2023

ZERO® PROSTATE CANCER SUMMIT

FEBRUARY 26-28, 2023

ADVOCATE GUIDE

TOGETHER WE CAN

#ZeroOutProstateCancer

Greetings ZERO Advocates and welcome to the 2023 ZERO Prostate Cancer Summit!

First, we are SO EXCITED to see you in person! It has been three long year since our community had the chance to come together in Washington, DC, and I know everyone is chomping at the bit to catch up, share some hugs (if you're comfortable with that), and share their stories in support of the pressing need for greater legislation and research funding surrounding prostate cancer.

This year's key advocacy efforts include:

- $120 million in funding for the Prostate Cancer Research Program (PCRP), which supports research focused on eradicating prostate cancer;
- $20 million in funding for prostate cancer at the CDC, and an emphasis on educating high- risk populations;
- The PSA Screening for HIM Act, which would eliminate cost sharing as a barrier to diagnosis of prostate cancer for those at highest risk of the disease, African-American males and men with family history of the disease; and,
- The PC-CARE Act, which would ensure that federal government agencies, and private organizations, are coordinated in research and policy initiatives to fight prostate cancer.

We thank all of you amazing ZERO advocates for your continued commitment in the fight against prostate cancer. Research has shown, over and over, that the personal stories you share are the key to influencing policymakers. I hope that knowing you have made a difference for future generations is satisfying and empowering.

We have a lot to do in a short few days during the Summit, but please take advantage of our time together to get to know some of your fellow advocates (40% of you are new this year!). Our community keeps growing bigger, stronger, and more impactful – and I hope to see every single one of you again in 2024!

Thank you for your commitment, your passion, and your time. Here's to ending prostate cancer together!

Sincerely,

Allison J Manson

Ali Manson

Vice President of Government Relations & Advocacy

Table of Contents

2023 ZERO Prostate Cancer Legislative Requests

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 focus is on basic research, and has resulted in three 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 FY2024 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 Menendez-Crapo Dear Colleague letter to the Senate Appropriations Committee supporting funding for the PCRP program.

Support Additional CDC Prostate Cancer Outreach to High-Risk Men – The FY23 Labor-HHS- Education appropriations bill included $15.2M in funding for CDC prostate cancer activities, an increase of $1M that recognized the agency's commitment to conduct outreach and education for high-risk men. We respectfully ask Congress to include an additional $4.8M, for a total of $20M, to increase outreach to African-American and other high-risk men, including support for webinars and virtual and in-person support groups. **We ask that Members include the following Labor-HHS report language in their individual request letters to the Appropriations Committee.**

> *Prostate Cancer— The Committee is aware of the continued rise in prostate cancer deaths and supports the CDC's work to increase public awareness of prostate cancer risks, screening and treatment in high-risk men. The Committee provides $20,000,000 for the CDC's prostate cancer activities, including $7,000,000 for initiatives to increase outreach and education among high-risk men, especially African-American men.*

Support PSA Screening for African-American & 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 at-risk men to be screened for prostate cancer. Rep. Larry Bucshon, MD (R-IN) and Rep. _____ (D-__) introduced the Prostate-Specific Antigen Screening for High-risk Insured Men Act (PSA Screening for HIM Act), H.R_____, 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 (H.R. _____).

Support Federal Research Coordination for Prostate Cancer – Rep. Greg Murphy (R-NC) is leading the Prostate Cancer Community Assistance, Research and Education Act of 2023, or the PC-CARE Act, to establish a Prostate Cancer Coordinating Committee to monitor, coordinate, and evaluate the activities of Federal prostate cancer research programs. This bill (bill number forthcoming) would ensure that federal agencies – including the NIH, DoD, CDC, VA, and others – are meeting regularly to discuss priorities in prostate cancer research and align their work with private funders in order to maximize value and move more quickly toward a cure. We ask for your support and cosponsorship of the PC-CARE Act when it is introduced.

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 2023, an estimated 288,300 men will be diagnosed with prostate cancer and 34,700 men will die from it.
    - After decades of decline, prostate cancer death rates on the rise: it is estimated that in 2023 over 125,000 more men than in 2017 will be diagnosed with prostate cancer and over 8,000 more men will die from prostate cancer than in 2017.
    - This represents a 78% increase in diagnoses and a 15% rise in the death rate.
- A man will be diagnosed with prostate cancer every 2 minutes in 2023, and die from it every 15 minutes.
- African American men are at increased risk for the disease. 1 in 7 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 1.8 times more likely to be diagnosed with the disease.
- Veterans who were exposed to herbicides like Agent Orange 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 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 in the proposal peer-review process and the panel that sets annual priorities for the program.

- 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 with origins in PCRP research. Additionally, validation of a genomic test for prostate cancer aggressiveness came from a PCRP- industry collaboration.

- 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 high-risk populations;
    - Define the biology of lethal prostate cancer to reduce death; and
    - Improve the quality of life for survivors of prostate cancer.

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 of the test.
    - The "D" rating for men 70 and above means the PSA test is not recommended for older men – no matter 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 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.
- 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. Larry Bucshon, MD (R-IN) and _____(D-x__) introduced the PSA Screening for HIM Act (H.R. xxx), which requires PSA screening coverage for those two categories (African Americans and family history). The bill would essentially 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.
- 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.

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, co-morbidities, and familial history), it is critical that clear communication tools are provided to both patients and providers.

- CDC funding conducts research and develops materials that explore how best to communicate and promote informed decision making related to prostate cancer screening, treatment, and quality of life.

- Surveillance activities enhance the prostate cancer data in cancer registries based on race and ethnicity, the state of prostate cancer at the time of diagnosis, and the quality of care.

- The advocacy community, providers, researchers, and epidemiologists rely on surveillance information to understand incidence in key populations and track disease stage. This information helps the CDC and other organizations make informed recommendations for effective interventions.

- Since FY20, at the direction of Congress, the CDC has undertaken additional outreach in African American and other high-risk communities around the country.

- CDC activities for outreach in the African American community include disseminating a new online decision-making aid, developing appropriate messaging, and creating a Prostate Cancer Resource Center.

- The CDC also working with governmental and non-profit organizations to disseminate prostate cancer resources to targeted communities.

- With $20M in funding, the CDC can increase its outreach to these communities and engage its partners to reach these men with virtual and in-person support groups.

Coordination of Prostate Cancer Research

- Many federal agencies conduct prostate cancer research, provide grants to academic and industry partners to perform research, or create and administer policies informed by research. For example:
    - National Institutes of Health (NIH) – funds academic and industry research; conducts its own research
    - Veterans Health Administration (VHA) – conducts its own research with academic partners; sets screening and treatment policies for Veterans
    - Department of Defense (DoD) – funds academic and industry research; conducts its own research; sets screening and treatment policies for active-duty service members and their families
    - Centers for Disease Control and Prevention (CDC) – disseminates information about screening and treatment
    - Centers for Medicare and Medicaid Services (CMS) – sets reimbursement policies for screening and treatment
    - Food and Drug Administration (FDA) – approves new diagnostics and treatments
    - Health Services and Resources Administration (HRSA) – sets screening and treatment policies for vulnerable populations

- In order to ensure that programs are not duplicative and have complementary objectives, coordination among agencies is necessary.

