Explore Prostate Cancer Support Programs Transcript

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Introduction and Guest Background

Hello again everyone. Welcome to the Prostate Cancer Summit. I'm your host, Doctor Geo Espinosa. Also known as Doctor Geo and today we have a special guest.

This is Miss Shelby Moneer, who is the vice president of patient programs and education at Zero Prostate Cancer, the leading national nonprofit with the mission to end prostate cancer and help all who are impacted by it.

Zero patient education and support programs, advocacy efforts and nationwide Run Walk series aim to reduce barriers, expand access, and provide support to everyone in the prostate cancer community.

Miss Moneer Before joining Zero, she serve as Director of Education at the Melanoma Research Foundation, and she is Certified Health at Certified Health Education Specialist and has served as a patient advocacy advocacy space for over 20 years.

Shelby, thank you so much for being on. I think it's very important to share your information how even how, you know, some of these groups work that these support groups and advocacy groups work. So thank you for being on.

Thank you for having me, doctor Geo. It's a real pleasure. We're just thrilled to be a part of this amazing summit this year. I appreciate that and I appreciate you.

Let's start here. I mean, I do have some questions to ask, but it's always more interesting if we can blend it in with things that we I'm interested in.

And I think that the audience will be interested. I hope you just have a good chat. Yeah. For those that don't know, how do these support groups work?

So I've given talks to a few. Back then it was us two, which I know that you guys are together. You guys merged with us two, and I've given talks and kind of also got a feel of, you know, how these things work.

So obviously men and their partners are looking for support. Somebody that. Look, no one really understands my situation because when I say prostate cancer, oh my God to cancer.

Oh it's prostate cancer is different. They're looking for other people to have these discussions. Some of them are newly diagnosed and are trying to figure out.

And I told my medical friends, they don't trust you. They're looking for peers. Right. For so, you know, you guys lost it and they left it. It's like, yeah, I get it. Right.

But they're looking for peers to talk to and say, look, what was when you had the prostatectomy or the radiation? What was your sexual function like afterwards?

Not from doctors who, you know, who do this. They do the treatment. And, you know, most of them never have gone through prostate cancer, but from their peers.

So what's a scenario with zero? And we could generalize to start with some of these, support groups. And I know, I know they function differently.

Why Support Groups Matter

But in general, how can why would somebody listening to this say up, you know what, I need to go to a support

group. And zero is the one that I'm that I'm going to.

Why why would they do that? Absolutely. Great questions. I was going to say great question, but lots of questions. But I think that's. Yeah, I mean the the first thing if, if zero had our way our, you know, our, our biggest wish is that every single time a doctor gives a prostate cancer diagnosis to someone, the first thing they say is join a support group.

Now of course, support groups aren't for everyone. Some some people don't want or don't think that they want to, you know, lay on the the couch and and share the feelings.

But we know time and time again we get feedback from individuals who attend our groups, get support, maybe they decide after attending a support group, you know, one on one support is is maybe better for me.

Or maybe I need to talk with a professional after being a part of this group. But what we know is that when we ask for feedback from the attendees at our support groups time and time again, what folks wish they would have done earlier is, you guessed it, join a support group.

In some way. Get connected with someone else that can listen to what they're going through, let them know they're not going through it alone, and offer feedback and, guidance.

And sometimes, most often really, we know just to just another ear, to listen to and some of our support groups have been meeting for years and years and years.

They have, they'll bring in professionals sometimes to talk about various treatment updates, maybe a new clinical trial, maybe a general kind of advancement in diagnostics so that the support group leaders are really maintaining that solid knowledge base so that they can, you know, they can welcome anyone to their group.

First of all, whether they're a long time survivor. They were diagnosed 20 years ago or they were diagnosed last week. There is a home for any any patient, any anyone who has had a diagnosis.

Sometimes the groups welcome caregivers, or care partners. Some of the groups are a little bit more. You know, we want to talk about, this disease that has metastasized because we want to talk about maybe bone pain or, we have some groups that are specific for, the Lgbtqia+ community.

