



STATEMENT FOR THE RECORD

**TRAGEDY ASSISTANCE PROGRAM FOR SURVIVORS (TAPS)
BEFORE THE
SUBCOMMITTEE ON DISABILITY AND MEMORIAL AFFAIRS
COMMITTEE ON VETERANS' AFFAIRS
UNITED STATES HOUSE OF REPRESENTATIVES**

**"THE TOXIC WORLD OF PRESUMPTIVE SERVICE CONNECTION
DETERMINATIONS: WHY SHOULD OUR VETERANS WAIT?"**

DECEMBER 9, 2020

The Tragedy Assistance Program for Survivors (TAPS) is the leading national nonprofit organization providing comfort, care and resources to all those grieving the death of a military loved one. TAPS provides comfort and hope 24/7 through a national peer support network and connection to grief resources, all at no cost to surviving families and loved ones.

TAPS provides programs to survivors across the nation and worldwide. Since 1994 its National Military Survivor Seminar and Good Grief Camp has been held annually in Washington, D.C. over Memorial Day weekend. TAPS also conducts regional survivor seminars for adults and youth programs at locations across the country, as well as adult retreats around the world. TAPS connects those in need with counseling in their community and helps navigate benefits and resources.

TAPS provides loving support and resources 24/7 through its National Military Survivor Helpline.

TAPS was founded in 1994 by Bonnie Carroll following the death of her husband in a military plane crash in Alaska in 1992. Since then, TAPS has offered care and support to more than 100,000 bereaved surviving family members. For more information, please visit TAPS.org/mission.

TAPS receives no government grants or funding.

Chairwoman Luria, Ranking Member Bost, and distinguished members of the House Committee on Veterans' Affairs Subcommittee on Disability Assistance and Memorial Affairs, the Tragedy Assistance Program for Survivors (TAPS) is grateful for the opportunity to provide a statement for the record on issues and concerns of importance to the families we serve, the families of the fallen.

The mission of TAPS is to offer comfort and support for surviving families of military loss regardless of the location or manner of their death. Part of that commitment includes advocating for improvements in programs and services provided by the Federal government through the Department of Defense (DoD), the Department of Veterans Affairs (VA), Department of Education (DoED), Department of Labor (DOL), Department of Health and Human Services (HHS), as well as State and local governments.

As their services provided to survivors of military and veteran loss are complimentary, TAPS and the VA have enjoyed a long-standing collaborative working relationship. In 2019, TAPS and the VA entered into a new and expanded Memorandum of Agreement that formalized their partnership intended to provide extraordinary services through closer collaboration.

Under this agreement, TAPS continues to work with surviving families to identify resources available to them within the VA and in the private sector. TAPS also collaborates with the VA in the areas of education, burial, benefits and entitlements, grief counseling, survivor assistance, and other areas of interest.

TAPS appreciates the opportunities provided by the quarterly Department of Veterans Affairs (VA) and Department of Defense (DoD) Survivors Forum, which works as a clearinghouse for information on government and private sector programs and policies affecting surviving families. TAPS was pleased to partner with the VA/DoD Survivors Forum to share information with our colleagues on the extent to which TAPS programs are supporting all military loved ones during the COVID-19 global crisis.

TAPS President and Founder, Bonnie Carroll, is honored to serve on the Department of Veterans Affairs Federal Advisory Committee on *Veterans' Families, Caregivers, and Survivors*. The Committee advises the Secretary of the VA, through the Chief Veterans Experience Officer, on matters related to Veterans' families, caregivers, and survivors across all generations, relationships, and Veteran status. Ms. Carroll also serves as a PREVENTS Ambassador for the VA's initiative on preventing suicide.

Understanding Illnesses That May Result From Toxic Exposure

According to the Department of Veterans Affairs, veterans who served after 9/11 may have been exposed to a dozen different wide-ranging environmental and chemical hazards, some of which carry very real risks. Whether from burn pits, depleted uranium, or toxic fragments, they are getting sick and dying young from uncommon illnesses and early onset disease.

The Tragedy Assistance Program for Survivors' (TAPS) interest in understanding illnesses that may result from toxic exposure stems from our desire to ensure surviving families have access to all available survivor benefits earned through the service of their loved one. The information that can be gathered from our survivor histories is also invaluable in establishing patterns and baselines that can be applied to the veteran community, save lives, and prevent this now and in the future.