- The Prostate Cancer Community Assistance, Research and Education Act (PC-CARE Act) would create a coordinating committee, run by the NIH with participation from HHS, DoD, the VA, and other agencies as well as representatives from relevant non-profit organizations and medical societies.

- The PC-CARE Act will be introduced by Representatives Greg Murphy (R-NC), who is also a urologist.

- Under the legislation, the Prostate Cancer Coordinating Committee would conduct a survey of federal prostate cancer research programs and create a research plan that would be updated every three years. The group would meet three times a year to stay up to date on the latest research and policy developments.

The Asks

1. Sign onto the Dunn-Bishop (House)/Menendez-Crapo (Senate) Dear Colleague letter supporting FY24 funding for DoD's Prostate Cancer Research Program (PCRP).

2. Support $20M in FY24 funding for the CDC's prostate cancer activities, including African American outreach.

3. Cosponsor H.R. ____ – Congressmen Larry Bucshon, MD (R-IN) and _____'s (D-x__) PSA for HIM Act requiring coverage for PSA testing for at-risk men.

4. Cosponsor the PC-CARE Act– Congressmen Greg Murphy (R-NC) PC-CARE Act creating a federal prostate cancer research coordinating committee when it is introduced.

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 FY23, Congress provided $110 million. We support a $120 million funding level in FY24.

- We ask that House Members sign on to the Dunn-Bishop letter to the Defense Appropriations Subcommittee supporting $120 million in FY24 funding. Senators can sign on to the Menendez-Crapo letter supporting keeping prostate cancer research, detection, and treatment a priority (no funding level mentioned).

CDC:

- The CDC prostate cancer activities received $15.2 million in FY23. $20M in funding would allow the CDC to continue conduct more outreach in African American and other at-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.

PSA Screening:

- Please cosponsor the PSA Screening for HIM Act (HR ____), which was introduced by Reps. Larry Bucshon, MD (R-IN) and _____ (D-__). The bill would essentially require that high-risk men (those with a close family history of disease or African American men) be treated as if they had an "A" rating from USPSTF (rather than a "C"/"D" rating), meaning the insurance coverage for the test would be guaranteed.

Coordinating Committee:

- Please cosponsor the Prostate Cancer Community Assistance, Research, and Education (PC-CARE) Act, soon to be introduced by Representative Greg Murphy (R-NC). This bill creates a coordinating committee to assess and coordinate prostate cancer research across the federal government and non-profit organizations.

The Prostate Cancer Research Program (PCRP)

What is the PCRP?

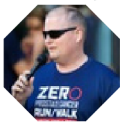
The Prostate Cancer Research Program (PCRP) began in 1997 as a part of the Congressionally Directed Medical Research Programs, or CDMRP. Created by Congress in 1992 and administered by the Department of Defense, CDMRP programs advance biomedical research, with a particular focus on applied research that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

Prostate cancer is a real threat to men who serve in the U.S. military, with 1 in 5 Veterans and active-duty military being diagnosed with the disease in their life time.
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 2024.

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 respond 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.

> **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 servicemembers 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

For more information about the Prostate Cancer Research Program, please contact Ali Manson: ali@zerocancer.org

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. In recent years, there have been efforts in Congress, primarily driven by budget concerns, to eliminate this highly effective program. We urge Congress to support funding of $120M for the PCRP and to recognize prostate cancer as a militarily relevant disease in the FY 2024 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 Menendez-Crapo 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 funder of biomedical research – 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 FY1992-2022, the CDMRP managed over $19.4 billion in congressional appropriations for peer-reviewed research, funding over 20,000 awards through FY2021. There are now 38 programs at the CDMRP.[i]

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.[ii] A blue ribbon committee of the IOM studied these major considerations and 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 in need of 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 review. 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 major role in maintaining the focus of the respective programs on research that is relevant and has the potential to make a significant impact on the affected communities. The CDMRP process is innovative in that it includes consumer reviewers on both the peer review panels and the programmatic panels. Consumers are engaged at all levels of the CDMRP process, and this level of consumer engagement is unique among government research funding agencies. Other organizations such as NIH are moving toward greater involvement of consumers in their funding processes, including setting research priorities, but the CDMRP has been doing this since its inception.

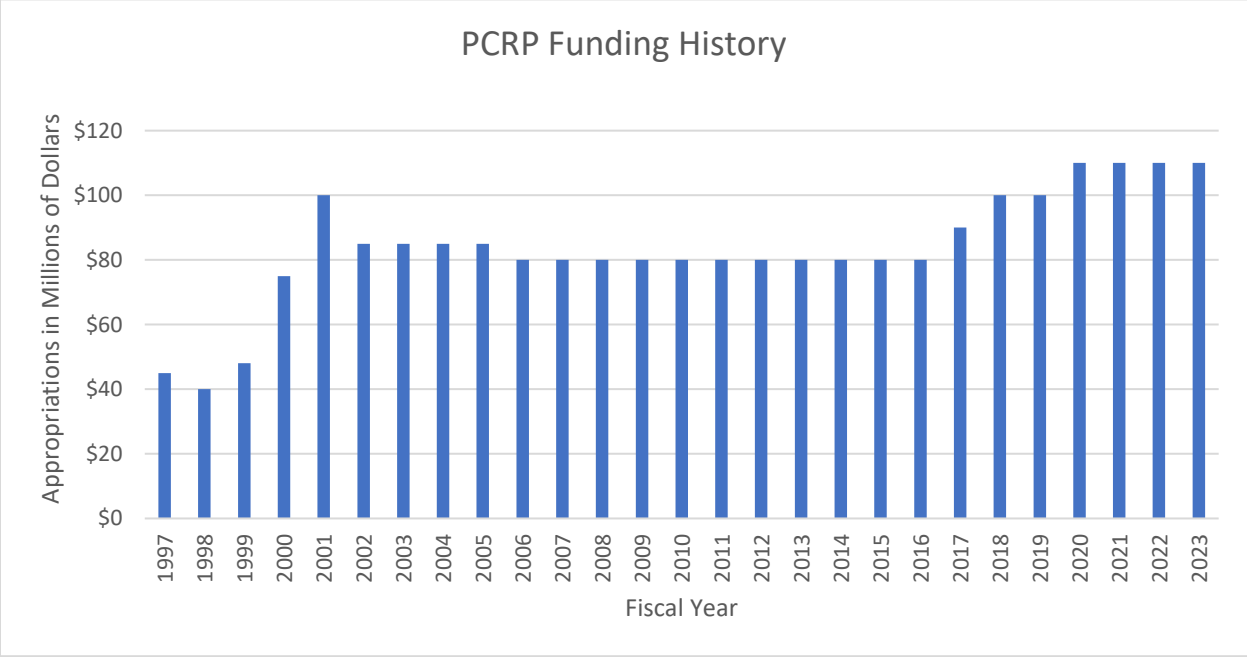
The two-tiered review process was designed to balance the most meritorious science across many disciplines and offer the greatest promise for fulfilling programmatic goals, providing greater flexibility to fund proposals that may not have scored as well in peer review but that addressed a program priority. 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 that are 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. The consideration of 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 on a continuing basis, 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.[iii] 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; thus, 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 for the release of 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 a total of $2.26 billion in congressional appropriations, and 3,676 proposals have been funded through FY2021.[iv] 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.



