

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.



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

A MESSAGE FROM DR. ALICIA MORGANS

Dear ZERO Community,

As we begin 2025, I am thrilled and grateful to share updates on our continued fight against prostate cancer. During the past year, the options for treatment have continued to expand, and there are more personalized care approaches than ever. ZERO and others continue to push for these, even as we also work to address the ongoing challenges in ensuring equal access to these advances for all communities that face the disease.

Recent data has shown encouraging progress in the treatment landscape for metastatic prostate cancer. Breakthrough developments this year include updates on studies describing the potential use of Pluvicto (177-Lutetium PSMA-617) before chemotherapy in people with PSMA-PET scan-positive metastatic castration-resistant prostate cancer (mCRPC). We also saw results from a separate trial that showed possible benefit for a second 177-Lutetium containing radioligand therapy (177-Lutetium PNT2002), giving early signs that

more radioligand treatments may be on the horizon for prostate cancer. In addition, we saw the approval of new combination therapies like talazoparib with enzalutamide that may provide a treatment option for patients with mCRPC with mutations other than BRCA, adding to the combination options of olaparib and abiraterone, and niraparib and abiraterone, that have been approved for people with BRCA mutations. These advances further emphasize the importance of widespread genetic testing in guiding personalized treatment decisions for advanced prostate cancer patients. More therapies may be on the way, with press releases towards the end of the year sharing that additional trials had positive results and may offer more options for treatment soon.

For updates over time, and for support when you need it most, I encourage you to stay connected with ZERO. The ZERO360 patient support helpline reached a milestone this year in connecting patients to over \$9 million in financial debt relief and resources since the program launched in 2016. Our peer support programs continue to grow and connect those impacted by prostate cancer to support from others affected by the disease. The MENtor one-to-one peer support program has grown by more than 25% since last year, and the number of support groups offered nationwide both in person and virtually totals nearly 170. We are also launching new professionally moderated support groups to expand the ways in which we can reach those who want to connect. You do not have to face prostate cancer alone.

As I wrap up, I want to highlight our advocacy work in Washington, D.C. for the annual ZERO Prostate Cancer Summit February 23-25, 2025. This event brings our community to meet with their senators and representatives to remind them of the impact that prostate cancer has on the people they serve. Your voice and participation are crucial to ensure meaningful change and ongoing support for the prostate cancer community.

Wishing you and your loved ones health and hope in 2025.

Sincerely,

Dr. Alicia Morgans

Q&A WITH DR. MORGANS



What makes you feel optimistic about where we currently are in caring for people with advanced prostate cancer?



I have never been more optimistic about what lies ahead for people with prostate cancer. Therapeutic developments are coming fast and furious, and the options for patients will continue to expand. In 2025, we are likely to see data from trials offering completely novel approaches to treatment, and doctors and patients will have more choices than ever before.

How can patients ensure they're getting the standard of care?



With so many new treatments and tests to think about, using trusted information from places like ZERO will be more important than ever. Other resources, including the American Cancer Society and the Prostate Cancer Foundation, are also reliable. For people who can travel, seeing a specialist for a second opinion in a National Cancer Institute-designated Comprehensive Cancer Center can also be a way to make sure that the care you are getting makes sense.



What can patients do to ensure coordination among different specialists involved in their care?



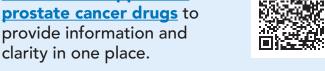
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This can be a complicated task, and may be best supported by asking your team to send copies of the notes from your visits to other people on your care team. Usually, this can be done through the electronic medical record system. You also should have access to your data and notes on patient portals that are typically part of healthcare systems. You can share these directly with your doctors by printing them out and bringing them to visits, if your doctor is not already getting notes. Trying to work with teams within a system who already practice together can also help.

PROSTATE CANCER MEDICATIONS TOOL

Do you have trouble keeping track of prostate cancer drugs or get their names confused? **ZERO developed**a list of FDA-approved

prostate cancer drugs to





What role does palliative care play in advanced prostate cancer management?



