# BURN PITS 360 STATEMENT FOR THE RECORD BEFORE THE SENATE COMMITTEE ON VETERANS'AFFAIRS UNITED STATES SENATE

# FOR A SEPTEMBER 25, 2019 HEARING ENTITLED: "TOXIC EXPOSURE: EXAMINING THE VA'S PRESUMPTIVE DISABILITY DECISION-MAKING PROCESS"

Thank you, Chairman Isakson, Ranking Member Tester and distinguished members of the Subcommittee for this opportunity to submit a statement for the record.

For the past decade, Burn Pits 360 has been at the forefront of the issues resulting from toxic exposure, advocating for the families of the forgotten and those battling life-threatening illnesses. They stand with us here today and many of their personal stories are included in Appendix A, which we encourage you to review with the care that they deserve. The most important question is how is DOD and VA jointly addressing this delay and deny tactic? We must address the immediate needs and wellbeing of our active duty, veterans, caregivers and widows? Failing to do so is risking the safety and national security of the country and denying them the right to life.

Burn Pits 360 is a 501(c)(3) non-profit veterans organization located in Robstown, Texas. Our mission is to advocate for veterans, active duty service members, and families affected by deployment-related toxic exposures through research, education, outreach and advocacy. Burn Pits 360 created and maintains an independent burn pits exposure registry, which we will discuss in more detail below.

Our organization's impact has included helping to provide impetus to legislation creating the Airborne Hazards and Open Burn Pit Registry (AHOBPR) signed into law in 2013, P.L. 112-260, which also directed a longitudinal burn pits exposure study to be jointly conducted by the U.S. Departments of Defense (DoD) and Veterans Affairs (VA). Recently Burn Pits 360 was also successful in Texas where Governor Abbott signed a law for the creation of the Texas State Burn Pit Registry that will track mortality and health effects.

Our work is extensive, we participated in the open comment period for registry revisions submitted to the VA Office of Public Health (OPH), resulting in the addition of constrictive bronchiolitis (CB) to the registry. We presented our registry data to the National Academy of Sciences, Engineering, and Medicine (NASEM) committee created under the 2013 legislation, which resulted in an insightful scientific publication online in 2015 and in a peer reviewed medical journal in 2017. We have presented key statements to the Defense Health Board and have actively participated in every VA/DOD AHOBPR Burn Pit Symposium.

<sup>&</sup>lt;sup>1</sup> Szema, Anthony et al, "Proposed Iraq/Afghanistan War-Lung Injury (IAW-LI) Clinical Practice Recommendations: National Academy of Sciences' Burn Pits Workshop," Am J Mens Health, 2017 Nov; 11(6): 1653-1663. https://dx.doi.org/10.1177%2F1557988315619005

Recently we have had the honor of collaborating our efforts with several allies including Wounded Warrior Project, IAVA, Vietnam Veterans of America, The Dixon Center, Veterans for Common Sense and several others. We are most honored to have the support of the 9/11 advocates from the Fealgood Foundation and actor & comedian Jon Stewart who recently partnered with us in an effort to release an important Public Service Announcement on burn pits. Here is link to the PSA <a href="https://youtu.be/3s3nHo4szE8">https://youtu.be/3s3nHo4szE8</a>

Burn Pits 360 continues to work with Veterans, Active Duty Service Members, Congress, VA, DOD, Veteran Service Organizations and community stake holders to address the immediate needs of the survivors and their families. For almost a decade Burn Pits 360 has developed a strong platform of awareness and outreach through several initiatives including: a new website, independent registry, pod casts, Burn Pit town hall meetings, newsletters, state advocacy pilot program and a national public service announcement campaign. We will continue to collect voluntary self-reported data from our independent burn pit registry to assist us in developing legislation and policies to address the immediate needs of our warriors and their families. We cannot continue to grant one individual a burn pit claim as an instrumentality of war injury and dismiss another claim as a psychosomatic condition.

# **Burn Pits and Health Consequences**

During the OEF and OIF wars, government contractors and the military burned up to 227 metric tons of hazardous waste per day at forward operating bases using jet fuel as an accelerant. This involved the burning of plastics, medical waste including human body parts, expired pharmaceutical drugs, chemicals including paint and solvents, petroleum products, and unexploded ordinance, which according to some reports may have also included Iraqi chemical warfare agents.

Additionally, some of the burn pits were reportedly built on top of soil contaminated by chemical warfare agents.<sup>2</sup> Due to the unacceptable risk posed by these burn pits to our service members, their use was eventually mostly banned, except under narrow circumstances, in 2010. Tens of thousands of service members have been exposed to toxic chemicals and microfine, highly respirable and dangerous particulates from burns pits and they continue to suffer serious, disabling health consequences upon their return.

The wars in Iraq and Afghanistan exposed U.S. service women and men to an unprecedented array of airborne health hazards including from open-air burning in vast burn pits; shock waves and toxic particulates from improvised explosive devices (IEDs), including vehicle-borne improvised explosive devices (VBIED) and those containing chemical warfare agents; and hazardous microfine sand particles.<sup>3</sup> Service members with new-onset, post-deployment

<sup>&</sup>lt;sup>2</sup> Walker, Lauren, "US military burn pits built on chemical weapons facilities tied to soldiers' illness," *The Guardian (UK)*, February 16, 2016. <a href="https://www.theguardian.com/us-news/2016/feb/16/us-military-burn-pits-chemical-weapons-cancer-illness-iraq-afghanistan-veterans">https://www.theguardian.com/us-news/2016/feb/16/us-military-burn-pits-chemical-weapons-cancer-illness-iraq-afghanistan-veterans</a>

<sup>&</sup>lt;sup>3</sup> Szema, Anthony et al, "Iraq dust is respirable, sharp, and metal-laden and induces lung inflammation with fibrosis in mice via IL-2 upregulation and depletion of regulatory T cells," J Occup Environ Med. 2014 Mar;56(3):243-51. https://dx.doi.org/10.1097/JOM.000000000000119

respiratory symptoms from these hazards have been labeled as having Iraq/Afghanistan War-Lung Injury (IAW-LI), <sup>4</sup> a term we will also use throughout this document.

# Burn Pits Health Consequences Led to Creation of Burn Pits 360's National Registry

In 2010, Burn Pits 360 created a national burn pits exposure registry, joining forces with other affected families who were united by the need to prove a correlation between the veterans' toxic exposures during their deployments and the post-deployment illnesses (that in some cases were resulting in death) that had since plagued them. Burn Pits 360 continues to manage this registry, which has since grown to about 6,000 participants. The registry allows participants to later report a decline in health function, and their survivors to record mortality information including the cause of death.

Here is some of what we now know:

- Air sampling data indicate that smoke from these burn pits contained toxic chemicals associated with cancers, lung diseases, cardiovascular disease, kidney disease, neurological disorders, and more.
- The Burn Pits 360 national registry confirms that the array of devastating health conditions being suffered by exposed veterans include rare forms of cancer, pulmonary diseases, neurological disorders, and many other otherwise-unexplained diseases and symptoms. (See Appendix A, Cancer data from BP 360 Registry)
- There are over 100 death entry submissions in the Burn Pits 360 registry, including from rare cancers and from suicide.
- Both active duty and veterans are facing a high rate of denials for burn pit serviceconnected claims.
- Burn Pits 360's registry data demonstrates the national failure to adequately prevent, diagnose, treat, and compensate burn pit-exposed service members and veterans.

# **Recommendations For The Committee**

The current lack of clear understanding on the health impacts of these exposures should not circumvent our national obligation to assist every affected military service member, veteran and widow. As we explore the current processes, modifications to the process and how to better utilize the Burn Pit registry data to support future research we will focus on the following 4 areas:

1) Identifying Illness & Establishing evidence-based clinical practice guidelines and specialized healthcare model for Iraq Afghanistan War-Lung Injury and comorbid conditions;

<sup>&</sup>lt;sup>4</sup> Szema, Anthony et al, "Proposed Iraq/Afghanistan War-Lung Injury (IAW-LI) Clinical Practice Recommendations: National Academy of Sciences' Burn Pits Workshop," Am J Mens Health, 2017 Nov; 11(6): 1653-1663. https://dx.doi.org/10.1177%2F1557988315619005

- 2) Improving VA and DOD disability compensation claims process, including establishing presumption of service-connection for debilitating symptoms and diseases that have been linked to toxic chemicals.
- 3) **Improving the VA's burn pit registry** so that it is can be an effective research tool for monitoring and identifying the health consequences of toxic exposure;
- 4) Conducting more and better research into the health consequences of toxic exposures and to develop effective treatments;

# 1) Identifying Illness & Establishing evidence-based clinical practice guidelines

According to a recent search of VA's website that appears to list and link to all of the existing VA/DoD Clinical Practice Guidelines, Currently VA and DoD have not yet developed evidence-based Clinical Practice Guidelines (CPG's) for health care providers to understand how to identify, evaluate, treat, and refer patients with IAW-LI or other conditions that may be associated with exposure to burn pits.<sup>5</sup> At least one other VA/DoD CPG has come under harsh fire in a 2013 hearing before this Committee for not being evidence-based, and worse.<sup>6</sup>

There remains an unmet need of adequately educating primary care clinicians in the evaluation and treatment of burn pit related physical illness, including in DOD, VA, and civilian healthcare environments. There also remains an unmet need of describing evidence-based treatment recommendations for IAW-LI (including post-exertional shortness of breath and diagnosed respiratory conditions), toxic brain injury, and all disease and illnesses associated with deployment toxic exposures including from burn pits.

