

TREATMENT TALKS

What you need to
know about
intravesical therapy to
treat bladder cancer



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Bladder Cancer Advocacy Network

Leading the way to awareness and a cure

Stephanie Chisolm:

This is really great, and I know that you have a really huge team of very capable people at Johns Hopkins and the Greenberg Bladder Cancer Institute, and you're doing a lot of cutting-edge research, so this has been really a powerful explanation. I know we have a number of questions that have come in. Remember that they need to come into the Q&A box at the bottom of your screen, but I hope you are going to get a lot of good information from our two patients who have joined us on here, so Tony, if you could turn your camera on as well, that would be lovely to be able to ask you to share while we're waiting. Good. Tony, I'm going to start with you because you had signed up first with us. And if you would give us a little history, a little bit about how were you diagnosed? Did you have any different kinds of symptoms that patients should know about, and what did you do in terms of going through your diagnoses and types of treatments that you had? Share a little bit about your experience, if you don't mind.

Tony K.:

Sure. Sure. Sure. I'm 56 years old, and in March of 2021, I happened to notice that, while going to the bathroom, urinating, I had some irritation that got worse to where it was very painful. I do have a great primary care physician, so I went there and initially they did a urine test, a culture test to see, and put me on antibiotics and thought I had a urinary tract infection, the normal first line of defense, and probably the most probable. Anyways, unfortunately that wasn't the case. They called me three days later and said, "Hey, we have to refer you to a urologist." And I wasn't in the Hopkins network. I'm maybe about an hour and a half outside, so I went to a local urologist. They did some testing and I guess it was probably April to May.

We did a cysto where they put me under, they went in and looked at the tumor, and then at the time they planned on doing whatever they needed to do, so at that point there was a carcinoma-in-situ, so there was a tumor bed inside the bladder on the right lateral wall. And he resected that tumor, and at the same time, he took samples enough to tell whether or not it was muscle invasive. So we got done that, we healed up, and the plan was that then June 21st, I think was the date, we'd go back in, he'd look at the tumor, and then we would start a course of immunotherapy, BCG treatments for six consecutive weeks. In the meantime, the bladder cancer came back and it wasn't muscle invasive, which was great news. It was high grade urothelial carcinoma, which was the bad news part of it.

On June 21st, when we went back into the local hospital with the local urologist, he noticed how fast the cancer, the tumor grew back. And one detail I didn't forget, there was a post-surgery where they retracted the tumor out. They did a chemo treatment right after the surgery as well. When he went back in, the tumor had grown back unfortunately pretty quickly, and he also noticed in the terminology on the right distal ureter, where it had entered the bladder, it looked as if it had some discoloration that caused concern of the tumor spreading. He obviously stopped the surgery, and once we had the follow-up, he referred me over to the Hopkins team. He said, really, at this point, that was where I needed to be, at the Bladder Cancer Institute there at Hopkins. I did obviously, with nobody there having set eyes on the tumor that I had inside me, I came and Dr. Singla did the initial intake cysto.

And he also went and made sure it was still, and he was comfortable with it, diagnosed as non-muscle invasive. Once we did that and he looked at the ureter, we then took a step back and that's when Dr. Hoffman-Censits was brought into the conversation. And we talked about different options as far as chemotherapy and some of the benefits and pros and cons that they touched on during the presentation. We opted to do the pre-surgery chemotherapy, so I had a port put in, went through the whole process, and I can tell you that a lot of the chemotherapy, I did miss one week, but there was some really good job that Dr. Hoffman did to minimize the obvious effects of the chemotherapy with either trying to hydrate and do some other things, change up the medications that I was on to try to minimize the effects of the chemotherapy.

That brings us to the surgery, so it would've been somewhere July. We went in... Oh, no, I'm sorry. I already did surgery, let me get my timelines straight. We did the chemotherapy, that ended somewhere around October 15th or somewhere in around there, so they wanted to wait a period of time for obviously the inflammation, [inaudible 00:40:36] system and all those things to heal from the chemotherapy effects. On December 29th, Dr. Singla went in and he took a section of my bladder, and he also took a section of my ureter where it met that bladder farther enough up the ureter where it actually cleared the margins. And he couldn't take all of the tumor bed out of the bladder because it would've been too much, and then he reattached it. And that's what would have been referred to earlier as a bladder or kidney-sparing surgery.

