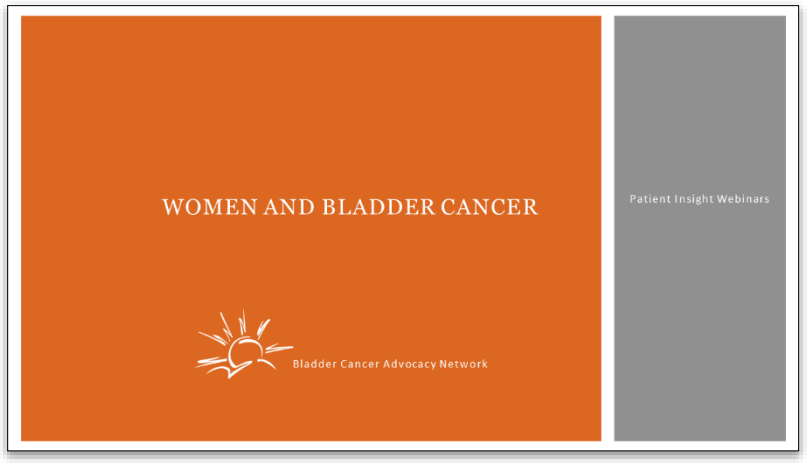

Stephanie Chisolm:

Bladder cancer has long been considered a disease of older men, and in 2022, the American Cancer Society estimates that more than 81,000 individuals in the United States will be diagnosed with bladder cancer. And of those, about 19,480 will be women. And though it's more prevalent in men, studies have shown that women are more likely to present at a much more advanced stage and usually after a delay in their diagnosis. And according to a report published by the National Cancer Institute, survival rates for women with bladder cancer tends to lag behind that of men at all stages of disease.

And African-American women in particular have poorer outcomes when they're diagnosed with bladder cancer. BCAN is very delighted to welcome four female urology experts who specialize in treating bladder cancer. So I'd like to welcome Dr. Sima Porten, a longtime member of our scientific advisory board who treats patients at the University of California in San Francisco. So welcome Dr. Porten. And then Dr. Anne Schuckman from the Keck Medical Center at the University of Southern California. And then from Vanderbilt Health in Nashville, Tennessee, Dr. Kristen Scarpato. And then coming in from Albany Medical Center, Dr. Svetlana Avulova. So we really have covered the country and now I know you want to hear what these experts have to say.

Dr. Sima Porten:

Hi everybody. Thank you all for being here. I am really delighted to be spending this time with great friends and colleagues and all of you on behalf of BCAN. As Stephanie said, my name's Sima Porten, I'm the associate professor at UCSF and a urologic oncologist. I think we'll just go ahead and jump right on in. I appreciate everybody submitting questions beforehand and of course feel free to submit questions into the chat into the Q&A box and either we'll take them as they come or if we don't get to them as we're talking and discussing, we'll do them at the end. And so I'm going to start with Dr. Scarpato. I think Stephanie described really nicely a little bit about the incidence of bladder cancer and some of the disparities that are reported in the literature and that we've also noticed clinically. **What do you think are some of the challenges in diagnosing women with bladder cancer? And tell me a little bit about some of the exposures or causes for bladder cancer and how that may differ between men and women.**

Dr. Kristen Scarpato:

Thank you, Sima. I just want to reiterate that it is really exciting to be here with this amazing group of female urologic oncologists and thank you all for joining and thank you to BCAN. I want to just start by

highlighting again some of the information you heard to start off this webinar about the incidents of bladder cancer. I think it's always important to start thinking about the big picture. So from an incident standpoint, you heard earlier that over 81,000 new cases of bladder cancer will be diagnosed in the US this year. That's making it the sixth most common cancer diagnosed. And of that number over close to 20,000 deaths will be attributed to bladder cancer. Patients tend to present at an older age. The median age of diagnosis is around 73. But when we look a little bit more in depth and think about males versus females, of that over 81,000, about 20,000 will be females.

So that accounts for about 25% of the diagnoses, but about 30% of the deaths from bladder cancer occur in women compared to men. And so when we look even more in depth at these gender disparities, some of what you heard earlier is a little bit alarming. Women tend to have worse outcomes stage for stage when compared to men, and women are more likely to have a higher stage at presentation than men. And overall bladder cancer has a worse prognosis in women than men. And this is true for both non-muscle invasive bladder cancer and muscle invasive bladder cancer. About 75% of bladder cancer is non-muscle invasive at bladder diagnosis compared to about 25% being muscle invasive. So there are a couple of reasons that we can talk about for why this might be, but I wanted to highlight as Sima asked some of the risk factors for bladder cancer.

