# Prostatepedia <sup>1</sup>expert insight + advice

## Bone + Prostate Cancer

Prostatepedia\_November <sup>2019</sup> Volume <sup>5</sup> No. <sup>3</sup>

# In this issue....

#### In this issue, we focus on the interaction of bone with prostate cancer, as well as treatment for this cancer.

In the first interview, Dr. Shore reviews the propensity of prostate cancer to bone and how that impacts treatment as well as clinical outcome. He also discusses available treatment approaches for the bone loss caused by hormonal therapy.

In the second interview, Dr Tward discusses a clinical trial he is conducting that seeks to control bone metastatic prostate cancer. In this trial, men with five or fewer bone metastases have these lesions treated with external beam radiation. In addition to the bone lesions that can be seen on scan, patients may have other bone metastases still too small to see. In this trial, those lesions are treated with Radium 223 (Xofigo). How does this trial differ from the standard treatment for men with bone metastatic prostate cancer? The standard approach would be to use hormonal therapy with or without radiation to the bone metastases. Thus, this trial tests whether Xofigo (radium-223) can replace hormonal therapy. Xofogo (radium-223) is much

better tolerated than hormonal therapy and the result would be an improvement in quality of life.

In the third interview, Dr. Denmeade discusses his clinical trial of bone marrow transplantation in prostate cancer. The thinking behind this trial is quite clever. The goal of the trial is to replace the patient's immune system with one better able to control prostate cancer. To this end, the bone marrow donor would be a female, usually a daughter. The immune system of the female donor would never have encountered prostate tissue, normal or malignant. It is hoped that this would increase the odds of an immune response to the cancer. As an added twist, testosterone levels are held low during transplantation and early engraftment to keep production of prostate antigens to a minimum. Then testosterone levels are restored and this will trigger production of prostate antigens and thus, hopefully, a clinically meaningful cancer immune response. While bone marrow transplantation is cumbersome, expensive and associated with significant side effects, if successful, this trial would be a potential game changer.

Finally, we have a short interview with Darryl Mittledorf, representing MaleCare about their new booklet on prostate cancer and African Americans.

Charles E. Myers, Jr., MD



### Contents:

P4 Neal Shore, MD Bone + Prostate Cancer

P8 Jonathan D. Tward, PhD, MD Clinical Trial: Xofigo + RT.

P14 Sam Denmeade, MD Clinical Trial: Bone Marrow Transplantation

P22 Darryl Mitteldorf: Prostate Cancer While Black

The information, products, and media advertised in *Prostatepedia* are advisory only. Individuals pictured are models and are used for illustrative purposes only. Please consult your physician for specific medical or therapeutic advice.

Copyright November 2019. Rivanna Health Publications, Inc. All rights reserved. ISSN: 2381-4020

Prostatepedia is published in Charlottesville, Virginia by Rivanna Health Publications, Inc.

### Contributors:

*Editor-in-Chief* Charles E. Myers, Jr., MD

*Publisher* Jessica Myers-Schecter

*Copyeditor* Lito Velazquez

*Proofreader* Robert M. Protz, MS

*Transcriptionist* Sarah Mason

*Designer* Verity Burgess

*Community Outreach* Corinne Halada

Sales Consultant Rod Schecter

Business Consultant Rose Sgarlat Myers, PT, PhD

*Editorial* + *Billing Offices* 274 Redwood Shores, #739 Redwood City, CA 94065 (800) 975 6238

*Administrative Offices* PO Box 655, Earlysville, VA 22936

## Neal Shore, MD Bone + Prostate Cancer



Dr. Neal D. Shore is the Medical Director for the Carolina Urologic Research Center and is a member of South Carolina's Atlantic Urology Clinics. He has conducted more than 400 clinical trials and has served on the Executive Boards of the Society of Urologic Oncology, the Society of Urologic Oncology Clinical Trials Consortium, and the Large Urology Group Practice Association.

Dr. Shore is also a board member of the Bladder Cancer Advocacy Network and serves on the editorial boards of Urology Times, UroToday, PLOS One, and the World Journal of Urology.

He spoke with *Prostatepedia* about the relationship between bone and prostate cancer.

#### What is the relationship between bone and the way prostate cancer spreads throughout the body?

Dr. Shore: Prostate cancer, more than any other cancer, spreads to bone when metastases occur. Over 90% of men who die of prostate cancer will have bone mets, and we have a lot to learn about why that is. Various factors called cytokines or chemokines make the bone microenvironment, or the bone compartment, a fertile bed for the adenocarcinoma cells of the prostate cancer.

