



Our Mission

ZERO Prostate Cancer is the leading national nonprofit with the mission to end prostate cancer and help all who are impacted. ZERO advances research, provides support, and creates solutions to achieve health equity to meet the most critical needs of our community.



Who We Are

ZERO is a 501(c)(3) philanthropic organization recognized with four out of four stars by Charity Navigator, accredited by the Better Business Bureau, with regional chapters across the country. We dedicate 85 cents of every dollar to programs for people with prostate cancer.



A MESSAGE FROM DR. ALICIA MORGANS

Dear Friends,

This past year was one of ups and downs as we learned of several advancements for people diagnosed with metastatic prostate cancer, but also that there is an increase in Black men being diagnosed with later stage prostate cancer. According to results published in the medical journal JAMA Network Open, survival rates for men with metastatic prostate cancer as a group has increased between 2008 and 2020, but minority men need further advocacy and dedicated care to achieve the same successes. We must continue to support advances for all to achieve true success for our community, and I appreciate your ongoing support as we strive to do this.

Alicia Morgans
M.D., M.P.H.
Dana-Farber Cancer
Institute
Chair – ZERO Medical
Advisory Board

Findings were presented at the 2023 ASCO Annual Meeting that are meaningful for metastatic castration-resistant prostate cancer (mCRPC). Two of these focused on patients with HRR (homologous recombination repair) gene alterations, including BRCA 1 and 2. These studies helped shine a light on outcomes for patients with HRR gene alterations as well as the emerging importance of combining androgen receptor signaling inhibitors in combination with PARP inhibitors for patients with BRCA mutations. These findings further remind us to make sure that all patients with metastatic prostate cancer undergo testing for both germline genetic mutations (what we inherit and share with family members) and somatic tumor mutations (next generation sequencing testing done on tumor tissue or circulating tumor DNA). This testing can inform families of what they need to do to understand potential risk for prostate, breast, ovarian and other cancers, and can identify potential treatment options for patients with prostate cancer to allow personalized treatment plans.

ZERO has long been committed to advancing health equity and working to eliminate health disparities and we are continuing to understand more about why these disparities exist and what we can do to eliminate them. Findings presented in October at the American Society for Radiation Oncology (ASTRO) annual meeting showed that Black prostate cancer patients were six times more likely to receive genomic testing if they were seen by a precision medicine navigator. These navigators identify patients eligible for genomic testing and then ensure those tests are completed. Unfortunately these navigators are not part of the majority of patients' healthcare plans. **Historically, Black patients have much lower genomic and genetic testing rates than white patients** – often because these tests are not discussed by their providers. Increased access to and use of these tests by Black patients is one way to reduce health disparities and improve outcomes for Black patients. Ongoing work with Black men is critical to ensuring success for all patients with prostate cancer.

As we continue to work to ensure patients and their loved ones have the critical information they need to make informed decisions, we also continue to partner with multiple accredited continuing medical education (CME) providers to educate and support healthcare providers. One of these partnerships was an Expert Think Tank on Applying the

A MESSAGE FROM DR. ALICIA MORGANS *(cont. from page 1)*

Latest Data to Individualize Treatment in Prostate Cancer. This activity included a treatment decision-making tool for providers and now features a treatment decision-making tool for patients who have advanced prostate cancer. Patients can input information about their prostate cancer diagnosis and will be provided with the opinions of five different prostate cancer experts on a recommended treatment path. I was happy to serve as one of the five clinicians providing recommendations for this project. Tools like these incorporate guideline based care into expert experience and opinion to give patients more information and insight into the management of their own care.