So as I said before, male, gender, and certainly age are risk factors. We don't often see patients younger than 40 being diagnosed with bladder cancer. That doesn't mean that it can't happen. Smoking is a major risk factor. I often will say to patients the number one, two and three risk factor for bladder cancer is smoking. And overall in the United States, the rates of smoking have decreased significantly, which is great to see. Generally men are using tobacco products more commonly than women are. It's about 15% of males to about 10 to 11% of women smokers. But that gap, that difference between men and women who are smokers is getting a little bit smaller. So that's something I think we need to pay attention to. And smoking cessation is a really important part of what urologists do because when patients stop smoking, they decrease their risk of bladder cancer.

And so that's important. Another risk factor, and this may be something that's particularly important in women, is chronic inflammation or infection. We know that the lining of the bladder reacts to chronic inflammation or infection, and one of the consequences of that can be the development of cancerous changes. And so we never want to ignore chronic infections or recurrent urinary tract infection in women. There's important data about environmental exposures beyond tobacco smoke and that can be related to certain industrial exposures or dyes. Patients who are hairdressers or working with certain caustic chemicals or textiles can be at increased risk for bladder cancer. Any history of radiation to the pelvis. So we think about patients who have had radiation for cervical cancer or other pelvic cancers can be at increased risk in the bladder. And then medications like cyclophosphamide, that is an agent that is utilized to treat certain cancers and that medication is processed by the kidneys and excreted in urine and can cause some significant changes in the bladder, irritation and something called hemorrhagic cystitis or basically blood and urine that can be really significant.

And that inflammation, like I alluded to before, can be associated with an increased risk of bladder cancer as well. And importantly, that gender disparity in bladder cancer persists even when you account for these exposures in our patients, we know that, that disparity continues. And so undoubtedly the epidemiology of bladder cancer I think contributes to the differences we see between men and women. You have to be thinking about a particular disease to be able to diagnose it. So we have to consider bladder cancer in all of our patients who present with blood in urine, either microscopic blood in the urine or gross blood in the urine, or patients who have recurrent urinary tract infections or significant lower urinary tract symptoms. And unfortunately there's a large amount of data that shows that the evaluation of men indifferent, particularly men and women is different particularly when we're looking at microscopic hematuria evaluation.

And so I would charge all primary care doctors and OBGYNs and urologists, all clinicians out there to be thinking about bladder cancer in our female patients even though they don't fit into that old white male descriptor that Stephanie mentioned before. And I would also encourage patients to be thinking about it too. I think we as women tend to power through things all the time and certain symptoms and signs really should not be ignored. And so I want everyone to feel empowered and comfortable speaking to their provider about any symptoms that are concerning for bladder cancer. So to get to a couple more things that Dr. Porten asked about, certainly there's this delay in diagnosis that can contribute to the differences between men and women, but there's also evidence to show that there may be hormonal differences between men and women that may contribute to the development of cancer, particularly bladder cancer.

And so I think that's being investigated a little bit further and women also are more likely to present with what we call variant histology or non-urothelial carcinoma. And so that tends to react a little bit differently and respond not as well to our standard therapies both for non-muscle invasive bladder cancer and muscle invasive bladder cancer. And that's really important consideration. And so what can we do about this? How can we improve on this?

And I think having webinars, this is a perfect example. So again, I just want to thank the BCAN for putting this together to raise awareness and to advocate for women. And so I'd want to highlight just one more thing before turning it back to Sima if that's okay. There are some new guidelines for microscopic hematuria that came out from the American Urological Association and they really highlight the importance of evaluating both men and women for non-malignant and malignant causes of blood in the urine. And these guidelines risk stratify patients according to things like age, number of blood cells in the urine, smoking history. And so guidelines I think can be an important part of moving forward and making good decisions for our patients hopefully to not miss any cancers.

Dr. Sima Porten:

And I think you bring up a good point with our new urologic guidelines. And I think the other important aspect of those that was kind of heard was the need for collaboration with other primary care providers for women. Our PCPs, but also with our gynecology colleagues. And so it was great that we saw that those guidelines were done in collaboration with some of these other large medical groups because hopefully that will help with dissemination and that will again raise awareness so that we can take out this aspect of delay in diagnosis.

