



Patient Experience

Stephanie Chisolm: I'd like to welcome Dr. Gupta's patient Guy Riegling, and Guy is going to talk to us a little bit about his experience. So can you give us a quick synopsis of how you got to that place where Dr. Gupta was suggesting that you use an Antibody-Drug Conjugate? What was your bladder cancer experience?

Guy: Well, my bladder cancer was diagnosed back in December. Well, actually, it was diagnosed earlier. Like about March of 2015, and I went through a few different treatments, BCG and some surgeries where they cut inside of my bladder and took tumors out of my bladder, and none of that really worked, and then I underwent a surgery where they took out my bladder made me a new bladder, and I was good for four years. My five-year scan, which I thought would be my scan to make... Is the five-year scan I always heard was the scan that you want to get clear, and then you should be good to go maybe for rest of your life.

Well, that came back as having the cancer had spread to my abdomen area, and I really was only having a little bit of pain not too much, but it seems... I don't know if it's... It was in my head or what, but soon after that the pain started to accelerate, and I was given Dr. Gupta as my cancer doctor, and she suggested this study and I was hoping to get into the best leg of it, and I did, but I was kind of on the fence whether I wanted to do it or not. My son-in-law, who's a biomedical engineer. I let him read over all the paperwork and he suggested that I should do this too, and so with him and Dr. Gupta being way more educated on this stuff than me, I decided to get into this study and the thing is after like maybe two treatments, the pain that I was having, that I was on oxycodone to stop the pain, the pain just seemed to go away within two treatments and to me it's just been miraculous, and I couldn't be happier with this.

Stephanie Chisolm: That's great. So you were part of a clinical trial that was probably used to help approve the treatment, what were some of the considerations that went through your mind when you spoke with your son-in-law and others about should you do this, and what about this particular treatment was appealing to you?

Guy: Well, the main appeal was, I mean, you can, you can do nothing and it's not going to be a good ending, and then after the doctor explained about how much more success they're having with the cancer treatment at this study as opposed to normal chemotherapy, that was the appealing part. She convinced me that this was much better than regular chemotherapy.

Stephanie Chisolm: You know, again, being in a clinical trial is a little bit different than having treatment choices, and so is there anything... Because I think in a clinical trial they're going to give you so much more information. Was there anything else you wish you had known in advance about this treatment or do you feel like you were well-prepared to handle or be aware of any potential side effects and things? Was there anything you wish you had known more about before you started treating it?

Guy: No. You know they gave me a lot of paperwork, and I read the paperwork and I understood the side effects. I mean, the paperwork shows a lot of side effects that people might really be afraid of, but my side effects haven't really amounted to too much at all. I mean, a little bit of tingling in my fingers, which is something I can handle easily. Tiny little bit of hair loss, but luckily I started with a lot to begin with. So that hasn't been bad, but no and the information I was given... And to be honest with you nothing has been as bad as it could have been. Nothing's been as bad as if you read the paperwork and you see the list of these are common, these are uncommon, and no. I was prepared for it and I'm happy so far with the treatment. Everything was pretty well explained to me.

Stephanie Chisolm: So, because the treatment takes a period of time to get the full treatment. Was that at all a barrier or a burden for you in terms of getting in for those treatments?

Guy: No, it hasn't. I'm lucky I'm retired now. I retired right about the time I had my surgery. You know I'm 67 now, and the time I spent getting treatments, it doesn't... No, it's not a problem, and my wife with the family medical leave act, she likes to come with me to my treatments. So I have her as a companion which is nice too, and so we get to spend our time together as we say, and it's not really an inconvenience. I mean, you're only at the treatment center maybe for four hours, five hours at the most, maybe not even that, and it's not really an inconvenience for me.

Stephanie Chisolm: Okay. Well, that's good to know. So Dr. Gupta, what about Guy? Obviously he was part of the clinical trial, but what about him kind of fits the general characteristic of patients that would benefit from Antibody-Drug Conjugates? What about Guy and his diagnosis and his disease progression makes him a good candidate for that?

Dr. Gupta: Yeah, that's a great question. Thanks Guy for sharing your experience, and I would like to add here that just like Guy mentioned, his five-year scan was a big shock to him and he was having symptoms, and fortunately we had the EV-302 trial where we discussed with him that look, the standard of care is chemo, but this trial offers the opportunity to either get chemo or EV and Pembro as first-line treatment, and he was randomized to the EV-Pembro arm, and has had a complete response, and as you mentioned, clinically all his symptoms disappeared, but these are the patients who are fit for these trials, any recurrence which amounts to measurable disease, who are overall in good state of health as determined by the trial eligibility and who are open to trying the clinical trials and whatever novel therapies we have to offer, but you know patients like Guy who have luckily he could have received chemotherapy too, and we discussed that 50% chance you will still get just chemo which really is the standard, and I think it really worked out great.

Guy: Yeah. When I heard the news I was in the Pembro part of the study, it was a good day for me. It really was. Yeah, and you know the side effects of the treatment... I had a slight rash for a while, but that's really cleared up. I was given a prescription for a cream to put on and I hardly ever used that, and besides the tingling, there's really no side effects. I still exercise like I did, I still ride my bike like I did, and I mean, maybe other people would have a different reaction, but to me, I think I've been pretty lucky and I'm satisfied.

Stephanie Chisolm: So Guy are you still in the trial? Is this an ongoing... You're still participating as a member of the trial or are you just switching over to being on this treatment now?

Guy: Well, I believe I'm still in the trial. I'm going to get a scan this coming... Well, Friday, I'm getting a scan, but you know I'm still in the trial as far as I'm concerned. I mean, Dr. Gupta might be able to answer that question better, but I mean, I have treatments ongoing and this'll be my second scan. The first scans came back it showed that the cancer was gone. I mean, microscopically maybe not, but what they could see on the scans, but yeah, the trial to me it just continues, but you'd have to ask Dr. Gupta because that's more technical than I really-

Dr. Gupta: Yeah, absolutely. Stephanie, Guy is on the study and luckily his first scan showed complete response with everything in the liver and lymph nodes that had resolved, and we discussed that this is a long-term treatment you know. We'll adjust the doses so he doesn't take quite that much toxicity and keep him on for as long as he's deriving benefit.

Stephanie Chisolm: That's good news and we'll be cheering for you Guy. So that's awesome.

