



## Support Servicemembers Who Have Been Exposed Occupationally While Serving in the US Military

**The Issue:** Over the past twenty years, millions of service members and veterans have been directly exposed to toxic chemicals released from burn pits that were commonly in use at our military bases across the Middle East and Afghanistan. These burn pits were the primary method of disposal for anything from daily trash and health waste to fuels and ordinance and were present at nearly every base our brave men and women were quartered. As these items were burned, their toxic components were released into the air and into the lungs of those who were defending our freedom.

As a result of this service-related exposure, many of our heroes have or will face significant health issues in the coming years. Until recently, neither the Department of Defense (DoD) nor the Veterans Administration (VA) documented burn pit exposure or had approved any link between this exposure and the diseases our brave servicemembers are facing, including bladder cancer. Without these direct links of service to ailment, many veterans have faced significant difficulty in obtaining the high-quality health care that they were promised.

In fact, many have characterized service member burn pit exposure, and their resulting fight for coverage, the “Agent Orange of our generation” due to similarities to the fight that Vietnam Veterans had to wage in order to receive the critical treatment they too were promised. Since 2007, over 10,500 veterans have made burn pit related disability claims to the VA.

**Legislative History:** As part of the FY 2020 National Defense Act, Congress included the text of H.R. 663, the Burn Pits Accountability Act, co-authored by Reps. Tulsi Gabbard (D-HI) and Brian Mast (R-FL), which created the first national burn pit registry. This legislation created a baseline of data, included as part of a person’s service record, that servicemembers and veterans will be able to point to as they make their case for the benefits they have been promised. This is a critical first step, and one that BCAN was proud to play a role in supporting.

**Current Legislation:** Building on their efforts in 2019, Reps. Gabbard and Mast have joined forces with Senators Sherrod Brown (D-OH) and Rob Portman (R-OH), to introduce *H.R. 7072/S. 3885, the SFC Heath Robinson Burn Pit Transparency Act*. This bi-partisan, bi-cameral legislation will require the VA to document, track, and report to Congress on all cases of burn pit exposure reported by veterans to the VA. It will improve data tracking and accountability as well as provide additional information necessary to logically identify and determine causation between burn pit exposure and reported chronic diseases. The bills have been referred to the House and Senate Armed Services Committees for consideration but neither committee has acted on the legislation.

**What Can You Do:** Contact your Member of Congress and both Senators and ask them to cosponsor and vote for the SFC Health Robinson Burn Pit Transparency Act. Contact House Armed Services Chairman Adam Smith (D-WA) and Ranking Member Mac Thornberry (R-GA), as well as Senate Armed Services Committee Chairman James Inhofe (R-OK) and Ranking Member Jack Reed (D-RI) and ask them to fight for our soldiers and veterans by passing the SFC Heath Robinson Burn Pit Transparency Act in their respective committees and give our service members the healthcare they were promised. Contact Senator Schumer to thank him for his leadership and encourage him to continue the fight.



## Protect the Rights of Americans With Pre-Existing Conditions

**The Issue:** On March 23, 2010, the *Affordable Care Act (ACA)*, commonly known as Obamacare, was signed into law. This law represents the single largest regulatory overhaul and expansion of healthcare coverage since the passage of Medicare and Medicaid in 1965. The law came into effect in 2014 and by 2016 had halved the population of uninsured Americans, extending coverage to an estimated 20-24 million Americans.

Among the significant provisions of the ACA was its guarantee of coverage to all Americans with pre-existing conditions. Before the ACA, insurance companies could deny coverage or charge significantly higher rates for those Americans who they deemed a higher risk, due to any pre-existing condition. Protecting this coverage has become a central part of any healthcare discussion in Congress. BCAN has been supportive of efforts to protect coverage for those with pre-existing conditions.

It is not an overstatement to say that debate surrounding the passage, implementation, and legal challenges to the ACA have been one of the dominant issues in public policy over the past decade. In fact, since it was signed into law, the ACA has been the subject of dozens of lawsuits in the courts and legislative efforts in Congress to either weaken its reach or outright repeal it, including two challenges at the US Supreme Court so far.

