

FEBRUARY 23-25, 2025



ADVOCATE GUIDE

TOGETHER WE CAN #ZeroOutProstateCancer



Welcome ZERO Advocates to the 2025 ZERO Prostate Cancer Summit!

I'm so glad you were able to join us here in Washington, D.C.! We're excited to be in the heart of our nation's capital, speaking up for the prostate cancer community. Change is the name of the game this year, but there is lots of uncertainty. We expect that much of that turmoil will die down when rhetoric meets reality (and possibly be replaced with new forms of disruption), and the most important thing is that we've been here all along, laying the groundwork for successful policy change that will make a difference for the next generation of prostate cancer patients, ensuring that they have access to the prostate cancer information, early detection, and groundbreaking treatments that can save lives.

During the Summit, you'll be among the first to hear about *Blitz the Barriers*, ZERO's bold new initiative to bring prostate cancer outreach and education into high-risk communities directly. As our outreach work grows, so does our advocacy. ZERO will be working to ensure that high-risk men in communities across the country know about their prostate cancer risk and have the tools to do something about it. Our advocacy work will ensure that when those same men go to their doctors for screening, they don't face an additional financial barrier. The **PSA Screening for HIM Act** is back, and we're better positioned to move it forward.

We're leaning into our advocacy to amplify this outreach work by requesting **additional funding for the CDC** to do one of the things they do best: public awareness campaigns, specifically targeting high-risk men in our pilot markets around the nation.

This year, we'll also be supporting:

- \$120 million in funding for the **Prostate Cancer Research Program** (PCRP), which supports research focused on eradicating prostate cancer; and
- The Precision Oncology Program for Cancer of the Prostate at the Veterans Health Administration
 a dedicated effort to offer personalized prostate cancer care and clinical research opportunities to Veterans.

Federal policy moves slowly, and it can be hard to see your impact with every action alert email and every trip to D.C. But everything you do is loosening the jar, so to speak. When extra research funding bursts free or a bill "suddenly" passes, those wins are built on years of work. Your efforts in D.C. this week are foundational to our future success in improving prostate cancer outcomes.

Thank you for your commitment, your passion, and your time. Together, we are too loud to ignore! Sincerely,

Ali Manson, MPH

Vice President of Government Relations & Advocacy

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AGENDA - Monday, February 24

TIME	TOPIC	SPEAKER
7:00 a.m. – 8:30 a.m.	Breakfast	
8:30 a.m. – 9:00 a.m.	Welcome	Ali Manson, MPH
9:00 a.m. – 9:45 a.m.	Update from the Prostate Cancer Research Program	Michael Hall, PhD
9:45 a.m. – 10:00 a.m.	PCRP Appropriations Request Training	Ali Manson, MPH Susan Sweat
10:00 a.m. – 10:30 a.m.	Break	
10:30 a.m. – 11:00 a.m.	Prostate Cancer Care for Veterans Request Training	Ali Manson, MPH Susan Sweat
11:00 a.m. – 11:30 a.m.	CDC Appropriations Request Training	Ali Manson, MPH Susan Sweat
11:30 a.m. – 12:45 p.m.	Lunch and State Group Networking	
12:00 p.m. – 12:30 p.m.	What's Going on in D.C.?	Stacy Rich Chris Hodgson
12:45 p.m. – 1:15 p.m.	Blitz the Barriers Panel	Moderator: Courtney Bugler, ZERO Brian Bragg, ZERO Rodney Gillespie, Novartis Malwan Johnson, Phi Beta Sigma Fraternity, Inc.
1:15 p.m. – 1:30 p.m.	Q&A Time	
1:30 p.m. – 2:30 p.m.	Keynote	Francis Collins, M.D. Ph.D.
2:30 p.m. – 2:45 p.m.	Break	
2:45 p.m. – 3:00 p.m.	PSA for HIM Request Training	Ali Manson, MPH Susan Sweat
3:00 p.m. – 3:30 p.m.	How to Do a Hill Meeting	Ali Manson, MPH Susan Sweat
3:30 p.m. – 4:30 p.m.	Q&A and State Group Coordination	Ali Manson, MPH
5:30 p.m. – 7:30 p.m.	Congressional Reception	Cannon Caucus Room

AGENDA - Tuesday, February 25

TIME	TOPIC	SPEAKER
7:00 a.m. – 8:00 a.m.	Breakfast	
8:00 a.m. – 9:00 a.m.	Congressional Speakers	
9:00 a.m. – 5:00 p.m.	Hill Meetings	

NOTE: All agenda items are subject to change. Please visit **zerocancer.org/summit** for the latest information and updates on the Summit.



2025 ZERO Prostate Cancer Legislative Requests

Support PSA Screening for High-Risk Men - The United States Preventive Services Task Force (USPSTF) rates preventive services, including cancer screening. These rates are used to determine which screenings are covered without copays by private insurance. The USPSTF's current recommendation for PSA screening to detect prostate cancer does not adequately protect men who are at the highest risk for developing and dying from the disease. Because this recommendation is tied to insurance coverage, significant barriers exist for high-risk men to be screened for prostate cancer. Representatives Neal Dunn, MD (R-FL) and Yvette Clarke (D-NY) and Senators John Boozman (R-AR) and Cory Booker (D-NJ) introduced the Prostate-Specific Antigen Screening for High-risk Insured Men Act (PSA Screening for HIM Act, H.R.1300/S.297) which would ensure screening coverage is provided with no cost-sharing requirements to African-American men and men with a family history of prostate cancer under private health insurance plans. We ask for your support and cosponsorship of the PSA for HIM Act.

For more information or to co-sponsor the bill, please contact Tucker Williamson (Tucker.Williamson@mail.house.gov) in Rep. Dunn's office, Kathleen Bochow (Kathleen Bochow@boozman.senate.gov) in Senator Boozman's office, or Nisha Thanawala (Nisha.Thanawala@mail.house.gov) in Rep. Clarke's office, Nadia Laniyan (Nadia Laniyan@booker.senate.gov) in Senator Booker's office.

Support Prostate Cancer Research at DoD — The Prostate Cancer Research Program (PCRP) at the Department of Defense (DoD) is the most impactful federally funded prostate cancer research program. This high-risk, high-reward translational approach differs from the National Institutes of Health (NIH), which focuses on basic research and has resulted in seven new treatments for advanced prostate cancer and one advanced diagnostic in the last decade. We urge Congress to support \$120M for the PCRP in the FY2026 defense appropriations bill. We ask House members to please sign the Dunn-Bishop Dear Colleague letter to the House Appropriations Committee, and we ask Senate members to please sign the Crapo-Bennet Dear Colleague letter to the Senate Appropriations Committee supporting funding for the PCRP program.

To sign on, please contact Tucker Williamson (<u>Tucker.Williamson@mail.house.gov</u>) in Rep. Dunn's office, Jonathan Halpern (<u>jonathan.halpern@mail.house.gov</u>) in Rep. Bishop's office, Sal Corasaniti (<u>salvatore corasaniti@crapo.senate.gov</u>) in Sen. Crapo's office, or Erin Doty (<u>erin doty@bennet.senate.gov</u>) in Sen. Bennet's office.



Support CDC Prostate Cancer Outreach & Awareness Campaign for High-Risk Men – The FY25 House Labor-HHS-Education appropriations bill includes \$15.2M level funding, and the FY25 Senate bill includes \$17.2M, an increase of \$2M to increase outreach to African-American and other high-risk men. Over the next three years, ZERO Prostate Cancer is investing in a targeted outreach program for high-risk men in at least 12 communities nationwide. We want to ensure there are CDC-produced national campaign materials to support our efforts in these communities and across the nation. We ask that Members include the following Labor-HHS report language in their individual request letters to the Appropriations Committee for FY26:

Prostate Cancer. — The Committee remains concerned about the rise in prostate cancer deaths and supports the CDC's work to address this trend by increasing public awareness of prostate cancer risks, screening, and treatment in high-risk men. Accordingly, the Committee provides \$3,000,000 above the request/the fiscal year 2025 level to support creating a national education and awareness campaign targeting high-risk men and their families.

<u>Support the VA's Precision Oncology Prostate Cancer Program (POPCaP)</u> – Since 2018, the VA has operated 21 centers of excellence in the POPCaP program. These centers of excellence give veterans access to genetic testing and counseling, prostate cancer clinical trials, and FDA-approved drugs targeted to specific cancer mutations. The VA is starting a new, broader precision oncology program with six sites, and plans to discontinue the POPCaP program. We ask that Members cosponsor legislation soon-to-be-introduced by Rep. Greg Murphy (R-NC) to authorize the POPCaP program in law.

For more information and to cosponsor/sign on, please contact Ray Celeste (Raymond.Celeste@mail.house.gov) in Representative Greg Murphy's office.



Talking Points

The Problem

- Prostate cancer is the most commonly diagnosed cancer in men.
- Prostate cancer is the second leading cause of cancer-related death in men.
- In 2025, an estimated 313,780 men will be diagnosed with prostate cancer, and 35,2770 men will die from it.
 - Rates of advanced prostate cancer are rising, reflecting the failure to screen and catch prostate cancer early.
- A man will be diagnosed with prostate cancer every 2 minutes in 2025 and die from it every 15 minutes.
- African American men are at increased risk for the disease. 1 in 6 African American men will be diagnosed with prostate cancer.
- African American men are more than 2 times more likely to die from the disease and 1.7 times more likely to be diagnosed with the disease.
- Veterans who were exposed to herbicides like Agent Orange and other toxic exposures are at increased risk for developing prostate cancer and are more likely to have an aggressive form of the disease.
- If caught early, prostate cancer has a five-year survival rate of nearly 100%. However, for late-stage prostate cancer, the five-year survival rate is 29%.
- The economic and social burden of prostate cancer is huge:
 - Prostate cancer is estimated to cost over \$8 billion in direct medical expenditures.
 - Men who survive after treatment frequently suffer from side effects, including impotence and incontinence



The PSA & USPSTF

- In 2018, the United States Preventive Services Task Force (USPSTF) issued a recommendation for prostate cancer screening. The PSA test was given a "C" rating for men ages 55-69 and a "D" rating for men 70 and over.
 - The "C" rating suggests that providers should offer the test for high-risk men in that category, but it does not require insurance coverage for the test.
 - The "D" rating for men 70 and above means the PSA test is not recommended for older men, regardless of their life expectancy or state of health.
- Unfortunately, this recommendation has led to much confusion about how and when
 providers should screen men for prostate cancer. The Affordable Care Act (ACA) tied
 USPSTF recommendations to insurance coverage. The law requires commercial insurers
 to cover screenings with "A" or "B" ratings without patient cost sharing.
- ZERO joined the provider community in submitting comments urging the USPSTF to reverse these ratings, but the USPSTF claims it needs more data to support screening even the common-sense screening of high-risk men. This data could take decades to generate.
- There is no alternative to the PSA test. Without its widespread use, prostate cancer is going undiagnosed. Many experts agree that more men will die because their cancer will not be detected in time to be treated successfully.
- In fact, after decades of declining death rates, there has been a 15 percent jump in the number of prostate cancer deaths since 2017.
- A decline in screening related to changing recommendations from the USPSTF corresponded with a later increase in advanced disease at first diagnosis.
- Researchers are working to develop a better, more precise diagnostic tool for prostate cancer. But until there is an alternative to the PSA test, we must make sure that men have access to the PSA test and can engage in an informed conversation with their doctors about the screening and treatment of prostate cancer.
- This is especially true for African American men and men with a family history of
 prostate cancer, who are at a much higher risk of developing the disease. USPSTF has
 reported a data gap for these populations and said that filling this gap is a national
 priority.