Tony K.:

That was December 29th. With that out, I went home with a stent in my ureter to make sure everything stayed copacetic as far as the ureter being reattached to the bladder. At that point, about a month ago, I went and had that stent taken out. And looking forward right now, it's going to be mid-March, we're going to go back in, look and see how things are. One of the things when Dr. Singla took the stent out, he did another urinalysis and cultured it, and it still showed, unfortunately. And I don't know that it wouldn't have shown that, but still showed high grade urothelial carcinoma, so [inaudible 00:41:56] were the journey and the things that we've gone through. We've kind of neutralized it, hopefully in the ureter, and we'll find out on March 15th, and we're going to go back to where we thought we were in June, once he looks at that tumor in the bladder and start the BCG treatments.

Ultimately, if we don't see what we'd like, that's going to be a different plan. And that's what I would say is the biggest lesson I could say with people, because I know I heard it referred to as safe space on the internet for information. You can go down many rabbit holes trying to find information, and ultimately sometimes the answers to the questions are not something that are black and white, and everything emerges or evolves over time. I know it's difficult to have patience as you're going through this process, but that's the only thing I could do is encourage people to take a breath, take a step.

I mean, I'm an optimistic person, but you can easily get down and do your best. I mean, lean on the people around you, lean on your surgeon and your oncologist. Both of them have been great. If I've got

a question I shoot them, and I am on the portal, and they get back to me right away. So that's where I'm at. I'm optimistic that on the 15th we're going to be kicking forward with the BCG treatments and then we'll just start a surveillance, quarterly surveillance interval, and life will go back to normal.

Stephanie Chisolm:

Well, we'll be sending positive thoughts your way on March the 15th. It'll be here before you know it, so thank you for sharing, Tony. And we'll get back to you with some questions a little bit later on. And now I'd like to talk to Christina. Christina, what about your experience?

Christina Y.:

Okay. Well, first of all, thank you for inviting me to share my experience through this journey. You can hear my voice is a little raspy. This has been happening throughout treatment, on and off, so it's a little bit inflamed. My story started quite a while ago actually. I presented with blood in the urine in October of 2018. Testing showed nothing, that there was nothing there, and in fact, my urologist, a local urologist said it was because I had beets for dinner and he really thought it was from the beets and that it was not blood in the urine. Fast forward six months, severe left flank pain took me to the emergency department at our local hospital where they did a CT and found a stricture around my ureter. I was seen by the local urologists after that, who placed stents into my ureter and said they were absolutely positive this was not a malignancy. This was probably something completely benign.

After three stents, the last one of which was a balloon stent, nothing opened up in the ureter, so then they sent me for, I forget the name of the test. I went in and they did radio something in my kidneys, both kidneys. And one kidney, the left kidney showed that it was functioning at 25% and the other one was fine, so then I was referred to Hopkins. I saw a urologist who is no longer with Hopkins. He too did not think that I presented with any type of cancer, and he was going to place a stent as well. The stent would not go in, so then he scheduled surgery for me. Now we're September of 2019. He said if he couldn't fix the ureter, there was a very, very slight possibility that he would have to take my kidney and my ureter. And that's exactly what happened.

Christina Y.:

After the surgery he told me that he wasn't worried, we'd wait for the path report, but wasn't concerned about what he saw. A week later I got a call that it was high grade upper tract urothelial carcinoma, and I needed to meet with Dr. Hoffman as soon as possible. So I did, and that was incredible experience. She is the absolute best physician in the entire universe, and I owe everything to her. I really mean that. We met, I have been healthy my entire life, never smoked, drank minimally, exercise, vegetarian, ate well and had no clue why I possibly could have gotten this cancer. Never heard of such a cancer, it was so rare and so aggressive. And she was very pragmatic and talked to me about what the options were, and we decided that... It was after surgery, so we were going to go on cisplatin and gemcitabine, which I did for four months.

And that was followed by another surgery, retroperitoneal lymphadenectomy, I think that's how you pronounce it, where 52 lymph nodes were removed, and 10 of those were malignant. In August of 2020, I started on immunotherapy, and that did not work well for me. I had a bad reaction and the tumor was growing, so Dr. Hoffman took me off that and I started on enfortumab, which was pretty successful. Tumor shrunk, but what happened was my liver enzymes elevated, so the dosage had to be decreased significantly, and as a result, the tumor grew back. In the summer of 2021, I had stereotactic ablative radiotherapy, and that stabilized the tumor, the size of the tumor.

And then I was off treatment until I got my scan in September, which showed that things were growing back, so then I was on many of the drugs that were on Dr. Hoffman's screen. I got on sacituzumab, was on that for a couple of months, that didn't work. And right now I am fortunate enough to be participating in the clinical trial, which I started in January, and we'll see what happens. I meet with Dr. Hoffman tomorrow, so that's my story.

Stephanie Chisolm:

Thank you so much for sharing it.

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