**The Current Challenge to the ACA:** In 2017 the Supreme Court ruled that the ACA, and its individual mandate, were constitutional due to Congress' right of taxation. In response, opponents in Congress reduced the tax penalty for the individual mandate to \$0. Once Congress took this action, the State of Texas then filed suit declaring the entire ACA unconstitutional and that case is pending in the courts.

**The Supreme Court Will Soon Decide the ACA's Fate:** On March 2, 2020, the Supreme Court announced that they will hear *Texas v California*, a case that will likely decide the fate of the ACA, during their fall session, possibly before the November Presidential election. The Court's decision would then likely be issued in the Spring or early Summer of 2021. If the Supreme Court rules in favor of Texas, the ACA would be deemed unconstitutional and the protections for pre-existing conditions would be eliminated.

In a filing with the Supreme Court, on July 26, 2020, the Trump Administration has reaffirmed its position in support of Texas, that the entire ACA should be ruled unconstitutional. The House of Representatives has passed several bills reaffirming Congress' view that the law is Constitutional and has worked to strengthen the law pending the Supreme Court decision.

**What Can You Do:** Contact your Member of Congress and both Senators and tell them to protect Americans with pre-existing conditions and oppose all efforts to eliminate these protections. Contact House Energy and Commerce Committee Chairman Frank Pallone (D-NJ) and Ranking Member Greg Weldon (R-OR) as well as Senate HELP Committee Chairman Lamar Alexander (R-TN) and Ranking Member Patty Murray (D-WA) and tell them to protect the rights of all Americans with pre-existing conditions.



## Support Increased BCG Production and Ease the Burden on Patients During the Shortage

**The Issue:** Bacille Calmette-Guérin (BCG) has been the gold standard of care for many patients with non-muscle invasive bladder cancer for decades. As a result of many factors, including increased usage, production and shipping difficulties, regulatory burdens and the shutdown of capacity, there is a critical shortage of BCG available in the United States to treat bladder cancer patients.

**Background:** For the past few decades, two companies, Sanofi-Pasteur and Merck and Co., have been the sole FDA approved suppliers of BCG to the United States. In 2016, following a series of contamination issues, Sanofi-Pasteur, which supplied 70% of the BCG in the US, left the marketplace. As a result, Merck and Co. found itself to be the sole FDA approved supplier of BCG to the United States, even though it previously only supplied 30% of the market.

At the same time, market demands for BCG have skyrocketed while its production has declined, largely due to a combination of its high production cost and low market price. Despite these market forces, Merck and Co. has significantly increased its production of BCG from 300,000 doses in 2012, to over 870,000 doses this year. While substantial, this increase has not kept up with global demand which is estimated at over 1 million doses annually. As demand has risen beyond production capacity, many doctors across the country have begun to administer partial doses to patients so to stretch the number of patients who can receive treatment.

**Current Federal Efforts to Increase BCG Availability:** The FDA is working closely with Merck and Co., to increase the production of BCG. However, due to BCG's 3-4 month growing period, there are firm limits to the ability of Merck to simply raise production. The FDA is also exploring the possibility of approving additional strains of BCG, for sale in the United States. This would help to bring an increased supply of BCG and add competition to the marketplace. In addition, on July 1, 2019, the Centers for Medicare Services (CMS), which is responsible for setting healthcare reimbursement rates, announced that it would reimburse physicians for using partial vials on multiple patients, clearing a barrier that had resulted in partial vials of BCG being thrown away rather than being used on multiple patients.

On July 8, 2019, Senator Chuck Schumer (D-NY) called on the FDA to streamline federal BCG regulations and remove any identifiable barriers to increased production while ensuring that local regulators reimburse for partial vial usage. No Congressional hearing have been held on this subject.

**What Can You Do:** Contact FDA Commissioner Scott Gottlieb and tell him to exercise every authority of his office to immediately and substantially increase both the volume and reliability of BCG, including the approval of a second strand of BCG for sale in the United States. Contact your Member of Congress and both Senators and tell them how a lack of access to BCG directly affects your treatment and ask them to put pressure of the FDA to take near term action to alleviate the BCG shortage. Sign the BCG Shortage Petition at [Change.org](https://www.change.org).