- Researchers are unlikely to fill these data gaps because prostate cancer is slow-growing, screening some men and not others is unethical, and enrolling African Americans and men with a family history in clinical trials is challenging.
- Reps. Neal Dunn, MD (R-FL) and Yvette Clarke (D-NY) introduced the PSA Screening for HIM Act (H.R. 1300) with original cosponsors Reps. Greg Murphy, MD (R-NC) and Troy Carter (D-LA), which requires PSA screening coverage for those two categories (African Americans and family history). The bill would require that these categories be treated as if they had an A rating, meaning that insurance coverage without copays for the test would be guaranteed.
- Senators John Boozman (R-AR) and Cory Booker (D-NJ) introduced S.297, the Senate companion to PSA Screening for HIM.
- This legislation would give prostate cancer parity with breast cancer, which had a similar problem with its 2012 mammography screening recommendation from USPSTF that was reversed by Congressional action.

The Prostate Cancer Research Program (PCRP)

- The Department of Defense's Prostate Cancer Research Program (PCRP) is part of the Congressionally Directed Medical Research Programs (CDMRP).
- PCRP complements National Institutes of Health (NIH) research. PCRP takes on higher-risk, higher-reward research that the NIH does not. Funding the PCRP and the NIH is not duplicative—in fact, the NIH does not have the ability to conduct programmatic, disease-specific reviews of proposals.
- PCRP responds to the prostate cancer community's needs by incorporating patient advocates into the proposal peer-review process and the panel that sets the program's annual priorities.
- This approach which annually defines the knowledge gaps in the fight against prostate cancer – operates much differently than NIH programs, which do not have mechanisms available for this approach. Rather than prioritizing proposals that meet the highest levels of medical need, the NIH designates funds based on proposals with the highest peer review scores.



- The PCRP produces results. In the last decade, the FDA has approved seven treatments that originated in PCRP research. Additionally, a PCRP-industry collaboration validated a genomic test for prostate cancer aggressiveness.
- More than 200 prostate cancer clinical trials have come through the PCRP clinical trial network.
- The program is now focused on our community's most urgent challenges:
 - Develop treatments that improve outcomes for men with lethal prostate cancer;
 - Reduce lethal prostate cancer in African Americans, Veterans, and other highrisk populations;
 - Define the biology of lethal prostate cancer to reduce death and
 - o Improve the quality of life for survivors of prostate cancer.

CDC Prostate Cancer Activities

- CDC's funding is used to support communication initiatives, research, and surveillance across many different types of cancer, including prostate cancer.
- We believe it is critical to not only support the CDC's ongoing activities but also increase outreach and education in high-risk communities, especially the African American community, which experiences much higher prostate cancer incidence and death rates.
- At the heart of every treatment and screening decision around prostate cancer is a conversation between men and their doctors. Given the complexity around when men should be screened (depending on age, race, ethnicity, comorbidities, and familial history), clear communication tools must be provided to both patients and providers.
- CDC funding conducts research and develops materials that bring more awareness to prostate cancer and promote informed decision-making related to prostate cancer screening, treatment, and quality of life.
- ZERO is launching Blitz the Barriers, the most ambitious initiative in the history of U.S.
 prostate cancer programs. It will use a comprehensive approach, working both incommunity and virtually, to dismantle obstacles, empower communities, and pave the
 way for more sustainable interventions through education, patient support, community
 engagement, and advocacy.



- The CDC has dozens of national awareness campaigns. Investment at CDC in a public awareness campaign targeting high-risk men in specific pilot communities before rolling out nationwide would maximize the campaign's impact and capitalize on Blitz the Barriers.
- This investment would combine CDC's expertise in health communication and ZERO's on-the-ground outreach directly into high-risk communities to ensure that messaging translates into action, driving screenings, early detection, and improved health outcomes.

The VA's POPCaP Program

- 15,000 Veterans are treated for prostate cancer each year at VA. It is the most common cancer diagnosed by VA.
- In 2016, the VA and the Prostate Cancer Foundation (PCF) created an innovative program to provide Veterans with prostate cancer with increased access to genetic testing and cutting-edge clinical trials: the Precision Oncology Prostate Cancer Program (POPCaP).
- As part of the agreement, PCF would provide funding for the POPCaP sites for 5 years before the VA absorbed their funding.
- The 14 POPCaP sites were so successful that the VA began funding 7 more sites on its own in 2021 (at lesser dollar amounts), adding trials for kidney and bladder cancer to the POPCaP model at those locations.
- Last year, Congress provided funding for the VA to expand the program to 6 new sites, for a total of 27 sites.
- Instead of moving forward as directed, the VA is now using POPCaP funding to:
 - o start a new program for all cancers in only 6 locations,
 - shutter the POPCaP administration office in Seattle,
 - eliminate 10 POPCaP sites altogether, and
 - change the mission of the other sites away from prostate cancer.
- This new oncology program only provides paperwork support to its locations, none of the mentoring and day-to-day engagement POPCaP provides to increase enrollment and the number of trials being conducted at its sites. It also removes a critical commitment to optimal prostate cancer care for Veterans.



The Asks

- 1) Cosponsor H.R.1300/ S.297— House Representatives Neal Dunn, MD (R-FL) and Yvette Clarke's (D-NY) and Senators John Boozman (R-AR) and Cory Booker's (D-NJ) PSA for HIM Act, requiring coverage for PSA testing for at-risk men.
- 2) Sign onto the Dunn-Bishop (House)/Crapo-Bennet (Senate) Dear Colleague letter supporting \$120M in funding for DoD's Prostate Cancer Research Program (PCRP) for FY26.
- 3) Support an additional \$3M in FY26 funding for a CDC prostate cancer awareness campaign targeting high-risk men.
- 4) We ask that your office cosponsor legislation soon-to-be-introduced by Representative Greg Murphy (R-NC) to protect the POPCaP program in law, ensuring our Veterans continue to receive the highest quality cancer care through the VA.

PSA Screening:

• Please cosponsor the PSA Screening for HIM Act (H.R.xxx), which was introduced by House Representatives Neal Dunn, MD (R-FL) and Yvette Clarke (D-NY). In the Senate, a version has been introduced as S.297 by Senators John Boozman (R-AR) and Cory Booker (D-NJ). The bill would require that high-risk men (those with a close family history of disease or African American men) have insurance coverage for prostate cancer screening without any out-of-pocket costs, removing an essential barrier to care.

PCRP:

- The PCRP, as part of the DoD's Congressionally Directed Medical Research Programs, is never included in the President's budget request, but Congress has funded it since 1997. In FY24, Congress provided \$110 million. We support a \$120 million funding level in FY26.
- We ask that House Members sign on to the Dunn-Bishop letter to the Defense Appropriations Crapo-Bennet letter supporting keeping prostate cancer research, detection, and treatment a priority (no funding level mentioned).

CDC:

• \$3M in funding would allow the CDC to engage in a targeted public awareness campaign amplified by ZERO's efforts in high-risk communities.



 We ask that Members of Congress increase funding for the CDC's prostate cancer activities by including our report language in their individual requests to the Appropriations Committee.

POPCaP:

• We ask that your office cosponsor legislation soon-to-be-introduced by Representative Greg Murphy (R-NC) to protect the POPCaP program in law, ensuring our Veterans continue to receive the highest quality cancer care through the VA.



The Prostate-Specific Antigen Screening for High-risk Insured Men Act (H.R. 1300 /S. 297)

WHAT IS THE PSA SCREENING FOR HIM ACT?

The PSA Screening for High-risk Insured Men Act, introduced in the Senate by Senators John Boozman (R-AR) and Cory Booker (D-NJ) and in the House by Representatives Neal Dunn, M.D. (R-FL) and Yvette Clarke (D-NY), would require health insurance providers to offer prostate cancer screenings without any cost-sharing requirements (co-pays, deductibles, or co-insurance) for high-risk men, including African-American men and men with a family history of prostate cancer or known genetic alteration, over the age of 40.



Only 33% of African-American men aged 50 or older had a PSA test in 2018.



Men with at least one close family member with prostate cancer are at least 2x the risk for prostate cancer; risk increases with each affected family member.

WHY ARE PSA TESTS SO IMPORTANT?

The Prostate-Specific Antigen (PSA) test is the most effective tool we have right now to detect prostate cancer, and, most instances of prostate cancer are initially detected with this test. PSA is a substance made by the prostate, and the levels of PSA in the blood can be higher in men who have prostate cancer. By testing the PSA levels, we are able to detect possible signs of prostate cancer. The earlier the disease is caught, the higher the survival rates: prostate cancer caught in Stage 1 is almost 100% survivable. However, if caught at a later stage, survival rates plummet to around 37%.

WHY IS THIS BILL SO IMPORTANT?

Studies have shown that even the smallest amount of cost-sharing is a barrier to access for many. Too many men in high-risk groups delay getting tested for prostate cancer, which decreases their odds for survival. **This bill would require insurance providers to cover PSA tests for the highest- risk patients at no cost,** similar to other high-value cancer screenings such as mammograms. With an estimated 310,000+ men in America being diagnosed with prostate cancer in 2025 alone and an estimated 35,770+ deaths, the urgency to act has never been greater.



African-American men are 1.7x more likely to be diagnosed with prostate cancer, and 2.1x more likely to die from the disease.

HOW CAN YOU HELP?

Co-sponsor the PSA Screening for HIM Act today and help improve early detection rates for prostate cancer! To co-sponsor in the House, please contact Rep. Dunn's office at Tucker.Williamson@mail.house.gov or Rep. Clarke's office at Nisha.Thanawala@mail.house.gov. In the Senate, reach out to Senator Boozman's office at Kathleen_Bochow@boozman.senate.gov or or Senator Booker's office at Nadia_Laniyan@booker.senate.gov. To learn more about ZERO's advocacy efforts please contact Advocacy@zerocancer.org.

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Overview of the PSA for HIM Act

Ask: PSA Screening for HIM Act – The United States Preventive Services Task Force's (USPSTF) current recommendation for PSA screening to detect prostate cancer does not adequately protect men who are at the highest risk for developing and dying from the disease. Because this recommendation is tied to insurance coverage, significant barriers exist for at-risk men to be screened for prostate cancer. Representatives Neal Dunn, MD (R-FL) and Yvette Clarke (D-NY) introduced the PSA for HIM Act (H.R.1300) in the House of Representatives with original cosponsors Reps. Greg Murphy, MD (R-NC) and Troy Carter (D-LA), to ensure that screening coverage is provided to men at high risk for prostate cancer, including African-American men and men with a family history of prostate cancer or known genetic mutation, regardless of the USPSTF recommendation for these populations. A Senate companion bill (S.297) has been introduced by Senators John Boozman (R-AR) and Cory Booker (D-NJ). We ask for your cosponsorship of H.R.1300 in the House and S.297 in the Senate.

Background: The USPSTF

The United States Preventive Services Task Force (USPSTF) was created to make evidence-based recommendations for clinical preventive services and health promotion. The Task Force aims to aid primary care professionals, patients, and families in deciding whether a particular preventive service is the right choice for an individual's needs. For instance, the Task Force may develop recommendations for the effectiveness of certain screening tests, counseling services, or preventive medications.