Of course, we have groups specifically for care partners, for black men, for deaf and hard of hearing men, for Spanish speaking individuals. So, you know, without getting too granular, we also want to make sure that the support groups are offering what people diagnosed or actually, you know, in need of of course.

An important it's such an important. Sorry to interrupt. Oh, no. No, I'm. Happy that you guys do that. Here's why I'm in the trenches with these patients every day.

Right. And I'm listening to them. So one of the things that, yeah, I'm a holistic practitioner. So one of the things is listen to your patient and kind of mind body and put it all together, oftentimes listen to what they're trying to say, but not saying.

Here's my perspective from listening to them. I went to the support group was good, but it's not really right, not really detailed for me. So I'm, you know, I'm 42 years old with prostate cancer.

Everyone there is like 65 and above. So my interests are different and blah blah, blah. So the more so it's not only prostate cancer is cultural black men versus white men versus Asian LGBTQ community.

That's a whole different ballgame, how they even see it. So I'm so I just want to emphasize that I'm so happy that you guys try to kind of narrow it down and make it more granular.

I think it's important. Well, and you made a good point earlier with, everyone who's got a diagnosis almost always

right there, their relationships are going to be affected with their partner or with their spouse, of course, with their family members.

But doctors are so limited in their time. And when we're thinking about having a conversation with a group of individuals, we've sort of gone through what what maybe you have, maybe not exactly.

To a tee, but having those conversations kind of knowing what could be coming, down the pike as far as challenges and side effect management and tips and tricks that other people have tried that didn't work and that did work, those conversations are far easier to have with someone who's been through it.

And not that the doctor isn't a great resource, but they're limited with time. And, and maybe sometimes we certainly have encountered this that some providers simply do not want to talk about sexual side effects.

They're not comfortable with it. They, you know, it just is not something that they're experts in. Experts on. And, and having that camaraderie and that ability to share, you know, not to get too specific to sexual side effects, but that is what comes up a lot.

You're in these support groups, but but just having someone to bounce ideas off of and, get to know and know that you're not going through this alone has been I mean, words can't describe how impactful, for for the patient community.

Now, things have changed since the Covid years or the Covid years, where it's almost like it was 25 years ago, but it was only a couple of years ago because those Covid years, things have changed quite a bit, where I remember all the meetings I went to, they were live in person and I thought, and human interaction is is still, you know, priceless, right?

There's nothing that compares with the interaction. Every meeting that I've been a part of as a speaker has been virtual. Now, a how has that impacted the meetings with zero and two?

Virtual, In-Person, and Specialized Groups

Right. So there's less peer to peer interaction when you're virtual. Is that or is there another way that some of these groups, some of these members can actually connect with each other, which is which is the value.

So what are you guys are doing now with these meetings and how can the members interact with each other? Yeah. Great questions. We're really kind of split on, in-person support groups, virtual support groups and then some groups really kind of hit their stride in a hybrid setting, believe it or not. So, we had close to and like you said, we merged with, amazing organization.

Us too, in 2021. So with that, we gained there, nearly or just over 200 support groups. The, the, you know, the Covid years happened there. There were some silver linings that came out of that.

And and one of those is certainly these platforms like Zoom and Google meets and, and, you know, all of these platforms that help us stay connected, got better.

We saw these improvements, but, it certainly made it easier to connect. But some of our support groups said, you know what? We're all done with that virtual space.

This is going to be a group for our community. That's our physical community as well. And, and what we've found is what works in one community certainly may not work in another community.

And so we've really tried to empower our amazing, amazing support group leaders, these ultra volunteers of ours, to dig in and truly get an understanding of what's going to work in their community for their group.

Constantly ask for feedback so that, you know, maybe a virtual group is going to be better for a select group of

patients, and we can help with recruiting a different support group leader.

