## TESTIMONY OF ANTHONY HARDIE, GULF WAR VETERAN, NATIONAL BOARD CHAIR AND DIRECTOR, VETERANS FOR COMMON SENSE

# BEFORE THE U.S. HOUSE OF REPRESENTATIVES, COMMITTEE ON VETERANS' AFFAIRS, SUBCOMMITTEE ON OVERSIGHT AND INVESTIGATIONS AND

#### SUBCOMMITTEE ON DISABILITY ASSISTANCE AND MEMORIAL AFFAIRS

### FOR A JOINT JULY 13, 2017 HEARING ENTITLED: "EXAMINING VA'S PROCESSING OF GULF WAR ILLNESS CLAIMS"

Thank you, Chairmen Bergman and Bost, Ranking Members Kuster and Esty, and Members of the Subcommittees for today's hearing and for the invitation to speak with you today.

I'm Anthony Hardie, National Board Chair and Director of Veterans for Common Sense (VCS), and a U.S. Army veteran of the 1991 Gulf War and Somalia. VCS and I have provided testimony on many previous occasions, most recently in February and March 2016 for Gulf War health and benefits hearings.

Today's hearing is focused on the latest Government Accountability (GAO) report related to Gulf War Illness (GWI) issues, with bottom line finding of an 87 percent overall denial rate that is three times worse than any other type of claim the Veterans Benefits Administration (VBA) adjudicates. However, the GAO report delves deeper into these GWI claims issues and their intertwined relationship with medical research.

These serious issues have profound real-world impact on Gulf War veterans. Please see *Exhibit* 1, attached to this testimony, that provides a number of Gulf War veterans' accounts of how their own VA claims for GWI issues were denied. The negative impact on these veterans compels us today to seek to find solutions to favorably impact them and help to relieve their suffering however we can.

#### **2017 GAO REPORT ON GWI CLAIMS**

Specifically for Gulf War Illness (Chronic Multisymptom (CMI) and Undiagnosed Illness (UDX)) claims, this new 2017 GAO report<sup>1</sup> found:

<sup>&</sup>lt;sup>1</sup> U.S. Government Accountability Office, "Gulf War Illness: Improvements Needed for VA to Better Understand, Process, and Communicate Decisions on Claims" (GAO-17-511), June 2017.

- TRIPLE THE DENIAL RATE: "...the approval rate for Gulf War Illness medical issues was 17 percent (about 18,000 of 102,00 issues rated), which was about 3 times lower than all other medical issues at 57 percent (about 14 million of 24.7 million issues rated)."; "This approval rate was consistently lower than that of the non-Gulf War Illness medical issues." (p. 18)
- WORSE FOR UDX CLAIMS: "...eight VBA regional offices had approval rates of 5 percent or less for undiagnosed illness medical issues." (p. 22)
- WORSENING OVER TIME: "Approval rates ... decreased from fiscal year 2010 to fiscal year 2015..." (p. 18)
- VA UNDERREPORTED GWI CLAIMS: "...the number of completed [GWI] claims ... may be underreported due to unclear guidance and inconsistent data entry over time by VBA's claim rating staff."; "...staff had not been consistently identifying these medical issues as Gulf War Illness-related."; "[GAO] tested the data to determine the potential magnitude of the underreporting [of GWI issues]... and found approximately 57,000..."; "The number of veterans associated with claims for these medical issues was about 41,000..."; "...VBA is not planning to correct these data from prior years." (pp. 15-16)
- **GWI CLAIMS TAKE 50% LONGER**: "...[GWI] claims took about 4 months longer for VBA to complete than all other types of claims, averaging about 1 year compared to about 8 months..." (p. 17); And, "...[GWI] claims with eight or more medical issues took on average 1 month longer to complete than Gulf War Illness claims with seven or fewer medical issue." (p. 17, footnote). *This means veterans who are the worst off have to wait the longest for the help they need*.
- **DECISION LETTERS ARE FLAWED:** "...decision letters for denied claims do not communicate key information to veterans", including, "why the claim was denied" (p. ii), and, "...could lead the veteran to conclude that their claim was denied because ... VBA had not considered it under the presumptive method of service connection." (pp. 24-25). This is despite a 2002 GAO report (GAO-02-395) that noted that "unclear decision letters can confuse claimants." (p. 25, footnote).
- NO CONSISTENCY BETWEEN EXAMINERS: "Medical examiners have different views on and approaches for how to assess veterans for undiagnosed illnesses, in part, because of the challenge of identifying something as an undiagnosed or unexplainable illness." (p. 22)
- UDX IS UNWORKABLE: "Medical examiners at one clinic told us that they could nearly always attribute a veteran's symptoms to a diagnosable illness, which would mean the veteran does not qualify for benefits under the undiagnosed illness presumptive category."; "...two examiners said that to determine that a veteran should be categorized as having an undiagnosed illness, they would have to rule out all known diseases that could cause the veterans symptoms. Doing so, however, is beyond the scope of a medical exam for disability compensation purposes." (p. 22)
- INADEQUATE TRAINING IMPEDES ACCURACY: "VA's ability to accurately process GWI claims is hampered by inadequate training"; "VA has developed elective GWI training for its

medical examiners, but only 10 percent of examiners had taken the training as of February 2017" (p. ii), an "...optional 90-minute web-based training course." (pp. 22-23). By contrast, "...they must complete training courses before performing certain specialty medical exams, such as for traumatic brain injury or post-traumatic stress disorder." (p. 23)

- EXAMINERS' ERRORS MAY RESULT IN CLAIM DENIAL: "...VHA medical examiners sometimes provide a medical opinion related to service connection when one is not necessary because the veteran has a presumptive condition.... This opinion may include language that indicates the veteran's presumptive condition may not be relate to their service."; "...if VBA claim raters do not recognize that the medical examiner has provided an unnecessary medical opinion about service connection for a presumptive condition, they may inadvertently deny a claim that should be presumptively granted." (p. 22)
- WITH AN 87% DENIAL RATE, TRAINING ISN'T THE ONLY ISSUE: This is evidenced by the finding that "...98 percent of VBA's rating staff had completed ... training." Despite this level of training, VA still denies GWI claims at extraordinary rates. (p. 21, footnote)
- NO CONSISTENCY BETWEEN REGIONAL OFFICES: "VBA provides guidance to its claims staff regarding when to request this medical exam; however, we found different interpretations of the guidance among staff in the four regional offices we visited." (p. 20)
- VA STAFF DON'T UNDERSTAND GWI: "These Gulf War Illness medical issues may be denied at a higher rate, in part, because according to VA officials, Gulf War Illness is not always well understood by VA staff...." (p. 19)
- NO GWI CASE DEFINITION, NO ACTION PLAN TO DEVELOP ONE: "The National Academy of Medicine and VA's Research Advisory Committee on Gulf War Veterans' Illnesses both recognize that establishing a single case definition has been challenging and noted the risks of adopting one that is either too narrow or too broad. Nevertheless, they both identified steps VA can take toward this goal." (p. 30, footnote). "In its 2015 Gulf War Research Strategic Plan, VA included an objective to develop a single case definition, but an official told GAO that VA had no action plan in place to achieve it." (p. ii); "...the persistent lack of a single case definition for Gulf War Illness contributes to many of the current challenges with the Gulf War Illness disability compensation program." ... "Without a documented plan to establish a single case definition, VA may miss opportunities to focus its efforts and advance knowledge about Gulf War Illness, and potentially improve the lives of hundreds of thousands of affected veterans." (p. 32)
- NO VA REPORTING: "According to VBA officials, VA does not publicly report on the total number of Gulf War veterans who receive disability compensation benefits for Gulf War Illness." (p. 1)
- VBA CAN'T ADEQUATELY REPORT ON OTHER PRESUMPTIONS: "VBA officials noted that it may be more useful to compare Gulf War Illness approval rates to those of other types of presumptive disability claims, such as those for presumptive illnesses VA associates with exposure to Agent Orange during the Vietnam War. However, the data provided to us by VBA did not allow us to conduct this analysis." (p. 18, footnote)