With prostate cancer, or any other cancer that spreads to the bones, there are sequelae from that progression. The involvement of bone from prostate cancer often causes pain that requires treatment.

However, pain is not the only consequence of bone metastasis. It can also lead to fractures and bone marrow suppression. This suppression affects the production of red and white blood cells and platelets, important factors in fighting cancer cells and protecting the body from infections.

If bone metastases involve areas of the spinal cord or other adjacent neural structures, there can be nerve impingement, a difficult and dangerous complication.

We want to be vigilant in understanding how to prevent spread to the bone, how to detect bone metastases, and how to recommend therapies that prevent complications.

Is bone health impacted by some of the prostate cancer treatments that men frequently undergo?

Dr. Shore: Absolutely yes. We use the words "mainstay" or "foundational" for the role of suppressing male testosterone or what we now regularly refer to as androgen deprivation therapy (ADT). When initiated, ADT puts the cancer cells in remission in more than 95% of cases. In addition to lowering the androgen (testosterone), ADT lowers dihydrotestosterone and estrogen levels.

Because ADT greatly reduces the hormones that are responsible for maintaining bone density, we're putting the prostate cancer cells in remission, but we're also having a negative effect on the strength of the bone, or bone mineralization. Bone demineralization is more profound in men than women who have post-menopausal bone demineralization. This can lead to fragility fractures due to the bone being weakened.

Though bone demineralization can result in complications, we have strategies to counteract it. The National Osteoporosis Foundation emphasizes the importance of looking at risk factors for bone demineralization, including family history, prior fractures, sedentary lifestyle, ADT, and patient age. Some factors are even country specific.







I use the Fracture Risk Assessment Tool (FRAX) 4 nomogram to help determine a patient's risk for a fracture, especially after starting ADT.

What do we do to protect bone during treatment? Do other medications positively or negatively impact the effectiveness of prostate cancer treatments like ADT?

Dr. Shore: We have many recommendations for patients. The first is to assess their risk. We also recommend that most patients begin vitamin D and calcium supplements once they start ADT. Patients should discuss their options with a physician or learn about it online.

Regular exercise is incredibly important. There are many ongoing Phase III trials that are working to prove the importance of avoiding a sedentary lifestyle. It's rather intuitive that maintaining a reasonable exercise program throughout life has a positive impact if you are diagnosed with prostate cancer, and if you're on a drug such as an ADT, which puts you at risk for bone demineralization.

There are other side effects of ADT. Because we see loss of muscle, or sarcopenia, weight bearing exercise is also important. Bone demineralization combined with sarcopenia can lead to an increased risk of falls. If an elderly patient falls while on ADT, they run a high risk of having a fracture.

Bone fractures can impact your lifestyle, requiring further medical or even surgical intervention. These complications can add up and affect the cost of your healthcare. It is important to avoid a sedentary life, smoking, and excessive alcohol.

After getting a bone densitometry, or a dual-energy X-ray absorptiometry (DEXA) scan, you can take advantage of approved medications to help improve the bone density. One example is the monoclonal antibody Prolia (denosumab), which has been available for several years and is also approved for post-menopausal women at risk for osteoporosis. or Prolia (denosumab) can be given subcutaneously one cc or one millimeter underneath the skin, every six months. It's also approved for men with prostate cancer on ADT who are at significant risk of bone fracture.

Another option is the class of drugs known as bisphosphonates, which can be used to help improve bone density and prevent fractures.

This all sounds like good, general, healthy lifestyle advice that would decrease the risk of a variety of diseases, and not just complications of therapies.

Dr. Shore: Yes. These are all good things to do as you age, in general, or if you have the misfortune of getting a diagnosis of cancer, and particularly an aggressive cancer.

Now that many prostate cancer diagnoses can be carefully followed, the diagnosis of prostate cancer shouldn't impact lifestyle. We want to be proactive in preventing complications of therapy, whether it's ADT or other approved therapies, because they can all have a negative impact on bone.

## Jonathan D. Tward, PhD, MD Clinical Trial: Xofigo + RT.

Dr. Jonathan Tward, is a radiation oncologist at the Huntsman Cancer Institute (HCI) and an associate professor in the Department of Radiation Oncology at the University of Utah. He serves as a co-leader of the Huntsman Cancer Institute's Genitourinary Malignancy Disease Oriented Team (GUMDOT).