If that's not for you, or finding a way that will help you ensure that everybody, finds a way to participate in a way that works for them. And what we're also looking at is, you know, kind of initially we were thinking, okay, we need a support group in every single state in the United States.

We still think that's important. But because we know that some people are very happy connecting virtually, we've sort of shifted our priorities as our feedback has, has told us, you know, I don't necessarily need to go to, the library on a Monday evening when my loved one has pickleball making this up, but.

Right. Nothing wrong with pickleball. And it is exercise, and exercise is medicine. Right. But but I'm actually okay with. Sure. Maybe I'll go to this meeting that is in person.

Happens to be, at the hospital or community center or library or whatever. But I'm also going to call in to this virtual group that is more specific to, my situation and my prostate cancer diagnosis and my experience.

So, really aiming to, to, to have a good number of sort of options for people to choose from while not getting too granular where no one shows up because, you know, there are only a handful of people whose needs that's, that's going to mean.

You know, I love it. You know, one of the things, as I got so I got into I'm an actual doctor, that's my doctorate degree and my training, and very few people choose, to kind of narrow their focus, you know, NDEs, become general practitioners.

And, the principles are it to some degree, doesn't matter what you have, treat the person, not the disease. I had a hard time with that process and that way of thinking, so I narrowed, narrowed, narrowed, and I do.

All I do is prostate, right and prostate conditions and prostate cancer. Then, as I started in my career, I got, you know, I became fond of some of the, nonprofit organizations that have advocacy groups.

Zero stood out how? They did a lot of run walk kind of events. And that's. Now you're talking to me, right? Right. Because. If you put a gun in my head, Shelby, and you say, listen, you talk about lifestyle and within lifestyle, there's, you know, eating, right?

There's meditation, there's there's sleep, there's exercise, you know, perhaps some a couple of good supplements. Maybe I can only do one. Which one? That's tough.

I always joke. It's like asking me which one of my three kids I love most. I don't, you know, depends on a day.

Run/Walk Events and Exercise Advocacy

Depends on many factors. Depend on, you know, who's behaving how and not. But, you know, I like to. Well, if they're around, I say no, I love you all three.

I'm not sorry. No no, no, no gun in my head. Which component is more important? Looking at the research over 25 years, very thoroughly looking at what I see with patients, I would say exercise.

Now, some people think there's a license for them to eat whatever they want and not worry about diet. That's not it. But if I have to put, you know, most of my time in terms of figuring out is exercise, you guys for many years have done the run, walks and so forth that I believe is the only ever going to eat.

That's how I knew about zero. Tell me more about that element of what zero does and how often do they do it, and where are the big cities that they do it in?

Yeah. Great. Well, I love that. I well, I'm, I like to exercise it. I think my husband might like it more, for me than I do.

Because, you know, I get a little cranky if it doesn't happen, right?

But, yeah, our run walk series, we were up to about 50, last year, and we were really excited about that. And we kind of found in turn that turned that back just a little bit.

So we're in, you know, 35, 40 cities and we just have, the best race directors and volunteers and, and grassroots fundraisers out there, kind of you know, making sure that people are aware of the disease.

It's a great awareness builder, of course, in, in that community setting. But I think even more so, it's a great opportunity for someone who's been diagnosed or the the loved ones of someone who has been diagnosed or maybe even lost, their life to the disease to come out, show their community what prostate cancer is, how it's affected them.

Make sure that their future generations are not as impacted by this disease. With early detection messaging. The importance of talking with your, doctor or your loved ones family history, we know is so, so important.

So we are really utilizing these run walks throughout the country to drive home that awareness message, raise funds that go back to the community, and that helped implement all of our patient programs nationwide.

But we we just we love our run walks. The it and what a better opportunity and place for a survivor to come out and say, this is my why and hear my story and let's connect.

They're just a really exciting way to talk about a really not exciting. Not that it's not exciting, but it's what can be a sad topic with, you know, with cancer.

But but our hope is to provide hope at these events. That treatment advances are coming every day. And we're learning more about about this disease. And if, you know, if these treatments aren't working, we might have these, these next couple down, down the pike.

