

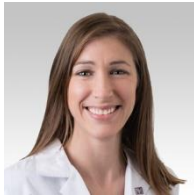
## WHAT I HAD WISHED I HAD KNOWN WHEN I WAS FIRST DIAGNOSED WITH BLADDER CANCER | OCT 28, 2020

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:** As you heard, my name is Alicia Morgans. I'm a GU medical oncologist. I really only see patients who have bladder cancer and prostate cancer, a couple other cancers as well, but that's the majority. I have to say, on behalf of Dr. Meeks and myself, we are so thrilled to have the opportunity to really talk with our patients and with you about all of the things that they wish they had heard and had known before.

Why don't we do a quick maybe two minutes each for Ms. Mardon, for Ann, and for Mr. Nakagawa, Darrell, to really give a brief summary of where you stand, your brief journey, and we'll get into the details later, but maybe one to two minutes on that. Let's start with Ann. Can you tell us a little bit about yourself, one to two minutes?

**Ann Mardon:** Sure. Actually, I was diagnosed with the bladder cancer in March of 2014, but it wasn't because I had any symptoms for bladder cancer. I was going for a bladder prolapse surgery and they were doing a testing, and I went home one night and found that I had really bad pains. The doctor said, "Come in," she said, "Because I think I think we'll do a CAT scan. It's probably stones." I went in and had the test. By the time I got home she was calling me and telling me to go meet up with Dr. Meeks, and it was a Friday afternoon and she was waiting for me and it was cancer. I've been doing great since then. It's over six years, and I'm just living my normal life and happy about it.

**Dr. Morgans:** Wonderful. We will ask you more questions about how you got to today, because I know it's been quite a journey and you are one tough grandma. We will get to that in a minute.

Darrell, can you tell us in one to two minutes what was your basic journey?

**Darrell Nakagawa:** Oops. Hi, I'm Darrell Nakagawa. I'm a 3-1/2 year RCIC survivor, thriving. My journey began actually as a result of my physical. The doctor noticed that I had microhematuria, and that it was time to go look or to find a urologist to probe. I'd also had seen elevated PSA levels for about two years before that, so we had been somewhat monitoring that and looked at the availability of doctors at Northwestern, and ended up with Dr. Kozlowski, and then due to his retirement, switched over to Dr. Meeks, and just jazzed that I'm with one of the best institutions, in my humble opinion, here in Chicago.

**Dr. Morgans:** Well, that's very, very kind of you to say, Darrell.

**Dr. Meeks:** Thanks Ann and Darrell for being with us today. I can't tell you how helpful this is for all of our patients as we sit in front of them and have discussions about their diagnosis. They go through such a journey. It all begins at one place, and I wanted to get your thoughts on that. If you can think back to that initial time when we had that discussion.

You've both elected to undergo surgery down the road. Tell me again about how that was like for you. What kind of thoughts were going through your mind when we first had that discussion? What was your first thought and how did that evolve? Just start us down that road. Darrell, do you want to start and then we'll go to Ann?

**Darrell Nakagawa:** Sure, sure. I accidentally found out that I had cancer before the doctor communicated that, and, again, I was with Dr. K, because I happened to be on a study for another liver thing. The research analyst let the cat out of the bag before I ever saw any of the results from the

pathology. From the initial consultation I had an MRI, then a CT scan, and they already diagnosed it there. Then had staging TURP, and then began chemotherapy. I was diagnosed with muscle-invasive urothelial carcinoma with carcinoma in situ and squamous cell differentiation, and I had no clue what any of that meant. Having the ability to understand what I was facing and have a logical path of treatment and survival was key.

**Dr. Meeks:** How did we do as far as... That's a pretty heavy amount of information. It hits words to us as providers. I'm not sure it's possible, quite honestly, to explain that. You seem like you did a lot of research into that. Again, we have a pretty bright group of folks that really know a lot about their cancer by the time they get far into it. How did we do as far as explaining that? Do you wish you would have known more? Did that matter? What did you take from that and how did you figure all that out?