Dr. Tward specializes in genitourinary malignancies. His clinical expertise lies in intensity-modulated radiation therapy (IMRT), image-guided radiation therapy (IGRT), stereotactic body radiation therapy (SBRT), and low-doserate (LDR) and high-dose-rate (HDR) brachytherapy.

*Prostatepedia* spoke with him about his clinical trial combining Xofigo (radium 223 dichloride) and radiotherapy for hormone-naïve men with oligometastatic prostate cancer to bone.

#### Why did you become a doctor?

Dr. Tward: I was not the kid who wanted to be a doctor when he grew up. I started studying aerospace engineering at UCLA, but that was a time when it wasn't easy for engineers to get jobs. "We would need to see patients back every 3 months for routine follow-up visits until 2 years has elapsed."

I wanted to ensure I had a job after graduation, so I decided to explore other career opportunities.

Because I always liked biology, I volunteered in a medical research lab with the Department of Radiation Oncology at UCLA, which kicked off my interest in medicine and oncology. I was impressed with how good the physicians were at alleviating fears and their compassion for patients in such a vulnerable state. It struck me as a valuable career that would also allow me to continue pursuing my interest in science.

## What is it about patient care that you liked as opposed to laboratory science?

Dr. Tward: I enjoy meeting people. It's interesting to sit down with people from all walks of life, learn about their families, hear about what they enjoy doing, what they do for work, and what their goals are. As a physician, being able to help somebody achieve their goals is incredibly fulfilling.

#### It sounds like the basis of everything you do is the initial patient interaction, and the medicine and treating the disease come after.

Dr. Tward: I don't want to say the disease is peripheral. It's central. But at the heart of the doctor/ patient relationship, the patient has goals and a life they want to live. The disease interferes with that.

At the end of the day, it's not about treating the disease. It's about getting people where they want to be, making sure they can rest easy at night by answering their questions and alleviating their anxiety. You don't always cure the disease, and you don't always meet the patient's goals. Most of your time is spent working towards those goals. Especially with a cancer diagnosis, patients are vulnerable. They need to know that we know what we're doing, that we've seen this before, and that we can help shepherd them through this difficult process.

## What is the context behind your trial?

Dr. Tward: I meet most men with prostate cancer in the localized prostate cancer setting. Typically, they were not aware that anything was wrong before their screening test.

Once a person is diagnosed with prostate cancer, they usually start looking for information online and elsewhere, which can give them anxiety about the side effects from treatment with radiation, surgery, hormone therapies, or other systemic therapies.

Most men who have gone through prostate cancer treatment of curative intent aren't feeling sick when they have a recurrence. Because men understand that androgen deprivation therapies (ADT) or other systemic therapies will affect their quality of life, I wanted to design a trial for an effective therapy in a limited metastatic disease state that would be easier to endure than ADT.

In the Alpharadin in Symptomatic Prostate Cancer (ALSYMPCA) trial, which led to FDA approval of Xofigo (radium 223 dichloride) in men with advanced prostate cancer, additional toxicity wasn't observed in the radium group when compared against the placebo group. This doesn't mean that the radium didn't have toxicity, only that untreated patients were worse off.

In the 1910s, a commercial product called Radithor was marketed to men to increase their vitality. It was a different isotope of radium, but it was still a radioactive radium particle that would be expected to integrate with bone. Because people were ingesting large doses



of Radithor without falling apart at the seams, I suspected that giving Xofigo (radium 223 dichloride) to a perfectly healthy person would not result in anything other than transient and minimal side effects.

The trial is looking for men who previously underwent surgery or radiation to the prostate who now have developed oligometastatic disease (five or fewer tumors) in the bone only. The goal of the trial is to see if a relatively nontoxic combination of therapies could result in a durable control of the cancer so men can avoid or delay starting hormone or other systemic therapies. Focal external beam radiation is used to destroy the tumors that we can see in the scans. But, we believe that these men also have numerous microscopic tumors that we can't see on the scans. I thought that Xofigo (radium 223 dichloride) could go to all the microscopic areas and destroy these invisible threats with minimal side effects.