- STILL NO CONSISTENT VA USE OF THE TERM "GULF WAR ILLNESS," despite strong NAS recommendations to use this term. "In 2015, VA's Office of Research and Development officially adopted the term 'Gulf War Illness presenting as chronic multisymptom illness' to describe symptoms of undiagnosed illness or medically unexplained chronic multisymptom illness." (p. 6, footnote)
- VA DOESN'T HEED RECOMMENDATIONS. "According to a June 2014 report published by [a VA] internal workgroup, VA had yet to implement many recommendations related to programs and services for Gulf War veterans made by internal task forces and external advisory committees to senior VA leadership over the years. In June 2014, this workgroup's environmental scan identified several deficiencies regarding VA's response to Gulf War Illness, including that there is: \*no overarching Department-level strategy for Gulf War veterans; \*no well-coordinated process for receiving recommendations or implementing plans to respond to recommendations; and \*no clear consensus on a single case definition for Gulf War Illness." (p. 12)
- PROCESS FOR NEW PRESUMPTIVES FLAWED. GAO notes that some VA research, "...is directly relevant to the disability compensation program; for example, it has been used to establish additional presumptive conditions." (p. 26). However, no examples are cited because, beyond nine infectious endemic diseases, VA has found none. "VA has not identified any new presumptive conditions that it associates with Gulf War service since adding the nine infectious diseases in 2010..." (p. 29). "Some presumptive conditions have been added through legislation. As we previously noted, in 1994 a presumptive service connection for "undiagnosed illness" for Gulf War veterans was established, and in 2001 legislation was enacted establishing "medically unexplained chronic multisymptom illnesses" as being presumptively service connected for these veterans." (p. 27, footnote)
- BRAIN CANCER PRESUMPTIVE DENIED: "VA officials said the agency decided not to proceed, citing limited scientific evidence from a 2016 National Academy of Medicine report." (p. 29)
- GAO RECOMMENDED VA: "...require medical examiners to complete training ... before conducting these exams."; "... require that decision letters indicate whether Gulf War Illness medical issues were evaluated under both a presumptive and direct service connection method."; and, "...prepare and document a plan to develop a single case definition of Gulf War Illness." ... "This plan should include near- and long-term specific actions, such as analyzing and leveraging information in existing datasets and identifying any areas for future research to help VA achieve this goal." (p. 32)
- VA AGREED: "VA said it plans to make its 90-minute web-based training course mandatory for its medical examiners who conduct Gulf War Illness exams. VA also stated it will improve how it communicates decisions to veterans and is in the process of updating its guidance to the regional offices to clarify the language required for its Gulf War Illness decision letters. Finally, VA said it will convene a group of subject matter experts to work on a plan—as described in our report—to establish a single case definition of Gulf War Illness." (p. 33)

- GAO ADMONISHMENT ACTION PLANS: "According to federal internal control standards, an agency's objectives should be defined in specific terms, including clearly defining how the objective is to be achieved and who is responsible for achieving the objective, as well as establishing time frames for meeting the agency's goal. These measures allow agencies to track progress toward achieving their goals." (p. 31, footnote)
- GAO ADMONISHMENT COMPETENCE IS A BASIC PRINCIPLE: "Demonstrating a commitment to competence is a principle of federal internal control standards." (p. 23, footnote)

#### **PREVIOUS INVESTIGATIONS**

This latest GAO report is just the latest in a long line of GAO, Congressional, and other investigations. In 1996, a GAO investigation found that VA had denied Gulf War veterans' undiagnosed illness (UDX) claims under the 1994 law at a rate of *95 percent*.<sup>2</sup> Additional hearings, legislation, advocacy, and major public outcry by the nation's ill Gulf War veterans eventually resulted in two major bills enacted in 1998 that sought to fix these issues with what appeared to be a clear, comprehensive framework for Gulf War veterans' healthcare, research, and disability benefits.<sup>3</sup>

The next major update followed shortly thereafter. Legislation in 2001 added signs and symptoms of undiagnosed illness, and "medically unexplained chronic multisymptom illness (such as chronic fatigue syndrome, fibromyalgia, and irritable bowel syndrome) that is defined by a cluster of signs or symptoms.)". This was the last significant legislative change to Gulf War Illness claims.

However, as we described last year, the implementation of all of these Gulf War laws aimed at helping ill Gulf War veterans has been fraught with challenges. Myriad VA-contracted National Academy of Medicine (formerly the Institute of Medicine (IOM)) literature reviews, at a cost of millions upon millions of dollars, have resulted in no new presumptive conditions related to Gulf War Illness, no new case definition of Gulf War Illness, no better assistance for ill Gulf War veterans seeking VA healthcare or benefits.

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<sup>&</sup>lt;sup>2</sup> U.S. General Accounting Office, "Veterans' Compensation: Evidence Considered in Persian Gulf War Undiagnosed Illness Claims" (GAO/HEHS-96-112), May 1996, p. 3.

As I noted in our testimony of February 23, 2016 to the Subcommittee on Oversight and Investigations (O&I), and our written submission for the record of March 6, 2016 for a joint O&I and Disability and Memorial Affairs subcommittees, these were the *Persian Gulf War Veterans Act of 1998* (Title XVI, P.L. 105-277) and the *Veterans Programs Enhancement Act of 1998* (P.L. 105-368, Title I—"Provisions Relating to Veterans of Persian Gulf War and Future Conflicts") were two landmark bills, that, "for those of us involved in fighting for the creation and enactment of these laws, they seemed clear and straightforward, with a comprehensive, statutorily-mandated plan that would guarantee research, treatments, appropriate benefits, and help ensure that lessons learned from our experiences would result in never again allowing what happened to us to happen to future generations of warriors."

<sup>&</sup>lt;sup>4</sup> Public Law 107-103, the "Veterans Education and Benefits Expansion Act of 2001," was enacted December 27, 2001; Section 202, "Payment of Compensation for Persian Gulf War Veterans with Certain Chronic Disabilities," took effect March 1, 2002.

Last year, detailed testimony<sup>5</sup> to the House Veterans' Affairs Subcommittee on Oversight and Investigations documented that the negative conclusions of these reports reflected the refusal of the NAM (with the blessing and at times collusion of VA) to follow the clear language of the statute requiring the reports as to the appropriate standard review.

Meanwhile, the challenges with VA continue, some specific to GWI and some more generally applicable. For example, in 2002, GAO found that VBA letters to claimants needed to be improved. However, this 2017 GAO report – with its major findings related to flawed GWI notification letters to claimants – shows that these 2002 recommendations to VBA were not fully heeded.

Then, in two 2004 reports, GAO found that the federal GWI research strategy needed reassessment, and that federal GWI research efforts had waned. In FY06, Congress created the Gulf War Illness Research Program (GWIRP) within the Congressionally Directed Medical Research Program (CDMRP) portfolio that is managed by the U.S. Army Medical Research and Materiel Command (USAMRMC). Also in 2004, GAO found that DoD conclusions about Gulf War troops' toxic exposures couldn't be supported.

#### **GWI CLAIMS DENIAL RATES**

Advocacy by Gulf War veterans brought limited attention to the ongoing issue of VA denials of these GWI claims. In 2007, analysis of publicly reported VA data showed a *74 percent* denial rate of all GWI claims. Advocacy related to these continued denials of GWI claims, and in 2010, VA intervened to clarify that the CMI's listed in the 2001 law were merely "examples" of, and not an exclusive list of CMI's. 11

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<sup>&</sup>lt;sup>5</sup> Statement of James H. Binns, U.S. House of Representatives Committee on Veterans' Affairs Subcommittee on Oversight and Investigations, hearing entitled, "Persian Gulf War: An Assessment of Health Outcomes on the 25th Anniversary", February 23, 2016, Washington, DC.

http://docs.house.gov/meetings/VR/VR08/20160223/104497/HHRG-114-VR08-Bio-BinnsJ-20160223.pdf <sup>6</sup> U.S. GAO, "Veterans Benefits Administration: Clarity of Letters to Claimants Needs to Be Improved" (GAO-02-395), April 23, 2002.

U.S. GAO, "Department of Veterans Affairs: Federal Gulf War Illnesses Research Strategy Needs Reassessment (GAO-04-767) June 1, 2004.

<sup>&</sup>lt;sup>8</sup> U.S. GAO, "Gulf War Illnesses: Federal Research Efforts Have Waned, and Research Findings Have Not Been Reassessed" (GAO-04-815T), June 1, 2004.

