STATEMENT FOR THE RECORD OF LE ROY TORRES, IRAQ WAR VETERAN AND CO-FOUNDER, BURN PITS 360

BEFORE THE U.S. HOUSE OF REPRESENTATIVES, COMMITTEE ON VETERANS' AFFAIRS, SUBCOMMITTEE ON HEALTH

FOR A JUNE 7, 2018 HEARING ENTITLED: "AN ASSESSMENT OF THE POTENTIAL HEALTH EFFECTS OF BURN PIT EXPOSURE AMONG VETERANS"

Thank you, Chairman Dunn, Ranking Member Brownley, and Members of the Subcommittee for today's hearing and for this opportunity to submit a statement for the record.

Introduction

My name is Le Roy Torres, Captain, U.S. Army Reserve (Retired). I am a 2007 Iraq War veteran, and Founder of the Burn Pits 360 veterans organization. My wife Rosie Torres, co-founder and Executive Director of Burn Pits 360 has provided a statement for the record on a previous occasion, but today is especially notable. After a decade of advocacy following my service in Iraq, we are grateful that the committee today is conducting a hearing on the health consequences of burn pits exposure and investigating how the government is treating veterans suffering from these toxic wounds of war. Today we ask each of you to stand in solidarity with us to honor with substantive measures the lives of thousands of my fellow comrades who lost their lives to the "war that followed us home."

I served a dual role as a Texas State Trooper for 14 years after being discharged from state service and as a Soldier for 23 years before being medically retired. I earned my graduate degree from the University of the Incarnate Word with the hopes of becoming an Army Chaplain. I deployed to Balad, Iraq from 2007 to 2008 where I was exposed to the largest burn pit within the Operation Iraqi Freedom (OIF) theatre of operations. As a husband, a father and a first responder, I have been deprived of my dignity, honor and health. I returned home from war to face a health care system that failed me and an employer too afraid to understand an uncommon war injury resulting in termination of my law enforcement career; subsequently facing foreclosure, while at the same time receiving VA denial letters for compensation for illnesses still not recognized by VA.

Since returning from Iraq, I have had over 250 medical visits and was hospitalized immediately upon returning from the war. In November 2010, I was diagnosed with a debilitating lung condition (constrictive bronchiolitis) following a lung biopsy at Vanderbilt University. My medical doctors determined last month that I have toxic brain injury due to exposure to toxins, likely resulting from my burn pits exposures in Iraq.

For the past decade, Burn Pits 360, which Rosie and I co-founded, has been at the forefront of this issue, advocating for the families of the forgotten and those battling life-threatening illnesses. They stand with us here today and will be standing with us later on the steps of Congress, and many of their personal stories are included in Appendix A, which we encourage you to review with the care that they deserve.

Burn Pits 360 is a 501(c)(3) non-profit veterans organization located in Robstown, Texas. Our mission is to advocate for veterans, service members, and families of the fallen affected by deployment-related toxic exposures. Burn Pits 360 created and maintains a 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).

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 2017.¹ We have presented key statements to the Defense Health Board and have actively participated in every VA/DOD AHOBPR Burn Pit Symposium.

Burn Pits and Health Consequences

Numerous military bases in the Operations Iraqi Freedom (OIF) and Enduring Freedom (OEF) theatres of operation produced several tons to several hundred tons of solid waste per day. Openair burn pits were the primary waste disposal method during the majority of the duration of these wars in Iraq and Afghanistan. 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.² 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

¹ 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. <u>https://dx.doi.org/10.1177%2F1557988315619005</u>

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

respirable and dangerous particulates from burns pits and they continue to suffer serious, disabling health consequences upon their return.

A defense contractor stationed at Al-Taqaddum in Iraq from 2006 to 2007 – roughly the same time as I was also stationed in Iraq – described the impact of burn pits and their health effects in a published news story: "Burn pit smoke would encircle the entire military base in an enormous dark ring that settled to the ground after darkfall.... A lot of people got rare cancers and died. Any exposed skin and mucous membranes, as experienced by many of us, felt on fire, and burning. Many of us developed shortness of breath."³

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.⁴ Service members with new-onset, post-deployment respiratory symptoms from these hazards have been labeled as having **Iraq/Afghanistan War-Lung Injury (IAW-LI)**, ⁵ 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 the 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. It appeared to be the only way to convince the federal government that its denials – of the reality of our exposures and resulting health issues, of granting us necessary health care, of approving our claims for needed disability compensation, and, "bottom line," of allowing us the continued right to live – must stop.

Burn Pits 360 continues to manage this registry, which has since grown to about 6,000 participants. This registry also allows registrants the ability 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 chemicals associated with cancers, lung diseases, cardiovascular disease, kidney disease, neurological disorders, and more.

³ Elizabeth Hilpert, quoted by Dan Sagalyn, "Photo essay: The burn pits of Iraq and Afghanistan," November 17, 2014, PBS News Hour. https://www.pbs.org/newshour/world/photo-essay-burn-pits-iraq-afghanistan

⁴ 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.00000000000119

⁵ 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. <u>https://dx.doi.org/10.1177%2F1557988315619005</u>

- 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.
- There are over 100 death entry submissions in the Burn Pits 360 registry, including from rare cancers and from suicide.
- Burn Pits 360's registry data demonstrates the national failure to adequately prevent, diagnose, treat, and compensate burn pit-exposed service members and veterans.

Proposed Agenda

There are a number of crucial issues related to burn pit exposure and IAW-LI that we strongly believe the House Veterans' Affairs Committee should investigate and which require the focused attention of the VA. The current lack of clear understanding of the health impacts of these exposures should not circumvent our national obligation to assist every affected military service member and veteran. In particular, we highlight the following important focus areas:

- 1) **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 burn pit exposure;
- 2) **Conducting more and better research** into the health consequences of burn pit exposures and to develop effective treatments;
- 3) Establishing evidence-based clinical practice guidelines and a specialized care program for IAW-LI and comorbid conditions;
- 4) Creating a scientific advisory committee related to burn pit exposures and IAW-LI;
- 5) **Improving VA disability compensation claims** for burn pit veterans, including establishing presumption of service-connection for debilitating symptoms and diseases that have been linked to burn pit exposure.

1) Improving the VA's Burn Pit Registry

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 141,246 registrants who completed and submitted the registry questionnaire.⁶

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

⁶ U.S. Department of Veterans affairs website, retrieved June 5, 2018,

<u>https://www.publichealth.va.gov/exposures/burnpits/registry.asp</u> 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.

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 and there is not yet a clear understanding why. 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.

Further, our constituents on the Burn Pits 360 registry have raised concerns as to how the VA's registry functions. Currently, there is no way for a service member or veteran to report a decline in health like we allow in our registry. 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 A 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 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. We have also received reports of inconsistent examinations, diagnoses, and treatments afforded to service members seeking care associated with their toxic exposures.

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 (ours does). 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.

