Patricia Rios:

Dr. Lee, thank you so much for your presentation. It was very comprehensive, and I hope those of our listeners enjoyed the many videos you shared because they really gave us that inside scoop into how these repairs are done.

And I want to begin by asking … Because a lot of the conversations or the content focused on ileal conduit. Could you speak a little bit about the techniques and all of these things apply to the other diversions?

Dr. Ziho Lee:

Yeah. So I think that's a great question, Patricia. I just focused on ileal conduit because that's the most common type, but these scar tissues, these strictures can happen with any type of urinary diversion, including neobladders. Reconstruction is very similar. I personally like managing patients … I think it's easier when patients have a neobladder because the location is where the normal bladder would be, and so it sometimes makes things a little bit easier to see.

But I will say all these techniques do apply to neobladders as well, and we certainly take care of our fair share of patients with neobladders as well.

Patricia Rios:

Dr. Lee, thank you for answering that, and thank you for also addressing some of the questions that are appearing in the Q&A button. There was a question that came in around … And you briefly mentioned this, the nephrostomy tubes. Can you speak a little bit about that and how that's used to manage?

Dr. Ziho Lee:

Yeah, so that's actually a great question. So I actually came up with that concept, it's called ureteral rest. And so I published a paper maybe seven years ago to coin this phrase, because if you think about it, scar tissue, it's a narrowing. So when you have a stent, what's happening is that stent is propping that narrowing open. So if I were to say, "Hey, let's go operate on you right now with a stent in place." When I go in, I may not be able to see all the scar. I may only be seeing a part of the scar, but the part where the stent was dilating quite a bit. I might leave some of that scar tissue there.

And so for me, I like to take all the hardware out of the inside, so nothing across the ureters, place a nephrostomy tube for about six weeks. And then what we do is we let the ureter rest and then I operate and that gives me the best visualization. In the initial study that I published, performing this rest was associated with a 21% higher success rates.

Patricia Rios:

Thank you. You mentioned stents. One of our listeners wanted to know if these ureter stents cause stricture or damage to the ureters in any way.

Dr. Ziho Lee:

Yeah, so you certainly can during placement, if you just try to jam it in there, you definitely want to be gentle while you place them. Typically though, if you have stents, they don't typically make the scar tissue worse. But I will say when you're placing stents or repeatedly placing stents, there is potential to make an injury worse. So let's say there's some scar tissue that's pretty dense. You have a stent in there right now and you're trying to exchange it. So you can have a little bit of injury or increased injury to the scar tissue when you're working with these.

Typically, I don't like long-term stents for that reason. Especially because the alternative is we can offer this more definitive option, that's just my mentality. I'd rather just do one surgery, do it right and be done than keep doing this and belaboring this issue.

Patricia Rios:

Okay, thank you. There's a question about ischemia and that causing a narrower caliber in a distal one-third of the ureters. This person would like to know what are the options available?

Dr. Ziho Lee:

For what?

Patricia Rios:

Yeah, no. So the question that was submitted is that there's this ischemia causing a narrower in the distal part of the one-third piece of the ureter. And so they want to know what are the options? You mentioned several. Would this be ... Yeah.

Dr. Ziho Lee:

That's a pretty long area if it's a third of it. What I would try to do is try to rotate that ileal conduit closer to healthy ureter and try to connect. If I'm not able to connect ... Depending on how long it is, sometimes I do that flat procedure that I was telling you about. I also have been involved with helping develop some innovative techniques. Sometimes I use skin from the inside of your mouth. It's called a buccal graft. It's always wet, there's no hair, it works perfectly in the urinary system. So sometimes I use skin from the inside of the cheek to repair these, and I've also used actually a patient's appendix to fix these.

There are options, and I think ... Here we can be pretty creative about how we go about fixing these. There are certainly options available to you, and it's just finding the right person to do that.

Patricia Rios:

Thank you. And when looking for the right person, what are some tips that you have for some of our listeners?

Dr. Ziho Lee:

At the end of the day, there's no guarantees with surgery. You could do a perfect surgery and get out and then the patient has a complication, or you could do surgery and be like, "Oh, man. That was a little shaky." And then the patient does amazing. I think for me, a lot of it is the patient-physician relationship. Do you trust that person? Can you look that person in the eye or can that person look you in the eye and say, "You know what? I'm going to take care of you." I think that's the biggest thing because having someone that you can trust, I think that's absolutely critical.

