

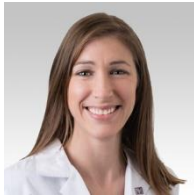
WHAT I HAD WISHED I HAD KNOWN WHEN I WAS FIRST DIAGNOSED WITH BLADDER CANCER | OCT 28, 2020

With Dr. Joshua Meeks and Dr. Alicia Morgans
Feinberg School of Medicine, Northwestern University

Meet Our Presenters:



Dr. Josh Meeks: Dr. Meeks is an Assistant Professor of Urology at the Northwestern University Feinberg School of Medicine, as well as Section Chief of Robotic Surgery at the Jesse Brown VA Medical Center. He is urologic surgeon with expertise in the diagnosis, treatment, and management of bladder cancer.



Dr. Alicia Morgans: Dr. Morgans is an Associate Professor of Medicine in Hematology and Oncology at the Northwestern University Feinberg School of Medicine. Her primary focus is hematology and medical oncology, with a special interest in genitourinary cancers.



Darrell Nakagawa is a long-time volunteer with BCAN. Darrell was originally destined for the opera stage, and appeared with national and international stars in performances in Hawaii, Houston, and Cincinnati. Since his diagnosis in May of 2017, he's continued to live a very active life.

Ann Mardon is a patient advocate who received treatment at Northwestern Medicine. She spent most of her early career on the East Coast teaching elementary school, and she's a recent transplant to Chicago to be close to her grandkids.

Dr. Morgans: Thank you, Darrell. Can I ask a quick question before we go back to Josh? I'm sorry to interrupt everybody, but we've had some questions about how to best access BCAN, and that can be to help understand who's a good surgeon, what's a good cancer center, sort of that thing we were just talking about. I wanted to ask Morgan Stout, Outreach and Education Manager here from BCAN, who can help us understand, because there is a concern by folks on the webinar, by folks in general, how do you find BCAN and what if you live somewhere where you're far away from all of these big centers? What do you say to that, Morgan?

Morgan Stout: Absolutely, and that's a really great question. The best way to access BCAN is via our website. We're open 24 hours a day online. Our participants have probably found us some way, shape, or form, and the best way that folks can find us is sometimes through their urologist. We have a lot of folks that come to us who say, "My urologist recommended that I look up BCAN," and there's a lot of other folks around the country that are doing a good job at spreading the word. Some folks give their urologist their information about BCAN and say, "Hey, I found them on my own Dr. Google search," and they take the information back to their urologist. We also have some great partners in industry who try and spread our information to the urologists they talk to as well. Overall, the best way to find us online.

Then as far as finding reputable doctors, with BCAN we do have a really great scientific advisory board. We don't typically recommend one doctor over another doctor, but there's great teams around the country, and we do try and point people in the right direction if they're just floundering, and say, "Well, we know that there are great doctors everywhere. You can probably find a doctor close to you, but if you need some help, here are three or four different places that are within driving distance of you."

Dr. Morgans: The one other thing I would say, the one good thing that has come out of Covid is that we're actually all doing a lot of telehealth right now, so if you need a referral for... or if you want to even just call a cancer center that BCAN recommends and say, "Can I see Dr. Meeks by telehealth," not Dr. Meeks, any doctor, you should probably be able to do a one-time consultation or even some follow-ups. Clearly not surgery through the phone or through the web, but that's one thing that has come out of Covid that we are able to see people remotely even when you can't drive sometimes. Back to you, Dr. Meeks.

Dr. Meeks: No, I think that's really wonderful. Again, I think those are great points. Even if you just want to talk about where things are and what kind of care you've received, I think most centers are open for that at this point. It's the fourth most common cancer, but at the same time there's a lot of heterogeneity in how it's managed. I think having a visit with a bigger cancer center or someone who specializes in it, it probably makes a lot of sense.

Ann Mardon: I had never even heard of BCAN, to tell you the truth, when I first started. I didn't know about BCAN until Dr. Morgans told me about it three years later when I was going for the chemo.

Dr. Morgans: I think BCAN was young. When you started, BCAN was young. BCAN's popularity and really just their ability to touch people has really expanded just time and time and time again now. They are so much more accessible. There's so much here. I'm glad you made it to them.