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.[v] Between 2010 and 2019, over 211,000 active duty service members and beneficiaries were treated for prostate cancer in the military health system.[vi]

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.[vii] 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. [viii]

While there is clearly a connection between prostate cancer and exposures in previous wars, 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 not only developing more effective therapeutics, but has also led to the development of a new diagnostic tool.[ix] By improving diagnosis to reduce over treatment and accurately distinguish life-threatening disease from indolent tumors,[x] the PCRP may have its greatest impact on active duty servicemen who can be confidently monitored through active surveillance,[xi] rather than compromising their service to undergo treatment.

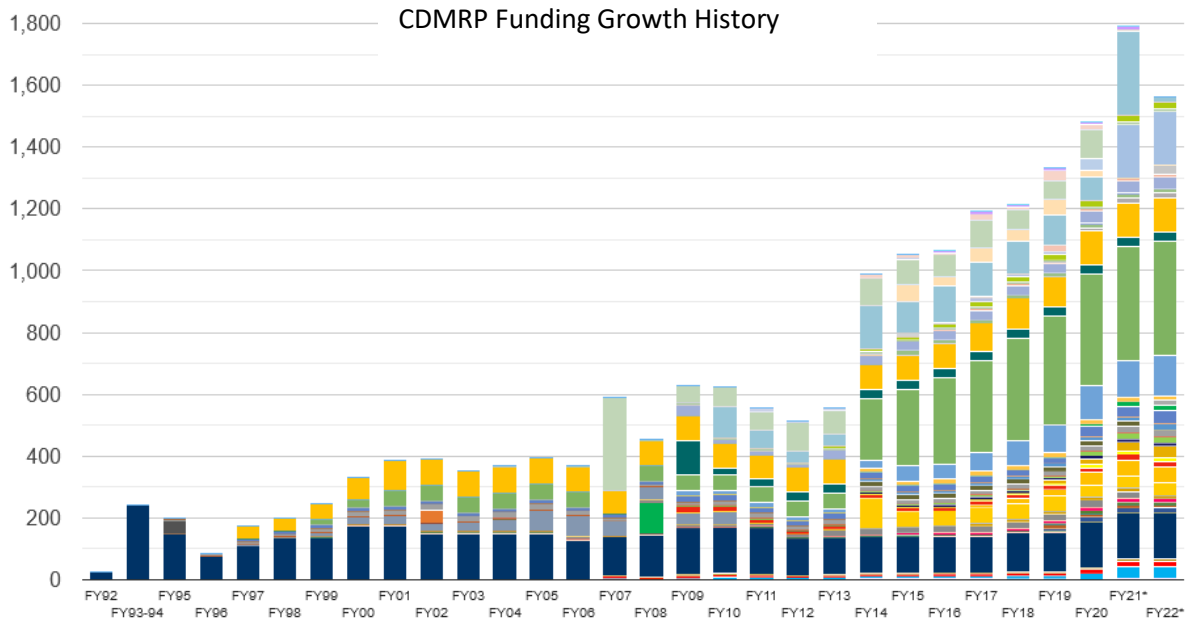
The PCRP program also has an important role in "readiness" – which is the concept of the day-to-day condition of the armed forces' military personnel (both mental and physical condition)

and their equipment. Troops and practitioners must be both mentally and physically fit for duty. A cancer diagnosis in the family 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' 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 in general can (and occasionally do) vary from year to year, in most cases 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 unique aspects of the CDMRP program. Beyond the standard protocols in place to ensure that research proposals are not inappropriately funded by both

agencies, staff at both the PCRP and the NIH communicate regularly to discuss proposals and funding decision 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 were again able to increase the program to $110 million and hold that funding level through FY2023. We hope to increase funding to $120 million FY2024. The Senate Appropriations Committee usually recommends a funding level lower than the House initially and ultimately recedes to the House funding level. In FY2023, the Senate recommended $75 million for the PCRP program.

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 between 50 and 150 Members of Congress each year, with 150 Members of Congress signing on for FY 2022. Senators Robert Menendez (D-NJ) and Mike Crapo (R-ID) lead the Senate letter, which attracted 22 Senators in 2022. This public support, coupled with internal requests to the Appropriations Committee from its members, is critical to building champions for the PCRP.

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[i] https://cdmrp.army.mil/about/fundinghistory
[ii] https://www.ncbi.nlm.nih.gov/books/NBK233669/
[iii] https://cdmrp.army.mil/about/fundingprocess
[iv] https://cdmrp.army.mil/pcrp/default
[v] https://cdmrp.army.mil/pcrp/default
[vi] https://cdmrp.health.mil/pcrp/pbks/pcrppbk2022.pdf
[vii] https://pubmed.ncbi.nlm.nih.gov/23670242/
[viii] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2780333/
[ix] 2018 Prostate Cancer Research Program Book. https://cdmrp.army.mil/pcrp/pbks/pcrppbk2018.pdf
[x] http://comptroller.defense.gov/Portals/45/Documents/defbudget/fy2015/budget_justification/pdfs/09_Defense_Health_Program/DHP_PB15_Vol_I-II.pdf
[xi] Tosoian JJ, Carter HB, Lepor A et al. 2016. Active surveillance for prostate cancer: current evidence and contemporary state of practice. Nat Rev Urol. 2016 Mar 8. doi: 10.1038/nrurol.2016.45. [Epub ahead of print].

Prostate Cancer deaths are increasing

Please help us continue needed Prostate Cancer research

DEADLINE: Wednesday, March __, 2023

Dear Colleague:

Please join us in writing to the House Appropriations Committee to express your support for the Prostate Cancer Research Program (PCRP) within the U.S. Department of Defense (DoD). Other than skin cancer, prostate cancer is the most common cancer in men and is the second leading cause of their cancer deaths. One in eight men will be diagnosed in their lifetime, and 3.1 million men are living with a prostate cancer diagnosis today.

An estimated 288,300 men will be diagnosed with prostate cancer in 2023 – a 15 percent increase over 2020. A more disturbing statistic is that about 34,700 men are expected to die this year from prostate cancer – over 8,000 more deaths than in 2017!

In the African-American population, the outlook is even more grim. African-American men are 73 percent more likely to develop prostate cancer than Caucasian men and more than twice as likely to die.

We can stop these trends with the help of targeted research.

The attached letter to the House Appropriations Committee requests $120 million for the PCRP in Fiscal Year (FY) 2024. This $10 million increase would be the first increase to the program since FY20.

We appreciate your support in this vital effort to save men's lives and support important scientific breakthroughs. Please contact Sarah Gilbert in Rep. Neal Dunn's office at sarah.gilbert@mail.house.gov or Jonathan Halpern in Rep. Sanford Bishop's office at Jonathan.halpern@mail.house.gov **by March ___, 2023** for more information or to sign-on.