USPSTF recommendations address services offered in primary care settings or services referred by primary care professionals and apply only to individuals without signs or symptoms of the disease or health condition under consideration. The Director of the Agency for Healthcare Research and Quality (AHRQ), with guidance from the Chair of the Task Force, appoints the sixteen volunteer members of the Task Force, representing the fields of internal medicine, family medicine, pediatrics, behavioral health, obstetrics/gynecology, and nursing. Within the Department of Health and Human Services (HHS), AHRQ provides administrative, research, technical, and communication support to the Task Force. The Task Force is an independent body, and its work does not require AHRQ or HHS approval.



The Task Force assigns a letter grade of A, B, C, D, or I to each recommendation based on the strength of the evidence and the advantages/disadvantages of the service under consideration:

Grade	Definition	Suggestions for Practice	
А	The USPSTF recommends the service. There is high certainty that the net benefit is substantial.	Offer or provide this service.	
В	The USPSTF recommends the service. There is high certainty that the net benefit is moderate, or there is moderate certainty that the net benefit is moderate to substantial.	Offer or provide this service.	
С	The USPSTF recommends selectively offering or providing this service to individual patients based on professional judgment and patient preferences. There is at least moderate certainty that the net benefit is small.	Offer or provide this service for selected patients depending on individual circumstances.	
D	The USPSTF recommends against the service. There is moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits.	Discourage the use of this service.	
ı	The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of the service. Evidence is lacking, of poor quality, or conflicting, and the balance of benefits and harms cannot be determined.	Read the clinical considerations section of the USPSTF Recommendation Statement. If the service is offered, patients should understand the uncertainty about the balance of benefits and harms.	

For years, the medical community has referred to USPSTF recommendations to decide which preventive services to use. Insurance companies sometimes use these recommendations to decide what to cover under their policies. However, this coverage was not mandated, and decisions were left largely to providers. In 2011, the Affordable Care Act (ACA) required private insurance plans and Medicare insurance plans to cover USPSTF "A" or "B" rated preventive services without any patient cost-sharing (such as copayments, coinsurance, or deductibles), removing a significant obstacle for individuals in need of preventive services. The law gives the Secretary of HHS the authority to cease Medicare coverage for a preventive service that receives a D grade from USPSTF. The result of this change has been that those screening tools receiving an "A" or "B" rating from USPSTF have benefited from increased access.



In contrast, other screening tools have experienced a marked decrease in access and confusion over screening options. Unfortunately, many of the preventive services on which the Task Force makes recommendations, including some of the most controversial decisions, are cancer screenings. Yet, no medical oncologists were consulted during the process.

The USPSTF has been scrutinized since its recommendations were linked to coverage decisions. The Task Force maintains that it does not conduct research but only analyzes research to make recommendations based on a harm/benefit analysis meant for patients without obvious signs or symptoms of disease in primary care settings – i.e., routine screening for otherwise healthy patients. The Task Force also maintains that it does not make coverage decisions – those decisions are made independently by insurers and Medicare.

However, the ACA does tie Task Force decisions to mandatory coverage and cost sharing by insurers, and this ACA provision has been the subject of recent legal challenges. In 2020, several small businesses and individuals challenged the ACA requirement for free prevention services, arguing in their lawsuit that the ACA provision makes it impossible for them to purchase health insurance that excludes free preventative care that they do not need or want. Siding with the plaintiffs, the trial judge invalidated all benefits recommended by the USPSTF after March 23, 2010, but the Fifth Circuit Court of Appeals issued a temporary hold on the trial court's decision while the case is under appeal. A decision from the Fifth Circuit is likely to be issued in mid-2024, but it is very likely that whatever the decision, it will be appealed to the Supreme Court – meaning the earliest this issue could be resolved would be in the summer of 2026.

The USPSTF PSA Recommendation:

While screening for several diseases has benefited from an "A" or "B" rating, many USPSTF recommendations contradict leading medical opinions, including mammography for breast cancer and prostate-specific antigen (PSA) screening for prostate cancer. The current USPSTF rating for PSA screening is a "C" for men aged 55-69 and a "D" rating for men over 70.

Many doctors and professional organizations, such as the American Urological Association (AUA), the National Comprehensive Cancer Network (NCCN), the American Society of Clinical Oncology (ASCO), the American College of Physicians-American Society of Internal Medicine, and the American Cancer Society, have encouraged yearly PSA screening for men beginning between age 40 and 55 depending on risk factors. The NCCN guidelines, which ZERO follows, recommend screening beginning at age 45. Since early-stage prostate cancer is marked by very few, if any, symptoms. The PSA blood test is invaluable in its ability to alert providers to the possible presence of prostate cancer before it metastasizes into a potentially fatal diagnosis. In addition, many medical societies and patient care groups recognize that consideration of individual patient risk factors, including age, race, family history, BRCA gene mutations, and



comorbidities, mean that some groups can benefit from earlier PSA screening distinct from the broader population.

After a controversial 2012 decision to give all PSA screening a "D" rating, in 2018, the USPSTF updated its recommendation for PSA screening to a "C" rating for men aged 55-69 and a "D" rating for men over age 70. The recommendation also included the following comments related to African American men and men with a family history of prostate cancer:

Within the report, the USPSTF acknowledged the following about African American men:

- "There is inadequate evidence to assess whether the benefits for African American men and men with a family history of prostate cancer aged 55 to 69 years are different than the benefits for the average-risk population. There is also inadequate evidence to assess whether there are benefits to starting screening in these high-risk groups before age 55 years... In the United States, African American men are more likely to develop prostate cancer than white men (191.5 vs 114.5 cases per 100,000 men). African American men are also more than twice as likely as white men to die of prostate cancer (37.2 vs 18.1 deaths per 100,000 men).
- "The higher death rate is attributable in part to an earlier age at cancer onset, more advanced cancer stage at diagnosis, and higher rates of more aggressive cancer (i.e., higher tumor grade)."
- "Decision analysis models suggest that given the higher rates of aggressive prostate cancer in African American men, PSA-based screening may provide greater benefit to African American men than the general population. These models also suggest a potential mortality benefit for African American men when beginning screening before age 55 years."
- "Although the USPSTF found inadequate evidence about how benefits may differ for African American men, it recognizes the epidemiologic data showing that African American men may develop prostate cancer at younger ages than average-risk men and understands that some African American men and their clinicians will continue to screen at younger ages."

Similarly, the USPSTF acknowledged concerns about men with a family history of prostate cancer:

 "Although the USPSTF found inadequate evidence about how benefits may differ for men with a family history of prostate cancer, it recognizes the epidemiologic data showing that these men are at a greater than average risk and understands that some men and their clinicians will continue to screen at younger ages in men with a family history."



In addition to these statements, the USPSTF identified many areas in need of research to improve screening. The research gaps included:

- "Screening for and treatment of prostate cancer in African American men, including understanding the potential benefits and harms of different starting ages and screening intervals and the use of active surveillance; given the large disparities in prostate cancer mortality in African American men, this should be a national priority."
- "How to better inform men with a family history of prostate cancer about the benefits and harms of PSA-based screening for prostate cancer, including the potential differences in outcomes between men with relatives who died of prostate cancer and men with relatives diagnosed with prostate cancer who died of other causes."

The USPSTF reiterated those data gaps in its 2018 annual report to Congress.

Prostate cancer usually progresses relatively slowly, and the impact of the USPSTF's decisions does not appear immediately. However, recent peer-reviewed publications have examined the results of the inadvertent experiment enacted by the USPSTF on American men since 2012. VA facilities with lower rates of prostate cancer screening in the years following the recommendation had higher subsequent rates of metastatic prostate cancer at diagnosis. In fact, while before the 2012 recommendation against prostate cancer screening, insured patients enjoyed better prostate cancer survival rates than their uninsured peers, in the years following that recommendation, the recommendation itself may have hindered prostate cancer screening among insured patients and led to worse disease outcomes in that group while leaving outcomes in uninsured patients unchanged.

The USPSTF began the process of updating the prostate cancer screening recommendation in 2023, and ZERO is providing comments to the agency to urge them to take into account the newer science around PSA testing, as well as the impacts of their previous recommendations on screening rates and incidence of metastatic disease. We anticipate this process will continue throughout 2025 but do not expect to see a draft recommendation until late this year or early in 2026.

The PSA for HIM Act:

Previously introduced in the 116th, 117th, and 118th Congresses, the PSA for Him Act (H.R.1300/S.297) requires federal agencies to treat PSA screening for African-American men and men with a family history or genetic mutation for prostate cancer as if it received an "A" recommendation from the USPSTF.

Specifically, the legislation ensures that "a group health plan, or a health insurance issuer offering group health insurance coverage, must provide coverage for and must not impose any cost-sharing requirements (such as a copayment, coinsurance, or a deductible)" for prostate



cancer screening for African American men and men with a family history of prostate cancer, other cancers known to be associated with an increased risk of prostate cancer, or genetic alterations known to be associated with an increased risk of prostate cancer.

This legislation has the practical effect of requiring insurance carriers to provide prostate cancer screening to these populations without a copay – making sure that men who are at the highest risk for developing lethal prostate cancer have the fewest barriers to accessing screening.

The legislation is similar to the approach used by breast cancer advocates when, in 2009, the USPSTF downgraded its recommendation on mammography screening for women under 50 to a "C." The Senate added a provision to the Affordable Care Act that made the USPSTF's previous mammography recommendation (a "B") the operative rating.

The USPSTF argues that more data on at-risk populations is needed to justify changes to its screening guidelines. However, there are several barriers to the completion of such studies in the near future:

- Since prostate cancer is slow-growing, a comprehensive research study would take twenty years to generate sufficient data to make a recommendation.
- Researchers have an ethical issue with screening some men and not others. Therefore, it is unlikely that researchers will conduct a study on PSA screening in African Americans and men with a family history.
- Even if we as a nation were willing to wait 20 years and researchers were willing to conduct what they consider an unethical study, it is extremely difficult to enroll a sufficient number of African Americans or men with a family history in research trials.

It is time for Congress to fill the screening recommendation gap where there is clear epidemiological data to screen our men at high risk for prostate cancer.