Ann and Darrell, we have had a lot of questions, just want to ask your opinions, how do you know if a doctor is the right doctor for you? Are there questions that you can ask? The things that I would ask are things like even just seeing if the doctor allows me to ask a question, because sometimes doctors don't

feel comfortable letting people ask questions, and that may be time pressures or personality or whatever it is, but I need to be able to ask questions of my doctor, so that would make me feel comfortable. But how do you know? How do you choose that person that's right for you? Darrell, what do you think?

Darrell Nakagawa: A lot of it is checking credentials. Even on the Northwestern site, being able to check the background of the doctor, publications. Both of you are great published professionals, and even Dr. Meeks having his history in robotics is awesome. That's a way of building trust. Also, Ann mentioned how at ease she felt with Dr. Meeks immediately. That's key. Communication, I think, is critical to having that patient/doctor relationship and trust, and say, "Feel free to ask questions any time. I'll get back to you as soon as I can." That's where you feel that the doctor cares about me, and I'm not just a patient.

Dr. Morgans: Absolutely. So credentials, making sure that they have the training that they need. If they're going to be doing a surgery on you, they should be a urologic oncologist so they have that training. That's really important. Are they engaged in academics? That's important for some people. Other people, they just want to know, "Hey, how many surgeries have you done? Do you do this every week or do you do this once every six months?" Because you really, I think, need to choose a doctor who does these surgeries on a regular basis. Like we said, that personal engagement, that connection that you have with that doctor. Ann, what are your thoughts?

Ann Mardon: I think you just have to trust the doctor from the beginning. I started off with Dr. Lewicki. She was recommended to me. She recommended Dr. Meeks to me, who recommended you, Dr. Morgans, to me. From the time I met each of these doctors, I have to say there was something there. I don't know what it is, and I haven't felt that way with every other doctor years ago for other things. There was just something there that made me feel like Dr. Meeks knows what he's talking about. Dr. Meeks understands what I'm going to go through. He's telling me the truth, because the questions my husband and I asked him, he was able to answer them, and he answered them on a down-to-earth basis, because medicine is not my thing, all these big medical words. He brought it down to earth. He made us understand what are our choices. This is what is going to happen. We put our trust in him. My husband felt the same way. I think if he had felt, "Oh wait a second. We need a second opinion," I probably would have gone for a second opinion, but the both of us had a feel right from the beginning about Dr. Meeks and about you, Dr. Morgans, that, yep, you guys are looking out for my benefit and you know what you're talking about.

Yeah, did I look later on when I got home to see what your credentials were or what you've done before. I did. I went on those sites. I would do that for any doctor. I was very happy. I could not see any reason to go get another opinion at that point. I just felt like, yep, I'm making the right choice.

Dr. Morgans: Can I just ask one quick question about support services? Not the support in your family, but about things like physical therapy, nutrition, lifestyle. These are all things that BCAN endorses on their website as well, that are part of the softer side of caring for cancer. I don't necessarily think they're softer. I think they're critical in keeping you whole as a person. I'm wondering what things did you find important as you were recovering from surgery, recovering from chemotherapy, trying to keep your life on track. Darrell, what do you think?

Darrell Nakagawa: The BCAN blog site, Inspire.com, was really part of my support network and a way to get more information. It's all patient to patient. I think that really helps understand when someone's been there with the same condition.

Dr. Meeks: That's great.

Ann Mardon: I didn't have that, so I really can't answer that. To me it was what I read.

Dr. Morgans: I do want to give Mary Kate an opportunity to talk about support groups, which are also a big part, for some people the way that they cope and the way that they move forward. Mary Kate.

Mary Kate: Thank you, Dr. Morgans. Yeah. We're excited to use this as our kickoff to start virtual support groups here at Northwestern. As Dr. Morgans mentioned, one of the good things of Covid is that we can do everything virtually. The group is open to anyone. You do not need to be a Northwestern patient to attend. Anyone on this webinar, we would love for you to attend. Information can be found on the BCAN website under support. You will need to RSVP. We will then send you a link of how to access the group. We're having a group for patients, caregivers, survivors, just a general group which will meet the third Wednesday of the month at 6:00 p.m. central standard time, and then one for females, which will meet the first Thursday of the month at noon. The groups will be led by our amazing patient advocates here. If you have any questions, just email marykate.keeter@nm.org, or look on the website and we can send you the information. Hope to see you there.