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."⁷

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

 ⁷ 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. <u>http://www.nationalacademies.org/hmd/reports/2017/assessment-of-the-va-airborne-hazards-and-openburn-pit-registry.aspx</u>

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.⁸

Finally, as of June 4, 2018, the VA's website currently states that "VA is working to improve the registry based on recommendations in the report"⁹ that was issued more than 15 months earlier. It appears that this sentence of the website was recently changed. 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 last year or the researchers' recommendations published online in 2015 and in a medical journal last year.¹⁰

<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 smoke from open burn pits burning of toxic waste can have lasting negative health consequences?
- 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?

⁸ NASEM 2017

⁹ ibid.

¹⁰ Szema et al, 2017

- 5. What records exist regarding complaints about the burn pit registry, including complaints from individual veterans 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 exam?
- 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 direct VA to conduct a national outreach campaign to include:

- Newsletters to registry participants
- Social media campaigns
- Development of VA registry outreach written materials for distribution in VA and veterans service organization (VSO) facilities, at events, and on all social media sites operated by DOD and VA.

2) 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:¹¹

- 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.

To date, it is unclear to us whether this has happened. 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</u> <u>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."¹²

VA goes on to say, "VA and the Department of Defense will conduct a long-term study that will

(2) SUBMITTAL TO CONGRESS.—

https://www.gpo.gov/fdsys/pkg/PLAW-112publ260/pdf/PLAW-112publ260.pdf

¹² U.S. Department of Veterans Affairs website, retrieved June 4, 2018:

https://www.publichealth.va.gov/exposures/burnpits/health-effects-studies.asp

 ¹¹ PUBLIC LAW 112–260—JAN. 10, 2013 126 STAT. 2423 – SEC. 201. ESTABLISHMENT OF OPEN BURN PIT REGISTRY.
(b) REPORT TO CONGRESS.—

⁽¹⁾ 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:

⁽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.

⁽ii) Recommendations to improve the collection and maintenance of such information.

⁽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.(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).

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

⁽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).

⁽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).

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> <u>Register</u> 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.

<u>Recommendation</u>. We encourage 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 our Burn Pits 360 Registry has already shown between burn pit exposure 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; (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 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 postdeployment, 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 understand the process for fiscal year 2019 Defense appropriations has already moved forward. However, we have seen there is great value in having a project like this led by Members of the House Veterans' Affairs Committee. 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.

3) Establishing Evidence-Based Clinical Practice Guidelines and Specialized Treatment

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, VA and DoD have not yet developed evidence-based Clinical Practice Guidelines (CPG's) for health care providers to know how to identify, evaluate,

treat, and refer patients with IAW-LI or other conditions that may be associated with exposure to burn pits.¹³ 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.¹⁴

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.

IAW-LI is debilitating to the affected veterans. This war-induced disease impacts multiple dimensions of everyday life, such as the ability to perform one's job and the ability to exercise. Research has shown that service members and veterans suffering from this war-related lung injury have new-onset asthma or fixed obstructed airways. Research has also reported titanium bound to iron in fixed mathematical ratios of 1:7, which is extremely rare in nature, in the lungs of soldiers, suggestive of an anthropogenic, man-made source. In more severe cases, these service members developed severe respiratory disability that required a lung transplant. IAW-LI has been shown to be long-term and does not improve, even though some of these veterans were exposed in 2003 – fifteen years ago. Yet almost counter intuitively, symptoms as severe as these are not detectable by routine testing and require sophisticated specialty care.

Currently, there are no evidence-based treatments available for this disease process, but researchers are investigating several candidate medications in development, which have been found to reverse IAW-LI injuries in mice exposure models. Because of the VA's dereliction of duty to this matter for the last fifteen years; it is our generation's Agent Orange.

IAW-LI sometimes is not easily diagnosed by physicians, because many are still unaware of this injury. Also, it is difficult for suffering patients to realize what their symptoms are because this is an unconventional disease. Many believe the symptoms are attributed to Post-Traumatic Stress Disorder (PTSD), not IAW-LI. Sophisticated tests such as impulse oscillometry and analysis of lung tissue for metals are only available at Quaternary Care Medical Centers. Quaternary care is very specialized and highly unusual and not offered at most medical facilities.

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

¹³ U.S. Department of Veterans Affairs website, retrieved June 5, 2018: <u>https://www.healthquality.va.gov</u>

¹⁴ U.S. House Committee on Veterans' Affairs, "Persian Gulf War: An Assessment of Health Outcomes on the 25th Anniversary," <u>https://veterans.house.gov/calendar/eventsingle.aspx?EventID=1104</u>

VA Clinical Care: Establishing a Specialized Health Care Program

Develop deployment related toxic exposure specialty clinic within the VA healthcare systems. Currently veterans are being misdiagnosed and symptoms are being dismissed as psychosomatic and not for the true illnesses they are suffering from.

<u>Recommendations</u>. We ask that Congress query VA leadership: Will VA commit to establishing a dedicated research center to study and develop treatments for health conditions resulting from burn pit exposure?

4) Develop a Burn Pits Exposure Scientific Advisory Committee

Currently, no federal advisory committee exists that is specific to burn pits exposures. And, there are few opportunities within current DoD and VA activities that allow for burn pit exposed service members and veterans to actively participate in making recommendations related to research or policymaking that directly affects their well-being.

Recommendation. Congress should mandate the establishment of a federal scientific advisory committee to provide a comprehensive review and recommendations on the full spectrum of burn pits exposure research. It should include several VA, DOD, and independent scientific researchers and clinicians who actively work on burn pits exposure research or clinical care, and should include several clearly representative, affected service members, veterans, and their survivors. Its activities should include review the experiences of affected service members and veterans, and scientific and medical evidence in order to make recommendations to DoD, VA, and possibly also the Department of Health and Human Services (HHS).

5) Improving VA Burn Pits Exposure Claims

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,"¹⁵ 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.

¹⁵ 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."

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

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 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 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 mandating training (and ensuring the appropriateness of that training) for VHA and contractor medical examiners and VBA claims adjudication staff.

VA Claims: Tracking Burn Pit Claims

Despite establishing the Airborne Hazards and Open Burn Pit Registry where veterans can selfreport burn pit exposure and related symptoms, VA does not adequately identify or track VA compensation claims related to burn pit exposure. VBA frequently uses "Special Issue Identifiers" to track certain types of claims. Claims related to military sexual assault, for example, would be marked so that VBA staff or VHA researchers could see claim-specific trends in wait times, approval rates, etc.

In VA Training Letter 10-03, VBA staff are instructed to use the only identifier pertaining to exposure claims: "Environmental Hazard in Gulf War." This identifier covers a range of exposures too diverse to draw any statistical conclusions about burn pit claims.

Without a tracking system, veterans' advocates are left in the dark. We don't know how many burn pit-related claims have been submitted, how many have been denied, which medical issues are being reported, or how long veterans are waiting to get an answer. Importantly, we cannot confirm that burn pit claims are being incorrectly processed in a systemic way, as it often appears.