In closing, I wanted to remind you of all of the support resources that ZERO offers. The ZERO360 patient helpline supported an average of 142 callers each month in 2023 and provides personalized case management, assisting with everything from insurance questions to psychosocial services. The MENtor program provides one-on-one support and you can sign up to become a MENtor for someone else, or be paired with a MENtor for yourself. The ZERO Us TOO Support Groups offer peer-to-peer networking opportunities for everyone impacted by prostate cancer. More than 15 new groups were added in the fall alone! Last, but certainly not least, please consider registering now for the annual ZERO Prostate Cancer Summit, coming up in-person February 25–27, 2024 and virtually March 12–14, 2024. Please make sure you are there to lend your voice and play a part in the change that we need to see for patients and their families. Learn more about all of these programs and events at ZERO's newly designed website, www.zerocancer.org.

Thank you for being a part of the ZERO family. I am wishing you and your family good health as we begin 2024.

Dr. Alicia Morgans

2023 FDA APPROVALS IN PROSTATE CANCER

Diagnostics – Radiopharmaceutical

In May the FDA approved **flotufolastat F 18 injection (Posluma)** for positron emission tomography (PET) of prostate-specific membrane antigen (PSMA)-positive lesions in men with prostate cancer with suspected metastasis who are eligible for initial definitive therapy or with suspected recurrence based on elevated PSA level. This adds to our arsenal of PSMA PET imaging agents for prostate cancer.

Hormone Therapy

In November, the FDA approved **enzalutamide (Xtandi)** for non-metastatic castration-sensitive prostate cancer (nmCSPC) patients with biochemical recurrence at high risk for metastasis.

PARP Inhibitors

In May the FDA approved **olaparib (Lynparza)** with abiraterone and prednisone (or prednisolone) for adult patients with deleterious or suspected deleterious BRCA-mutated mCRPC, as determined by an FDA-approved companion diagnostic test.

In June the FDA approved **talazoparib (Talzenna)** with enzalutamide for homologous recombination repair (HRR) gene-mutated mCRPC.

In August the FDA approved the fixed dose combination of **niraparib and abiraterone acetate (Akeega)**, with prednisone, for adult patients with deleterious or suspected deleterious BRCA-mutated mCRPC, as determined by an FDA-approved test.

New Patient Treatment Decision Tool

ZERO partnered with Clinical Care Options to develop a Treatment Decision-Making Tool for advanced prostate cancer patients. Enter information about your prostate cancer diagnosis and see treatment path recommendations from five prostate cancer specialists. **Check the patient tool out today!**





Hakim Asadi
LMSW
Beyond Living

HOW TO CONNECT TO SUPPORT AND MENTAL WELLNESS

Men with advanced prostate cancer often face unique challenges that can impact them and their loved ones, mentally, emotionally, and physically. Coping with the diagnosis, treatment, and potential side effects can take a toll on their overall well-being. Here are some insights and ways to look out for mental health challenges in men with advanced prostate cancer:

Acknowledge Your Feelings: It's essential to recognize and accept your emotions. It's natural to experience fear, anger, sadness, anxiety, and grief. It's important to practice vulnerability, (acknowledge and address feelings) with yourself and those you love and trust.

Ask Questions and Stay Informed: Understanding your condition and the treatments available can help reduce anxiety and fear. Ask your healthcare team questions and seek reliable information from reputable sources.

Seek Support and Other Support Strategies: Identify your support system, including family, friends, and support groups. Sharing your thoughts and feelings with others can be therapeutic. Prostate cancer support groups are available, both in-person and online.

Professional Help: Consider speaking with a mental health professional, such as a therapist or counselor. They can provide strategies for managing stress, anxiety, and depression.

Maintain a Healthy Lifestyle: Eating a balanced diet, staying physically active (within your doctor's recommendations), and getting enough sleep can positively impact your mental health.

Mind-Body Techniques: Practices like meditation, yoga, and deep breathing can help reduce stress and improve mental well-being.

Advance Care Planning: It may be helpful to have discussions with your healthcare provider and loved ones about your long-term care plan. Knowing your options can provide a sense of control and peace of mind.

Stay Socially Engaged: Isolation can lead to feelings of loneliness and depression. Try to stay engaged in social activities or maintain connections with friends and family.