Sincerely,

Representative Neal Dunn

Representative Sanford D. Bishop, Jr.

Congress of the United States
Washington, DC 20515

March X, 2023

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 Chairwoman McCollum and Ranking Member Calvert:

This year, over 288,000 men will be diagnosed with prostate cancer, and more than 34,700 men will likely die from this disease.[1] As you consider the Fiscal Year (FY) 2024 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,[2] there has been a recent reversal.[3] Since 2014, the incidence rate for advanced-stage prostate cancer has increased by about five percent per year. This is significant because while prostate cancer has a nearly 100 percent survival rate when caught early,[4] when the cancer has metastasized, the survival rate drops to 30 percent.[5] As more men are diagnosed with late-stage cancer, death rates are increasing. It is estimated that nearly 200 more men will die this year than in 2022 of prostate cancer,[6] which reflects an increase of almost 8,000 more deaths when compared to 2017.[7]

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

[1] https://www.cancer.org/cancer/prostate-cancer/about/key-statistics.html
[2] https://seer.cancer.gov/explorer/application.html?site=66&data_type=2&graph_type=1&compareBy=race&chk_race_3=3&chk_race_2=2&hdn_sex=2&age_range=1&advopt_precision=1&advopt_display=2
[3] https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2017/cancer-facts-and-figures-2017.pdf
[4] https://www.cancer.org/cancer/prostate-cancer/detection-diagnosis-staging/survival-rates.html
[5] Ibid.
[6] https://seer.cancer.gov/statfacts/html/prost.html
[7] https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2017/cancer-facts-and-figures-2017.pdf

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.[8]

The PCRP is both effective and military relevant. Prostate cancer is the most frequently diagnosed cancer among veteran men. Servicemembers 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.[9] 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 FY2024 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 (R-FL)

Rep. Sanford Bishop (D-GA)

[8] https://zerocancer.org/wp-content/uploads/2022/02/PCRP-Treatments-Infographic.pdf

[9] https://cdmrp.army.mil/pcrp/default

XXX XX, 2023

The Honorable Jon Tester
Chairman
Subcommittee on Defense
Senate Appropriations Committee
S-128, The Capitol
Washington, DC 20510

The Honorable Susan Collins
Vice Chairman
Subcommittee on Defense
Senate Appropriations Committee
S-146A, The Capitol
Washington, DC 20510

Dear Chairman Tester and Vice Chairman Collins:

This year, nearly 288,000 men will be diagnosed with prostate cancer, representing a 15 percent increase since 2020. It is estimated that more than 34,700 men will die from this disease in 2023. As you consider the Fiscal Year (FY) 2024 Defense Appropriations Act, we respectfully request that the Committee provide robust funding for the Department of Defense's (DOD's) Prostate Cancer Research Program (PCRP).

After almost two decades of falling, prostate cancer deaths are now on the rise. When caught early, prostate cancer has a nearly one hundred percent five-year survival rate. When it has metastasized the survival rate drops to 30 percent. It is estimated that nearly 200 more men will die this year than in 2022 of prostate cancer. And that number reflects an increase of 8,000 more deaths when compared to 2017. Now more than ever we need research to better treat and diagnose prostate cancer.

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 FY2024 appropriation for CDMRP. In FY2023, Congress provided $110 million for this vital program. In FY2024, 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,

MEMBERS OF THE U.S. HOUSE OF REPRESENTATIVES WHO SIGNED THE BISHOP-DUNN FY23

PROSTATE CANCER RESEARCH PROGRAM (PCRP) DEAR COLLEAGUE APPROPRIATIONS LETTER IN 2022

Alma Adams	NC 12
Colin Allred	TX 32
Jake Auchincloss	MA 4
Nanette Barragan	CA 44
Karen Bass	CA 37
Joyce Beatty	OH 3
Ami Bera	CA 7
Donald Beyer	VA 8
Gus Bilirakis	FL 12
Sanford Bishop	GA 2
Earl Blumenauer	OR 3
Lisa Blunt Rochester	DE 1
Suzanne Bonamici	OR 1
Jamaal Bowman	NY 16
Brendan Boyle	PA 2
Anthony Brown	MD 4
Julia Brownley	CA 26
G K Butterfield	NC 1
Andre Carson	IN 7
Troy Carter	LA 2
Sean Casten	IL 6
Joaquin Castro	TX 20
Steve Chabot	OH 1
Sheila Cherfilus-McCormick	FL 20
David Cicilline	RI 1
Gerry Connolly	VA 11
Lou Correa	CA 46
Angie Craig	MN 2
Jason Crow	CO 6
Sharice Davids	KS 3
Danny Davis	IL 7
Madeleine Dean	PA 4
Pete DeFazio	OR 4
Antonio Delgado	NY 19
Mark DeSaulnier	CA 11
Debbie Dingell	MI 12
Lloyd Doggett	TX 35
Mike Doyle	PA 18
Neal Dunn	FL 2
Anna Eshoo	CA 18

Dwight Evans	PA 3
Brian Fitzpatrick	PA 1
Lizzie Fletcher	TX 7
Bill Foster	IL 11
Matt Gaetz	FL 1
John Garamendi	CA 3
Chuy Garcia	IL 4
Jimmy Gomez	CA 34
Vicente Gonzalez	TX 15
Jenniffer Gonzalez Colon	PR 1
Josh Gottheimer	NJ 5
Al Green	TX 9
Raul Grijalva	AZ 3
Michael Guest	MS 3
Jahana Hayes	CT 5
Brian Higgins	NY 26
Jim Himes	CT 4
Eleanor Holmes-Norton	DC 1
Sara Jacobs	CA 53
Pramila Jayapal	WA 7
Hank Johnson	GA 4
Mondaire Jones	NY 17
John Katko	NY 24
Bill Keating	MA 9
Mike Kelly	PA 16
Andy Kim	NJ 3
Ron Kind	WI 3
Raja Krishnamoorthi	IL 8
Doug LaMalfa	CA 1
Conor Lamb	PA 17
Jim Langevin	RI 2
Rick Larsen	WA 2
John Larson	CT 1
Alfred Lawson	FL 5
Barbara Lee	CA 13
Teresa Leger-Fernandez	NM 3
Mike Levin	CA 49
Ted Lieu	CA 33
Zoe Lofgren	CA 19
Elaine Luria	VA 2
Stephen Lynch	MA 8

