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## Panelists:

### **Dr. Sima Porten and Dr. Sam Washington**

University of California San Francisco, Department of Urology

### **Ben S. and Brittney T.**

Patient Advocates

## Question and Answer

**Stephanie Chisolm:** I'm just talking to myself, I'm sorry, we should just go ahead and take some questions from our participants. The first question that came in was literally targeting Brittney and saying, **"Did you have any trouble getting physicians to believe that you were having the symptoms that you were having?"**

**Brittney:** So, I think, thankfully when I went to the ER, thankfully and unthankfully I was so bad that they had to take me seriously. I get more frustrated when I think back of when I went and saw my gynecologist, two months prior. I brought a full on list to front and back of, "I'm experiencing this, I'm experiencing this, I'm experiencing this, this is not my baseline, this is not normal." And she's, "Okay, okay, okay." And yeah she did the exam I remember her saying, "It wasn't as painful for you last time, was it?" I was like, "No." And for her to only test for... She just swabbed and she's like, "Well, I think you have BP, I think you have a UTI." They only ran my urine sample for UTI, even though the nurse who took it remarked that my urine was dark. When they took my blood they only ran a thyroid screen on it, because my mom has thyroid cancer.

And I was like, "Why aren't you looking at more?" And I know for a fact that they just did a basic CBC. As sick as I already was in May of 2019, they were just like, "Ha, [inaudible 00:51:38] those to your GP." I feel like if they had, instead of saying, "It's your menstrual stuff, the clotting's menstrual." I just felt like they didn't really take it seriously, and I get it, I hear that story from so many women that even if it's not

cancer related you go to your gynecologist. You explain all these things and they're like, "It's menstrual, it's this, it's this." Hopefully not all gynecologists like that but mine was. But by the time I got myself admitted to the ER, that I was that sick, they knew something was up and the argument at that point was, "What kind of cancer you have."

So, unfortunately I didn't recognize the earlier symptoms for what they were because they were so cyclical, they wind up with my cycle. I pretty much spotted which is something that we expect on the type of birth control I was on at the time, so I was fine, I was fine until May and I was like, "Hey Doc, I'm having these things," and then they just [inaudible 00:52:41], unfortunately. And hopefully not everyone's story is like that, hopefully, like in Ben's case, you go, "There's blood in my urine. This isn't right." And you go see someone and you make it a priority. I feel like there's also onus on me, when my gynecologist didn't take me seriously I should have turned around and gone to my GP and said, "Hey, I explained all this stuff my gynecologist and she wrote it off, what do you think?" And there's onus on me on that, I probably should have tracks this a little bit better, but it what it is now.

**Stephanie Chisolm:** That's important. Dr. Porten, I'm seeing you nodding. So, you're in agreement with Brittney's story, that happens often doesn't it?

**Dr. Sima Porten:** Yes, I would say. And I think we addressed this on a different webinar with Jeannie, specifically, for women who come and present with some of these symptoms and the conundrum of the repetitive UTI testing and treatment. And so, we see this but, then on the flip side, when you look at a whole population this is what's always the hard part is, how do you really get the right patient diagnosed at the right time, and do the right test on the correct set of patients. And that's always a really difficult thing in medicine, because when you look at the population perspective of other 20 probably people maybe that day who came in with similar different, though, symptoms, how do you sort through that and go through and make the right diagnosis, and order the right test? And I would say that I just don't think you shouldn't blame yourself. I think you both, it's amazing what you've been through and that you're advocates and sharing your story. And so, I would say that I admire you guys and your outlooks in looking toward the future and living the best life that you can, day to day. And I really appreciate you taking the time to share your stories and talk to others about this.

**Stephanie Chisolm:** And, Ben, you were probably the youngest man in the urologists office, I'm guessing?

**Ben:** Oh, yeah. I've got the chairman of Urology to be my doctor and another oncologist that was highly respected in the urology unit, so they saw me as a specimen. And the first time they all came in it was like, "Wow, I've never seen someone this young come in." So, it was definitely an experience at first, and three years later luckily everything's gone well for me. And it's been a tough battle, I mean, obviously when you're 29, 30, you never think about facing death of any sort and luckily I was able to catch something before it got a lot worse. And if I could be an advocate for this disease, or any cancer in general, to younger people, to tell them to get checked out don't be so macho about it.

