

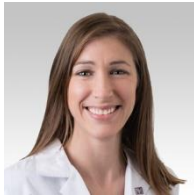
## WHAT I HAD WISHED I HAD KNOWN WHEN I WAS FIRST DIAGNOSED WITH BLADDER CANCER | OCT 28, 2020

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. Meeks:** Ann, you've always had one of the most optimistic impressive perseverance that I've encountered. No matter what kind of things we went through, and everyone who goes through this journey has that, again, do you think that... I've always been impressed by your family support. Do you think that's where a lot of that comes from, Ann, or do you think that's from... Again, this is the first time that we had met is when you felt this. Is this something that's been consistent as you went along for your whole life?

**Ann Mardon:** Yeah. I think I've always been positive. I think I've always felt like I'd accept any challenge that there is, even in my career. To me this was a challenge. This was my own personal health challenge. I was going to get through it. That's how I've always been, yeah. I don't think it's just something new to the fact that it was a health issue. I've never had a health issue before. This was the first time. This was the first time I've ever even been in a hospital other than having my daughters, so it was really all new to me. Of course, I made up for all those years of not being in a hospital, because they got to know me very well at Northwestern. Yeah, I guess it is my attitude, but I really do think that a lot of it was... The biggest part was my family support and you, Dr. Meeks. Dr. Morgans at that time I didn't know, but Dr. Meeks you really got us through this, and I think that was it. I think you need a very supportive doctor, but I also think you have to have a lot of faith in your doctor, which, of course, I do. I did for you, and I always will. I'm sure that's what got me through this.

**Dr. Meeks:** Then, Darrell, on your side of it, how was your experience and what did you do to... What was your support like and how did you come to make decisions and really try and just power through all of this?

**Darrell Nakagawa:** Well, I'm intensely independent, and at diagnosis my belief was, "We're going to get through this."

I've always been that way. I've managed major projects professionally, and projects have ups and downs and challenges, and I was leading one of the largest programs at work at the time, so it was like, okay, this is just another hiccup with me that just has to be surmounted, and we'll just go forward. This is part of the journey. You and I have talked about positivity and drive, and I think that is critical to any patient diagnosed with a major health challenge.

**Ann Mardon:** I think the family support is really... For me, it was the biggest thing. Dr. Morgans and Dr. Meeks both know that no sooner did I get home from the hospital our three-month-old grandson was coming to stay with us, and at the time our granddaughter was four and our grandson was two, and they were coming over after school. The two year old stayed with us. That's what I wanted. It wasn't like I could play with them or do anything. I just knew they were there. They were having fun. They were playing. My husband was taking care of them and me, and that did so much for me. It just made me feel that, okay, this part of my life is normal. We'll get to the next step.

And I did. Eventually, I was in the schoolyard waiting for them to come out of school. This was just goals I set for myself. Dr. Meeks told me it would take about three months to get back to normal, and it took me about six weeks. In my opinion, I felt normal. I went out to dinner six weeks later. I was at the schoolyard six weeks later. I was feeling good. To me it was a great thing to be out there with other people, and that's what I wanted, and that was my goal.

**Dr. Meeks:** Now, you've both been very... You've talked to other patients who are trying to make those choices. Looking back through your own journey, where did we go wrong? Where do you wish that we would have done a better job? Or what do you wish you would have known, knowing what you know now? Trying to look backwards, where do you wish you had more information or had a different perspective? Is there something that we could have... that could have been told to you or that you said, "Oh, boy, that was not what I thought it was going to be like"?

**Ann Mardon:** For me... Go ahead. I don't think there's anything that I could have known before. One of the things I do wish that, not just me, that I think is more well publicized should be bladder cancer. I've always heard breast cancer, colon cancer. Those are the ones you hear about all the time. Those are the ones you read about. So and so had this. Bladder cancer to me was like... I had never really even heard of it. Never thought of it. Probably never heard of it. I wish it had been more publicized. Not publicized, but where I would have heard more about it. To me it was a total shock, because I thought I was going in for prolapse surgery and I ended up not having my bladder. I don't think there was any more that you could have done, as far as... I think you educated me really well with that. Like I said, I went on the Northwestern site. I learned really a lot about the bladder and about what happens. That was a lot of information for me, and that was fine. I don't know what else could have been done, unless I knew more previously about the cancer itself.