So, really galvanizing the community and making sure that everyone diagnosed knows that there is that that big group of people, that community around them.

And the fact that, look, exercise is medicine. I mean, if we're not reading the research, I mean, if you and I were to bottle exercise and and Pat and it it would be $1 trillion, right?

$1 trillion drug. And you mentioned something very important, how it affects you mentally. There are physiological elements that are very good and important, even from a, particularly from a cancer perspective.

But the psychological which, you know, you get diagnosed with a disease like the cancer, you know, that's daunting. And and then guys on Andrew, deprivation therapy and so forth.

So this is another method of them feeling better and doing something that's proactive and, you know, putting the patient back in the driver's seat, which, you know, zero is very, very fond of and support shared decision making, shared decision making.

That's the premise of, you know, my work with my podcast and so forth shared does it. But you have to be a well informed, you know, with good in, you know, internet, you could get good, you can get bad information and you could go down a rabbit hole.

Where is the right information? So, I love what you guys do in that regard. And, you know, I hope to stay in touch with regard to all your run and walk.

So that's, again, that's right up my alley. Yeah, absolutely. We have some great cities. And we have, a run walk kind of finder. We have a support group finder tool on our, on our website.

So, really, regardless of where you're listening from, to take a look and and find one of those if you'd like to get, get more involved. But I love what your message is on shared decision making.

We talk a lot about it. It's maybe some inside baseball jargon that doesn't resonate with all patients, but it should, you know, and, and all of these health care decisions we're making, not just specific, you know, specific to prostate cancer, all of these decisions that we are making about our health, need to be made and conjunction with an expert.

And if you can't find an expert, we can help you find another one. Right. That that, you know, this the center of all of these decisions has to be the patient.

What are, you know, what are the the patient's, priorities and what kind of quality of life are you expecting? A 40 year old may have very different expectations and a than a 66 year old, which is the average age of a diagnosis.

So making sure that your provider and your health care team fully understands what your priorities are and how you guys can make those decisions together, based on your individual situation.

It's just there's nothing more important. There'll be we we spoke a lot about the patient. Tell me about the caregiver. What do we do for them? How can they get involved in with an organization like zero?

Caregivers and Shared Decision-Making

Look, they prostate cancer affects not only the patient, it affects everyone is it affects the spouse or it affects the children. And what I see in my practice is that, many things so often, for example, the spouse oftentimes they even sacrifice their own health to help their partner.

They want to do so much for them, right? So they kind of let themselves go. And sometimes while I'm recommending, look, you can apply these same exact principles and you get the help and you know, you benefit from it, and you guys are doing it together as partners.

How can zero for prostate cancer help the caregivers? Yeah, the caregivers are just so, so important. And everyone, all patients know it. And many of them do a great job of communicating that, but you just can't stress enough how important it is for a caregiver to take care of themselves so that they can continue being that caregiver or that care partner for their loved one who who is being diagnosed.

And we all know that a caregiver comes in all shapes and sizes and roles. It could be a daughter or son. It can be a partner spouse. It can be, you know, a niece or nephew.

So same sex, spouse, right? Of course, a spouse. Right. So we have, we have a caregiver guide that's new was we drafted it with some caregivers for caregivers.

So we're really proud of that. We have this new zero plus one, caregiver and care partner initiative. And the message really is, who is your plus one?

It doesn't have to be the standard plus one, but who is that person that you are taking to, doctor's visits? Who's going to help you do the research? Who are you going to rely on?

And maybe it's more than one person to help you. You know, think about treatment options or manage side effects or, you know, the the the list is, is endless.

But, so, so important to have that person or those people to ask for help, but in return, that care partner has to also ask for help. If and when that time comes, because, the role of the caregiver is, you know, you can hardly put words to it, but, you know, to your point, that mental, aspect and, and psychological, safety and toll that, that it can take, you know, is it can't be discounted.

