



Stephanie Chisolm: Hello, and welcome to Thinking Through Decision Making: Keeping a Grip on the Emotional Roller Coaster When Bladder Cancer Returns After BCG Treatment. This webinar is jointly sponsored by the CISTO Bladder Cancer Study, a clinical trial comparing bladder removal with medical therapy for patients with the recurrence non-muscle invasive bladder cancer. CISTO is led by Dr. John Gore of the University of Washington and Dr. Angela Smith at the University of North Carolina. Taking the lead in tonight's program is urologist, Dr. Jennifer Taylor. She is an assistant professor at Baylor College of Medicine in Texas, and very involved in the CISTO Study.

Dr. Jennifer Taylor: Thank you so much. Hello, good afternoon. Thank you for joining us. In today's discussion, we will be focusing on what patients like you found important to think about consider while making a decision about treatment. We will also be focusing on the emotional side of that decision, and how the decision making experience felt. We hope that today's discussion will help you feel less alone as you think about the right treatment for you.

Today's webinar is co-sponsored by the Bladder Cancer Advocacy Network, BCAN, and the CISTO Research Study. BCAN is the only national advocacy organization devoted to advancing bladder cancer research, and supporting those impacted by the disease. As Stephanie said, the CISTO Study is an observational clinical trial comparing two treatment options for non-muscle invasive bladder cancer that returns after BCG treatment. CISTO is led by researchers at the University of Washington and University of North Carolina, and has more than 20 sites around the United States enrolling patients. We will share more at the end of our discussion today about how you can access BCAN resources and learn more about participating in the CISTO Study.

Today, we're going to focus on the process of making a treatment decision, rather than the details of any one specific treatment. For details on a particular treatment, the BCAN website, BCAN.org, is a great place to start. We'll share that URL again at the end of our discussion today. First, we would like to hear from all of our participants to learn a little bit more about their backgrounds and their connection to this topic.

Lori Roscoe: Hi. My name is Lori Roscoe. I'm a college professor of communication and a bladder cancer survivor. I was diagnosed in May of 2018, when I was 60, with T1 mixed grade non-muscle

invasive bladder cancer. It was a complete shock to me. I had no known risk factors. Everybody assured me, of course, it wasn't cancer, but it was cancer. I had a TURBT the next day, which was very fortunate in terms of my mental health. For the next 20 months, I had induction BCG and maintenance BCG with cystoscopies every three months and had, excuse me, no evidence of disease for 20 months. I was feeling pretty good about how things were going.

In January of 2020, I had a recurrence. My urologist said, "It's 97% chance it's not a recurrence. It's probably inflammation. Let's do a biopsy just to be sure," and sure enough, it was a recurrence. This created quite a quandary for both of us. My urologist suggested having a radical cystectomy, and I just said, "No. I'm not ready to talk about that at all." He said, "We could do more BCG." He encouraged me to get other opinions. I met with doctors at University of Florida and at Johns Hopkins. They both said, "If you want, we can do other things, if you want to delay a radical cystectomy, but that's really the treatment for you. This treatment, even though you go from a pretty low disease burden to a very major surgery, this surgery was really meant for patients like you."

Lori Roscoe: I had a radical cystectomy, hysterectomy in March of 2020, and recovered from that with some ups and downs, which I think we'll discuss in the webinar. Then when I went back for my CT scan results in August of this year, was diagnosed with stage one lung cancer. Again, a total surprise. This was an incidental finding on some of the many CT scans I had, and frankly, I wasn't worried about it. I just pretty much said, "I have bladder cancer. That's enough. This thing is scar tissue or it's nothing. Just let's not worry about it." Then in August, the thoracic surgeon that had been consulting with me said, "I don't like the way it's changed. I want you to have a needle biopsy," and then turned out to be lung cancer, and I had lung cancer surgery in September of this year.

