

### **Stephanie Chisolm:**

Absolutely. So Lori, if you could put your camera back on, that would be fabulous. Great. So I have a couple of big questions that I wanted to ask you. So I guess we can start with you first Lori and then the next question, we'll start with Ron. But Lori, could you just give us a brief description of your experience leading up to your TURBT procedure. How many did you have and how prepared were you in advance of that? And what do you think you could tell people that you wish you had known prior to your first TURBT?

## Lori R.:

Sure. Thank you for inviting me to participate, Stephanie. I was pretty much dragged to a urologist taking and screening by my primary care doctor after I had blood in my urine for the third time. And she refused to take my excuse that it was just a UTI and just give me an antibiotic and please leave me alone. I was absolutely terrified to have a cystoscopy. And I think part of that fear was that I had been very healthy. I had given birth to two children, but somehow I put that in a different category. I had not had any medical issue. I had not had any medical procedures. I had not had surgery. I had not seen a specialist. So, and I think in the back of my mind, I knew something was wrong. So, the urologist did this cystoscopy and said, I could wait and biopsy this but you have bladder cancer. And I think at that point there's sort of a truism that it's like, somebody puts a metal bucket over your head and starts banging on it once you hear that cancer word. And I really couldn't focus on much, but I think he did prepare me and he was very compassionate. He said, "You can wait to 10 days until I get back from this conference." And I told him, I didn't think I'd live that long. Quite frankly, I was too anxious and upset. And he said, "Or you can go to the emergency room right now. I'll admit you through the ER, I'll do the TURBT tomorrow, it's my last day here before I leave and I'll fit you into my schedule." So he was extremely compassionate not just to my medical situation which didn't really require that sort of urgency, but to my mental state which was not good. And he also prescribed Ativan for me in the interim. So I was able to manage. So I had the TURBT the next morning.

## Lori R.:

That was the only one I had. Physically, I think I was prepared. I did go home with a catheter which is uncomfortable, but bearable. Like Dr. Lotan said, "You don't do much the next day. So it's not a terrible impediment." Although it's nothing to look forward to. I didn't have any bleeding, I didn't have any cramping. I didn't have any physical problems. The thing that was most troubling to me is that, and my urologist told me this. He said, "I wish I could tell you that this is a one-and-done experience." He said,

"Most of the time it's not, and you're going to be under very regular surveillance and we'll discuss treatment options once we get the path report." And waiting for that pathology report is a unique kind of torture as anyone who's waited for one knows. So the idea that I was about to have an experience of some grave uncertainty to me was particularly difficult. And I don't know that I could really absorb that at the time. I just wanted to get through the TURBT, go to the next step of getting pathology. But I think I was prepared. I just don't think sort of the gravity of the situation of I wasn't able to really process that. And I really appreciated Dr. Lotan saying that this is such a typical routine surgery for urologists, not always for patients, as he mentioned. For me, this is the first surgery I'd ever had. So and the first time I ever felt at risk for any type of cancer. So acknowledging that and with the sort of compassion with which I was treated was just really made it bearable.

# **Stephanie Chisolm:**

Thank you so much, Lori. It's really helpful to get that perspective from your lived experience. And now, Ron if you don't mind sharing a little bit about what led up to your bladder cancer and going into your first TURBT, and I know you said you've had more than one to TURBT, how prepared do you think you were? What do you think you'd like to tell other people before they have a procedure if they haven't already had one?

### Ron K.:

Well, I find that bladder cancer is it's a continuum of treatment. I've been treated now at the clinic for over 10 years. I've had four endoscopies and biopsies. I've had chemotherapy insertions at the clinic some of which were uncomfortable. But I feel much the same way as the other patient that once you leave the day surgery, especially if you don't need a catheter, the recovery is easy. You stay home for a couple of days and do light activities for a week. So I just think that it's the thing that's hard to digest is that it's not one and done. It's the continuum of treatment and you may have multiple cystos over the years and you just have to follow up very closely. I have a friend who did not follow up for a year and a half, and unfortunately, he has invasive cancer and it has spread to his lungs. And you can't leave it alone. I argue with Dr. Lotan each time when he says, "Come back in three months." And I say, "How about four?" And we negotiate for three and a half but you have to do your clinic follow-ups. It's very important.