We, we see so many relationships, go through challenges after a prostate cancer diagnosis. And prostate cancer is unique if you're if you have a partner or spouse, it truly is a couple's disease that you know, they're in.

And you hate to stereotype, but but we often see a prostate cancer diagnosis really kind of can take hold of men in particular and say, well, this is questioning my, my, my, my, my sexual, livelihood.

And how is my partner going to stay, with me if I can't if I'm having issues with erectile dysfunction and urinary incontinence, you know, and so we talk a lot about where sexual health and side effect management and different ways to be intimate and the different professionals.

I think, are often really news to, to patients and couples and their loved ones. And I didn't know there was a, you know, a sexual health therapist. I couldn't talk to.

And, you know, these these sexual health and sexual medicine experts that can help guide, help guide us and help us kind of get through this very challenging, time again, I don't want to harp too much on the couple experience, but, you know, the the caregivers are immensely important.

And helping patients navigate a diagnosis. Absolutely. I often times so my patient that once I know they they have a partner, I said, don't you dare come without that partner.

Yeah. Yeah. Because it's like it's particularly when you're diagnosed after the diagnosis comes out of the practice, the physicians mouth, it's all like Charlie Brown episodes after that.

What the patient is listening to this is like, why they're not even listening to the details. They saying, oh, shoot, now what? And then they go into it.

They go into fix it mode or into solutions mode, like, okay, so then they're not listening to the details. And a partner does and takes better notes often.

And I have to say female partners are amazing at all these things. Way more than than than the male either male part of the or the patient themselves.

So I have to say, I always say bring a female partner with you or a female friend. So if you find a female in the parking lot on the way and bring. Her in, just, just just bring it right in, you know, pay her a little money.

If you have, it'll be worth it. That's a much better notes and ask better questions, by the way. Yeah, yeah. Shelby, thank you so much for being on this summit and educating everyone on support groups and a zero, prostate cancer.

Final words, if you have any. And how can people find zero prostate cancer? Well, thank you again for for having us. We are, thrilled to, to be a part of this amazing event.

But, I think just the final message that that zero would like to share with all of you as listeners is simply find a way to get connected with other people in the in the prostate cancer community in whatever ways that fit your needs.

You know, whether it's virtually or in person or one on one or as a group.

Finding Resources and Final Takeaways

You know, that connection is incredibly important as we continue to learn more about this disease and diagnostics and treatment and clinical trials, trials and research, you know, find a way to get connected and, if it's a zero, we love that.

But if it's other organizations local to your community or nationwide, you know, that's also fine. But that connectivity and that network and getting to know other people, is, is incredibly important as as we all navigate this disease

together, and all of the information and support groups and, clinical trial finders and run walk finders and our advocacy efforts, which we didn't even touch on, efforts like the PSA for Home Act and additional funding for the Prostate Cancer Research program.

All of these great things that will help move the needle and raise awareness for prostate cancer. Find you can find that at Zero cancer.org and navigate from there.

But really that connectivity just we can't we can't talk about it enough. Thank you so much. I really appreciate your time, your knowledge, expertise and your passion for helping our prostate.

You know, I have a hard time with survivor, you know, so the term that I've used, I wrote a book called thrive Don't Only Survive and is a prostate cancer book.

So the term that I use often is thriver. How can you get diagnosed? And actually from that point on, thrive and do better and talk about lifestyle changes.

People are ready to go after such a diagnosis? Yeah, absolutely. Yeah. Survivor does not resonate with everyone. I think there are there like I am still trying to survive this.

Please do not call me a survivor. Right, exactly. But, that's where I kind of get stuck when I, when I'm using that word is like, you just got to be a part of my lexicon.

You know? We do too. Yeah. All right. Thank you so much, Shelby. Thank you, doctor Geo. Great to be here with you. Thank you. All right, everyone, stay tuned for the next episode.

Of the from the prostate cancer Summit. It just gets better and better. So enjoy. Have a great day.