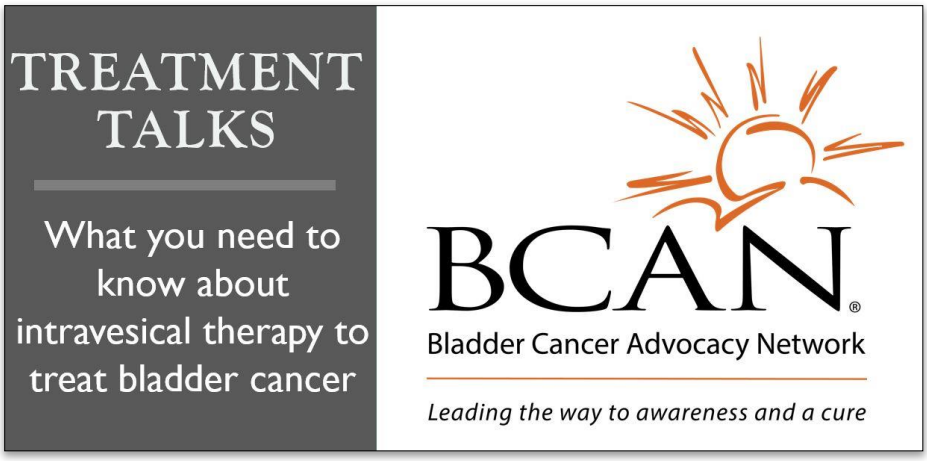

Stephanie Chisolm: So welcome back, everybody. And I think it really answered some of the questions that were coming in. But what I'd like to do first before we open it up to questions from our participants, is get a little bit of feedback from Judy and Jay on their experience with intravesical therapy.

Judy Walker: Yes, I was very fortunate to have Dr. Kukreja as my doctor and also to get into the Tokyo strain study. So I'm one of those patients and that is, excuse me, one of the advantages of connecting with a research hospital which has been just terrific for me. And, obviously, like everybody else, I'm sure, well, I can't speak for everybody else, but I'm going to guess that a lot of people have been just as anxious as I have been and it's been great to have doctors and nurses and also study coordinators, people in public health and residents from the med school and other participants who can answer questions as they inevitably come up as we manage how we feel about it.

So far, I seem to be doing just fine on BCG. I tend to go home and take off the rest of the afternoon because once you're over the couple of hours that you have to spend not voiding, then I do feel a little bit low. And so I just reserve time for a nap. Fortunately, I'm retired. So I'm able to do that. I understand it might be harder for some people. Maybe a UTI here and there but other than that, I've been very grateful that I've had the opportunity to take the afternoon.

Stephanie Chisolm: Great, thank you for sharing that. Jay, what about you?

Jay Powers: Well, likewise, I was very fortunate to have Dr. Janet Kukreja. Her expertise and efficiency in the field has impressed us and my family. When I first met Dr. Kukreja I had a lot of apprehensions and concerns because of cancer is not something that is a favorite word. It's the six letter word that you don't like to hear. And you certainly don't like to be diagnosed with. But Dr. Kukreja arrested those fears and she was able to actually meet with my oldest son who was 40 as well as my wife, because, of course, they were concerned that maybe the best thing would be to remove my bladder. But Dr. Kukreja said, "No, that's not necessary."

Jay Powers: She did find cancer in my bladder, and she was able to remove that, the TURBT, I think is the correct terminology, I may not be right on that. And then follow up with the BCG treatments. And it's just been wonderful to be able to keep my natural body part, which I think is important. For all of us, we'd like to have that. It's what we want to be and continue our normal lifestyle. So that was refreshing.

And the other thing was that for a man, I think it's more comfortable and less awkward and embarrassing to have a female doctor perhaps because it's a sense of embarrassment to have any an issue but doctor arrested all of those fears and has done a wonderful job of keeping me healthy.

Stephanie Chisolm: Well, you were obviously in good hands, because we love Dr. Kukreja. And she's doing a great job for all the things that she's doing on behalf of the bladder cancer community. So what were some of the most important considerations for you both as patient as you were learning about these treatment options? What were some of the concerns you had? Or some of the things you thought, "Wow, this is good," because as you just mentioned, Jay, we know that the best bladder you can have is the one you were born with.

Stephanie Chisolm: That's not always the case when people need to have their bladder removed, and you can live a full life without a bladder. But what were some of the important considerations that you had to go through in your mind as you were beginning to start this treatment?

Judy Walker: Yeah. Well, I completely agree with Jay, that the first thing I did was catastrophize, which is, "Oh my gosh, I'm going to have to live a life without a ladder and what's that going to mean for every part of my life?" And Dr. Kukreja did a good job of saying there is a lot of slip between the cup and that there are many other options that she just gone through. And if I have to have my bladder out at some point, I'm sure I'm going to need some more hand holding, that's really true. But at the same time doing my own research and having good online resources including BCAN and PubMed and all those types of reputable resources, you realize what kinds of options are available.