<u>Recommendation</u>. Congress should mandate that VA track and report on a quarterly basis all relevant data for VA compensation claims related to burn pit exposure, including numbers of claims submitted, approved, denied, reasons for denial, and numbers of claims denied per reason for denial.

VA Claims: 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.

Recommendations. We ask that Congress 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.
- 6) Legislation

We urge Congress to introduce a healthcare and compensation act.

APPENDICES

- Appendix A: Burn Pits 360 Registry Testimonies Appendix B: Medical Opinions
- Appendix C: Burn Pits 360 Staff Biographies
- Appendix D: Burn Pits Photos

APPENDIX A: Burn Pits 360 Registry Testimonies

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

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

Jay Seals (Nashville, Tennessee)

In March 2008 my husband joined the Army. He went to Basic training at Ft. Jackson, AIT at Ft Gordon, and then was stationed at Ft. Campbell to be assigned the 101st airborne division 2-502 HHC from November 2008 to August 2012. While serving with the 2-502 HHC he was deployed to Howz-e Madad Afghanistan from June 2010 to April 2011. In August of 2012 he was assigned to SHAPE in Belgium until November 2013. While serving in Belgium he received surgery for a hernia. Shortly before the surgery, according to documentation, a scan was done and a small mass was found. This information was added to his Military Medical records but no follow up was done and he was not informed of the mass. In December 2013 Jay returned to Ft.Campbell and was assigned to 101st airborne division 5-101 CAB HHC. During this time he had many appointments with various medical staff about this stomach and abdominal pain. He was given OTC pain meds and told to hydrate. Jay was Honorably discharged from the Army April 19, 2016. He was then hospitalized for a bowel blockage from April 27th to April 30th 2016 at Blanchfield Army Community Hospital. He reported for duty with the Tennessee National Guard in May of 2016. He filled out all of the paperwork with the VA and was seen by VA doctors. He was experiencing weight loss and esophageal spasms. On September 12, 2016 he was diagnosed with stage 2 gastric cancer. On October 3, 2016 surgeons installed a port for chemo and performed an exploratory laparoscopy. During the laparoscopic procedure they found that the cancer had broken through the stomach wall and "spots" of cancer was found throughout the peritoneal cavity. This changed the diagnosis to Stage 4 gastric/stomach (terminal) cancer and was placed on a palliative care plan. After finding the document stating that a mass was found in 2012 was reviled by the Tennessee National Guard, it was requested that Jay receive Line of Duty status and be placed as Activated National Guard assigned to the Warrior transition Battalion. He has been in this position since November 29, 2016. Jay is currently being treated by the VA and Vanderbilt Oncology teams in Nashville. I was told at the beginning of this that Jay might have 6-9 months to live but he has exceeded the expectations. Jay knows he will pass in the next year or two and he hopes to still be with the WTB to make sure that I will have a support base to fall back on when he is gone.

*A brief bio for me *

Cheryl "Tori" Seals is a mother, wife, advocate and palliative caregiver. She is the mother of 2 children that have now ventured out on adventures of their own. Tori is a full-time caregiver for her husband, Jay, who is fighting terminal stage 4 stomach cancer. Care giving for Jay includes everything from getting him to all his medical appointments and chemo sessions to assisting him in all his daily routines including but not limited to making sure he eats, personal grooming, making him as comfortable and happy as possible and taking medication. Since his cancer is terminal, we know we must prepare for his end of life needs as well. When late night insomnia strikes she is preparing for her future by working on becoming an advocate and lobbyist

for soldiers and their families by taking online training on political science and advocacy. Prior to being a full-time caregiver, she has had a variety of careers, Including but not limited to Information Technology Specialist for a Defense Contractor; Designer, Production Manager and Sales Representative for a Promotions Company; Federal Compliance Officer for a Home Loan Company; Artist and Creative designer/sales for a couple of Renaissance Festivals; Personal Assistant to an Executive Sales Representative; and Talent/Celebrity Handler, Physical Security, Logistics and Operations Specialist for many Conventions and Festivals across many genres and locations throughout the US.

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. I thank you for your time and understanding in this matter and I hope that you have a pleasant rest of the day. I look forward to meeting with you all on the 7th of June.

Staff Sgt. David L. Thomas (Colorado)

Noncommissioned officer in charge, S-2, 1st Space Battalion, was diagnosed with Stage IV lung cancer that metastasized to the brain in April 2013, but has chosen to continue his service. "I 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. Upon enlisting, he intended to be a career service member.

"Joining the Army was something that was always on my mind since I was a child," Thomas said. "The attacks made up my mind for me. Defending my family and America itself was no longer an option, but rather a duty.

Thomas deployed to Iraq for the first time. After 13 months in Baghdad and a few months at home, he deployed again in September 2005, back to Baghdad. He returned home in January 2007, reclassed his job specialty, and in December 2008 deployed to Northern Iraq, first to Kirkuk and then to Mosul. He returned home in September 2009 and began preparing for his next deployment, this time to Kandahar, Afghanistan, in May 2011. It was during this fourth deployment that he began to notice a prevalent and chronic cough. He returned from this deployment in May 2012, and in October 2012, Thomas transferred to the 1st Space Battalion headquarters in Colorado Springs, Colo. "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." Elizabeth had begun insisting that he go to the doctor because of the chronic cough, and finally on April 19, Thomas decided to "My wife and I were in bed watching TV when I had an episode of chest pain. I seek medical advice. thought I had a mild heart attack," Thomas said. "The next morning I went to the emergency room since sick call could not see me for chest pain." After diagnostic testing, Thomas was informed that he had a nodule in his medial left lobe, and additional doctor visits and testing were conducted. "It was the day after my 46th birthday that I was diagnosed," Thomas said. "I also learned that I had actually had lung cancer for more than two years, including during my last deployment to Afghanistan." Elizabeth said her initial reaction was shock. "I remember thinking, 'I can't believe I'm hearing these words," she said. "I felt cheated. This was the first time in a while we were going to have uninterrupted family time free from deployment. I thought we were going to have all of this time together." Thomas began treatment in May 2013. "I determined to fight cancer and have been undergoing chemotherapy," Thomas said. "I have also undergone two cyber knife procedures to my brain for tumors and a week of radiation to my chest."

. Through David's fight both internally and externally without complaint, we are witness to his courage and commitment to complete the mission. Thomas, however, does not feel like he is doing anything extraordinary. "Never did quitting my career in the U.S. Army cross my mind," Thomas said. "Nor will I allow this illness to prematurely cause me to leave the Army. If it is up to me, I will be a member of the armed forces until the day I do leave this world to be with my father in heaven. "I have made a decision that I will not let cancer change my duty to my country, family or friends," he said. "I will fight cancer and continue to work as long as I am able. I will continue to place the mission first while acting with professionalism and continuing to mentor my NCOs and Soldiers." 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."