## What can patients expect to happen in this trial?

Dr. Tward: Patients are eligible for this particular study if they have been previously treated with either surgery or radiation therapies with curative intent. If they then developed oligometastatic disease, which is five or fewer tumors in the bone only, then they could be eligible. Men with recurrences outside of the bone, for example lymph nodes, will not be eligible to participate in this study

Xofigo (radium 223 dichloride) is given in a series of six cycles. The cycles are delivered monthly through infusion therapy. After the first cycle, the patient is mapped





and measured for radiation therapy to be delivered to the bone metastases we can see on the scans. The external beam radiation therapy is delivered before the second cycle of Xofigo (radium 223 dichloride) one month later.

After each cycle of Xofigo (radium 223 dichloride), we measure the prostate-specific antigen (PSA). After the third and sixth cycles, we repeat bone scans and other imaging studies as needed. We are also offering a companion study concurrently with this trial in which men who elect that study can also receive an Axumin (fluciclovine F 18) PET/CT scan before the first cycle, and after cycles three and six of Xofigo (radium 223 dichloride).

Xofigo (radium 223 dichloride) is considered an experimental drug in this trial because it's not FDAapproved in this context, although it is approved and routinely used in patients who have progressed after hormone therapy. The external beam radiation targeted toward the lesions visible on scans are considered standard-of-care therapy. The external beam radiations are usually given in 5 treatment sessions, every other day.

## How long do you follow them after the sixth cycle?

Dr. Tward: We follow them per protocol for two years after the sixth cycle. The primary aim of the study is to determine what proportion of patients will not need any additional systemic therapies by 15 months from the first cycle of Xofigo (radium 223 dichloride).

Do patients have to be close to your facility or only during the cycles of Xofigo (radium 223 dichloride)? Dr. Tward: Patients should plan to be here for a few days during each Xofigo (radium 223 dichloride) cycle infusion, and two weeks continuously while receiving the external beam therapy, over the course of six months. We need to see patients back every three months for routine follow-up visits until two years has elapsed.

Xofigo (radium 223 dichloride) has to be infused at the Huntsman Cancer Institute at the University of Utah, which would require travel to our facility once a month for six months. The external beam radiation therapy is also administered at our facility, which ranges from one to five treatments.

The American Cancer Society has a facility called the Hope Lodge near our cancer center, which allows patients from far away to stay for free. It's close, and it's an excellent zero-cost option.

Patients who travel from far away are also reimbursed for their travel expenses at \$0.30 per mile through the trial. We also reimburse hotel cost up to \$55 per night if they can't get into the Hope Lodge. By offering travel and lodging compensation, we are encouraging people who otherwise wouldn't have access to clinical trials to participate.

## Are there any fees associated with participating?

Dr. Tward: Patients can't be charged any fees for anything that's considered research, for example the cost of the Xofigo (radium 223 dichloride) infusions. There are no fees to participate whatsoever. However, many of the things that we do on this trial are standard-ofcare procedures, and those things are still submitted to the patient's insurer for payment. The major economic impact of participating in this trial, if you're traveling from far away, comes from not being able to work on the days you are visiting our cancer center. We try to defray costs by reimbursing hotels or travel mileage as stated earlier.

## *How difficult is it to get into the Hope Lodge?*

Dr. Tward: I am unaware of any difficulty we have had of getting somebody into the Hope Lodge. But if a patient is here to participate in the trial and they can't get into that facility, we'll reimburse a hotel cost up to \$55 per night. One has to be able to take care of themselves to stay in the Hope Lodge, and they do not accept pets. Because there's not typically an urgent need to start this therapy, we can usually arrange for patients to stay at the Hope Lodge as space becomes available.

## Is there anything else patients should know about the trial?

Dr. Tward: We've already enrolled 14 participants, which means that there are six spots left before the trial closes to enrollment. If somebody is interested in participating, I encourage them to call Brett Johnson at our clinical trials office on 801-587-4429 or email brett.johnson@hci.utah.edu to find out if they're eligible and how to get in. More information is also available at clinicaltrials.gov.

And because a patient who is on this trial can expect to feel normal during all phases of the therapy, I encourage them to bring their skis or snowboard with them.





## Sam Denmeade, MD Clinical Trial: Bone Marrow Transplantation

**Dr. Samuel Denmeade is** a professor of oncology and urology at the Johns Hopkins **University School of Medicine** and Director of Genitourinary **Oncology for the Sidney Kimmel Comprehensive Cancer Center** at Johns Hopkins. He also has appointments in the Department of Urology, Pharmacology, and Molecular Sciences and the Department of Biomolecular **Engineering. His areas of clinical** expertise include bladder cancer, kidney cancer, prostate cancer, and testicular cancer.