More importantly, the current process fails to assist the veteran in identifying their own illnesses. Because of the VA's dereliction of duty to this matter for the last fifteen years; it is our generation's Agent Orange.

<u>Recommendation</u>. Congress should mandate that VA create evidence-based clinical practice guidelines for IAW-LI that are appropriate for DOD, VA, and private healthcare providers to be able to identify, evaluate, treat, and refer patients with conditions that may be associated with exposure to burn pits including Iraq Afghanistan War-Lung Injury and comorbid cancers, respiratory, and other diagnosed diseases.

<sup>&</sup>lt;sup>5</sup> U.S. Department of Veterans Affairs website, retrieved June 5, 2018: <a href="https://www.healthquality.va.gov">https://www.healthquality.va.gov</a>

<sup>&</sup>lt;sup>6</sup> U.S. House Committee on Veterans' Affairs, "Persian Gulf War: An Assessment of Health Outcomes on the 25th Anniversary," <a href="https://veterans.house.gov/calendar/eventsingle.aspx?EventID=1104">https://veterans.house.gov/calendar/eventsingle.aspx?EventID=1104</a>

## VA & DOD Clinical Care: Establishing a Specialized Health Care Program

Develop deployment related toxic exposure specialty clinics within every VA and DOD healthcare systems led by physicians with a background in epidemiology and toxic exposure. The WRIISC Center model is not ideal for veterans unable to travel due to financial hardship and illness. Currently veterans are being misdiagnosed and symptoms are being dismissed as psychosomatic and not for the true illnesses they are suffering from.

<u>Recommendation</u>. We ask that Congress query VA leadership: Will VA commit to establishing specialty clinics at every CBOC, VA/DOD healthcare facility and develop a healthcare model to help identify life-saving treatments?

# 2. Improving VA and DOD Burn Pit Compensation Process

At the 2019 VA/DOD Burn Pit Symposium the Veterans Benefits Administration provided the group Key National Statistics as of 2/1/19.

- National Pending Claims Inventory
   -324,093 Compensation Claims (1,523 claims based on Burn Pit Exposure)
- Total # Veterans Claiming Disabilities Based on Burn Pit Exposure (since June 2007)
   -10,588 Veterans
- Total # Veterans Granted Compensation Based on Burn Pit Exposure (since June 2007)
   -2,360 Veterans
- Total # Veterans Denied Compensation Based on Burn Pit Exposure (since June 2007)
   -8,228 Veterans

<u>Recommendation</u> We urge the Committee to investigate the Veterans Benefits Administration about how the VA is handling burn pit claims. The disclosure of the information requested supplement the research done, filling in missing information that will allow us a better understanding of the health effects of burn pits.

- 1. What data did the VA use to arrive at its number (10,588) of total burn pit related claims? Please provide a copy and explanation of the data used to arrive at this number.
- 2. How did VA arrive at the number (2,360) of burn pit related claims wherein VA states it awarded benefits? Does the number (2,360) represent just the burn pit related issues granted in said claims, or does it represent "any" award of benefits, burn pit related or not, out of the total number in question one? Please provide a copy and explanation of this data.
- 3. Out of the number of claims VA states were granted (2,360), how many of the veterans who had their claims granted developed symptoms or received diagnoses while still serving in the military?

4. VA had no claims adjudication policy on burn pit related claims, or any other OIF/OEF exposure related claims, prior to issuing VBA Training Letter 10-03 in April 2010. The policy states:

Employees involved in the development of these claims must choose the appropriate Special Issue identifier on the MAP-D Contentions screen. Currently, the only identifier pertaining to exposure claims is "Environmental Hazard in Gulf War," which is only appropriate for exposure within Southwest Asia.

If these instructions were released in April 2010, and even then, the only identifier for such claims was the same identifier used for claims for the first Gulf War, then how did VA identify the number of post 9/11 burn pit-specific claims from 2007, especially when VA's own policy document in 2010 states it did not have that capability?

- 5. How many Veterans' claims with service *after* September 2001 in Iraq/Afghanistan were tracked with the special issue identifier "Environmental Hazards in Gulf War"?
- 6. The portion of VA Training Letter 10-03 pertaining to constrictive bronchiolitis states the following:

Regional office personnel may have a difficult time rating disabilities in this population. In most cases, the affected soldiers are comfortable at rest and are able to perform the activities of daily living. They have normal or near normal pulmonary function tests, but, at the same time, become short of breath on slight physical exertion, cannot meet physical training requirements, and are considered unfit for deployment. This unique circumstance challenges those who must determine a disability rating. Pulmonary function testing is the usual standard for rating respiratory disabilities. Therefore, rating authorities should utilize an appropriate analogous code (such as 6600-6604) since the condition does not have its own diagnostic code, and consider extra-scheduler ratings in such cases when there is evidence that a Veteran's employment is affected.

Of the claimants *granted* service connection for constrictive bronchiolitis, how many were referred to Compensation Service for an extra-scheduler evaluation and what training is in place for regional personnel to rate disabilities with this population?

- 7. Since VA has acknowledged, near 10 years ago, that it does not have rating criteria for constrictive bronchiolitis, what progress, if any, has been made toward developing rating criteria for this disability?
- 8. How many Veterans with service after September 2001 who served in Iraq and/or Afghanistan have been issued a rating decision wherein VA coded (on the rating decision code sheet) a 6600 series diagnostic code?
  - 1. Among those, how many were granted and how many were denied? Among those, both granted and denied, please provide a breakdown of which of the 6600 series codes were use.
  - 2. How many were coded under an "analogous" diagnostic code?

9. Out of the 8,228 burn pit claims granted and denied, how many of those were claims for death benefits?

VA's Compensation and Pension Manual, M21-1MR, provides guidance for adjudicating claims resulting from various toxic exposures. The relevant section, entitled, "Service Connection for Disabilities Resulting from Exposure to Other Specific Environmental Hazards," at least partially governs VA's burn pits exposure-related compensation claims. Relevant identified hazards include "large pit burns throughout Iraq, Afghanistan, and Djibouti on the Horn of Africa" and "particulate matter in Iraq and Afghanistan."

VA Training Letter 10-03, identified in the manual, provides more specific policy guidance on processing burn pit claims.

Additionally, after the 1991 Gulf War, Congress enacted statutory directives at 38 U.S.C.§ 1117, which addressed a range of disabilities in veterans who served in Southwest Asia. VA then promulgated its regulations at 38 C.F.R. § 3.317. Although rarely applied correctly by VA, the law provides for presumptive service connection for a "qualifying chronic disability." A qualifying chronic disability means a chronic disability resulting from "an undiagnosed illness" (UDX) or "a medically unexplained chronic multi-symptom illness [CMI] that is defined by a cluster of signs or symptoms, such as: (1) chronic fatigue syndrome; (2) fibromyalgia; (3) functional gastrointestinal disorders" [including irritable bowel syndrome (IBS)]. If a veteran's disability pattern is either one of these, then VA must grant service connection based on § 3.317. Veterans with burn pit exposure who served in the Southwest Asia theatre of operations (which does not include Afghanistan or Djibouti) anytime from August 1991 the present may also qualify to have their claims adjudicated under these provisions.

VA and DOD should have little problem establishing exposure in burn pit cases because nearly every forward operating base (FOB) in Iraq, Afghanistan, and Djibouti had a burn pit. Given the widespread nature of the burn pits, and the inability of military personnel records to identify all duty locations, VA adjudicators are generally supposed to accept the veteran's lay statement of burn pit exposure as sufficient to establish the occurrence of such exposure if the Veteran served in Iraq or Afghanistan.