Another thing is someone that will answer your questions. I think everyone is busy, not just me, but everyone is busy. It's hard to get to some of these messages right away, but someone who is available to talk and is going to go through these options with you, I think those are the major things. And then someone who feels good about doing surgery on you. Ask them like, "Do you feel comfortable doing this? How many do you do?" I think that's a big surrogate, and I think patients have every right to ask questions like that because it's your body. Really you get, really one good shot at this. And so you want to take your best shot first and you want to be comfortable and trust the person. And I think those are really critical for success.

Patricia Rios:

Thank you. Those are phenomenal tips. Thank you, Dr. Lee. Okay. So I'm going to direct the questions more to our listeners with neobladders. So there's two questions related to that. One is the probability of getting this condition within 10 years of receiving the neobladder.

Dr. Ziho Lee:

Incidence goes down. I would say, most you'll find out within six months or so. It'd be surprising to me if it was after two years you really had problems. I think in long-term, I do see some patients who've had ileal conduits for other reasons as a child. I've seen things happen 40, 50 years after. If you haven't had any problems within two years, it's probably unlikely you're going to have an issue.

Patricia Rios:

That's comforting to hear. This is a very specific question, again, relating to neobladder. How often should a single kidney, mild hydronephrosis person with neobladder get image follow-ups?

Dr. Ziho Lee:

It's variable. I would say it really depends if the patient's having symptoms or if the patient is having problems with the kidney. I think it's very variable. Not knowing all the information, I would probably start with a renal scan. It's a special type of study that helps see if things are draining. I'd probably start there. And if that looked okay, to me, I'd probably get an ultrasound once a year. But hydronephrosis by itself is not abnormal. I tell all my patients that, especially when you're having an ileal conduit or a neobladder. So if it's mild, I wouldn't really be worried about it because that's sometimes normal just because of the way the urine ...

Normally, we don't have hydronephrosis because in your bladder, the ureter tunnels through and there's a stop gap, so it doesn't go backwards. But when we do these complex reconstructions ... When you do these reconstructions, what happens is that you just plug them right in. And so it can reflux and go back and cause a little bit of hydro. To me, not that big of a deal.

Patricia Rios:

Sorry, can you explain what hydronephrosis is?

Dr. Ziho Lee:

Oh, yeah. Sorry, sorry. So hydronephrosis is like dilation. It's just like distension. So remember, if you have that hose and someone is stepping on your hose, the water behind there is going to swell up. It's going to get bigger and bigger. That's called hydronephrosis, essentially, where your kidney swells up a little bit.

Patricia Rios:

Okay, great. Thank you. Thank you. I'm going to ask our friend Tony to come back on screen. I see we're near the end. Thank you for answering the questions directly in the chat, Dr. Lee, and for also addressing the live questions. I have one question for the both of you to close us off. As it's customary, we ask all of our guest speakers to leave us with what is the one message or one thing that you want our listeners to remember from this talk.

We're going to start with Tony, if that's okay Tony, if you don't mind sharing. What is that one takeaway that you would like those individuals who are listening today, who may be experiencing this or maybe considering surgery? What would you like them to keep in mind?

Anthony Vacek:

Well, I don't think they should be afraid of it. I had it, like I said, in December of 2022 is when I started this journey, and everything is great. My lifestyle has actually improved. One of the reasons was I was getting up to go to the bathroom six, seven, eight times a night. And after having gone through this, I sleep like a normal person. It's nice to get a good night's sleep. Don't be afraid of it. Like I've said, I've been fortunate. I haven't had any complications. I've had excellent care and follow-up with Dr. Lee and everything is great. So that's what I'd like to leave the listeners with.

Patricia Rios:

Thank you, Tony. Thank you for sharing your experience with us. Dr. Lee.

Dr. Ziho Lee:

Yeah. I mean, I would say this is not an uncommon issue, but it sometimes can be pretty tricky to manage. At the end of the day, I think find someone that is going to be there for you and try ... Everyone tries their best, I think. At the end of the day, it's a patient comfort thing. I think finding someone who you feel comfortable with. I think what's great is you have this network like BCAN that can find resources, other patients who've been through similar experiences to really reflect and see what experiences they had.

There's a lot of power to talking over these issues because again, they're challenging to manage. I've seen patients who've had stents for 10 years before they came to see me. These types of groups, even if it's not this issue, are extremely empowering for our patients because it's a group of like-minded individuals who really can help each other out. I really applaud this group and all the work, Allison and Patricia, that you guys go through to host these webinars because I really think that it's important and it's such a great resource for patients because education just empowers the patients, which at the end of the day, I think is absolutely critical.

Patricia Rios:

Thank you, Dr. Lee. And we would not be able to do these webinars without clinicians, experts like you, who are willing to donate your time to educate and support our community. So thank you so much for spending this hour with us. We really appreciate it.