So thank you for that wonderful overview of setting the stage to move along with the rest of the conversation. And so once a woman is diagnosed with bladder cancer, I wanted to pick your guys' brains about discussing how you discuss treatment options. So let's start with non-muscle invasive bladder cancer. **Do you guys have any different considerations regarding treatment with BCG or intravesical therapy? Would you counsel a woman different from a man with regards to these treatments?** And then we can move on next to considerations for muscle invasive bladder cancer. But I wanted to start with Dr. Schuckman and sort of what she does in practice.

Dr. Anne Schuckman:

Hi, thanks Sima, and again, thanks to everybody for allowing me to participate in this panel today. So for non-muscle invasive, I wouldn't say that I counsel men and women differently with regard to what treatments I offer at what time. And I think exactly what those treatments are isn't really the focus of our discussion today. But I think that there are, as far as I know, really no different sort of gender related responses with non-muscle invasive disease, whether it's high grade papillary disease or carcinoma in situ with men and women. Completely anecdotally, I guess some things that may be a little different in

practice are not so much with BCG, but with some of the intravesical chemotherapies, I do worry a little bit about some of the skin toxicity, particularly with things like Mitomycin if a woman has some incontinence. So I worry with men generally they're not going to leak that out or it's a lot easier to control if they can't detain the therapy in their bladder for the hour.

And with women, I worry a lot about the skin being irritated and I think I'm a lot more cautious about sort of cleaning the skin or advising women to really clean around the labia so they don't end up with skin rashes. And even more anecdotally, I have had more women complain about hair loss when they're receiving intravesical gemcitabine in particular. And I don't know if that's related to maybe thinner bladders than women in more systemic absorption or maybe women are just more aware of their hair honestly. But we're putting together a series at our institution about women who have had that kind of systemic side effect actually from the intravesical therapy. And I don't hear that as much from the men. So again, pretty anecdotal but not insignificant.

Dr. Sima Porten:

I think I worry a little bit about the extra toxicity on the skin too. So our infusion center nurses have barrier cream available to help, particularly in women who kind of talk about having a hard time with continence. And so they sort of counsel and they'll help put that on before someone gets to go home, hopefully to protect the skin a little bit. I think another big question that had come from a couple of my patients is our counseling regarding when it's okay for sexual activity while you're on intravesical treatment.

Because in general we counsel men to wear barrier protection for at least a week after the last treatment because we know that BCG hangs around the periurethral glands for about a week or so. But I don't know, I'm not aware of any data of that being reported in women. However, we recommend that in terms of the same precautions and I don't know if you guys have any insights into that and I know a lot of this is antidotal and things that we kind of encounter and practice and learn from our patients, but I still think it's valuable in terms of thinking, okay, we still use guideline based treatment, it's really important to get patients diagnosed on time and started on that type of therapy.

But maybe there's some nuances in what we talk about and do clinically. Any thoughts from either Dr. Avulova or Scarpato?

Dr. Svetlana Avulova:

I mean I think that's a real concern that we have to be aware of. I mean besides a dental dam protection for the vagina and the vulva, I'm not aware of any barrier protection available. I do think that maybe in general like abstaining from penetrative intercourse for a week just as a sort of good rule of thumb probably is safe. But I'm not aware of any data and I haven't had that question pop up yet, but I think it's a fascinating one.

Dr. Kristen Scarpato:

Yeah, I agree and I think it points to the fact that it's important to talk about this and the fact that none of us have had this question come up I think also sort of says a lot, but we definitely need more data and we need to make sure that we all feel comfortable talking about things like this because we know that patients are going to have questions about it, whether or not they verbalize them.

Dr. Anne Schuckman:

Sima, there's an interesting question I think in the chat from Christine K. talking about sort of medications that we can use related to chemical cystitis during BCG therapy aside from Pyridium and anticholinergics. So I was curious if anybody had any comments on that. It struck me that lots of providers, and I think Dr. Porten can speak to this specifically, are looking at things like acupuncture related to BCG therapy and thought that might be interesting to mention in this portion of our talk.

Dr. Sima Porten:

Yeah, for sure. I can comment on that. So I think in managing BCG cystitis for both women and men, we have our usual dose reduction strategy doing two out of the three maintenance aspects and many are having to give reduced dose anyways because of the shortage and a less of a holding time. In terms of maintaining efficacy all of those are valid ways of hopefully reducing BCG toxicity while still maintaining efficacy.