## Support Increased Federal Funding for Bladder Cancer Research

**The Issue:** The federal government of the United States is the single largest funder of cancer research in the world. Public support of research through the National Institutes of Health (NIH) and the National Cancer Institute (NCI) is the foundation of this support. Public funding is truly the lifeblood of cancer research, and we can trace almost every advance in cancer prevention, detection, and treatment back to research funded by the NIH and NCI. In FY 2021, the NIH will receive \$47 billion in federal funding and its NCI will receive nearly \$6.3 billion in funding.

In addition, the Department of Defense (DoD) funds over \$1.4 billion in medical research through the Congressionally Directed Medical Research Program (CDMRP). Since 2016, BCAN has been proud to work with the CDMRP to establish bladder cancer as a fundable disease within the program. As a direct result of these actions, our community has seen over \$20M in new federal bladder cancer research since we first became eligible for the program.

BCAN has also worked to establish a permanent funding line, within the CDMRP, for bladder cancer and those efforts continue to this day.

Every dollar of this critical research is designated on a yearly basis with the passage of annual appropriations bills in Congress. Like all federal funding, these critical programs are subject to be increased or decreased, depending on the priorities of Congress. It is up to advocacy organizations such as BCAN to fight to protect and increase this critical funding every year.

**Current Legislative Status:** On July 31, 2020, the House of Representatives passed the FY 21 Labor, HHS, and Education appropriations bill by a vote of 217-197, as part of a larger 6 bill “mini-bus” funding measure. The bill has been sent to the US Senate which is expected to pass its version in September. At this time both the NIH and the NCI have received considerable funding increases including an additional \$5.5 billion at the NIH but those increases must also be approved by the Senate.

**What Can You Do:** Contact both of your Senators and tell them to support the House-passed funding levels for both the National Institutes of Health and the National Cancer Institute. Contact your Member of Congress and both Senators and ask them to support the establishment of a \$10M dedicated fund, within the CDMRP, for bladder cancer research.



## Ensure Affordable Access to Prescription Drugs and Next Generation Treatments

**The Issue:** The high cost that consumers must pay for the lifesaving medication that they need has become one of the highest priority issues on Capitol Hill. Over the past decade, along with the tremendous advances in prescription drugs and the development of new treatments, consumers have seen a tremendous increase in the cost they must pay for access to these advances. This often leaves American consumers to take partial doses or otherwise attempt to stretch out their prescription drug supply as far as possible. In addition, some of the newest and most promising treatments can come with price tags as big as the promise the treatment holds, a barrier that can be too much for a patient to overcome.

The high cost of prescription drugs routinely polls as one of the most important issues to the American voter. As a result, both political parties have advanced their own plans to address this topic.

**The House of Representatives (Democratic) Plan:** *HR 3, The Elijah Cummings Lower Drug Costs Now Act*, passed the House of Representatives on December 12, 2019 on a party line vote. For the first time, this bill caps out of pocket prescription drug costs for Medicare enrollees and authorizes the federal government to negotiate cost for up to 250 of the highest cost drugs annually. Seniors out of pocket expenses would be capped at \$2,000 annually. Finally, the legislation would expand the benefits offered by Medicare including dental, vision and hearing. This bill has been strongly opposed by the pharmaceutical industry.

**The Senate (Republican) Plan:** *S. 2543, The Prescription Drug Pricing Reduction Act*, by Senator Chuck Grassley (R-IA) was introduced into the Senate on December 9, 2019. This bill, often referred to as the Grassley-Wyden bill, was co-introduced by Senator Ron Wyden (D-OR) and passed by the Senate Finance Committee following a very contentious vote.

This bill would cap seniors out of pocket expenses at \$3,100 annually and attempt to control prescription drug costs by requiring pharmaceutical companies to pay a rebate to the federal government whenever they raise prices at a level above inflation.

**Current Legislative Status:** Both bills have been sent to the Senate. It will be up to Senate Majority Leader Mitch McConnell (R-KY) to bring either bill up for a vote. Leader McConnell is coordinating with the Trump Administration on this issue and it is unclear if the US Senate will act on either bill before the November election.

**What Can You Do:** Contact Senate Majority Leader Mitch McConnell and tell him to pass legislation that will bring down the cost of prescription drugs. Contact both of your Senators and tell them your personal story, why this issue is so important to you, and that we relief from the high cost of prescription drugs.