# **VA Claims: Medical Diagnosis and Adjudication Practices**

At times, VBA staff have exhibited confusion about relevant diagnosis for veterans with burn pits exposures. Confounding burn pit claims with Gulf War Illness claims, they have returned documentation explaining that service-connection could not be granted because the veteran did not have an undiagnosed illness (UDX) or a medically unexplained chronic multi symptom

https://www.benefits.va.gov/WARMS/docs/admin21/m21 1/mr/part3/subptiii/ch05/pt03 sp03 ch05 secj.doc

<sup>&</sup>lt;sup>7</sup> U.S. Department of Veterans Affairs, Veterans Benefits Administration, M21-1MR, Part IV, Subpart ii, Chapter 2, Section C, Topic 12, "Service Connection for Disabilities Resulting from Exposure to Other Specific Environmental Hazards."

illness (CMI). These are complex regulations that VA has systemically failed in correctly applying to the appropriate cases.

Burn Pit related claims are not the same claims as under the Persian Gulf War regulations. Claims based on the Gulf War regulations are granted, if at all, on a legal presumption that the disability is related to service in Southwest Asia. Whereas, claims based on OIF/OEF exposures, such as burn pits, are granted, if at all on a direct basis (i.e., event or exposure during service; diagnosed disability; and, a medical nexus between the two.)

There are times, however, when VA claims staff appropriately apply both sets of rules. A good example is when a veteran who served in Iraq after September 11, 2001 files a service connection claim for a disability that could satisfy the "qualifying chronic disability" requirements of 38 C.F.R. § 3.317 but is also a disability that may be directly related to exposures in Iraq after September 11, 2001, such as burn pits. In such a case, VA should consider both sets of rules separately and then grant the veteran's claim under whichever is of greatest benefit to the veteran.

<u>Recommendation</u>. The Committee should request detailed information from VA on the gaps and overlaps between the application of these two types of claims adjudication processes for veterans with burn pits exposure and resultant disability.

# **VA Claims: Adjudication Issues**

Most disability claims require a medical examination from a VA practitioner or contracted VA examiner. In burn pit claims, these so-called Compensation and Pension (C&P) exams are very important because VA has not yet acknowledged a medical nexus between burn pit exposure and the disabilities burn pit veterans are experiencing. Often, the veteran's only chance to show a medical link between their symptoms and contact with burn pit emission is a medical opinion issued by one of these C&P examiners.

This makes it all the more troubling that VBA staff so routinely fail to follow VA guidance on requesting C&P exams for burn pit exposure claims. When they do follow the guidance, the only training C&P examiners receive on burn pit emissions is a one-page "fact sheet" produced by VBA when it issued Training Letter 10-03.

VBA staff also frequently neglect to send the minimalist fact sheet required for all C&P exam requests pursuant to VBA's M-21 procedural manual. This leaves examiners with little to no information about which chemicals have been detected in burn pits emissions, how burn pits were operated, and other potentially critical medical information.

Most examination reports serve little more purpose than to reveal the person conducting the examination has no experience in burn-pit related claims or are simply not aware they even exist. The status quo answer in response to requests for VA medical opinions is quickly becoming that VA has not found the particular veteran's disease process is caused by service in Southwest Asia.

Such opinions rarely acknowledge the claim is even burn pit related, much less provide any analysis on the chemicals produced by the burn pits in relation to the veteran's disability.

If a veteran files a disability claim within a year of their separation from service, a C&P exam is generally ordered for all claims. A year or more after a Veteran's separation, C&P exams are ordered if the claim meets a certain threshold of evidence. VBA usually manages to verify exposure and thus request an exam in burn pit cases. But confusion about burn pit claims has led to mistakes that could prevent or delay the ordering of a C&P exam. Or, if the wrong type of exam is ordered, a second exam may need to be requested. Veterans often have to wait months to get an exam due to the longstanding backlog of disability claims.

In developing for a medical nexus between burn pit exposure and the veteran's diagnosis, VBA staff have ordered medical examinations for the wrong condition (often Gulf War Illness related). Or, when claims staff ordered the correct exam, they have requested medical opinions from examiners who, by VA's own standards, are unqualified to give them-for example, physicians assistants (PAs).

Inadequacy of training on burn pits exposure and Gulf War claims appears to be a deciding factor in the negative outcomes veterans are experiencing with these claims. This inadequate training appears to extend from VHA and contractor medical examiners to VBA claims adjudication staff.

These errors and confusion in the development process have led to unnecessarily long wait times for veterans suffering from often debilitating, and sometimes life-threatening, disabilities resulting from their burn pits exposures.

<u>Recommendation</u>. Congress should make necessary statutory changes to ensure appropriate outcomes for burn pits exposure claims, including mandatory training (and ensuring the appropriateness of that training) for VHA and contractor medical examiners and VBA claims adjudication staff.

## **Establishing presumptions of service-connection**

Among the serious diagnosed medical conditions identified in service members with IAW-LI is an extremely rare, irreversible, and often fatal respiratory disease called constrictive bronchiolitis (CB) and sometimes also called bronchiolitis obliterans (OB). The medical literature reveals CB/OB to be caused by occupational exposure to diacetyl ("popcorn lung"), in Iranian survivors of Iraqi sulfur mustard (mustard gas) attacks during the 1981-88 Iran-Iraq war, and in OIF/OEF veterans.

Currently, CB/OB can only be can only be identified by a highly invasive lung biopsy conducted under general anesthesia, though medical research is currently underway in the Congressionally Directed Medical Research Program (CDMRP) that if successful would allow for non-invasive diagnostic methods.

Biopsies have been performed on numerous OEF/OIF Veterans whose worsening breathing problems including shortness of breath, especially following even limited exertion, could not be diagnosed by traditional tests, such as x-rays, CT scans, MRIs, or pulmonary function testing. Lung biopsies have returned a positive diagnosis for CB/OB in approximately 90 percent of these cases.

There are several issues of concern here. First, we are hearing from veterans that VA is not currently service-connecting their CB/OB without a confirmatory biopsy.

And, even with such confirmation, VA often denies service-connection on the basis of lack of proof of in-service causation. For veterans without a confirmatory biopsy of CB/OB, it is nearly impossible for them to get VA (or DoD) to provide one.

And, veterans returning without a formal CB diagnosis but with debilitating post-deployment respiratory and other chronic symptoms, which for many veterans developed while they were still deployed, far too often are denied by VA for service-connection.

In short, VA's requirements for these debilitating post-deployment respiratory conditions are nearly impossible for most veterans to meet, despite their serious disability. By contrast, the U.S. Social Security Administration (SSA) has added CB as a Compassionate Allowance after medical research identified the disease as causally related to environmental toxins, including burn pits, in Iraq and Afghanistan. Not so with VA.

Additionally, many of Burn Pits 360's members and constituents have been diagnosed with unexplained cancers, including an array of leukemias, brain cancers, and other cancers. Many of these veterans are young. Many have died, without compensation or appropriate VA assistance for themselves or their survivors.

<u>Recommendations</u>. We ask that Congress pass H.R. 1005, The Burn Pits Veterans Revision Act of 2019, adding a diagnostic code and evaluation criteria for the war lung disease Obilterative Bronchiolitis and amend Title 38, United States Code, to:

- A.) Provide a presumption of service-connection for VA compensation for symptombased respiratory disability in veterans exposed with presumed exposure to these airborne hazards;
- B.) Provide a presumption of service-connection in cases where the veteran has been given a diagnosis of CB/OB or other debilitating respiratory diseases, including chronic obstructive pulmonary disease (COPD), post-exertional asthma, pulmonary fibrosis, and other diagnosed respiratory conditions;
- C.) Provide a presumption of service-connection in cases where the veteran has developed any of the array of post-deployment cancers that we have identified in these veterans.

## 3) Improving the VA's Burn Pit Registry & Burn Pit Exam

As noted earlier, in 2013, DOD and VA were directed by Congress to set up a registry to collect information from service members who may have been exposed to toxic chemicals and fumes caused by open air burn pits and other airborne hazards. The resulting Airborne Hazards and Open Burn Pit Registry (AHOBPR) to date has 178,654 registrants who completed and submitted the registry questionnaire.<sup>8</sup>

And, on February 28, 2017, the NASEM committee mandated in P.L. 112-220 (the Committee on the Assessment of the Department of Veterans Affairs Airborne Hazards and Open Burn Pit Registry) released its final report, entitled, "Assessment of the Department of Veterans Affairs Airborne Hazards and Open Burn Pit Registry." Several key points emerged that we will mention shortly.