Nicole Malliotakis	NY 11
Sean Patrick Maloney	NY 18
Doris Matsui	CA 6
Lucy McBath	GA 6
Michael McCaul	TX 10
Donald McEachin	VA 4
Jim McGovern	MA 2
Jerry McNerney	CA 9
Dan Meuser	PA 9
Mariannette Miller-Meeks	IA 2
Alex Mooney	WV 2
Gwen Moore	WI 4
Joseph Morelle	NY 25
Seth Moulton	MA 6
Greg Murphy	NC 3
Jerrold Nadler	NY 10
Richard Neal	MA 1
Marie Newman	IL 3
Tom O'Halleran	AZ 1
Ilhan Omar	MN 5
Jimmy Panetta	CA 20
Chris Pappas	NH 1
Donald Payne	NJ 10
Scott Peters	CA 52
Chellie Pingree	ME 1
Bill Posey	FL 8
Ayanna Pressley	MA 7
Jamie Raskin	MD 8
Kathleen Rice	NY 4
Raul Ruiz	CA 36
Bobby Rush	IL 1
Gregorio Sablan	MP 1
Maria Elvira Salazar	FL 27
Linda Sanchez	CA 38
Mary Scanlon	PA 5
Janice Schakowsky	IL 9
Bradley Schneider	IL 10
Kim Schrier	WA 8
David Scott	GA 13
Terri Sewell	AL 7
Elissa Slotkin	MI 8

Chris Smith	NJ 4
Darren Soto	FL 9
Abigail Spanberger	VA 7
Jackie Speier	CA 14
Pete Stauber	MN 8
Haley Stevens	MI 11
Tom Suozzi	NY 3
Eric Swalwell	CA 15
Mark Takano	CA 41
Mike Thompson	CA 5
Bennie Thompson	MS 2
William Timmons	SC 4
Rashida Tlaib	MI 13
Lori Trahan	MA 3
Jeff Van Drew	NJ 2
Juan Vargas	CA 51
Marc Veasey	TX 33
Nydia Velazquez	NY 7
Jackie Walorski	IN 2
Peter Welch	VT 1
Bruce Westerman	AR 4
Susan Wild	PA 7
Roger Williams	TX 25
Nikema Williams	GA 5
Joe Wilson	SC 2
John Yarmuth	KY 3

MEMBERS OF THE U.S. SENATE WHO SIGNED THE MENENDEZ-CRAPO FY23

PROSTATE CANCER RESEARCH PROGRAM (PCRP) DEAR COLLEAGUE APPROPRIATIONS LETTER IN 2022

Mark Kelly	Arizona
Kyrsten Sinema	Arizona
Dianne Feinstein	California
Alex Padilla	California
Michael Bennet	Colorado
Richard Blumenthal	Connecticut
Mike Crapo	Idaho
Jim Risch	Idaho
Tammy Duckworth	Illinois
Roger Marshall	Kansas
Susan Collins	Maine
Angus King	Maine
Chris Van Hollen	Maryland
Elizabeth Warren	Massachusetts
Gary Peters	Michigan
Debbie Stabenow	Michigan
Jacky Rosen	Nevada
Cory Booker	New Jersey
Bob Menendez	New Jersey
Ben Ray Lujan	New Mexico
Ronald Wyden	Oregon
Maria Cantwell	Washington

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; however, the CDC's Division of Cancer Prevention and Control supports various prostate cancer activities. The National Comprehensive Cancer Control Program includes support for state health departments' prostate cancer activities within their state prostate cancer programs. And the CDC works at a national level conducting applied research and surveillance and communication and outreach initiatives.

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

How can we improve things?

ZERO is supporting a funding level of **$20 million** in Fiscal Year 2024 for the CDC's prostate cancer activities to increase outreach, education and resources for men at high risk of developing prostate cancer, including African-American men. This funding level would be an increase of $4.8 million over the FY23 level of $15.2 million, which recognizes the agency's commitment to outreach and education for high-risk men. With additional monies in FY24, the CDC can fund prostate cancer support groups and increase outreach and education to help high-risk men make decisions that best meet their values and preferences.

We are requesting that the following language be included in the report accompanying the FY24 Labor-HHS-Education Appropriations Act:

> *Prostate Cancer.— The Committee is aware of the continued rise in prostate cancer deaths and supports the CDC's work to increase public awareness of prostate cancer risks, screening and treatment in high-risk men. The Committee provides $20,000,000 for the CDC's prostate cancer activities, including $7,000,000 for initiatives to increase outreach and education among high-risk men, especially African-American men.*

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 Additional CDC Prostate Cancer Outreach to High-Risk Men – The FY23 Labor-HHS-Education appropriations bill included $15.2M in funding for CDC prostate cancer activities, an increase of $1M that recognized the agency's commitment to conduct outreach and education for high-risk men. We would like Congress to increase the prostate cancer activities line to a total of $20M, to support outreach to African-American and other high-risk men. We ask that Members include the following Labor-HHS report language in their individual request letters to the Appropriations Committee:

Prostate Cancer — The Committee is aware of the continued rise in prostate cancer deaths and supports the CDC's work to increase public awareness of prostate cancer risks, screening, and treatment in high-risk men. The Committee provides $20,000,000 for the CDC's prostate cancer activities, including $7,000,000 for initiatives to increase outreach and education among high-risk men, especially African-American men.

Background

The Centers for Disease Control and Prevention (CDC), an agency within the Department of Health and Human Services (HHS), is the nation's health protection agency, working to safeguard Americans from health and safety threats, both foreign and domestic. It is responsible for providing credible information to enhance 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). Aside from COVID-related expenditures, the CDC provides about $7 billion per year in grants to state, local, municipal, tribal, and foreign governments, as well as to academic and non-profit 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. These objectives are supported by 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. This has resulted in effective interventions that protect people from scores of public health threats each year.

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 is used to support: 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 the body of knowledge on 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 materials on prostate cancer, released both in print and web formats. These materials require consistent evidence-based updating and are widely used by provider and advocacy groups to promote informed decision-making and open discussion between patients and providers. CDC, working with ZERO and other groups, launched "Nathan" an interactive avatar simulation decision aid focusing on prostate cancer screening and treatment decisions. Nathan helps providers, patients, and caregivers make more informed choices regarding prostate cancer screening and treatment decisions.

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 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–present), including in: Arizona, Massachusetts, Michigan, New Mexico, Ohio, Pennsylvania, South Carolina, South Dakota, Missouri, Tennessee, Virginia, Washington, Wisconsin, and Wyoming. Some examples of prostate cancer-related activities that grantees have conducted include:

- Development and implementation of community- and faith-based organization prostate cancer awareness campaigns.
- Creation of prostate health media campaign protocols and procedures
- Production of professional educational videoconference lectures, podcasts, and webinars.
- Implementation of American Cancer Society (ACS) physician practice strategy encouraging physicians to educate patients about screening guidelines and preventive screening benefits using "Put Prevention into Practice" model.
- Providing professional continuing education and peer-to-peer evidence-based trainings.
- Establishment of partnerships and collaborations within communities and targeted organizations to provide professional medical education for shared decision-making, public awareness campaigns on informed decision-making, evaluation, and surveillance.

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."

CDC prostate cancer funding and the White House Cancer Moonshot Initiative

In 2022, the Biden Administration reignited the Cancer Moonshot, an effort to "end cancer as we know it" with a new national goal: "to cut the death rate from cancer by at least 50% over the next 25 years, and improve the experience of people and their families living with and surviving cancer. The FY23 CDC appropriations made a small investment in this effort by increasing prostate cancer funding within the National Center for Chronic Disease Prevention and Health Promotion.