118th Congress – House PSA for HIM Cosponsors

Rep. Bucshon, Larry [R-IN-08]*
Rep. Dunn, Neal [R-FL-02]*
Rep. Clarke, Yvette [D-NY-09]*
Rep. Carter, Troy [D-LA-02]*
Rep. Adams, Alma [D-NC-12]
Rep. Babin, Brian [R-TX-36]
Rep. Bilirakis, Gus [R-FL-12]
Rep. Bishop, Sanford [D-GA-02]
Rep. Brown, Shontel [D-OH-11]
Rep. Budzinski, Nikki [D-IL-13]
Rep. Carbajal, Salud [D-CA-24]
Rep. Carey, Mike [R-OH-15]
Rep. Cherfilus-McCormick, Sheila [D-FL-20]
Rep. Cleaver, Emanuel [D-MO-05]
Rep. Cohen, Steve [D-TN-9]
Rep. Connolly, Gerald [D-VA-11]
Rep. Crow, Jason [D-CO-06]
Rep. Davids, Sharice [D-KS-03]
Rep. Davis, Donald [D-NC-01]
Rep. Dingell, Debbie [D-MI-06]
Rep. Fitzpatrick, Brian [R-PA-01]
Rep. Foushee, Valerie [D-NC-04]
Rep. Frost, Maxwell [D-FL-10]
Rep. Gomez, Jimmy [D-CA-34]
Rep. Gooden, Lance [R-TX-05]
Rep. Grijalva, Raul [D-AZ-07]
Rep. Horsford, Steven [D-NV-04]
Rep. Houlahan, Chrissy [D-PA-06]
Rep. Ivey, Glenn [D-MD-04]
Rep. Joyce, John [R-PA-13]
Rep. Keating, William [D-MA-09]
Rep. Landsman, Greg [D-OH-01]
Rep. Lawler, Michael [R-NY-17]
Rep. Levin, Mike [D-CA-49]
Rep. Lofgren, Zoe [D-CA-18]
Rep. Magaziner, Seth [D-RI-02]
Rep. Matsui, Doris [D-CA-07]
Rep. McClellan, Jennifer [D-VA-04]

Rep. McCollum, Betty [D-MN-04]
Rep. Meng, Grace [D-NY-06]
Rep. Mfume, Kweisi [D-MD-07]
Rep. Miller, Max [R-OH-07]
Rep. Moore, Gwen [D-WI-04]
Rep. Morelle, Joseph [D-NY-25]
Rep. Mrvan, Frank [D-IN-01]
Rep. Murphy, Gregory [R-NC-03]
Rep. Neguse, Joe [D-CO-02]
Rep. Pappas, Chris [D-NH-01]
Rep. Peters, Scott [D-CA-50]
Rep. Pettersen, Brittany [D-CO-07]
Rep. Pingree, Chellie [D-ME-01]
Rep. Quigley, Mike [D-IL-05]
Rep. Raskin, Jamie [D-MD-08]
Rep. Ross, Deborah [D-NC-02]
Rep. Rutherford, John [R-FL-05]
Rep. Ryan, Patrick [D-NY-18]
Rep. Salinas, Andrea [D-OR-06]
Rep. Schneider, Bradley [D-IL-10]
Rep. Scott, David [D-GA-13]
Rep. Sherrill, Mikie [D-NJ-11]
Rep. Smith, Adam [D-WA-09]
Rep. Soto, Darren [D-FL-09]
Rep. Stansbury, Melanie [D-NM-01]
Rep. Sykes, Emilia [D-OH-13]
Rep. Thompson, Bennie [D-MS-02]
Rep. Tlaib, Rashida [D-MI-12]
Rep. Tonko, Paul [D-NY-20]
Rep. Turner, Michael [R-OH-10]
Rep. Valadao, David [R-CA-22]
Rep. Wasserman Schultz, Debbie [D-FL-25]
Rep. Watson Coleman, Bonnie [D-NJ-12]
Rep. Wilson, Frederica [D-FL-24]
Rep. Wilson, Joe [R-SC-02]

^{*} Members who were original cosponsors of the bill



118th Congress – Senate PSA for HIM Cosponsors

Sen. Boozman, John [R-AR]*
Sen. Booker, Cory [D-NJ]*
Sen. Capito, Shelley Moore [R-WV]
Sen. Cantwell, Maria [D-WA]
Sen. Padilla, Alex [D-CA]
Sen. Warnock, Raphael [D-GA]
Sen. Banks, Jim (R-IN)**
Sen. Blunt Rochester, Lisa [D-DE]**
Sen. Kim, Andy [D-NJ]**

 $[\]ensuremath{^{*}}$ Members who were original cosponsors of the bill

^{**} House cosponsors who are now in the Senate



The Prostate Cancer Research Program (PCRP)



WHAT IS THE PCRP?

The Prostate Cancer Research Program (PCRP) began in 1997 as a part of the Congressionally Directed Medical Research Programs, or CDMRP. Created by Congress in 1992 and administered by the Department of Defense, CDMRP programs advance biomedical research, with a particular focus on applied research that supports the greatest needs of the disease community and U.S. service members.

Military personnel are **twice as likely** to be diagnosed with prostate cancer as the general public.

The PCRP is dedicated to supporting high-risk, high-reward research with near-term clinical application to eradicate prostate cancer deaths and promote groundbreaking development of new tests and treatments. **ZERO supports increasing funding for the PCRP from \$110M to \$120M for Fiscal Year 2026.**

A key component of the PCRP is the Consumer Reviewer Panel, comprised of patients, providers, clinicians, and caregivers who act as lay experts on prostate cancer, bringing their lived experiences and perspectives to the evaluation of research grant proposals. This helps ensure that the research conducted will make a meaningful difference in the lives of prostate cancer patients.



The PCRP has contributed to developing 7 new treatments in the last decade. These include multiple therapies for metastatic cancer that no longer responds to other treatments. PCRP investment has also supported the development of a new test that helps identify aggressive prostate cancers to allow patients and their doctors to better determine the best treatment method.

66 77

The PCRP is a critical component of the fight against prostate cancer and the country's cancer research enterprise. As a Veteran, prostate cancer survivor, and prior PCRP reviewer, I've seen the tremendous work that the program does for the prostate cancer community as a whole and the specific value to military service members and Veterans like myself. In fact, I credit several therapeutics developed with PCRP funding as the reason why I'm alive today after a stage 4 cancer diagnosis almost ten years ago.

Col. Paul Taylor, U.S. Army, Retired



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Overview of the Department of Defense's (DoD)

Prostate Cancer Research Program (PCRP)

ASK: Prostate Cancer Research at DoD – The Prostate Cancer Research Program (PCRP) at the Department of Defense (DoD) is the most impactful federally funded prostate cancer research program, employing a unique structure to set annual goals addressing gaps in understanding of the disease's diagnosis and treatment. This high-risk, high-reward translational approach, which differs from the National Institutes of Health (NIH) focus on basic research, has resulted in seven new treatments for advanced prostate cancer and one advanced diagnostic in the last decade. We urge Congress to support funding of \$120M for the PCRP and to recognize prostate cancer as a militarily relevant disease in the FY26 defense appropriations bill. We ask House members to please sign the Dunn-Bishop Dear Colleague letter to the House Appropriations Committee, and we ask Senate members to please sign the Crapo-Bennet Dear Colleague letter to the Senate Appropriations Committee supporting funding for the PCRP program.

Background:

The Department of Defense's (DoD) Prostate Cancer Research Program (PCRP) was established in 1996 as a part of the Fiscal Year (FY) 1997 Department of Defense Appropriations Act. It was the second research program in the DoD's fledgling Congressionally Directed Medical Research Program (CDMRP). The first, added in 1993, focused on breast cancer in response to the lobbying efforts of the women's advocacy movement. Congress authorized funds for a substantial increase in support of new and promising research aimed at the eradication of breast cancer. Because Congress, with rare exceptions, does not direct the National Institutes of Health (NIH) – the nation's largest biomedical research funder to fund specific disease research, the breast cancer-specific appropriation required a new agency to be established within the DoD's biomedical research infrastructure. From FY1992-2023, the CDMRP managed over \$21 billion in congressional appropriations for peer-reviewed research, funding over 20,000 awards through FY2021. As of FY2024, there are now 38 programs at the CDMRP.

CDMRP's Unique Structure and Process:

To ensure the establishment of a scientifically sound program that could address the needs of both consumers and clinical and research communities, in 1993, the DoD sought advice from the National Academy of Sciences' Institutes of Medicine (IOM) to advise on an investment strategy for the wisest expenditure of the funds and an appropriate review system for the evaluation of competitive proposals. A blue-ribbon committee of the IOM studied these major considerations. It issued a report recommending a traditional peer review of proposals submitted, an approach similar to the NIH model of Study Sections, followed by a second-tier review of all of the proposals for program relevance, to be performed by an Integration Panel (IP).



To identify important research areas that need support, the CDMRP depends on three sources of advice and counsel: the community of stakeholders, the IPs, and the scientists and consumers who participate in peer and programmatic reviews. In addition to the unique review process, all review panels, stakeholder meetings, and IPs are composed of scientists, clinicians, members of the military as applicable, and consumers from advocacy communities. Consumers serve as full voting members and play a significant role in maintaining the focus of the respective programs on relevant research that has the potential to impact the affected communities significantly. The CDMRP process is innovative in including consumer reviewers on both the peer review and programmatic panels. Consumers are engaged at all levels of the CDMRP process, which is unique among government research funding agencies. Other organizations, such as NIH, are moving toward more significant involvement of consumers in their funding processes, including setting research priorities. The CDMRP has been doing this since its inception.

The two-tiered review process was designed to balance the most meritorious science across many disciplines and offer the greatest promise for fulfilling programmatic goals, providing greater flexibility to fund proposals that may not have scored as well in peer review but that addressed a program priority. This review of all projects considered eligible for funding by the peer reviewers is a comparison-based process in which proposals from multiple research areas compete in a common pool. Those projects deemed to have the highest relevance and importance to the CDMRP mission and specific program vision are recommended for funding. Programmatic reviewers do not automatically recommend funding for submissions highly scored by scientific peer review panels. Thus, unlike many other agencies that support research, proposals are not funded strictly in order of scientific merit. Considering programmatic intent and portfolio balances means that applications are not funded using an established "pay line." Proposals with low programmatic relevance are less likely to be funded.

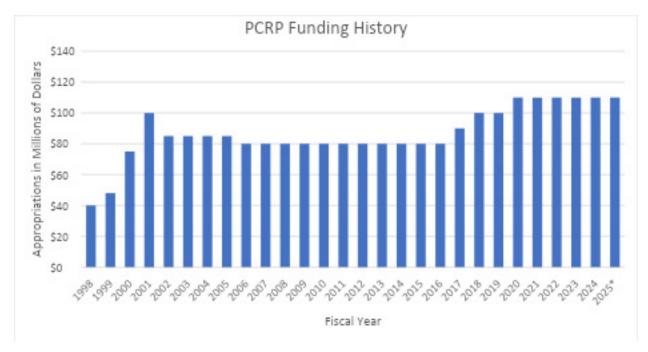
Unlike other federal agencies for which the budgets for biomedical research are assured continuingly, Congress appropriates funds for the CDMRP yearly. Additionally, congressional language may identify targeted research initiatives for a particular year. Thus, planning occurs one year at a time. This arrangement means that with each new funding cycle, the CDMRP can create new research opportunities and focus funding on the most recently recognized research gaps or controversies.

After the CDMRP receives its appropriations, it has two years by law to obligate the money; each CDMRP award is fully funded upfront. However, even though each award is fully funded, principal investigators do not necessarily receive all their funding at once; rather, milestones are established and must be met to release further funds. Program announcements specify the maximum length over which award money may be allocated; the length of the award may not exceed five years.



Prostate Cancer Research Program (PCRP):

The Prostate Cancer Research Program (PCRP) began in FY1997 with a \$45 million appropriation and an overall vision of conquering this disease. Its present mission is to fund research that will result in substantial improvements over current approaches to preventing, detecting, diagnosing, and treating prostate cancer. From FY1997 through FY2023, the PCRP has received \$2.26 billion in congressional appropriations, and 3,773 proposals have been funded through FY2022. Funding for the PCRP program remained flat for a decade until FY 2017. It has been at the current level of \$110 million since FY2020.



*FY2025 funding level has not been signed into law yet.