First, with a total of over 3.5 million eligible personnel, participation in the VA's registry is far below expectations. Without a drastic increase in registration, it is difficult to see how the VA's registry can provide an accurate assessment of the health effects of open-air burn pits on our service members and veterans.

Currently, there is no way for a service member or veteran to report a decline in health. If registrants initially register as having no ill effects from the burn pits but are subsequently diagnosed with a disease or illness, they cannot later add that information to the VA registry. This limits the long-term effectiveness of using the VA registry to assess the impact of toxic burn pits on our service members' health over an extended period of their lives and to conduct longitudinal studies regarding the health effects associated with burn pit exposures.

We are also concerned with the participation rate in the VA Registry's Burn Pit Exam, the initial in-person medical evaluation. As we understand it, the evaluation's intent is to have a VA practitioner systematically assess a service member or veteran for symptoms related to their toxic exposures. This would allow for the creation of a fuller picture of the patient's health than can be obtained through the self-reported survey alone. However, according to a presentation given by Stephanie Eber and Susan Santos of the VA, as of April 2017, *only 2.8 percent* of registry participants have undergone this exam.

Another serious shortfall of the VA registry is that it does not allow family members to register the death of registry participants, especially important when there is reason to believe the death was a result of toxic exposure from burn pits. Without tracking the mortality rate through methods such as allowing surviving family members to report deaths and the cause of death, the registry's ability to establish mortality rates related to conditions and diseases associated with toxic exposure is precluded. We recommend Congress pass H.R. 1001, the Family Member access to Burn Pit Registry Act, which will direct the Secretary of Veterans Affairs to provide a

<sup>&</sup>lt;sup>8</sup> U.S. Department of Veterans affairs website, retrieved June 5, 2018, <a href="https://www.publichealth.va.gov/exposures/burnpits/registry.asp">https://www.publichealth.va.gov/exposures/burnpits/registry.asp</a> Registrants completed and submitted the registry questionnaire between April 25, 2014 and May 1, 2018, including from OIF, OEF, Operation New Dawn, Djibouti since 9/11, and Southwest Asia since August 1990.

process by which a family member of a deceased individual who is eligible for the Department of Veteran Affairs burn pit registry may register for such registry on behalf of the deceased individual.

Most significantly, the NASEM committee on the assessment of VA's registry stated in its final report: "On the basis of its evaluation of the data, the committee concluded that the exposure data are of insufficient quality or reliability to make them useful in anything other than the most general assessments of exposure potential."

### The Committee concluded:

Attributes inherent to registries that rely on voluntary participation and self-reported information make them fundamentally unsuitable for addressing the question of whether burn pit exposures have caused health problems. Addressing the issues identified by the committee would, though, improve the AH&OBP Registry's utility as a means of generating a roster of concerned individuals and creating a record of self-reported exposures and health concerns.

All parties—service members, veterans, and their families; VA; Congress; and other concerned people—would benefit from having a realistic understanding of the strengths and limitations of registry data so that they can make best use of them and, if desired, conduct the kind of investigations that might yield salient health information and improve health care for those affected.<sup>10</sup>

Previously, the website stated, "A workgroup of VA subject matter experts is reviewing the report's nine recommendations to determine ways to improve the health status and medical care of veterans." To date, we are not yet aware of improvements to the VA's registry recommended either by the NASEM report or the researchers' recommendations published online in 2015 and in a medical journal two years ago. 11

<u>Recommendation</u>. We encourage the Committee to seek answers from the VA for the following important questions, and legislating or otherwise ensuring changes as may be appropriate based on VA's responses:

1. Thousands of veterans who were exposed to toxic smoke from burn pits in Afghanistan and Iraq are coming home and developing serious illnesses like constrictive bronchiolitis, other respiratory conditions, and cancers. Is it VA's position that prolonged exposure to toxic chemicals from open air burning can have lasting negative health consequences?

<sup>&</sup>lt;sup>9</sup> National Academy of Science, Engineering, and Medicine (NASEM), Committee on the Assessment of the Department of Veterans Affairs Airborne Hazards and Open Burn Pit Registry, "Report Highlights," February 28, 2017. <a href="http://www.nationalacademies.org/hmd/reports/2017/assessment-of-the-va-airborne-hazards-and-open-burn-pit-registry.aspx">http://www.nationalacademies.org/hmd/reports/2017/assessment-of-the-va-airborne-hazards-and-open-burn-pit-registry.aspx</a>

<sup>&</sup>lt;sup>10</sup> NASEM 2017

<sup>&</sup>lt;sup>11</sup> Szema et al, 2017

- 2. The VA has not seriously researched the consequences of burn pit exposure. Congress mandated that VA implement the Registry to monitor health conditions affecting veterans and service members who were exposed to toxic smoke from burn pits and other hazards. But, according to a 2017 report from the National Academy of Sciences, the registry is fatally flawed and ineffective as a way to investigate the true health consequences of burn pits. Will VA commit to reforming the burn pits registry to make it a genuinely useful tool for documenting the true health consequences of burn pits?
- 3. Who is on the "workgroup of VA subject matter experts" that was reviewing the nine recommendations? What records reflect their work in response to the 2017 National Academy of Sciences report, including their recommendations or determinations?
- 4. What records reflect the improvements that the VA is considering to the Registry based on the recommendations of the 2017 report?
- 5. What records exist regarding concerns about the burn pit registry, including concerns from individual veterans and Veteran Service Organizations regarding the registry?
- 6. What outreach methods are in place to ensure that service members deployed to Iraq and Afghanistan post-9/11 are aware of the registry and are encouraged to register if they believe they have been exposed to toxic matter through open air burn pits?
- 7. What factors explain the discrepancy between the numbers of service members potentially exposed, versus the number of registrants to the burn pits registry?
- 8. What is the VA's strategy to increase participation in the registry?
- 9. Does the VA regularly communicate with registrants?
- 10. How is the VA gathering data, if at all, to assess change or decline in health among service members, to support a longitudinal assessment? Why would the VA not support including an option for updated reporting in the registry?
- 11. How is the VA gathering mortality data, if at all, associated with toxic exposures through burn pits? Why would the VA not support including an option for reporting deaths in the registry?
- 12. What factors explain the low participation rate of registrants with the associated exam?

- 13. Has the VA adopted a strategy to increase the participation rate in the initial Burn Pit exam? Why has there only been 6 million combined dollars allocated to DOD and VA for outreach?
- 14. Is there a uniform protocol in place that practitioners who administer the exam are following? If yes, what is the protocol and has it proven effective in recognizing common warning signs and symptoms indicating toxic exposure?
- 15. What protocol does the VA have in place to ensure that its practitioners are equipped to detect and treat medical issues associated with toxic exposure among registry participants VA examines?

<u>Recommendation</u>. To encourage full Registry participation, Congress should offer Veteran Service Organizations grant funding to execute effective national outreach campaigns to their constituents.

## 3. Active Burn Pits

In the April 2019 DOD Open Burn Pit Report to Congress reported that we have 9 active burn pits in operation, 7 U.S. Forces and 2 Contractor operated. DOD stated in the report several times that "no location has more than 500 personnel assigned" implying that this amount of personnel shouldn't generate high volumes of trash resulting in a less toxic environment. According to the 2011 NAM report each soldier generates 8-10lbs of waste per day. A soldier on a 6-month tour will generate around 1800 lbs. of waste and a soldier on a 12-month tour generates 3600 lbs. of waste. In 12 months, that is 1,800,000 lbs. of waste for 500 personnel.

Another statement made is that the small locations do not generate waste streams that require incinerators and that large logistics do generate enough waste suitable for incinerator use but according to DOD open burning remains an alternative to protect troops from disease. So, the excuse of not using the safety of incinerators goes from significant funding to the amount of trash generated.

According to the VA Office of Public Health, the active burn pit sites are quite different and may represent a different composition of airborne hazards than the area currently covered by the AHOBPR. The VA denied our request to add the 9 active burn pit sites to the VA Registry. As of today, service members being exposed to toxic chemicals cannot register.

# 4) Conducting More and Better Research

The VA was directed under P.L. 112-260 to contract for an independent scientific report that would contain the following:<sup>12</sup>

 $<sup>^{12}</sup>$  PUBLIC LAW 112–260—JAN. 10, 2013 126 STAT. 2423 – SEC. 201. ESTABLISHMENT OF OPEN BURN PIT REGISTRY. (b) REPORT TO CONGRESS.—

<sup>(1)</sup> REPORTS BY INDEPENDENT SCIENTIFIC ORGANIZATION.— The Secretary of Veterans Affairs shall enter into an agreement with an independent scientific organization to prepare reports as follows:

- An assessment of the effectiveness of actions taken by the Secretaries to collect and maintain information on the health effects of exposure to toxic airborne chemicals and fumes caused by open burn pits.
- Recommendations to improve the collection and maintenance of such information.
- Using established and previously published epidemiological studies, recommendations regarding the most effective and prudent means of addressing the medical needs of eligible individuals with respect to conditions that are likely to result from exposure to open burn pits.

