

William Oh:

Hello, everyone. Welcome to our webinar tonight. Thank you for joining. My name is William Oh. I'm the Chief Medical Officer for the Prostate Cancer Foundation, and we're going to be talking tonight about a hormonal therapy. So first we want to acknowledge Sumitomo Pharma America for their support of this event, but I'll remind you that all views expressed during this webinar represent those of the speakers. So just as a reminder, Prostate Cancer Foundation was founded 30 years ago with a mission to reduce death and suffering from prostate cancer. PCF funds the most promising research in over 28 countries around the world. We have teams of scientists across disciplines and institutions that collaborate and share data, and we're trying to identify and close gaps in prostate cancer treatment implementation for diagnosed patients. What that means is we want to make sure that every person who's a candidate for a treatment is able to receive those treatments.

There's resources available for you. Obviously, we're going to cover an important topic today, but you may want to read about it afterwards. Please go to [pcf.org](http://pcf.org), sign up for updates, download guides, and view past webinars and as well as this webinar, which will be available in a short time. In addition, we have a new website called Prostate Cancer Patient Voices where you can listen to other men who've gone through diagnosis and treatment and share their experiences with you. So it's a really wonderful website. I encourage you to go to Prostate Cancer Patient Voices. Our two guests today are distinguished panelists, Dr. Alicia Morgans. She's a genital urinary medical oncologist, Medical Director of the Survivorship Program at Dana-Farber Cancer Institute and Harvard Medical School. She has studied Prostate Cancer Survivorship for many years through clinical trials, through patient reported outcomes and is doing everything to make the prostate cancer patient experience and family experiences as favorable as possible. She's also been awarded two Challenge Awards and a Creativity Award from the Prostate Cancer Foundation.

Our other panelist joining us in the second half is a prostate cancer survivor, Dr. Michael Holick. But he's also, as you can see, a very distinguished endocrinologist, Professor of Medicine at Boston University School of Medicine and the Emeritus Director of the Bone Health Clinic. There, he has seen thousands of children and adults with metabolic bone disease. He's one of the most influential physician scientists in the world. Based on his research, he has authored over 650 peer reviewed publications and over 220 review articles and book chapters. And he's going to talk about both his expertise in this space, but also his own personal experience. So let's dive right in, and I'll welcome Dr. Morgans to join me. Hi, Dr. Holick. Thank you for joining us.

Dr. Michael Holick:

My pleasure, William.

William Oh:

Could you just tell us a little bit about your personal story and then we're going to dive right into the side effects in the second half of our webinar?

Dr. Michael Holick:

So I'm Professor of Medicine at Boston University School of Medicine. I set up Endocrinology, Nutrition, Diabetes, and was chief of it back in the '80s, '90s and 2000s. I set up the Metabolic Bone Clinic because prostate cancer patients on anti-hormone therapy can have issues with bone. I got to see all the prostate cancer patients, and I got to see all of them in terms of their side effects. And now my new title is Prostate Cancer Survivor, and I'm most grateful to Dana-Farber. They've been fantastic. I mean, they

had a wonderful team that gave me lots of options as to how to deal with stage 3 Gleason score 9, and Alicia's my oncologist. And what I really appreciated about all of the oncologists and radio oncologists at Dana-Farber, they're up on the literature because that's what I always make sure to do, and Alicia's been outstanding and I've been blessed to have her.

And so for me as an endocrinologist, I've seen a lot of men with no testosterone or low testosterone, and I know the consequences. And one of the major consequences is muscle weakness, getting flabby, becoming obese, having depression, and on and on. So I decided when I had initiated my androgen deprivation therapy, my New Year's resolution when I was diagnosed back in 2021 on Christmas, my New Year's resolution for 2022 was to walk five to 10 miles a day and to increase my physical therapy weight training twice a week because you don't wake up one day with no testosterone and fat, and flabby and depressed. And so my thinking is that to prevent that from happening is you need to be aggressive, and so that I did. One of the other major complications that you've already heard about that a lot of people are asking about is hot flashes.

I have severe hot flashes up to 20 a day, and as you've heard, there's a variety of medications out there. But I went on the internet, my scientist reminded me and said, "There must be other ways," and I found what's called KÜLKUF, K-U-L-K-U-F. It's a device that when you turn it on, it goes down to 47 degrees Fahrenheit immediately on your wrist. And what happens is it sends a signal to your brain saying, "Hey, you are not high, you are cold," and it often will shut it off. I've set up now a clinical research program and inviting patients with cancer and hot flashes to participate in our clinical research program. Anemia, which often doctors don't think about very much, is a significant problem when you have no testosterone. And for me, my hematocrit went from 45 down to 36.5. That in and of itself causes severe fatigue.