There's also the thoughts of fluoroquinolone antibiotics day before, day of, day after. Not a lot of people use it in practice, but it's not really purported in any of our guidelines. We tend to use also some alternative medicine techniques, mindful based strategies at University of Washington. Dr. Psutka is actually looking at acupuncture specifically at trying to manage lower urinary tract symptoms and we tend to rely on tibial nerve stimulation that many of our female urologists and male urologists due to kind of manage side effects. And for anyone sort of struggling with BCG. I wanted to move on over into specifically talking about muscle invasive bladder cancer.

And back to you, Anne, in terms of anything different that you discuss or talk about in terms of counseling with regards to treatment or surgery planning from that aspect?

Dr. Anne Schuckman:

Yeah, I think that's a great question and I would say almost the entire conversation is different for me with women patients than it is with male patients when it comes to talking about radical cystectomy. And that really comes down to I think, real differences in functional outcomes with the different types of reconstruction in men and women. So I think that the conversation for me always starts with talking about, okay, where are we from a cancer perspective, and what are our oncologic options? And so that really starts with a good exam and figuring out where is the tumor in the bladder, what is it involving and what is it that actually needs to come out as opposed to what is just the traditional way to do a cystectomy. So I think that's the first step, figuring out is the vagina involved with disease, and/or can it be preserved?

I think the second step, and probably more important long-term is really talking about what functional outcomes are important to a patient going forward. And that's really divided into two major categories, which are sort of the urinary functional outcomes and then sexual functional outcomes. And maybe thirdly sort of overall lifestyle functional outcomes. And those are all really big categories. So when we talk about urinary diversion options in women, we first have to figure out whether somebody is a candidate for a continent diversion and whether that can be to the urethra where you just urinate out the normal way or whether it could be a continent diversion to something like the skin or to the belly button where you catheterize through the belly button. And kind of figuring out that difference first between whether somebody wants to have a continent diversion or to use a urostomy bag where the urine just flows out into the bag is the first major difference.

And women do really differently than men with continent diversions. So we know that most men are able to just urinate with their neobladder, but for women, about half of women will have to catheterize if they have a neobladder. And so I think that's a really, really big question that women have to consider,

and generally most people have a pretty strong opinion about it right away in my experience. So I tell women who are considering a neobladder, if we think that's an option, you almost have to assume you're going to catheterize and are you going to be able to do that through the urethra? And I find many women say, "Well that might be kind of tricky, but I'd be happy to catheterize through my belly button. That seems easy." So I think that's a pretty different conversation with women than it is with men for me.

And then the second part of the conversation really is about, well, what actually needs to come out in this surgery? And historically for women having cystectomies, the uterus would come out, the vagina, the ovaries, everything. And now we know that really for most patients there's only about a 2-3% chance that what we call female organs would be actually involved with the cancer. And that there are several series showing that those organs can be very safely spared from a cancer perspective without running the risk of cancer coming back.

And again, we have to know exactly what the cancer stage is and where it is, but I think that it's really important to talk about one, is this an option and two, what does that mean? Is it important to women or not? So that's a very large portion of the conversation and we know that sparing those organs can have a big impact down the road, both on functional outcomes in terms of how well you can control your urine, how well you can void. Obviously sexual outcomes if we're able to spare those organs have been definitely shown to be better. If women have a vagina that's preserved, it's a lot easier to have penetrative intercourse down the road if that's something that's important to them. So that's a wide and broad overview, but I think that's kind of a start and maybe we can go from here.

Dr. Sima Porten:

Thank you for sharing that. I wanted to take one pause before we move on to talk a little bit more about sexual function and that's where I really want to get Dr. Avulova thoughts on that as she's done a lot of really cool research both in the immediate setting and the later setting. But one question that came up in the Q&A that I thought was also really great is that, **what is the role of genetic testing in women, in terms of especially those that are diagnosed at a young age?** And then also just across the spectrum. I think from my personal experience, of course there's Lynch syndrome that I think about particularly when you take a family history and there's a lot of colon cancers, endometrial cancers and others that you sort of see dispersed throughout relatives. Although Lynch syndrome is more directly related to tumors of the lining of the ureter or the lining of the kidney, I think we're seeing a lot more patients with also tumors of the lower tract and in the bladder.

