr. Wu added, "when I think about soldiers that have gone to a different environment and Gulf War illness, maybe something has changed in the environment, and that is sort of in parallel with these very powerful environmental effects." "What this also means," he continued, "is that this is an enormous opportunity…in engineering the environment they've got through diet or changing the composition of the microbiota in some way that might make these drugs work better or could be a standalone therapeutic opportunity…."

Regarding dysbiosis associated with disease, Dr. Wu suggested, "Maybe you could change that dysbiotic microbiota using a multitude of different methods to try to promote health." He reviewed that treatment of IBD may be through defined formula diets that either provide something good (enteral nutrition) or exclude something bad (emulsifiers and artificial sweeteners). Dr. Wu summarized, that in "thinking about how to engineer the environment, …the paradigm that we think about for treatment of inflammatory bowel disease [is] engineering the environment of the gut."

Session 2: IBS and FGIDs: A Conceptual Understanding and the Role of Infections and Microbiome

—Drs. Douglas Drossman and Madhu Grover, University of North Carolina at Chapel Hill, Mayo Clinic

With his presentation, Dr. Drossman gave a conceptual overview of functional GI disorders (FGIDs) and noted that Dr. Grover's presentation would dive deeper into the role of the microbiome in these disorders. Dr. Drossman commented on the relevance of FGIDs and irritable bowel syndrome (IBS) to Gulf War Veterans, stating that these conditions are seen as "an outcome of deployment in a war zone" and that "there's a harmony between IBS functional GI disorders and maybe other conditions like Gulf War illness, chronic fatigue syndrome, and the like, in terms of the physiology." He pointed out that it is important to make the distinction that "functional GI disorders are not organic disorders," in the sense that they lack structural abnormalities that you can see. Instead, "Functional GI disorders are really defined by symptom clusters, where epidemiologic and factor analysis define subgroups," and he noted IBS is one of them. He went on to discuss that the term "functional" has a stigma attached to it and suggested the need to reframe IBS and FGIDs as disorders of gut–brain interaction.

Dr. Drossman spoke about the physiological connectedness of the brain and gut and how this can impact other organ systems: "So the disorders of gut/brain interaction include the bowel, which is irritable bowel, but many other organ systems, including the esophagus, chest pain, even the biliary system, the pelvic floor, rectal pain, pelvic floor dyssynergia." He proceeded to provide an historical perspective and present data related to the perception of FGIDs and associated stigma. He also presented on associations of GI disorders with military deployment to the Gulf War. In closing, he stressed the importance of regulation of the gut-brain interaction and hinted at a role for the microbiome in this regulation.

After Dr. Drossman provided a conceptual understanding of functional GI disorders, Dr. Grover delved into the relationship of IBS and FGIDs to infections and the microbiome. He described the role of the microbiome and bidirectional crosstalk between the brain and the microbiota of the gut in the development of post-infectious IBS (PI-IBS). He related the 100-year history of observations about the epidemiology and interactions of infection and microbiota in development PI-IBS in military populations returning from war. He noted the importance of the interaction of infection and concomitant stress in mechanisms of visceral hypersensitivity and development of PI-IBS. He stated that the gut microbiota "can be assumed to play an influence in a lot of physiological changes that we see in IBS, such as changes in visceral hypersensitivity, motility, permeability, and the brain/gut access" with implications for peripheral mechanisms, symptom severity, and microbial signatures. Dr. Grover discussed how the FODMAP diet (fermentable oligosaccharides, disaccharides, monosaccharides, and polyols) improves microbiota and "can have a significant impact on symptom presentation in IBS."

Session 3: Development of a Single Gulf War Illness Case Definition

—Dr. Peter Rumm, VA Office of Post-Deployment Health Services

Dr. Rumm summarized how planning for a case definition for GWI is being undertaken by the VA in response to a recent Government Accountability Office (GAO) report that included a recommendation that the VA develop a single case definition for GWI. In addition to developing a single case definition, he and a group of subject matter experts, he said, "were hoping to take that further and actually develop an operational plan to actually implement the definition." He noted the targeted completion date of the plan was March 2018, but he stated: "We're actually farther along than that. We're hoping to finish up by the end of the month [November 2017] to get the sign-off within VA." He indicated there is a review and clearance process in progress right now. He stated, the real goal is to get the draft plan to actually work and do some testing and validation "with a definition that actually works."