Over the past five years, the number of survivors of a military death due to illness seeking TAPS services increased by 246 percent. As of December 1, 2020, more than twenty-nine percent of all military survivors connecting with TAPS this year have experienced a loss due to illness. Military deaths due to illnesses (29%) and suicide (29%) are the leading causes of death among new military survivors connecting with TAPS and far surpasses all other circumstances of death, including hostile action.

TAPS recently re-launched its Illness Loss Survivor Survey, aimed at understanding the issues faced by military members who have passed away post-deployment. Among 505 respondents, the survey found that 287 (57%) service members had been diagnosed with a form of cancer prior to passing away, with rates nearly equivalent for those that served pre-9/11 and post-9/11. Among 304 respondents who indicated their loved one served post-9/11, it was found that 182 (60%) of these service members required a caregiver prior to their death. In addition, the survey looked into misdiagnosis rates of those who have passed away. From a sample of 314 respondents who indicated their loved one served post-9/11, 130 (41%) indicated that a loved one's illness had been initially misdiagnosed. Results included only demonstrate initial findings. To strengthen the validity of these findings, TAPS plans to collect and analyze additional survey data to provide further insight into the experiences of service members and illustrate any trends that may warrant continued research.

TAPS and other partners are working together to advocate for veterans exposed to toxins, their families, caregivers, and survivors. Through this partnership, we have made great strides over the past three years to create a growing awareness of the issue of toxic exposure by enlisting support from other organizations, such as members of The Military Coalition (TMC).

TAPS is also a founding member of the Toxic Exposure in the American Military (TEAM) coalition, a group of 30 military and veteran service organizations and experts. The TEAM coalition is collectively gathering data, raising awareness, and promoting research. The TEAM coalition was also instrumental in drafting landmark legislation, introduced during the 116th Congress, that fundamentally reforms and improves how veterans exposed to toxic substances receive health care from the Department of Veterans Affairs.

Illness Loss Survivor Testimonials

Death by illness is one of the leading causes of death among military survivors. Since 2008, TAPS has been contacted by over 13,000 survivors whose military loved ones died due to an illness. Sadly, we project this number to increase by more than 2,300 each year based on current trends.

While we know there's a significant number of veterans who die of common illnesses, we have become deeply concerned that like the Vietnam era, post 9/11 veterans have been exposed to toxins that are known to cause cancer. TAPS is working to gather survivor stories and aggregate data to better understand the scope and types of illness loss.

Here are a few of the many stories we have collected from our surviving families:

Coleen Bowman, Widow of SGM Robert Bowman

"Rob was the picture of health before he deployed, he was an Airborne Ranger. When he returned from his second deployment from Iraq, he was sick. In June 2011, Rob was diagnosed with an extremely rare cancer Cholangiocarcinoma (bile duct cancer). During deployments, Rob was in close proximity to an open air burn pit that burned around the clock. His vehicle was struck at least ten times by IEDs, stirring up particulate matter.

Had we known he had been exposed and to what toxins, we could've shared the information with doctors, and it wouldn't have taken six months of misdiagnoses before we learned he had stage 4 inoperable cancer. Had we

known earlier he might still be alive today. For 19 months my daughters and I cared for him, and on January 13, 2013 Rob passed away at the age of 44. Several of the men that Rob served with have many different illnesses, to include cancer, and several have passed away since at very young ages."

Tim Merkh, Father of Corpsman Richard Merkh

"My son Richard Merkh, was a Corpsman in the Navy. He had served over 15 years and died from cancer on October 3, 2018. Richard served several tours with the Marines during the war. His lodging facilities were on only trash or dump sites. It is my belief that Richard contracted stage 4 cancer from his exposure during the war. Cancer does NOT run in my DNA, nor my wife's. So where did he contract the cancer....his exposure. Unfortunately he was diagnosed after his entire liver and colon was infected with cancer.

I am a retired USAF veteran. I know what we put our troops through. Some things must change. Richard was survived by his wife of twelve years and a beautiful 4 year old daughter, my precious granddaughter. We can't change Richard's outcome, but we must ensure we treat and support our troops better."

Nicoele, Drew, and Maggie Arseneau, Widow and Children of Specialist Andrew Arseneau- US Army

"My children Drew and Maggie and I lost our father and husband, Andy, six years ago on September 12, 2014 to lung and heart failures due to toxic exposures during his service in Iraq, Saudi Arabia, and Kuwait during Desert Storm. He was only 46.