<sup>&</sup>lt;sup>9</sup> U.S. GAO, "Gulf War Illnesses: DOD's Conclusions About U.S. Troops' Exposure Cannot Be Adequately Supported" (GAO-04-821T), June 1, 2004.

As noted in my March 6, 2016 submission for the record, a May 2007 report from VA's Gulf War Information System (GWVIS) showed that of 13,027 GWI claims, only 3,384 had been approved – a 74 percent overall denial rate.

<sup>&</sup>lt;sup>11</sup> U.S. Department of Veterans Affairs, "All VA Regional Offices Training Letter, SUBJECT: Adjudicating Claims Based on Service in the Gulf War and Southwest Asia" (10-01), stated in part: "The chronic disability patterns associated with these Southwest Asia environmental hazards have two distinct outcomes. One is referred to as "undiagnosed illnesses" and the other as 'diagnosed medically unexplained chronic multisymptom illnesses" that are without conclusive pathophysiology or etiology. *Examples of* these medically unexplained chronic multi-

Fast forward a few years, and VA once stopped its public reporting of GWI data. Data obtained in 2014 by a Congressional office from VA showed a nearly 80 percent overall denial rate of GWI claims. That data also showed that VA approved 52 percent of denied GWI claims for other conditions, demonstrating an implicit VA bias against approving GWI claims; however, two in very five (38 percent) of Gulf War veterans were denied in totality.

Rounded off, according to VCS analysis of VA data, this most recent data shows a **78 percent VA denial rate** of Chronic Multisymtom Illness (CMI) GWI claims, **an overall denial rate of these GWI claims of 87 percent**, and **a staggering 90 percent denial rate** of Undiagnosed Illness (UDX) GWI claims. Data shown in in this new GAO investigation<sup>13</sup> is entirely consistent with the exceedingly high denial rates reported over the last two decades.

That UDX denial rate is approaching the 95 percent denial rate identified by GAO in a 1996 report that was part of the impetus for 1998 Persian Gulf War veterans legislation.

In more detail, the rates of VA denial of GWI claims continues to worsen. From a VCS analysis of VA data, for chronic multisymptom illness  $(CMI)^{14}$  claims, VA's denial rates were as follows: in Fiscal Year 2011 – **72.5**%, in FY12 – **72.1**%, in FY13 – **75.3**%, in FY14 – **77.0**%, and in FY15 – **77.5**%, as shown by VCS's analysis of GAO's newly reported FY15 full year VA data.

For undiagnosed illness  $(UDX)^{15}$  claims, veterans' odds of approval are even worse and that VA's denial of these UDX claims is worsening: in FY11 – **80.5**%, in FY12 – **78.4**%, in FY13 – **78.6**%, in FY14 – **83.1**%, and in FY15 – **89.8**%, again using the same methodology.

Combining these CMI and UDX data, VA's overall denial rates for GWI claims show a true downward spiral: in FY11 – **76.3**%, in FY12 – **74.7**%, in FY13 – **76.6**%, in FY14 – **83.1**%, and in FY15 – **86.7**%, again using the same methodology.

This data also shows that that the rate of denial for UDX claims was higher than that of CMI claims in all but five of the 58 VA Regional Offices for which GAO reported FY15 GWI claims data. This is also significant, and demonstrates the disparity between Gulf War veterans getting a UDX GWI claim approved versus a CMI GWI claim approved. It also suggests that the Congressional intervention in 2001, which introduced CMI's to GWI claims, improved the plight of Gulf War veterans.

symptom illnesses include, *but are not limited to*: (1) chronic fatigue syndrome, (2) fibromyalgia, and (3) irritable bowel syndrome.'" [Emphasis added]

<sup>&</sup>lt;sup>12</sup> U.S. Department of Veteran Affairs data, provided to the office of then-Representative Kerry Bentivolio, March 28, 2014. Analysis by VCS – Out of 54,193 GWI claims filed: 11,216 approved (20.7%), 42,977 denied (79.3%); 22,470 approved for other non-GWI conditions (41.5% of GWI claims filed, 52.3% of denied GWI claims), 20,507 denied for GWI and all other conditions (37.8%); average disability rating granted for GWI claims was 67 percent.

<sup>&</sup>lt;sup>13</sup> U.S. Government Accountability Office, "Gulf War Illness: Improvements Needed for VA to Better Understand, Process, and Communicate Decisions on Claims" (GAO-17-811), June 2017.

<sup>&</sup>lt;sup>14</sup> "CMI = Chronic Multisymptom Illness (Fibromyalgia DC 5025; Irritable Bowel Syndrome, DC 7319; Chronic Fatigue Syndrome, DC 6354) in either the hyphenated or primary code. If condition is both UDX and CMI, it is included in UDX counts."

<sup>&</sup>lt;sup>15</sup> "UDX = Undiagnosed Illness, defined as diagnostic codes containing 88xx in either the hyphenated or primary code."

#### VBA REGIONAL OFFICES VARY WILDLY WHILE BAD PERFORMERS ARE DOING MORE CLAIMS

One aspect of these denials of GWI claims that went unremarked upon by GAO in this 2017 report is that one-third (9,875) of all the adjudicated FY15 GWI claims (28,250) were in just six of the 58 VA Regional Offices: Muskogee, OK (2,431, 94% denied); Roanoke, VA (2,124, 95% denied); Nashville, TN (1,763, 83% denied); Atlanta, GA (1,339, 93% denied); Columbia, SC (1,130, 90% denied); and Waco, TX (1,088, 92% denied). This implied that VA is sending claims from elsewhere in the country to at least these six offices, five of which have worse or far worse denial rates than the 86.7% national average.

GAO also did not remark on the discrepancies *between* VA Regional Offices, which are profound and imply extreme variation in claims processing standards of these claims depending on location and local management. Overall FY15 GWI denial rates ranged from 47% at Boston to 100% at Anchorage. CMI denial rates varied even more widely, ranging from 36% in Manila and 38% at Boston to 92% at Roanoke and 100% again at Anchorage.

Since VA has this data (it is VA-provided data, after all), it is entirely unclear why there has not been an internal investigation not only of these discrepancies, but also why there hasn't been a complete overhaul of GWI claims adjudication at the worst performers like Roanoke and Muskogee. Given that it can be inferred that VA is sending GWI claims to these offices from elsewhere, and that the data shows these regional offices have far higher than average denial rates, a cynical person might conclude this consolidation of GWI claims processing to high-denying offices was intentional.

#### **RECOMMENDATIONS FOR LEGISLATION**

In past testimony, we have provided numerous recommendations for legislative action. Today, we will focus on just a few.

A) Fixing GWI Claims should be the centerpiece of a legislative fix to help Gulf War veterans. After years of critiques, recommendations, hearings, investigative reports, and bad press, VA has yet to fix the GWI claims problem. Despite enactment in 2001 of legislation that created the new CMI presumptive and fine-tuned the original 1994 UDX presumptive, VA still remains hampered by training issues and inconsistent implementation between locales. However, though GAO reported VBA assertions of a training rate of 98 percent of its claims examiners, the issues continue.

In short, underlying these issues is that the "Undiagnosed Illness" claims adjudication framework utilized by VA simply doesn't work as Congress intended in 1994 and subsequent updates. This premise is supported by several factors, including the persistence of near-total denial rates of UDX claims and GAO's 2017 finding that some claims examiners will in essence never find in favor of an "undiagnosed illness" and "always attribute a veteran's symptoms to a diagnosable illness".

However, there may be another option. First, we note that that Congressional intervention in 2001, with the introduction of CMI's, consistently shows a better approval rate over claims adjudicated as UDX under the 1994 law that instituted these claims.

Next, we note that both PTSD and TBI claims have seen dramatic overhauls in recent years that made significant improvements over earlier processes. As a potential model of sorts for a future GWI claims schema, the current TBI rating system (DC 8045) uses a system of "buckets" of symptom sets, scored for severity as mild, moderate, or severe. While not perfect, it's not hard to envision major GWI symptom sets as a parallel to these TBI symptom "buckets" under DC 8045.

And, just like for TBI claims, it would be important to ensure that there are direct tie-in's for diagnosed conditions related to GWI. For example, sleep apnea, gastro-esophageal reflux disease (GERD), and chronic sinusitis are three of several commonly reported conditions among ill Gulf War veterans. However, due to epidemiological research inadequacies and the inherent requirements of undiagnosed illness claims, once diagnosed these conditions – more likely symptoms of the underlying GWI – no longer qualify to be rated under the UDX presumptive.