Certainly VA has not yet determined the "most effective and prudent means of addressing the medical needs of eligible individuals with respect to conditions that are likely to result from exposure to open burn pits."

<u>Recommendation</u>. We encourage the Committee to provide continued oversight with regards to the status of this report and the implementation of its recommendations.

According to VA's website, NASEM's 2011 report, <u>Long-Term Health Consequences of Exposure to Burn Pits in Iraq and Afghanistan</u>, "found limited but suggestive evidence of a link between exposure to combustion products and *reduced lung function* in various cohorts similar to deployed Service members, such as firefighters and incinerator workers. This finding focused on pulmonary (lung) function, not respiratory disease, and noted that further studies are required. There is little current scientific evidence on long-term health consequences of reduced lung function."<sup>13</sup>

VA goes on to say, "VA and the Department of Defense will conduct a long-term study that will follow Veterans for decades looking at their exposures and health issues to determine the impact of deployment to Iraq and Afghanistan. Read the <u>February 4, 2013 notice in the Federal</u> Register to learn more."

It has been more than five years since VA announced it planned to conduct this long-term study. VA has had ample opportunity to conduct it.

<sup>(</sup>A) Not later than two years after the date on which the registry under subsection (a) is established, an initial report containing the following: (i) An assessment of the effectiveness of actions taken by the Secretaries to collect and maintain information on the health effects of exposure to toxic airborne chemicals and fumes caused by open burn pits.

<sup>(</sup>ii) Recommendations to improve the collection and maintenance of such information.

<sup>(</sup>iii) Using established and previously published epidemiological studies, recommendations regarding the most effective and prudent means of addressing the medical needs of eligible individuals with respect to conditions that are likely to result from exposure to open burn pits.

<sup>(</sup>B) Not later than five years after completing the initial report described in subparagraph (A), a follow-up report containing the following: (i) An update to the initial report described in subparagraph (A).

<sup>(</sup>ii) An assessment of whether and to what degree the content of the registry established under subsection (a) is current and scientifically up-to-date.

<sup>(2)</sup> SUBMITTAL TO CONGRESS.—

<sup>(</sup>A) INITIAL REPORT.—Not later than two years after the date on which the registry under subsection (a) is established, the Secretary of Veterans Affairs shall submit to Congress the initial report prepared under paragraph (1)(A).

<sup>(</sup>B) FOLLOW-UP REPORT.—Not later than five years after submitting the report under subparagraph (A), the Secretary of Veterans Affairs shall submit to Congress the follow-up report prepared under paragraph (1)(B). https://www.gpo.gov/fdsys/pkg/PLAW-112publ260/pdf/PLAW-112publ260.pdf

<sup>&</sup>lt;sup>13</sup> U.S. Department of Veterans Affairs website, retrieved June 4, 2018: https://www.publichealth.va.gov/exposures/burnpits/health-effects-studies.asp

<u>Recommendation</u>. We urge Congress to mandate an independent epidemiologic research study – outside of VA, which has already had ample opportunity to do so – that will help to more formally identify the association between inhaling toxic chemicals from burn pit smoke and resultant health conditions and deaths.

Such research should include determining the incidence and prevalence of IAW-LI and other potentially related health conditions in: (1) military service members and veterans currently in treatment for post-burn pit exposure health complaints; (2) Iraqi local populations similarly exposed to U.S. burn pits (see appendix C); (3) healthy control populations of Iraq and Afghanistan War deployed and non-deployed era service members/veterans.

<u>Recommendation</u>. We encourage the Committee to seek answers from the DOD and VA for the following important questions, and legislating or otherwise ensuring changes as may be appropriate based on VA's responses:

- 1. Which specific office(s), working group(s) or people are assessing the adequacy and effectiveness of data gathering and surveillance of the health consequences of burn pits?
- 2. Does VA have any unpublished studies, reports, or similar documents regarding health effects of burn pits?
- 3. How does VA review, assess, and assimilate studies into (i) its assessment of the long-term health consequences of burn pits and (ii) its screening for potential burn-pit related disease and (iii) its treatment for burn-pit related disease?
- 4. What records exist that would reflect VA's assessment of such studies (including, potentially, internal correspondence, memos, etc.)
- 5. What internal assessments, memos, or other documents underlie the VA's determination that "At this time, research does not show evidence of long-term health problems from exposure to burn pits."
- 6. Which specific office (or which officials) are involved in internal reassessment or reevaluation of VA's determination that there is currently no evidence of long-term health problems? What records exist that would reflect any such ongoing assessment or evaluation?
- 7. The VA's "fact sheet" on burn pits, which describes ongoing research into the health effects of burn pits and the inconclusive nature of prior research. The last time we reviewed it, that fact sheet was last updated in November 2013 and only referred to studies from 2009 and 2011. Which specific office (or which officials) are involved in reassessing the statements in that fact sheet in light of more recent research? What records exist that would reflect potential reassessments or updates of the fact sheet?

# **DOD-CDMRP Burn Pit Exposure Medical Research**

As many of the members of this Committee know from past hearings on another toxic exposure issue, Gulf War Illness, many ill Gulf War veterans are encouraged by ongoing treatment research directed by Congress, including by many of you and other leaders and Members of the House Veterans' Affairs Committee. Specifically, that treatment research is being done by the

Gulf War Illness Research Program (GWIRP), part of the Congressionally Directed Medical Research Program (CDMRP) that is funded under the Department of Defense (DOD) health budget.

Like the GWIRP, many of the health research programs within the CDMRP are standalone programs. However, others are congressionally designated topic areas within broader programs like the CDMRP's Peer Reviewed Medical Research Program (PRMRP). The specific topic areas to be pursued are determined by Congress each year through annual Defense appropriations.

For Fiscal Year 2018, there are several medical research topic areas in the CDMRP-PRMRP that remain of strong interest to veterans affected by burn pit exposure, including: Acute Lung Injury; Burn Pit Exposure; Constrictive Bronchiolitis; Lung Injury; Metals Toxicology; Mitochondrial Disease; Pulmonary Fibrosis; and Respiratory Health. We are grateful to Congress for including all of these research topic areas, particularly the restoration of the Burn Pits Exposure topic area.

CDMRP is important for this treatment-focused research for several reasons. First, CDMRP has the ability to fund any qualified research team, not just those employed by the funding agency. By contrast, VA's medical research program is solely intramural and open only to VA-employed researchers. Much of the valuable medical research related to burn pits exposure has been led by researchers at independent, academic medical centers including Vanderbilt University, Stony Brook University, the Deployment-Related Lung Disease Center at National Jewish Health, and others.

Second, CDMRP includes in all levels of planning, proposal review, and funding decisions the active participation of consumer reviewers – patients (or their caregivers) who are actually affected by the disease. This is of critical importance. VA offers no opportunity for similar involvement in research decision-making by the patients who are ultimately affected by such decisions.

Finally, CDMRP has already shown its effectiveness with regards to other complex post-deployment, toxic exposure health conditions including traumatic brain injury (TBI) and Gulf War Illness (GWI), including through its emphasis on collaboration, treatment focus, and effective two-tiered peer review.

