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Meet the Expert: Shelby Moneer, MS, CHES, from ZERO Prostate Cancer

Benjamin Lowentritt, MD, FACS

Prostate Cancer Care Program, Chesapeake Urology, Baltimore, Maryland



Benjamin Lowentritt,
MD, FACS, moderator



Shelby Moneer,
MS, CHES

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Meet the Expert

Thank you for joining us today for our third “Meet the Expert” session with our special guest Shelby Moneer. Shelby is vice president of patient programs and education at ZERO Prostate Cancer. I’m your moderator for today, Benjamin Lowentritt. I’m the medical director of the prostate cancer program at Chesapeake Urology, and I am fortunate enough to be one of the medical advisors for ZERO, as well.

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Interview

Benjamin Lowentritt, MD, FACS: I have a passion for prostate cancer education and advocacy, and ZERO [Prostate Cancer] as an organization really has a focus on that. And I think when we’re busy taking care of patients, we do everything we can for that patient that’s in front of us, but sometimes it’s so difficult to fully understand the wide range of challenges that they are facing with their diagnosis.

We can be somewhat hyper-focused on just what we’re doing for them in the office, so I think being able to sometimes look above the clouds and really engage in some of the things that, frankly, really impact their lives and their family’s lives is really important.

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Corresponding author: Benjamin Lowentritt, MD, FACS, Medical Director, Prostate Cancer Care Program, Chesapeake Urology, 6535 N Charles St, Ste 500, Towson, MD 21204 (blowentritt@chesuro.com)

I've been very fortunate to have a partner in ZERO in my practice and, I think, for my patients, most importantly, as a resource. And I think as we look to serve this population of patients, it's really critical that we find reliable partners, so with that I shall bring Shelby into the conversation. Please tell us more about ZERO and what you're doing now.

Shelby Moneer, MS, CHES: Yeah, thank you, Dr Lowentritt. I really appreciate the opportunity to join this important conversation. ZERO has been around since 1996, and initially we were very focused, almost solely, on patient advocacy on Capitol Hill. And we have since kind of morphed. As the needs have changed, so has ZERO. We are very proud to be the leading national nonprofit with the mission to end prostate cancer.

We want to end prostate cancer as we know it. We want to focus on, like you said, [issues that are] high level: What do patients need to know? How can we help the health care providers and ease [patients'] burden a little bit?

We are focused on, of course, still advancing research. . . . We want to increase federal spending on prostate cancer research, and we want to make sure that at the end of the day, every single person who hears the words "You have prostate cancer" is guided to a patient advocacy organization.

Sure, we hope it's ZERO, but there are lots of really great organizations out there that can give them not only that support but also information that's unbiased and written at a level that they can understand. We want to meet those patients where they are . . . so that we can truly give them information at the time that they need it the most, where they need it the most. And it's really a 2-way conversation between ZERO and patients and patients to ZERO.

One of the things I love most here is when we hear about a new unmet need or a gap in education or support, whether it's from a provider or it's from a patient or a caregiver or a loved one. [With that information,] we are able to morph what we do into better meeting those needs.

ABBREVIATIONS

PSA	prostate-specific antigen
USPSTF	United States Preventive Services Task Force

We also have a really robust 5K run/walk program all over the country that's really going to hit the ground running, no pun intended, or maybe pun intended, in September. We have several planned all over the country, so [there are] lots of ways to get involved.

ZERO [also offers] patient education and support programs. We have one-on-one opportunities that pair patients and mentors—so, pairing a survivor with someone who's really just going through it. We have support groups, too; I think we're sitting at maybe 165 in-person and virtual support groups.

So that was really long-winded, but I really just want to send the message that the prostate cancer advocacy organizations are there to be a partner in this prostate cancer experience and journey.

Dr Lowentritt: It is amazing to have partners like ZERO in the space trying to take care of our patients with us, and I know personally when I'm trying to guide a patient through discussions around their prostate cancer, whether it be newly diagnosed or more advanced, those are tough periods. Those are the times when they're most likely to go to "Dr Google," and it's really important to know that sources like ZERO are providing reliable information to support patients in confidently making decisions about their care.

We often refer patients to ZERO's website for the resources that are there and certainly for some of those other unmet needs that they may have around their diagnosis, whether they be financial stresses or just very practical day-to-day life concerns. It's great to have resources, and the team at ZERO really helps provide that. And I want to say thank you.

Ms Moneer: Well, yeah, we appreciate that. You're very welcome, and thank you for all that you're doing for your patients, as well. We love creating these materials and these opportunities and these programs

for the patient community, and we know that patients want to get information from their providers.

We know that a provider's time is limited, and so we've tried to really create a huge portfolio of resources and support and literature that meets various needs. There is not a blanket treatment plan. Every diagnosis is different; every experience is different.

