



Panelists:

Dr. Sima Porten and Dr. Sam Washington

University of California San Francisco, Department of Urology

Ben S. and Brittney T.

Patient Advocates

Introduction and Patient Experience

Stephanie Chisolm: Hello, and welcome to Bladder Cancer Under 40. Yes, it's rare, and yes it does happen. Statistically bladder cancer strikes most adults later in life, in fact, the average male patient is in the 70s. Yet, we know that there are young men and young women who are occasionally diagnosed with bladder cancer. And so, what happens when you're not old enough to be a bladder cancer patient? Today they're all here to share with you a lot of information about bladder cancer and young people, and also to identify that we don't always have a lot of information, because it doesn't happen as often. So, let's talk about the experience with being diagnosed with the sixth most common cancer as a young adult first, and then our experts are going to share what's known about bladder cancer in this particular population. And I'll just give you a little spoiler alert, there's not a lot, but there's a lot of similarities to other kinds of cancer and we're going to make some predictions and assessments based on what we know from other cancers. Why don't you share a little bit of your lived experience with bladder cancer?

Brittney: Absolutely. So, my name is Brittney and I'm the face and voice behind No Bladder Don't Matter, and I was diagnosed on July 25th 2019 with stage four metastatic bladder cancer. I was 28 at the time. And, honestly, 2020 right? At the time I had no idea what was going on. I had gone to my gynecologist in May, and told her, "Hey I'm having some clotting, it tends to happen around my cycle." It was very cyclical, "Some pain during sexual intercourse and just general pelvic pain." She did an exam and she didn't really find anything conclusive. She said, "Well, I think you'd have BV (bacterial vaginosis) and UTI (urinary tract infection). We'll schedule a follow up ultrasound down the road." And I just went

downhill from there. And so, I was in so much pain in my left hip that I drove myself, at three o'clock in the morning, to the ER and, of course, ER's like, "Why is a 28 year old here complaining about her hip?"

Brittney: And when they do vitals they saw everything was off the charts, my heart rate was crazy, my blood pressure was low, my hemoglobin was non-existent, and they admitted me. They saw the mass on X-ray and confirmation through CT that I had a grapefruit-sized mass in my bladder, but where my story starts deviating from the normal bladder cancer story was being a woman, and being young, I then had a gynecology oncology specialist and a urology oncology specialist who spent two weeks arguing, "Is this gynecological cancer or is this urological cancer?" And so I lived in this like weird plays of not knowing what the heck kind of cancer I had until they finally biopsied and did a pathology, then we knew it was fire cancer. I transferred my care to Emory University Hospital in Atlanta, had my radical cystectomy with a hysterectomy and they took out as many lymph nodes as they could find. This was all a palliative measure, my surgery was not going to be a cure my surgery was not going to actually help my cancer, it was just to relieve the severe amount of pain I was in. And then we just figured out where we would go from there.

My recovery was rough and thankfully, early on, I had genetic testing done because I was recovering so poorly, the traditional route of doing radiation and chemo was just not going to be an option, and my genetic test showed that I had the right PD-L1 gene to try immunotherapy. So, I started Keytruda October fourth of 2019, and everything has been on the upswing since then. My last CT scan, we're down to monitoring one lymph node and one area of soft tissue that could just be, I'm 30 and I've gained a little weight. But to go from where it was to now has been incredible, but along the way I've also been absolutely alone, 28, 29, now 30 I'm still one of the youngest people I personally know with this cancer. So, all of the support, all the books they hand me are usually a picture of someone with gray hair, and a lot older than me and are retired, and have the availability to have an adult child be your caregiver whereas I have my mom who's helping me through this, so that's why I started to share my story, was to hopefully find the other people that were my age out there and show them there is a face that looks like yours.

Stephanie Chisolm: Thank you so much for sharing that, that's a really powerful story. Ben, what about you?

Ben: Similar to Brittney. My name is Ben, I was diagnosed at age 29 in February 2018. Unfortunately it was the week after we just announced that we were having our first child, so it was a great swing of emotion from you're on top of the world to the next week, "Am I even get to be around for this?" Luckily we caught it early on, but it was muscle invasive just the beginnings of it. I had some blood in my urine, and luckily I'm married to a nurse practitioner who saw a lot of symptoms that were not right, so we immediately went to the emergency room. From there we had an X-ray and another scan, and they discovered there was a mass inside my bladder. Then a very long weekend until I got surgery and they removed the mass. A couple more long days later, not knowing what it was, we discovered that I had bladder cancer. We then got a second opinion based off of what the original hospital wanted to do, just to see because most of the treatments for this cancer were for 70 year old men or women. So, we wanted to make sure we were... And luckily we're in the New York City area which has some great hospitals, so we got some second opinions and we landed at Columbia Presbyterian in New York City.

From there they went in again and discovered that the first hospital actually missed part of the tumor because of the technologies that Columbia had, the blue light, and since then I've gone back, now I'm at

yearly scans, and eight scans later I've been cancer free ever since. So, that's been a big relief. And, like Brittney, it's been hard to relate with people. I've been to support groups but majority of those people are older, different situations, and it's been a journey both physically and mentally, that's for sure. Especially being 29 to now 32, it's been a ride for sure.

Stephanie Chisolm: I bet, and certainly challenges. Thank you for sharing your story Ben.

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