Thomas established the David Thomas IAWL Foundation to promote awareness of the disease. "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, and not just because of his current fight. "David kept saying, Tm never going to deploy again. I need to be able to. It's my job," she said. "He loves what he does. He's always saying he wished he could do more; that what he's done isn't enough. He's a hero to me. Not just that he's kept going, but his whole Army career. Even with all of this, he doesn't take the praise. But just by getting up every day and going to work, he shows everyone that he doesn't quit. He always replies with, "Where else would I be?"

CSM James Hubbard (Kansas)

My name is Katie Hubbard, and I am the widow of Command Sergeant Major James W. Hubbard, Jr. CSM Hubbard. He was a great husband, father, grandfather, and soldier. CSM Hubbard served eight years on active duty before becoming a soldier in the United States Army Reserve.

CSM Hubbard's unit was called to Active Duty orders and sent to Iraq as part of Operation Enduring Freedom and Operation Iraqi Freedom 1. During those campaigns, CSM Hubbard served as the Command Sergeant Major for the 450th Movement Control Battalion, Talil Air Base in Iraq and Camp Arifjan in Kuwait. CSM Hubbard stated that he had to climb into check the remnants of tanks that were blown up by depleted uranium as well as living and working around burn pits throughout the country. CSM Hubbard noted the smells and smoke that he observed from the burn pits and even noted on his post-deployment medical check that he was concerned about the chemicals in the air at Talil, as well as smoke from oil fires, pollution, other fuels, solvents, paints, radiation, lasers, and other environmental exposure concerns.

Upon his return from Iraq, the medical doctors noted his blood was "wonky" and referred him to his civilian provider. He was followed for six months after before being initially cleared. In 2007, CSM Hubbard was deployed as the CSM for the 139th Med Group, Task Force Falcon IX to Camp Bond steel in Kosovo. While there, he complained of getting more tired easily and that his run was not as good as he was used to. He would also often reflect on his service in Iraq, what he saw, and the concerns he had about all the things that were released into the air from all the stuff that they burnt in the burn pits.

When he returned in late summer of 2008, he was sent to the VA hospital in Topeka, KS for a postdeployment check-up and is cleared to return to his civilian job. The VA was concerned with his blood work and called him to immediately return, stating he may have to be hospitalized. CSM Hubbard and I were in shock and were not told what may be going on. He went back to the VA for a follow-up after taking a military trip to Washington State, where it was noted that his hemoglobin levels were very concerning, and he was referred to the oncology department. His first appointment the VA oncology doctor stated to us that he did not think it was cancer that it was possibly just a bug from his deployment, but if it were cancer it would not be the "bad" kind. He ordered a bone marrow biopsy on October 24, 2008. We were to return on November 14, 2008, where the VA oncologist told him that he had cancer. Specifically, he was diagnosed with Acute Lymphocytic Leukemia, or ALL, which is common in young children not 50+yr old men!

We were then sent to the VFW service office where we met with the officer and the social worker for the VA. When meeting with the service officer and social worker, we were told they had seen an increase in the number of service members coming back from Iraq and Afghanistan with leukemia and other cancers. Our doctor also stated he believed the cancer was due to the burn pits and depleted uranium. CSM Hubbard was

given a 100% service connected disability rating from his leukemia diagnosis. CSM Hubbard went to MD Anderson in Houston, TX for treatment, where they stated that 85% of his blasts in his blood were cancerous when he began treatment.

Unfortunately, during cycle four of treatment, he died suddenly on May 21, 2009. He was serving as the interim brigade CSM for the 330th Med Brigade in Fort Sheridan, IL and the CSM for the 139th Med Group in Independence, MO, at the time of his death. After his death, I wanted to learn more about the areas he served and what he may have been exposed to that contributed to his death, which the Topeka VA had told us that his leukemia was a result of the burn pits and depleted uranium he was exposed to in Iraq. We were one of the lucky few that had his cancer acknowledged and rated as service-connected. I found many reports during my research that substantiated CSM Hubbard's concerns about the toxins in the air from the burn pits, including government documents listing chemicals found in the air in Iraq. CSM Hubbard had also expressed difficulty running and tiredness, which were the result of his leukemia. The VA also had told us that they had noticed that it was taking five to ten years after deployment for some of the cancers to be found, which fit in the timeline of James' exposure and subsequent diagnosis. His cancer was also not common at all for people his age, further connecting the effects of deployment to his cancer. CSM Hubbard is greatly missed, and it is my hope that his death will help shine a light on the toxic effects of the burn pits and help to create the necessary steps to protect service members, take care of the ones effected, and honor the ones that have died as casualties of war.

Alyssa Holschbach

I appreciate all the great work Burn Pits 360 has been doing for years. I first learned of your excellent organization in September of 2012, when I was stationed at Bagram and being sickened by a burn pit that was moved very close to my camp (Sabalu-Harrison).

Over the course of about three weeks after that pit was moved close to my camp, I got very ill. The smoke was so thick, you could taste it. It engulfed our whole camp, including our living spaces. I guarded the prison and was up in the towers most days. It would get so thick; you couldn't see the next tower over. We all were suffering. They gave us respirators you would maybe use for painting. They didn't do anything to block the smoke and fumes. The cartridges were also only good for eight hours and we never received replacements. We worked twelve-hour shifts. They probably only gave them to us in an attempt to shut us up. I developed symptoms similar to a severe allergic reaction. My face swelled up with hives (which it hurt to put that useless respirator on over). My skin, tongue, and lips tingled. I had sharp pains in my chest while I breathed and it was very hard to breathe. I was so miserable; I maybe could get one to hours of sleep a night because I felt like I was suffocating. I was finally Medevaced to Germany on October 1, 2012. In the years since, I've struggled with respiratory and skin issues. I'm very worried about health consequences down the line, but VA doctors blow off my concerns. Some don't even know what a burn pit is.

Congress needs to take action to ensure that all service members exposed are taken care of properly and receive appropriate screenings given our risk for rare cancers and other diseases. The "Burn Pits Accountability Act" is a great start, but it doesn't impact veterans already out of the service from my understanding. More needs to be done for all of us.

Thank you for your time and for letting me share my story, P.S. I've attached pictures of the burn pit I was exposed to. One is a picture of it engulfing our living area.

SFC Heath Robinson (Ohio)

The oncologist's first words were, "WHAT THE HELL HAVE YOU BEEN EXPOSED TO?" before continuing on with my husband's diagnosis of Stage IV terminal lung cancer with no primary tumor. He explained that this type of cancer is ONLY caused by toxic exposure and in tears told us that if the cancer can't be controlled the prognosis was 6 to 8 weeks for Heath to live. With no primary tumor to target, we learned that any treatment would be experimental. After consulting with 20 fellow oncologists to determine the best course of treatment, no one had an answer. The cancer is so rare that there aren't enough statistics regarding life expectancy or which treatments have the best results. A month prior to the cancer diagnosis, Heath was suffering from chronic nose bleeds and eventually bleeding from his ears which was determined to be manifestations of a rare autoimmune disorder, Mucous Membrane Pemphigoid

The cancer had metastasized to Heath's mucous membranes, scapula, pericardium, lymph nodes and his entire thoracic cavity. The immunotherapy, Keytruda has extended his life and improved his quality of life, however, we are unable to attend your hearing on June 7 due to his scheduled treatment day and his condition right now isn't very good for him to travel.