Stay Positive and Stay Active: Engage in activities that bring you joy – a hobby, volunteering, or spending time with loved ones. A positive attitude can make a significant difference in your mental well-being.

Regular Follow-up: Keep regular appointments with your healthcare team to monitor your condition and address any concerns promptly.



Remember, there's no one-size-fits-all approach to managing mental health challenges while dealing with advanced prostate cancer. It's important to identify and reflect on your needs to tailor your coping strategies to your specific needs.

MENTAL HEALTH AND WELLNESS RESOURCES

For more information on coping with a prostate cancer diagnosis and for more resources, go to zerocancer.org/mentalhealth.

See page 7 of this newsletter for a list of all of ZERO's support programs.



Kathie Houchens

DOES YOUR LOVED ONE HAVE ADVANCED PROSTATE CANCER?

Words of Wisdom from Our Caregiver Support Group Members

Kathie Houchens and Karen Bernatis, [A Forum for Her](#) support group leaders

Kathie and Karen co-facilitate multiple support groups for women whose partners have advanced/metastatic prostate cancer, as part of ZERO's Us TOO support group network. They reached out to more than 20 support group participants to glean their wisdom to share.



Karen Bernatis

What would you have liked to have known sooner?

"I wish I had known at the beginning that survival times are a HUGE bell curve. Things change. New treatments are coming along and we now feel like we have possibilities again. After... being told at the outset that this is not curable, then last week his PSA was undetectable for the second month! The doctor said 'You could live a long and healthy life.' It puts our minds in a whole new place. One of hope!"

"As treatment options evolve, so do the combination of various treatments. Men are beginning to go through second cycles of new drugs like Pluvicto, increasing their longevity. Being told at the beginning that there is a vibrant pipeline of possibility would have eased the panic of a stage IV diagnosis."

"I wish I had known more about how my husband's body would change and how that would affect him. The loss of muscle mass and fatigue was downplayed... I think doctors could do a better job of incorporating the mental healthcare aspect at the time of diagnosis. And include the partner or spouse as an equal. Both of us need emotional support. I was not adequately prepared for how to handle it all."

"I wish someone would have helped me find a group of other prostate cancer co-survivors in the beginning. Wives and partners are overlooked, undervalued, and overwhelmed in a strange new world of medical terms. There is little to no information about support groups like ZERO's Us TOO."

What has your experience been like in these caregiver support groups?

"I appreciate the "safe space" – this is the one group of people with whom I can freely say what I have to say. Also, to hear other women talk takes away my feelings of isolation. I am not alone!"

"We've built enough trust that we can share our innermost fears. We can laugh and cry with each other. I think it's helped my husband, too, because we learn of other treatments, side effects, etc. from each other which helps us all."

How do you practice self-care?

"I do a 10-min "over age 50 arms workout" on YouTube with an instructor who is always smiling and makes me feel good."

"Yoga helps me stay grounded in my body and in this present moment. It is a time I set aside to relax and refresh my body, mind, and spirit."

"I try to have a full body massage once a month. It is a luxury, but one I need right now."

"I attend a guided meditation class. I also try to swim or exercise regularly. I see a therapist once a month and that helps, too, as this journey is hard and I want to have the tools to be able to handle things when times get tougher."

"I nap when I feel like it. Some days the emotional energy drains me and I allow myself to rest."

To read more advice from these caregivers, see our caregiver blog series at <https://zerocancer.org/blog/forum-her-support-group-members-caregiving-self-care-and-more-part-1>. For more on resources for caregivers, visit zerocancer.org/caregivers.