Given VA's track record of failure on these issues, including the failure to heed recommendations as noted in this 2017 GAO report, the process to create this new GWI claims schema should also be statutorily mandated. It should include a statutorily-mandated panel to lead this process composed of VHA and VBA key personnel and subject matter experts (including those involved in the process to create the new TBI claims rating schedule), clinical and research experts on GWI including as identified by the Gulf War Illness Research Program within the DoD Congressionally Directed Medical Research Program, representatives of stakeholder veterans service organizations, and engaged Gulf War veteran advocate stakeholders.

It should be given a timeline to conclude its work, as short as feasible given the many years ill Gulf War veterans have been suffering under the present unworkable UDX and CMI GWI claims system. And, with these medical experts included, a scientific case definition that may still be years in the future may not be needed to create a workable GWI claims adjudication mechanism favorable to ill Gulf War veterans. Finally, the new rating schedule developed under this process should be published by VA as regulation with sufficient opportunity for public comment.

We want to work with VA to fix this. To that end, in collaboration with other veterans service organization we have requested a meeting with top VA officials to seek resolution. However, given that VA has had decades to find a solution on its own but hasn't, active Congressional involvement and statutory mandates seem likely to be necessary to mandate this process.

**Recommendation**: As the centerpiece of a legislative package to right as many ongoing wrongs as possible for Gulf War veterans, Congress should statutorily mandate a process to create a new, more viable GWI claims adjudication rating schedule in as short a timeline as possible.

**B)** Mandatory Training. In this new report, GAO identified areas of concern related to staff training as one probable cause of GWI claims denials. Therefore, it is worth referencing VA's new performance standards for claims rating staff (Rating Veterans Service Representatives, or RVSR's) that went into effect on July  $1^{st}$ . In these new performance standards, staff training was listed as a "non-critical element" of performance. Similarly deemphasized in these new

performance standards was "Organizational Support – qualitative and quantitative measurement of positive internal and external customer service and organizational support."

By contrast, the "critical elements" of these new performance standards include only accuracy, speed, and output. And, it remains unclear how appropriately VBA measures accuracy, given the high rates of success among veterans who appeal their denied claims (not GWI-specific).

It is unconscionable that Gulf War (and other) veterans' disability claims rely upon being reviewed by untrained medical examiners and claims staff, and that VBA has deprioritized training and customer satisfaction over speedy output. These new performance standards help underscore how these negative GWI claims outcomes are, in part, systematically allowed to occur.

And last year, we reported to your Subcommittees in our statement for the record that VA had amended Gulf War provisions in the M21-1 "Veterans Benefits Manual," which is used by VBA for rating claims. However, the spiraling VA claims denial rates and GAO's most recent findings of untrained staff and an array of reasons underlying VA's denial of Gulf War veterans' claims suggest that this intervention had far too little positive effect, if any.

Indeed, last year the Senate Appropriations Committee included the following proviso in report language accompanying the FY 2017 Defense Appropriations Bill: "While the Committee commends VA on its efforts to revise the Compensation and Pension manual for "Service Connection for Certain Disabilities Associated with Gulf War Service," concern remains that VA claims adjudicators are not consistently following these changes."

However, it is presently unclear whether there was any response by VA to this or any of the sixteen (16) Gulf-War veteran-related provisos included by the Senate Appropriations Committee or the several similar provisos included by the House Appropriations Committee and by the conference committee in its Joint Explanatory Statement.

**Recommendation:** Specialized training related to the type of claim involved should be statutorily mandated for all VA claims staff, including medical examiners and rating staff.

**Recommendation**: VBA should be statutorily mandated to report data to Congress that emphasizes and measures training, and the consistency of training and claims adjudication between each VBA regional office.

**C) Gulf War Veterans Who Aren't Gulf War Veterans to VA**. The federal government has two different definitions for service in Southwest Asia (SWA), the geographic location of the Gulf War. The U.S. Department of Defense (DOD) uses a more expansive definition for military service with its criteria for awarding the Southwest Asia Service Medal (SWASM). Meanwhile, the U.S. Department of Veterans Affairs (VA) uses a narrower definition of SWA to determine eligibility for benefits.

As a result of these two different definitions, a small number of U.S. service members who deployed to Israel, Egypt, Turkey, Syria, and Jordan, including airspace and territorial waters, are eligible to receive the SWASM as Gulf War veteran but are not eligible for Gulf War-specific benefits administered by VA.

**Recommendation:** VA should be statutorily mandated to amend the definition of SWA at 38 CFR § 3.317(e) to include the additional geographic locations in 32 CFR § 578.27(b) listed above.

**D)** VA Needs to Track, Analyze, and Regularly Report VA Utilization Data for 1990-91 Gulf War Veterans. In 2010, VCS testified, "At present, VA has no idea how many UDX claims have been granted or denied." This 2017 GAO report makes it clear that VA has not been consistently tracking GWI claim denials and approvals, with about 41,000 veterans' GWI claims not included in VA's data reporting.

VA should have a statutory mandate to report quarterly and in perpetuity a comprehensive package of VBA and VHA usage and benefits data. These reports should include raw and analyzed data on the numbers and rates of claims filed, approved, and denied by era and actual war service (i.e., 1991 Persian Gulf War, etc.), and healthcare utilization also broken down by cohort. For 1991 Gulf War data, the recommendations adopted unanimously in 2012 by the Research Advisory Committee on Gulf War Veterans' Illnesses (RAC) should be implemented. These new quarterly data reports should be publicly accessible to enhance VA accountability.

**Recommendation**: VA should have a statutory mandate to publicly report quarterly and in perpetuity a comprehensive package of VBA and VHA usage and benefits data that includes the 2012 recommendations adopted unanimously by the RAC.

- **E)** Other recommendations for legislation. Along with comprehensive reviews of the 1994, 1998, and 2001 laws, our numerous recommendations for legislative action made in previous testimony that should now be reviewed, including:
  - Added Presumptives. As part of a tie-in with a new claims schema for GWI claims, there should be consideration of statutory mandates for presumptives for Gulf War veterans for brain cancer, lung cancer, migraines, GERD, chronic sinusitis, and the numerous other conditions shown in one or more VA epidemiological studies as occurring at higher rates than control populations.
  - National Toxic Exposures Advisory Committee. Creation of a new, interagency (HHS, DoD including CDMRP, and VA including both VHA-ORD and VHA-PDHS) national advisory committee on toxic exposures, with a scope that spans quality of life measures from healthcare to benefits. Examples of toxic exposures include Agent Orange, 1991 Gulf War exposures, chemical warfare agent exposures, burn pits and airborne hazards, Camp Lejeune drinking water, and so on.
  - WRIISC's. Expanding VHA's War Related Illness and Injury Study Centers to make them more accessible and for clinical treatment, not just one-time clinical evaluation and medical research.
  - **Gulf War Registry**. Enhancing VA's Gulf War Registry to make it a meaningful medical surveillance tool to help identify emerging medical trends among Gulf War veterans.
  - **Gulf War Spouses and Children Registry**. Consider restoring this former registry, also as a meaningful medical surveillance tool to help identify emerging medical trends.

- Reform of the relationship between VA and the National Academy of Medicine. Congress depends on the National Academy of Medicine for unbiased judgment medical issues involving veterans. Congress orders VA to contract with the NAM for reports on these issues. Too often, the reports fail to live up to this unbiased standard. VA routinely fails to contract for the report as specified by Congress. And NAM committees frequently include former VA officials and contractors in the areas addressed by the reports. Legislation is sorely needed to restore the impartiality of NAM reports on veterans' medical issues.
- RAC restoration. In 2013, the U.S. House passed legislation under unanimous consent that would restore the Research Advisory Committee on Gulf War Veterans' Illnesses (RAC) to its original intent, though it failed to be taken up in the Senate before the Congress ended. That legislation should be reviewed for potential revision and reintroduction.