We first filed his health claims with the VA in 2010. They were denied and we were in the very lengthy appeals process when he passed away in 2014. He was approved 100%, permanent and total for his PTSD, but his toxic exposure claim was denied. He could no longer work due to his illness and I was his full time caregiver for four years.

I filed for DIC benefits for the children and myself immediately after his death. I'm still fighting today for approval after paperwork was lost by the VA forcing me to lose possible back pay and start the process from the beginning after ten long years. He has been gone for six years and this process has taken a toll on our family."

June Heston, Widow of BG Michael Heston

"Mike was active duty in the Vermont National Guard. Mike deployed to Afghanistan three times. First in 2003 for 7 months, then 2006-2008 for 15 months, and last 2011-2012 for one year. In April of 2016, Mike had gone into the doctor not feeling well. For 10 months doctors couldn't figure out what was wrong with him. Finally, in January of 2017, Mike was diagnosed with a very rare form of pancreatic cancer, stage 4. Mike passed away shortly after that on November 14, 2018."

Laura Forshey, Widow of Sgt Curtis Forshey

"Three months into his deployment, he began to experience bloody noses that would go on for hours at a time. He went to the doctor there on the FOB where they ran bloodwork. The results showed his white blood count was way off. They flew him to Landstuhl, Germany. His wife, Laura, and 3 month-old son, Ben, along with Curt's parents flew to be with him in Germany. While they were in flight, Curt passed away. His cause of death was a brain aneurysm, caused from the cancer they discovered, Acute Promyelocytic Leukemia. Curt was 22 years old. He died on March 27, 2007. With proper diagnosis and treatment it is curable in 80-90% of patients."

Rev. Jennifer Moser, Widow of LTC Gregory Moser

"My husband LTC Greg Moser was an IL National Guard Chaplain, deployed to camp Phoenix. He left healthy in 2008. He returned in 2009 with a wracking cough that never fully went away. He died on December 24, 2016 from complications of the stage IV lung cancer he'd been diagnosed with six months earlier. Being a Chaplain and parish Pastor, he had no history of Toxic Exposures from any other source (he didn't work in heavy industry or some such in his civilian life). And there was no history of cancer in his family whatsoever. Heart disease and diabetes, yes. Cancer, no!

As a result of his death being ruled active duty, honorable but not in the line of duty, I do not qualify to receive his pension, and Greg's four children do not qualify for tuition help, such as the Fry Scholarship. Moreover, the "not in the line of duty" ruling is an emotional slap in the face to our National Guard soldiers who fought a ten year war with multiple deployments. Often taking pay cuts to serve and dealing with trauma to families of multiple and sudden deployments, only to have DoD tell us those deaths aren't service-connected."

Kris Marbutt, Widow of Sgt John Marbutt

"He worked very closely to the burn pits. In 2010 he was diagnosed with a brain tumor and told it was benign. He was initially denied a CT scan. He was diagnosed with a second 'huge tumor' glioblastoma. He died on October 21, 2016. He was 34 years old."

Amber Bunch, Widow of LCPL Mark Bunch

"After returning from his second deployment he was different mentally and physically. From the outside looking in one could see the effects of war followed him home facing P.T.S.D. and Survivors Guilt. On the other hand, the more noticeable conditions began to appear including insomnia paired with night terrors, breathing issues, constant coughing, stomach issues that could not be resolved, migraines that lasted for days, sudden mood changes, lower back pain, sleep apnea, memory loss, and the list could go on. I fought and fought for us, for our family.

On February 26, 2014, my battle for my husband Mark Bunch Jr's legacy began upon his passing. I never imagined six years later I would still be fighting for benefits."

Louise Carroll, Widow of Vietnam Veteran Larry Carroll

"My husband Larry was in the Army and Navy for 27 years. He was in Vietnam where he contracted Agent Orange. From 2004 to 2017, I watched my husband die slowly with new comorbidities that were from cancer to COPD plus all kinds of lipomas and heart problems. His percentage of disability was 265 percent. He was on morphine for pain.

I touched every part of his body not knowing the terrible problems to me. For three years now, I have had places come up on my face and body that end up like burns. I have been treated for everything but cannot be given a diagnosis. I believe, because I was exposed to all of his secretions, that through his blood I contracted Agent Orange. I called the VA for help in testing and they refused, very hurriedly telling me this was impossible. At the time, I had surgery on my knee and hip from lifting him and dressing my own wounds. No way it was sterile. I am retired from the medical field and know I am sick."