The PCRP is focused on eradicating prostate cancer by promoting:

- Highly innovative, groundbreaking research;
- High-impact research with near-term clinical relevance;
- The next generation of prostate cancer investigators, through mentored research, and
- Resources that will facilitate translational research

The PCRP prioritizes research that will: 1) develop treatments that improve outcomes for men with lethal prostate cancer; 2) reduce lethal prostate cancer in African Americans, Veterans, and other high-risk populations; 3) define the biology of lethal prostate cancer to reduce death; and, 4) improve the quality of life for survivors of prostate cancer.



Prostate Cancer's Military Relevance:

Military relevance is an important requirement for all CDMRP programs. Eighty percent of the U.S. military's active-duty population are men, and 11.7% of the almost 9,000 new cancer diagnoses of active-duty members of the U.S. Armed Forces between 2005 and 2014 were prostate cancer diagnoses. Between 2010 and 2019, over 211,000 active-duty service members and beneficiaries were treated for prostate cancer in the military health system.

A 2013 study conducted at the Portland VA Medical Center and Oregon Health and Science University found that Veterans exposed to Agent Orange are not only at higher risk for prostate cancer, but they are also more likely to have aggressive forms of the disease. According to a 2009 NIH-sponsored study, prostate cancer incidence rates in the active-duty military population are significantly higher than in the civilian population. As new data becomes available about the impact of burn pits and other toxic exposures following the enactment of the PACT Act, we expect to learn more about which service members are at an elevated risk for prostate cancer and why.

While there is clearly a connection between prostate cancer and exposures during military service, many speculate that active-duty incidence rates may be the result of mandatory annual physicals for service members coupled with the comparative lack of barriers to accessing care due to the universality of the military health care system. Others cite the possible exposure to depleted uranium in Middle East conflicts as a likely cause for recent prostate cancer diagnoses. More research is required to provide certainty on this point.

The program focuses on developing more effective therapeutics and has led to the development of a new diagnostic tool. By improving diagnosis to reduce overtreatment and accurately distinguish life-threatening disease from indolent tumors, the PCRP may have its greatest impact on active-duty servicemen who can be confidently monitored through active surveillance rather than compromising their service to undergo treatment.

The PCRP program also has an important role in "readiness," which is the concept of the day-to-day condition of armed forces military personnel (both mental and physical condition) and their equipment. Troops and practitioners must be mentally and physically fit for duty. A family cancer diagnosis and subsequent concerns over treatment and prognosis degrade military readiness.

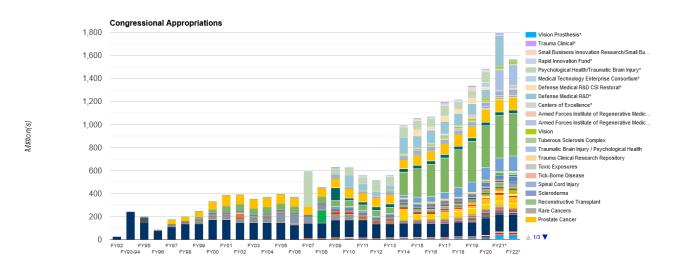
CDMRP Growth:

The creation and growth of the CDMRP in the 1990s coincided with the revival of Congress's use of the Constitutional power of the purse to provide checks on the Executive Branch in the annual budgeting and appropriations process. This was most commonly seen through the practice of "earmarks," and the CDMRP, whose funding is never requested in the President's budget, still struggles to distance itself from this association. The CDMRP was created at DoD



to allow Members of Congress to direct medical research into specific diseases, as a gentleman's agreement has prevented that practice with the NIH.

Although appropriations for individual research programs can (and occasionally do) vary from year to year, funding for the individual programs has stayed relatively consistent since their inception. As Congress has added programs, the CDMRP has seen a growth in funding—from \$200 million in FY1993 to almost \$1.5 billion in FY2023.



This growth has elevated the CDMRP's profile with budget hawks and caused some to question whether or not CDMRP programs are duplicated in the NIH. These questions arise, in part, from a lack of understanding of the CDMRP program's unique aspects. Beyond the standard protocols to ensure that both agencies do not inappropriately fund research proposals, staff at both the PCRP and the NIH communicate regularly to discuss proposals and funding decisions and prevent duplication.

Recent Activity:

PCRP Funding – Congress funded the PCRP program at the \$80 million level for ten years until FY2017, when the program received a \$10 million increase, raising the funding level to \$90 million. For FY2018 and FY2019, Congress provided \$100 million for the PCRP program. In FY2020, we could again increase the program to \$110 million and hold that funding level through FY2024 (and likely FY2025). We hope to increase funding to \$120 million in FY2026. The Senate Appropriations Committee usually recommends a funding level lower than the House initially and ultimately recedes to the House funding level. In FY2025, the Senate recommended \$75 million for the PCRP program, while the House recommended \$110 million.

Most of the Members of the House and Senate Appropriations Committees are supportive of the CDMRP. However, a few Republicans on each committee believe this research is better housed at NIH. For several years, Members of Congress in both the House and Senate have sent letters to their respective Appropriations Committees requesting funding for the PCRP.



Representative Neal Dunn (R-FL) and Representative Sanford Bishop (D-GA) have organized the House letter, which garners signatures from 130 and 150 Members of Congress each year, with 137 Members of Congress signing on in 2024. Senators Mike Crapo (R-ID) and Michael Bennet (D-CO) led the Senate letter, which attracted 21 Senators in 2024. This public support, coupled with internal requests from its members to the Appropriations Committee, is critical to building champions for the PCRP.



Co-Signers of the FY25 PCRP Letter

House

Representative	Party	District
Adams, Alma	D	VA-08
Barragan, Nanette	R	FL-12
Beaty, Joyce	D	GA-02
Bera, Ami	D	OR-01
Beyer, Jr., Donald	D	CA-44
Bilirakis, Gus	D	PA-02
Bishop, Sanford	D	CA-06
Bonamici, Suzanne	D	CA-26
Boyle, Brendan	D	IL-13
Brown, Shontel	D	OH-11
Brownley, Julia	D	IN-07
Budzinski, Nikki	D	CA-46
Carson, Andre	D	CO-06
Carter, Troy	D	TN-09
Casten, Sean	D	CO-01
Castro, Joaquin	D	MN-02
Cherfilus-McCormick, Sheila	D	VA-11
Cleaver, Emanuel	D	KS-03
Cohen, Steve	D	TX-30
Connolly, Gerald	D	PA-17
Correa, Luis	D	IL-07
Costa, Jim	D	MI-06
Craig, Angie	D	CA-10
Crockett, Jasmine	D	TX-35
Crow, Jason	D	NC-01
Davids, Sharice	R	PA-01
Davis, Danny	R	TN-04
Davis, Donald	R	FL-02
Dean, Madeleine	D	PA-04
DeGette, Diana	D	TX-07
Deluzio, Chris	D	TX-16
DeSaulnier, Mark	D	TX-20
DesJarlais, Scott	D	NC-12
Dingell, Debbie	D	LA-02
Doggett, Lloyd	D	IL-11
Dunn, Neal	D	OH-03
Escobar, Veronica	D	IL-06

Evans, Dwight	D	PA-03
Fitzpatrick, Brian	D	MO-05
Fletcher, Lizzie	D	FL-20
Foster, Bill	D	CA-21
Garamendi, John	D	CA-08
Garbarino, Andrew	R	NY-02
Garcia, Jesus	D	IL-04
Gimenez, Carlos	D	CT-05
Goldman, Dan	D	TX-34
Gomez, Jimmy	D	NY-10
Gonzalez, Vicente	D	CA-34
Gottheimer, Josh	R	FL-28
Hayes, Jahana	D	NJ-05
Himes, Jim	D	OR-04
Horsford, Steven	D	GA-05
Hoyle, Val	D	FL-24
Ivey, Glenn	D	NV-04
Jackson, Jonathan	D	CA-49
Jacobs, Sara	D	MD-04
Johnson, Henry	D	CT-04
Kamlager-Dove, Sydney	D	CA-37
Kean, Thomas	D	MA-08
Keating, William	D	IL-01
Kelly, Mike	D	GA-04
Khanna, Ro	R	NJ-07
Krishnamoorthi, Raja	D	CA-51
LaLota, Nick	D	CT-01
LaMalfa, Doug	D	MA-09
Larsen, Rick	D	IL-08
Larson, John	R	PA-16
Lawler, Michael	R	NY-17
Lee, Laurel	D	WA-02
Levin, Mike	D	CA-17
Lieu, Ted	R	NY-01
Lynch, Stephen	R	CA-01
Magaziner, Seth	D	CA-36
Matsui, Doris	D	CA-07
McCaul, Michael	R	TX-10



McGovern, James	R	NY-11
Miller-Meeks, Mariannette	D	RI-02
Moore, Gwen	D	MA-02
Moskowitz, Jared	R	IA-01
Mullin, Kevin	D	CA-15
Murphy, Gregory	D	WI-04
Nadler, Jerrold	D	D.C.
Neal, Richard	D	MA-01
Neguse, Joe	R	NC-03
Norton, Eleanor	D	FL-23
Omar, Ilhan	D	MN-05
Pappas, Chris	D	CO-02
Pingree, Chellie	D	MD-08
Plaskett, Stacey	D	NY-12
Radewagen, Amata Coleman	D	ME-01
Raskin, Jamie	R	AS-01
Rose, John	R	TN-06
Ruiz, Raul	D	NH-01
Ryan, Patrick	D	VI-01
Sanchez, Linda	D	IL-10
Scanlon, Mary Gay	D	CA-25
Schakowsky, Jan	D	CA-38
Schneider, Brad	D	IL-09
Schrier, Kim	D	WA-08
Scott, David	D	NY-18
Sherrill, Mikie	D	PA-05
Smith, Christopher	D	GA-13
Soto, Darren	D	NJ-11
Stauber, Pete	R	NJ-04
Stevens, Haley	R	KS-33
Swalwell, Eric	D	FL-09
Thompson, Bennie	D	MI-11
Thompson, Mike	D	MS-02
Tlaib, Rashida	D	MI-12
Tonko, Paul	R	MN-08
Trahan, Lori	D	CA-14
Van Orden, Derrick	D	CA-52
Vargas, Juan	D	NY-07
Veasey, Marc	D	MA-03
Velazquez, Nydia	R	WI-03
Williams, Nikema	D	TX-33
Williams, Roger	D	NY-20
Wilson, Frederica	R	TX-25
Wilson, Joe	R	SC-02

SENATE

Senator	Party	State
Crapo, Mike*	R	ID
Bennet, Michael*	D	CO
Blumenthal, Richard	D	CT
Blunt Rochester, Lisa**	D	DE
Booker, Cory	D	NJ
Cantwell, Maria	D	WA
Coons, Chris	D	DE
Gillibrand, Kirsten	D	NY
Kelly, Mark	D	AZ
Kim, Andy**	D	NJ
King, Angus	1	ME
Lujan, Ben Ray	D	NM
Markey, Ed	D	MA
Marshall, Roger	R	KS
Padilla, Alex	D	CA
Peters, Gary	D	MI
Risch, James	R	ID
Slotkin, Elissa**	D	MI
Smith, Tina	D	MN
Van Hollen, Chris	D	MD
Warnock, Raphael	D	GA
Warren, Elizabeth	D	MA
Wyden, Ron	D	OR

^{*} Members who were original cosponsors of the letter

 $[\]ensuremath{^{**}}$ House co-signers who are now in the Senate

March X, 2025

The Honorable Ken Calvert Chairman Subcommittee on Defense House Appropriations Committee H-405, The Capitol Washington, DC 20515 The Honorable Betty McCollum Ranking Member Subcommittee on Defense House Appropriations Committee 1016 Longworth House Office Building Washington, DC 20515

Dear Chairman Calvert and Ranking Member McCollum:

This year, over 310,000 men will be diagnosed with prostate cancer, and more than 35,700 men will likely die from this disease. As you consider the Fiscal Year (FY) 2026 Defense Appropriations Act, we respectfully request that the Committee appropriate \$120 million to the U.S. Department of Defense's (DOD's) Prostate Cancer Research Program (PCRP).