## EXHIBIT 1: GULF WAR VETERANS AFFECTED BY VA'S GWI CLAIMS DENIALS

Collected July 2017

The following are accounts from Gulf War veterans – in their own words -- whose claims have been denied by VA for Gulf War Illness presumptives, including undiagnosed illnesses (UDX) and chronic multisymptom illnesses (CMI's) like fibromyalgia, chronic fatigue syndrome (CFS), and functional gastro-intestinal disorders (including irritable bowel syndrome (IBS)).

#### Arizona

I just moved to Arizona from being in California for past 7 years. I was diagnosed with Multiple sclerosis and Lhermitte's while working up in Oregon. This was in Sept 2015. The VA kept me overnight to run more tests, and next morning the Neurology team came in and asked how long I had this disease, and I said 3 weeks. They said I had this at least 15 years or more. The main neurologist was surprised that I was not blind, paralyzed, or both by looking at my charts.

- \* I filed my claim when I got back to Huntington beach CA. in July 26th 2016.
- \* After getting more exams from Long beach VA, and getting my Rep with Paralyzed Veterans of America, we filed a claim. My presumptive conditions are: Multiple sclerosis and Lhermitte's, Chronic Fatigue, Chronic Joint Pain, degeneration discs and right hip, shooting pain in feet.
- \* I have a Nexus letter from my primary doctor from Salem OR, that was a specialist in MS. Stating that my condition was highly rated from being triggered from the Gulf War exposure of Oil well fires and possible Gas exposure. He had gone through my records to confirm of my unit and locations. I have x-rays of my joints, spine, and hip to confirm degeneration. I have multiple MRI's to confirm of the lesions on my brain and my spine for Multiple sclerosis and Lhermitte's. Paralyzed Veterans of America have my first contact info from 1994 of the first Gulf War Registry of me having the same issues that I have today, only now they are more extreme. I have letters/statements from veterans, current military servicemen, and family members. I have followed the book on preparing my case to file my claim only to be denied. I have a mountain of evidence and doctors to back my claim up. Doctors have been actually shocked that I am not on disability.
- \*The only reason I have from the VA for being denied is "Not service connected".
- \* My next step as of Monday July 10th, 2017, is getting my Rep with Paralyzed Veterans of America to get me answers and sent a letter of to an Accredited Claims Agent to see my next step.
- \*Not sure what an appeal would do except wait another 2-5 years for a response.
- \*Impact on me is that now that I have heard the stories of the VA and now that I am in the process of being pushed aside is appalling. It is completely amazing how bad the process is for all of us Veterans. Just disgusted.

#### **Arkansas**

I was diagnosed with a myoclonus (research this condition, it is the perfect example of an undiagnosed condition) a few weeks (May 1991) after I spent 8 months during desert shield/storm. I was told it was a seizure disorder and prescribed seizure medication. Not knowing that the medication side effects would cause me to get discharged, I was told at the time I did not have a claim. This diagnosis was re-affirmed in 1992, 2007, and 2010. And I'm still fighting the validity of the claim of "Gulf War Illness" and seizure disorder, as the V.A. has denied both and reworded my claim. That is a small example of the many medical conditions that I have that fall under GWI that I am fighting since 2007 when GWI was recognized by congress.

#### California

Around 1990 I was invited to attend SFOD-D, during the selection process I was given a flight physical which I passed with no issues and was given a class date in March of 1991. Desert Storm kicked off not long after this and I was cross-levelled to 2nd ACR for Desert Storm where I served as a Bradley Cmdr. Upon my return I was ordered to the 101st. Where I was seen for rash, heart rhythm disturbances and tachycardia (POTS) and vertigo, also present was persistent flu like body aches after physical exertion. I was informed these issues were psychological. I left the Infantry in 1994 and filed a claim which was denied. I filed another claim in 2007 which was denied.

I filed another claim in 2009 for IBS which was granted.

In 2015 I had a serious flair which again brought the heart rhythm disturbances (NSVT, PSVT and POTS) along with many of the issues associated with GWI:

- Neuropsychological deficits (documented by exam)
- Cardiovascular signs or symptoms (documented by exam with no explanation or identifiable pathology)
- CFS, (documented by WRIISC) and recently Dr. Baraniuk.

These and a few others were included in a claim filed in May of 2015, all of which were denied.

It was not until [VSO's] took my case before the director did I receive a partial award for CFS, all other issues are on appeal with no end in sight.

There is no way I can cover everything, I am too cognitively compromised and intend to hire an attorney to engage the VBA from this point forward.

[VSO's] have some of these documents but I assure you there is evidence to back up each of these claims. The VBA has it in their files.

Most, if not all denials were "Not service connected" per the VBA.

#### Florida

I live in the Tampa bay area in Florida. I made a claim for CFS in 2008 and subsequently in 2010 pointing specifically to the presumptive law. Both were denied for lack of evidence. I included doctors' notes, and diagnosis from the VA primary care and chronic pain clinics. I did not appeal as I was at my wits end at this point given the VBA denied a claim with diagnostics from the VAMC. (The VA denied a claim based on a diagnosis for a presumptive condition by the VA) I am contemplating reopening the claim and adding more evidence in terms of diagnosis and treatment records however the previous two attempts were denied specifically because there was no evidence in my service medical records. At least I presume that given "lack of evidence" is a broad statement. At the time I was being treated for chronic fatigue and chronic pain. This again is for a presumptive...

I was informed by a claims examiner that if they can offer a diagnosis then undiagnosed illness is out the window given it is then diagnosed. This leaves a veteran suffering with a now known condition that the VA can comfortably deny any claim against. That is a huge loophole given often a diagnosis may not be well grounded and based solely on symptoms presented. Often the symptoms may fit many diagnosis and they pick one. I claimed CFS specifically along with physical symptoms that were at the time present but undiagnosed.

The impact of the denial has both a psychological and a physical impact. It makes you feel like you are being brushed away and are wasting energy and time on an impossible brick wall of bureaucratic red tape. This seems to encourage you to abandon hope of any successful claim. I do not have the resources to mount a legal challenge and frankly do not have the energy to either. Physically this leaves me paying out of pocket often to treat the conditions if I seek treatment outside of the VA. The medical supports would be wonderful but seem out of reach. The compensation would assist in support of life in general that tends to revolve around managing chronic conditions first and working when and where one is able so as to survive without becoming homeless.

This feeds stress generally which exacerbates said chronic conditions. Ultimately if we are really dedicated to the care and wellbeing of our veterans then it is Congress that must act to clarify title 38 and end this debacle. It is Congress that

as well needs to properly fund the VA or other programs that will provide care and compensation. It is a cost of war and it is hard to define... how much is a Semi-normal life worth over what time span and by how many hundreds of thousands of impacted persons? We stood up... we are still paying a price... help please.

#### Indiana

I live in Indiana (Jeffersonville) and I filed in 2015 for gastrointestinal issue and IBS problems. I submitted a direct questionnaire from my personal doctor on these issues.

The VA denied saying that it was not service related. I appealed and got denied again.

Without the meds I take I couldn't do the job I do every day with an approved claim I could go back to school and do something easier on my body.

#### Iowa

I am a retired Army MSG. I am also disabled through the VA. I served in the Gulf War from October 1990 through June 1991. I served all over the theater from Saudi Arabia, Southern Iraq, Kuwait, and Northern Iraq. I am a combat veteran. I currently live approximately 45 miles from Des Moines Iowa.

I originally filed with the VA for Gulf War Illness in the summer of 1998 while living in NC, just after I retired at the end of May. I was just getting my notices for exams when my Gulf War veteran wife took her own life. Due to circumstance and the severe depression and other health issues I was unable to comply with those notices. The VA denied everything due to that failure.

My second filing was in lowa in 2008. I filed for the same issues. I had been seeing medical professionals continuously since retirement. All of that information was either directly obtained by myself or provided or the VA obtained it through permission from me. My first compensation and pension examination was right after Memorial Day 2009. I was unable to comply because I was hospitalized with pancreatitis during that weekend.

Even though my physician notified the VA my file was pulled for non-compliance. I fought and involved my congressman and eventually the file was returned and I was examined the first time in 2009 and other times into 2010. None of the exams were for GWI specifically. That exam was referred to Public Health.

However, I had claimed Chronic Fatigue Syndrome/Fibromyalgia, Irritable Bowel Syndrome, as well as sleep disorder/sleep apnea and much more symptomology that was unexplained and still is. All was denied except 10% for IBS. All were appealed and again IBS was approved at 30% and all other denied. IBS was not approved as a GWI presumptive. All denials were stated to be unrelated to my service although most if not all were recorded on my retirement physical. The appeal awarded me 100% P&T with only one GWI related issue. Due to the huge backlog in claims I was advised not to pursue at that time.