Dan Peddie

MY PROSTATE CANCER CLINICAL TRIAL JOURNEY

My cancer journey started two weeks after my 65th birthday. In September 2019, I was diagnosed with aggressive metastatic prostate cancer. I had experienced back pain for 18 months but thought it was from lifelong scoliosis. My

primary care doctor – who never previously did PSA tests – ordered one, along with an MRI and CT scan. My PSA was over 1000. A confirming biopsy revealed Gleason of 4+3 = 7. A bone scan showed 80% of the body had cancer – from my knees to skull. Fortunately, the ADT plus abiraterone and prednisone therapy had immediate effect. By January, my cancer had reduced significantly – PSA was between 1 and 2. Bone pain was still the primary symptom. I had very nominal side effects from hormone therapy.

The abiraterone, and a prior diagnosis of atrial fibrillation (Afib), contributed to a brain stem stroke in January 2020 that almost took me out. I lost my motor functions in my right leg and arm, which I recovered soon with therapy. My swallowing was impacted so I had a feeding tube for 15 weeks. I lost 40 pounds through the whole process.

Abiraterone worked for 32 months until April 2022 when my PSA started to double. I was switched to enzalutamide. My PSA continued to double each month until September when I was switched to olaparib. A blood biopsy in August 2022 revealed I had a rare genetic mutation that about 5–7% of metastatic castration-resistant prostate cancer (mCRPC) patients have. After another treatment failure, my oncologist and I determined a clinical trial might be appropriate due to the obvious disease progression.

I joined a trial at the University of California San Diego in February 2023. The trial is testing the effectiveness of the

monoclonal antibody cirmtuzumab, in combination with chemo (docetaxel), in treating prostate cancer. I finished this combination phase in July. There were initial positive results of less cancer and no progression. My PSA went from 168 to 63. It has since risen to 134. While I'm on a maintenance plan – cirmtuzumab once a month – we are doing an updated PSMA scan to see why the PSA is rising aggressively now.

I've known of the benefits of clinical trials through my consulting career with medical-based clients. Now I've experienced the great level of care in this clinical trial. It has been remarkable. I recommend a trial for its comprehensive approach to care. As well, even if I don't gain benefits from the experimental drug combination, I hope to benefit future patients through participation in a trial. Someone did this for me awhile back, now I can return the favor myself.



So, after four years I've learned a lot about the science of prostate cancer but more about life. Like the Tim McGraw song says, "Live like you were dying", I have changed my perceptions of what is important, have learned to focus on gratitude for who is in my life, and gained a new perspective on suffering specific to my faith. I believe cancer has changed me for the better.

CLINICAL TRIALS IN PROSTATE CANCER

There are many clinical trials available for advanced prostate cancer patients. Oftentimes people do not participate in a clinical trial because they don't know they are eligible or that one is available. Be sure to ask your doctor if a clinical trial may be right for you.

To learn more about clinical trials, find available trials, and see our list of questions for your doctor, please visit:

<https://zerocancer.org/clinical-trials>.

BLACK MEN'S PROSTATE CANCER INITIATIVE



Kris Bennett
ZERO Director, Health Equity, Community Organizing and Engagement

ZERO is committed to eliminating disparities in prostate cancer and ending prostate cancer for all. We work to ensure that **everyone** has a fair and just opportunity to prevent, find, treat, and survive prostate cancer, regardless of race, the financial resources one has or has access to, or where one lives.

We unfortunately still see the most evident disparities in prostate cancer experienced by Black men. Black men are 1.7 times more likely to get prostate cancer, often with a more advanced stage of the disease and higher PSA number, and are 2.1 times more likely to die from prostate cancer when compared to their White counterparts.

To address this disparity and work towards achieving true health equity, ZERO has continued its work through the Black Men's Prostate Cancer Initiative (BMPCI). This initiative provides Black men, their families, and

their communities with prostate cancer education, resources, and support. The BMPCI also serves as a vehicle to help introduce communities to ZERO and give ZERO the opportunity to prove itself as a trusted partner in the fight to end prostate cancer for all.