After more than two decades of progress in reducing prostate cancer deaths, there has been a recent reversal. Prostate cancer is the most diagnosed cancer in men, and second deadliest cancer in men (behind lung cancer). Since 2014, the incidence rate for advanced-stage prostate cancer has increased by about five percent per year. This increase is significant because while prostate cancer has a nearly 100 percent survival rate when caught early, the survival rate drops to 30 percent when the cancer has metastasized. As more men are diagnosed with late-stage cancer, death rates are increasing. It is estimated that over 500 more men will die this year of prostate cancer than in 2024, which reflects an increase of 9,000 more deaths when compared to 2017.

Since 1996, the Committee has been instrumental in advancing prostate cancer research by funding the DOD's Congressionally Directed Medical Research Program (CDMRP) for prostate cancer. CDRMP's administrative structure has demonstrated an ability to be flexible and quickly adjust responses to changing medical research needs and priorities. The PCRP, which complements wider NIH basic science efforts, is the gold standard in prostate cancer research and an integral weapon in the national fight against prostate cancer.

Unlike the NIH, PCRP has clear priorities each year that target gaps in prostate cancer diagnostics, care, and treatment with an emphasis on meeting the needs of the prostate cancer community. The programmatic review of all proposals ensures that the government is not spending scarce dollars on duplicative research. This structure works. In the last ten years, the PCRP has produced three new treatments for metastatic prostate cancer and one new advanced diagnostic.

The PCRP is both effective and military relevant. Prostate cancer is the most frequently diagnosed cancer among veteran men. Service members on active duty also have an incidence rate that is twice that of the general population. Between 2005 and 2014, prostate cancer accounted for 11.7 percent of cancer diagnoses in active-duty men. In addition, it is well known that cancer diagnoses among service members or their families have a negative impact on psychological health and military readiness.

For these reasons, we request a FY2026 appropriation of \$120 million for the PCRP within the CDMRP. Researchers will use this funding to develop treatments that improve outcomes for men with lethal prostate cancer; reduce lethal prostate cancer in African Americans, veterans, and other high-risk populations; and improve the quality of life for survivors of prostate cancer. With prostate cancer deaths on the rise, we need your help now more than ever to increase research that will produce tools for earlier detection and later-stage treatment and save lives.

Please join us in making prostate cancer research, awareness, and early detection a national health care priority by ensuring that adequate resources are available for the DOD PCRP. We recognize the difficult task ahead in setting priorities among many needs, but we appreciate your thoughtful consideration of this request.

Sincerely,

Rep. Neal Dunn, M.D. (R-FL)

Rep. Sanford D. Bishop, Jr. (D-GA)

XXX XX, 2025

The Honorable Mitch McConnell Chairman Subcommittee on Defense Senate Appropriations Committee S-128, The Capitol Washington, DC 20510 The Honorable Chris Coons Vice Chairman Subcommittee on Defense Senate Appropriations Committee S-146A, The Capitol Washington, DC 20510

Dear Chairman McConnell and Vice Chairman Coons:

This year, over 310,000 men will be diagnosed with prostate cancer, and more than 35,700 men will likely die from this disease. As you consider the Fiscal Year (FY) 2026 Defense Appropriations Act, we respectfully request that the Committee appropriate \$120 million to the U.S. Department of Defense's (DOD's) Prostate Cancer Research Program (PCRP).

After more than two decades of progress in reducing prostate cancer deaths, there has been a recent reversal. Prostate cancer is the most diagnosed cancer in men, and second deadliest cancer in men (behind lung cancer). Since 2014, the incidence rate for advanced-stage prostate cancer has increased by about five percent per year. This increase is significant because while prostate cancer has a nearly 100 percent survival rate when caught early, the survival rate drops to 30 percent when the cancer has metastasized. As more men are diagnosed with late-stage cancer, death rates are increasing. It is estimated that more than 500 more men will die this year of prostate cancer than in 2024, which reflects an increase of 9,000 more deaths when compared to 2017.

The PCRP is military relevant. Prostate cancer is the most frequently diagnosed cancer among veteran men and active duty men have an incidence rate that is twice that of the general population. Between 2005 and 2014, prostate cancer accounted for 11.7 percent of cancer diagnoses in active duty men. In addition, it is well known that cancer diagnoses among service members or their families have a negative impact on psychological health and military readiness.

Since 1996, the Committee has been instrumental in advancing prostate cancer research by funding the DOD's Congressionally Directed Medical Research Program (CDMRP) for prostate cancer. Its administrative structure has demonstrated an ability to be flexible and quickly adjust responses to changing medical research needs and priorities. The PCRP, which complements larger NIH basic science efforts, is the gold standard in prostate cancer research and an integral weapon in the national fight against prostate cancer.

Unlike the NIH, PCRP has clear priorities each year that target gaps in prostate cancer diagnostics, care, and treatment, with an emphasis on meeting the needs of the prostate cancer community. The programmatic review of all proposals ensures that the government is not spending scarce dollars on duplicative research. This structure works. In the last ten years, PCRP

research has resulted in seven new treatments for metastatic prostate cancer and one new advanced diagnostic.

For these reasons, we respectfully request that the Committee provide robust funding for the PCRP program within the FY2026 appropriation for CDMRP. In FY2025, Congress provided \$110 million for this vital program. In FY2026, researchers will use this funding to develop treatments that improve outcomes for men with lethal prostate cancer; reduce lethal prostate cancer in African Americans, Veterans, and other high-risk populations; define the biology of lethal prostate cancer to reduce death; and improve the quality of life for survivors of prostate cancer.

Please join us in making prostate cancer research, awareness and early detection a national health care priority by ensuring that adequate resources are available for the DOD PCRP. We recognize the difficult task ahead of your subcommittee in setting priorities among the many needs of our nation, but we appreciate your consideration of this request.

Sincerely,



Prostate Cancer at the Centers for Disease Control and Prevention

WHAT DOES THE CDC DO FOR PROSTATE CANCER?

While there is no dedicated national program for prostate cancer within the CDC, the CDC's Division of Cancer Prevention and Control supports various prostate cancer activities. Within the Division, the National Comprehensive Cancer Control Program includes support for state health departments' prostate cancer activities within their state cancer programs. The Division also works at a national level conducting applied research and surveillance on prostate cancer and creating significant communication and outreach initiatives.



MEET NATHAN

One such communication initiative is Nathan, a virtual human simulation that was created by the CDC to help men better understand their prostate cancer risk, screening options, and options for treatment if they are diagnosed.

HOW CAN WE IMPROVE?

ZERO supports a **\$3M** increase over the Fiscal Year (FY) 2025 level for the CDC's prostate cancer activities, to support a nationwide public awareness campaign targeted to high-risk men. This campaign will capitalize on ZERO's *Blitz the Barriers* program and amplify CDC's expertise in health communication with on the ground outreach directly into high-risk communities. The awareness campaign will ensure that messaging translates into action and drive screenings, early detection, and improved health outcomes.

We ask that the following language be included in the report accompanying the FY26 Labor-HHS-Education Appropriations Act:

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Prostate Cancer — The Committee remains concerned about the rise in prostate cancer deaths and supports the CDC's work to address this trend by increasing public awareness of prostate cancer risks, screening, and treatment in high-risk men.

Accordingly, the Committee provides \$3,000,000 above the request/the fiscal year 2025 level to support the creation of a national education and awareness campaign targeting highrisk men and their families.

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For more information about the CDC's prostate cancer activities, please contact Ali Manson: ali@zerocancer.org



Overview of CDC's Prostate Cancer Activities

ASK: Support Investment in Prostate Cancer Public Awareness at the CDC – We would like Congress to provide a \$3M increase over the Fiscal Year (FY) 2025 level for the CDC's prostate cancer activities to support public awareness efforts targeted to high-risk men in specific communities. This campaign will capitalize on ZERO's *Blitz the Barriers* program and amplify CDC's expertise in health communication with on-the-ground outreach directly to high-risk communities. The awareness campaign will ensure that messaging translates into action and drives screenings, early detection, and improved health outcomes. We ask that Members include the following Labor-HHS report language in their individual request letters to the Appropriations Committee for FY26:

Prostate Cancer — The Committee remains concerned about the rise in prostate cancer deaths and supports the CDC's work to address this trend by increasing public awareness of prostate cancer risks, screening, and treatment in high-risk men. Accordingly, the Committee provides \$3,000,000 above the request/the fiscal year 2025 level to support creating a national education and awareness campaign targeting high-risk men and their families.

Background

The Centers for Disease Control and Prevention (CDC), an agency within the Department of Health and Human Services (HHS), is the nation's public health protection agency, working to safeguard Americans from health and safety threats. It is responsible for providing credible information to support health decisions and for promoting health through strong partnerships. The CDC is organized into a number of centers, institutes, and offices, some focused on specific public health challenges (e.g., injury prevention, chronic disease) and others focused on general public health capabilities (e.g., surveillance and laboratory services). About seventy percent of the CDC's annual \$8B budget provides grants to state, local, municipal, tribal, and foreign governments, and academic and nonprofit entities. It has few regulatory responsibilities, instead issuing voluntary guidelines for the public health community.

In addition to the very public work of CDC staff around the world in response to public health emergencies, the CDC also promotes quality of life and prevention of leading causes of disease, injury, disability, and death through programs that provide Americans with the essential health information and tools they need to make informed decisions to protect and advance their health. CDC scientists collect and analyze health data, determining how health threats affect specific populations, issuing reports for health professionals and patients alike on all manner of



disease and injury, and conducting public awareness campaigns to help inform the public about key health information.

Prostate Cancer Activities

The CDC's National Center for Chronic Disease Prevention and Health Promotion has eight divisions and offices that carry out its work, including the Division of Cancer Prevention and Control, which runs the National Comprehensive Cancer Control Program (NCCCP). The Chronic Disease Center has no designated prostate cancer program, but some activities of the NCCCP awardees and within the Division's work are specific to prostate cancer. The CDC's prostate cancer funding supports communication initiatives, applied research and analysis, surveillance, and prostate cancer activities in the NCCCP. According to the CDC, providers are often unaware of current guidelines concerning prostate cancer counseling and do not adequately inform patients of the risks and benefits of screening. As such, many of the CDC's research and surveillance activities have focused on enhancing knowledge of effective prostate cancer communication and intervention, such as efforts related to informed decision-making around screening and treatment.

The CDC's funding for **prostate cancer communication** supports the agency's work with partner organizations to research pertinent questions and promote messages that may benefit men at risk for prostate cancer, prostate cancer patients and their families, and providers. The CDC develops prostate cancer materials, which are released in print and web formats. These materials require consistent, evidence-based updating and are widely used by providers and advocacy groups to promote informed decision-making and open discussion between patients and providers. A few years ago, the CDC, working with ZERO and other groups, launched "Nathan," an interactive avatar simulation decision aid focusing on prostate cancer screening and treatment decisions. More recently, the CDC has been creating a digital prostate cancer resource center for easier and more widely disseminated materials. As part of this process, the CDC will create new materials based on the identified needs of the patient, caregiver, and provider communities. As part of its dissemination of information, the CDC is actively engaged with USPSTF, providing surveillance and other data to the Task Force as it updates its PSA screening recommendation this year.