And so we really are trying to make it a personalized experience. Not everything is going to be right for every patient. One patient might just need maybe a newly diagnosed guide, and they want to take it home and read it. Someone else may hate printed literature, and we can guide them to a webinar or a podcast such as this because they like to learn more by listening. So we really try to have every creative way that we can think of—animated videos are another great one. We're kind of starting to dabble in animation. So we know that people learn in different ways and feel supported in different ways, so, really, thank you for guiding people to our resources.

Dr Lowentritt: Is there a best way for people out there who aren't as familiar with ZERO to get familiar with what services are offered and to connect with somebody if they have patients in need?

Ms Moneer: Yeah, I mean, we all get very reliant on our website, of course, which is ZEROcancer.org, and that's where everything really is housed, but I think it's important to know that we're also people at ZERO. Sure, we're a big national organization, but if you pick up the phone and call us or if you send us an email, we have folks who are ready to get the patient or their loved ones connected in the ways that make sense for them.

I think starting with our website and sifting through what we have to offer [makes sense], but again, don't be afraid to shoot us an email or give us a call, and we can really make sure that you feel well supported.

We have a couple of tools that are really great, too. If you just want to chat with somebody else who's been through this, we can get you in touch with a support group leader or that mentor I mentioned earlier. And you really can take it from there and be as involved or not as involved as you want. But we know that

when patients are well informed and can be an active participant in their care decision-making, their quality of life improves, so I really encourage any physician seeing patients to have them get connected with a patient advocacy group.

Dr Lowentritt: I think it's really wonderful what ZERO offers, and you mentioned that some of the origins were in advocacy, and then evolving into some of the races. And I've been fortunate to be a little bit involved in both and really have seen our local run/walk really take off and succeed and become a part of our community. That event brings a shining light onto the needs around prostate cancer, and it's been a really rewarding partnership there.

I will say, just a few years ago, we were all reeling from some of the changes that the USPSTF [United States Preventive Services Task Force] had recommended around patients' access to PSA [prostate-specific antigen] screening and awareness of prostate cancer. There was a real concern that insurance companies were going to stop paying for [screening], and Medicare was considering stopping paying for annual PSA screening—not just recommending it but really making it a not-covered option.

And we took action, and ZERO really led. And I was fortunate to work in our state in Maryland to pass a law that required annual PSA screening to be covered for patients that were being counseled and wanted to pursue it. So that was something that as an individual would've been very difficult for any of us to uphold, but the partnership with ZERO and local doctors—and then eventually we brought in other organizations—helped get that across the finish line in 1 year, which was really a great victory for our patients.

And I believe we were the second state to have passed that law, and that's continued across the country in a number of different states. And I'd encourage anyone who's looking to protect their patients' access to screening and information about prostate cancer to reach out, as well, if that's an interest.

Ms Moneer: Yeah, absolutely. Thanks for mentioning that. It's such a great point, and I think a lot of times patients, caregivers, and loved ones don't really know

what to do. They've heard about a prostate cancer diagnosis in either themselves or someone they care about, and they're kind of at a loss.

How do I get involved? How can I show support and advocacy? It can be scary for a lot of people. It's nerve-racking when it's not something you do every day. You think, "OK, I'm going to go in here on Capitol Hill with this group of folks, and sure, I'm kind of trained on what I'm supposed to say, but who am I going to meet? Do they even care?" And they do.

Our annual summit is actually coming up at the end of February 2025, and so we'll bring the prostate cancer community to Washington, DC. We'll have a celebration and a training [session], and we'll go through the importance of the asks and the importance of storytelling and how you can work your story into these conversations on Capitol Hill.

And we really set you up in that training for success so that you feel confident. You do a practice run or 2; you know who you're going to meet. You're going to get a lot of steps in bouncing back and forth to the different buildings to meet with those representatives or their staffers, and it really makes a difference. I think we had almost 200 meetings on Capitol Hill last February. Several folks signed on, and it's bipartisan, which is even better. But we've had great success working across party lines to move this initiative forward.

Dr Lowentritt: Well, I mean, it is such a great effort. It is a herculean task to try to get anything in front of, and then through a legislative process, and so we definitely need the partnership. Well, Shelby, thank you so much for your time today. This is a great discussion, and I hope for anyone reading or listening to this, [you realize] this is what it takes. It takes partnership. It takes people doing the effort to really serve our patients on the treatment side.

Certainly, we have to recognize that our patients need a lot more than what they get from us in the interactions that we are able to have. And so [it's critical] having a partner that can help us build really quality

education and follow that up with efforts on the legislative [side] and beyond for all the things that we need to protect and treat our patients in the best ways possible.

It's really a wonderful organization and a great partnership. And I encourage anyone who's interested to reach out and get involved at any one of the levels that Shelby was talking about with the activities that ZERO performs.

Ms Moneer: Well, thank you for having me, Dr Lowentritt. It was a real pleasure.

Dr Lowentritt: Great. And for our readership, if you would like to listen to this full interview along with other, similar interviews, please visit our website or download the *Reviews in Urology* app, now available in both the Apple Store and Google Play.

If you would like to learn more about ZERO, please visit their website, www.ZEROCancer.org. Thank you all very much.

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