



Patient Experience with Maintenance Therapy

Morgan Stout: Absolutely. I'm actually going to invite Gail and Joseph to turn on their cameras and microphones, because we'd love to hear a little bit about your experience as real patients who have experienced maintenance therapy.

Gail, do you want tell us a little bit since you follow Petros' slides so closely?

Gail Dykstra: Hi, my name's Gail Dykstra. In disclosure I am a patient at the University of Washington SCCA, and Dr. Grivas is my medical oncologist. I was diagnosed with muscle invasive bladder cancer T2 and 3 at the end of 2017. The tumor was removed and staging occurred in January, as a result of a cardiac issue I was deemed ineligible for chemotherapy, for radiation, and, or for surgery, and was only able to avail myself of immunotherapy, which I knew absolutely nothing about. The confidence that I have in the treatment I have received is in great part due to Dr. Grivas and the UW SCCA team. I want to give a shoutout to BCAN, because at a time when I knew nothing, and needed a great deal of information coming at me in language I could understand, and with compassion BCAN was there. I think that talking about treatment and maintenance is another example of why BCAN is so important to all of us.

I was treated with pembrolizumab alone, and over a course of an initial treatment that normally takes about two years. I am now in the maintenance section of it, and at the point where I needed to make a decision, and talk with Dr. Grivas and the team at SCCA about what next. I had all of the what if questions, "What if it comes back?" Even though I'd had immediate response in a very positive manner to immunotherapy, and although I had some side effects, they were manageable, they were identified, and they were monitored all the way along I still have the, "What if it comes back? What do I do now? Do I continue? Do I not continue?" There's not a great deal of data at this point, as Dr. Grivas was talking about UW SCCA and others are studying what happens to patients who have just had immunotherapy, how long-lasting is the treatment. Because I've had a good response, because the side effects were manageable, and that I knew that they would be monitored and managed by the team I opted to continue, and I'm in to year three of my treatment.

I continue to get CT scans every three months, of course I have cystoscopy on a regular basis, and continue to keep become aware of any possible side effects that have grown or changed, and so far they have been good. One other thing that was a big part of my decision, is that the cost of immunotherapy, as all cancer patients know, all cancer treatments are expensive, immunotherapy is enormously expensive. I needed to know in advance whether my insurance would cover that cost, because if it didn't I would not be able to make the kind of decision that I was able to make. The thing that I would think that is the most important, is to be able to know what you are going to be personally emotionally comfortable with. Would I be comfortable just cutting off the immunotherapy at the initial stage? I didn't think so. I wanted to be able to wait until more data was developed so that I had a better appreciation of the long lasting benefits.

Morgan Stout: Thank you so much for sharing your story with us, Gail. We really appreciate that. Joseph, you're on the other end of the spectrum with non-muscle invasive bladder cancer, would you like to share your story about BCG maintenance?

Joseph King: I am two years out with Ta CIS. I had a recurrence on Thursday, and Monday I had surgery, so we've done a biopsy and resection so hopefully I'll still be non-invasive. I live in Palm Springs, and one of the challenges has been for me is that I belong to Kaiser Permanente, which is the largest HMO in the country, unfortunately this is a service area so I can't get care here in Palm Springs. I am forced to travel for all maintenance and for induction to either Montana, or California, or Ontario Riverside, they're about 50 to 70 miles away, each of them. So it's very challenging for me to drive to the medical centers, and then drive back after I've had BCG, holding it in the car.

I actually had a problem, my original surgery was in San Diego, and on the way back I actually had to jump, and I would take a jump in the trees because I had a lot of problems with that. I want to say that maintenance for me was not really a decision that I could ignore, I have CIS and it's responded very well to BCG, so there wasn't for any moment a consideration of anything else. The treatment results have been good until unfortunately Thursday. I'm waiting what my doctor will do now, and it'd be interesting to see what that tumor was.

So for me, the difficulty with BCG has been the painful urination afterward, that is probably the hardest. I found that for me, I was very nervous about it so I looked into YouTube, and I looked into the Bladder Cancer Advocacy Network inspire list, which I encourage people to please go on, because the members are wonderful, and we all have tried to help all new people, and those that are getting BCG who are afraid, and I was too. So that was very helpful to me, and when I received the treatment I was surprised that it wasn't as bad as I thought it would be. I'm a person that was a registered nurse in one time, and actually was on the other side, but getting the catheters as often as I get them has been very challenging. Because it is painful to get a catheter each time they do it, and I've had so many. Right now I'm having pain from what I have now at this point.

In terms of, I'm trying to look at some of the questions, in terms of my maintenance, I have been very lucky, Kaiser Permanente has a policy system-wide of giving one-third dose. They have felt that that's the fairest way to do it, but my case is that the last six doses, I've had 18, have all been full-strength BCG, which is unusual for a maintenance program. So I've been very grateful that I've achieved that. The nurses are wonderful I have to say, particularly a woman named Maria, she's been terrific.

Also, for me, I guess maybe the biggest problem, and I think for those of us in the bladder cancer community, has been the shock of it, and then trying to work through the emotions. This came about through a cystoscopy that my urologist in San Diego was doing, because I was going to have a UroLift. It's a prostate surgery, that's all I knew. We were going to do that. He's the only one of the doctors in the country that would do this, and he said, "I found a little something here. I don't know what it is, but we'll biopsy later. I don't think it's anything." Then he called me a week later and said I had bladder cancer, so it's one of the things that I, as a person had no knowledge about, absolutely knew nothing about maintenance. I didn't know Ta. I didn't know any of these things, and that was very difficult. The physician I started off with originally was not helpful in that regard.

A lot of the physicians have great clinical skills, but in terms of their ability to tell us about these maintenance therapies, and those things, my doctor right now is an oncologist-urologist, he has given me a lot of information more so than the other doctor. I've gone to support groups, and they have given me some information. Dr. Schuckman at USC, I have met with and she's a world-famous uro-oncologist. For those cases I've been very grateful because she's giving me statistics, what is it with BCG, what isn't with BCG, what are the chances of your recurrence, what kinds of things do we look at, and this has been ... It's really a challenge, but for me, the question came up, well, was it's difficult for me in terms of scheduling, things like that. The entire illness has been nothing but a rescheduling for me.

My whole life changed March 26, 2019. My whole life is never the same, and never will be, but I have learned to cope with this, it is always over my head. Those of us in bladder cancer community always say we're part of a club we didn't want to join. So this is something that has really gotten me through all of my treatment, through my original surgery and my initial induction, and now the maintenance that I do. I'm very grateful to Kaiser because they did have this policy. There are many people in my BCAN group who can't even get, even for the induction they've had a hard time getting the six doses of BCG. So anyway, I won't speak any longer, but I thank you for giving me the opportunity to talk about this, and I'm starting a support group by the way for non-invasive muscle bladder cancer patients. Thank you.

Morgan Stout: Thank you, Joseph. Thanks so much for sharing your story, and we're looking forward to that support group. It will be a great thing in the bladder cancer community.