Palliative care specialists are experts in symptom management, as well as in helping people identify and maximize things in their lives that are important to them. I encourage anyone who has pain that is limiting enough to require daily use of narcotic pain medications to work with palliative care specialists if they are available. Patients will benefit from their expertise if the pain gets worse, or if other issues come up due to using narcotics (constipation, sleepiness). It is never wrong to work as aggressively to control symptoms as you do in fighting the cancer with cancer-directed treatments. A palliative care specialist is the person with that expertise, and they can be a critically important member of the care team.



What promising research directions might impact advanced prostate cancer treatment in the near future?



Newer targeted options are just around the corner, so be on the lookout for these. Some target genetic mutations, others are new radioligand treatments, and there will likely be use of the drugs that we have now in more settings, too. Treatments are also being developed for less common forms of prostate cancer, like small cell prostate cancer. I expect a lot of change in prostate cancer in 2025/2026, so we have a lot to look forward to.

CLINICAL TRIAL MYTHS VS. FACTS



MYTH: Clinical trials are only for people with no other treatment options.



FACT: Clinical trials are available for patients at all stages of cancer. Some trials improve current treatments, while others test new therapies for cancers that haven't responded to the best-known treatment. Trials are also available to improve quality of life, such as those focused on nutrition or exercise.



MYTH: Participating in a clinical trial will be too expensive and not covered by insurance.

trial participation, reducing travel needs. Some

companies will assist with travel for clinical trials

and other financial considerations.



FACT: Clinical trial sponsors cover most trial-related costs, including study treatments and additional tests. Routine care costs - the expenses for basic, everyday healthcare services - are usually covered by insurance. Many sponsors offer travel and other cost reimbursements. Discuss potential costs with the trial team and your insurance provider.



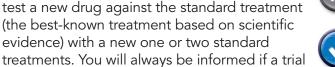
MYTH: If I participate in a clinical trial, I might receive a placebo or "sugar pill" instead of real treatment.

FACT: A placebo is a harmless, inactive

substance with no effect. Most clinical trials



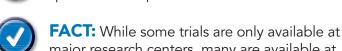
MYTH: Participating in a clinical trial means I will lose control over my treatment decisions.



FACT: Patients keep full control over their treatment decisions in clinical trials. Participation is voluntary, and you can leave the trial at any time without penalty or losing the ability to get access to standard care. Discuss any concerns with your healthcare team.



MYTH: Clinical trials are only available at large, specialized hospitals far from home.



major research centers, many are available at local hospitals and clinics. Telemedicine and local healthcare providers can also support

*Based on the Cholangiocarcinoma Foundation's resource "Myth vs. Fact: Participating in Clinical Trials," used with permission.

CLINICAL TRIALS IN PROSTATE CANCER

involves a placebo.

Be sure to ask your doctor if a clinical trial may be right for you. <u>Learn more about clinical trials and find available trials.</u>



TREATMENT DECISION TOOL

ZERO partnered with Clinical Care Options to develop a Treatment Decision-Making Tool for people with advanced prostate cancer. Enter information and see treatment path recommendations from five experts.

<u>Check the tool out and share the findings</u>

<u>with your doctor!</u>





Meredith Morgan NP, MSN, ACNP-BC Rogel Cancer Center, Univ. of Michigan Member – ZERO Medical Advisory Board

COPING WITH HORMONE THERAPY SIDE EFFECTS

Living with prostate cancer is difficult to navigate day-to-day. Add in side effects from androgen deprivation therapy (ADT), and living with advanced prostate cancer can be even more of a burden. So how does one cope with the main side effects of ADT? Let's tackle a few of the most common issues.

Hot flashes – These can occur at any time of day but seem to be most bothersome at night when they wake folks from sleep or keep them up. They also tend to be more bothersome in warmer weather with increased activity. Sleeping with a fan on can help, and I have one patient who swears by a "cooling blanket." Prescription medications, including gabapentin and venlafaxine, may decrease the frequency and intensity of hot flashes.