SFC Heath Robinson served as an army combat medic being deployed to Kosovo and eventually Iraq for Operation Iraqi Freedom. He was exposed to burn pits during both deployments and more so in Iraq. He lived on Camp Liberty in late 2006 and worked a lot of the time on Camp Victory. Both bases had notorious burn pits, however, one job he held for 3 months placed him within 75 yards of a burn pit for hours on end each day.

Our family is devastated, as we have been living this nightmare with him battling to stay alive for just over a year. Even more devastating for us is worrying about what's going to happen to our 4 year old daughter and me if he doesn't survive this. It's even more mortifying to hear the V.A. continuing to deny a connection between toxic emissions from burn pits and illnesses while they claim research and data supports their conclusion. This is ridiculous as other credible studies have already proven and warned of the dangers of serious health issues those in close proximity to those burn pits could contract. These studies have been totally ignored by the V.A. and that's shameful.

I am asking you today, as the wife of a terminally ill wounded soldier and now his caregiver, counselor and the one making sure every day he has left on this earth is a good one...to please stop this nonsense of the V.A. commissioning burn pits research. An outside entity not controlling the outcomes to favor the V.A. should be in charge. Robert F. Miller, M.D. Pulmonary Medicine; Vanderbilt University and Dr. Anthony Szema, 2500 Nesconset Highway, Suite 17A, Stony Brook, New York 11790 have both done tireless studies and research on why thousands of Iraq and Afghanistan War veterans have succumbed or are battling serious, rare and unheard of diseases. It's an injustice to all potential burn pit victims that these two physicians were not invited to testify at your subcommittee on veterans' health hearing on June 7, 2018.

Thank you for reading my letter. My veteran husband is truly discouraged and disappointed that he won't have an opportunity to testify before a congressional committee. He's proud to have served his country with honor and dignity and wouldn't hesitate to do it again, however, he is deeply disturbed that his country refuses to acknowledge his toxic wounds as combat related and that hurts.

Heath's wife, Danielle Robinson June 2, 2018

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.

His exposure to the Toxic Burn Pits occurred during his 2 deployments, 2009 in Southern Afghanistan and 2011 in North Eastern Afghanistan. Fred & his troops had their living & working quarters combined in the same building, less than 25ft from the burn pits, that burned 24 hours a day, 7 days a week; unless a General or the SECDEF was coming. These burn pits were shoveled/raked by my husband's soldiers, with little to no protective clothing on. The soldiers breathed this black acrid smoke morning, noon and night, even in their sleep. My husband had mentioned to his commanders that the Burn Pits were causing difficulty breathing and that they were going to kill somebody, to which they replied Stop being so dramatic, SFC Slape. My husband told me that they burned items, such as vehicle fluids, aerosol cans, computers, Styrofoam, human waste, plastic water bottles, medical waste, amputated body parts, uniforms, dead animals – many things that shouldn't be burned, much less burned together. 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

Robert Elesky

I served four years active duty 1981-85 US Army. During that time, I served in the 172nd, Fort Hood 2nd Armor Division, and in the Sinai Desert Egypt on the MFO Peace Keeping Force. When the war started in Afghanistan they needed Veterans to fill crucial support roles for our military and I needed a job, so I signed on with KBR. I ended up on Kandahar Airfield on January 2, 2004. I for sure will never forget the stench of the five-acre sewage pond on the west end of the base. When units would leave, anything they didn't take with them went into a pile on the southwest end of the base. We would go to that pile daily to salvage things we needed for repair of vehicles and whatever else we might need. Then a big armored bulldozer showed up, dug a big hole, and push the pile into it and it was set afire, exactly when I can't recall, but not too long after the pile was pushed into the pit. After they started burning the stuff my sinuses were a disaster. The burn pit was set on fire every evening around dark. I could see the burn pit from my tent is how close it was to us. We slept in the fumes, worked in the fumes, and ate in the fumes.

In 2012 I developed difficulties in breathing out of my right nostril and started developing nose bleeds. I then went to the Dr. and they diagnosed me after scans a nasal biopsy with a solitary sphenoid sinus plasmacytoma, very very rare, with most cases in the Middle East to my understanding. When I was diagnosed I immediately wanted to know what I had, and how I got it. All my research led me back to "Toxic Exposure" The only place I was ever exposed to toxins that would cause something like this was Kandahar Airbase in 2004-2005 and Balad, Iraq 2005. During my research I discovered I could file a DBA claim which is workers compensation for civilians who work oversea in support of our military. I did that right away. My case drug on for years and KBR eventually settled with me for an amount that was nowhere near what was needed for such a situation, but we had no choice because of the financial situation this illness had put us in.

After my diagnoses they immediately started radiation therapy on me and was able to kill the plasmacytoma in my nasal cavity. However subsequent PET scans revealed a bone lesion on my sternum which they again radiated but it didn't work, so I ended up on sixteen weeks of chemo therapy.

After recovery I went back to work in Medical sales. I then developed other lesions on my right cheek bone about the size of a golf ball. Again, I was put back into radiation treatment. Having to take more time off work to go to Portland for radiation treatments again. Devastating to our income. Again, the radiation was successful, but by now my employer could see I couldn't do my job like I used to with my illness and I was terminated in the hospital while undergoing treatment. They didn't say my illness was the reason, I'm just if, but based on my past performance and the current performance the conclusion is a logical one.

So, after being terminated I found odd jobs to do to keep busy as my wife was working at the time and I just needed some time to recoup.

I was sent for another PET scan that revealed multiple bone lesions on my head, arm, knee, and femur. What has everyone a bit baffled is my blood work is always unremarkable and my bone marrow biopsies always come back clean. So currently I have been on chemo therapy since January unable to work due to my treatments and on my way to Seattle for a bone marrow transplant. My wife no longer works at the post office to support us as her position there was seasonal, my youngest son who is a firefighter and EMT is having to take leave of his work to be my care provider in Seattle, so my wife can continue to work the only job she can find to try and pay our mortgage and bills.

This has been devastating to us emotionally, financially, anyway that you can't think of something like this can negatively affect your life. The anxiety of the cancer, the anxiety of wondering if you'll have a home to come home to is overwhelming. I'm not the only one in this position. There are literally thousands of us who went down range in defense of our nation who are being discarded as if we were garbage with little to no compensation.

All we hear is that there's no direct link between the Burn Pits and our illnesses. I find that insulting. If that's true, why don't we just burn trash in our neighborhoods? Why do we have an EPA? The data already exists. That's why we don't burn trash in our neighborhoods. We already know breathing toxins make people sick, don't we?