Dr. Rumm discussed some planned methods for developing a case definition for GWI, including analytic techniques for validation. He explained that a definition developed by a work group drew on the clinical practice guideline (CPG) for CMI (chronic multisymptom illness) as well as the Kansas and the CDC definitions. He reviewed the developmental steps for the operational plan as first a continuing review of the current literature for advances on biomarkers; then reviewing patient charts at the War Related Illness and Injury Study Center (WRIISC) for existing dataset information on group symptoms, diagnosis, laboratory findings, and medication orders associated with deployment in the Gulf War; next working with the Veterans Benefits Administration to review GAO recommendations that centered around claims/benefits; and finally using a sophisticated tool called Chart Review to look in the VA's VINCI database system to compare definitions with predictive analytics. He continued that "there's going to be a number of databases used to do these predictive analytics" and "VA will perform predictive modeling to compare the first three [CPG, Kansas, and CDC] definitions with what a machine learning algorithm identifies as significant predictors of Gulf War service." After a case definition has been established it can also be used to impact clinical care, he noted. Dr. Rumm stated, "ideally, once a predictive model for CMI has been built and validated, a similar computer algorithm can be developed for CPRS, which is our data system, clinical data system, and cases of probable GWI can be flagged for the primary care provider."

Session 4: CFS & GWI Deep Phenotyping Study

—Dr. Avindra "Avi" Nath, Intramural Clinical Director of the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health.

Dr. Nath provided an overview of the NIH study underway to study post-infectious myalgic encephalomyelitis/chronic fatigue syndrome (PI-ME/CFS). For the deep phenotyping portion of the study, the NIH and VA are in talks to collaborate and add a GWI component to the study.

The study, Dr. Nath described, recruits patients primarily from well-characterized ME/CFS cohorts and consists of three phases. Phase I is a cross-sectional deep phenotyping to comprehensively characterize pathophysiology. Research aims for the first phase include defining the (1) clinical phenotype, (2) underlying pathophysiology, (3) abnormal immune and microbiome profiles, and (4) reproducibility of features in ex-vivo studies. Future directions include implementation of follow-up phases. Phase II would aim to validate selected biomarkers, and Phase III would aim to conduct an early phase intervention study targeting biomarkers validated in Phase II.

Dr. Nath described that in initiating the study there was much consideration given to studying the right patients and using an appropriate definition of the disease. He noted that the community of chronic

fatigue patients voiced fear that the syndrome was not being taken seriously and concern that it was not well defined clinically. He stated, "their concern was that if you don't really have the right criteria for defining these patients, you could end up studying some other disease."

Dr. Nath reviewed implementation and progress as well as data obtained in the study, including data pertaining to metabolic dysfunction in ME/CFS patients. The questions and discussion with Dr. Nath led directly into the follow-up Roundtable Discussion on GWI and CFS.

GWI and CFS Roundtable Discussion:

—Invited Guests and Research Advisory Committee on Gulf War Veterans' Illnesses

For the discussion, joining the table with the Committee members were previous speakers (Drs. Drossman, Grover, Nath, Rumm, and Wu) and guests (Dr. Dawn Provenzale, Dr. Matthew Reinhard, and Dr. Brian Walitt).

Participants discussed details and progress of the NIH–VA collaboration to add a Gulf War illness cohort to the NIH CFS deep phenotyping study. Committee members and invited guests discussed the NIH study specifications of CFS sample size and reviewed limitations of using a relatively small sample size. They made extensive comments on study methodology as well as dissected the details of recruiting, populations, and control groups for CFS and GWI. There was also much deliberation regarding the appropriate control group for the study, including benefits and drawbacks of using a healthy non-deployed group versus a healthy deployed group as the control.

Additional considerations about the study included how to approach procedures related to the microbiome, in particular the role and spectrum of gastrointestinal disorders in the GWI cohort. The points were made that the study may be imperfect and preliminary but that it has tremendous potential to further understanding of the pathophysiology underlying GWI.

Dr. Reinhard, Director of the DC WRIISC, stated the recruitment plan and comparison groups are still being developed. He said, "I don't think the purpose here is to … prove the presence of Gulf War illness or something like that" but to look at the deployed Veterans and "see what's the difference between the people that are ill and who are healthy."

Dr. Provenzale, Director of the VA Cooperative Studies Epidemiology Center in Durham, NC, who is assisting in planning this study stated, "it's going to be critical to understand … exactly what's our objective, and what products do we expect from the study. And that will determine our sample size, our sampling cohort, you know, our cases and controls, et cetera."