Fatigue – Patients often say that in the late afternoon/early evening, they have a "crash" in their energy level. The last thing you may want to do when you feel tired is exercise, but exercising really is the best thing for fatigue. Men are surprised to find that exercise gives them energy, rather than taking energy away. And never underestimate the power of an afternoon cat nap in a chair to recharge. Try not to rest too long (more than one hour or so), or you may have difficulty with sleep overnight.

Decreased bone strength – We generally recommend calcium and Vitamin D supplements and weight-bearing exercises (like walking or using an elliptical). Some patients are prescribed medications like zoledronic acid or denosumab, depending on their particular situation, to help strengthen bones. A DEXA (bone density) scan can be done to evaluate bone strength.

Weight gain/metabolic syndrome – Eating a healthy diet and exercising will help curb weight gain, but there is no denying that men may notice their abdomen getting bigger and arms/legs getting smaller on ADT.

Low libido/erectile dysfunction (ED) – There are many medications, external or internal pumps, and injections that can help with ED. Unfortunately, there is not a lot we can currently do to increase libido.

Mood swings – Men report feeling moodier – sometimes with a "shorter fuse" on ADT. Others feel sad or say they cry more easily. Some of this can be managed with coping strategies, but others may require an antidepressant.

As caregivers or loved ones of patients on ADT, it is important to not only know common side effects but acknowledge them and not minimize their effect on quality of life. Patients can find tips from other patients and personal trial and error, but it is also important to talk to your provider if prescriptions or referrals are needed to help manage 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.



Darik Pearson

MY ADVANCED PROSTATE CANCER JOURNEY

'Twas the day before Christmas 2020, the weather was mostly cloudy with some light snow in the area and Christmas spirit in the air. Little did I know that in a matter of a few hours, I would be handed a diagnosis that would change every aspect of my life as I knew it.

"So why are you here?" the oncologist said. My wife and I looked at each other bewildered..."Umm, I was hoping you could tell us..." I answered. Now, I knew I had prostate cancer by the time I reached this appointment, but no one would tell me how bad my prognosis was. I was afraid to Google too much because my mindset at this juncture was "it's not a thing 'til it's a thing."

So for the most part I was going about my daily life as I always had been. At the time of this appointment, I knew very little about the disease, the treatments involved, or what the average life expectancy was. I was completely clueless about what was coming. "Your disease is not curable but it can be managed, similar to diabetes" the oncologist stoically stated. I thought to myself, "well that doesn't sound that bad." Except, of course, diabetes doesn't typically have the same end game. Perhaps this was just my doctor's soft handling of delivering a Stage 4 Gleason 9 de novo diagnosis to a 48-year-old man in the prime of his life with two young children. To this day, I don't really know how I reacted in that moment. Numb is the only adjective that comes to mind. Little did I know that the next four years would become the greatest education in life that I would ever experience.

Years 1-3 were full of adjustments. I had to learn how to become a person undergoing cancer treatment. NOT a person surviving cancer, but surviving cancer treatment. You see, even though I recognize that it's ultimately the tumor growth that will be my end, it's the treatment prolonging that end that I needed to survive. I needed to learn how to survive life without testosterone which for me meant hourly hot flashes, unparalleled fatigue, and nausea. I needed to learn how to cope with metabolic challenges like high blood pressure, weight management, heart health, bone health, and mood control. I had to learn how to re-invent myself from the in-it-to-win-it "party guy" to the more deliberate "what can I do today to keep myself alive" guy. I learned the importance of resistance training for wellness over

vanity, food as nutrition over comfort, and mental health for survival over shame. Mind, Body, Soul; the trifecta that life force fed to me in a crash course for survival. In short, I learned how to exist in this new life and accept that this was as good as it was going to get.