I still suffer all the symptoms I had following the GW and they have progressively worsened. The lack of diagnoses prohibits possible treatments. The entire merry go round of seek and deny exasperates the depressive disorder I share with my PTSD.

#### Kentucky

I am in Louisville, Kentucky.

I filed for a constellation of neurological symptoms with no diagnosis in 2013, and was denied for each symptom of my undiagnosed illness.

I appealed in 2014 with a new diagnosis of cramp fasciculation syndrome on the argument that I should have been approved for undiagnosed illness, but now should be approved for an idiopathic chronic multisymptom illness. I was

then denied for no service connection.

I appealed that decision citing the presumptive in 2015. My appeal has been reviewed by the Star team twice and sent back to the regional office and denied each time. The examiner's opinion, a nurse practitioner, seems to carry more weight than my VA neurologist who diagnosed me, and the Chief Examiner in DC. The last statement of the case said the nurse practitioner's opinion was more compelling.

The claim is now awaiting a hearing with the board of appeals.

I filed for IBS in 2016. The same examiner stated it could not be service connected. I was denied for no service connection. The Star team sent it back for correction. The examiner literally described my severe symptoms, and stated I experience them moderately. I am currently rated at 10%, and have appealed for 30%. This claim is also going to the board.

I am facing an early retirement due to my health. The failure of the VA to provide me with adequate care, and then basing the rating decision on that same inadequate care is causing me an unnecessary amount of distress and financial hardship.

#### Louisiana

I am in Louisiana and continue to be denied for fibromyalgia since 2000. I have documentation signed by a rheumatologist in a Gulf War exam in 1994 with that diagnosis. I am currently on Cymbalta with VA medical records stating that I declined Lyrica because it has not worked for me in the past. An NP at a C&P exam recently told me that I was never diagnosed with fibromyalgia, and I am not on any medications to treat fibromyalgia. I received a call last week from a VA employee at the central office stating that there was enough evidence in my file for service connection, and that I need to get my case out of my regional office.

There is more to the story. I was sitting in my VSO's office on 27 March 2017, discussing which conditions we would forward to DC on appeal, when my phone rang, it was an employee from legal at the RO. He told me there was enough evidence for a CUE. As he was talking, my VSO was typing. That too has been denied. After several calls, to include one to the White House complaint line, a supervisor from the RO called me and told me that the VBA judges have "more leniency" than she has, and that she would need a nexus letter. I informed her that it was my understanding that for presumptive conditions, with a diagnosis, no nexus was needed.

I came home from vacation today and this was in my mail. I might find the irony in this funny if they had not been denying me since 2000. "Dear [Veteran's name], We received your correspondence indicating that you would like to file a claim for benefits. VA regulations now require all claims to be submitted on a standardized form. What Should You Do? In order for us to begin processing your claim, you must submit an application for benefits…" [From the U.S. Department of Veterans Affairs]

#### Maryland #1

I have been diagnosed with fibromyalgia, CFS, IBS, and migraines. VA states I'm only eligible for migraines and Fibromyalgia. They sent my appeal to board without a review. Stating all my symptoms are fibromyalgia related.

This case was done at the Baltimore RO, it was expedited to clear the backlog. The VBA's Star Team review, but only looked at the IBS and agreed it was separate from the fibromyalgia and recommended that a claim for IU be submitted. They didn't look at the Chronic Fatigue Syndrome diagnosis. The case was denied because supposedly [the] diagnosed condition of CFS isn't related to military service, the decision is in violation of the statute.

The RO never communicated that they received diagnosis of IBS, they did in fact communicate receiving diagnosis and DBQ for Chronic Fatigue Syndrome, but stated that the CFS wasn't related to military service.

#### Maryland #2

I now live in Maryland. I filed for the first time in 1991 three months after coming home for headaches and fatigue and was denied. There are other issues that I have filed for over the years that fall under the Presumptive Illness List but I will concentrate on these two diagnoses.

I never had a migraine in my life until 3 months after I returned from the Gulf. The headaches over the years went from here and there to daily occurrences that included migraines thrown in every few days. I am on daily medication to help keep the headaches from turning into migraines on a daily basis.

The fatigue is just as bad. Some days it hits me out of the blue and I literally can't get out of bed for days on end. I just sleep. As an example, I just went through a phase this week: I slept 14 1/2 hours, woke up for 3 hours, slept for another 8 1/2. This is right off my Fitbit.

Yet, after filing in 1991 again in 2012 and again last year I have been denied each time. How am I supposed work when I LITERALLY can not get out of bed? I wish I could work EVERYDAY! This is not how I saw my life at 47 years old. But I would go and serve all over again knowing where I am now. Because I know that I helped people while I served my time in the sandbox with my unit, Fleet Hospital 15.

#### Ohio

I suffer from dizziness. It's constant, but comes with episodes of severe debilitating loss if muscle control. I call it dizziness because it feels like I don't have my balance, but it's more than that, I get unreasonably depressed, can't walk, feel like I'm falling all the time. It started years earlier, but being young I just wrote it off as being hungry or tired.

When it became debilitating i went to the best neurologist at the Cleveland clinic. They have no idea what it is, but tried treating me with anti-seizure medicine, migraine and multiple other things. None of them worked. He believes they are caused by constant migraine headaches without aura or pain. He found the VA presumptive conditions and suggested I should pursue it because he couldn't solve it.

In about 2013 I applied under the gulf war presumptive conditions first for dizziness. They denied me because in the 90s I had positional vertigo, they said it was the same thing. I appealed in 2014, they denied me.

I then filed in 2015 for migraine induced dizziness, they denied me for chronic fatigue syndrome. You will note, I did not apply for chronic fatigue syndrome, I applied for migraine induced dizziness, which meant not only was I denied, I could not appeal it because I had no evidence for chronic fatigue. It was no mistake on my or my VSC representative's fault, they just changed it.

So we refiled, with another note and more evidence from my neurologist, headache with a secondary condition of dizziness. They denied it because I once had a tension headache.

We appealed with another note from my neurologist stating I was not having tension headaches, listing the clinical and medical definitions of both, and quoting the VAs presumptive description which didn't specify any particular type of headache anyway.

It's been about eight months since that. I'm still disabled, employed by the grace of my employer that understands and gives me time off any time I am ill. I pass out randomly and have symptoms mimicking heart attack because of also having a rating for irritable bowel.

I'm tens of thousands in debt for the bills I've incurred. My life is changed forever. There are days that I can't get out of my chair.

#### Pennsylvania #1

I live in Pennsylvania. The following is my statement of claim for denial of CFS and Fibro:

The AOJ provided a VA examination dated April 7, 2017 unfortunately the exam was inadequate. The exam was not based upon the medical record, specifically the Georgetown University Progress Notes dated March 02, 2017 in which James N. Baraniuk, MD (Professor of Medicine, Division of Rheumatology, Immunology and Allergy, Director of the Chronic Pain and Fatigue Research Center, Georgetown University) diagnosed me with Chronic Fatigue Syndrome using the Centers for Disease Control (Fukuda 1994) criteria, and he diagnosed me with Fibromyalgia using the 2010, & 2011 Modified American College of Rheumatology criteria (SEE: Georgetown University Progress Notes dated March 02, 2017). A medical examination is considered adequate "where it is based upon consideration of the veteran's prior medical history" (SEE: Ardison v. Brown, 6 Vet.App. 405, 407 (1994).

The examiner falsified the April 7, 2017 exam; he never touched me on any area of my body to check for tenderness, in fact the only contact with this examiner was to shake my hand upon arrival and departure. He spent approximately half of the allotted time for the VA examination admiring my service dog which had nothing to do with my claimed conditions of fibromyalgia and chronic fatigue syndrome. He then leafed thru the Georgetown University progress notes and asked about Dr. Baraniuk's credentials, but apparently investigated no further because he stated that my condition (fibromyalgia) "was never confirmed by a specialist." (SEE: VA Form 21-4138, statement concerning exam of April 7, 2017).