It's been a rather dramatic year in terms of my health. I've had the wonderful support of my husband. I really couldn't have done it without him. He was the last person, caregiver, partner that they allowed in the hospital before COVID, so actually the last few days, he kind of had to hide because the hospital had shut down from having any visitors whatsoever. I really feel for any patient that was in that situation, because not having someone there to just reassure you that this is going to be okay would have been really difficult. At present, I'm still in the sort of recovery phase from both of these surgeries, but doing pretty well. Getting a little more active every day, and very happy to be alive, and very happy to be sharing my experiences with this group.

Sue Oliver: Hi. My name is Sue Oliver, and I'm Rick's wife. I was and continue to be Rick's main support person throughout all the steps that he has gone through with his bladder cancer. Rick is now going to talk about his personal journey with bladder cancer.

Rick Oliver: Hi, again. I'm 62 years of age. My first indication of a medical issue was on the 7th of July in 2018, when I had blood in my urine that morning. Prior to that, I was a very healthy individual, having no issues with my health, with the exception of high blood pressure. I was very fortunate to have such good health for such a long time. I went through the normal medical process when you first see blood in your urine. I went to the ... Going to the urgent care first. After being diagnosed there, they sent me to the hospital, and the initial diagnosis was a urinary tract infection.

Rick Oliver: After that, I went to my primary care physician, and I was sent for CT scans. The first one was a CT scan without contrast, and then the next one was a CT scan with contrast. Both of them

were negative. I then proceeded to go to a local urologist. Initially when I went there, he didn't know why I was there, which was a surprise. We made another appointment, and I came back, and I had my cystoscopy, and that was in the beginning of September, and that's when I first found out I had cancer. A huge shock, and it changed my life. After that, we had scheduled to have a TURBT to be able to stage the cancer, and also see how bad it was. I had my TURBT in September, and when that happened, I was diagnosed with TTa high-grade. The course of action with being high-grade was I was going to start BCG treatments.

I started BCG treatments on the 1st of November, and I went through until the middle of December with my six BCG treatments. I went back five days later, another cystoscopy to take a look to see what was happening inside my bladder and low and behold, it was very red. The urologist made the recommendation that I come back six weeks later to take another check. When I came back and did another check, at that point, my bladder was still red and he scheduled another TURBT. When he went and did the second TURBT it was really a biopsy. He went in to check what the redness was, and again, I had papillary bladder cancer and CIS.

At that point, the urologist, the scope of this was beyond the urologist's ability to treat, so I was sent to three different institutes to get second opinions. We went to those three places, and at that point, we decided that we were going to go with UNC. The reason we went with UNC to make that decision was the doctor at UNC was very straightforward and pretty much laid out the whole process for us in a very clinical, but in a very professional manner, but in a very caring manner also. As they did not get a deep enough sample, I had to have another TURBT, number three, to determine staging again.

Once the staging was done there in April, I went back on April 14th, and at that point, it was determined that my cancer had increased in stage from TTa to T1 high-grade. Dr. Smith had already recommended that I have a radical cystectomy, as there was no clinical trials to do and the cancer was growing very fast. On May 14th, 2019, I had my radical cystectomy and I had an ileal conduit installed. During that time, Dr. Smith had contacted me and the pathology report came back from my RC. The good news was my lymph nodes were clear. My ureter, on the left side of the cancer up in the throat of the bladder and also, I had found out I had prostate cancer, which we did not know about, but everything was okay there and the margins were clear. Then again, my cancer had gone again from a different stage, from T1 high-grade to T2a high-grade. At that point, I started going through CT scans, cytology, urine sampling, which has shown no evidence of disease. I've gone through four CT scans with no evidence of disease, currently.

Doug Maclean: Hello. My name is Doug Maclean. I was first diagnosed with non-muscle invasive bladder cancer in January of 2016 at the age of 63. I have no knowledge of any other immediate family members who have had cancer. However, that said, I underwent successful prostate cancer surgery at the age of 54. I have been a lifelong competitive runner. I've run over 100 marathons and still today, I have a very active lifestyle, and involved in many outdoor sporting activities. All of which is to say that retaining my bladder has been a real priority. The first bladder cancer symptom I noticed was blood in my urine, and a subsequent biopsy in January of 2016 confirmed that I had cancer in situ, also known as CIS.

