



STATEMENT FOR THE RECORD

TRAGEDY ASSISTANCE PROGRAM FOR SURVIVORS (TAPS)

BEFORE THE

COMMITTEE ON VETERANS' AFFAIRS

UNITED STATES SENATE

"MILITARY TOXIC EXPOSURES: THE HUMAN CONSEQUENCES OF WAR"

MARCH 10, 2021

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 through a national peer support network and connection to grief resources, at no cost to surviving families and loved ones.

TAPS provides programs to survivors across the nation and worldwide. Since 1994 the 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.

Chairman Tester, Ranking Member Moran, and distinguished members of the Senate Committee on Veterans' 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.

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 partners 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, serves 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, a significant number of veterans who served after 9/11 were exposed to more than a dozen different wide-ranging environmental and chemical hazards, most of which cause serious health risks. Whether from open burn pits, depleted uranium, toxic fragments, or particulate matter, service members and veterans are getting sick and prematurely dying from uncommon illnesses and diseases that are tied to exposures to toxins.

The Tragedy Assistance Program for Survivors' (TAPS) interest in understanding illnesses that may result from exposures to toxins 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 and military 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 143 percent. As of January 1, 2021, more than thirty percent of all military survivors connecting with TAPS have experienced a loss due to illness. Military deaths due to illnesses (30%) and suicide (31%) 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 re-launched a national Military Survivor Illness Loss Survey, to learn more about the issues faced by military members who have passed away post-deployment. Among the 722 respondents who accessed the survey, the survey found that 66% of survivors reported their service members served post 9/11. The rates of cancer among pre- and post-9/11 service members are similar at 58% and 57% respectively. Survivors reported that their loved one was misdiagnosed in over 40% of post-9/11 cases. Among age groups, those ages 31 - 40 reported the highest misdiagnosis rate. A majority of post-9/11 service members reported requiring a caregiver. While 67% of all survivor respondents reported their service member required a caregiver, 60% of post-9/11 service members reported that they required a caregiver. 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 veterans, and illustrate any trends that may warrant continued research.

Together with other partners in the military and veteran community, TAPS is working to advocate for veterans exposed to toxins, their families, caregivers, and survivors. Through these partnerships, 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), comprised of 35 organizations representing more than 5.5 million members of the uniformed services - active, reserve, retired, survivors, veterans - and their families.

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 instrumental in drafting landmark legislation, the *Toxic Exposure in the American Military Act of 2020* (TEAM Act), 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. The TEAM Act will be reintroduced in the 117th Congress.

ILLNESS LOSS SURVIVOR TESTIMONIALS

Death by illness is one of the leading causes of death among military survivors. Since 2008, TAPS has been supporting 13,870 survivors whose military loved ones died due to an illness. In 2020 alone, 2,283 new survivors of a death by illness reached out to TAPS for support and services. 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 terminal illnesses. 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 lost their father, and I lost my 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 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. He 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 PTSD 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

Exposures to deadly toxins as a result of military service is not a new phenomenon, unfortunately generations of service members have been exposed and many have died as a result. Our country must do more to prevent exposures, properly treat and provide benefits for those who have been exposed. 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 service members and veterans that may have been exposed to toxins while serving after 9/11, including but not limited to service during Operation Enduring Freedom and Operation Iraqi Freedom.

Currently, there are more than 230,000 veterans enrolled in the VA Airborne Hazards and Open Burn Pit Registry – those who deployed to the Southwest Asia theater of operations after August 1990 or served on or after 9/11 and were deployed to a base or station where open burn pits were used. While the federal government has created a self-report registry, they admit it is a flawed and limited system that covers only exposures to burn pits. There has not been enough attention placed on ensuring that ALL those exposed to burn pits have been included and it is widely (and justifiably) criticized as focusing too narrowly on one type of many exposures. Sadly most young veterans who have died as a result of their exposures to toxins 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.

In 2021, TAPS believes that deaths due to illness will be the leading cause of death among military survivors. It's time to take action and learn more about which toxins are causing rare cancers and other illnesses 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. The Department of Defense has the ability to determine who was exposed to what toxins, when they were exposed and can work together with the VA to notify every affected service member and veteran. We must get this

information into the hands of veterans and their medical providers so they can plan for early screening, make connections for accurate diagnosis and effective early treatments and ensure that they are receiving the benefits and services they have earned through their service to our nation.

The Departments of Defense and Veterans Affairs are working to mine data to match exposures to veterans, but they must work harder and faster. The information that should be mined from the Individual Longitudinal Exposure Record (ILER) could be groundbreaking, and TAPS is proud to have strenuously advocated that the final version of the *National Defense Authorization Act (NDAA) for Fiscal Year 2021*, requires the ILER be expanded to allow veterans to access their personal records. We continue to call on Congress to require DoD and VA make this critical information available to veterans' families and survivors.

We know pre- and post-9/11 generation 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 exposure to toxins.

WHAT TAPS IS DOING

We must provide answers to our survivors of military loss. 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 respondents who accessed the Illness Loss Survivor Survey, 60% 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 standing up our “Caregiver to Survivor” program and formalizing existing partnerships with the American Red Cross and other nonprofit organizations to warmly transition caregiver families to surviving families. Our program will provide hope and healing to thousands of veteran and military families who are experiencing the devastating loss of loved ones to illnesses and/or 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 leadership of the Senate Committee on Veterans’ Affairs and it’s distinguished members for holding this important hearing on toxic exposure, and providing TAPS the opportunity to submit a statement for the record.