I'm outraged that memos were sent to the pentagon as far back as 2000 with air quality reports saying that we should stop burning this trash next to the bases. Those memos were ignored and shoved in someone's desk drawer. Why? Who did that? I'd like to know.

So, for now we are just barely making it. I rarely see my wife, children and grandchildren because of their work schedules and I fear of getting a sickness from one of the grandkids. One

of them always has a runny nose or something. I live in constant pain and isolation wondering how it's all going to end and I'm not alone. There are "Thousands" if not "Tens of Thousands of us, and we'd like to know what you're going to do for us after sending us down range in defense of freedom, and knowingly poisoning us. Can you answer that question? We willingly accepted the risk of war.

APPENDIX B: Medical Opinions

(see below)

DONALD AND BARBARA ZUCKER SCHOOL of MEDICINE AT HOFSTRAINORTHWELL

June 1, 2018

This past Memorial Day honored our brave patriots who have lost their lives in the Iraq and Afghanistan War, but today we must not forget the noble obligation to help those still suffering. The wars in Iraq Afghanistan have been unprecedented because women and men have been exposed to novel airborne hazards such as: 1) Burning trash "in burn pits"; 2) Vehicle Improvised Explosive Devices (VID); 3) Dust storms; 4) Shock waves from exploding bombs. Soldiers with new onset respiratory symptoms from these hazards post deployment are being diagnosed with Iraq Afghanistan War Lung Injury (IAW-LI).

IAW-LI is hazardous for soldiers' health; this war-induced disease impacts multiple dimensions of everyday life, such as the ability to perform one's job and the ability to exercise. We have conducted research on this disease and discovered soldiers suffering from this war-related lung injury have new onset asthma or fixed obstructed airways. We have reported titanium that is bound to iron in fixed mathematical ratios of 1:7, which is extremely rare in nature, in the lungs of soldiers. This suggests an anthropogenic, man-made source. In more severe cases, these soldiers became respiratory cripples that required a lung transplant. IAW-LI is a long-term disease that does not disappear years later, even though some of these soldiers were exposed in 2003. Symptoms as severe as these are not detectable by routine testing and require sophisticated quaternary care.

Currently, there is no treatment available for this disease process, but we are investigating several candidate medications in development which we have seen to reverse IAW-LI injuries in mice. While this problem requires a bipartisan solution, we urge the current Trump Administration to foster interdisciplinary collegiate collaborations to expedite novel therapies for our soldiers. It is important that independent, academic medical centers, such as: the International Center of Excellence in Deployment Health and Medical Geosciences, Northwell Health; Vanderbilt; and National Jewish Deployment Center, receive funding for this emerging, critically-important disease. Because of the VA's dereliction of duty to this matter for the last fifteen years; it is our generation's Agent Orange. These independent academic medical centers can report annually to Congress, analogous to World Trade Center monitoring programs. The World Trade Center Monitoring Programs have provided care and research to improve health and quality of life of those affected by airborne bioterrorism attacks at Ground Zero.

IAW-LI sometimes is not easily diagnosed by physicians, because many are still unaware of this injury. Also, it is difficult for suffering patients to realize what their symptoms are because this is an unconventional disease. Many believe the symptoms are attributed to Post Traumatic Stress Disorder, not IAW-LI. Sophisticated tests as impulse oscillometry and analysis of lung tissue for metals are only available at Quaternary Care Medical Centers.

On Memorial Day we honored all the men and women who sacrificed their lives for our country. As fellow citizens, it is our patriotic duty to raise awareness of this potentially-life altering injury. These brave individuals need the public to aid them. We owe our heroes the knowledge, treatment, and care to best help them recover from this injury. The amount of funding is miniscule compared to the sacrifices these extraordinary citizens make daily. On this Memorial Day, please urge the Trump Administration to fund academic research to stop the suffering of these patriots and their families.

Anthony M. Szema, M.D., FCCP, FACAAI, FAAAAI, FACP, ATSF

inthony Szema, M.D.

American Thoracic Society Fellow, Inaugural Class of 2018

Co-Investigator and Member, Columbia University Global Psychiatric Epidemiology Group CDC NIOSH U01 OHO11308 "9/11 Trauma and Toxicity in Childhood: Longitudinal Health and Behavioral Outcomes"

Faculty, Internal Medicine Residency Program at Mather Hospital, Northwell Health Clinical Associate Professor of Medicine, Division of Pulmonary and Critical Care, Northwell Health Clinical Associate Professor, Division of Allergy/Immunology, Northwell Health Clinical Associate Professor of Occupational Medicine, Epidemiology, and Prevention Director, International Center of Excellence in Deployment Health and Medical Geosciences, Northwell Health Donald and Barbara Zucker School of Medicine at Hofstra/Northwell

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CEO, RDS2 Solutions, Inc. (RDS2solutions.com) Managing Member, Three Village Allergy & Asthma, PLLC (threevillageallergy.com)

Mohin Dig

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To whom it may concern,

I, Anthony Szema, and I, Malvika Singh, give specific written permission for the submission of this document to testimony to Congress.

Sincerely, Anthony Szema Malvika Singh





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

I 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,

1 Amil

Robert Miller, M.D. Associate Professor of Medicine

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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, nonsmoking 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

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njhealth.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 <u>exposures which</u> 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_{2.5}), an exposure which is linked to several cardiovascular and pulmonary disorders (2). The Department of Defense has consistently documented airborne PM_{2.5} 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 <u>quantified</u> 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. Noninvasive 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 <u>well-recognized</u> in patients

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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

- <u>The diagnosis of deployment-related lung disease (DRLD) requires specialized</u> <u>pulmonary evaluation and testing</u>, which may include metabolic exercise testing, <u>complete</u> 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 should be revised (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 National Jewish Health 1400 Jackson St Denver, CO 80206

