



Stephanie Chisolm:

That was just a recap of everything that we did. I'm sure that stimulated a couple more questions. Again, that was just a recap, so let's start talking to our patients and then Dr. Poch, if you have anything to add to their comments, I think that would be great. I'm going to introduce you to Jonathan, to Tom and to Denver. We're going to start with Jonathan first. So Jonathan, what type of urinary diversion do you have and what factors led to that option and what was important to you back at the time? Because it's been a little while for you that you had your bladder removed.

Jonathan:

It's been almost 13 years. I have an ileal conduit and I don't really have a very interesting story because my surgeon told me that that's what we were going to do. He said the other ones... I said, "Well, there's other things, aren't they?" He said, "No, they don't work." I said, "Okay." And so I have an ileal conduit. Now, in retrospect, if I had to do it all over again, this is exactly the diversion that I would use, for a lot of reasons. You saw the pros and cons and there aren't many of either. An ileal conduit is kind of like a Ford F-150 truck. They're not pretty, but they work, and they just don't ever break down, so I've had really no problems with this and it's been great.

I mean, of course having no diversion at all, not having bladder cancer would've been my preference. But once we cross that bridge, I'm very happy with this. I want to show y'all a little thing here, in case you're wondering how big the pouch is. It's that big. It doesn't protrude. It's basically invisible to everybody around me. Nobody knows that I have an ileal conduit unless I tell them. Nobody says, "Gee, what's that funny-looking thing under your shirt?" Or whatever. So that's what I have.

Stephanie Chisolm:

Right, so your life hasn't been super impacted by that. You haven't had to change drastically things that you would do down there in Georgia.

Jonathan:

It's still hot. No, there've been no lifestyle changes other than the lifestyle change that every one of us has, and they advise against picking up heavy objects. I have been advised not to pick up anything over

40 pounds because of the basic hernia that they've built into you, they got to keep that muscle sheath open. But at 72 years old, I don't really want to pick up anything over 40 pounds, so I'm good.

Stephanie Chisolm:

Okay. Well, great. If you have questions for Jonathan, drop them in the chat box there in the Q&A box. Thank you so much. Another Georgian, we're going to go to Thomas next. Tell us, what kind of urinary diversion do you have and what factors led to that decision? Oh, you're on mute, Thomas.

Thomas:

There we go.

Stephanie Chisolm:

There you go.

Thomas:

I was diagnosed in 61 and my doctor in Macon gave me two options, either the BCG or he would refer me to a surgeon in Atlanta. My wife was already a patient at MD Anderson, so I elected to go there. The two doctors there, we discussed and I have a neobladder. I'm happy with it. I am right at two years post-op. I was out in Houston in early June. I had my seventh scan. Everything was clear and healthy. I've got one more scan to go and it'll be a two-year period of time and my doctor said I can either come back once every six months or once a year. But at present, I work, I'm very active in my yard. I hunt, I fish, I'm picking up pickleball. Life is getting back to a normal and it's working. Of course, you have your good days and bad days depending on lifestyle, but so far, so good. I look forward to being 13 years like Jonathan and hope to meet you one day. But with the neobladder, it seemed to fit my lifestyle and my health factors. Very pleased.

Stephanie Chisolm:

Maybe we'll get both of you to come to the fall summit, which is coming up in Nashville in October and you could all get to meet each other and hopefully Denver will come down as well. Have you made any modifications in your life to fit in the neobladder?

Thomas:

Not really. I have tried to pick up new healthy habits, pickleball is one. My wife played tennis and she had to give tennis up and I've decided I was going to pick up pickleball and start that as an activity, just for good exercise and something different to do.

Stephanie Chisolm:

Okay. Well, this is great. Denver, thank you for joining us. Tell us about your diversion and what led you to that decision.

Denver:

Originally I went to my urologist and basically said, "I'm tired of getting up in the middle of the night, but I realize I'm probably just getting older and that's normal." He said, "Let's check out your bladder." He went in and looked and he said, "Yeah, we're going to do some more." So they did the TURBT and he said, "It's cancer." With him, I did the six rounds of BCG. After that, they went in again, did more biopsy

and he said, "You still have cancer, so we're going to do surgery." I said, "Timeout," because in Toledo I think all they know how to do is the ileal conduit. My sister had gone to Ohio State, The James, with bladder cancer and the BCG worked for her. So I went to her surgeon down there, Dr. Pohar, and he said, "Let's try a maintenance of three more BCG and see what we come up with.

We did that at The James and he went in and did the TURBT with the blue light and he said, "Everything looks great." The blue light detects the CIS better and everything else. He said, "Everything looks great." But when he came back after the biopsy, cancer was still there and it was spreading, it was on the inside of the prostate and into the urethra. By being into the urethra, that pretty much eliminated the neobladder, so I opted for the Indiana pouch, and it is a long surgery, scary how long that surgery can be. Mine was 15 and a half hours, and I'm five years this past Tuesday with my Indiana pouch. I visited with him Tuesday and I am good, no cancer detected at all, so everything is going well.