But how do you guys manage that or how do you refer? For me, I offer almost every patient genetic testing or at least a meeting with our genetic counselors because of telehealth and now the ability to do these zoom visits, particularly at UCSF, it's opened up the ability to have that conversation and for them to be able to send these home testing saliva kits. And so we've been taking advantage of that a lot more. I know there's some emerging data particularly from the group at Memorial Sloan Kettering, but I know this is a lot more geared toward folks with advanced disease. I'd be curious to see what you guys are doing.

Dr. Kristen Scarpato:

I think that urologists have become a lot more facile, fortunately with talking about genetic syndromes, talking about genetic testing and health systems in general have become a lot more equipped with genetic counselors readily available and referral systems in place via telehealth or in person. And so certainly the importance of taking a thorough family history cannot be understated and then referring when appropriate, and sometimes even collaborating with colleagues in medical oncology who have

also a great awareness can be very helpful about certain syndromes that I might not be thinking about. But Lynch is always the first one that I think about with bladder cancer patients.

Dr. Svetlana Avulova:

I would agree. I think a strong multidisciplinary approach in collaboration with our medical oncology partners. I often tell patients who are much younger than expected that we need to consider genetic testing right away and often even before they even think of that question. And they appreciate that thoroughness and that sort of forward thinking.

Dr. Sima Porten:

Thanks. So again, I wanted to think, Dr. Schuckman, you brought up really, really great points when **we're looking at counseling patients who are facing this pretty large operation, and I kind of wanted to move on, what about after? In terms of sexual health, sexual function, and I really wanted to spend a lot of your thoughts about that, and what do you think is important in terms of considerations and what has your recent research kind of taught you and what should we be aware of?**

Dr. Svetlana Avulova:

Yeah, thank you so much for that and for BCAN again for hosting this and Stephanie for getting us all together again. So I think it's really important to set the stage from the beginning to bring up whether women have any issues even before any treatment in terms of sexual function. A lot of them do, but are just afraid to bring it up, and sort of understand what those issues are before any surgery is done. So a lot of women who are unfortunately diagnosed are postmenopausal. Oftentimes they have genital urinary syndrome of menopause, they have associated vaginal atrophy and dyspareunia, so they might not even be engaging in penetrative intercourse to begin with, let alone because of the anxiety of having a bladder cancer diagnosis or any side effects from treatments thereafter. So important to set the stage, important to find out what their baseline function is and then kind of understand where their interests are and the level of importance of sexual activity is for them.

Most of them will say like, oh, my partner's not interested, or my partner has erectile dysfunction. Or sometimes they can be very shy and just think that we don't want to hear them say that they're sexually active because maybe it's their age or just their upbringing. And so again, normalizing that sexual activity for women all ages is important, it's vital to their health and that they can talk to us about this. And so then once you set the stage and you kind of tell them what the options are as Dr. Schuckman so eloquently sort of outlined for us, bring up the fact that they are surgical considerations that would have to be made at the time of these invasive surgeries. And then work with our colleagues in our female urology groups, in our gynecology groups, our psychotherapy colleagues, wonderful resources in terms of understanding the availability of sex therapists in the region, looking at the different societies and availability of these sex therapists.

So one organization that comes to mind is ISSWSH, which is the International Society for Sexuality for Women. I feel like I always butcher that acronym, but you can easily look that up online and you can find a sex therapist at the discretion and privacy of your own computer and find out if there are resources available to speak to someone. Again, whether it's before surgery, after surgery, but having that conversation and engaging our patients. In addition, there's some topical treatments that we can provide for vaginal atrophy and that can start even before you do the surgeries. So vaginal estrogen, DHEA suppositories where again, if some women have a history of breast cancer diagnosis or they may be wary of any estrogen with systemic absorption, DHEA is a viable option for improving vaginal epithelialization. And what I like to tell women, just as when we get older, our skin gets thinner, the skin

around the vagina gets thinner and it's okay to give it a little bit of love in terms of these wonderful therapies.

Dr. Kristen Scarpato:

Can I just jump in for one second and say how awesome this work is. I haven't been a urologic oncologist for all that long, and to see since 2014 when I finished residency to now, the market change that has occurred around this discussion is huge. And this was not something that I was trained in as a resident and it hasn't been that long. And I think all of our practices have benefited from the work that Svetlana and others like Svetlana have done and the discussion around this important issue. Quality of life is important and sexual health is part of quality of life. And I'm so glad to see that this is an important part of counseling and planning for our patients today.