#### His research interests include prostate targeted drug development and design of new methods to use hormone therapy in prostate cancer.

Dr. Denmeade spoke with *Prostatepedia* about his clinical trial on sex-mismatched allogeneic bone marrow transplantation for men with metastatic castration-resistant prostate cancer.

### Why did you become a doctor?

Dr. Denmeade: I was interested in science through high school and college. I got a degree in biochemistry to do organic chemistry research, but I started thinking I wanted to do something else. I did some volunteer work at a local hospital in New York City, which showed me a way to include science in my career while also helping people. Then, I applied to medical school.

Oncology was always interesting to me. It can be satisfying to help people, but there's also an aspect of cutting-edge science going on in oncology. Those two things guided me in my career. I did my oncology fellowship at Johns Hopkins and then got a faculty position, and I've been on the faculty for 21 years now.

I started out as a laboratory investigator trying to develop new drugs for prostate cancer and taking care of patients. But in the last few years, I've become more interested in clinical research.

### Are they two different mindsets?

Dr. Denmeade: The laboratory component makes you think a lot about how you impact the disease, study the disease, and work towards ways you might treat the cancer. The clinical component allows you to test those ideas. You can move from your laboratory into the clinic. But most of the time, you're on one side of the fence or the other. In both cases, you're trying to come up with new ways to help people.

### What's the thinking behind your trial?

Dr. Denmeade: My clinical focus is prostate cancer. People think of prostate cancer primarily as a disease of older men. The median age of diagnosis is 66, but I have a lot of younger patients too.

The primary treatment we use is hormonal. Once those patients become resistant to hormonal treatment, the median survival rate is only three years.

I tell all my patients my goal is that they don't die of prostate cancer. I feel bad if they die of a heart attack, but at least I can check off the box saying, "Not on my watch." That's easier with older patients because it's an achievable goal.

But the younger patients are likely going to die of prostate cancer. While the current treatment can increase how long people live, none of the treatments we have right now are curative once the disease has escaped from the prostate gland and spread. That's true for most cancers that we take care of.







We started thinking about treatments for other types of cancer that result in a cure. One way is with a bone marrow transplant, which gives the patient a new immune system that's able to kill the cancer as if it were a foreign thing.

At first, we thought that was a crazy idea for prostate cancer. It's one treatment that's curative that's never been tried in solid cancers.

We met with bone marrow transplant specialists, and we discussed that prostate cancer is a male cancer. Females don't have a prostate gland, so their immune system has never seen a prostate gland. Maybe if we took a female's immune system and put it into a male, we could achieve a significant anticancer effect. There's some evidence in cases of leukemia and lymphoma, which are diseases treated with bone marrow transplants, that suggests transplanting female bone marrow into males achieves better results.

Another innovation started at Johns Hopkins was to develop a way to use donors whose immune systems do not have to be fully identical, but only have to be half matched. This means children, siblings, cousins, or parents can now be donors. This makes it much easier to find a donor. This also showed that you could do a bone marrow transplant for people into their 70s and the side effects were no different.

The main treatment for prostate cancer is to lower hormone levels. We also have a research program that demonstrates a positive response when you give men high doses of testosterone. Our thinking was to keep patients on low hormones which turns off prostate cancer proteins, perform a bone marrow transplant, and then give them testosterone. If we turn on all the prostate proteins with testosterone, maybe the new immune system will suddenly see the cancer that it didn't see before.

There's some evidence from leukemia/lymphoma that, even if the transplant doesn't cure the patient, treatments you give after the transplants work better with the new immune system. The immune system is able to see and get rid of injured cells better.

In doing a sex mismatched bone marrow transplant, one of the biggest hurdles is financial. We have to investigate the patient's insurance to confirm if the treatment would get paid for.

Because bone marrow transplants are now done as an outpatient procedure, it saves a lot of money, but it's still a \$150,000 treatment.

We've been successful in getting insurance approval, which includes cost for the procedures and housing. Patients usually have to stay in or near Baltimore for two months.

Because prostate cancer can grow slowly, trying to select candidates for this trial is a challenge. The median survival rate is about three years, and many patients have even shorter survival rates than that. Also, there is a mortality rate associated with bone marrow transplants. Five to 10% of patients can die from the transplant, usually from an infection.