The CDC's funding for **prostate cancer applied research and analysis** supports and conducts research on prostate cancer across a wide spectrum of public health topics, ranging from early detection with prostate-specific antigen screening to prostate cancer survivorship. Examples of current topics of special interest include:



- Analysis of surveillance data to assess the impact of U.S. Preventive Services Task Force recommendations (and changes in recommendations) on prostate cancer screening and shared decision-making;
- Development and evaluation of a decision aid to promote active surveillance management for men with low-grade, local-stage prostate cancer;
- Follow-up of needs of long-term prostate cancer survivors and their spouses; and,
- Studies of prostate cancer incidence and survival by demographic and tumor characteristics to assess prostate cancer burden and identify racial and ethnic disparities.

The CDC's **surveillance funding** is used to monitor trends in prostate cancer incidence, enhance prostate cancer data quality in cancer registries, and conduct research on the stage of disease at the time of diagnosis, the race and ethnicity of men with prostate cancer, and patterns of care for prostate cancer treatment. This work is done through the United States Cancer Statistics and the National Program of Cancer Registries programs.

The CDC's funding for **the NCCCP** is used to bring together cancer coalitions to identify the burden of cancer, set priorities for action, and develop and implement cancer plans to address the burden. A total of 19 grantees have developed and implemented specific activities related to prostate cancer in the most recent reporting years of the cooperative agreement (2012–2023), including in Arizona, Massachusetts, Michigan, New Mexico, Ohio, Pennsylvania, South Carolina, South Dakota, Missouri, Tennessee, Virginia, Washington, Wisconsin, and Wyoming.

In addition to the Chronic Disease Center's prostate cancer activity funding, the CDC's Healthy People 2030 initiative includes one prostate cancer-specific goal: to "reduce the prostate cancer death rate."

Prostate Cancer Public Awareness

The CDC conducts education and outreach and regularly develops educational materials for state and local public health agencies, health care providers, and the general public. Health education is a component of almost all of CDC's programs related to specific diseases and health issues. Currently, the CDC has many ongoing awareness campaigns, including some that are designed to:

- Inform seniors about injury prevention
- Increase HIV testing, prevention, and treatment
- Raise awareness of urgent maternal warning signs during and after pregnancy
- Help Americans understand their risk for prediabetes



In 2025, ZERO Prostate Cancer is embarking on the most ambitious initiative in the history of U.S. prostate cancer programs and services. Prostate cancer exacts a devastating toll on underresourced and under-served communities across the country. African American men, Veterans, and rural underserved populations, in particular, carry the disease's greatest burden. Barriers exist at every point, from screening and diagnosis to accessing cutting-edge treatment. Through *Blitz the Barriers*, ZERO will work both in-community and virtually to dismantle obstacles, empower communities, and pave the way for more sustainable interventions.

Blitz the Barriers will launch awareness, outreach, education, and support initiatives in pilot communities of greatest need nationwide over the next three years. These efforts will drive screenings through education and awareness and offer personalized navigation to patients as they receive care. A 24-7 support tool will immediately assist patients and caregivers. This comprehensive approach will increase screening in our pilot communities by 20 percent, saving 30,0000 lives by 2030. By combining ZERO's on-the-ground efforts with CDC's proven record of public awareness and health communication, we can amplify the impact of both efforts.

ZERO has developed a strong working relationship with the CDC. Through that engagement, ZERO has grown to better understand the work that could be done if the CDC had funding for prostate cancer outreach. Since FY20, we have been able to secure an additional \$2 million a year for CDC to undertake new initiatives to increase outreach, education, and resources for men at high risk of developing prostate cancer, including African-American men. This funding has allowed the CDC to work with and support appropriate governmental and non-governmental organizations to develop and disseminate additional information about prostate cancer.

We hope to increase funding by \$3 million in FY2026. This investment will allow the CDC to begin work on a national public awareness campaign to raise awareness of prostate cancer in high-risk populations and encourage men to talk to their doctors about screening. The campaign would likely take about one year to design before being piloted in ZERO's Blitz the Barriers locations the following year and then rolled out nationwide.

Recent Funding History

In FY24, Congress provided \$15.2M for the CDC's prostate cancer activities. While we await a final bill for FY25 funding, the House bill included the same funding level as FY24, and the Senate bill provided \$17.2M. Both bills included the report language listed below:



FY25 House Report:

Cancer Prevention and Control — The Committee provides \$417,049,000 for CDC cancer prevention and control activities, a \$7,000,000 increase from the fiscal year 2024 enacted level. The Committee directs CDC to fund the following activities at not less than the fiscal year 2024 enacted level: breast and cervical cancer, including WISEWOMEN, breast cancer awareness for young women, cancer registries, colorectal cancer, comprehensive cancer control, Johanna's Law, ovarian cancer, prostate cancer, skin cancer, and the cancer survivorship resource center.

Prostate Cancer — The Committee is aware of the continued rise in prostate cancer deaths. It supports the CDC's work to increase public awareness of prostate cancer risks, screening, and treatment in high-risk populations.

FY25 Senate Report:

Prostate Cancer — The Committee is aware of the continued rise in prostate cancer deaths and supports CDC's work to promote public awareness of prostate cancer risks, screening, and treatment in high-risk men. The Committee provides \$17,205,000 for CDC's prostate cancer activities, including outreach and education initiatives among African-American men and other high-risk groups



The Precision Oncology Program for Cancer of the Prostate (POPCaP)

Prostate cancer significantly impacts both active duty servicemen, Veterans, and their families; in fact, active duty males are **twice as likely** to be diagnosed with prostate cancer as their civilian counterparts, with negative effects on their ability to serve. In addition, servicemembers exposed to toxins such as Agent Orange, burn pits, and PFAS and PFOA, are considered to be at increased risk of death from prostate cancer. **Prostate cancer is the most commonly diagnosed cancer in the U.S. Department of Veterans Affairs (VA) healthcare system.**

WHAT IS POPCaP?

In 2016, the VA Office of Research & Development launched the VA Precision Oncology Program to conduct state-of-the-art precision oncology research to improve care for Veterans and others with cancer. As part of this initiative, in 2016 the VA partnered with the Prostate Cancer Foundation to establish the Precision Oncology Program for Cancer of the Prostate (POPCaP). This program seeks to use precision medicine to tailor individualized treatments for Veterans with prostate cancer.



Since its inception in 2016 and launch in 2018, the POPCaP program has operated a network of precision oncology centers across the country, giving Veterans with prostate cancer access to genetic testing and counseling, prostate cancer clinical trials, and FDA-approved drugs targeted to specific cancer mutations.

WHAT IS THE ISSUE?

In Fiscal Year 2024, Congress had allocated \$5 million in funds to expand POPCaP to new sites. However, the VA responded by outlining plans to shutter POPCaP sites, close the POPCaP administrative office in Seattle, and fold POPCaP into a newly created Precision Oncology Program by September 2025. This would dilute the quality of care that Veterans with prostate cancer receive, and potentially make it more difficult for Veterans to receive state-of-the-art treatments.

We ask that your office cosponsor legislation soon-to-be-introduced by Representative Greg Murphy (R-NC) to protect the POPCaP program in law, ensuring our Veterans continue to receive the highest quality cancer care through the VA. To cosponsor, please contact Ray Celeste (Raymond.Celeste@mail.house.gov)

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Overview of VA's Precision Oncology Prostate Cancer Program (POPCaP)

ASK: Protect the VA's POPCaP Program – The Department of Veterans Affairs' (VA) Precision Oncology Program for Cancer of the Prostate (POPCaP) uses genetic information to tailor individualizes treatments for veterans with advanced prostate cancer and mentors VA staff to increase clinical trials at 21 POPCaP sites around the country. Even though prostate cancer is the most commonly diagnosed cancer in VA, the Department is seeking to dismantle the POPCaP program as part of a larger restructuring of its precision oncology efforts. Bipartisan efforts are underway in Congress to ensure the POPCaP program is maintained. We ask that House members please cosponsor Dr. Greg Murphy's (R-NC) soon-to-be-introduced legislation authorizing the POPCaP program as it is currently structured.

Prostate Cancer at the VA

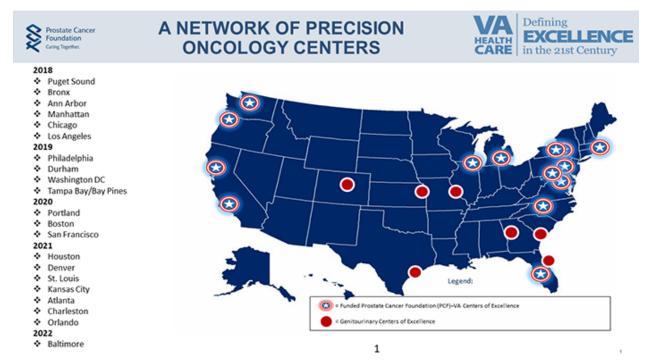
Every year, about 15,000 veterans are diagnosed and treated for prostate cancer by the VA. VA has a complicated history of prostate cancer care. In 2014, a whistleblower alleged that veterans at the Phoenix VA died while waiting for appointments. Subsequent investigations by the VA Inspector General, Congress, and the media showed that some of the deaths were due to delayed treatment for prostate cancer. The Administration and Congress undertook changes to the VA's appointment scheduling and other reforms in the aftermath of the investigations. In 2014 and 2018, Congress passed legislation expanding eligibility criteria for veterans who wanted or needed to access "community care" --- care paid for by VA but provided by non-VA providers. In 2022, with ZERO's advocacy support, Congress passed additional legislation (sponsored by Rep. Neal Dunn, M.D. (R-FL) and Sen. Jerry Moran (R-KS), which required the VA to create a clinical pathway for VA providers to follow. In 2024, the VA Oncology Office released the prostate cancer clinical pathway, an evidence-based roadmap that guides providers to help standardize care across the VA. ZERO is working with the VA and Congress to strengthen the pathway.

POPCaP Background

In 2016, the Prostate Cancer Foundation (PCF) partnered with the Department of Veterans Affairs (VA) to create a network of precision oncology centers across the VA. Under the terms of the agreement, PCF would cover the centers' costs for the first five years. The first Precision Oncology Program for Cancer of the Prostate (POPCaP) sites began in 2018, and their funding was due to be absorbed by VA in 2023. Additional POPCaP Centers of Excellence were added through 2022. POPCaP sites, chosen by PCF, have clustered mainly on the coasts near PCF donors underwriting the investments. Due to the success of the program and noting the geographic disparity, VA opened seven non-PCF-supported sites in 2021 to expand on the successful POPCaP model and to include other cancers. These Genitourinary Centers of Excellence apply the POPCaP model to prostate, kidney, and bladder cancer.

POPCaP uses genetic information to tailor individualized treatments for veterans with advanced prostate cancer. Components of POPCaP include access to genetic testing and counseling,





prostate cancer clinical trials, and FDA-approved drugs targeted to specific cancer mutations. The POPCaP program maintains a data repository and provides liaisons for industry-funded clinical trials to ensure VA engagement in study design, participation, and credit, coordinates multiple sites for VA participation in National Cancer Institute Cooperative Group Studies, and facilitates the development of VA investigator-initiated studies. POPCaP has the expertise to provide varying levels of decentralized support for clinical research across VA, including research coordination, regulatory startup and maintenance, and data management without a local institutional review board (IRB) approval. POPCaP also provides support and training for investigators who do not have experience in developing proposals or creating studies.