If this examiner had taken the time to investigate the credentials of Dr. Baraniuk, he would have found with a simple search on the internet that James N. Baraniuk, M.D. is the Associate Professor of Medicine, Division of Rheumatology, Immunology and Allergy, at Georgetown University. He is the Director of Georgetown's Chronic Pain and Fatigue Research Center and is one of the nation's leading experts on both fibromyalgia and chronic fatigue syndrome (SEE: <a href="mee-pedia.org">mee-pedia.org</a> James Baraniuk printable). He is also one of the nation's leading experts on disabilities occurring in Persian Gulf veterans. His curriculum vita (CV doc) is 41 pages long (SEE: James N. Baraniuk, M.D., curriculum vita).

The examiner errored in his rational when he stated that because exposures to environmental hazards were about 25 years ago, he could not confirm any disability pattern that would be related to Southwest Asia service. The Department of Veterans Affairs' Employee Education System and the Office of Disability and Medical Assessment (DMA) offer a Gulf War General Medical Examination Course. If the examiner had participated in this training or referenced the notice to examiners in Southwest Asia claims, found in Part IV, subpart ii, 1.E. 19.g of the M21-1 manual he would have understood that the examiner is to provide a medical statement explaining the Veteran's disability pattern. Fibromyalgia and Chronic fatigue Syndrome are both diagnosable but medically unexplained chronic multi-symptom illnesses of unknown etiology, and they are disability pattern 2, a diagnosable but medically unexplained chronic multisymptom illness. The notice to examiners in Southwest Asia claims tells the examiner that he or she shall not provide a medical opinion (nexus) for disability pattern (1) or (2) as to whether the condition was incurred - caused by service. Clearly the notice to examiners in Southwest Asia claims was not followed as this examiner, in violation of the statue, imposed a nexus requirement.

The AOJ's adjudicator failed to recognize that a Gulf War veteran does not have to prove any link to the veteran's service and the VA cannot impose a nexus requirement under the provisions of 38 CFR § 3.317. Fibromyalgia and chronic fatigue syndrome are presumptive illnesses for Gulf War veterans; VA presumes that these conditions were caused by military service. The decision of May 12, 2017 is clearly and unmistakably erroneous as it is in violation of statue, VA regulations and VA procedures.

This C&) was done April 7, 2016. Denial was dated May 26, 2016. Less than 32 days. (working days)

#### Pennsylvania #2

I am a 20 year Marine Corps Veteran (1984-2004) who served in the Persian Gulf from August 1990 - April 1991.It was mandated that I receive the Anthrax Vaccinations (Series of 6 shots) but I only received 5 shots because the

program was Temporarily halted prior to my 6 shot and at a later date restarted. No explanation! I was also required to take the progesterone Bromide Pills (3 weeks) while serving in country during Operation Desert Storm. Prior to and since my retirement from Active Duty, I have reported numerous medical problems that have not been adequately treated or document to include: I am from Pennsylvania (Pittsburgh VA Healthcare System).

2006 - MAJOR DEPRESSIVE DISORDER: I was diagnosed and medicated for the treatment of Major Depression. I filed a claim through the VA that was DENIED and the examiner inappropriately diagnosed me, based off of personal opinion as being an Alcohol Abuser. I never drank in the military and have only been a Social drinker since being discharged. I have NEVER abused Alcohol or any other Illegal drugs.

On February 6-9, 2017, because of the intense pain and Fatigue that I suffer from among other things on A DAILY BASIS, I applied for, was accepted and participated in a DOD Gulf War Illness Research Study conducted at Georgetown University by Dr. James N. Baraniuk M D. My decision to participate in the aforementioned study was based off of the fact that Dr. Baraniuk is an Associate Professor of Medicine, Director of Rheumatology, Immunology and Allergy, Director of Chronic Pain and Research at Georgetown University. He is also one of the Nation's leading experts on both Fibromyalgia and Chronic Fatigue (SEE; me-pedia.org James Baraniuk). I found this information through a simple search on the internet.

Through this intense 4 day study Dr. Baraniuk spent more than 15 1/2 hours with me, one on one, after the testing. I also had my service Medical Records and Deployment Records with me for review. As a result of the study, I received a POSITIVE diagnosis for GWI (per the Kansas Criteria), Fibromyalgia (per the 1999, 2010 & 2011 standards), IBS-C and Chronic Fatigue. The doctor also noted, utilizing my VA treatment records, PTSD, DEPRESSION and SLEEP APNEA.

Upon completion of the study, I spent the next 3 Months conducting follow up appointments through the Pittsburgh VA for testing evaluation and treatment. I also filed claims through the VA.

The Medical Examiner, who lacked the specialized credentials that Dr. Baraniuk possesses, proceeded to discredit Dr. Baraniuk's progress notes by stating "that study is done for research purposes only... Not for diagnosis proposes" the Medical Examiner, a Nurse Practicioner... NOT an MD, wow these remarks in her notes.

My claims for IBS and Fibromyalgia were DENIED under the Chronic Multisymptom Illnesses (CMI) because the medical examiner noted that I have clear and diagnosable illnesses.

I clearly have a Medical diagnosis for IBS and Fibromyalgia (both are Gulf War Presumptives seperate from CMI) From Dr. Baraniuk and also from the VA since 2016 yet both were DENIED by the VA 's Rating Specialist.

The constant delay and deny and the Lack of understanding of the Gulf War Symptoms cause me daily anguish and pain. As a result of the lack of a proper diagnosis and treatment, my conditions have continually worsened to the point that I had to quit working at the age of 49 due to my mental and physical conditions yet the VA has still not recognized the importance of training their medical staff to understand and identify the issues that we, Gulf War Veterans, suffer from even though there is medical knowledge and research that has confirmed these issues that has been paid for and conducted by the Department of Defense!

I was also Service Connected at 0% from the VA in June 2017 for the frequent headaches that I suffer from (another Gulf War Presumptive). I've also had my CFS and Sinus (respiratory) claims denied twice. I have Sinusitis all through my Service Medical Records but the VA calls it Sinus Rhinitis

#### **South Dakota**

South Dakota, 1994 CFS, degenerative disease of the joints, memory issues, headaches Denied for not being noted on Service Records, same story on the Appeal. "filed as joint pain, headaches, memory issues, and being tired constantly" x-rays, lab work, Doctors reports submitted. 2001 Doctors claim it is arthritis, and not degenerative disease of the joints. New Claim, denied, Appeal Denied. Did not appear in Service. Doctors notes submitted. 2006 Doctor said I have CFS, New Claim, New Evidence denied again, Appeal Denied. Did not appear in Service. All records were forwarded with all claims from V.A. Doctors since 1993. Presumptive Laws never applied for my claims, I asked. Frustration with the whole V.A. claims system!

#### **Texas**

I'm writing this letter on behalf of my recently deceased husband, whose death took almost 26 years to complete, and waiting for compensation took a chunk of years as well. My husband came back from Dessert Storm with several symptoms, ranging from burning eyes, chronic fatigue, rashes, sore throat and various other flu like symptoms. Within 3 months of coming back while doing an exercise with the unit, was flipped over in his kayak. He came home pretty sore.

The next day his leg was swollen and very painful, he was rushed to Walter Reed and diagnosed with Antiphospholipid Syndrome, sticky blood? He had many other illnesses pop up such as a parathyroidectomy, scalp cysts removed, anemia and with these came much suffering. He was adamant about pushing forward, not complaining, being a soldier. His commander had a special meeting with a board at NSA regarding the need to keep this soldier because he was necessary for the missions due to his extensive language abilities... he was to stay stateside and work from here. During this time he had many bouts of illness without much complaining. In 2001 he retired after 21 years' service. At discharge he was giveb 30% disability.

By 2003 my husband had an attack of Retroperitoneal Fibrosis. Then Rhabdomyolysis and again the chronic fatigue was taking its toll. He applied to VA again, was denied and we presented more evidence taking a year to finally receive 60%. In the meantime we were in Fort Lewis and Madigan felt they could not help this man with such complicated problems so gave him the ability to use a private doctor. Then things got worse, he was diagnosed with Raynaud's Syndrome, toe removed, Sympathectomy surgery, and we were having to pay out of pocket up towards the thousands. The Autoimmune diseases seemed to cascade to 7 active diseases. My husband's dream was to move to New Braunfels, Texas and I researched the doctors in San Antonio. The trek across country began. This time I realized we had to have a doctor that would understand GULF WAR SYNDROME. This doctor did. My husband applied again in 2015 and by Jan. 2016 he was awarded 100% with the help of the doctor advocating for him. Twenty-six years of suffering and one year of that time he was 100%. He died, and written on the death certificate was pulmonary fibrosis as a result of Antiphospholipid Syndrome. He gave his all and had to fight to get just a piece of what was rightfully his!