So one way of dealing with it is that this past year I decided not only am I going to walk, but I'm going to start running. And so I've never run in my life and my goal is to run the Boston Marathon next year, and I'm now running typically at least 10K and up to 20 miles on the weekend, and my hematocrit came up to 39.5. So there are I think, ways of intervening that men with prostate cancer, with all of these side effects should just not accept them, but to really figure ways out to intervene to minimize them.

William Oh:

So thank you, Dr. Holick. And Alicia, can I ask you to comment on a couple of topics that Dr. Holick brought up? Let's start with the hot flashes. He showed that wristband, but what are the general things because we all know that hot flashes are very, very common? This is a type of male menopause. What do you usually counsel your patients on? What seems to help?

Dr. Alicia Morgans:

So I do think I'm very interested in the non-pharmacologic options for hot flashes, and so thank you, Dr. Holick, for mentioning that. And we've done some investigations with other devices that do put that cool pressure on the thermo receptors. So I would say most men actually end up using supportive care. So these are just things like layering, using fans and trying to figure out ways and strategies to cope. This works for some people, but not usually people who have 20 hot flashes a day or people who cannot sleep through the night because they're just flashing and flashing and flashing. I think some of the tried and true things that we have used from a pharmacologic perspective for hot flashes have been things like venlafaxine or older generation drugs in the same class like gabapentin. And these are neural directed therapies that try to reduce that signaling that may be influenced and causing some of these hot flashes, which we think are probably autonomic nervous reactions to the hormone levels being so low.

And the other thing that I have used more frequently has been oxybutynin, which has been shown in women with hot flashes who have breast cancer and are receiving hormonal therapy to actually be quite an effective therapy in reducing hot flash intensity. And oxybutynin is actually a medicine that in many cases we would think about using in men with prostate cancer because it calms down the bladder. And so if people are having a lot of bladder spasm, urgency of urination, feeling like when they've got to go, they really have got to go, this can actually help some of those symptoms and also help hot flashes.

This is a medicine we think of in the anticholinergic category, so just again, trying to work on the nerves and get them to just calm down. But I would say that there's a lot of room for research in this particular area because it is extremely bothersome and it is not an area where we have a perfect answer, and so I would say the combination of medicines and supportive management and dietary considerations like low caffeine, low alcohol, low chilies, and very hot foods can also be really important. Sometimes it takes everything you've got to try to turn these things off if they're very, very bothersome.

William Oh:

So thank you very much. Michael, you brought up the issue of fatigue, which is very common. How did you deal with the fatigue and what type of choices do patients have to deal with the tiredness that they get with hormonal therapy?

Dr. Michael Holick:

Well, first of all, I find that you're waking up almost already fatigued, and so you have to have a mindset that you need to push forward because sometimes in the morning when I get up, I just want to stay in bed, and I refuse to do that because I know that if I do that, you become fat and flabby and really inactive, and so I basically forced myself. And like I said, exercise really makes a difference. It really helps the mind and it helps the body, and I've not lost any muscle mass nor strength because of my activity of weightlifting twice a week and now running at least 10 to 20 miles a week and I think that, that's what I would encourage men to think about. They may not want to run, but walking is ideal. And if they could put on 10,000 steps a day, that's a step in the right direction, forgive the pun.

William Oh:

Yeah. No, I think that's right. And I think not everyone on this call is going to run 10 to 20 miles a day or a week, but they can walk more than they do now. And I think one of the things is, you have to do more to maintain the same level of energy you might have had before. Exercise and nutrition probably are really important. What type of nutritional recommendations do you usually give, Alicia, to your patients in terms of dealing with side effects?

Dr. Alicia Morgans:

So I usually give nutritional advice around trying to maintain heart health rather than necessarily around side effects. Though I have had some friends who are dietitians talk to people with really bad hot flashes to counsel them against some of the things that I talked about earlier. When I think about men with prostate cancer, I think of them from a holistic perspective which is that, if they didn't have prostate cancer, the most important and dangerous thing to them is their potential for heart disease and heart risk. That's the number one killer in the United States for men as they age. So I talk to people about using a heart healthy diet, which is going to be one that's low in saturated fats, low in red meats generally, maybe higher in things like vegetables, fibers.