Dr. Sima Porten:

And I also think it's really heartening to see that some of the therapies, because we were talking about some of the different hormonal differences in terms of its interaction with bladder cancer, and I think that's a lot more complex than maybe first realized. And so a little bit of the fear of that some of these therapies which are hormonally based can really help quality of life and how you reconcile that with some of these signals that we're seeing. And I think there's a question from Carrie that talks about **what are some of the hormonal differences that may cause bladder cancer?** And a lot of patients ask me this question and I usually say that it's all about the time point that you're looking at. So when we talk about what hormonal differences cause you to develop a cancer and particularly bladder cancer, there is data on this that actually doesn't really show a very strong link.

And so looking at the nurses, the huge nurses' health study, a multidisciplinary group looked at, well based on the time your period starts when menopause starts, how many children you've had, did you take hormonal replacement therapy? Did you take birth control? When you look at all of those factors and you try to say, does estrogen exposure in any of these different varying ways affect if you develop bladder cancer, there doesn't seem to be a strong link. Our home hormonal relationship with bladder cancer tends to be more well studied in when it's on the worse side or metastatic side in terms of what are the different responses to therapies? Can we use hormonal agents to help in the treatment of patients? Something like tamoxifen and that. So I think we're just getting into some of this and it's a lot more complex than I would say we know. And I'd say we haven't really found strong links yet, a lot of associations, but it's really heartening to see all the work done. I don't know if you guys have any thoughts specifically on that question. I know it's jumping back a little.

Dr. Anne Schuckman:

I don't on that question, but I did want to make a comment on what Dr. Avulova was discussing because she's doing all this great work. And this is just sort of going back to basics. We want to encourage patients to talk about what their baseline function is, and we want to talk about all this great stuff about what we can do surgically, potentially to spare the possibility of function in organs. But I guess one thing that comes to my mind that comes up all the time in clinic is we go through this cystectomy, and three months down the road patients are finally feeling pretty good and they've gone through all the stuff, and I realize a lot of women have no idea what actually happened in the operating room. We have all these great talks up front and they're not having intercourse during that first few months, obviously there's a lot going on.

And at some point a lot of them will say, "Well, whatever happened? Did you spare the vagina? What's going on in there? Do I have a uterus?" We talk about the pathology report postoperatively and talk

about the lymph nodes and all these other things, but it's not necessarily part of the routine discussion for us to go back and say, "Oh, by the way, we spared your right ovary and we took out your left." And so I think it's a really important to remember for us as providers to revisit that and say, "Okay, here's what you have, here's we're working with here." And also for patients to feel empowered to ask. People really have basic... "I have literally no idea what would happen if I tried to have sex right now." So that just kind of crossed my mind while I was listening to talks on it.

Dr. Sima Porten:

Yeah, and I think there's a question that follow ups on the vaginal estrogen. **Are you aware of anything that would increase the growth of bladder tumors or urothelial proliferation?** And I would say I'm not because vaginal estrogen's used fairly frequently. I know by my colleagues in terms of as part of recurrent UTIs and in other kind of situations, so I'm not aware of any data. Are you aware of anything like that?

Dr. Svetlana Avulova:

No, and I think that is such a fascinating question. I think about that question a lot. And going back to your point about the data that we do have from the nurses' health study, one of the important points, and just like you eloquently pointed out, it's not one thing in particular, it's not one hormone in particular, it's actually estrogen and progesterone. We don't think of it like that, but there have been different studies where they show, okay, it's not just the estrogen that may be protective, but it's actually the estrogen and progesterone and having estrogen without the progesterone may actually be more harmful. And one other study that's kind of interesting is when you look at it in a completely different way. Patients who have Turner's syndrome, for example. One study that comes into mind, well, those women who actually have one X chromosome and they have less estrogen during their lifetime, they're actually more prone to bladder cancer.

And so that's interesting. So you can look at it at one particular time point. I do think that there's this sort of protective effect and then for whatever reason when women hit menopause, it's almost like the cancer has been at bay and all of a sudden it's this aggressive thing that comes on. And I have no way to prove that yet, but it's coming. And so to answer that question, well, is vaginal estrogen, is that going to prevent me from having bladder cancer? I don't know, and I don't think there are studies available to show that. I don't think there ever will be at this point just because women, like we said, just have less common bladder cancer. So it's really hard to study these questions.