<u>Recommendation</u>. We encourage Members of the Committee work to create a Congressionally directed standalone Burn Pits Exposure Research Program (BPERP) within the Congressionally Directed Medical Research Program (CDMRP), modeled after the successes of other CDMRPs including the treatment-focused Gulf War Illness Research Program, as follows:

A standalone burn pits exposure CDMRP would ideally be laser-focused on improving the health and lives of veterans suffering the negative health effects of burn pit exposures and on learning all that is possible from their health experiences to help future veterans similarly exposed. Like the existing standalone CDMRPs, the proposed Burn Pits Exposure Research Program would have its own dedicated staff, focused exclusively on advancing the Congressional directives

related to this burn pit exposure medical research program. Ideally, it would be focused on several major areas to more rapidly improve the health and lives of veterans affected by burn pits exposure:

- Accelerating the development of treatments and their clinical translation for Iraq/Afghanistan War Lung Injury (IAW-LI) and comorbid associated conditions
- Improving scientific understanding of the pathobiology resulting from burn pit exposures, including in both affected veterans and in animal models of burn pit exposures, and including research priorities to identify biomarkers of exposure, biomarkers of exposure effect, and biomarkers of illness all critical in improving the definition and diagnosis, disease monitoring, and monitoring of the effectiveness of tested treatments of veterans affected by burn pit exposure
- Assessing comorbidities, including the incidence, prevalence, early detection and diagnosis, treatments for, and any unique factors related to burn pits exposed veterans': constrictive bronchiolitis (CB/OB), pulmonary fibrosis, sarcoidosis, chronic obstructive pulmonary disease (COPD), post-exertional asthmas, and other respiratory diseases; cancers including lung cancer, leukemia, glioblastoma and other brain cancers, renal cancer, and other cancers
- Identifying force health protection prevention measures to prevent future burn pit exposures, and to provide early assistance to future military service members exposed to burn pits
- Using other CDMRP successes as a model, investing appropriated medical research funding to **develop a collaborative**, **inter-institutional**, **interdisciplinary burn pits exposure research consortium**, while investing other appropriated medical research funding to support focused medical research in the areas described above

We would be pleased to work early next year with any Members interested in creating, on a bipartisan, bicameral basis, a cosigned request for fiscal year 2020 funding to create such a Burn Pits Exposure Research Program.

# **APPENDICES**

Appendix A: Burn Pits 360 Registry Cancer Data

**Appendix B: Physician Disability Claims Statements** 

Appendix C: Dr. Savabieasfahani Iraqi Population Study

**Appendix D: Personal Testimonies** 

**Appendix E: Photos** 



As of March, 2019, at least 506 veterans and others who were exposed to toxic smoke from the burn pits in Iraq and Afghanistan have reported to Burn Pits 360 what they believe to be service related cancers that they are now receiving treatment for.

# THE TOP 10 CANCERS SO FAR ARE

Skin (139)

A

Soft Tissue Sarcoma (42)

A

Lymphoma (116)

A

Lung (39)



**Brain (97)** 



Testicular (39)



Esophageal (45)



Prostate (34)



Leukemia (42)



**Blood (31)** 

The Veteran's Administration maintains that their research does not show evidence of long-term health problems from exposure to burn pits.



# Appendix B: Physician Disability Claims Statements





Hillsboro Medical Group at Vanderbilt

November 12, 2015

To: Congresswoman Elizabeth Esty Captain Leroy Torres, Ret Rosie Torres

Re: Veterans Administration Compensation Code for Constrictive Bronchiolitis

l am writing to support adding constrictive bronchiolitis to the VA compensation code. This is an otherwise rare pulmonary condition that has been linked to service in Iraq and Afghanistan. The current code does not allow compensation for the typical patient with this service-connected illness.

I began seeing Ft. Campbell soldiers with constrictive bronchiolitis in 2005. The typical service member deployed as an elite athlete and returned from deployment incapable of completing a two mile run. In most cases, their inability to meet the Army's physical fitness standard ended their eligibility to remain in the armed forces. Service members with constrictive bronchiolitis typically experience exercise limitation, chest tightness and cough. Despite these symptoms and severely abnormal biopsies, they usually have normal x-rays, CT scans and pulmonary function testing. These findings have been widely accepted by academia and have been published in the New England Journal of Medicine (July, 2011). The United States' Defense Health Board Deployment Pulmonary Health Report agrees that constrictive bronchiolitis among service members is a medical condition which is usually missed by routine x-rays, CT scans and pulmonary function testing.

The current VA Compensation Code requires abnormal x-rays, pulmonary function testing or cardiopulmonary exercise testing to provide a disability rating for a service member or veteran. The system fails to provide compensation for the vast number of veterans diagnosed with constrictive bronchiolitis.

I am writing to support legislation that would change the code to allow service members with constrictive bronchiolitis an appropriate rating even in the setting of their having normal noninvasive studies. This condition is very rare and is clearly related to deployment exposures. It is not fair to dismiss this diagnosis which is what is done with the current Veterans Administration Compensation Code.

Thank you for your consideration.

Sincerely,

Robert Miller, M.D.

1 sul

Associate Professor of Medicine



DEPARTMENT OF VETERANS AFFAIRS G. V. "Sonny" Montgomery Veterans Affairs Medical Center Jackson, MS 39216

January 27, 2016

Dear Senator,

Many veterans of the wars in Iraq and Afghanistan are returning home disabled from a respiratory condition known as constrictive bronchiolitis. This disease affects young, non-smoking men and women and presents as slowly progressive shortness of breath. In its mildest form it limits exercise capacity, and in its more severe form affects daily life sometimes requiring supplemental oxygen 24 hours a day.

I serve veterans as a pulmonologist at the VA Medical Center in Jackson, Mississippi where I am confronting this disease daily. Currently, there are over 100 patients seen at our hospital with this condition confirmed or suspected. The medical community needs your support for research dollars to learn more about this disease and possible treatments. We also need constrictive bronchiolitis listed as a presumptive service connected disease as it is clearly related to airborne exposures suffered in the theater of OEF/OIF. Thank you for your support in this matter and I would be happy to answer any questions you may have.

Sincerely,

Allyn Harris, M.D.
Assistant Professor
Division of Pulmonary/Critical Care
G.V. Sonny Montgomery VA Medical Center
Jackson, MS
abond@umc.edu



Main Health Campus 1400 Jackson St. Denver, CO 80206

303-388.446

nihealth.org

To Congressional Staff

06.01.2018

Regarding: Small Airway Injury Due to Deployment Related Lung Disease (DRLD), Airborne Hazard exposures and VA Disability Evaluation Criteria

#### Background

Over 2.5 million US service men and woman have honorably served in Iraq and Afghanistan in support of OIF and OEF since 2001. Forty percent of those returning from service rely on VA providers and a significant number of those seeking care have experienced respiratory symptoms and diseases associated with deployment. While the specific cause(s) for deployment related lung disease (DRLD) have not been proven, there are many significant exposures which have been implicated. The air quality in those regions is poor due to; high levels of ambient air particulates, industrial air pollution, combat operations and open air burn pits used for disposing of medical waste, metals, plastics, electronics and other combustible products (1). The first incinerators were not placed in Iraq until 2009. These activities contribute to high levels of air particulate matter (PM<sub>2.5</sub>), an exposure which is linked to several cardiovascular and pulmonary disorders (2). The Department of Defense has consistently documented airborne PM<sub>2.5</sub> concentrations throughout Iraq and Afghanistan that exceed US Military Exposure Guidelines (3). These high levels of particulate matter carry toxins, noxious agents and microbes that can lodge in the small airways of the lung and result in diseases such as asthma, constrictive bronchiolitis, emphysema and other disorders (4).

Both DOD and civilian academic medical centers have described respiratory diseases associated with military deployment. The Millennium Cohort Study, which surveyed 46,000 deployers, reported a higher incidence of respiratory symptoms in deployers compared to non-deployers. Other studies have shown an increased incidence of asthma, eosinophilic pneumonia, constrictive bronchiolitis, granulomatous lung disease and emphysema in deployers, many of whom were never smokers (5-10). Unfortunately, the magnitude of the problem is not quantified as there are no longitudinal studies to adequately determine the long-term health consequences of veterans exposed to inhalation hazards due to OIF and OEF deployments.

There are a number of unique challenges in diagnosing lung diseases following deployment to Southwest Asia, particularly for those diseases affecting the small airways of the lungs. Non-invasive studies such as pulmonary function testing (PFTs), high resolution computed tomography (HRCT) and cardiopulmonary exercise testing (CPET) are normal in some patients. For many, the only definitive diagnostic test has been surgical lung biopsy. This disparity between non-invasive testing and more invasive lung biopsy is well-recognized in patients

suffering from small airways disease such as constrictive bronchiolitis and was acknowledged by the United States Defense Health Board in its 2014 study on (DRLD) (11-12). One large DOD facility, which did not pursue video-assisted thorascopid surgical lung biopsies (VATS), was unable to identify the cause of respiratory symptoms in 40% of their deployers (13). Symptomatic deployers may face discharge from military service because they are unable to pass mandatory fitness testing (8).

In summary, a substantial number of service members have returned from OIF and OEF with respiratory diseases that are both unique to deployment and difficult to diagnose. This group of veterans requires specialty <u>care which</u> is not consistently found throughout the VA system. Moreover, the current VA disability guidelines do not adequately address some of the respiratory disability issues affecting service men and women returning from OIF and OEF.