You can have some fruits in there, but lean sources of protein, whether that's fish or even things like tofu, white meat can be really helpful. And there are some really important and interesting sources of nutrition information that are reviewed by and approved by physicians on the Prostate Cancer Foundation website, and you showed information about the guides that are up there. I would strongly suggest anyone who's really interested in lifestyle and diet information to pull through those guides because the Prostate Cancer Foundation has supported a lot of research on different foods that might be helpful, harmful, and really supporting and adding to that Mediterranean type diet that I just mentioned as a heart healthy approach.

William Oh:

Thank you.

Dr. Michael Holick:

One other comment about nutrition is that vitamin D deficiency causes severe muscle weakness, and often men with prostate cancer are probably not outside, not very active. High likelihood they're vitamin D deficient, so I had put all of my prostate cancer patients and my own personal self on a minimum of 1500 to 2000 international units a day. That can make a big difference.

William Oh:

Do they have to take calcium also, Michael?

Dr. Michael Holick:

It always makes good sense. I mean, I usually recommend two to three glasses of milk a day. It's an ideal source not only of calcium but whey protein with all the essential amino acids, so it's really a good source of nutrition. And you need that calcium and vitamin D to maintain your bone health because as you know, the androgen deprivation therapy definitely can cause osteoporosis in men, increased risk of fracture, and so I make sure that men are walking at least three to five miles a week. It helps to maintain lumbosacral spine and hip bone density, and adequate calcium vitamin D to maximize your bone health.

William Oh:

Thank you. Did you want to add something, Alicia?

Dr. Alicia Morgans:

I was just going to say that absolutely, I counsel all of my patients to be on calcium and vitamin D, and even those people who think that they're in the sun a lot, potentially, depending on where they live in the country, they're just not getting enough vitamin D. And Dr. Holick's other name is Dr. Sunshine. He knows this better than anybody. But in the Massachusetts area, we're just pretty much never getting the right amount of vitamin D, even if we're outside all the time. When I lived in Chicago, it was the same thing. We're just not getting it, so you have to supplement.

William Oh:

Yeah. I think vitamin D is probably the single most important hormone replacement supplement that you can take. I mean, there's a lot of research on a lot of different supplements. Vitamin D seems to not only have this benefit in the bone, but it may have some anti-cancer benefit as well. And you don't need to, I think what you're saying, Dr. Holick, to this group is you don't even need to get a level. Most

patients should replace, should take a supplemental vitamin D with calcium as a combined capsule or tablet, right?

Dr. Michael Holick:

That's correct, yes.

William Oh:

Okay. There are some comments about black cohosh and vitamin E also helping with hot flashes. I have used black cohosh with modest success. It's an over-the-counter. Sometimes some patients want to try it, but it doesn't work in most patients and we're usually going to some of the other medicines. I wanted to talk a little bit about cognitive issues. Dr. Holick, did you have any of these? A lot of patients complain about their memory, and what can we recommend that they do to try to counteract the cognitive issues associated with hormonal therapy?

Dr. Michael Holick:

Well, I mean, it's even more deep than that. It's really neuro psychological impact of ADT that can lead to depression and even increased risk for suicide. It's been reported that men with prostate cancer during the first five years that they have almost a three to four fold increased risk of committing suicide. And I have to admit from my own experience, even though I sound like I'm a reasonable person and I don't sound like I'm depressed, but I had that experience where I had planned to finally just end this because for reasons that we don't understand, these medications play in your brain and they try to convince you of things that are not realistic, and it's really important to have family support. It's really important to tell family members of what you're going through. I mean, when they hear you initially, like I told my son when I was in Alaska fishing with him, my plan was never to come home.

And I had planned out exactly what I wanted to do. And when I told him this, he said, "Well, why did you come with me?" And just the fact that I could talk to him made all the difference in the world. And so I encourage men with prostate cancer that have these of crazy ideas, talk to family members, talk to your doctor, seek mental health assistance because this is a very big deal. When I get up in the morning, I'm always trying to keep my mind active. I read the newspaper, I keep up on the literature. Whatever it is that makes your mind go better, playing chess or checkers, or whatever, you've got to keep your mind active, otherwise you can easily get depressed and easily get into that concept of suicidal thoughts.