Each POPCaP site requires approximately \$500,000 a year for operations, and the program's annual administration cost is about \$1 million. PCF has covered the annual costs for 14 of the 21 sites for the first five years. As sites rotate out of PCF funding and shift to VA funding, the program's base costs are increasing for VA—from \$8 million in FY23 to \$11.5 million in FY26.

POPCaP leadership, based at the Seattle Puget Sound VA, is working to add six additional POPCaP sites across the country to ensure better access to oncology clinical trials for veterans. Ideally, they would locate new sites in:

- VISN 16 (Louisiana, Arkansas, South Mississippi, or East Texas)
- VISN 7 or 8 (South Georgia/North Florida)
- VISN 17 (North/Northwest Texas)
- VISN 12 or 23 (the Upper Midwest)
- VISN 22 (Arizona or New Mexico)
- Utah (in VISN 19)



Six additional sites would add a \$3 million annual cost to the program, for a total program cost of \$14.5 million in FY26.

The FY24 Milcon-VA Appropriations Act's Joint Explanatory Statement included increased funding to expand the POPCaP program:

Due to the lack of capacity to enhance and increase current clinical cancer trials in additional areas of the country, the Committees direct that up to an additional \$5,000,000 be allocated to expand the Precision Oncology Program for Cancer of the Prostate (POPCaP) program to new sites to facilitate additional partnerships between VA medical centers and university cancer centers.

Precision Oncology Changes at VA

In the spring of 2024, in response to a request for information, VA outlined plans to shutter the POPCaP Centers of Excellence sites, close the POPCaP administrative office in Seattle, and fold the seven POPCaP genitourinary sites into a newly designed Precision Oncology Program, which would eventually have one Clinical Research Center (CRC) per VISN. Ignoring Congressional intent, the VA plans to use the appropriations funding for POPCaP program expansion to support six Precision Oncology CRCs (Boston; Kansas City; Madison; Minneapolis; Philadelphia; and Washington, DC). The CRC model differs substantially from the POPCaP program, providing only minimal administrative/paperwork support for sites but none of the mentoring, liaisons, or coaching in clinical trial development or planning supported by POPCaP, which is vital to provide the best clinical care for veterans with prostate cancer.

Both the Senate Milcon-VA Appropriations Subcommittee and the Senate VA Committee have made inquiries into the future of POPCaP. VA's oncology office, based in Durham, has defended its decision to shut down POPCaP, suggesting that POPCaP sites are free to compete and become one of the precision oncology sites if funding becomes available. If not altered, under current plans, the VA plans to shutter the POPCaP program at the end of September 2025.



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info@zerocancer.org

Advocacy Tips and Best Practices

Remember:

- **Do your homework.** Read and understand the materials in your advocate email, including the "Legislative Priorities" and the "Dear Colleague" letters. Get comfortable with the "Talking Points."
- **Be aware** of notable items in a member's history and/or recent events.
- **Remember**, staff are principal advisors and are instrumental in shaping decisions.
- MAKE THE ASK! It is always expected, regardless of the answer.

Pre-Meeting Preparation

Know your asks. This packet contains information to help you become acquainted with the bills and programs ZERO supports and your role as an advocate when attending meetings on Capitol Hill.

Practice telling your story. The "Share Your Story" section will help you develop a compelling story. We encourage you to practice telling your story in advance to increase confidence for your meetings.

Learn more about your Senators and Representatives. It is extremely helpful to familiarize yourself with your members' priorities and views by visiting their websites at www.house.gov.

Be prepared to meet with your legislator's staff. Your legislator may not be able to attend the meeting. Staff may be young, but they are instrumental in shaping the legislator's views. It is not unusual for the legislator to defer to his/her staff for an opinion on your issue. It is important to demonstrate respect to everyone you encounter during your visit.



Meeting Pointers

Prepare as a group. We are expecting over 140 advocates. However, there may only be one or two advocates in any district. You will <u>not</u> be attending your legislative visits alone. You will be in a group of approximately 2-5 advocates grouped with members of your state or nearby states if necessary. If there is no Summit Leader in your group, you will assign a "leader" to each group to start and conclude the meeting. One group member must take notes and report the details of each meeting. Make sure you assign this task in your group **before** you are at the visit! We ask groups to make time before your meetings to prepare together.

The constituents are most important. The legislators' primary concern is being responsive to their constituents—the people who hired them. If you live in the district, you are important. The spokesperson should begin the meeting by identifying himself/herself as a constituent and introducing all participants. Indicate your relationship to the issue (i.e., patient, survivor, family member, doctor, etc.) and briefly identify your request early in case time runs short.

Cover the priority issue. Now is the time you've been waiting for. Tell your story and explain why the PSA for HIM Act, funding for DoD research, or any of our other requests is important to you. Make your remarks brief and to the point. Encourage them to learn more and do more.

Avoid focusing solely on the medical details. Your story is more powerful and memorable when you keep it simple and accessible. See the "Share your Story" section for help. Remember to tie your story back to this year's request — cosponsoring the PSA for HIM Act, funding for the Department of Defense's Prostate Cancer Research Program and the CDC, and supporting the VA's POPCaP program.

Stay on topic. A little chit-chat is acceptable, but be sure to stay on topic and not be drawn into storytelling—you'll never know where the time went! Be concise and stick to the issue, but do not rush the conversation.

Solicit the legislator's views on this issue. Review your request and do some research on your legislator. Does your legislator focus on defense or health issues? Do they sit on relevant committees? Do they have a personal connection to prostate cancer? If they do, focus on these issues. Make sure to thank them for their time and support and to take action as outlined in the material you will leave with them. Never argue with your legislator or staff if there is a disagreement. Listen to his/ her perspective and then present your views. You will enhance your effectiveness if you demonstrate a willingness to participate in a friendly exchange of ideas. Record your legislator's response to facilitate follow-up.

Conclude your meeting. Ensure your legislator and/or staff has received briefing materials with ZERO's contact information. Thank them for their time and offer to be a resource on prostate cancer issues.



Share Your Story

Many of us have been through a lot in our journey with prostate cancer. Unfortunately, in the world of advocacy, you don't have time to share a book with your lawmakers. In fact, you may only have 30 seconds.

Whether writing an email, making a phone call, doing an interview or meeting your legislator face-to-face, your story is the most powerful tool you have. It is important to develop this story to have maximum impact.

When with your lawmakers or their staff, you will begin with a quick "30-second speech." In many cases this will be all the opportunity that you have. Other times they will follow-up with comments and additional questions. It may be helpful to write down the other things you think are important in case you have the opportunity to share.

Your "30-second speech" should contain 3 components:

- **Introduction**: State your name, where you are from, your relationship to prostate cancer, any relationship you may have with your Member of Congress (if appropriate).
- **Key Message**: Share the very brief, 2-3 sentence version of your story. Describe the relevant issue and why it is important to you.
- Request: What you want them to do. In our case it is to cosponsor the PSA Screening for HIM
 Act, support \$120 million for the DoD prostate cancer research program, an additional \$3
 million for CDC prostate cancer activities, and support the Veterans Health Administration's
 POPCaP program.

It can be beneficial to practice this story with others in your group in order to get more comfortable speaking succinctly about what we are requesting and how it impacts you personally. We will spend some time going over the requests to Congress and how to tell your story during the Advocacy Day, but it helps to have thought about the question beforehand.



Advocacy Dos and Don'ts

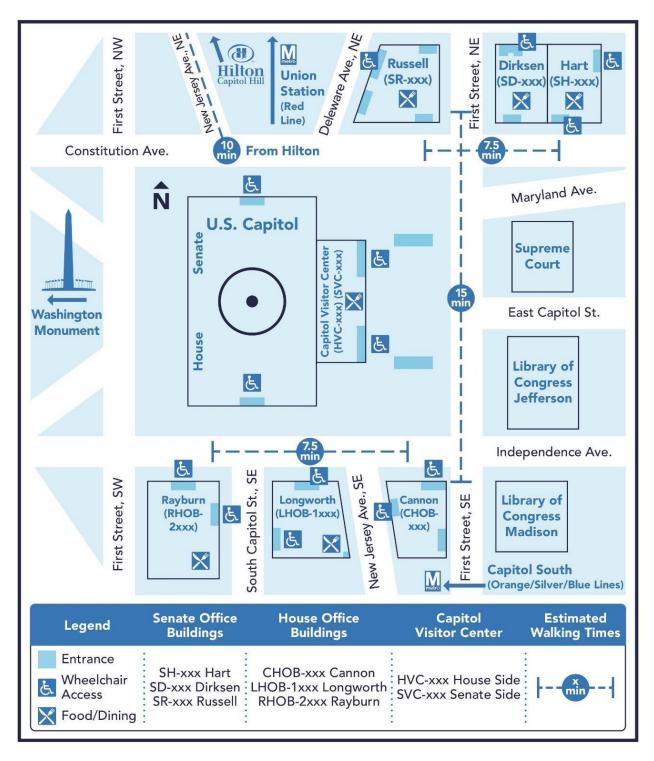
Dos

- Do be on time. 5 minutes early <u>is</u> on time.
- Do be polite, professional, and friendly.
- **Do** be concise and to the point.
- Do let them interrupt with questions.
- Do adhere to time limits they set.
- Do ask if they have questions.
- Do ask your own questions.
- Do offer to provide additional information.
- Do get the staffer's name and follow up via email.
- Do contact Sydney (sblair@cgagroup.com) if you need help or have questions about your schedule.

Don'ts

- Don't just make up an answer if you are confronted with a question you cannot answer. Write the question down and let them know you will have someone at ZERO respond later.
- Don't show up too early. Offices are small and arriving more than 5 minutes early can inconvenience staff.
- Don't forget to say "Thank you"
- Don't do all the talking.
- Don't try to be completely comprehensive, hit the key points.
- Don't be negative.
- Don't overextend your welcome.
- Don't talk personal politics.





Hotel Address: Hilton Washington DC Capitol Hill 525 New Jersey Avenue, NW

Washington, DC 20001



To get to the Hilton Washington, D.C. Capitol Hill from Union Station:



The above map shows two roughly equidistant routes to the hotel by walking from Union Station.

To get to Union Station from Ronald Reagan Washington National Airport (DCA) via public transit:

- 1. Take the Yellow Metro line from the airport towards Mount Vernon Square.
 - a. Transfer to the Red Metro line at Gallery Pl-Chinatown towards Glenmont (6 stops).
 - b. Exit at Union Station (2 stops).
- 2. Take the Blue Metro line from the airport towards Largo.
 - a. Transfer to the Red Metro line at Metro Center towards Glenmont (9 stops).
 - b. Exit at Union Station (3 stops).

To get to Union Station from Washington Dulles International Airport (IAD) via public transit:

- 1. Take the Silver Metro line from the airport towards Largo.
 - a. Transfer to the Red Metro line at Metro Center towards Glenmont (18 stops).
 - b. Exit at Union Station (3 stops).



Thank you to Pfizer Oncology for sponsoring the 2025 ZERO Prostate Cancer Advocacy Summit Advocate Guide



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