Doug Maclean: I immediately started BCG instillations and had cystoscopies in May and August of 2016, which still showed the CIS to be present. In the fall of 2016, I underwent a procedure called

TURBT, which basically is a resectioning of my bladder, which removes any visible signs of cancer. I continued with my BCG instillations following the surgery, and a cystoscopy in January of 2017 indicated I was cancer-free. It took approximately a year, but through the surgery and the BCG, I was able to have no signs of cancer in my bladder. I continued with the BCG for another 18 months, and remained cancer-free. However, a cystoscopy and biopsy in October of 2018 confirmed the recurrence of my BCG ... Excuse me. Of my CIS, or cancer in situ.

At that time, a new trial was beginning at UCLA, where they were accepting patients into the trial who had failed with their BCG treatments. I was accepted into that trial, and I began instillations of a new immunotherapy drug in combination with BCG. That drug was called ALT or ALT-803, which basically was an enhanced immunotherapy drug. It was injected, instilled, I should say, into my bladder in the same way as the BCG. In February of 2019, after my first regimen of BCG and ALT-803, a cystoscopy showed no presence of the cancer or the CIS.

I thus continued in the trial until the fall of 2019, and then I had a biopsy, which showed that the cancer had returned. That made it impossible to continue with the trial, and I now was faced with another major decision, that is, "I have failed now with BCG and BCG, Alt-803. What's the next step?" I conferred with my urologist, Dr. John Gore at the University of Washington, and we decided that we would try a regimen of chemotherapy drugs, and those drugs are gemcitabine and docetaxel. They are instilled into the bladder in the same manner as the immunotherapy drugs, however, their action is to kill any cancer in the bladder, rather than to teach my immune system to fight it.

I began that regimen of drugs in January of 2020, so about one year ago. I've had subsequent cystoscopies since then, and all those cystoscopies have proven negative. In fact, it's rather ironic that I have my next cystoscopy tomorrow, the day after this webinar, and of course, we're hoping for the same good results in that. In summary, I would liken the fight against my bladder cancer to that of running the marathons that I've run. The fight is challenging, and it does require an unrelenting commitment to try to stay ahead of the pack. The pack, in this case, being the return of my cancer. With that, I look forward to our webinar today. Thank you for allowing me to participate.

Dr. Jennifer Taylor: Thank you all so much for sharing each of your individual stories. We're going to go through first some moderated discussion of your treatment course and decision making. We'll talk first about the time of your diagnosis. Describe to us each of your emotional states when you were diagnosed with non-muscle invasive bladder cancer, for which BCG did not work.

Doug Maclean: I would have to say that when I first was diagnosed with my cancer, I really became interested in the causes of it, the treatments available and so forth, so I really became what I refer to as a student of this disease. For the next, what, 24 months while I was using BCG, I really was studying the disease, all the different treatments available, reading about dozens of trials. I would say that when I was finally diagnosed with the return of the disease, I was fairly unemotional. I felt I was well-educated. I felt I knew a lot of alternatives out there, and so I would say that I was prepared to address the next step, without getting too emotional about it. I would have to say that because I immersed myself in the literature and all the research, and talked to patients, and talked to many BCAN participants, I felt confident that we would pick the next step and it would be appropriate for me.

Rick Oliver: For me, part of my diagnosis, my urologist was very optimistic, so I was feeling pretty good about beating this, so I heard that the BCG treatment did not work for me, and my cancer had gotten worse, I was pretty much devastated, and I was really numb about it. That's really the emotions I

had, because it was such a surreal moment when that happened. Initially, when I go back and think about it, and I've thought about it for a while now, I was very angry. I was angry at the urologist for allowing this to happen to me, and trusting him. That was not the right thing to do but at that time, I was very angry. This was just the natural progression of this cancer inside of me.