#### Recommendations

- The diagnosis of deployment-related lung disease (DRLD) requires specialized
   pulmonary evaluation and testing, which may include metabolic exercise testing,
   complete pulmonary function testing, high resolution chest CT scans that are interpreted
   by thoracic radiologists and sometimes surgical lung biopsy. Since these capabilities are
   not available at most VA medical centers, the VA should encourage providers to refer
   veterans suffering from these complex exposure related pulmonary disorders using the
   "VA Choice" option to academic or tertiary referral centers with expertise in DRLD.
- The current VA disability criteria for DRLD and, specifically, small airways disease
   <u>should be revised</u> (14). Current clinical disability guidelines requiring resting PFTS and
   oxygen saturation testing for bronchitis, asthma and COPD are not sufficient for
   assessing small airway injury due to Southwest Asia inhalation exposures.

#### Richard Meehan, MD

CAPT, MC, USN (ret)
Co-Director, NJH Center for Deployment Related lung Disease
Professor of Medicine
Rheumatology Division
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1400 Jackson St
Denver, CO 80206

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Social Security Official Social Security Website

Program Operations Manual System (POMS)

Effective Dates: 08/21/2012 - Present

DI 23022.840 Obliterative Bronchiolitis

COMPASSIONATE ALLOWANCE INFORMATION

**OBLITERATIVE BRONCHIOLITIS** 

TN 7 (08-12)

#### DESCRIPTION

Bronchiolitis Obliterans; Constrictive Bronchiolitis

Obliterative Bronchiolitis (OB) is a rare, irreversible, life-threatening form of interstitial lung disease that occurs when the small airway branches of the lungs (bronchioles) are compressed and narrowed by scar tissue (fibrosis) and inflammation. Extensive scarring results in decreased lung function. Causes of OB include collagen vascular disease, organ transplant rejection, viral infections, drug reactions, prematurity complications, rheumatoid arthritis, oral emergency medicines (for example, activated charcoal), exposure to toxic fumes (for example, diacetyl, sulfur dioxide, ammonia, chlorine, mustard gas, ozone), and idiopathic (no known cause). Symptoms of OB include coughing (usually without phlegm), shortness of breath on exertion, wheezing, fever, night sweats, weight loss, frequent or persistent eye, nose, and throat or skin irritation.

**OB** is **not** the same disorder as **bronchiolitis obliterans organizing pneumonia** (**BOOP**), which is a treatable disorder with a favorable prognosis. OB is also a distinctly different disorder than pediatric bronchiolitis, which is a very common childhood respiratory illness with a good prognosis.

### DIAGNOSTIC TESTING, PHYSICAL FINDINGS, AND ICD-9-CM CODING

#### **ONSET AND PROGRESSION**

**Diagnostic testing:** OB can only be definitely diagnosed by a lung biopsy. Other diagnostic testing for OB includes lung volume assessments and chest x-ray with evidence of hyperinflation; and high resolution computerized tomography (CT) of the chest at full inspiration and expiration showing evidence of heterogeneous air trapping, mosaic attenuation, bronchial wall thickening, cylindrical bronchiectasis, or scattered ground glass opacities. Spirometry may show airway obstruction or restriction that is generally unresponsive to bronchodilators. OB can only be definitely diagnosed by a lung biopsy.

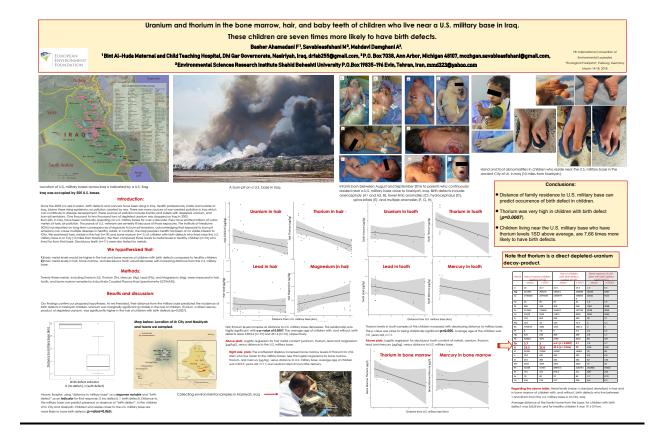
ICD-9: 491.8

The progression of OB varies from person to person with symptoms starting either gradually or suddenly. Two to eight weeks after a respiratory illness or exposure to toxic fumes, dry cough, shortness of breath (especially on exertion), fatigue, and wheezing may occur. Severe cases often require a lung transplant. Post-lung transplantation, OB continues to be a major life-threatening complication, affecting up to 50-60% of people who survive five years after transplantation.

There is currently no cure for OB. Bronchodilators, inhaled corticosteroids, oxygen supplementation, and, in the case of lung transplantation, immunosuppressants, are prescribed to control symptoms. Response to treatment is generally poor.

#### TREATMENT

# <u> Appendix C: Dr. Savabieasfahani Iraqi Population Study</u>



## **Appendix D: Personal Testimonies**

The following are testimonies of active duty service members, veterans, and Gold Star families affected by this generation's Agent Orange. These are their stories in their own words.

# **SURVIVORS**

## Greg (Caro, Michigan)

Mrs. Torres, I talked to you a couple of years ago when my health really started getting bad. Well, here I am and my health is more than bad. I am standing at deaths door, my lungs are shutting down and the VA will do nothing. I would just appreciate if you would help my wife Theresa and my son Travis after I am gone...help them to go after the VA, and get something for the hassle of it all and for having to watch me slowly die. I would appreciate it, Thanks Greg

# Megan Kingston (Virginia)

My story begins in 2007, when I was deployed to Iraq for Operation Iraqi Freedom. We were stationed at Camp Liberty, pad 12. We literally ate, slept, and lived right next to one of the largest burn pits in the country. Every morning we would wake up to go to work and be rained upon by large pieces of black soot and debris from the pit. We would walk through this to get to the chow hall, and we would be in it all day

long. On some nights, we were even able to see the flames change different colors based on what they were burning. (Different colors mean different types of heavy metals.) I can recall on many occasions, I would have upper respiratory infections and I also treated many people in my unit for the same. I was the medic. It was like this day in and day out.

On some occasions, I even lit burn pits on fire using jet fuel and a flare to get it going, so we could dispose of our trash while out in the field. To paint the best picture, this is every day life in Iraq, for over 365 days.

After returning home from the War, I remember coughing up so much black stuff in the first six months. I though nothing of it other than we are finally in clean air and it was my body getting rid of the toxins of war. To my surprise, that was just the beginning of my medical issues to come later. The year was 2014 and I was training for a triathlon and remaining fit for work, as I was a plain-clothes officer for the US Government. I went for a run one day, and couldn't breathe the next. Over the course of two years, I finally underwent an open lung biopsy to diagnosis Obliterative Bronchiolitis. This disease is more commonly known as Constrictive Bronchiolitis and, it is terminal. I continue to progress to the point where I am on oxygen 24/7 and can no longer do my job. I was medically retired and now I focus my energy on school and remaining as healthy as possible. If it were not for these Pits, I would still be able to have my career and my health.

# **GOLD STAR FAMILIES**

# Staff Sgt. David L. Thomas (Colorado)

David was diagnosed with Stage IV lung cancer that metastasized to the brain in April 2013. "He was given a prognosis of six to 18 months survival rate," Thomas said. "What I was most disappointed about at that moment was the fact that I was selling Bethe (his wife) and our children short. Second was the fact that I would no longer be here serving in the U.S. Army doing what was the most important thing: overseeing the safety of my family and our great country via my service.

"I saw a doctor in January 2013, and was told I had an upper respiratory infection or the flu," Thomas said. "I did not receive any diagnostic testing such as a chest X-ray or lung function test. I was given an antibiotic and sent on my way." After diagnostic testing, Thomas was informed that he had a nodule in his medial left lobe, and additional doctor visits and testing were conducted. "I also learned that I had actually had lung cancer for more than two years, including during my last deployment to Afghanistan." Upon learning of his cancer, Thomas began to research what could have caused it. "I began to uncover the research and studies on Iraq Afghanistan War Lung disease, and the devastating effects of the 'burn pits' on service members and civilians who have served overseas," Thomas said. "Through my research I learned that IAWL is a chronic pulmonary condition that will affect one in seven service members who have served overseas. While Veterans Affairs and the services have not officially recognized IAWL or the effects of the burn pits, there are a lot of people suffering and awareness of IAWL needs to be brought to the public's attention." "Eventually, through fundraising, we hope that the foundation has enough funds to provide basic testing for veterans or active duty service members who might need to determine if they have IAWL," Thomas said. "In many ways, through my foundation, my last mission is to bring awareness to IAWL and those who are suffering." Elizabeth said that her husband is her hero. "David kept saying, I'm never going to deploy again. I need to be able to. It's my job," she said.