And I know a lot of people that say, "Oh, I have some pain here but I'm not going to deal with it, because I'm a man," or any of that macho stuff. And it pays to just be caught... I mean, don't WebMD everything, but if there's something serious that you think go get it checked out and hopefully you can get in the hands with the right people, and they'll solve whatever it is before it gets worse.

**Stephanie Chisolm:** Yeah, Absolutely. I think it's really important, and you are both... Even though, Ben, you said you're kind of shy, you've managed maybe with your wife's support because she's a nurse practitioner, she's in the field. She knew how to ask the right questions, so you might not have done it on your own.

**Ben:** Absolutely.

**Thinking about the kinds of things that you went through, you had the TURBT, and some of the questions were, what else happened to you that then? What other treatments, did you have?**

**Ben:** Initially, the first place I was at they wanted to do a BCG, and when we have my second opinion they thought that the first hospital was just going that normal routine of bladder cancer diagnosis, at whatever stage I was, to BCG for couple of weeks in a row, whatever it was. But the second place where I ended up, they've decided, "At this stage, at your age, I want to monitor it closely." They used the blue light cystoscopy to look at it the first however many times to see if there's anything developing. And then as we started to break out my procedures from every three months into every six months, and now every year, then they just go in and they check it out. So, I was lucky in that sense, I was that early on that nothing drastic had to happen.

**Brittney:** Can I just say, and I bet Ben agrees with this, having someone in your life who has experience in the medical field. I don't know how people do this without that, my mom's a nurse and if she have been in my hospital room, first of all, translating everything that they would tell, and she was the Bulldog for me she knew what questions to ask, "Britney, need to make sure they do this. You guys need to make sure you do this." I mean, having that person in your life, I feel like I wish I could like clone with your wife, clone my mom and be like, "Here, here's someone who can walk you through this."

**Ben:** Yeah, I mean, I would agree 1,000% With that. If I went in just myself, I mean, if it was just myself to begin with I don't know if I would have gone to the doctor, I might have been too afraid to figure something out. But, when you're in the doctor's office you have to ask the right questions, to even get a second opinion wouldn't have never crossed my mind. And the people that I've come in contact with now that get a cancer diagnosis, I always tell them, "Just get that second opinion." Not to bash at a local hospital or anything, but I mean just get to the people that specialize in this, and some people, they don't even think they do that.

**Stephanie Chisolm:** This has really been really amazing, thank you both for sharing. Dr, Porten and Dr. Washington we're coming up on the hour, do you have any closing remarks before we shut down?

**Dr. Sima Porten:** I don't have any final remarks I just think this is a really important issue, and I'm hoping that this webinar and others like this hopefully drives research forward. I think there was a question that someone has specifically, about what is the effectiveness of BCG in younger patients? And I think what they mean is, we quote these two and five year numbers but what happens after those five year numbers that as doctors we quote a lot. And I would say that many times we don't know, because when you look at it as we start going further and further out, as people pass away from natural causes, other things, because most of our data is on older patients you have four patients out there at the 20 year mark, who are in their hundreds. Who were making decisions by, and I would say this only gets

better as we start looking in studying this more, and as people participate in trials and registries and in different studies. And then we can keep moving research forward. And it's really imPortent to hear voices like yours out there and advocating, and that ensures that we're really making sure we're studying the right questions.

**Stephanie Chisolm:** Absolutely. Dr. Washington?

**Dr. Sam Washington:** I think an important thing is that if people have concerns, keep asking questions. And if people aren't giving you answers keep asking someone else. There's information out there but there's a lot that we don't know, but I think at the end of the day it's better to ask the questions and at least try to find the answers. And I know on the physician side we're working to get some of those answers, but just as Ben and Brittney said before, not asking those questions, not being a self advocate can delay things if there is something, and hopefully there's not anything but if there is it's better to ask those questions and get an answer, or some idea of it earlier rather than later.

**Stephanie Chisolm:** Absolutely. Well, again, thank you all so much. This has been a wonderful program.

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