Lori Roscoe: Well, my experience was somewhat different. I was completely undone by the news of my initial diagnosis, and more so by my recurrence after 20 months of good results with BCG. I was not prepared for BCG to fail me, even though I knew that was a possibility. I considered not doing any treatment. I actually contemplated committing suicide, which I hesitated to share in this webinar, but my friends told me, "If you're going to do it, be honest." I was at the absolute brink of despair. I couldn't discuss with my urologist radical surgery. I had never had surgery, except for the TURBT that I had 20 months before. I couldn't imagine going through that kind of surgery. I just didn't think I had what it took to do. My husband, and my sons, and my friends all begged me to reconsider, and to at least see what my options were because they really wanted me to be around, and so that was encouraging.

I kept hoping that this wasn't happening to me, and that this was a mistake, and that something else would come along. I was so anxious, that I had to take an immediate leave of absence from my university teaching position. I could not really function at all, so my decision making was absolutely clouded initially by fear, and anxiety, depression, and hopelessness. I think that's why it's so important to do the CISTO Study and continue other research on bladder cancer. Because this is a really very difficult decision point, whether you approach it emotionally or more analytically. I also want to say that if you are faced with this choice, you can work through this darkness. I'm here to tell you that it's not easy, but it's doable, and you can survive and you can actually thrive. Even though the choices seem very difficult to comprehend at the time, you can do it. If I can do it, you can do it, believe me.

Dr. Jennifer Taylor: These are all very natural and understandable reactions to this news. If you can describe a little more, how did those emotions affect your approach to decision making once you started learning what the treatment choices and options were? I think you might have touched on that so far.

Lori Roscoe: Well, I finally was able to call up the more rational part of my researcher, analytical side, and talked with my urologist. My husband and I had a long conversation with him. He encouraged us to get other opinions, much as Rick and Sue mentioned, and we did that, and everybody ... I consulted with a urologist friend also, they all said they could offer things that would postpone this decision, if that was my desire, but they all strongly recommended that given my course of, the way the disease was progressing, that a radical cystectomy would be my best bet. I'm a kind of patient that needs to hear the whole story, even the bad parts that you don't necessarily want to hear, which doesn't suit anybody or everybody.

I've spent my professional life researching how patients make end of life decisions, and too often, I've seen patients encouraged to make the next decision without fully understanding that you need to take into account the whole trajectory here, and that if you don't, sometimes you end up in a place that you don't necessarily want to be. I needed to figure out mostly, whether I could do this, what my recovery might be like. Nobody sugarcoats that. And what my quality of life would be, both in the near-term and, hopefully, in the future. I did finally decide to have a radical cystectomy last March, in 2020. I sat in the waiting room, waiting to be called back, absolutely undone, crying hysterically, not knowing what kind of

person was going to show up at the end of this experience. That's what I did to decide on an Ileal Conduit.

Rick Oliver: After the initial shock of that BCG didn't work, I was really at that point, unlike Lori, but I was able to separate my emotions from my decision making process. I'm not sure if that was because of my engineer or my analytical background, but that was definitely something I did. My decision was relatively straightforward at that time, so I was pretty good with that, because I had a big chance of my cancer getting worse. It was really easy for me, because I was relatively young and I wanted the best chance of survival.

Dr. Jennifer Taylor: Yours was an incredible development of more invasive disease on final discovery when you had the final surgery too.

Rick Oliver: That's true, Jen. Really looking back at this though, I put that analytical hat on and I did all that, but realistically, when I was looking back at it and thinking about it in these past few months, I'm sure I was in denial. I used avoidance to separate myself from this horrible thing that was happening to me.

Dr. Jennifer Taylor: Thanks, Rick. Doug?

Doug Maclean: Well, wow. I really appreciate what Lori and Rick just shared. I almost feel, I don't know whether I should feel naïve or what, but I'm a very optimistic personality. You probably picked up on that, and so I approach things, I think, in that vein. I've always been optimistic that there is another fork in the road that we can study and pick an alternative for. I've never been, I would say, depressed. I felt challenged certainly, but I'm not a person that ... I just don't lay awake thinking about, "What if?" Or, "If this wouldn't have happened." I will just say, again, I'm not trying to make it less than it is. It is a tough, challenging decision, but I just didn't let my emotions and my stress take over. That's my mind state today.