**Darrell Nakagawa:** Well, unfortunately, I also consulted Dr. Google, and I got the pathology reports before I ever got to talk with my doctor, Dr. K at the time. Communication at this point is really critical to really understand. I think I could have had a lot more conversation to really help me understand what some of the challenges might be and what the journey was.

**Dr. Meeks:** I will come back, because there's more we can unpack from that. Ann, you and I had this discussion together. Tell me again about that and the information that you got. How did you guys process it?

**Ann Mardon:** I had about an hour to process the fact that I had cancer before I met you. When Dr. Lewicki called me and she said, "Are you still at the hospital?" I was like, "No," I was in Costco. I'll never forget. She said, "I really need you to see my colleague now." I was like, "Now?" She was like, "Yes. She's waiting for you." It was a Friday afternoon. I went home, grabbed my husband, and we went down to see you, so I really didn't have that much time to think about it.

I think you handled it really well, because I probably was shocked a bit, but you told me exactly what was happening, how you wanted me first thing Monday morning to do the scraping, and you explained it very well with your little diagrams. I was just taking it from there. Once I had the scrapings and then you explained to us my choices, I just felt, well, I want to get rid of the cancer. I don't care if I go through the chemo and I'm still going to have to have the bladder replacement, a Neobladder, I didn't want to go through the chemo first. That's how I got to the point with you. I just put all my trust in you, and I'm glad I did. I was happy with everything. I did end up with chemo three years later, but that's okay. That doesn't bother me at all. It was a tough time, but I got through that as well with Dr. Morgans.

**Dr. Meeks:** Right. To go back to Darrell, you received chemotherapy before surgery. At the time, I'll admit that's become the standard of care. It wasn't that it wasn't the standard of care at the time, but honestly it wasn't as well accepted. How was that decision made? How did you elect to make that? What were you thinking about as far as weighing the benefits of that?

**Darrell Nakagawa:** I would say that this was provided as the best... It was positioned as the best treatment. Again, this was 3-1/2 years ago, and I had had some lighter forms of chemotherapy before then, so it was like, "Okay, if we think that would be the best course, let's go for it."

**Dr. Meeks:** Can I ask, as far as at this point you're looking at this potential long course of treatment, some form of surgery, likely some form of chemotherapy involved, what do you think played the biggest

influence on you? Was it us as providers? Was it BCAN? Was it your family? What was playing a role? Everyone goes through usually a dark period where you're facing probably for the first time your own mortality. You two are incredibly resilient, as far as people that I've known, and trajectory just moving up so high. Tell me about how you got there, because if I could bottle that, I would love to figure out how to provide that for everybody. Maybe you could each talk about that.

**Ann Mardon:** I really think you, Dr. Meeks, did a really great job of getting me through this step by step. I know the word cancer to me was like a bad word, it really was, and when I heard it I just wanted it gone. When you gave me my choices as far as, "You could go through the chemo. There's no guarantee that it will come back." When we made the decision as a family, because my husband and my daughters were with me, we decided this was the best way to go. I really wanted the surgery and I felt that was what was going to get me back to a more normal life, the kind of life that I wanted to keep on going with. That's why I chose that. It wasn't that I didn't... I mean, I've heard things about chemo before this, but it wasn't that I was totally against the chemo. I was just totally wanting the cancer gone, and if surgery was the way to go and Neobladder was the way to go, it all sounded very good to me. I did some research, basically on the Northwestern site. At the time I didn't even know about BCAN. It just sounded like the right thing to do.

As you know, Dr. Meeks. I couldn't wait to get the surgery done, and I was really happy that I did it. I still am. I don't regret anything. I don't regret the fact that three years later the cancer did come back and I did end up with chemo and more surgery, because to this day I feel like my new normal is fine. My new normal is great. I'm doing exactly what I wanted to do and would have been doing with or without this health situation.

I guess the biggest thing is staying positive. I just hoped all along that it will all work out, and it did. I was lucky and I was determined.