In a prostate cancer roundtable held as part of the Cancer Moonshot Initiative in late 2022, HHS Secretary Becerra committed to exploring the role of the CDC in prostate cancer education and outreach and the investment required to be successful in that effort.

Additional Prostate Cancer Outreach

ZERO has developed a strong working relationship with the CDC, and through the course of that engagement ZERO has grown to better understand the work that could be done if the CDC had funding dedicated to prostate cancer outreach. In FY2020 and FY2021, we were able to secure an additional $1 million 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 provide support to appropriate governmental and non-governmental organizations to develop and disseminate additional information about prostate cancer, including:

- The creation and dissemination of Nathan, an interactive avatar simulation decision aid to men at high risk for prostate cancer, including African-Americans, and their partners;
- Creating additional prostate cancer resources for men and their providers to complement the avatar simulation; and
- Funding partners to create decision aids and easy to understand one-pagers about the risks and benefits of prostate cancer screening, understanding their risk for prostate cancer, and the risks and benefits of prostate cancer treatment options.

We hope to increase funding to $20 million in FY2024. This investment will allow CDC to have an increased and broader impact in at-risk communities and fund support groups for men with prostate cancer and survivors of prostate cancer as their target audience. These groups would help survivors feel more hopeful, connected, and better cope with side effects of treatment. These groups would also help connect them to resources. Support groups could be coordinated through organizations focused on public health and may be in person, by phone, and/or online (e.g., webinars, social media, or moderated discussion groups).

The Prostate-Specific Antigen Screening for High-risk Insured Men Act of 2023

What is the PSA Screening for HIM Act?

The PSA Screening for High-risk Insured Men Act (H.R. ____), introduced by Representative Larry Bucshon (R-IN), would require health insurance providers to offer PSA screenings without any cost- sharing requirements (copays, deductibles, or coinsurance) for African-American men or men with a family history of prostate cancer between the ages of 55 and 69.

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 below 30%.

Why is this bill so important?

Studies have shown that even the smallest amount in cost-sharing is a barrier to access for many. Too many men in vulnerable groups delay getting tested for prostate cancer, which decreases their odds for survival. H.R. ____ 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 288,000+ men in America being diagnosed with prostate cancer in 2023 alone, 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?

Cosponsor H.R. _____ today and help improve early detection rates for prostate cancer!

For information about cosponsoring, please contact Rep. Bucshon's office at **Emily.Mace@mail.house.gov**

To learn more about ZERO's advocacy efforts please contact **Ali@zerocancer.org**

#ZEROStrong

Overview of the PSA for HIM Act

Ask: PSA 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. Reps. Larry Bucshon, MD (R-IN) and _____ (D-__) introduced the PSA for HIM Act (H.R._____) 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. We ask for your cosponsorship of H.R. _____.

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 in order to aid primary care professionals, patients, and families in deciding whether a particular preventive service is the right choice for the 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
A	The USPSTF recommends the service. There is high certainty that the net benefit is substantial.	Offer or provide this service.
B	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.
C	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.
I	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 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. In some cases, insurance companies 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, co-insurance, 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.[i] The result of this change has been that those screening tools receiving an “A” or “B” rating from USPSTF have benefited from increased access, while other screening tools have experienced a marked decrease in access coupled with 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 there were no medical oncologists consulted in the process.

The USPSTF has come under more scrutiny 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.

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 age 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 (203.5 vs 121.9 cases per 100,000 men). African American men are also more than twice as likely as white men to die of prostate cancer (44.1 vs 19.1 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 (ie, 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."

In their 2018 annual report to Congress, the USPSTF issued a report to Congress that reiterated those data gaps.

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 in the years since 2012. In 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.[ii] In fact, while prior to 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.[iii]

The PSA for HIM Act:

Previously introduced in the 116th and 117th Congresses, Representatives Larry Bucshon, MD (R-IN) and _____ (D-__) have introduced legislation that 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 alterati0ns 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 access for 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 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 American and men with a family history.
- Even if we as a nation were willing to wait 20 years and there were researchers 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.

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[i] 42 U.S.C. § 300GG-13 (https://www.gpo.gov/fdsys/pkg/USCODE-2010-title42/pdf/USCODE-2010-title42-chap6A-subchapXXV-partA-subpartii-sec300gg-13.pdf)

[ii] Bryant AK, Lee KM, Alba PR, et al. Association of Prostate-Specific Antigen Screening Rates With Subsequent Metastatic Prostate Cancer Incidence at US Veterans Health Administration Facilities. JAMA Oncol. 2022;8(12):1747–1755. doi:10.1001/jamaoncol.2022.4319

[iii] Kim, I.E., Kim, D.D., Kim, S. et al. Changes in prostate cancer survival among insured patients in relation to USPSTF screening recommendations. BMC Urol 22, 91 (2022). https://doi.org/10.1186/s12894-022-01045-0

PSA 4 HIM Cosponsors in the 117th Congress
Rep. Rush, Bobby [D-IL-1]*
Rep. Bucshon, Larry [R-IN-8]*
Rep. Axne, Cynthia [D-IA-3]
Rep. Babin, Brian [R-TX-36]
Rep. Bishop, Sanford D., Jr. [D-GA-2]
Rep. Blunt Rochester, Lisa [D-DE-At Large]
Rep. Butterfield, G. K. [D-NC-1]
Rep. Carson, Andre [D-IN-7]
Rep. Carter, Troy [D-LA-2]
Rep. Chu, Judy [D-CA-27]
Rep. Cohen, Steve [D-TN-9]
Rep. Correa, J. Luis [D-CA-46]
Rep. Davids, Sharice [D-KS-3]
Rep. Fitzpatrick, Brian K. [R-PA-1]
Rep. Gallego, Ruben [D-AZ-7]
Rep. Gomez, Jimmy [D-CA-34]
Rep. Gonzalez, Anthony [R-OH-16]
Rep. Grijalva, Raúl M. [D-AZ-3]
Rep. Hayes, Jahana [D-CT-5]
Rep. Jones, Mondaire [D-NY-17]
Rep. Lee, Barbara [D-CA-13]
Rep. Matsui, Doris O. [D-CA-6]
Rep. Mfume, Kweisi [D-MD-7]
Rep. Moore, Gwen [D-WI-4]
Del. Norton, Eleanor Holmes [D-DC-At Large]
Rep. Payne, Donald M., Jr. [D-NJ-10]
Rep. Pence, Greg [R-IN-6]
Rep. Ryan, Tim [D-OH-13]
Rep. Schneider, Bradley Scott [D-IL-10]
Rep. Scott, David [D-GA-13]
Rep. Sires, Albio [D-NJ-8]
Rep. Soto, Darren [D-FL-9]
Rep. Stansbury, Melanie Ann [D-NM-1]
Rep. Thompson, Bennie G. [D-MS-2]
Rep. Tlaib, Rashida [D-MI-13]
Rep. Tonko, Paul [D-NY-20]
Rep. Van Drew, Jefferson [R-NJ-2]
Rep. Veasey, Marc A. [D-TX-33]
Rep. Williams, Roger [R-TX-25]

ZERO PROSTATE CANCER

The Prostate Cancer Community Assistance, Research and Education Act (PC-CARE Act)

What will this bill do?