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References

- National Research Council. Long-Term Health consequences of exposure to Burn Pits in Iraq and Afghanistan. Washington DC the National Academies Press; 2011:
- World Health Organization. Burden of Disease from the joint effects of household and ambient air pollution for 2012. Geneva Switzerland: Public Health, Social and Environmental Determinations of Health Department. World Health Organization. 2014
- Engelbrecht JP, McDonald EV, Gillies JA, Jayanty RK, Casuccio G, Gertler AW. Characterizing mineral dusts and other aerosols from the middle- East Part 1: ambient sampling. Inhal Toxicol. 2009; 21: 297-326.
- Leski TA, Malanoski AP, Gregory MJ, Lin B, Stenger DA. Application of a broad-range resequencing array for detection of pathogens in desert dust samples from Kuwait and Iraq. *Applied Environ Microbiology* 2011; 77: 4285-4292.
- Smith B, Wong CA, Smith TC, Boyko EJ, et al. Newly reported respiratory symptoms and conditions among military personnel deployed to Iraq and Afghanistan A prospective population based study. Am J Epidemiol 2009; 170: 1433-1442.
- Szema AM, Peters MC Weissinger KM et al. New onset asthma among soldiers serving in Iraq and Afghanistan. Allergy Asthma Proc. 2010/31:L67-71.
- Shorr AF, Scoville SL, Cersovsky, Shankd GD et al Acute Eosinophilic pneumonia among US military personnel Deployed in or near Iraq. JAMA 2004; 292:2997-3005
- King MS Eisenberg R, Newman JH et al Constrictive bronchiolitis in soldiers returning from Iraq and Afghanistan N Engl J Med 2011l 365:222-230.
- Rose C, Abraham J Harkins D Miller R et al. Overview and recommendations for Medical Screening and Diagnostic Evaluation for post-Deployment Lung Disease in Returning US Warfighters. J Occ Env Med. 2012; 54:746-658.
- Dhoma S, Gottschall B, Robinson M, Williams A, Meehan R, Groshong S. Lung disease in deployers returning from Afghanistan and Iraq. Am J Respir Crit Care Med. 2013; 187: A3669.
- Madar CS, Lewin-Smith MR, Franks TJ, Harley RA, Klaric JS, Morris MJ. Histological diagnosis of military personnel undergoing lung biopsy after deployment to southwest Asia. Lung; 2017; DOI 10.1007/s00408-017-0009-2
- Rose C, Abraham J Harkins D Miller R et al. Overview and recommendations for Medical Screening and Diagnostic Evaluation for post-Deployment Lung Disease in Returning US Warfighters. J Occ Env Med. 2012; 54:746-658.
- Morris MJ, Dodson DW, Lucero PF et al. Study of active duty military for pulmonary disease related to environmental dust exposure (STAMPEDE). Am J Respir Crit Care Med 2014; 190: 77-84.
- 14. www.benefits.va.gov/warms/docs/regs/38CFR/BOOKC/PART4/S4_97.doc

§4.97—Schedule of ratings-respiratory system 4.97-1

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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, <u>immunosuppressants</u>, are prescribed to control symptoms. Response to treatment is generally poor.

TREATMENT

SUGGESTED PROGRAMMATIC ASSESSMENT*

Suggested MER for evaluation:

Clinical history and examination that describes diagnostic features and physical findings

Biopsy reportsCT scans, pulmonary function tests (PFTs, spirometry, DLCO, or ABG) Response, if any, to a regimen of treatment

Suggested Listings for Evaluation

DETERMINATION LISTING Meets Listing 3.02

103.02

Medical Equals

* Adjudicators may, at their discretion, use the Medical Evidence of Record or Listings suggested to evaluate the claim. However, the decision to allow or deny the claim rests with the adjudicator.

REMARKS

A description of findings establishing the diagnosis and response to treatment is needed when evaluating this condition. To meet listings 3.02 A, B or C, lung biopsy results and program compliant PFTs documenting listing level severity are required.

To Link to this section - Use this URL:

http://policy.ssa.gov/poms.nsf/lnx/0423022840

DI 23022.840 - Obliterative Bronchiolitis - 08/21/2012 Batch run: 08/21/2012 Rev:08/21/2012

APPENDIX C: Burn Pits 360 Staff Biographies

CPT (Army Ret.) Le Roy Torres, Founder

Le Roy Torres is the co-founder of Burn Pits 360 Veterans non-profit organization. Torres was medically retired from the Army after 23 years with the rank of Captain following his diagnosis from a lung biopsy to include other secondary medical diagnosis. He served 7 years Active and 16 years Reserve. Torres also worked as a State Trooper for the Texas Highway Patrol after he was forced to accept a medical discharge following his 14 years of state service. Torres earned his B.A. and M.A. in Administration - Organizational Development at the University of the Incarnate Word. Torres also enrolled in Seminary and completed several courses through Liberty University during his application process for the Army Chaplaincy Program. Subsequently Torres was medically boarded from the Army Reserve due to his medical conditions associated with burn pit exposure forcing him to discontinue the Army chaplaincy process.

Torres is an ardent advocate alongside his wife Rosie for the military families and warriors battling illnesses associated with deployment related environmental toxic exposures during the OEF/OIF War Campaigns. Torres alongside his wife founded the first Burn Pits 360 Warrior Support Center in Robstown, Texas. Torres is also passionate about assisting the first responder community that serve a dual role to their state and country that are battling not only medical conditions from exposure; but also those facing battles with invisible wounds, job loss, and other challenges that arise from such hardships that have taken a toll on so many Veterans and their families.

Rosie Torres, Executive Director

Rosie Lopez Torres is the co-founder of Burn Pits 360 Veterans Organization. Rosie held a civil service position at the Department of Veteran Affairs Health Care System for 23 years. Rosie advocates full time for Veterans, Service members and families suffering from deployment related illnesses. She co-founded Burn Pits 360 alongside her husband Le Roy Torres. Rosie also co-founded the Warrior Support Center, which is the organization's headquarters but also a center where local Veterans and their families can seek access to training, a computer room, recreation room, and peer support services. Rosie is currently attending Liberty University where she is studying law.

Tammy McCracken, Secretary

Professionally, Tammy McCracken works full time as a Senior Technical Architect with GISinc., a location analytics company. She has managed over \$250M in technical projects over the course of her career. She is responsible for client relations and designing solutions that meet the unique needs of her clients. She is a Certified Information Systems Auditor and is currently pursuing her Master's in Data Analytics at Georgia Tech.

In addition to her technical career, she is a military widow serving on several non-profit boards promoting healing and health to Veterans and Widows. Her passion is to ensure that her husband, Colonel David A McCracken's memory and legacy live on and that no other widows face the trials and challenges she has painfully navigated subsequent to his untimely and unnecessary death.

Cindy Aman, Legislative Liaison

In her professional life, Cynthia Aman works full time for the Delaware State Public Defender's office as a Mitigation Specialist. She has her Master's in Forensic Psychology and continues to pursue continued education in this field.

Cynthia is also a Veteran who was assigned to the 1138th Military Police Company with the Missouri Army National Guard. She developed an irreversible, progressive lung disease called Constrictive Bronchiolitis, from her deployment to the Middle East. Since her diagnosis she has worked as an advocate on Burn Pits and Toxic Exposure. She is currently the Legislative Liaison with Burn Pits 360 and spends her free time working hard to represent and speak for those who have been silenced.

Stacy Pennington, Legislative Liaison

Stacy Pennington has been an advocate for veterans fighting for rights of those affected by toxic exposure caused from burn pits in Iraq and Afghanistan. This deep commitment to fight for those affected by toxic exposure occurred a decade ago after the onset of her brother's sudden illness and death.

Stacy is the Community Outreach Director for AARP. She is dedicated to the field of Gerontology. She is active in educating, providing services and advocating for those 50 plus. Stacy has worked for the AARP for thirty years.

In addition, Stacy is a part of several non-profit organizations including Burn Pits 360, Leadership Cheatham County and Leadership Middle Tennessee.