Dr. Sima Porten:

Yeah, I definitely agree. There's another question here from Carrie, and I think I'm going to direct this one to you, Anne. **She was wondering if, as we know women do have a little bit thinner bladders than men, and does it mean that the number of TURBTs that a woman can have is less?** And I'm not aware of any data that sort of states that. I think it just means that as urologists, we're all very careful when we actually do the procedure, but if it's needed, those differences don't stop us from going and doing the next thing. And there's no data that suggests that it creates more thinning down the road or any sort of issues from that. I'd be interested in what you guys think.

Dr. Anne Schuckman:

Yeah, I would agree with you Sima. I think it just means that from a technical point of view, we need to approach men and women differently, even just during something like a bladder biopsy or a TURBT and not assume that every bladder is the same as every other bladder. And so I'm always particularly when

operating with residents and trainees, sort of saying, okay, we got to think about this is not a man with a thick bladder from a prostate. And just really try to guide the depth of the biopsy or the resection with that in mind and be a little bit more ginger up front. But we know that, that urothelium sort of regenerates over time and it doesn't have a permanent thin spot there per se, as far as I would interpret that. And I don't think there's any limit to the number of procedures that somebody could have.

Dr. Kristen Scarpato:

Sima, can I make one more comment?

Dr. Sima Porten:

Of course.

Dr. Kristen Scarpato:

All of this discussion is just making me think of a lot of things. But one aspect of bladder cancer care that I just wanted to point out was how important the patients are in offering their feedback and answering surveys and participating in clinical trials. And so I want to thank all of you who are on the call or who are listening for participating in these studies that help us understand how patients feel and respond and how your quality of life is impacted by the treatments that you're given.

And so one trial that comes to mind right now is a big multi-institutional trial CISTO looking at patients who have non-muscle invasive bladder cancer and have failed BCG. And some patients go on to have a radical cystectomy in that trial. Other patients try intravesical therapies. But regular survey responses from patients following whatever treatment decision patients choose gives us insight into the impact of treatment on patient-centered outcomes. And so thank you for participating in these trials and hopefully studies like CISTO will help us understand a little bit better how we can counsel patients and help you make the best decisions for you.

Dr. Sima Porten:

And I think that does dovetail into some questions that had come in even before about **how can patients and women find out about clinical trials?** And I think Stephanie will be so kind as to put BCAN's resource there in the webinar chat that kind of keeps people updated about tools that are available. And then the other part I wanted to ask you guys to see, **how do support groups interface at your guys' institutions?** Are you aware of any support groups that are specifically geared toward women? And could you highlight resources out there that are open for anyone to sort of join? We have a support group, but it's blended group, but I know that others have other opportunities and resources out there.

Dr. Anne Schuckman:

We have a support group, it's a blended group, but a couple times a year, I do girls only sessions. And so it's usually twice a year that we do that. And they're kind of funny. I mean people are really shy. But it tends to be a core group of patients who attend the Bladder Cancer Support group. And the more we do them, I think people are getting a little more open. But this is kind of new. And some of that work has come out of BCAN inspiring me actually to do those. And I think it's been a really nice change. I know that through BCAN, through Inspire, I think there are some women's groups and I think others on this may be able to speak more to that than I can.

Dr. Svetlana Avulova:

Yeah, I would say that I've been told by patients to let my patients know about Inspire. And so I do that now and they love it. The first thing I do is I actually give them this booklet, which I have a full drawer of these. So literally every patient that comes, I give them this and they really appreciate it. And so again, this is to BCAN's amazing resource for our patients.

Stephanie Chisolm:

Well ladies, thank you for queuing up my announcement that starting the latter part of January in 2023, we will be introducing an online women's support group to really help garner information, garner the ideas about what we need to be doing a better job as an organization, as BCAN is. But then we also share this information through our think tank, our scientific reading, and also directly with these really incredible women who are doing so much phenomenal research. So thank you for queuing that up because we will be sending out an invitation to join the group sometime after the early beginning of next year. So you'll see something right away in your email coming up, because it will be here before you know it. So we're really looking forward to that. It looks like a couple more questions have come in.

Dr. Sima Porten:

Yes, I think it's actually wonderful suggestions that I'm copying and pasting on my side document here, was both Pat and Nancy shared that Sibley Hospital at Johns Hopkins also has a women's support group that has been really helpful.