#### Wisconsin

I am a Gulf War Veteran from Wisconsin. Entering the Marines out of High School, I was very experienced long distance runner at the peak of my health. In basic training, I very proudly placed second in the "Company Iron Man". Ultimately out performing all but one of 402 other Marines from all over the United States. Little did I know at the time however that within two years of that performance and my return from the Persian Gulf, I would never run or regularly participate in athletics again without debilitating consequences. Ultimately I left the Military Reserves directly due to my inability to physically perform. Despite a written request for legal support and medical testing, I was denied this examination and given a General Discharge. I still had my honorable discharge from active duty and the war so I didn't really care.

I have fought my physical battle completely on my own for the last thirty years until visiting the VA for the first time about 5 years ago at the urging of my former company Gunny and other members of my Unit. I first applied for connected disability in May of 2014. If there ever was a text book case of Gulf War Illness, it is me. Due to a VSO error my claim was not placed until November of that year. Approximately one year later, I was denied all issues claimed to include Chronic Fatigue, Gastrointestinal Issues, Sleep Deprivation, Joint and Tendon Issues (Fibromyalgia), Depression, and a chest injury which occurred while in active service.

Evidence provided was my SRB, and all of my medical records from the VA to that point which included all labs and imaging. I had also participated in a War Related Illness Study which I also provided records of. It was the conclusion of this VA Department that all of my current medical conditions and symptoms "are consistent and meet the VA Case definition of Gulf War Illness. I have now been invited to participate in no less than four gulf war illness studies through the VA.

While some aspects of my initial denial were from "conveniently" missing components of my service records, the common thread across nearly all denials was a "lack of diagnosis". I had also tested positive for RA so they were able to apply that to anything else that I claimed. I was being treated for all of these issues but apparently none were

diagnosed? I was amazed one arm of the VA could conclude I met the criteria while the disability governing body could not. I brought this up to a doctor at the VA Hospital and he explained they treat symptoms and do not diagnose! I thought to myself this ultimately would make it impossible to ever be granted anything!! This seemed to defy sanity that one department of the VA was demanding diagnosis and the hospitals were saying they could not be provide any! It is very apparent to me the hospital staff has been groomed to very carefully stay away from the issue of Gulf War Illness. Every time I bring it up to this day, I have never been provided any written or even oral connection from the Hospital to Gulf War Illness. It was finally eluded to me in confidence that hospital staff could get into trouble for referencing Gulf War Illness in their treatment records and that they could not provide that nexus.

With this apparent and deliberate conflict of my interests for my VA Doctors to provide me the diagnosis I needed, I ultimately decided to leave the VA and go to a third party provider. I applied for copies of all of my medical records from the VA and traveled with them at my own very significant expense to the Mayo Clinic in Rochester MN for some real answers. I got a hotel and stayed there for three days in hopes of finally finding out what was so wrong with me.

Within three days, YES ONLY THREE DAYS I had the following diagnosis. This is something I have been unable to get at the VA in the four years I have been going there for treatment.

DIAGNOSES #1 Rheumatoid arthritis #2 Bilateral peroneal tendinopathy #3 Subpatellar degenerative arthritis of the left foot #4 Chronic fatigue, fibromyalgia #5 Gastroesophageal reflux disease #6 Chronic diarrhea #7 Prior chronic lower abdominal pain #8 Major depressive disorder, recurrent, moderate symptoms #9 Obstructive sleep apnea #11 Insomnia

So now in addition to the War Related Illness Center, I have diagnosis of all of the above from the Mayo Clinic. Clearly a connection right?? WRONG. While I considered this the smoking gun evidence I needed, I have still have not been awarded any connected disability to this day. ZERO PERCENT.

I have since resumed my treatment at the VA. I was told from my VSO there is approximately a two year wait before my appeal will even be opened. I have heard more recently that this wait is now up to four years. Over the last ten years I have lost two jobs and have lost my home and land due to bankruptcy. We have had to move twice and change schools which was really tough for my kids. I feel like I am on the verge of losing another job and I am afraid I can't rebuild things again. I am very fortunate to work from home where I have been able to hide and disguise my fatigue and sleep from my employer. My prayer is that I am granted some partial disability (50%+) so I can be honest with my employer and try to reduce my hours to accommodate the severe fatigue.

My VA psychologist told me Wednesday that it was an awful long time to hold onto life by my fingernails and I agreed. I have put a belt around my next twice and told my Doctor Wednesday that I would blow my brains out if I am denied again. 22 per day don't kill themselves because of PTSD—it's for being continually denied and called a liar by the administration that is supposed to be helping us. Veteran's and particularly those of war like me look at life very differently than most. If I have no hope-I will not continue to be a burden on myself, family, or country. I will however do my best to let them know I was destroyed by the Veterans Administration.

#### BRAIN CANCER (Not yet presumptive) - Missouri

My husband passed away from Glioblastoma Brain Cancer stage 4, three Brain tumors on March 21, 2013. He was diagnosed on January 20, 2013 with the tumors. Although this is not a presumptive, this is to be examined on a case by case bases. The claims examiner is to evaluate the available evidence to determine if it is at least likely that the Veteran's Brain Cancer is related to his or hers exposure to environmental hazards while Serving in the Gulf War.

Environmental hazards include but are not limited to reports of chemical alarms sounding of in Saudi Arabia as early as Jan 1991 and Sabotage of Kuwait Oil Wells in Jan 1991.

I have provided the Veterans Affairs Office and claims examiner over 59 medical files for review, However, the Denial determined by the V. A. Compensation claim examiner was denied with a review of only TWO medical files. I must say I have felt like a dog and pony show jumping through Circus hoops chasing down medical records, faxing. Following up,

hand delivering notices. The V.A. faxed a small Death Certificate that was not legible and I had to hand carry the document to the Physicians and Providers. This did stir up much emotion, to say the least.

I reside in Missouri, a small town close to Whiteman Air Force Base. I laid him to rest on our Wedding Anniversary. The most precious gift I could give him, His Military Honors.

My husband suffered with many illnesses for over nine years prior to the Glioblastoma Brain Cancer, some would have been presumptive, the headaches, undiagnosed neurological disorder, irritable bowel syndrome, degenerative disc disease, many surgeries. He had seven shots in his hands every four months. He immediately went to the V.A. and was put on the Gulf War Registry when his illnesses first started in 2002. We never ever thought he would pass away. It all happened so fast. I didn't have time to process anything. I lost the Love of my life. I was mentally and completely broken. I went to Therapy, eventually was treated with in-patient therapy as the Loss was so great I couldn't go on with my life. I never thought of contacting the VA until a little over a year of his passing. I made the funeral arrangements and paid for the marker myself. I wasn't aware he could be laid to rest in the National Cemetery just 20 minutes away with a Proper Military Marker. Although I Love the marker I purchased, I feel a bit cheated that His Air Force isn't displayed. I called the VA after getting my Gulf War Newsletter, to tell them in case they were keeping track and they told me to file a claim. I filed in July 2014. I provided so much medical evidence and proof, there is no way any Medical person could deny this. I am a common housewife and I can see the evidence clear as day. I have had two denials. I am currently collecting more Medical Evidence. I was asked to get Buddy Letters. Now that's impossible. The government admits the exposure, admits it causes Cancer of the Brain, yet throws ridiculous and impossible task on the Surviving Spouse. I can't ask my husband who his Buddies were now can I? The ongoing fight for Justice, I am HIS VOICE is a Daily struggle for me. I have panic attacks, I want to give up at times. Then I think about Him. His Strength. His Love for me. He fought to stay with me when he was suffering because I was crying and weeping and couldn't let him go.

Now it's my turn to fight for Him.

He wanted to take care of His Wife. He fought hard on His Death Bed for me. Now it's time for me to fight for him. I am His voice. May Justice and Truth Prevail for Our Hero's.

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