We don't know in solid tumors what the transplant mortality rate

is; those numbers are from people with leukemia, who already have a higher risk of infection. Balancing the 5% risk of dying of the transplant against the 50% chance that you won't be alive in three years is tricky.

To date, the people that we've treated have a high amount of cancer and don't have a lot of treatment options left. Unfortunately, those are the worst patients to have a bone marrow transplant.

In the leukemia world, you want patients who have the least disease so that you have the best chance of treatment. Maybe someday we'll get there, but for now, we're taking patients who we consider not ideal because, in part, we're trying to do a proof of concept to show that we can help these patients.

#### How many patients have you treated already; and how many are you looking to enroll?

Dr. Denmeade: We've treated three patients, and we have one in screening. One of the patients we had in screening had disease progression before we could get through the screening.

We want to treat about 10, which would give us enough information to know if the treatment is viable. It would be great to cure somebody right out of the box. But a more reasonable expectation is taking men we think have a shorter lifespan and make it a longer lifespan. That's probably a more reasonable expectation. It might be a little harder because it's only a small number of patients.

The three patients we've treated all got through the transplant and their blood counts came back quickly. They're all still alive. They're on different treatments, and we're following them.

We're also trying different treatments after the transplant. One patient received radiation. Another patient received hormone treatment. The third patient received a different form of chemotherapy.

We think the rationale for this is reasonable as are the risks. But at the end of the day, until we treat more patients, it's hard to know.

It's been a tough sell to patients because you have to live in Baltimore for two months. And usually the patient's daughter is the donor. The choices would be the mother, the daughter, a sister, or a cousin. Most of these patients are older, so their mothers aren't good donors. Younger people have better bone marrow, so the ideal patient donor is a daughter. From the patients we've screened so far, two of them had daughters that were the donor, and the third had an unrelated donor.

Because you don't have to be as matched, it's also easier to find someone who's reasonably matched to you. These are called matched unrelated donors. There's a database of people who donated into the bone marrow base, so you can look for these people. One of the patients got one of those.

#### Can you give some general guidelines as to what kind of patients you're looking for and who they can contact if they think they may be a fit?

Dr. Denmeade: We've seen in leukemia studies that these approaches are safe for people into their 70s.We're ideally looking for folks in their 50s or early 60s.









One of our patients was 46. Our eligibility is broad in terms of prior treatments and disease burden, though we'd like patients who have had less treatment and who have a smaller volume of metastases. Patients must be somewhat healthy.

Even if patients don't have a donor, we could get an unrelated donor. People interested in participating can contact Connie Collins, RN on 410-955-1017 or ccolli23@jhmi. edu in my office through our new patient intake clinic coordinator.

## What can patients expect from participating in the trial?

Dr. Denmeade: After meeting with one of our prostate cancer doctors at Johns Hopkins, the patient meets with the bone marrow transplant physicians to go through what to expect during the process. If the insurance company approves the treatment, we go through some screening tests for the patient and the donor to make sure the donor doesn't have hepatitis or HIV.

We harvest the donor's bone marrow and process it for transplant. Then, the patient receives some chemotherapy and radiation before finally getting an infusion of the new bone marrow. Afterwards, the patient gets more chemotherapy to kill off cells from the new bone marrow that become immediately activated to kill normal cells. Patients come in for daily blood checks and checkups to ensure they don't have a fever or infection. Most of these procedures are done as an outpatient. Patients only come into the hospital if they get a bad infection or have other complications from the bone marrow transplant

This process continues until the patient's blood counts recover sufficiently, which means they are no longer at risk for infection. Depending on their red blood count, they may need a blood transfusion. After two months, we give them injections of testosterone. They get three injections, one per month for three months.

They can go home two months after the transplant, and we monitor them with scans going forward. They also follow up with the bone marrow team periodically.

We haven't given anybody the new immune therapy drugs like Opdivo (nivolumab) and Keytruda (pembrolizumab) yet. These drugs have not proven successful in prostate cancer, but there's some evidence that they may work better in patients after a bone marrow transplant because of the new immune system. They're not FDA-approved for prostate cancer, so it's another hurdle to get insurance companies to approve these kinds of drugs, which are expensive. We haven't quite gotten there yet, but that's where we're headed with each of these patients.

We recently got funding through a Program Project grant sponsored by the National Cancer Institute to look at using bone marrow transplants in solid tumors like prostate cancer. Again, the original inspiration for this trial is the track record of curing cancer with bone marrow transplants.