## SFC Fred Slape (Texas)

My name is Diane Slape, I am the widow of SFC Frederick T Slape, Retired US Army. When we retired in 2012, I was certain War Zone dangers were behind us. In late August 2015, days after we'd sent our daughter to her first year of college and started building our Forever Home, Fred went to his routine VA Drs appointment. Just to be told again "your White Blood Cell count is elevated, you need to stop smoking." But this time was different, The VA called to tell Fred, they were concerned about the results, to call for a lab appointment, one he couldn't get until October. Despite my 43yr old husband's overall good health, according to his Oncologist Team, Fred died 9 weeks after he was diagnosed with Stage 4 Adenocarcinoma of the Brain & Lung lymph nodes, a disease that usually strikes 70-80yr old people. Most Veterans exposed to the Toxic Burn Pits, who are diagnosed with cancer, aren't living past 18-24 months, due to the aggressive nature.

In August 2015, Fred still showed no symptoms, then 2 days of sporadic headaches along with seriously impaired vision, an MRI discovered the mass in Fred's brain. As if we had expected it, when the Dr told us of the brain mass – Fred & I looked at each other and said "Burn Pits". After 5 days in the hospital, every infectious disease test known to man, and a CAT scan, they discovered the mass in his chest. Many asked Why didn't we go to the VA? My husband said chuckling "What? And Die there?" After reviewing 3 years of lab results, the VA Drs should have been concerned about Fred's blood work since 2012. Being Retirees, we had Tricare coverage too, as well as VA access. Most non-retired veterans do not have the Tricare option, leading to possibly better care.

In the remaining 5 weeks of Fred's life, he would have 1 round of the most intense 3 day chemo treatment, his first and only seizure, brain surgery to remove an aggressively growing brain tumor, during the 2 wk recovery from surgery, He had chest radiation & a stomach tube inserted, just in case the radiation closed off his esophagus. During this recovery period, 4 new inoperable tumors were growing quite rapidly inside Fred's brain. 1 very large one in the Temporal lobe where the initial one was removed, 1 in the Frontal lobe that tripled in size and 2 in the cerebellum, never seen before in all the CAT Scans previously. 3 days later Fred had started brain radiation, which hospitalized him the next day. Oncologists informed us the chest/brain radiation, as well as the 1 round of Chemo had no effect on the cancer in his chest or brain. We opted for 1 more round of brain radiation, which rapidly led to Fred's death 2 days later. Please help so that Fred's young soldiers, who are 20 & 30 yrs old and currently healthy, do not struggle or suffer as Fred did, but without Healthcare that is specific to their exposures & services for their families.

# Colonel Mc Cracken (Georgia)

Dear Mr. Vice President,

I am so very sorry for the loss of your son, Beau. My husband, USA Colonel David A. McCracken served an active duty tour at Victory Base Complex (VBC), Baghdad, Iraq in 2007. My husband also died of glioblastoma multiform on September 2, 2011 after an 11-month battle. A year after his death, it was brought to my attention that exposure to toxic chemicals from the open-air burn pits were an attributing factor to his cancer.

My husband was also mentioned in the book, "The Burn Pits, the Poisoning of America's Soldiers" by Joseph Hickman, page 126. As you know, grief is a powerful emotion and I make a choice everyday to

ensure that my journey is one of healing and hope. I can't imagine the pain associated with the loss of a child. I can only see and experience this loss from my own perspective and that of my children.

I have researched, spoken of and supported efforts regarding the effects of these burn pit toxins. I do this so that my children will see that this effort is a worthy one. It can be exhausting, frustrating straight through to my soul. I've spent more restless nights than I like relentlessly learning and researching this issue with limited return on this particular 'investment'.

It is a special breed of people who take up the calling to serve. I will continue the fight with my small voice to keep my husband's memory alive and to show my children that where there is a passion to make things right, change can be affected.

My husband, a 45-year-old in perfect health returned coughing and complaining of headaches. I watched his health decline rapidly as I'm sure you have witnessed as well. If anything, I want my husband's death to mean something. Some small thing. Not an 'agent of change' but an 'angel of change'. Sir, my spirit was renewed with your words during your recent interview with PBS. It is my greatest hope that you are able to embrace - with similar passion - an outlook of support that brings awareness to the effects of burn pits on our loved ones. I have long felt that I didn't want David's death to be simply a memory, but a catalyst for change and action. I have every hope that you feel the same.

Please continue this fight. Continue to engage and bring awareness to this issue.

Signed with hope and renewed spirit, Tammy J. McCracken Proud Wife of deceased USA Colonel David A. McCracken

# **Timothy Johnson**

Dear Vice President,

First off I was so very saddened to hear of your sons diagnosis and eventual passing. I too am a parent whose son has died because of brain cancer.

I am writing in regards to the burn pits in Iraq and their link to cancers. My son Sgt. Timothy Lee Johnson of the USMC died of glioblastoma multiform at the age of 35. He was a bomb dog handler deployed to Iraq. Upon his diagnosis he was deemed 100% disabled service connected with the VA. He had a wonderful doctor who believed the exposure to these toxins were the contributing factor in his cancer. My hope is more investigation and subsequent help to victims will take place.

I am glad to hear more safety and equipment is now in place.

I have attached the memorial from His funeral. The photo is him with his dog in Iraq. I believe there are thousands of other veterans who have suffered many illnesses and cancers because of the exposure to the burn pit toxins. I believe many have not come forward not realizing they are sick because of their exposure. May the word continue to be declared so they too can get the medical care they need. Sincerely, A hurting mom, Donna Johnson

P.S. If this letter can be added to many more of those whose lives and loves were lost.

## Major Kevin Wilkins (Eustis, Florida)

Dear Vice President

I do not want to take up much of your time, so this letter to you will be short and to the point. My husband, USAF Major Kevin E. Wilkins, RN., served an active duty tour at the Balad Air Force Base, Balad, Iraq in 2006 where your son Beau was also stationed. My husband died of a glioblastoma brain tumor in 2008 after exposure to the toxic chemicals from the open-air burn pit at that base. (He was also mentioned in the book, "Burn Pits" by Joseph Hickman on page 32). I won't go into the effect his death had on my 2 children and me because you already know the pain.

VP Biden, you can help by talking about the effects these burn pits have had on you, Beau's wife and the entire family. I know you promised Beau that you would run for President, but I believe that standing up for Beau in the light of what has happened to him and many other soldier's and their families, is so much greater than being President of the United States. Everything happens for a reason, and I believe it is your calling to help the many other soldiers who are still alive but fighting to live.

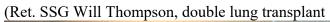
If you would like to see the work I have been doing to try to help other families whose soldiers have been exposed to the toxic chemicals, please Google "Jill Wilkins Burn Pits" and you will see the media coverage I have been involved in including CNN.

Very Sincerely, Jill R. Wilkins Proud Wife of deceased USAF Major Kevin E. Wilkins, RN

# **APPENDIX E: Photos**

(Brian Alvarado & his daughter Rihanna)





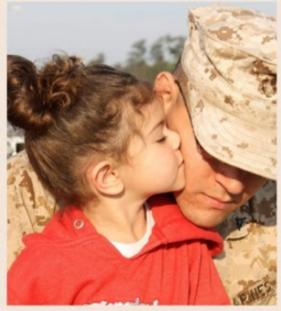


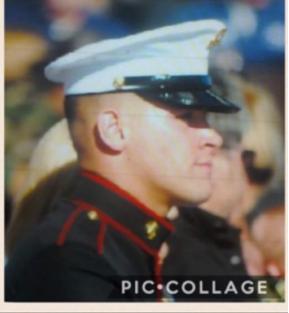


# WWW.BURNPITS 360.0RG

These are the faces of America's fallen heroes who lost the battle to toxic wounds of war after serving in the post 9/11 wars. Every one of these warriors died as a result of an instrumentality of war and each one leaves behind a legacy of heroism and honor. Their families are their voices and we will stand in solidarity alongside their families. Our mission is to bring awareness and accountability so that war heroes suffering from these invisible wounds of war will be granted specialized health care, benefits and compensation. No longer will any service member, veteran, or their families be ignored to feel they are alone in this fight. We will fight to protect those still undiagnosed, suffering and those who earned the right not to be forgotten.







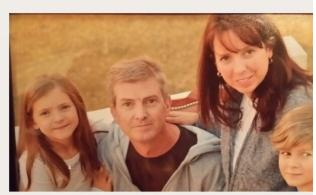














I want my hids To know the value of friendship... the value of had work... the value of had work... the value of doing something meaningful... the importance of family.... courage and determination... stead fast morals