Dr. Morgans: Thanks, Mary Kate. Morgan are there any questions in the Q&A box?

Morgan Stout: Yes. We just (a) wanted to thank you so much for being such valuable panelists today, and I think there was one question that I saw that I think I can generalize, because I saw it pop up a couple times for Darrell and Ann. As patients, when you were first diagnosed, would you say that it was easier to take it just one step at a time and kind of wrap your head around that one step, or did you think that there was more that you could be doing?

Ann Mardon: I just took it step by step as it was recommended to me what I should be doing and what my choices were. I didn't want to wait any longer. I just wanted the cancer gone. That was my main thing. It was like the sooner the better, and I just kept asking when can the surgery be done? When, when, when? I don't know if I would have taken more time. Dr. Meeks said, "Don't worry about it. It's not going to get worse and the next few weeks, months," but I didn't want to do that. That was my choice. Just do it as I know what to do, and just do it and get on with my life. I guess that was my main thing.

Morgan Stout: What about you, Darrell?

Darrell Nakagawa: I'm a certified geek, so I need to know a lot of information, but I do try to take everything step by step. It's hard when you've got a busy life to fit it all in, so understanding what is the timeline overall is key.

Morgan Stout: Absolutely. Thanks so much for your insight. Dr. Meeks and Dr. Morgans, let's take this to a non-muscle invasive point of view. If you have patients that are non-muscle invasive, are there

things that you suggest to them in that same vein, whether just trust the process, take it step by step, what else they could be doing, that sort of thing?

Dr. Meeks: Just for non-muscle invasive, I think the hard thing is for the patients diagnosed understanding the spectrum of bladder cancer, as far as where they fit in that risk spectrum. I think that's the first thing. The patient diagnosed with a low risk tumor thinks that they're in the same boat as someone with a muscle-invasive cancer, and really these are biologically very different. We treat them very differently. It's our responsibility to try to explain that to them in the best way that we can as far as recurrence, progression. I think having someone that's willing to sit there and have that discussion with you, as far as, "This is what's next, this is what I see the next two to three years looking like for you. Our major obstacle is your cancer coming back, but not necessarily getting worse. These are the therapies that we are looking at."

I think it's really hard, because when you're diagnosed everyone thinks about bladder removal as being the next step, almost no matter what grade and stage you are, so, again, I think trying to get clarity and get a good discussion about where people fit on that spectrum, because, again, 80% of folks are going to be non-muscle invasive and will probably be able to preserve their bladder, and then the 20% who are in the more muscle invasive and advanced state, that's almost a different treatment group entirely, and it's a different momentum and a different timing, and so having that together... The good news I'd say for the non-muscle invasive folks is that we have so many more options. We have systemic therapies now we can offer patients. We had less than one therapy. When people don't respond to BCG they get bladder removal. Now we have so many more options for them. I think that's quickly becoming a team approach, again, with how we're treating folks. I think the future is only going to be brighter for patients.

Dr. Morgans: I would agree, and I would say as you go through the process, I'm never the kind of person who will just trust in whatever process. Like I said, I need to be able to ask questions, so if you can trust and that's your personality, then trust your doctor and go with that. If you can't, it's okay to ask questions, and you should. When you have non-muscle invasive disease, just like with any other health condition, you're going to go through your treatments, but you do need to try to have a diet that's a nutritious diet, a heart healthy diet, low in saturated fats, high in vegetables, high in healthy grains and fruits. Get some physical activity. You don't need to run a marathon, but try to be as active as you can be. Pandemic or not, we all have to try to do that, because the healthier your body can be regardless of what you're dealing with in terms of BCG or other installations and other treatments, the healthier that you're going to be, both physically and mentally.

That's the other piece. Make sure you pay attention to your mental health. Make sure you talk to people when you need to. If you feel like you need extra help, you can always ask your team, "Can I speak with somebody? Is there a social worker? What other supports can I have?" Never be embarrassed to ask questions or to ask for extra support, because you deserve it.

Morgan Stout: Great. Thank you so much. I want to thank the panel again so very much for your time, your expertise, and generally providing this resource for others who are in the same situation.

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