**Dr. Meeks:** I don't believe... You didn't have the opportunity to really speak to anyone?

**Ann Mardon:** No, because you did ask me if I would, and I said yes it would be a good idea, but obviously you couldn't get anybody, so I really couldn't talk to anybody who had this before. To be honest, I really didn't even know that many people who had cancer. A cousin of mine had just finished the year before with breast cancer, but that was it. I really didn't know much about the treatments. Luckily it doesn't run in our family.

**Dr. Meeks:** Darrell, what were you going to say?

**Darrell Nakagawa:** I wish I had known more about the options. I was pretty much advised that I would end up with an IC purely because I'm a diabetic, but even today in 2020 we have so many more options, including bladder sparing, that I sometimes wonder how life would be different. Having much more education or the ability to tap into, and BCAN is great about having that information easily available, even in other webinars that are on their site as well.

**Ann Mardon:** Yeah, now that I think of it, I can't say that I didn't know anything about cancer, because my husband had had colon cancer a few years before, and he didn't go through chemo. He had surgery done. Believe it or not, two weeks later he was at work. I guess I just followed in those footsteps. I did what he did. I felt like I can keep on going, and maybe he's part of the reason why I have this positive attitude towards it. He got through it, I could get through it.

**Dr. Morgans:** I think the positive attitude is so, so important. That's important for kids when they're going through school. When they get something wrong they have to get up and try again. It is equally, if not more, important when we're adults and we face some of the biggest challenges that you've had to face. I really appreciate you talking about the things that you had in your life to draw from, whether it was personal, just who you were while you were working on these projects. This is just another hiccup. I'm just going to keep on rolling. That's fantastic. Or whether it's your family, whether it's your loved

ones, whether it's places like BCAN where you can come to at least find information. As we continue, there are a lot of questions coming in, just trying to understand a little bit more about each of your personal stories, because at the point where you are now, you're looking back, it seems like, "Oh, I just had this, I just had that," but could we walk through each of those just a little bit more so that people can understand it wasn't just, "Oh, last week I did this, and then this week I'm off running to pick kids up and running this project." You guys went through a lot, and so this resilience that you had is really clearly coming into play.

Darrell, can you just walk us through diagnosis. What happened then, and explain what's an IC, what's an ileal conduit, so folks, if they don't have such experience can really understand.

**Darrell Nakagawa:** Sure. My initial visit was October of 2016 with the urologist. My CT was early November, MRI was the week after. That's when the final diagnosis happened. My TURP was December 2, and that's when it was diagnosed as muscle invasive with the carcinoma in situ and with squamous cell differentiation. After that was when we chose a course of chemotherapy, so I got to meet with the oncologist later in December. We weren't sure what course I would go through. I ended up with dense dose MVAC as treatment, and then post-chemo I had another cystoscopy to see if the chemo had worked effectively. His observation was he expected white scarring in the tumor area. Instead, he saw pink. That's when the recommendation of going ahead with the cystoprostatectomy. Early on in the course of treatment they saw that the prostate test that they did showed a high propensity for prostate cancer as well, so that's why I ended up with a cystoprostatectomy.

**Dr. Morgans:** That means they took out your bladder and your prostate, which is probably the most common combination for men. Sorry, I just wanted to make sure we put that into non-medical terms. You're like a doctor now, Darrell. You know all these terms. Anyway, continue.

**Darrell Nakagawa:** You should have seen me trying to spell that as I was going through it. It was laughable. Thankfully, I had a skilled surgeon, Dr. Meeks, that was able to do nerve-sparing, so that's important to us guys. Since then, I went back to work after four weeks, and actually the day after surgery I was in a conference call with vendors in China because they were so incompetent. Again, it's that drive that I have to get well.

**Dr. Morgans:** Yeah, absolutely, and I cannot believe it. I hope you were not on pain medications on that conference call, but either way, I guess, you got through it, right?

**Darrell Nakagawa:** Absolutely.

**Dr. Morgans:** And you were better equipped than them, it sounds like.

**Darrell Nakagawa:** Yep.

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