Diane Slape, Director of Gold Star Families Program

Diane Slape's professional career is currently the Project Administrator for NNAC, Inc., a Commercial Construction firm with the majority of their projects in the Military Sector, all over the Northwest and Texas. Diane always knew she wanted to help Vietnam Veterans with PTSD, but financial aid and family contribution couldn't handle the requirement. So she volunteered for many non-profit Military organizations, to give back as much of her free time in appreciation of their sacrifices. She volunteered to be her husband's unit Family Readiness Group leader. She developed a working relationship with the unit's Chain of Command in garrison and downrange, as well as a loving, supportive relationship with the soldiers and their families. She made it her mission to support the soldiers and their missions and helps guide their families through their military experience, to include consecutive deployments and Duty Station moves, even after her husband retired from Military Service.

Her career involvement with the Military didn't stop, after becoming a military widow. She still had soldiers and Veterans to support, as well as their families. She serves on several non-profit organizations assisting Veterans reintegrating into Civilian life after the Military, as well as promoting their mental & physical health, despite their exposures. Her life's mission is to carry on her husband, SFC Frederick T Slape's caring and compassion for his fellow soldiers in need and to do whatever possible so that soldiers or widows do not

have to endure the same struggles and tragedies that she found herself involved in, so abruptly and unprepared for.

Will Wisner, Program Manager

William is a Senior Director at CCS Fundraising, a strategic fundraising firm that partners with nonprofits for transformational change. Prior to joining CCS, William served as the Veteran Fellow for Mission Leadership at the Sergeant Thomas Joseph Sullivan Center, a nonprofit organization dedicated to the issue of toxic exposure illnesses in Iraq and Afghanistan veterans. William holds a M.A. in Nonprofit Management from Washington University in Saint Louis.

William was a Staff Sergeant in the United States Army and is a veteran of Operation Iraqi Freedom having served as Cavalry Scout in the 3rd Squadron of the 1st Cavalry Regiment, 3rd Heavy Combat Brigade, 3rd Infantry Division.

Daniella Molina, Director of Community Development

Daniella Molina currently serves as the volunteer Director of Community Development with Burn Pits360 Veterans Organization. Outside of her volunteer services Daniella is a full-time caregiver, mother of two, and student. She is currently pursuing a degree in Psychology: Military Resilience through Liberty University. Upon graduation, she plans to assist active/veteran service members and their families through the challenges associated with life after war. Daniella is the wife of retired Army veteran, Jonathan Ray Molina.

Advisory Board Members

Former Congressman Solomon Ortiz Solomon Ortiz Jr. Ret. Colonel David Sutherland Ret. Lt. Col Gregg Deeb Ret. Lt. Col. Brian Lawler Dr. Robert Miller Dr. Steven Coughlin Kerry Baker

APPENDIX D: Burn Pits photos

(Ret. CPT. Le Roy Torres & his sons Kenneth and Christopher)



(Brian Alvarado & his daughter Rihanna)





(Ret. SSG Will Thompson, double lung transplant recipient)



Fallen Heroes



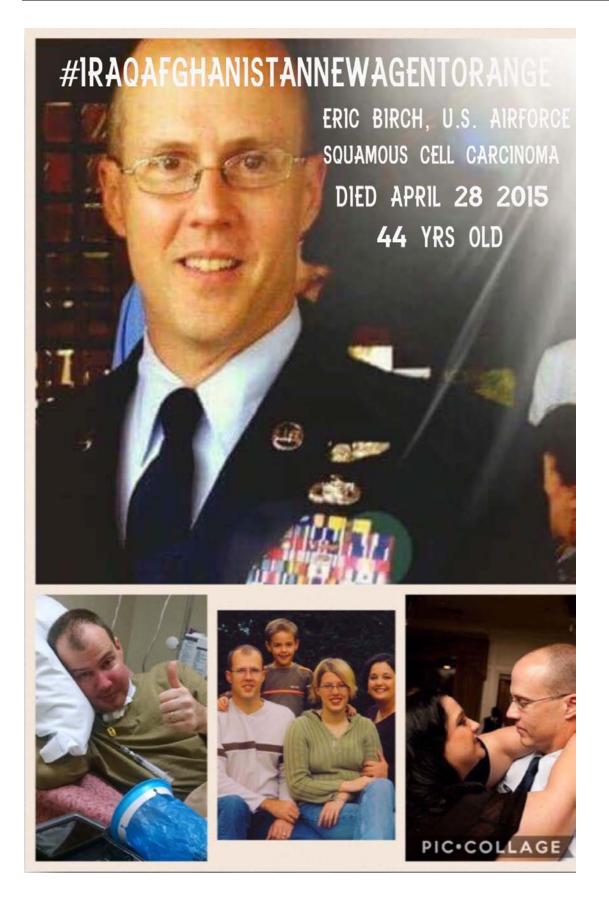


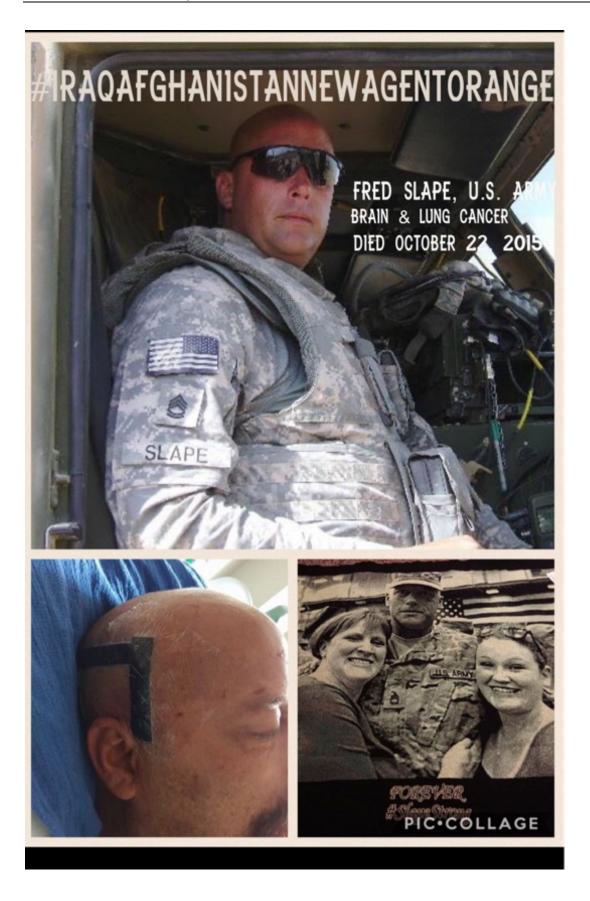


















Major Kevin Wilkins

FALLEN HERO COL. DAVID MCCRACKEN GLIOBLASTOMA I want my hids To know the value at triendship.... The value I had work ... the value at doing something at family courage and determination stead fast manale