If there's even a remote chance we might cure somebody before the sun sets on my career, I'd like to know. Pp

## Darryl Mitteldorf: Prostate Cancer While Black

Mr. Darryl Mitteldorf, an oncology social worker, is the founder of Malecare (https://malecare.org/).

*Prostatepedia* spoke with him about a new booklet they produced for African American men with prostate cancer.

What are the differences in how often black men get prostate cancer versus other men?

Darryl: When we talk about black men in the United States, we mean men who have a genetic heritage from somewhere in Sub-Saharan Africa. Those men face the most disparity among all cancer types.

Prostate cancer kills African American men at 2.4 times the rate it does white men. In 2019, about 70% of black men received a higher Gleason Score than comparable white men of the same age group.

They're getting diagnosed with more virulent disease and they're dying at an extraordinarily higher rate. That's something that's not yet understood. Some researchers say it's a genetic thing. Some say it's a diet thing. Some say it's an economic and class thing, like access to healthcare.

Malecare understands that access to healthcare is just as critical to a man's health as the quality of healthcare they receive. If you can't access it, or you have access to low-quality healthcare, you're in a worse state than somebody who has access to quality care. Many people misunderstand or don't accept that concept.

A study of black men compared to white men in the military found that the disparity between positive and negative outcomes for prostate cancer disappears within a military setting. This means when you put a black man and a white man in a similar setting with access to the same quality of care, the potential for a positive outcome is comparable.

As an NIH-funded institution, Malecare has the ability to do psychosocial research, and we are conducting prominent clinical trials to understand how to disrupt that disparity. We now understand that racism is a huge barrier of access to healthcare, which is a simple concept to understand, but it's not readily accepted by doctors, patients, or society in general. "Prostate cancer kills African American men at 2.4 times the rate it does white men."

What can we do to disrupt racism, increase access to healthcare, and validate the experience of black men in the United States regarding prostate cancer, treatment, and therapies?

Darryl: We spent several years interviewing black men from urban and rural areas, different economic strata, different educational strata, single versus married, young versus old, and gay versus straight. We published our findings in "Prostate Cancer While Black," a 20-page distillation of those interviews to validate what black men are going through in the United States when they're diagnosed with prostate cancer and to give them strategies to getting past the barriers that they face regarding their healthcare.







#### Is "Prostate Cancer While Black" available in printed form for support groups who want to distribute it to their members?

Darryl: Yes, you can contact Malecare for printed copies. For large quantities, you will have to pay for the cost, but for one or two copies, we'll send it free of charge. The PDF is also available online to download and print at www.malecare.org.

#### Can you highlight a few of the key issues that you discuss in "Prostate Cancer While Black"?

Darryl: Most of what we do at Malecare is measured by a simple metric called "patient activation." What can we do that gets a patient to take action, not just to read something and go to sleep, but to read something and then feel motivated to either discuss it with their doctor or to do something different or better?

"Malecare understands access to healthcare is just as critical to a man's health as the quality of healthcare they receive"

Prostate cancer's not the only instance of black men at risk in the United States. Black men are at risk the minute they're born and until the minute they die. Prostate cancer doesn't make that better or worse. It just becomes another problem. That's what this brochure highlights.

## For more information....

Contact Malecare at 212-673-4920 or info@malecare.org

What is it like to choose a doctor as a black man? At some point, most men, no matter who they are, have to say, "I may not like this doctor, but this one knows how to fix me. I'm going to go with them." That's an important thing to validate.

What is erectile dysfunction like for a black man? There's a history of wanting less men of color in the United States from the white, dominant perspective. So, a black man hearing that a treatment will make him impotent is different than a white man hearing it.

What's it like for a black man to have a white woman show him how to inject a chemical into their penis for erectile dysfunction? There's a long history of white women abusing black men in the United States. Why isn't that brought into the doctor's office in an understanding and empathetic manner so that black men can feel comfortable discussing their treatment?

What's it like to get cancer care in a racist society? It's better in 2019 than it was in 1950, but racism still exists in all aspects of society, and men of color deal with that every day.

"Prostate Cancer While Black" says, "This is the truth of your experience. We accept your experience. Now, let's figure out how to deal with it, how you can deal with it, and how the people in your life can deal with it." 274 Redwood Shores, #739 Redwood City, CA 94065 (800) 975 6238 info@prostatepedia.net www.prostatepedia.net

## Coming Up!

*December: Diet, Exercise* + *Prostate Cancer*