Over the last year, the BMPCI has seen tremendous growth with the implementation of support groups, both virtually and in-person in Atlanta, that are specifically for Black men diagnosed with prostate cancer. There have also been numerous podcasts on many subjects critical to Black men and their communities. We are busy planning our next Health Equity Symposium in June 2024. We have hosted over 13 editions of our "Prostate Cancer in the Black Community" film series, which has reached nearly 1,000 people since its inception in late 2022. And finally, through our work with dedicated partners, we've seen 370+ men receive a PSA test and linked to ZERO resources as well as a medical home.

We're excited to continue our work and scale our efforts to more communities. For more information on the BMPCI and other updates, visit: <https://zerocancer.org/black-men/prostate-cancer-initiative>.

VETERANS UPDATE



Ali Manson
ZERO Vice President, Government Relations and Advocacy

A year ago, we launched our Veterans Advisory Board (VAB), composed of a highly motivated group of Veterans committed to helping find solutions for the issues Veterans with prostate cancer face. 1 in 5 Veterans are diagnosed with prostate cancer, making Veterans a group at highest risk for prostate cancer in the United States.

Over the past year, the VAB advised ZERO on a complete revamp of the [Veterans 101 pamphlet](#), helping to create a product that is unique to Veterans and helping readers understand their risk and unique options for care. VAB members have also been working hard to disseminate information about prostate cancer to other Veterans in their communities by visiting local Veteran health facilities and attending events.

On the advocacy front, President Biden signed legislation in December of 2022 establishing a clinical pathway for prostate cancer within the Veterans Health Administration, the first step to ensuring that all Veterans have access to high-quality, evidence-based prostate cancer care when they need it, no matter where they live. ZERO has been working closely with the VA to ensure that implementation of that pathway is patient-centric and comprehensive, beginning with prostate cancer education and screening, and running through advanced disease treatment and survivorship.

To help inform the process, ZERO facilitated two discussions between VA personnel and Veterans, exploring ways the VA can improve healthcare for Veterans with prostate cancer. We'll continue to work with the VA and other partners and look forward to the enactment of the pathway at the end of the year.

Go to zerocancer.org/veterans to learn more about ZERO's efforts to help Veterans with prostate cancer.

PROSTATE CANCER SUPPORT PROGRAMS

ZERO360: Comprehensive Patient Support zerocancer.org/zero360

ZERO360 helps patients navigate insurance, find financial aid resources, connect with support services, and secure access to care. To connect, call 1 (844) 244-1309.

Us TOO Support Groups zerocancer.org/supportgroups

Us TOO Support Groups offer in-person and virtual peer support, resources, and education to empower men to make informed decisions on testing, treatment, and management of side effects. Groups are also available for special interests, including: Veterans, Black Men, LGBTQIA+ Community, Caregivers, Spanish Language, Deaf Men, and others.

Online Support Services

ZERO Connect (facebook.com/groups/zeroconnect) is a Facebook-based support group for participants to share stories, ask questions, and connect. Invite-only Facebook groups also exist for **Black Men** (email info@zerocancer.org for information).

The **Inspire Online Support Community** (zero.inspire.com) connects patients, families, friends, and caregivers.

Peer Support

MENtor is a peer support network at zerocancer.org/mentor for anyone who has received a prostate cancer diagnosis. ZERO's trained, volunteer MENtors have a wealth of insights to share based on their experiences.

Educational Resources zerocancer.org/learn

ZERO offers a variety of educational events and resources for prostate cancer awareness, early detection, screening, treatment, and side effects.

DO YOU HAVE QUESTIONS ABOUT ADT?

Check out our "[Questions For Your Doctor: Hormone Therapy](#)" guide to start the conversation with your healthcare provider.



ZERO[®]
PROSTATE CANCER
SUMMIT

FEBRUARY 25–27
Washington, D.C.

Visit
zerocancer.org/summit

This publication is provided with support from:



ADVANCED PROSTATE CANCER **NEWS**



515 King Street, Suite 310
Alexandria, VA 22314
Phone: 202-463-9455
info@zerocancer.org