Stephanie Chisolm:

Yeah, absolutely. And that's headed up by Armine Smith and Jean Hoffman-Censits. So you have both the urology perspective and the medical oncology perspective. And I'm really delighted to say that Karen S., who is on this call, happens to be an oncology nurse and she also happens to have gone through non muscle invasive bladder cancer and then also had the pain and privilege of taking care of her husband as he went through muscle invasive bladder cancer.

And she will be moderating our support group. So we're really thrilled that she'll be doing that. But we'll send out some announcements in the next week or two just so you have that on your calendar and you can join us. But I think obviously sharing your concerns with these wonderful people on this call are really going to help change the landscape for bladder cancer for women going forward. So we really appreciate your input. I know we're going to be closing down in just a minute, but I do want to remind you, any suggestions, any other thoughts that you have when you get this survey at the end of today's program, make sure you drop those in there because that's really going to be beneficial to us as we begin to plan for 2023.

So doctors, do you have any closing comments? Anything you think women should pay attention to?

Dr. Anne Schuckman:

Well, I'll always have a closing comment of some sort, I guess. I mean, I would just say look around and make sure you find a provider you're comfortable with. There are a growing number of female urologists and female urologic oncologists scattered around the nation. And just because you're a female patient doesn't mean you need to go to a female doctor. But there are lots of options and if you have friends or family members who are not finding somebody who's talking to them about options and only talking to them about what they have to do, that might not be the best provider.

And so I think that, again, just look around, know there are options. For something particularly I think like a cystectomy, it's worth it to travel a little ways if you need to find a provider you connect with. And

this is a lifelong relationship that you have with your doctor. I see my patients forever after a cystectomy. And so you want to find somebody who you think is going to be on your team. And there are people out there so look hard and find a connection that makes sense to you. And thank you so much for your participation in the webinar today.

Stephanie Chisolm:

Dr. Porten, do you have anything else?

Dr. Sima Porten:

I would say that keep out there, keep at it. Make sure you share with your providers' questions, experiences. I would say I learned as much from my patients as probably more than I can teach them or help them through their journey. And so these are all amazing, important questions. I've already, from the conversation and that I've like, we have a couple things that we have to add to our teaching documents and some of our information booklets and maybe some things to look into in terms of trying to answer some of these questions. So I would say stay engaged. You guys can do this, you can make it through this journey and still have a joyful productive life. And so that would be my closing comment.

Stephanie Chisolm:

Okay. Dr. Avulova and Dr. Scarpato, we'll get to you in just a second. Because there was another question, because this is a topic that's very relevant to our research community about the microbiome and gut bacteria. And there was a question that came in**. Is there anything about women's gut bacteria that plays a role in how women process treatments? Or is this a topic that, wow, we need to do more research on that?** What are your thoughts?

Dr. Sima Porten:

I would say that we need to do more research on this. However, much of it's being done, some supported by BCAN. I think the early stages of this are being investigated. I know of probably four or five projects across from different institutions, primarily at Fox Chase, by Dr. Bukavina. And I think that happens to be BCAN funded as well. And so I would say it's a really interesting question with some very strong roots in science borrowing from other cancers. And I think it remains to be seen how much our gut bacteria affects how we respond to treatment and also how we develop disease.

Dr. Kristen Scarpato:

And Dr. Bukavina, another female urologic oncologist who I think is a force to be reckoned with and is doing some really exciting work. I will just add for my closing comment that it's an exciting time for bladder cancer. I've seen, again, in my relatively short career, a large amount of resources and energy being shifted appropriately to bladder cancer and even more recently into women with bladder cancer. And so I think the future is bright. There is a lot of exciting discussion, research, support, and I'm very optimistic about where we get with bladder cancer and how our female patients end up doing particularly in important areas that we haven't always focused like sexual health after cystectomy.

Dr. Svetlana Avulova:

Yeah, I mean, I would echo everyone's comments. I would say that there's still a lot of research to be done and I think the most important questions we get are from our patients. And so keep bugging us with questions because we need to figure this out.

Stephanie Chisolm:

Great. Well doctors, I will share all of the questions that came in with you because I think that is something that we get a archive of, so I'll share that with you as well. So if that sparks your thoughts for future awards, that's a great idea and we really look forward to seeing you again on other programs. Thank you so much for your time. We're really delighted. This was a very different format for us and I hope everybody really appreciated this nice dialogue with experts who also happen to be women talking about women and bladder cancer.