## **Stephanie Chisolm:**

So, Ron, do you do anything mentally or physically when you know you're going to have another one of those TURBT procedures, is there anything that you do to prepare yourself for that?

## Ron K.:

Not really. You have to be prepared that you're going to have a day surgery procedure. I pray they don't have to put in a catheter when I go home because it gives me pretty bad spasms. And the last couple I've had, I've had no catheter after, and I've had very good recoveries that after four or five days of light bleeding, I feel very normal.

## **Stephanie Chisolm:**

Dr. Lotan, I have a question for you because Ron just talked about having a bladder spasms. How frequently, what percentage of patients have problems like a bladder spasm as a result of having that TURBT?

### Dr. Yair Lotan:

A lot of it does depend on whether or not you leave a catheter. It also depends on the extent of the resection and the location of the tumor. But I mean, I would say it's probably 10 to 15% probably have some, maybe not specifically bladder spasm, but they have some sense of urgency, maybe frequency, like early on, they feel like they have to go to the bathroom more. And sometimes people have some burning and discomfort. And the good news is that we do have medications that help with that. And so if you are having symptoms, don't be shy, especially in how it is with electronic medical records, people will send me something and I can give them a variety of medications whether or not it's perdium to help with burning, detropen or detrol, or they're probably about six or seven medications that help with overactivity. I just don't like to start off patients with too many medications, especially the antispasmodics, and cause dry mouth and constipation. And so I don't like to just immediately start you with it, but if people have symptoms, we certainly do have some remedies that can help with that.

## **Stephanie Chisolm:**

Okay. So everybody should make sure that they're telling you what's going on after they have their procedure because there might be something that you could do to mitigate some problems and make them feel a whole lot better, right?

#### Dr. Yair Lotan:

Right. And usually I give my cell phone to my patients who are having surgery, so they can always text me and they don't have to go through some of the rigmarole, but we have MyChart through Epic and it's relatively straightforward. It's just, it is important. There's no reason to suffer. If we have medications to help, then we're happy to provide them.

#### **Stephanie Chisolm:**

Thank you. So, Ron, I'm going to start with you. So are there any lessons learned or challenges from your experiences with the TURBT procedures that you want to share with the 50 people that are on this call?

#### Ron K.:

Well, it's a day surgery. It's the discomfort is really minimal and the recovery is not difficult. I've had four and I don't say I look forward to it. I just know when the doctor wants to do it, it's because he's seen something that he can't handle in the office and he needs a patient under anesthesia. And you just got to do it. This is a tumor that keeps popping up at multifocal and it's just you have to do your due diligence and you have to do the procedure.

#### **Stephanie Chisolm:**

Sure. And again, I'm just going to remind all of the viewers that are on this program, there's a lot of information about this on the BCAN, bcan.org website as well. So, Lori, what about you? Do you have any lessons learned after having your first TURBT or what challenges did you have that you might want to share with the listeners?

### Lori R.:

I think that there's something to be said for having your first surgery be something that's very routine that the medical staff is very comfortable with, that they do all the time that serves the dual purpose of staging and treatment. So in that sense, I would say it's like Ron said, you wouldn't look forward to it, but it's not something to dread or fear. And to realize that whatever comes after is there are people like the wonderful doctors that have been in my life that will help you through it. And I think for me, and the thing that I needed, in addition, was physicians who understood how emotionally challenging this was for me. I just was not at all prepared. And so I really appreciated every doctor who didn't say, "Oh, come on, we do this all the time. Buck up." And treated my anxiety as an important thing to manage.

So I would say like Dr. Lotan encourages patients, "Don't be afraid to say I'm really scared. I'm really anxious. I don't know what's going to come next." And get a referral to a mental health professional, get on a low dose of some medication that can be helpful. There's no reason to suffer whether it's with bladder spasms or anxiety and that as much as you don't necessarily want the lessons that a cancer diagnosis is going to have for you, try as best as you can, to trust, to be grateful for the care that you get, advocate for yourself, ask questions, don't be embarrassed. I mean, I couldn't even say the word bladder cancer for about six months. I didn't tell anybody but my family. And in retrospect, that's the way I had to deal with it, but it's nothing to be embarrassed about. It's just something to get the help you need, however that looks.