William Oh:

Thank you for that. I think it's a really, really important point. Men are maybe trained in this country to be stoic, to keep everything in. And I think it only makes it worse. Talk to your doctor, talk to your spouse, talk to your family. There are many people who care about you, and it is very, very common. You're a hundred percent right, and even people who seem well-adjusted are going through these thoughts. It's normal to be sad and depressed from a diagnosis of cancer and for what hormonal therapy might do to you, but there are so many treatments and so many options here that it's very important to bring it out to your health team really. I want to point out, somebody asked that calcium has been said to be bad for you. So can you just clarify, is calcium bad for prostate cancer or is it unopposed calcium? Can you just comment on that, versus vitamin D plus calcium?

Dr. Michael Holick:

Sure. So it turns out that some men with prostate cancer start increasing their blood concentration of calcium, and this is because of another hormone that their cancer cells are making called parathyroid hormone related peptide. But studies have been done to show that even those men taking normal calcium intake does not increase their calcium any further. It's because this other hormone is actually removing calcium from your skeleton, and so that you need to therefore be treated for the skeletal removal of calcium. Increased calcium above the recommendation of about a thousand milligrams a day, preferably from diet is for the most part, perfectly safe. If you have a history of kidney stones, used to be then taking calcium citrate rather than calcium carbonate, or better yet, like I said, to get it from your diet.

William Oh:

So I want to just emphasize a point you brought up about the cognitive function. And sometimes when I describe hormonal therapy to my patients, to keep it as simple as possible, I describe hormonal therapy almost like aging. And we know that people as they age, if you retire and you don't use your brain, you lose your cognitive function. There's actually really prospective studies that have looked at this. So I think your point about staying as brain active as possible, whether it's puzzles or reading or doing activities with your brain, I think is a very important part of slowing that cognitive process. Alicia, can I ask you about a sexual function? Obviously, human beings are sexual and there's a big loss at the time of prostate cancer treatment, for example, with loss of erections for men. But then when they go on hormonal therapy, there's something different that happens regarding libido and the ability to get erections. Can you just describe that process and what options there are for men in terms of libido and sexual function?

Dr. Alicia Morgans:

Sure. This is another one of the big challenges I think related to hormonal deprivation therapy. So it's not just erections, it also can be sex drive that is really eradicated when this happens. And when you couple that with low mood and couple that with feeling like you're getting more flabby and you're less muscular, and you're less manly, I think that people can really find themselves in a negative spiral when it comes to their sexual health. One thing that I've been really appreciative of is that I do have a colleague who is a behavioral therapist whose specialty is in sexual health, I would say that her waiting list is at this point six to nine months long. So she is just constantly overwhelmed with people and there are so many people in need, and we need more access to sexual therapists.

But what she always talks about is that intimacy comes in many ways and we can build intimacy with our partner that is beyond erections, and that intimacy can lead to enhanced sexual drive, even though the drive itself, that instantaneous, "Oh, I just saw something and now I immediately have an erection," I don't mean to simplify it, but it can be a very fast process in some cases, but when you're on hormonal therapy, that's just not going to be the way. So she really counsels people to think about togetherness, think about touching, think about sharing things, bonding, emotional connectedness, and using that and that physical touch in other ways to enhance that physical intimacy and sexual health, even if it is not based around erections. I would just say that one more thing, that there are ways to have erections even if you don't have an easy erection, the sensation of the penis is completely intact, so the nerves that are disrupted when you have a prostatectomy or the ones that are fried by radiation are not nerves for the way that the things feel on the penis.

The nerves that really regulate how the penis gets engorged with blood and becomes erect, the sensation nerves are still all there. So there are other ways that we can help your penis get erect, and since the sensation's intact, that can sometimes be really rewarding for people. So penile prosthesis,

which are essentially things that can be surgically implanted in the penis, they feel like a breast implant. There's usually something inside of you that you don't see or feel, but that you can pump on the scrotum once or twice, and the penis can go up, and you pump it and the penis can go down, so you can get around the physical things, but the libido, the drive and the intimacy, that's something that does take work. But I think for those who engage in that and for whom it's important, is very, very valuable.

Dr. Michael Holick:

And I concur 100%, and I personally had exactly the same experience, and my wife has just been incredibly understanding. And you're right, I mean, just to be together, that tactile sensation really makes a big difference. And you're right that there are a variety of options for men that they could see their urologist, including the injection that at least for me, has been very functional. And so like you said, men should not think that they're not having the ability to get an erection and to be intimate with their partner, but it does take effort. And just like William said, you've got to keep your mind going. And as long as you do that with everything that you're doing, including your sexual health, makes a big difference.