Session 5: Office of Research and Development Gulf War Research Strategic Plan Update

—Dr. Victor Kalasinsky, VA Office of Research and Development

Dr. Kalasinsky's presented a very brief overall view of the update on the ORD Gulf War Research Strategic Plan (2018 – 2022) and noted the Committee members should review his slides. He said the focus has been on Section 7, Scientific Approaches and Research Goals, with six writing groups meeting from time to time. He pointed out that the writing teams have outlined preliminary information, the challenges, progress, and opportunities for each scientific section and that the Committee members can review these write-ups in the binders. Dr. Kalasinsky asked the Committee members to look at the material and make comments.

Dr. Kalasinsky announced that as of October 1st the amount of money spent towards Gulf War research projects in fiscal year 2017 was $13.5 million and 13 proposals were received for the December study section.

Committee Updates and Discussion:

—Dr. Stephen Hauser, Chairman, Research Advisory Committee on Gulf War Veterans' Illnesses

Dr. Hauser asked the Committee members to consider the current version of the 2017 Committee recommendations that had been developed over the course of the year and circulated amongst the group. He noted two very positive aspects: first, moving the focus from a few recommendations to two, and second, continuing to drive home the same message.

During the Public Comment, Dr. Van Leeuwen read aloud the Committee 2017 Recommendations to the VA that were circulated within the Committee:

The first recommendation: "Partner with the National Institutes of Health to conduct a deep phenotyping study of Gulf War Illness and Chronic Fatigue Syndrome" would better characterize the disease and potentially identify biomarkers and treatment strategies to achieve improved clinical care.

The second recommendation: "Commit to piloting and establishing a coordinated system of centers and expertise focused on complex chronic conditions of post-deployment, and operationalize the beginning stages of such a system by 2019" would more closely integrate research with a stepped model of clinical care.

The Committee unanimously approved the recommendations.

Public Comment:

Veteran Paul Johnston spoke in person about his difficulty getting care from the VA and although he has not been "denied care, … but it is definitely delayed over time." He stated that for Gulf War Veterans the VA needs to do a Persian Gulf Clinic "where the Persian Gulf Vets can talk about what's going on, what the problems are, and actually deal with somebody that's an expert in their illness." Mr. Johnson emphasized: "We are not people that you can just throw away. We are getting sicker, we do need help, we need medical care. But we need honest medical care. We're not getting it."

Veteran Hector Figueroa called in on the phone line to note that he and other Veterans have been unable to get documentation of deployment vaccinations to provide to the VA for Gulf War illness connected to vaccinations. Committee member Dr. Stephen Hunt spoke up and offered advice to help Mr. Figueroa resolve this problem.

Veteran Chuck Girard called in on the phone line to express frustration that VA doctors are not looking at the big picture on Gulf War illness and all of the many different types of exposures. He said that what he found "at the VA is that every individual department wants to treat every individual thing, and nobody seems to be looking at the big picture." He noted, "all those different types of exposures have got to tie the big picture together with the whole-body conditions and deteriorating health."

Veteran John Montecalvo called in on the phone line to discuss the significance and timing of exposure symptoms and treatments as well as vaccinations he received. Dr. Nancy Klimas responded to offer perspective on medical findings.

Veteran Kirt Love spoke on the phone to describe the recent excision of his cancer tumors and described his frustration at the indifferent behavior and reactions from medical staff. He noted, “Each person wanted to pass me on to someone else because they really didn't know what to do or how to deal with it.” He eventually was treated in a civilian hospital but was concerned that his results would not be reported to the VA. He also noted regarding VA follow-up, “if there's a cancer cluster out there, they're not trying to look for it and they don't understand it and they're certainly not going to post their findings, especially if it's being done through civilian hospitals.” Committee members Mr. Jeffrey Nast and Ms. Marylyn Harris responded to offer support and help with follow-up.

Veteran Kelly Degan spoke in person about being a Gulf War Veteran who has spent years of frustration being sick with fatigue and only recently has started to be recognized by holistic practitioners as needing treatments for a plethora of symptoms related to Gulf War illness that the VA is finally beginning to recognize and treat.

An email from Veteran advocate Peter Sullivan was read by Dr. Kalasinsky regarding the proposed Centers of Excellence being a good idea.

Veteran Denise Nichols reviewed concerns of other Veterans undergoing medical treatments and pleaded for the Committee to continue good work and to work on providing standing orders and standards of care for review and treatment of Gulf War Veterans.

Adjourn:

Dr. Hauser, RAC-GWVI Chair, adjourned the Committee meeting and announced the Committee will meet again in the Spring of 2018.