The Prostate Cancer Community Assistance, Research and Education Act, or the PC- CARE Act, led by Representative Greg Murphy (NC-03), would establish a Prostate Cancer Coordinating Committee to monitor, coordinate, and evaluate the activities of Federal prostate cancer research programs. This bill was introduced in 2022 as H.R. 7750 with former Congressman Bobby Rush (D-IL), and is currently awaiting re-introduction in the 118th Congress.

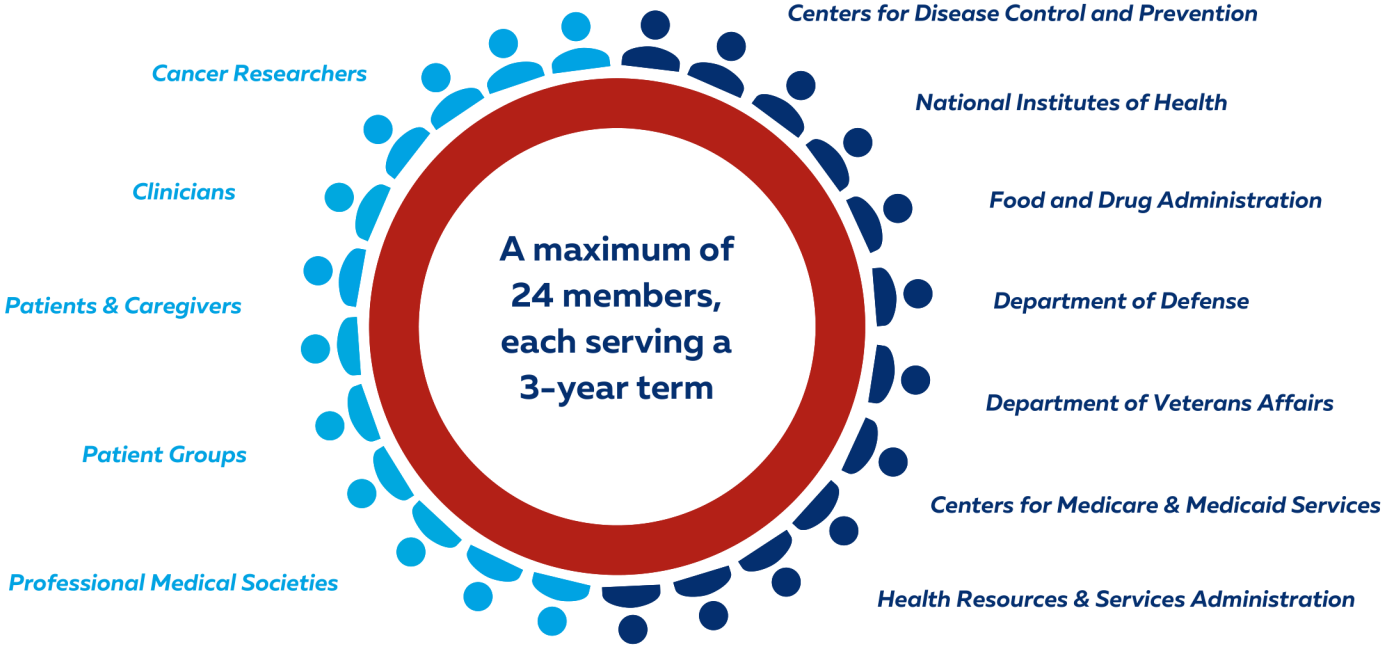
Why is this bill important?

A broad range of Federal agencies support prostate cancer research, including the NIH, CDC, DoD and VA. To efficiently steward these federal investments and move toward a cure as quickly as possible, it is vital to ensure that the various federal programs are coordinated to best fill research gaps, delineate research priorities, and prioritize the most critical work. This bill will require Federal agencies participating in prostate cancer research to meet regularly, and with the largest private funders of prostate cancer research, to chart a path to fight against this disease.

Why prostate cancer?

Prostate cancer is the second leading cause of cancer death among American men and is the most commonly diagnosed; 1 in 8 American men will be diagnosed with prostate cancer during their lifetime. The American Cancer Society estimates that over 288,000 men will be told they have prostate cancer in 2023. Currently, over 3.1 million American men are living with the disease – more than the population of Chicago, America's third-largest city.

Who will be on this committee?



For information about cosponsoring, please contact Rep. Greg Murphy's office at McLean.Piner@mail.house.gov

Overview of the PC-CARE Act

Ask: The Prostate Cancer Community Assistance, Research and Education (PC-CARE) Act – Rep. Greg Murphy (R-NC) will soon introduce the PC-CARE Act to establish a Prostate Cancer Coordinating Committee to monitor, coordinate, and evaluate the activities of Federal prostate cancer research programs. This bill would ensure that federal agencies – including the NIH, DoD, CDC, VA, and others – are meeting regularly to discuss priorities in prostate cancer research and align their work with private funders in order to maximize value and move more quickly toward a cure. We ask for your support and cosponsorship of the PC-CARE Act as soon as it is introduced.

Background:

There are dozens of offices and agencies across the federal government involved in prostate cancer care, treatment, and research. Many important formal partnerships and informal networks exist to link the disparate federal agencies with each other and with the prostate cancer community. However, our community could benefit significantly from a formalized structure to ensure that the major funders of research, both governmental and private, and policy writers are informed by each other's activities and by the patient community. Many other disease groups, including Alzheimer's, muscular dystrophy, breast cancer, HIV/AIDS, autoimmune diseases, arthritis, tick-borne diseases, asthma, sickle cell disease, and autism, have had their coordination aided by federal leadership to convene and organize the various entities involved in their research and treatment policies. We believe this approach could be beneficial for the prostate cancer community as well.

Prostate Cancer Relevant Organizations:

The federal agencies most commonly engaged in prostate cancer research and research-informed policy include:

National Institutes of Health (NIH). The NIH provides over $47 billion in biomedical research support annually to academic and industry partners across the country. Within the NIH, the National Cancer Institute (NCI) is responsible for the lion's share of the $295 million in extramural prostate cancer research granted out each year by the NIH. The National Institute for Biomedical Imaging and Bioengineering (NIBIB) and the National institute on Minority

Health and Health Disparities (NIMHD) also have important contributions to prostate cancer research. Additionally, the NIH Clinical Center conducts intramural prostate cancer research.

Department of Defense (DoD). The DoD's Congressionally Directed Medical Research Program (CDMRP) provides $110 million in extramural research grants to academic and industry investigators. The DoD's military treatment facilities, including the Walter Reed Prostate Cancer Center of Excellence, provide screening and care to active-duty service members diagnosed with prostate cancer. The Defense Health Agency (DHA) makes decisions about Tricare's coverage of prostate cancer treatment for active-duty service members, their dependents, and retirees.