William Oh:

Very good points. I'm going to ask one more question and then we'll get to the wrap up. We had a lot of questions about really related to intermittent hormones. Let's say you're on treatment and you stop, let's say you've been on hormone therapy for two years and then you stop, but your testosterone doesn't really recover. Are patients candidates for testosterone replacement? Is a prostate cancer patient, somebody, Alicia, that you would give back a testosterone supplement too? And what are the circumstances in which you would consider it?

Dr. Alicia Morgans:

This is a great question and a really, really tricky one because I think as a medical oncologist, I personally would feel uncomfortable giving testosterone myself to someone. However, the American Neurologic Association does have guidance, particularly for patients with low risk prostate cancers and some of the favorable intermediate risk and maybe even unfavorable intermediate risk prostate cancers. When they've been out long enough from their treatment and their testosterone should have recovered, but it is still not recovered, there's guidance for urologists to give them testosterone under a very closely supervised situation. Not every urologist will feel comfortable, so I want to put that out there. And again, I wouldn't feel comfortable because I'm a cancer doctor and all I really feel comfortable with is taking away testosterone and certainly don't feel comfortable, but I do work with a urologist who does monitor and keep patients on a very short leash in terms of monitoring because it is possible that giving testosterone back could stimulate cancer cells if they are in your body, so that's the fear that I have and the thing that I think we all think about.

There is research being done. I think there's a study being done at MD Anderson and some of the Texas Programs where they're looking at this in a standardized fashion and trying to see, "Can we do it safely?" Because I think I want to give someone testosterone if I have data to say that I can do that safely. It's not that I don't want to help someone, but I think that the data that directs us is a little bit less than clear. That being said, some of the urologists are able to do it because they do have guidance on how to monitor and do it safely.

William Oh:

Yeah, thank you. And there are a lot of questions about whether many of these symptoms improve if you stop the hormonal treatment, and the short answer is they do. When your testosterone recovers, they do get better, but not instantly. They slowly recover, and it is possible to lose the weight, build your muscle. We see it every day in our practice and in our clinic. So we're really at time. I want to thank Dr. Morgans and Dr. Holick, but I want to give you one last word each for our audience about what you see really in terms of the future of hormonal therapy and your own hope for this audience in terms of how hormonal therapies, side effects, which we discussed at length can be balanced against the good that it does. So I'm going to start with you Dr. Holick, as a patient and as an expert in endocrinology, what last words do you have for our audience tonight?

Dr. Michael Holick:

Well, I think the most important, I hope I got the message across is that men with prostate cancer can do almost everything that they did before they had the diagnosis. They just have to put their mind and body to it, and that includes exercise is really important. And I think it's very important to have good communication with family about everything that's going on in your life. It can improve your mood, and like you already heard from Alicia and for me, is that intimacy is incredibly important for human health and welfare. And I encourage men with prostate cancer, just don't ever give up. Don't ever let anything diminish in you if you can maintain it, and that's what I've been doing with my own. I'm going to be now going on social media to actually expand on my story and to offer men an opportunity to be now in closer touch because I really am keen, I want to get this message out.

William Oh:

Thank you for that inspiring message. Dr. Morgans?

Dr. Alicia Morgans:

I would say that hormonal therapy is so important for what we do in terms of cancer control. It is truly one of the most, if not the most effective way we have at shutting down these cancer cells by lowering testosterone. But just because we have a primary aim of doing that does not mean that we should not either elevate that to a secondary aim for some people, or just importantly, think about how we can help people live well despite having low testosterone, and we can do that. And there are ways that you can feel better, but I do think it's important to talk to your doctor, talk to your family, put yourself out there, ask the questions because what you're feeling is probably something someone's felt before, and there are ways that we can help you feel better, and hopefully we can cure or really control your prostate cancer and help you just have a good life, have a normal life as much as possible while dealing with something that's been so disruptive.

William Oh:

Thank you. I just want to end on two notes. The first is, there were a lot of questions about what to do when hormonal therapy stops working or ADT stops working, and we will have a future session on that. That's an hour long webinar in and of itself. So please tune into that. And the second point I would make is, there are many, many men to the points made by both of our panelists tonight who live full active lives for many years and even decades. In fact, the chairman of the Prostate Cancer Foundation, Michael Milken, has been on hormonal therapy for 30 years, exercises, eats healthy and really has helped this foundation try to find better answers for all prostate cancer patients. So on that note, I want to thank you all for joining us. This webinar will be available to review, and I hope to see you in a future webinar. Thank you.



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Dr. Alicia Morgans:

Thank you.

Dr. Michael Holick:

Thank you, real pleasure.