I start year 5 this month and it hasn't been without its share of anxiety. I participated in my first clinical trial in July 2023 when faced with castrate resistance to hormone therapy which led to disease progression. During this time I also had 10 cycles of radiation to the most aggressive spinal tumors which seemingly shrunk those and I haven't had any significant pain in that area for quite some time.

In July 2024, I started a Phase 1 trial using bipolar androgen therapy with Sipuleucel-T. By August my PSA shot up to 272. Today, I am not without worry. My latest PSA shows rising numbers and at the time of this writing, I live every day not knowing if this is the start of the slow crawl to "game over" or if my body still has some fight left in it. It's mostly out of my hands now other than the way I live with it. I continue to treat my mind and body well and do not take a single day for granted. I practice gratitude and continue to lean into healthy habits and behaviors that keep my mindset where it needs to be to survive this disease. Hope is a powerful drug and I can only hope that my time on this earth isn't nearly over yet. I will continue to do what I need to do to be here as long as I can. I can only hope that a cure is not too far down the road. I hope.



CAREGIVER CORNER

Caregivers from around the country gathered in Chicago in October for our first annual **ZERO+One Caregiver Retreat.** This in-person event brought together 100+ prostate cancer caregivers, speakers, and wellness experts to educate and connect those who understand the unique struggles and triumphs of a cancer journey. Go to the **event webpage** to view recorded videos of caregiver and expert sessions and to **look out for details on the event in November 2025!**





Last year, members of A Forum for Her, one of ZERO's support groups for female caregivers, shared lessons learned caring for their loved ones with advanced prostate cancer. To read advice and helpful tips from these caregivers, see our caregiver blog series at <u>zerocancer.org/blog/forum-her-part-1</u>.

ZERO's newest resource is "Care for the Prostate Cancer Caregiver: Tips & Resources." This quick guide empowers caregivers with information about managing doctor's visits, communicating with their loved ones, and understanding the importance of self-care. View this guide at zerocancer.org/educational-materials/caregiver-tips-and-resources-pdf.



For more resources for caregivers, visit <u>zerocancer.org/caregivers</u>.



Pictured (L to R): Brandy Nunes, Keisha Hampton-Williams, Landi Maduro

NEW SUPPORT GROUP STARTING!

ZERO is launching a new, virtual, professionally moderated prostate cancer support group, led by ZERO Medical Advisory Board member, Alison Mayer Sachs, MSW, CSW, LSW, FAOSW.

This support group will provide evidence-based information and clinical expertise while creating a safe, structured environment for sharing experiences. The group is open to anyone impacted by prostate cancer.

Beginning February 5, 2025, the group will meet on the first and third Wednesdays of the month from 7:00 pm to 8:30 pm ET.

PROSTATE CANCER SUPPORT PROGRAMS



ZERO360: Comprehensive Patient Support <u>zerocancer.org/zero360</u>

A free, comprehensive support service where trained case managers help patients and families navigate insurance, find financial resources, and connect with emotional support services. To connect, call 1 (844) 244-1309.



Support Groups <u>zerocancer.org/supportgroups</u>

Peer-led virtual and in-person groups are available offering emotional support, resources, and education to empower those impacted by prostate cancer to make informed decisions. Groups are also available for special interests, including Veterans, Black Men, the LGBTQIA+ Community, Caregivers, Spanish Language, and Deaf Men.



MENtor Program <u>zerocancer.org/mentor</u>

ZERO's one-on-one peer support program matches trained volunteer survivors with prostate cancer patients who want to connect and get support from someone with similar experiences.



Online Support Communities

Options of online communities for patients, survivors, and caregivers to ask questions and connect include:

Inspire zero.inspire.com

ZERO Connect facebook.com/groups/zeroconnect

Black Men's/Caregiver Group facebook.com/groups/zerobmpcisupportgroup/





FEBRUARY 23–25 Washington, D.C.



Visit <u>zerocancer.org/summit</u>





ADVANCED PROSTATE CANCER VEVS



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