Veterans Administration (VA). The VA's Veterans Health Administration provides screening and treatment to veterans diagnosed with prostate cancer at clinics and hospitals across the VA's national system, including about 15,000 each year who are diagnosed with prostate cancer. The VA also conducts intramural research with its academic partners on prostate cancer.

Food and Drug Administration (FDA). The FDA is responsible for reviewing and approving drugs, biologics, and medical devices for medical use in the United States. The agency plays a significant role in moving research breakthroughs to bedside treatments for prostate cancer.

Centers for Medicare and Medicaid Services (CMS). CMS sets prostate cancer screening and treatment reimbursement rates for Medicare and Medicaid, the government health insurance programs for older, low-income, and disabled Americans. The agency also makes determinations about what prostate cancer services will or will not be covered and under what circumstances those services can be offered. CMS sets the tone for how private payers engage with providers, and private insurers are greatly influenced by CMS rates and coverage decisions.

Health Resources and Services Administration (HRSA). HRSA's oversees the Health Center Program, a national network of health centers that provide comprehensive primary health care services to more than 30 million people nationwide, regardless of a patients' ability to pay. This year, HRSA is doubling its investment in cancer screening at health centers by partnering with NCI-designated cancer centers to facilitate access to screening and early diagnosis. HRSA's screening decisions for prostate cancer are important because health centers are often the key primary care provider for low-income individuals.

Centers for Disease Control and Prevention (CDC). The CDC provides grants to states to conduct cancer education and prevention work, and many states have prostate cancer activities incorporated into those programs. The CDC also conducts outreach and education on prostate cancer at a national scale, engaging private sector partners to help disseminate their materials and information about screening and treatment options. Importantly, the CDC also conducts vital surveillance around prostate cancer and runs the nation's cancer registries.

Coordination between these agencies, and several other smaller federal offices involved in prostate cancer treatment and research, is imperative for our community to work collaboratively to eliminate prostate cancer deaths and reduce its incidence rate across the country. While some agencies do engage each other in formal and informal ways (for example the DoD includes NIH program managers on its integration panels and conducts outreach to the VA on prostate cancer incidence among veterans), these agencies do not routinely meet to discuss their priorities in prostate cancer research and treatment.

In addition to federal government organizations, private sector groups can also play a vital role in informing prostate cancer policies. Organizations representing providers and patients and funding research all have unique perspectives and relationships with federal agencies that when coordinated can provide strong, complementary and comprehensive inputs into a broader prostate cancer strategy. For example, the Prostate Cancer Foundation (PCF) is one of the largest private funders of prostate cancer research, awarding over $20 million a year in research grants. PCF hosts scientific conferences and partners individually with some federal agencies, like the VA. Additionally, the American Urological Association (AUA) is the premiere medical society for urologists with over 23,000 members. They conduct extensive continuing education for members and establish standards of care and clinical guidelines for the treatment of prostate cancer. The AUA often works with agencies like CMS on reimbursement issues. ZERO also provides a unique and complementary perspective focused on patients and with strong relationships with the DoD and CDC.

Coordinating Committee Model:

Congress, the President, and agency heads can establish federal advisory committees (which can also be called commissions, councils, task forces, or working groups) to assist congressional and executive branch policymaking and grantmaking. In some cases, federal advisory committees assist in solving complex or divisive issues while others provide ongoing advice on long-standing topics of concern. There are over 1,000 federal advisory committees. The Federal Advisory Committee Act (FACA) regulates how these committees are run, dictating requirements for meetings be open to the public, accept comments, and for committee to be accessible to the public.

Among the various federal advisory committees, there are several models for organizing. For some groups, all the members are from the private sector, while other committees have a mix of government and private sector members. In general, one agency acts as the sponsoring organization for the committee and provides administrative support for the committee's activities.

PC-CARE Act:

Representative Greg Murphy (R-NC) is a urologist with a strong interest in prostate cancer issues. He introduced the Prostate Cancer Community Assistance, Research and Education (PC-CARE) Act in the 117th Congress with Congressman Bobby Rush (D-IL), a longstanding supporter of the prostate cancer community and is planning to reintroduce the bill in the 118th. This legislation would create a prostate cancer coordinating committee administered by NIH to monitor, coordinate, and evaluate prostate cancer research programs carried out by Federal agencies. The coordinating committee would meet times a year, and in its first year would produce a report outlining federal work of the Departments of Defense, Veterans Affairs, and Health and Human Services with regard prostate cancer programs and activities. This report would also evaluate the effectiveness of the following activities and make recommendations for improvements related to:

- Research activities on the underlying causes, prevalence, treatment, and mortality of prostate cancer, including disparities for high-risk men;
- Current screening and diagnostic techniques;
- Current treatments;
- Clinical practice guidelines;
- Clinical pathways;
- Research on quality of life improvements for survivors; and,
- Outreach and education programs for providers and the public, including high-risk men.

The committee would be required to update the report every three years. The committee would be limited to 24 members on three-year rotating terms. Half of the membership would be required to be physicians, and half would be representatives from federal agencies. Federal government members would be from the NIH, CDC, HRSA, CMS, FDA, DoD, and the VA. Non-government members would include at least three of each of the following categories: patients (or their caregivers), clinicians, researchers, patient group representatives, and professional medical society representatives. These groups can overlap. For example: a physician employed by the NIH to do intramural research could fulfill the physician, NIH representative, and researcher membership requirements.

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 any 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. In this packet you will find information to help you become acquainted with the bills and programs ZERO supports and your role as an advocate at when attending meetings on Capitol Hill.

Practice telling your story. The "Share Your Story" section will help you develop an effective 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.senate.gov or www.house.gov.

Be prepared to meet with your legislator's legislative assistant. Your legislator may not 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 approximately over 120 advocates. However, there may only be one or two advocates in any district. You will not 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. You will assign a "leader" to each group to start and conclude the meeting. One group member must take notes and report back 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 whether you can elect him or her into office. 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, indicating 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 funding for the Department of Defense's program (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 – funding for the Department of Defense's Prostate Cancer Research Program, the CDC and our bills.

Stay on topic. Be careful: 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 at hand, 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. If there is a disagreement, never argue with your legislator or their staff. Listen to his/ her perspective and then present your views. You will enhance your effectiveness if you can demonstrate a willingness to participate in a friendly exchange of ideas. Record the response of your legislator to facilitate follow-up.

Conclude your meeting. Make sure 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 to them on issues surrounding prostate cancer.

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 often 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, you will begin with a quick "30-second speech." In many cases this will be all the opportunity that you have. Other times your member 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 (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 support $120 million for the DoD prostate cancer research program, $20 million for CDC prostate cancer activities and, for House members, to cosponsor two bills.

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.

ZERO PROSTATE CANCER SUMMIT

Advocacy Do's and Don'ts

Do's

- **Do** be on time. 5 minutes early *is* 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 June (jzhu@cgagroup.com) if you need help or have questions.

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** 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.

Map

Advocacy Lounge: Lutheran Church of the Reformation, Shalom Room
212 East Capitol St NE
Washington, DC 20003

Congressional Reception: House Capitol 5 (HC-5)
Enter at the south entrance to the Capitol