Couple years after I had the pouch, my wife and I took a trip to Israel, so traveling is not an issue. I was able to be on a 14 and a half hour flight. As long as I have my supplies with me with my catheter and some lube, I'm good to go, and I carry my pocket wherever I go. I work in my shop, I'm mow my lawn, I do exercises, I golf, so life is normal and I love it. I'm really glad I got the Indiana pouch. Now that I have it, I wouldn't change a thing.

Stephanie Chisolm:

Great. So three different diversions and three different positive experiences. Dr. Poch, do you have any comments or questions for any of these gentlemen?

Dr. Poch:

I guess first I'd like to... I'm just very thankful that you guys are all cancer-free and I think that that's great news, so I would like to say that. I guess my follow-up question for the panelists would be, what do you wish your doctor had discussed with you prior to choosing the diversion or prior to surgery? Is there things that didn't come up in those initial conversations that you wish were addressed, be it sexual function or how long the recovery actually is or something like that that you really didn't get to ask questions about or didn't think at the time to ask questions about or weren't brought up?

Jonathan:

Well, I didn't have any questions because I didn't see my surgeon but twice before. He was not very open. He's a great guy and did a great job, but he just didn't answer many questions, and that's kind of what led me to where I am now. I just don't want anybody to go through what I went through, and that's why I'm a huge advocate of BCAN. I have on my BCAN shirt, as a matter of fact. Stephanie gave me this after 10 years. Yeah, there's all kind of questions and answers that didn't occur. I was the most frightened I've ever been in my life the night before surgery. I really, really was terrified because I did not know what was going to happen. I didn't know how long it was going to take. I didn't know what to expect from the hospital or from... I didn't know anything.

About that time, my wife and I decided that we were going to have to be our own advocates because there didn't seem to be much outside help. As a commercial, I looked for help online for years and never found any. After two years, a BCAN member just came across me online and pulled me in. It's been hugely helpful in terms of not only advice, but in terms of just the comradery. You can't really understand bladder cancer or after bladder cancer unless you're talking to somebody who's done that. I mean, I've talked to researchers and stuff like that and I said, "Have any of you guys ever been catheterized?" "No." "Anybody ever had a TURP?" "No." "Anybody ever had anything?" They say, "No." So you feel like you're kind of out on an island and then you meet other people who've done that and

been there, and BCAN has just been a tremendous help. I realize that this was not a BCAN commercial that we were in, but I figured while I was here, I'd promote it.

Stephanie Chisolm:

Thomas, you had something?

Thomas:

Well, when I went for the second opinion in Houston, my surgeon there, I had made a laundry list of questions to ask, and my wife asked questions as well. He pretty much covered a very broad spectrum of those, but he also referred us to BCAN and I went online and registered and I received three calls before my second trip to Houston for prepping for chemotherapy and then consultation on my selection. After those calls with advocates, like we are here today, and asking them questions and my wife asked questions as well, it became apparent that I understood what was probably the best option for me if I was truly a candidate for a neobladder. I was 62 at that point in life and I wanted to be made whole again. But I understood that being made whole was not possible, but at least I could function as I once did before.

I would say the surgeon there, the three calls I received from BCAN members and actual patients, and then my own research and question, I knew what I faced, I knew what the outcomes would be and I knew post-op, how my life would be from that point forward. The questions I asked, my wife asked, the answers we got back from the surgeons pretty much covered it. Would I change anything today? No, I wouldn't. I'm 65, and you know what? At this point in life, if I'm healthy and I have to cath once, here, there, you know what, that's a small price to pay, and I'm very pleased with where I am health-wise. If I can help others make that choice or at least educate them, that's my mission. I applaud BCAN for what they did for me with those three men that called me. One was from Ohio, one was from Orange County, California, and the other one was from a Georgian in Atlanta. So, that's my song, that's my story.

Stephanie Chisolm:

Well, full disclosure, the three gentlemen on this call today are members of our survivor to survivor volunteer squad, and we do appreciate everything that they do. Denver, do you have anything else to add?

Denver:

When I first went and saw my urologist, I mean, his option was, "Okay, we're going to do an ileal conduit surgery." Not knowing even what that was at the time, there was no explanation or anything, so I got a second opinion and I strongly recommend, even if you're very comfortable with your current doctor, get a second opinion. It doesn't hurt to get a second opinion whatsoever. When I went to The James, they were very thorough. We did everything that needed to be done. I didn't know about BCAN, but at one of the preoperative visits there was a pamphlet there and that's when I found out about BCAN, so I was able to pick it up. In my case, the cancer was moving so rapidly that he bumped other patients and got me into surgery within a few weeks, so I didn't have a lot of time to contact anything or do a lot of research, but I did as much as I could.

I would just say that second opinion and being comfortable with your doctor is huge. You got to be comfortable with your doctor when he's going to be the one that's going to be taking care of you. One thing about Dr. Pohar is they always have a continence nurse that'll train you to do things, whether it's with ileal conduit and how to put the bag on or anything, or in my case with the Indiana pouch. There was a nurse there that was going to show me how to catheterize, but Dr. Pohar actually trained me how

to catheterize myself. He took the interest in me in showing me how to do that and "Be patient with it and everything will work out," and it's been fantastic.