And also in my personal life, my husband is a liver transplant patient at the University of Colorado Hospital. And he's had an ileostomy since he was 30 years old and he's 78 now. And so I have lots of personal experience with how you can lead a full life even if you don't have a body part that as Jay said, we'd like to say. So that was my first concern. I jumped immediately to the, "Oh my gosh, what's going to happen if I have to have my bladder out?" So backing away from that, everything else pretty much seemed like gravy to me and still does.

Jay Powers: I think the concern that I had was, was I going to die from this cancer? And for her to be able to explain to me that this was something that hadn't penetrate the muscle walls of my bladder and that there was an effective treatment for it and then I was eligible for this treatment was very consoling, comforting. And I'm happy that I was able to enroll in this program and I received the treatment because it's been very effective.

Stephanie Chisolm: As you saw, when the doctor was explaining all these treatments, they take a long time. Talk to us a little bit about the commitment that you made to go to this type of treatment that requires you to be a regular participant going in and having intravesical therapies instilled into your bladder. Jay, you want to go ahead? Is that a problem for you? Is it an issue? How's your family handled that?

Jay Powers: No. Family has always been very supportive, and the medical team has been more supportive. And they make it very efficient for you to do so because they have this you connect thing through the hospital and university there. And they're always sending a notification in advance of when you have to be there. And when you do come, it's a short period of time that you're there. You're coming to the office and next thing you know, you're given a urine sample and you're back getting a

cystoscopy or getting a treatment, and you're in and out of there so quickly. No, it's not discomfortable at all. It's something that more people should do, I think because to let it go could lead to the alternative, which is not good, where it would lead to something worse or greater form of cancer.

Judy Walker: I agree. Again, I feel fortunate because I am retired. And I can deeply appreciate how much it might impact someone's life to set aside the once a week or the day off during the weeks of getting BCG. In particular, I had no problem signing up for the study. I'm comfortable with clinical trials, particularly after meeting with the people who were running it and asking a lot of questions as everyone should.

Judy Walker: It's interesting that the COVID situation has affected everything. So I'm more shut down than usual in terms of maybe not only my emotions, but also my ability to travel and to take vacations and to do the things I want. But as Jay was just saying, first things first and this is first. So I go through the reorientation of priorities. And if I feel some disappointment that let's say, Dr. Kukreja found after my next cystoscopy that tumors come back, I know that I have to clear my calendar for some other TURBT. And I know how long that's going to take to go through that process. And that sure beats having my bladder out or dying.

Jay Powers: Indeed.

Stephanie Chisolm: True. Very true. So, are there any regrets that you might have had about your treatment? About choosing this treatment.

Judy Walker: Not for me.

Jay Powers: No, I'd agree with Judy. It's just wonderful. It's been a blessing that it's been available to us.

Stephanie Chisolm: Before we open it up to questions from our participants, if you were speaking to somebody who was newly diagnosed, who said, "Yes, I had my doctor tell me that I have to have this treatment." What would you tell them? Jay, you want to go first?

Jay Powers: I'd say go ahead full steam, because it's the best thing that you could do for your health.

Judy Walker: I would say the exact same thing. And as best I can tell, because of the treatments that are available, not just BCG, the big C isn't automatically a death sentence for this. And I think that people get scared or I messages here, I was scared not only about, "Oh gee, what if I have to catheterized myself every six hours when I have no bladder?" Even that is a small price to pay for worrying about dying. I do think and I'm sure men have related but different sorts of issues with respect to worrying about having your bladder out, and there are a lot of issues that are attended to that. So, the first thing I think is important is to have a great relationship with your doctor, and the old term for it is bedside manner, but I'm going to use it again and Dr. Kukreja has that in spades.

And so that level of trust and respect is really important and I saw here in your BCAN materials that, of course we should all ask for second opinion if the fit is not good, because a lot of our reactions to this diagnosis are inevitably emotional. Some people shut down. Me, I freak out. And it's really good to have

doctors and their support staff who really understand that and make you feel that it's okay. It's normal to be terrified.

Dr. Kukreja: Yeah, I mean, I think for the newly diagnosed out there and for possibly patients that have had recurrences, I think something that both Judy and Jay said is that something to focus on that it is still a curable disease at that point.And I think that's one of the things that really differentiates the non-muscle invasive bladder cancer from the muscle invasive bladder cancer, is that if you catch it before it goes to the muscle invasion, the survival is excellent.

Dr. Kukreja: Judy and Jay just have wonderful outlooks on it. These treatments are barriers to curing a disease and they do take a long time, they are a lot of commitment. But in the end, I think if you have a great attitude, it really does pay off. And this is a treatable cancer that you can treat with your urologist and get through it and really have good outcomes.