Tanja Smith, Military Spouse

“While I haven't lost someone due to this, my husband was deployed several times and spent time at the burn pits, which makes me worry about the future and how the burn pits may cause issues with his health.”

Exposure-related Illnesses

Toxic exposures in the military have unfortunately been experienced by multiple generations of service members over the years. There are more than 2.7 million veterans affected by Agent Orange and over 425,000 veterans affected by Gulf War Syndrome. There are more than 3 million current and former service members impacted during Operation Enduring Freedom and Operation Iraqi Freedom.

Currently, there are more than 200,000 veterans enrolled in the VA Burn Pit Registry – all of whom served on or after 9/11 and were deployed to a base or station where open burn pits were used. While the government has created a self-report registry, they admit it is a flawed and limited system that covers only exposures to burn pits. There are many other instances of exposure that are not tracked, and only a small number of those exposed to burn pits have actually registered. Sadly most young veterans who have died of rare cancers never knew to register.

There are millions of service members and veterans who were exposed to burn pits and other toxins while serving, and sadly many will die from exposure-related illnesses. Their loved ones will make up a large portion of the next generation of TAPS survivors.

By the year 2021, TAPS believes that deaths due to illness will surpass all combat deaths, non-combat deaths, accidents, and suicides combined. It's time to take action and learn more about which toxins are causing rare cancers in our young people. Research must be done in and outside of government. We don't have time on our side, we already know a number of toxins our troops were exposed to are carcinogens. We must get that information into the hands of veterans and their medical providers so they can plan for early screening and make connections for accurate diagnosis and effective early treatments.

The Departments of Defense and Veterans Affairs are working hard to mine data to match exposures to veterans but we must work harder and faster. The Individual Longitudinal Exposure Record (ILER) is groundbreaking and TAPS is

grateful the ILER provision was included in the final version of the Fiscal Year 2021 National Defense Authorization Act (NDAA). We continue to call on Congress to make this critical information available to service members, veterans, their families and survivors.

In both pre and post 9/11 generations many service members were exposed to toxins while serving overseas. The sobering consequence has been thousands of unexplained illnesses, many of them terminal. The loss of a service member or veteran to illness can be especially difficult when the survivor is unable to “prove” a service connection. This results in an absence of death benefits for survivors or acknowledgement of responsibility by the government that the illness and/or death of the loved one was caused by exposures to toxins.

What TAPS Is Doing

In the case of our TAPS families, we must provide answers to our survivors. So many are left wondering how their loved one survived deployments and returned home safely, only to succumb to illnesses years after returning home.

Like we did when we saw increasing trends and deaths by suicide, TAPS is developing a program to specifically address the needs of our survivors who grieve the death of their loved one to an illness. Many are left wondering how their physically fit military member could succumb to such an aggressive and rare illness that ended their life.

Through our research, TAPS has learned that many illness loss survivors have been caregivers first. Of the 722 survivors who responded to our Illness Loss Survivor Survey, fifty-eight percent of Post-9/11 service members required a caregiver before their death to perform their activities of daily living, to administer medications and be at the bedside - sometimes for lengthy periods of time.

TAPS recognizes the urgent need to support families who have lost a military loved one after having been caregivers. As a result, TAPS is building a “Caregiver to Survivor” program. This program will raise awareness of illness loss due to exposures to toxins and will formalize existing partnerships with other nonprofit organizations to warmly transition all caregiver families to surviving families. The program will address the need to provide hope and healing to thousands of families who are experiencing the devastating loss of loved ones to illnesses and injuries related to their overseas service.

Conclusion

TAPS applauds Congress and this committee for conducting oversight of the devastating effects of toxic exposure on our veterans, their caregivers and survivors. We urge Congress to legislate critical funding for toxic exposure research and education; expand healthcare and benefits for veterans, caregivers and survivors; and build a public awareness campaign so we can save lives.

Those who volunteer their lives to protect the freedom of our nation and the families who stand beside them are ready to know America's priority is to protect and provide for all those who are ready to make the ultimate sacrifice.

The Tragedy Assistance Program for Survivors thanks the Subcommittee On Disability And Memorial Affairs and its distinguished members for holding this important hearing on toxic exposure, and providing TAPS the opportunity to submit a statement for the record.